UNIVERSITY OF GHANA

AFRICENTRIC WORLDVIEW AND PSYCHOLOGICAL HEALTH AMONG PRIMARY CAREGIVERS OF CHILDREN WITH INTELLECTUAL DISABILITY IN GHANA

BY

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(10046009)

THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF PhD PSYCHOLOGY DEGREE

JULY, 2015
DECLARATION

I, MABEL OTI-BOADI declare that this thesis has not been submitted for a degree at this or any other University and is entirely my own work. It has been submitted in fulfilment by me, a graduate student of the department of Psychology, University of Ghana, Legon, for the degree of Doctor of Philosophy.

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ABSTRACT

This study examined the extent to which Africentric worldview influence the relationship between stress and psychological health among primary caregivers of children with intellectual disability in Ghana using the mixed methods design. The quantitative phase recruited and assessed 160 primary caregivers using standardized measures assessing Stress, Africentric worldview, Africultural coping, and Psychological health. Results from MANOVA indicated that primary caregivers of children with intellectual disability experience significantly high levels of stress and poor psychological health than primary caregivers of children with sickle cell disease and healthy controls. Results from hierarchical regression analyses on primary caregivers of children with intellectual disability indicated that; first, caring for an intellectually disabled child is associated with high levels of stress which further leads to poor psychological health. Second, spirituality buffered the relationship between stress and anxiety. Third, Africentric values of spirituality and intuition predicted spiritual coping.

The qualitative phase adopted semi-structured interviews with 11 primary caregivers of children with intellectual disability to inquire about their stressors and coping strategies. Using thematic analysis, emergent themes included: psychological reactions, caregiving challenges, societal reactions, coping strategies, psychological functioning, knowledge of condition, and perceived cause of disability. Despite the numerous challenges associated with caregiving, primary caregivers of children with intellectual disability reported the significance of their spirituality, family/community support systems, and hope as effective coping strategies in raising their children. Results from both the quantitative and qualitative phases demonstrated the stressful
nature of raising a child with intellectual disability and the importance of Africentric values of spirituality and communal support systems in coping. Implications for clinical intervention programmes, research, policy, and psychological education are discussed.
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CHAPTER ONE
INTRODUCTION

Background of the Study

A plethora of research exist globally on psychological health symptoms often expressed as depression, anxiety (Ambikile & Outwater, 2012; Cramm & Nieboer, 2011; Nebbah, 2010), and somatic symptoms (Gallagher & Whiteley, 2012) among primary caregivers of children with intellectual disability. Generally, primary caregivers raising children with intellectual disability report increase stress levels and poor psychological health compared to primary caregivers of children without intellectual disability (Duarte, Bordin, Yazigi, & Mooney, 2005; Hung, Wu, Chiang, Wu, & Yeh, 2010; Norlin & Broberg, 2013). The presence of an intellectually disabled child is unequivocally associated with several factors including; parenting daily hassles, child behaviour problems, future of the child, communication problems, and employment and financial difficulties (Gallagher & Whiteley, 2012; Olsson & Hwang, 2008; Pisula, 2007).

Regardless of the chronic burden of caregiving, there is increasing evidence that some primary caregivers emerge emotionally strong in caring for their children (Bayat, 2007; Hastings, Allen, McDermott, & Still, 2002). This state of psychological health is attributed to the effective coping strategies utilized by primary caregivers (Benson, 2010; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Pottie & Ingram, 2008).

Considerable evidence exist on the buffering role of coping strategies on stress and psychological health of primary caregivers of children with intellectual disability (Pottie & Ingram, 2008; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). Nevertheless, few studies exist on the influence of culture on coping and psychological health of parents of children with
intellectual disability (e.g. Bishop, Richler, Cain, Lord, & Floyd, 2007; Blacher & McIntyre, 2006; Neeley-Barnes, Marcenko, & Taylor, 2004).

In recent years, cross-cultural research is illuminating the strengths of cultural values in coping among parents raising children with intellectual disability (Alston & Turner, 1994; Bishop et al., 2007; Gardner, Scherman, Efthimiadis, & Shultz, 2004; Wilgosh, Sobsey, & Scorgie, 2003). Primary caregivers of African descent (e.g. African Americans) have been found to be more resilient than White caregivers raising children with intellectual disability and this is attributed to the utilization of their cultural values of family/community support systems and spirituality as coping strategies (Neeley-Barnes et al., 2004; Pruchno, 1999).

A growing body of research suggests that culture plays a unique role in coping among people of diverse cultural groups (Kuo, 2010; Slavin, Rainer, McCreary, & Gowda, 1991; Utsey, Adams, & Bolden, 2000). Worldview is a cultural construct that significantly influences people’s interpretation of the world (Ivey, D’Andrea, Ivey, & Simek-Morgan, 2002; Swartz, 2009) and how they adjust to stressful events (Jackson & Sears, 1992; Myers, Montgomery, Fine, & Reese, 1996; Parham, 2002). Subsequently, several scholars interested in studying the psychological functioning of people of African descent accentuate the need to study them from their own worldview described as the Africentric or African worldview in order to better understand them (Akbar, 1991; 2004; Azibo, 1996; Belgrave & Allison, 2006; Nobles, 1991; Utsey et al., 2000).

Africentric worldview refers to African cultural values, beliefs, and assumptions that guide the perceptions and behaviours of people of African descent (Belgrave & Allison, 2006; Jackson & Sears, 1992; Myers et al., 1996). Although the concept has been generally studied among African Americans, the basic principles are relevant to continental Africans including Ghanaians. Scholars contend that Africentric values originated in Africa and were transferred by Africans who
were taken as slaves to the New World (Akbar, 1991; Azibo, 1996; Nobles, 1991). Africentric values such as spirituality, communalism, and collective social orientation are common to most people of African descent including Ghanaians and are often utilized in their interpretation of life events (Belgrave & Allison, 2006; Gyekye, 2003; Kwate, 2003; Nobles, 1991). For the purpose of this study, Africentric values and African cultural values are utilized interchangeably to represent Africentric worldview.

Several scholars have suggested that Africentric worldview provide a positive framework through which people of African descent react to their problems as it motivates the perception of stressful events as less threatening and an opportunity for psychological growth (Azibo, 1996; Jackson & Sears, 1992; Myers et al., 1996; Neblett et al., 2010). Africentric values protect people of African descent from a variety of problems including depression, stress, blood pressure, and suicide (Neblett et al., 2010; Neblett & Carter, 2012; Wang, Wong, Tran, Nyutu, & Spears, 2013). Spiritual and communal values of family and community support systems are very important dimensions of the Africentric worldview frequently used as coping strategies among people of African descent (Belgrave & Allison, 2006; Smith, 2003; Taylor, Chatters, & Jackson, 2009; Utsey et al., 2000).

Additionally, adherence to Africentric values of spirituality and communalism may typically predict the adoption of several cultural coping strategies such as prayers, interdependence, and other spiritual practices, not exclusive to people of African descent, but often preferred by them in dealing with stressful events (Anderson, 2006; Lewis-Coles, 2006; Utsey, Brown, & Bolden, 2004).

In recent years, research among families of children with disabilities is shifting from a deficit-based approach which only focused on the problems associated with caregiving to a
strength-based approach which emphasizes on strengths and resources within the family in solving problems (Gupta & Singhal, 2004; Mashego, 2005; Scorgie & Sobsey, 2000). Africentric values such as spirituality and family/community support systems have been explored as providing strengths for African American kinship caregivers of other populations (Anderson, 2006; Ince, 2010; Laurence-Webb & Okundaye, 2007) and primary caregivers of children with disabilities (Allen & Marshall, 2010; Ha, Greenberg, & Seltzer, 2011; Kirsch, 2013).

Among African primary caregivers of children with intellectual disability on the continent, there exist few studies that have mentioned spirituality and family support systems as coping strategies (Anum, 2011; Hervie, 2013; Mashego, 2005; McNally & Mannan, 2013). Moreover, specific examination of Africentric values of spirituality and communalism (family/community support systems) have not been explored.

In summary, the foregoing discussion highlights the importance of African cultural values in coping with stress. However, few studies have examined the rewarding aspects of caregiving through the use of African cultural values of spirituality and family/community support system in improving the psychological health of Ghanaian primary caregivers of children with intellectual disability. An examination of African cultural values as coping strategies among Ghanaian primary caregivers of children with intellectual disability may significantly improve their psychological health as well as have implications for the development of culturally sensitive support programmes for them. At this point, it is relevant to provide a brief definition, causes, classification, and prevalence of intellectual disability.

Intellectual disability

Intellectual disability refers to a group of disabilities associated with significant impairments in intellectual and adaptive functioning, occurring before age 18 (American
Association of Intellectual and Developmental Disabilities [AAIDD], 2009; American Psychiatric Association [APA], 2013). Intellectual disability has emerged as the preferred term for what was referred to as ‘mental retardation’ due to the negative and derogatory attributes associated with ‘mental retardation’ (AAIDD, 2006).

The causes of intellectual disability vary greatly but are often attributed to biological and environmental factors. Research suggest that genetics play an important role in the development of intellectual disability (Ainsworth & Baker, 2004; Reynolds, Zupanick, & Dombeck, 2014). Moreover, environmental factors such as the use of alcohol and other drugs (Ornoy & Ergaz, 2010) and exposure to toxins such as arsenic levels in local soils during pregnancy contribute significantly to the development of intellectual disability (Liu, McDermott, Lawson, & Aelion, 2010). Intellectual disability often coexists with other mental health disorders including; Down syndrome, autism spectrum disorders, disruptive behaviour, and attention deficit hyperactive disorders (Fombonne, 1997).

Classification of Intellectual Disability

The four main classification systems for intellectual disability include (1) the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, APA, 2013), (2) the American Association of Intellectual and Developmental Disabilities, AAIDD, 2009), (3) the Tenth Revision of the International Classification of Disease (ICD-10) (WHO, 1992), and (4) the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

DSM-V; American Psychiatric Association (2013) and the American Association of Intellectual and Developmental Disabilities (2009). These two classification systems provide three criteria for classifying intellectual disability. Firstly, a person must have significant impairment in
intellectual functioning including; reasoning, problem solving, abstract thinking, planning, judgment, academic, and experiential learning. Additionally, intellectual disability should be determined by standardized and culturally appropriate IQ tests with approximate scores of two standard deviations below average which could occur in about 2.5% of the population or scores below 70 (APA, 2013). Secondly, there should be impairment in adaptive functioning including living independently and being responsible for oneself. Areas of functioning that should be considered using standardized, culturally appropriate tests include communication, social skills, school or work functioning, and personal independence either at home or in the community. Thirdly, the onset of impairment is prior to age 18, otherwise it fails to be classified as intellectual disability.

The DSM-V also indicate that a diagnosis of intellectual disability should fall within one of four categories comprising; mild, moderate, severe or profound. One difference that exist between the two classification systems is that, whilst the APA serve to identify limitations that facilitate diagnosis, the AAIDD leans toward identifying abilities that facilitate rehabilitation (Reynolds et al., 2014).

*The Tenth Revision of the International Classification of Disease (ICD 10; WHO, 1992).* This system defines intellectual disability as a condition of incomplete development of the mind, often depicted by impairment of skills (i.e. language, motor, cognitive, and social abilities) that are manifested during the developmental period. The ICD 10 classification of intellectual disability is the most widely used across all member countries of the World Health Organization (WHO, 1992). This system of classification indicates that the level of mental retardation can be categorized into five; (1) mild mental retardation (IQ of 50-69); (2) moderate mental retardation (IQ of 35-49), (3) severe mental retardation (IQ of 20-34); and (4) profound mental retardation.
(IQ<20). Moreover, mental retardation can be diagnosed using standardized intelligence tests, often complemented by other scales that assess social adaptation in a given environment. This is necessary because the system claims that improvements may occur in intellectual disability and social adaptation with training and rehabilitation.

The International Classification of Functioning, Disability and Health (ICF; WHO, 2001). This system moves away from the medical models DSM-V and the Tenth Revision of the International Classification of Disease (WHO, 1992) which have highlighted disability as a disease to a social model of disability. The ICF perceives disability as: “an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)” (WHO, 2001:2013). This system asserts that individuals are not disabled by impairments but by social barriers in society (Oliver, 2013). In other words, this system does not only focus on the cognitive, physical manifestations or genetic causes of disabilities, but also on the impact of society and family on the expression and degree of disability (Albrecht, Seelman & Bury, 2001). Oliver (1990), noted that the ICF criterion focuses on the barriers imposed by society in the form of inaccessible education systems, working environments, discriminatory media images, and inefficient social support services for individuals with disability. Therefore, treatment for disability does not only involve medical treatments for the individual, but also necessitate changes in the structure of society (Siebers, 2011).

WHO proposes that the Tenth Revision of the International Classification of Disease (1992) be used in combination with the International Classification of Functioning, Disability, and Health (2001) to broadly classify disability, such that both medical and social models are applied in understanding disability.
Assessment and diagnosis of intellectual disability in most developing countries including Ghana is beset with numerous challenges. The challenges include using intelligent tests which are normed on people in developed countries with different cultural norms to measure IQ and personnel expertise to administer such tests. There have been recommendations of adopting an ecological approach to assessment where parents and teachers work together to develop inventories for each child. This approach has been found to be suitable for planning intervention programmes for children with intellectual disability in both developing and advanced countries (Mohsin, 2009).

**Prevalence of Intellectual Disability**

Global prevalence rates of intellectual disability is estimated at 1-2% of the world’s population (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). In contrast to the rates from developed countries, there exist higher prevalence rates of intellectual disability in lower and middle income countries (Maulik et al., 2011; WHO, 2001). Generally, a dearth of data exist on the prevalence of persons with intellectual disability in Ghana. According to the 2010 population census, there are 737,743 persons with disability (PWD) in Ghana, representing about 3% of the country’s total population and 15.2% with intellectual malfunctioning (Ghana Statistical Service (GSS), 2012). Moreover, Badoe (2009) asserted that there is a gradual increase in the diagnosis of children with autism in Ghana, with a total of 67 children in three years. Rural Integrated Relief Service-Ghana (2010) also reported that 1 in 87 children under age three has autism in Ghana. Currently, little is known about the impact of having a child with intellectual disability on the psychological health of primary caregivers in Ghana. Therefore, in order to fully understand the experiences of Ghanaian primary caregivers of children with intellectual disability, it is crucial to look beyond the Western perspective and study them from their own cultural perspective.
Statement of the Problem

Primary caregivers of children with intellectual disability constantly have to cope with the negative impact of raising a child with intellectual disability (Dunn et al., 2001; Pottie & Ingram, 2008). In addition, caring for a child with intellectual disability may be exceedingly stressful for primary caregivers living on the African continent due to the stigmatizing nature of the condition and limited community supports (Ambikile & Outwater, 2012; Anum, 2011; Baffoe, 2013).

Despite the highlights of developing culturally sensitive interventions for people of diverse cultures (Anderson, 2007; Neblett et al., 2010), a dearth of research exist on the role of culturally-related coping among primary caregivers of children with intellectual disability in non-Western cultures. The few cross-cultural studies that exist suggest that cultural values play a significant role in coping among primary caregivers of children with intellectual disability from different cultural backgrounds (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010; Mashego, 2005; Muderedzi, 2013).

Historically, studies on intellectual disability in most African countries including Ghana have focused primarily on the negative aspects of culture in terms of the stigma to the child and family (e.g. Agbenyega, 2003; Avoke, 2002; Baffoe, 2013), with very few reporting the positive influence of cultural values of spirituality and family support systems on psychological health of primary caregivers of children with intellectual disability (Anum, 2011; Hervie, 2013; Nebbah, 2010). Moreover, none of the studies specifically examined spirituality and communalism (family/community support systems) as sources of strength for primary caregivers of children with intellectual disability. Therefore, much remains to be done relative to the utilization of African cultural values of spirituality and communalism (family/community support systems) as coping strategies among Ghanaian primary caregivers of children with intellectual disability, since these
values are generally known as protective coping mechanisms for most people of African descent, including Ghanaians (Belgrave & Allison, 2006; Gyekye, 2003; Utsey et al., 2004).

Additionally, many of the existing studies on primary caregivers of children with intellectual disability have utilized coping measures meant to assess extant categorization of coping strategies used in Western cultures (problem-focused and emotion-focused coping) without utilizing any culture-specific coping measure to assess the influence of culture on coping. (Neblett et al., 2010; Utsey et al., 2000).

The current study sought to increase an understanding of the role of African cultural values in successful coping among primary caregivers of children with intellectual disability. Specifically, the study examined how Africentric values (e.g. spirituality, communalism/family and community support systems) moderate the impact of stress on psychological health among primary caregivers of children with intellectual disability in Ghana. Additionally, the study investigated how stress and psychological health relate to being a primary caregiver of a child with intellectual disability in Ghana.

A cultural conceptual model such as the Africentric model which values spiritual and collective strengths to survival among people of African descent was utilized (e.g. Azibo, 1996; Belgrave & Allison, 2006). It is expected that the results of this study will help irradiate the lived experiences of mothers parenting a child with intellectual disability in the Ghanaian context and inform the development of culturally sensitive intervention programmes including the supports necessary to care for their children, themselves, and their families. This study also moved a step beyond existing studies to utilize the mixed methods approach which required the collection and analysis of both quantitative and qualitative data to provide detailed and empathetic understanding
of the experiences of primary caregivers of children with intellectual disability in the Ghanaian cultural context.

**Aims of the Study**

**Main Aim**

To gain a better understanding regarding the relationship of stress, Africentric worldview, and psychological health among primary caregivers of children with intellectual disability.

**Specific Aims**

1. To examine how caregiving stress and psychological health relate to being a primary caregiver of a child with intellectual disability.
2. To examine how Africentric values (spirituality and communalism) influence the relationship between stress and psychological health.
3. To examine whether Africentric worldview predict the adoption of Africultural coping strategies.

**Relevance of the Study**

This study is relevant to researchers, mental health professionals, government, non-governmental agencies, and primary caregivers that have interest in issues regarding parenting children with intellectual disability.

This study highlights the influence of African cultural values on the psychological health of primary caregivers and other groups who suffer from discrimination and stigmatization from society. The results of this study would serve as a model for continued research into specific family
strengths based on their cultural values and to create intervention programmes based upon those strengths.

The results of this study would reorient training programmes to include the effectiveness of cultural values that propel families to cope with problems associated with the management of children with intellectual disability. This research would further prompt the need to examine the cultural competence of mental health professionals and the impact on family and child outcomes.

As regards government and nongovernmental organizations, the results of this study would inform institutions in advocacy campaigns to promote knowledge on the influential nature of African cultural values in coping with the stress of raising children with intellectual disability.

The final potential relevance of the study is the focus of research lenses on Ghanaian primary caregivers of children with intellectual disability who are often ignored in research as well as in therapy. This study encourages primary caregivers to rely on their cultural values of coping which would in turn help them to adequately deal with the stress associated with raising their children with intellectual disability.
CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter provides an overview of theoretical and empirical information that guided this study. The review begins with the theoretical frameworks which guided the study; the Transactional model of stress and coping (Lazarus & Folkman, 1984) and the Africentric model (e.g. Azibo, 1996; Belgrave & Allison, 2006). These frameworks provide a theoretical understanding of the relationships among stress, coping resources, and psychological health outcomes. However, the Africentric model is used to expand the transactional model such that culturally relevant dimensions of coping are recognized as essential in understanding primary caregivers’ responses to stress. Secondly, the chapter presents a review of empirical literature, reflecting studies on stress, psychological health, and coping in Western cultures, cross-cultural studies, and studies in African and Ghanaian primary caregivers of children with intellectual disability. Lastly, a conceptual model for understanding the moderating role of Africentric worldview on the relationship between parenting stress and psychological health is proposed. The theoretical frameworks were selected because of their relevance for studies on stress and coping among people of African descent.

Theoretical Frameworks

Transactional model of stress and coping (Lazarus & Folkman, 1984). The transactional model is premised on the assumption that individuals only experience stress when they appraise a situation as harmful and beyond their resources with which to cope (Lazarus & Folkman, 1984). Appraisal is influenced by individuals’ beliefs, attitudes, expectations, and motives (Lazarus,
Lazarus and Folkman (1984) identified appraisal as either primary or secondary. Primary appraisal involves an individual’s initial evaluation of an encounter in terms of the values, goals, and beliefs and what psychological outcome may emerge, whereas secondary appraisal involves an individual’s evaluation of an event in terms of what coping resources are available to deal with the situation (Lazarus & Folkman, 1984).

Hence, the way an individual evaluates the significance of an event for one's wellbeing (i.e. threat to wellbeing) determines whether the person will experience stress and the coping strategy the person adopts in dealing with the stress (Lazarus & Folkman, 1984). Thus, if there is any potential threat to an individual’s wellbeing in the transaction, the person uses secondary appraisal to determine if the harmful situation can be prevented or wellbeing can be enhanced. The result that occurs between whether the situation is harmful or challenging leads to the utilization of coping resources (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) asserted that, the combination of appraisal and coping efforts lead to outcomes such as emotional wellbeing, functional status, and healthy behaviours.

Coping refers to efforts made both cognitively and behaviourally to manage specific external or internal stressors that are perceived as exceeding the resources of a person (Lazarus & Folkman, 1984). According to Folkman and Moskowitz (2004), coping is often initiated in an emotional environment and strongly related to managing and regulating the emotional distress throughout the stress encounter. The authors placed coping strategies into two main categories: problem-focused and emotion-focused coping. Problem-focused strategies, on one hand, involve an individual making efforts to change the stressful situation by confronting the problem and generating strategies to deal with it. Examples include; taking direct action to solve problems, seeking social support, and positive reappraisal. On the other hand, emotion-focused coping
strategies involve efforts at regulating one’s emotional response to a stressful situation. Examples include: denial, reframing, distancing, wishful thinking, escape-avoidance coping, and self-blame. Research demonstrates that problem-focused coping is more favourable when a situation is appraised as changeable and is often linked to better wellbeing (Lazarus & Folkman, 1984). However, emotion-focused coping is more favourable in situations that cannot be changed, and has often been associated with poor psychological wellbeing (Lazarus & Folkman, 1984).

An interesting observation of this model is that, the effectiveness of a coping strategy is determined by the transaction between the specific stressor and the coping strategy used to manage the stressor and at best evaluated by the subsequent emotions, and not prejudging the usefulness of particular coping strategies (Folkman, 2001; Folkman & Moskowitz, 2004).

The transactional model has since been revised (Park, 2010; Park & Folkman, 1997). Meaning-making has been proposed as adaptive in dealing with chronic and uncontrollable situations. Meaning-making encompasses an individual's values, beliefs, and goals in the appraisal and coping process (Park, 2010). Meaning-making is involved in cognitive appraisal and reappraisal to determine successful adjustment under stressful events that are either chronic or not easily restored by coping strategies (Park, 2010). Under uncontrollable or low control situations such as serious illness, loss, and trauma which do not respond to direct problem solving, meaning-making has been found to be most effective (Park, Folkman, & Bostrom, 2010). Whilst, an individual’s ability to create meaning when faced with a stressful event often promotes successful coping and adjustment (Larner & Blow, 2011; Park, 2010), an individual’s inability to create meaning leads to unsuccessful coping and psychological distress (Mattis, 2000).
On the whole, although, the transactional model of stress and coping have been used to examine the psychological consequences of stress and coping in various populations including parents of children with disabilities (e.g., Peer, 2011; Pottie & Ingram), the model has been criticized in a number of ways. Firstly, despite Lazarus and Folkman’s conceptual implication in their stress and coping theory that a person’s specific cultural values and beliefs affect their appraisal of stress and adoption of coping strategies, their theory has been described as limited in its universalizing and individualizing coping and not addressing the unique role of culture in coping among people of diverse cultures (Hobfoll, 2001; Slavin et al., 1991; Wong & Wong, 2006). Secondly, there are suggestions from scholars that the transactional model neither tested culture-related variables in their model of stress and coping, nor did they provide a culturally relevant framework through which people of different cultural backgrounds cope with stressful events in their lives (Hobfoll, 2001; Slavin et al., 1991; Utsey et al., 2000). Research has shown that people of diverse cultures may appraise and cope with stress differently (Chun, Moos, & Cronkite, 2006; Hobfoll, 2001; Lam & Zane, 2004).

*Cultural Context of Coping.* Culture influences the way people evaluate and cope with stress (Chun et al., 2006; Hobfoll, 2001; Utsey et al., 2000). Culture refers to that complex whole which includes knowledge, beliefs, art, morals, law, custom, and any other capabilities and habits acquired by man as a member of society (Sarpong, 2002:40). Slavin et al. (1991) proposed that culture affects primary and secondary appraisal of events. According to them, primary appraisal should depend on the link between the situation and the cultural understanding of it. Whilst some cultural groups may perceive the situation as a personal problem, other cultural groups may perceive a stressful situation as a family or community problem. With regards to secondary
appraisal, belonging to a particular cultural group affects the adoption of coping strategies (Lam & Zane, 2004; Slavin et al., 1991; Utsey et al., 2000; Utsey et al., 2004).

Moreover, research has shown that since the individual is part of a group or society, coping with stressful events would involve the collective efforts of both the individual and the group (Aldwin, 2007; Chun et al., 2006; Hobfoll, 2001). Studies have shown that people in collectivist cultures endure stress through their relationship with their families, neighbours, religious institutions, and cultural groups they belong to (Hobfoll, 2001; Kuo, 2010; Lam & Zane, 2004).

Utsey et al. (2000) asserted that the existing coping models including the transactional model are firmly rooted in the Eurocentric worldview and do not adequately capture coping strategies utilized by people of African descent. These criticisms became evident in a recent study, where Neblett et al. (2010) found a negative relationship between Africentric worldview and emotion-focused coping, but no relationship between Africentric worldview and problem-focused coping. The authors suggested that the coping behaviours of people of African descent may be influenced by their worldview (i.e. Africentric worldview) which is not adequately captured by traditional or existing coping measures developed from a Eurocentric worldview.

Coping strategies frequently used by people in non-Western cultures including African cultures are prayers, meditations, religious service attendance, family, and social support networks found to be associated with their worldview (Daly, Jennings, Beckett, Thus, & Leashore, 1995; Parham, 2009; Utsey, Bolden, Lanier, & Williams, 2007). Utsey et al. (2007) noted that while these strategies are not only utilized by African Americans or people of African descent, they have been found to have a preference for culturally specific coping strategies (e.g. spirituality and communalistic coping).
The seminal works of Jackson and Sears (1992), Slavin et al. (1991), and Utsey et al. (2000) among others, emphasized the importance of culture and coping among people of African descent. Utsey et al. (2000) adopted and utilized the Africentric or African worldview as a conceptual framework to develop a culture-specific coping model known as the Africultural Coping Systems Inventory (ACSI). The coping model comprises four main components namely; spiritual-centered coping, collective coping, cognitive-emotional debriefing, and ritual-centered coping (Utsey et al., 2000). By and large, Africentric model has been found as an alternative model to existing stress and coping models as it considers the influence of culture in appraising and coping with stressful events (Belgrave & Allison, 2006; Jackson & Sears, 1992; Neblett et al., 2010; Utsey et al., 2000). The Africentric model allows for a profound analysis of culturally relevant coping responses often associated with people of African descent.

The preceding discussion makes it plausible for the current study to embrace the Africentric model as a cultural perspective on coping in which to examine the interactions among Africentric/African centered cultural coping (e.g. spirituality, communal values), stress, and psychological health among primary caregivers of children with intellectual disability in Ghana.

_Africentric Model._ Research has demonstrated that the Africentric model, also known as Africentric worldview, addresses the important role of culture in coping among people of African descent. For example, Schiele (2000) asserted that Africentric values and beliefs are very essential to the cultural development of Africans. Research arguments have been made to the effect that Africentric worldview is a reflection of the basic cultural values and traditions of most people of African descent all over the world (Belgrave & Allison, 2006; Kwate, 2003; Utsey et al., 2004).

A myriad of perspectives exist on the nature of the Africentric worldview (Azibo, 1996; Kambon, 1992; 2003; Myers, 1988; Nobles, 1991). However, the primary theoretical perspectives
evaluated in this study are the Nguzo Saba or Seven Principles (Karenga, 1980), the African Self-consciousness theory (Kambon, 1992), Optimal Africentric Worldview theory (Myers, 1988), and Azibo nosology (Azibo, 1996). These perspectives have spirituality, communalism/collectivism, and affective awareness as part of their core value system.

Theoretical Perspectives of Africentric Worldview

Nguzo Saba is a Swahili word representing the seven basic principles of the African culture including: unity, self-determination, purpose, collective work and responsibility, cooperative economics, creativity, and faith (Karenga, 1996). Nguzo Saba represent principles of Kawaida theory (an African philosophy of cultural and social change paradigm) (Karenga, 1997). These principles correspond to Africentric values which are considered universal human survival values, applicable to all people of African descent (Karenga & Karenga, 2007).

African Self-Consciousness theory (ASC) was postulated by Baldwin and Bell (1985). Baldwin, later became known as Kobi Kambon. Kambon’s contribution to Africentric worldview focused on the development of the African personality through identification with African/African American culture. According to this theory, Africentric worldview is rooted in the principles of communalism and interdependence, collective survival, and corporate responsibility towards affirming African life, liberation, and cultural tradition (Kambon, 1992; 2003). According to Kambon, the African Self-Consciousness theory (ASC) is an innate collective unconsciousness defined by the concept of spirituality, a dynamic energy that allows the self to merge the past and present cultural and historical experiences to develop a sense of self. Kambon’s personality theory described two types of African personality namely; the African Self-Extension Orientation (ASEO) and the African Consciousness (Kambon, 1992; 2003).
The AESO is considered a basic component of the African personality and is further regarded as the unconscious component of the African personality (Baldwin, 1981). This component also provides some basic African-derived behaviours and functioning for African heritage people. The other personality component called the African Self-Consciousness (ASC) refers to the conscious expression of the African personality (Baldwin, 1981). Moreover, this component is influenced by both genetic and environmental factors. There has been an extension of the ASC construct, which is called Cultural MisOrientation (CM) found among African Americans and represents a variation in the behavioural and psychological functioning of the ASC (Kambon, 2003; Kambon & Bowen-Reid, 2010). In this new African personality, one’s Africentric worldview is replaced with a non-Africentric worldview (Kambon, 2003; Kambon & Bowen-Reid, 2010). Research has shown that Kambon developed the African Self-Consciousness scale to measure the African personality and to assess how African Americans feel about African/African American culture associated with racism (Baldwin & Bell, 1985).

Myers (1988), described the Africentric worldview as an Optimal Africentric worldview which focuses on the significance of ancient and traditional African culture as an optimal frame of reference for all people’s mental health functioning (Myers, 1988). Optimal theory emphasizes the interdependence and interrelatedness of spiritual, mental, physical, social, and environmental wellbeing. Myers (1988) describes the Africentric worldview as an alternative, universal worldview that is “centered in Africa as the historical point of generation” (Myers et al., 1996, p. 19).

According to the Optimal Africentric theory, an Africentric worldview is characterized by both material and spiritual reality, value for interrelatedness, honesty, integrity, trustworthiness, and compassion and self-knowledge as opposed to the more material, external criteria such as
personal appearance, academic degrees, possessions, and renown associated with the Eurocentric worldview or what she calls suboptimal worldview. A suboptimal worldview has been found to be associated with psychological dysfunction, and is not limited to African Americans (Myers, 1998). Optimal Africentric worldview is associated with good physical and mental health as well as social justice (Myers, 1988).

Azibo (1996) contributed to Africentric worldview through his development of the Azibo nosology, a system of diagnosing diseases and disorders among Blacks with psychological problems (Atwell & Azibo, 1991). Azibo does not dispute the effectiveness of Eurocentric diagnostic systems among people of African descent, but contends that, to enhance a healthy African life, therapeutic interventions should be culturally sensitive and address disorders peculiar to the African personality (Azibo, 1996). This system has been found to be effective in diagnosing psychological conditions among African Americans (Atwell & Azibo, 1991).

Disparities exist among scholars as to whether an Africentric worldview is biologically determined (Kambon, 1992; 2004) or exclusive to African Americans. Research has however, shown that Africentric worldview is a reflection of the basic cultural values traditions among most people of African descent (Belgrave & Allison, 2006; Kwate, 2003; Nobles, 1991). According to Egbeke (2000), though the African continent is made up of diverse tribes, languages, and values, there are similarities in values of communalism, family system, and traditional religion which suggest a common ethos among people of African descent.

Belgrave and Allison (2006) argued that the possession of Africentric values by people of African descent does not refute diversity in values and customs among Africans on the continent and other parts of the world. According to the authors, people of African descent may have a range
of African values alongside Eurocentric values, and people of European descent may also have both Eurocentric and African values. Research has shown that there are shared cultural values that are unique to people of African descent, and which support an African reality different from Western reality (Nobles, 2013).

Regardless of the perspective on some shared cultural values among people of African descent, some researchers (e.g. Amuleru-Marshall & Amuleru-Marshall, 2013; Appiah, 1997) have raised strong arguments against generalizing Africentric values to all people of African descent. Appiah (1997) argued that Africentrism is a misconception as it seeks gratification in the racially focused judgment of the Eurocentric worldview as well as attempting to create cultural unity among all people of African descent. Meanwhile, other researchers have suggested that the Africentric and Eurocentric worldviews should not be perceived as mutually exclusive; instead they should be perceived as interrelated and complimentary (e.g. Schreiber, 2000).

**Africentric Values**

Many scholars have identified several Africentric values (Akbar, 1991; Belgrave & Allison, 2006; Randolph & Banks, 1993). The values comprise spirituality (belief in a being or force greater than oneself); communalism/collectivism (emphasis on cooperation); sensitivity to affect (acknowledging and understanding emotional and affective states of others); time orientation (equal importance attributed to past, present, and future); Orality (preference for receiving stimuli and information orally); Verve and rhythm (rhythmic and creative behaviour); and Balance and harmony with nature (balance between one’s mental, physical, and spiritual states). These values are in contrast to the Eurocentric values characterized by individualism, materialism, and future time orientation (Akbar, 1991; Belgrave & Allison, 2006).
However, these values could also be found in people of other collective cultures including Asians, Native Americans, and Latinos (Gaines, Larbie, Patel, Pereira, & Sereke-Melake, 2005; Zea, Quezada, & Belgrave, 1994). For example, though, Gaines et al. (2005) found that people of African descent scored higher on collectivism, familism, and romanticism, than people of European descent, they did not find significant differences on scores of spirituality and individualism. Moreover, people of African descent and Asian descent did not differ on any of the cultural values.

Africentric values relevant to the current study are; spirituality and communalism (e.g. family and community support system) which have been indicated by scholars of the Africentric worldview (e.g. Jagers & Mock, 1993; Schiele, 2000) as relevant to psychological adjustment.

**Spirituality.** Spirituality is a central feature of an Africentric or African centered worldview (Ani, 1997; Belgrave & Allison, 2006; Nobles, 1991). According to Schiele (2000), spirituality refers to the non-material or invisible substance that connects all elements in the universe. Additionally, people are perceived as spiritually connected to each other, with its origin from a universal source (Schiele, 2000). Spirituality has generally been associated with a belief in or a relationship with a Supreme Being (Belgrave & Allison, 2006). Africans have a strong belief in God or a Supreme Being and respond to events that happen to them in a spiritual manner (Belgrave & Allison, 2006; Gyekye, 2003; Steyne, 1990). Among Africans, there is an absolute dependence on God or the Supreme Being for everything (Gyekye, 2003; Oduyoye, 1995; Steyne, 1990). This reliance on God or the Supreme Being is expressed in symbols such as the well-known *Gye Nyame* in the Akan language of Ghana, meaning (without God nothing holds together) (Oduyoye, 1995). Majority of Ghanaians are spiritual and have their spirituality embedded in virtually everything
including naming, dressing, and all other aspects of their lives (Atiemo, 2010; Gyekye, 2003; Reich, 2012).

One major concern in research has been the definition of spirituality. Spirituality and religion have been used interchangeably as both have been associated with a search for the sacred including concepts of God, a higher power, ultimate reality, and the transcendent (Hill et al., 2000; Pargament, 1999). Over the years, however, researchers have not reached a consensus on the definition of spirituality and religion (Hill et al., 2000; Mattis, 2002; Zinnbauer, Pargament, & Scott, 1999). Spirituality has been associated with an expression of one’s belief in God or a Supreme Being, connections with oneself, others, nature, or God (Meraviglia, 1999; Wilkinson, 2012). Religion is also associated with organized beliefs and practices that nurture a relationship with God (Meraviglia, 1999; Wilkinson, 2012). Blando (2006) asserted that spirituality concerns a relationship with others and comprises three components, including: connection to someone or something beyond oneself, sense of compassion for others, and desire to contribute to the good of others.

Despite the proposed differences in spirituality and religion, Hill et al. (2000) noted that, spirituality and religion are related and not independent concepts. Among African Americans, Martin and Martin (2002) asserted that Black religiosity is a manifestation of Black spirituality often perceived in terms of organized religion and denomination. Therefore, among people of African descent, including Ghanaians, spirituality is not restricted to a belief in a Supreme Being but is also associated with relationships with God and others in an organized manner.

Communalism. Communalism is another traditional value of people of African descent (Broodryk, 2006; Gyekye, 2003; Oduro, 2006). The central theme of the communal orientation of the African culture is summed up in the Swahili proverb, “I am, because we are; and since we are,
therefore I am” (Mbiti, 1991, p. 106). According to Boykin, Jagers, Ellison, and Albury (1997), communalism is characterized by interdependence and cooperation among people of African descent and where the social identity is valued over individual identity. Among people of African descent, no distinction exists between the self and others (Nobles, 1991). People are empathetic and compassionate to the needs of one another. Broodryk (cited in Broodryk, 2006) describes the communal nature of Africans in the Zulu language of South Africa as *Ubuntu*, meaning ‘humanness’ and in the Akan language of Ghana as ‘*biakoye*’ meaning “oneness” (Oduro, cited in Broodryk, 2006).

A significant communal feature of the African culture is the extended family system (Boyd-Franklin, 2003; Gyekye, 2003; Nukunya, 2003). Research has shown that the family is very essential to the collective survival of people of African descent (Boyd-Franklin, 2003; Gyekye, 2003; Nukunya, 2003). The family does not only refer to the father, mother, and children; it is largely an extended system comprising blood relations and non-relatives such as friends, neighbours, and church members with a sense of obligation towards the development of each other (Boyd-Franklin, 2003; Gyekye, 2003; Nukunya, 2003). According to Gyekye (2003), in the African context, the value of communalism is inculcated in a person during the socialization process.

Generally, the communal or collective responsibility for children highlight the value of children within African and African-American communities and this is reflected in the African proverb “It takes a village to raise a child” is often used to elucidate the significance of this concept (Mbiti 1977, p. 23). Turner (1991) asserted that, in African communities, parenting is a collective responsibility compared to other communities. The sick, aged, and the weak are taken care of by the family (Okafor, 1974). The belief in the extended family system is so strong that members
perceive it as a duty to assist each other emotionally and financially even when they are
geographically apart (Billingsely, 1992; Gyekye, 2003). Research has shown that the wellbeing of
the group takes precedence over the wellbeing of the individual (Schiele, 2000).

Currently, in Ghana and other African countries, modernization and urbanization are
causing social changes in society such that the strength of interdependence often associated with
the extended family system is eroding (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta,
2005; Madukwe & Madukwe, 2010; Nukunya, 2003). Many family members who used to reside
and eat under one roof are dispersing due to urbanization and difficult economic conditions
(Nukunya, 2003). People are now concentrating on their nuclear families due to limited incomes,
space, and time and this in itself have been found to promote individualism (Wolf, 1994).
Currently, the saying that “each one for himself God for us all” is gradually replacing “everyone
is the brother’s keeper”. Though the family is less of an extended one as was in the past, people
are still socialized to perceive themselves in relation to others and to provide support for each other
(Gyekye, 2003; Madukwe & Madukwe, 2010).

Communalism contrasts the individualistic nature of people of Western descent (Belgrave
& Allison, 2006). However, the uniqueness of the individual is also recognized and cannot be
weakened by belonging to the community (Gyekye, 2003). Gyekye (2003) suggested a balance
between communalistic and individualistic responsibilities.

The Africentric worldview provides a basis for understanding the role of spirituality and
family/community support systems in coping among Africans, and particularly Ghanaians.
Africentric Worldview and Psychological Health

According to Myers et al. (1996), Africentric worldview protect people of African descent from the harmful effects of stress. Individuals who adhere to the values of Africentric worldview perceive less stress (Jackson & Sears, 1992; Neblett et al., 2010). Among Ghanaians, Jones (2003) found that individuals who endorsed the values and beliefs of TRIOS (time, rhythm, improvisation, orality, and spirituality) similar to the Africentric worldview have less stressful lives than those who do not. Research has shown that one mechanism through which Africentric worldview influences psychological adjustment is through its moderating effect (Neblett et al., 2010; Neblett & Carter, 2012; Truitt, 2011; Wang et al., 2013). Whilst spirituality predicted spiritual coping (Smith III, 2012), Africentric values did not predict spiritual coping but predicted collective coping (Conner, 2003). In some studies, the protective effects of Africentric worldview were not found (Anderson, 2007; Jackson, 2008).

Spirituality and Psychological health. Spirituality has been given considerable attention by researchers regarding its use in appraising and coping with stressful situations among people of African descent (Belgrave & Allison, 2006; Reutter, 2012; Smith III, 2012; Taylor et al., 2009). People of African descent perceive spirituality as a source of strength in times of adversity and enhance psychological health (Gyekye, 2003; Houltberg, Henry, Merten, & Robinson, 2011; Watlington & Murphey, 2006). Spiritually oriented individuals are able to reframe stressful events as challenging or less threatening (Newton & McIntosh, 2010; Park, 2005), as an opportunity for growth (George, Larson, Koenig, & McCullough, 2000), and promotes hope and optimism (Ciarrocchi, Dy-Liacco, & Deneke, 2008; Levin & Chatters, 1998). On the contrary, spirituality does not always mitigate the impact of stress on mental health (Jackson, 2008; Smith, 2003).
An increasing number of studies demonstrate how spiritual and religious beliefs influence psychological health of parents of children with intellectual disabilities (e.g. Belgrave, 1998; Jegatheesan, Miller, & Fowler, 2010; Tarakeshwar & Pargament, 2001). Spiritually oriented parents enjoyed church attendance which was linked to higher levels of happiness (Biesinger & Arikawa, 2007). Additionally, spiritual beliefs provide a basis for positively interpreting a child’s disability (Belgrave, 1998; Durà-Vilà, Dein, & Hodes, 2010; O’Hara & Bouras, 2007; Marshall, Olsen, Mandeleco, Dyches, Allred, & Sansom, 2003) or negatively interpreting it as a punishment for past sins (Thomas, Dowling, & Nicoll, 2004).

**Communalism (family/community support systems) and Psychological health.** Communal values of support from family, friends, and community serve as protective coping strategies in times of difficulty (Gaylord-Harden & Cunningham, 2009; Pierre, 2013). Most people of African descent rely on informal support networks such as families, friends, neighbours, and church members in times of crises (Daly et al., 1995; Jones, 2007, Taylor, Chatters, Hardison, & Riley, 2001). Among primary caregivers of children with disabilities, family and social support systems have arguably been found to reduce the stress associated with having a child with disability and improved the psychological health of parents (Brannan & Heflinger, 2002; Ha et al., 2011; Mashego, 2005). Nevertheless, there are some indications that these support systems may not always be received or function as expected (Ambikile & Outwater, 2012; Edwardraj et al. 2010; Gallagher & Whiteley, 2012; Plumb, 2011). Munsell, Kilmer, Cook, and Reeve (2012) found that social connections do not moderate the relationship between caregiver strain and psychological health.
Ghanaians and Africentric values of coping

Most Ghanaians have been found to have a worldview similar to the Africentric worldview where beliefs and values associated with interpretation of events are based on their spirituality and communal nature (Gyekye, 2003; Oduyoye, 1995; Reich, 2012). Research has shown that most Ghanaians resort to the use of spiritual resources to resolve their problems in life (Atiemo, 2010; Gyekye, 2003; Nukunya, 2003). Schreoder, Akotia, and Apekey (2001) found in their study on coping among Ghanaian teachers that, they generally cope with having faith in God or praying and thinking about the problem and making efforts to manage the situation. In a recent study, Bonsu, Aziato, and Clegg-Lamptey (2014) reported that breast cancer patients coped with their condition by having faith in God and receiving support from families, colleagues, health professionals, and spiritual leaders. With regards to raising children in the Ghanaian culture, the kinship system comprising family, friends, and neighbours is very helpful in coping with difficult situations (Gyekye, 2003; Nukunya, 2003). In considering the role of culture in coping among primary caregivers of children with intellectual disability, it is important to present a brief overview of the experiences of Ghanaian parents of children with intellectual disability.

Ghanaian Parents of Children with Intellectual Disability

Ghanaian parents live in a culture where attributions about intellectual disabilities are deeply entrenched in the traditional spiritual belief systems (e.g. Anthony, 2009; Anum, 2011; Avoke, 2002). This is in contrast to environmental factors such as mercury in the blood from immunizations causing disability (e.g. autism) in Western cultures (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). In Ghana, intellectual disability is perceived as a curse and punishment from the gods, and caused by supernatural or evil forces (Avoke, 2002).
Ghana comprises several ethnic groups with specific names for intellectual disability. For instance, a child born with intellectual disability (e.g. Down syndrome) is referred to as “nsuoba,” meaning a child from the river gods in the Akan language; “asotowo” meaning idiot or fool, and “buulu” meaning reduced mental abilities in the Ga language (Avoke, 1997, as cited in Agbenyega, 2003). There is also a belief that wealthy parents of children with intellectual disability use their children for “juju”, meaning the child is used for making money (Inclusion Ghana, 2011).

These beliefs are so deep-seated that even the introduction of Christianity and Islam could not entirely eradicate the interpretation of intellectual disability in spiritual terms. Specifically, people belonging to both Christian and Islamic faiths perceive intellectual disability as the will of God (Andin, 2008; Hervie, 2013; Jegatheesan et al., 2010). Mashego (2005) asserted that the inability of Black mothers of children with behavioural problems to know the cause of their child’s condition could be due to their external locus of control and attributing their child’s situation to supernatural causes such as witchcraft or punishment from God or ancestors. However, recent studies have shown that people in Ghana and Asian countries hold both biomedical and theological beliefs about the causes of intellectual disability (Andin, 2008; Kaur, 2011).

Researchers have noted that these beliefs inform negative reactions in the form of disrespect and social exclusion experienced by families of children with intellectual disability from family members and the larger society (Anum, 2011; Avoke, 2002; Baffoe, 2013; Hervie, 2013). Moreover, research has shown that the stigma to parents with intellectual disability cause emotional burden to parents (Anum, 2011; Avoke, 2002; Gray, 2003) and often lead to physical and psychological isolation of parents and their children (Anum, 2011; Gray, 2002; Hervie, 2013). Additionally, in some communities, the negative social interactions lead some families to abandon
their children at river banks to be taken up by the river or even get them killed at birth as it is happening in the Bongo district of northern Ghana (Ghana News Agency cited in Anum, 2011).

For many African and particularly Ghanaian parents, spiritual explanations and healing are sought for their child’s condition (Hartley et al., 2005; Hervie, 2013). Hartley et al. (2005) asserted that parents of children with disability often turned to God and spiritual leaders as a form of coping strategy for raising their children with disability. Furthermore, the extended family system provide emotional support for parents in caring for their children (Anum, 2011; Hervie, 2013; McNally & Mannan, 2013). Moreover, some parents accept and show love to their children (Anum, 2011; Govender, 2002). However, Hartley et al. (2005) found among carers in Uganda that, they were not adequately supported by the family and this attitude was attributed to the breaking down of the extended family system. Thus, the question that remains to be answered is whether these African cultural values serve as protective mechanisms for this sample of primary caregivers of children with intellectual disability in Ghana.

In the current study, psychological health served as the outcome variable on which the Africentric values and parenting stress were measured. The next section begins with related studies addressing psychological health, stress, and coping among primary caregivers raising children with intellectual disability in Western or individualistic cultures as well as studies in non-Western or collectivist cultures including Asia, Africa, and Ghana.

**Review of Related Literature**

Globally, there is a dearth of literature on the interactions among cultural coping, stress, and psychological health among primary caregivers of children with intellectual disability. The current review is based on general literature on stress, coping, and psychological health in primary caregivers of children with intellectual disabilities in Western countries. It was then narrowed
Primary Caregivers of Children with Intellectual Disability and Stress

Several studies have shown an extensive array of factors influencing primary caregivers’ experience of stress and psychological health. One key variable that has been associated with parenting stress and psychological health is the presence of disability or condition of the child.

Gupta (2007) compared stress levels among caregivers raising children with developmental disabilities, AHD, HIV/AIDS, and asthma. Caregivers were selected from a pediatric clinic that served low income families from various cultural backgrounds. Caregivers were placed in four categories including: behavioural, developmental, medical, and control, based on their child’s condition. There were 50 caregivers of children with ADHD, 28 caregivers of children with developmental delays, and 46 caregivers of the medical group made up of children with HIV/AIDS and asthma. The control group comprised parents of children with chronic illnesses such as HIV, asthma or typically developing children. Using one way analysis of variance, results indicated that caregivers of children with behavioural problems such as ADHD and developmental disorders reported significantly higher levels of stress compared to caregivers raising typically developing children and chronic medical problems.

Among parents of children with autism, Duarte et al. (2005) concluded that having a child with Autism Spectrum Disorders (ASD) is the main factor associated with a mother’s stress. The authors also asserted that parents having little affection, low interest in people, and being an older mother (34-45 years) were found to influence parenting stress. Davis and Carter (2008) reported that impaired social relatedness in children with autism were related to the overall parent stress and parent-child interactions.
Plant and Sanders (2007) reported in their study that the problems parents experienced in completing specific caregiving responsibilities, child behavioural problems, and level of child disability were significant predictors of level of parental stress. In addition, parents’ perceived sense of personal control of caregiving was associated with higher stress. Similarly, Brannan and Heflinger (2001) found in their study that worry, guilt, sadness, fatigue, embarrassment, resentment, and anger associated with the child were strong indicators of parental distress. Additionally, Hastings and Brown (2002) found that difficult child behaviour during care-giving tasks predicts parenting stress.

Similarly, Khamis (2007) studied predictors of parenting stress and psychological distress among 225 parents of children with mental retardation in United Arab Emirates. Using hierarchical regression analysis, the author found that child characteristics, parents’ demographic characteristics, and family environment significantly predicted stress and psychological distress. However, it was found that the child’s disability predicted psychological distress and not parenting stress. Spratt, Saylor, and Macias (2007) noted that caregivers of children with behavioural problems experienced more stress than those raising children with medical or developmental issues. Parents of children with disabilities have been found to have more demands of care than parents of children without disabilities (Daire, Munyon, Carlson, Kimemia, & Mitcham, 2011). It is worth noting that primary caregivers of children with intellectual disability often use the term “stressful” when talking about raising a child with autism (e.g. Gray, 2002).

Tomanik, Harris, and Hawkins (2004) investigated the relationship between behaviours of children with autism and maternal stress. Participants comprised 60 mothers of children diagnosed with a pervasive developmental disorder using DSM-IV criteria. The sample consisted of 56 (93%) white mothers, 3(5%) Hispanic/Latino mothers, and 1 Asian-American. The children were
between the ages of 2 and 7 years. Findings from the analyses revealed that two-thirds of the mothers had significantly elevated stress levels. Regression analyses also revealed that child maladaptive behaviour and child adaptive behaviour accounted for a significant proportion of the variance in maternal stress. Regardless of the significant relationship between child behaviour and maternal stress, the researchers noted that their inability to obtain information about the child’s intellectual functioning (i.e. IQ), made it impossible for them to determine if it was the diagnosis of autism or the child’s intellectual disability that was the major source of stress for mothers.

However, a recent study by Mitchell and Hauser-Cram (2008) and Patenaude (2011) did not find the presence or absence of a child’s diagnosis as predicting parenting stress. Smith, Matthew, Oliver, and Innocenti (2001) found that factors such as income, social support, and having time to interact with the child predicted parenting stress after controlling for the functioning of the child. Thus, increased exposure to stress places primary caregivers at higher risk for psychological symptoms.

**Primary Caregivers of Children with Intellectual Disability and Psychological Health**

Azeem, Dogar, Shah, Cheema, Asmat, Akbar, Kousar, and Haider (2013) conducted a cross-sectional study to assess the levels of anxiety and depression among parents of children with intellectual disability in Pakistan. The study was done among 198 parents, comprising 99 fathers and 99 mothers of 100 children with intellectual disability at a tertiary care hospital in Pakistan. The children were between the ages of 2–18 years. The parents were assessed for anxiety and depression using the DSM-IV criteria. Results of the study indicated a significant percentage of mothers (89%) had anxiety, depression, or both anxiety and depression together as compared to fathers. The authors also found a significant association between mother’s anxiety, depression, and
both and degree of intellectual disability of their children among mothers but not fathers. The results are quite inconsistent with findings that have found that mothers did not differ in their stress and depression levels from fathers though they scored higher on anxiety (Hastings, 2003). The findings of the study illuminate the psychological distress of parents of children with intellectual disability experience, however the study’s reliance on only the DSM-IV criteria and no self-report measures probably accounted for the very high levels of anxiety and depression. Moreover, the lack of comparison group of parents of healthy children does not allow for any basis of comparison on the mental health status of parents with healthy children.

In their study, Estes, Munson, Dawson, Koehler, Zhoe, and Abbott (2009) studied factors predicting psychological functioning among mothers of preschool children with autism and developmental delays. Fifty-one (51) mothers of children with autism (ASD) and 22 mothers of children with developmental delays (DD) without autism, ranging in age from birth to 68 months were involved in the study. The study determined how child characteristics influence parenting stress and psychological distress. Findings from the study indicated that higher levels of parenting stress and psychological distress were associated with having a child with autism compared with the developmental disability group. Additionally, higher levels of child problem behaviours was significantly related to increased maternal parenting stress and psychological distress for both mothers of children with ASDs and children with developmental delays, but unlike previous studies (Olsson & Hwang, 2001), the relationship was stronger in the DD group. The authors also found that daily living skills was not related to parenting stress and psychological distress.

Examining predictors of excess psychological morbidity in parents of children with intellectual disabilities, Gallagher, Phillips, Oliver, and Carroll (2008) used standardized self-report measures to assess thirty-two (32) parents of children with intellectual disabilities (autism,
66%); Down syndrome (22%); 12% of children with other syndromes (e.g., Cornelia de Lange), and 29 parents of typically developing children. The children ranged in age from 3 to 19 years. The authors found that parents of children with Downs’ syndrome and other syndromes did not differ from the parents of children with autism on the outcome variables and thus they were treated as one group in the analysis. Results showed that parents of children with intellectual disabilities reported high levels of depression and anxiety, leading to a criteria for clinical depression and anxiety compared to parents of typically developing children.

However, unlike other studies that indicated only the psychological distress of parents, in this study, psychological morbidity was strongly predicted by caregiver burden. The authors also found through further analysis that feelings of guilt dimension of caregiver burden was the greatest predictor of depression and anxiety. Gallagher and Whiteley (2012) discovered that parents of children with intellectual disability reported higher problems with their physical health than parents of typically developing children. This was however, not found by Seltzer, Greenberg, Floyd, Pettee, and Hong (2001).

Comparing families of children with intellectual disability and control families, Olsson and Hwang (2001) investigated the prevalence and severity of parental depression. The objective of this study is consistent with that of the current study which also explored depression as part of a parent’s psychological health. The sample size was 216 families of children with intellectual disability (207 mothers and 167 fathers) and 214 healthy control families (204 mothers and 167 fathers). Results from the study supported the hypotheses; mothers of children with autism had higher depression than mothers of children with intellectual disability without autism, but had higher levels of depression than fathers of children with autism, fathers of children with intellectual disability without autism, and healthy control mothers and fathers.
The researchers found that mothers of children with autism scored high on depression than mothers of children with intellectual disability without autism, but the latter group had higher depression scores than fathers of children with or without autism (Olsson & Hwang, 2001). All the groups scored higher than the control mothers and fathers. The authors also found that 45% of mothers of children with intellectual disability without autism and 50% of mothers of children with autism had elevated depression scores as compared to 15-20% of the other groups. Moreover, single mothers of children with disabilities had higher levels of depression than mothers of children with partners.

One significant strength of Olsson and Hwang’s study was the utilization of a large sample size which was able to detect about 15-20% of the other groups with depression. Bayat, Salehi, Bozorgnezhad, and Asghari (2011) found that parents of children with intellectual disability scored high on psychological symptoms such as hostility, anxiety, obsession, interpersonal sensitivity, psychoticism, somatization, and depression as compared with parents of typically developing children. Differences were not found on phobic anxiety and paranoid ideation states.

However, Baker, Blacher, and Olsson (2005) reported that parents of delayed and non-delayed preschoolers did not differ generally on depression or marital adjustment, though child behavioural problems were related strongly to scores on both measures. Olsson and Hwang (2008) also indicated that mothers of children with intellectual disability had lower levels of wellbeing than fathers and healthy controls. Though, the presence of the child with intellectual disability did not predict maternal wellbeing, their economic, and health problems predicted wellbeing.

Majority of the studies reviewed have focused on comparing parents of children with intellectual disability and healthy controls on their levels of stress and psychological health (e.g.
Gallagher & Whiteley; 2012; Olsson & Hwang, 2001). However, few studies have also compared parents of children with intellectual disability and chronic conditions and healthy controls on the same variables to determine how they differ.

In comparison to healthy controls, studies have shown that primary caregivers of children with sickle cell disease experienced increased family stress and distress (Thompson, Gustafson, Bonner, & Ware, 2002; van den Tweel, Hatzmann, Ensink, van der Lee, Peters, Fijnvandraat, & Grootenhuis, 2008). However, this difference was not found by Midence, McManus, Fuggle, and Davies (1996) in their study. Primary caregivers of children with chronic conditions have been found to experience significant high levels of stress and poor health (Allen & Marshall, 2010; Cousino & Hazen, 2013; Welkom, 2009). The psychological health of parents of children with sickle cell disease have often been associated with pain crises experienced by the child and financial problems that comes with high medical bills (Ievers-Landis, Brown, Drotar, Bunke, Lambert, & Walker, 2001).

It is worth mentioning that some studies have found similarities between primary caregivers of children with intellectual disability and other chronic conditions and how they differed from healthy controls (Hall, Neeley-Barnes, Graff, Krcek, Roberts, & Hankins, 2012; Magill-Evan, Darrah, Pain, Adkins, & Kratochvil, 2001; Nebbah, 2010). For example, Hall et al. (2012) found similarities in the level of stress and psychological functioning in parents of children with autism, cerebral palsy, Down syndrome, and sickle cell disease. Similarly, Magill-Evan et al. (2001) found that families of adolescents and young adults with cerebral palsy reported similar scores on family functioning and life satisfaction as families of adolescents without a disability. Nebbah (2010) found in her study that parents of children with intellectual disability and sickle cell disease did not differ significantly on depression scores but differed from the healthy controls.
However, some studies have not found the presence or absence of a child’s diagnosis as predicting parenting stress and depression (Mitchell & Hauser-Cram, 2008; Olsson & Hwang, 2008). Green (2007) noted that the emotional distress experienced by parents of children with disabilities is not related to the severity of disability but related to the intensity of social stigma towards people with disabilities in society. This was confirmed by Shin and Crittenden (2003) who also attributed high levels of depression in Korean mothers compared to American mothers to negative attitudes of society. Recently, Resch, Eliot, & Benz (2012) asserted that the child’s disability is not a strong predictor of depression in parents of children with disabilities compared to family and marital relationships. The above findings postulate a strong association between being a primary caregiver of a child with intellectual disability and psychological symptoms.

Primary Caregiving Stress and Psychological Health among Primary Caregivers of Children with Intellectual Disability

Over the years, parenting stress has been found as one of the predictors of psychological health, expressed as depression among parents of children with intellectual disability (Cramm & Nieboer, 2011; Jeffery, 2013; Whitson, Martinez, & Kaufman, 2011). Cramm and Nieboer (2011) utilized a cross-sectional design to study the psychological wellbeing of caregivers of children with intellectual disabilities. The study was made up of caregivers who were about to seek support and care outside. Additionally, it sought to identify the conditions under which psychological wellbeing and parenting stress are affected using parental stress as a mediating factor. Participants consisted of 147 parents of children from birth to 18 years. Results from multiple regression analysis indicated that parenting stress and the child’s depressive feelings significantly predicted depression. There was also an indirect relation of restricted caregiver’s social activities through parental stress. Jeffery (2013) examined the mediating role of parenting stress in the relation
between parent depressive symptoms and behavioural problems of the child. Fifty-eight (58) mothers were involved in the study measuring depression, stress, and the child’s behaviour problems using standardized measures. Findings from multiple regression analysis revealed that parenting stress mediated the relationship between parental depression and child behavioural problems.

Additionally, Whitson et al. (2011) examined a sample of 172 poor Black and Hispanic adolescent mothers, examining their levels of parenting stress, depression, child abuse potential, social support, and the development of their children. Results from multiple regression analysis showed an association between parenting stress and maternal depression. In addition, the authors found that parents reporting higher levels of depression and parenting stress were more likely to have infants with developmental delays, and the infants were at a greater risk for maltreatment.

By and large, a careful look at the above studies suggest that the relationship between type of primary caregiver, parenting stress, and psychological health need to be understood clearly in order to improve the lives of primary caregivers and their children. Whereas the relationship between being a primary caregiver of a child disability and psychological health has been established in literature, research examining what factors explain this relationship is sparse and deserves attention. The current study looks at how stress mediates the relationship between being a primary caregiver of a child with intellectual disability and psychological health.

Despite the high levels of stress and poor psychological health experienced by primary caregivers of children with intellectual disability and other chronic conditions, empirical evidence suggests that they also exhibit incredible resilience and mobilize resources to cope with their caregiving challenges. The past few years have seen research on families of children with
disabilities evolving from deficit-based approach to strength-based approach which focuses on coping strategies that promote the health of families of children with intellectual disability (Bayat, 2007; Hastings et al., 2002). An examination of coping among primary caregivers raising children with intellectual disability is especially relevant, as there are indications in research of greater reliance on spiritual and religious coping (Poston & Turnbull, 2004; Tarakeshwar & Pargament, 2001), family and community sources of support (Boyd, 2002; Pottie & Ingram, 2008; White & Hastings, 2004).

Coping among Primary Caregivers of Children with Intellectual Disability

Research has shown that when primary caregivers of children with intellectual disability are distressed, they often resort to religion to assuage their distress (Poston & Turnbull, 2004; Tarakeshwar & Pargament, 2001). Additionally, in a qualitative study of parents of children with disabilities of the Latter Day Saint Church in Provo, Utah, USA, Marshall et al. (2003) reported that parents describe having a child with a disability as a spiritual experience and their spiritual beliefs provided them with strength in raising their children. Studies have indicated that both Christianity and Islam contributed to guiding parents to perceive having a child with intellectual disability as a gain (Durà-Vilà et al., 2010; Skinner, Correa, Skinner, & Bailey, 2001), God’s gift for them (O’Hara & Bouras, 2007; Skinner et al., 2001), and to further accept their situation as a responsibility from God and not a burden (Jegatheesan et al., 2010; Skinner et al., 2001).

Contrary findings also exist on the effect of spirituality on parenting stress. For example, not all studies report positive effects of spiritual beliefs on psychological distress associated with raising a child with intellectual disability (Hastings et al., 2005; Skinner & Weisner, 2007). Among parents of children with special needs, Speraw (2006) reported that the church community was a
source of stress for families when they did not show their support and acceptance of children with special needs.

Parker, Mandleco, Roper, Freeborn, and Dyches (2011) argued that though differences existed on public religiosity in parents of children with disabilities and those with typically developing children, no significant differences were found in their levels of spirituality. The authors interpreted this finding as spirituality of parents not playing a significant role in the interpretation of having a child with disability. Gallagher, Philips, Lee, and Carroll (2014) found a positive association between spirituality and depression in parents of children with intellectual disability. Other studies have also reported that spiritual coping was the least coping strategy adopted by parents of children with intellectual disability (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010; Moawad, 2012).

Family and social support have also been found as protecting parents from stress and psychological distress. Pottie and Ingram (2008) conducted a study on stress, coping, and wellbeing in parents of children with autism. The moderating effects of coping on the distress experienced by parents as well as the wellbeing of parents were also examined. The sample consisted of 93 parents of children with autism who provided reports on their daily stress, coping responses, and end-of-day mood twice in a week. Results from multilevel modeling analysis showed that social support moderated the relationship between stress and mood. The authors suggest that social support can possibly enhance wellbeing and reduce daily distress in parents of children with autism.

Primary caregivers of children with disabilities seek more social support (Paster, Brandwein, & Walsh, 2009) than primary caregivers of typically developing children. White and Hastings (2004) selected 33 parents of adolescent children with moderate to severe intellectual
disabilities to examine parental wellbeing, social support, and child characteristics. Results from correlational analyses showed that parental wellbeing is associated with behavioural problems of the child and diagnosis of autism. Parents also reported the usefulness of informal support to their wellbeing. Similarly, Bromley, Hare, Davison, and Emerson (2004) interviewed 68 mothers of children with autism to examine facets of their psychological wellbeing including; family support and their satisfaction with services. Findings revealed that, about half of the parents reported high psychological distress, and this was associated with low levels of family support and having a child with higher behavioural problems.

Gerkensmeyer, Perkins, Scott, and Wu (2008) studied depressive symptoms among primary caregivers of children with mental health needs using mediating and moderating variables. One hundred and fifty-five (155) primary caregivers of children with mental health problems were examined for the severity of depressive symptoms and other variables that mediated or moderated the association of child behavioural problems with caregivers’ depressive symptoms. Results showed that 40% of participants scored 22 or higher on the Center for Epidemiological Studies Depression Scale, indicating severe depression. Additionally, perceived personal control, subjective distress, and role disruption were found to mediate the relationship between internalizing child behavioural problems and depressive symptoms. The authors also found that tangible social support moderated the relationship between internalizing behaviour problems and depressive symptoms. Intangible social support also moderated the relationship between externalizing behavioural problems and depressive symptoms. Other studies have found social support as not moderating the relationship between stress and physical health (Gallagher & Whitley, 2012), not related to parenting stress (Peer, 2011), and sometimes increasing stress (Plumb, 2011).
Whilst majority of the studies reviewed were conducted on Western samples and may not be directly applicable to non-western and/or African samples, findings highlight the idea that many primary caregivers of children with intellectual disability and other chronic condition experience much burden raising their children. The studies also revealed how the utilization of coping resources such as spirituality and family support strengthen primary caregivers through their journey of caregiving. In order to understand the role that stress play in affecting the psychological health outcomes associated with coping strategies, more research attention should be devoted to understanding potential mechanisms of primary caregivers’ coping behaviours. Further studies have been conducted in some non-western cultures to determine possible effects of the culture on coping behaviours of primary caregivers of children with intellectual disability.

Coping and Psychological Health (Cross-Cultural Studies)

In a cross-cultural study, Blacher and McIntyre (2006) examined cross-cultural differences in the impact of syndrome specificity and behavioural disorders of young adults with intellectual disability on their parents. Participants included 282 parents of young adults with different diagnosis of intellectual disability only, cerebral palsy, Down syndrome, and autism as well as different cultural groups involving 150 Anglo parents and 132 Spanish speaking Latino parents living in Southern California. Results from the study indicated that, young adults from both cultural groups exhibited behavioural disorders. Parents also reported similar maternal wellbeing across all the disability types. However, young adults with autism exhibited the highest level of behavioural problems and their parents reported lower wellbeing. Young adults with Down syndrome exhibited lower behavioural problems but their parents also had lower wellbeing. With regard to the cultural groups, Latino mothers were found to be more depressed and had lower
moral than their Anglo counterparts. Nevertheless, Latino mothers were more positive about having a child with intellectual disability.

McConkey, Truesdale-Kennedy, Chang, Jarrah, and Shukri (2008) studied the impact of having a child with disability on parent’s wellbeing and their coping strategies in the Irish, Taiwanese, and Jordanian cultures. The study was conducted in Northern Ireland, Taiwan, and Jordan. Participants included 206 mothers of children with a diagnosis of intellectual disability between the ages of 5–18 years. Using interviews, mothers in all three cultures reported low levels of mental health, high levels of child-related stress, and lesser family functioning, with the child’s behavioural problems as the strongest predictor of wellbeing. Further, the authors found that poor maternal wellbeing was not mitigated by access to professional supports or use of coping strategies. These results were consistent with a study by Azar and Kurdahi Badr (2006) who did not find any relationship between coping resources and maternal well-being. Unfortunately, like the other studies mentioned above, McConkey et al. (2008) used coping measures normed on Western samples, though the sample included parents from collectivist cultures who may have had different ways of coping. Contrary to their expectations, problem-focused coping did not reduce maternal stress, but emotion focused coping increased maternal stress.

In a qualitative study, Luong, Yoder, and Canham (2009) investigated coping styles of Southeast Asian parents raising a child with autism. Participants involved 9 Southeast Asian American parents belonging to the first-generation of Southeast Asian Americans. The study aimed to determine the impact of autism on coping styles and support systems of the family. Parents resided in northern California where their children attended school. Eight (8) of the participants were mothers and a father. The children were between the ages of 3 and 10 years. Results from qualitative analysis revealed nine coping styles including; denial/passive coping,
redirecting energy, empowerment, shifting of focus, changed expectations, rearranging life and relationships, social withdrawal, acceptance, and spiritual coping. The authors found that many parents relied on their extended families for support, but this support was not enough as majority of parents indicated that they were on their own and did not depend on others for support. Moreover, unlike other studies (e.g. McConkey et al., 2008), participants indicated that they got more formal support (i.e. support from the child’s school). This finding corroborates research that assert that families who received both formal and informal support appear better adjusted (Hastings & Johnson, 2001; McNally & Mannan, 2013).

Though some studies have indicated that differences in coping in parents from different cultures is attributable to the role of culture, Croot, Grant, Mathers, and Cooper (2012) did not find this when they explored the coping strategies of Pakistani parents living in the UK and caring for children with severe learning disabilities. Fundamentally, the study examined factors that influenced participants’ choice or ability to use the different strategies using qualitative design and analysis. Nine (9) parents were selected from special schools designated for Pakistan families of children with disabilities in the UK. Results from the analysis indicated that coping strategies used by parents included sharing care with others, recognizing and enjoying the rewards of caregiving, and using external support. The authors noted that coping strategies are not specific to the Pakistani population but certain characteristics of the strategies may be distinct to those used by parents with a different heritage. It was also found that parents interpreted having a child with disability as God’s purpose in their lives and also had the belief that the child was from God.

The authors, however, argued that though culture influenced the meanings parents ascribed to having a child with disability (e.g. the child is given to them by God), the coping strategies they reported were not culture specific to the Pakistan culture. The researchers believed that their
finding followed the universal approach where basic human characteristics are universal with cultural background influencing the demonstration of these characteristics. In an earlier study, Croot, Grant, Cooper, and Mathers (2008) asserted that cultural beliefs were very prominent in the way parents perceive the cause of their child’s disability. Parents in their study attributed the cause of their child’s disability to supernatural explanations as well as biological or medical causes.

Azar and Kurdahi Badr (2010) conducted a cross-sectional study to assess the predictors of coping behaviours of 147 Lebanese parents (101 mothers and 46 fathers) with children with intellectual disability. Children between the ages of 5 and 12 years were selected from 8 special education centres in Beirut, Lebanon. The study focused on the impact of characteristics of child and parent, informal social support, and stress on the coping behaviours of fathers and mothers. Multiple regression analysis showed that informal social support, father's educational level, and stress were the strongest predictors of coping. Factors such as the age of the child, severity of illnesses, and parental health did not significantly predict coping behaviours as have been observed in some studies (Gray, 2006; Hastings et al., 2005; Khamis, 2007; Smith et al., 2008).

In a related study, Edwardraj et al. (2010) qualitatively explored the perceptions of Indian families about intellectual disability. Specifically, the authors explored the cultural beliefs and attitudes about intellectual disability, the perceived needs, and burden of parents caring for children with intellectual disability in Vellore, South India. The authors conducted eight focus groups of 29 participants. Two groups of community health workers with 17 participants and two groups of school teachers with 16 participants in three settings. Using thematic analysis, the study revealed that negative attitudes towards disability were driven by cultural and religious beliefs. Parents were found to experience high emotional burden, lacked acceptance and support from family and other members of society who often stigmatized against them. However, they indicated that sometimes
the mother’s family provided some level of support. In the absence of family and social support, parents also reported relying on their spiritual and cultural beliefs to cope with their situation. Khamis (2007) asserted that religious beliefs of parents of children with mental retardation predicted parenting stress.

The findings of this study shows that, though the extended family system is distinctive of the Indian culture, the stigma associated with intellectual disability is so pervasive that support from the family and society which have often been associated with collectivist cultures is limited. Gupta, Mehrotra, and Mehrotra (2012) and Pal, Das, Chaudhury, Sengupta, and McConachie (2005) also reported in their respective studies that parents of children with disabilities reported receiving very little support from the family. Support from family, friends, and the community have been found in some instances as rather exacerbating stress levels of parents as a result of the stigma associated with intellectual disability (Edwardraj et al., 2010; Green, 2003).

Coping and Psychological Health among African American Families

Coping among people of African descent are often based on the Africentric worldview (e.g. Constantine, Donnelly, & Myers, 2002; Utsey et al., 2000). Among African Americans, studies have been conducted in primary caregivers of children with intellectual disability and chronic illnesses. Allen and Marshall (2010) utilized a descriptive correlation design to examine spirituality as a coping resource for a sample of African American parents having a child with a chronic condition. Participants consisted of 168 African American parents who completed demographic and other standardized questions to assess their coping resources. Results from frequency distributions and Pearson correlations indicated that the most frequently reported coping resource of parents were positive coping patterns which included their faith in God, seeking
information from a family doctor, and showing strength in the face of their stresses. Pearson correlations showed the existence of a significant positive relationship between positive parental coping patterns and spirituality. The current study moves beyond just establishing relations to looking at the interactive effects of among other variables, spirituality, family and community supports, stress, and psychological health of primary caregivers of children with intellectual disability.

Anderson (2006), used a qualitative design to examine the role of spirituality in coping among 29 African-American informal kinship caregivers selected from 207 participants in the Individual and Social Protective Factors for Children in Informal Kinship Care study. Data was collected with an in-depth semi-structured interview. Five themes emerged on how caregivers' defined spirituality, namely: belief in a higher power/something greater than self, connection to a higher power, something within, life doctrine, and religious faith. Spirituality played an important role in the lives of these caregivers' as it mostly influenced their decision to raise a relative's child. Caregivers described that spiritual coping strategies including prayer, contact with church leadership and members, meditation, religious television and music, and others facilitated their coping with stress. Most of the caregivers believed that caregiving is easier with the help of God aside from the support they received from other relatives.

Laurence-Webb and Okundaye (2007) used two focus groups to examine values and beliefs regarding religion and spirituality among 19 African American kinship caregivers between the ages of 40 and 70 years. Findings from the study indicated that in spite of the problems of caregiving, caregivers perceived their role as satisfying a historical, religious, family responsibility, and sharing a faith that God would strengthen them and see them through their challenges. The difficulties associated with caregiving were supposed to be lessons from God.
Faith, determination, and spirituality were the coping skills they utilized to maintain a positive attitude despite their difficulties. Again, it was found that caregivers decided not to give up on their problems and utilized prayer to maintain their relationship with God and their faith as a source of emotional and physical wellbeing.

Apart from relying so much on their faith, African-American families have been noted in research to prefer support from family, friends, and church before seeking for professional support for their child with autism (Dyches et al., 2004). In other words, they perceive informal support as more crucial to their wellbeing. In examining the impact of having a child with a disability on parent’s mental health, Ha et al. (2011) studied urban-dwelling African American parents and further examined the extent to which positive and negative social interactions with family members other than the spouse moderate the effect of a child’s disability on parents’ adjustment. Participants included 48 parents of children with a disability and 144 parents of children without disability living in Milwaukee, Wisconsin. Results showed that having a child with a disability is associated with higher levels of somatic symptoms. However, the negative effects of having a child with disability on parents’ mental health reduced when parents received more positive support from family.

Coping and Psychological Health among African Families

Among countries on the African continent, there is a dearth of studies on stress, coping, and psychological health of parents of children with intellectual disability. Aldersey (2012) studied parents of children with intellectual disability in Dar es Salaam, Tanzania. Findings were that families felt stigmatized and lacked both formal and informal support. Some participants also reported of immense support from the centre where their children were attending school, regardless
of the spiritual beliefs demonstrated by parents as helpful in coping. The current study employed a mixed methods approach in gathering the lived experiences of primary caregivers of children with intellectual disability.

Mashego (2005) investigated the coping strategies of South African mothers of children with behavioural problems using the mixed methods design. Forty-eight (48) Black mothers and 32 White mothers as a control group were involved in the study. Participants were conveniently selected from clinical populations in public hospitals in the Limpopo province, South Africa. Participants were assessed with both standardized questionnaires and semi-structured interviews on support and coping with raising a child with behavioural problems. Out of each group, 10 mothers were selected to be part of the qualitative study. Results from quantitative analysis revealed that contrary to expectations of the author, White mothers coped better than Black mothers. However, Black African mothers received more social support than White mothers, with perceived level of health increasing as social support increased. Higher support reported by Black mothers was attributed to the extended family support system of the African culture. Black mothers also exhibited external locus of control in terms of their experiences of having a child with behavioural problems.

McNally and Mannan (2013) studied family’s perceptions of caring for children with disabilities in Moshi, Tanzania. The authors utilized a qualitative method to better understand the experiences of parents in terms of both negative and positive impact of raising a child with disabilities in Tanzania. Participants included 14 families who were purposively selected based on their children’s attendance of day centres managed by a local NGO in Moshi, Tanzania. Findings from the study revealed five themes, including: objective challenges, subjective challenges, positive experiences, material and financial needs, and coping strategies. The authors discovered
that though parents reported the negative impacts of caring for a child with disabilities, the process was not entirely negative as they also reported some positive experiences especially associated with their cultural beliefs of spirituality and social support. Participants emphasized their belief in God and His power to carry them through in addition to support they received from family and friends in their community.

Among parents of children with disabilities in Zimbabwe, Muderedzi (2013) studied the coping behaviours of parents of children with disabilities from a cultural perspective. Specifically, the study focused on the impact of cultural beliefs and coping behaviours on caring for a child with disabilities on the family and the potential factors that may influence the process. Thirty (30) in-depth interviews were conducted and 3 focused groups with 10 participants in each group in an ethnographic triangulated qualitative method. Results showed that disability was attributed to several causes such as extended family, neighbours, and ancestors but had nothing to do with the immediate family. Within the cultural context of the participants, coping behaviours that emerged explained disability in spiritual terms and believing that they had been chosen by God to care for a child with disability.

**Coping and Psychological Health among Ghanaian Families**

Few studies exist on the influence of the Ghanaian culture on coping among primary caregivers of children with intellectual disability. Anum (2011) explored the living experiences, including; social, economic, practical challenges, and coping among parents of children with disabilities. The author utilized interviews, observations, informal conversations, and narrative analysis among 4 families of children with disabilities. The study was conducted in the Dangme West district of the Greater Accra region of Ghana. Findings revealed that families experienced
stigma, lack of institutional support, and poor family relationships. However, they also reported of the beneficial nature of family support they received in dealing with the stress associated with caregiving. The focus of this study was predominantly on the stigma experiences of families. However, one strength of this study was using parents in the rural part of the Greater Accra region which illuminated the experiences of parents in rural Ghana often ignored in research. The current study focused more on the culture-specific coping strategies utilized by primary caregivers of children with intellectual disability. Moreover, the sample size was also increased to ensure a better representation in the current study.

Investigating the perspectives of parents and teachers on the social inclusion of children with intellectual disabilities in Ghana, Hervie (2013) recruited 6 biological parents and 6 teachers of children with intellectual disabilities from some Special schools for children with intellectual disability in Accra. Findings from this study related to the negative cultural perceptions of children with intellectual disabilities and their families and lack of both community and extended family supports. However, in the course of analysis, the author reported of some positive aspects of the Ghanaian culture, including family supports and spiritual faith found as helping families remain resilient in the face of stress associated with having a child with intellectual disability. The author recommended that these positive aspects of the Ghanaian culture should be explored in future research in order to strengthen parents. The current research focused on how the cultural values of spirituality and family supports strengthen primary caregivers in raising their children.

Studying the emotional health of primary caregivers of children with mental retardation, Nebbah (2010) sampled 100 participants between the ages of 22-70 years in a descriptive cross-sectional design. There were 71 females and 29 males. Information was collected on primary caregivers of children with mental retardation (37), chronic conditions (33), and healthy controls
recruited from Special schools, health facilities, and other basic schools for healthy controls. Results from a one way Analysis of variance indicated that consistent with the study’s hypotheses, primary caregivers of children with mental retardation did not differ significantly on stress from primary caregivers of chronically ill and healthy children.

On depression scores, primary caregivers of children with mental retardation did not differ significantly from primary caregivers of chronic conditions but from healthy controls. However, on anxiety, there were no significant differences among the three groups. There were significant differences in the three groups on self-esteem, even though healthy controls reported higher self-esteem than primary caregivers of children with chronic conditions. Pearson correlation analysis showed that contrary to the stated hypothesis, there was no significant negative correlation between spirituality and stress and no significant positive correlation between spirituality and self-esteem. The three groups did not differ on coping, but a positive correlation was found between spirituality and coping among all three groups of primary caregivers. Although findings from the above studies suggest protective effects of coping strategies for primary caregivers, they are limited in their scope on the examination of Africentric coping strategies as they could not determine which levels of the coping strategies influenced the impact of stress on psychological health.

Summary and Critique

The literature review addressed a number of issues which lend insight into the stress, coping, and psychological health of primary caregivers of children with intellectual disability. First, the transactional model of stress and coping (Lazarus & Folkman, 1984) was briefly presented to provide an overview of the stress and psychological health relationship and how they are impacted by coping resources. Secondly, cultural context of coping was introduced to establish
a link between culture and coping among people of diverse cultures (Hobfoll, 2001; Lam & Zane, 2004; Utsey et al., 2000). Based on the culture context of coping, Africentric model was presented with its values and how they protect people of African descent from psychological distress (Azibo, 1996; Belgrave & Allison, 2006; Kambon, 1992; Myers, 1988). In particular, several studies were referenced in which Africentric values (e.g. spirituality, communalism) were conceptualized as coping resources which buffer the effect of stress on psychological functioning (Belgrave & Allison, 2006; Gaylord-Harden & Cunningham, 2009; Gyekye, 2003; Pierre, 2013). Finally, a vast research literature of empirical findings were reviewed, revealing significant relationships among study variables.

Gleaning from the studies reviewed from both Western and non-Western cultures, there is evidence to suggest that parenting a child with intellectual disability can present challenges for families and the larger society. The studies examined reports that having a child with intellectual disability has negative effects on the psychological health of primary caregivers. Nevertheless, there is some evidence that the parenting experience can also be rewarding for some primary caregivers.

Additionally, the influential nature of the fundamental cultural values (e.g. spirituality, family/community support systems) of the Africentric worldview in coping with stress of caregiving among primary caregivers of African descent was apparent. Despite this, not much is known about the influential nature of spirituality and communalism values or specific interactions between stress, African cultural values of coping (spirituality and family/community support systems), and psychological health among primary caregivers of children with intellectual disability in Ghana.
Furthermore, most of the studies reviewed were beset with limitations regarding small sample sizes, homogeneity of the samples, and the focus on only quantitative data which did not allow participants to express their experiences vividly. The utilization of a mixed methods approach involving quantitative and qualitative data in the current study may ensure that primary caregivers express the actual experiences regarding raising children with intellectual disability. Again, most of the studies were conducted in Western and other countries. A Ghanaian perspective is needed to expand our knowledge of culturally-related coping and psychological health among Ghanaian primary caregivers of children with intellectual disability. Thus, the purpose of this study was to examine the extent to which spirituality and communalism moderate the relationship between primary caregiving stress and psychological symptoms of depression and anxiety among primary caregivers of children with intellectual disability.

**Rationale for the Study**

The psychological health of primary caregivers of children with intellectual disability has spurred a lot of interest in research globally because of the vital role they play in the care of their children (Hastings, 2002; Jamison, 2011). Several countries including Ghana have adopted the United Nations (UN) conventions on integrating persons with disabilities into the family and community to improve their lives. However, the effectiveness of these policies depend on knowing and understanding the experiences of parents of children with intellectual disability as their role in the wellbeing of their children cannot be underrated (United Nations, 2006; Ngatunga, 2004).

Limited research exist on coping and psychological health in parents of children with intellectual disability in non-Western cultures especially Africa and Ghana (e.g. Anum, 2011; Mashego, 2005). Culture influences the way parents of children with intellectual disability
interpret and cope with the stress associated with raising their children (Mashego, 2005; Muderedzi, 2006; Wilgosh et al., 2003).

Research has shown that generally, cultural values have been neglected in traditional mental health treatment (Ibrahim, Roysircar-Sodowski & Ohnishi, 2001). Many contemporary models on coping and mental health have been developed from a Eurocentric worldview, ignoring the unique cultural values of people of African descent. This dearth of information leaves a gap in meeting the coping needs of people of African descent. Several researchers (e.g. Ibrahim et al., 2001; Mkhize, 2004) have noted the importance of culture in psychological interventions.

Consequently, the purpose of the current study is to examine the potential moderating effect of Africentric values in the relationship between stress and psychological health of primary caregivers of children with intellectual disability. Thus, the effect of primary caregiving stress on psychological health would vary depending on the levels of spiritual and communal values (i.e. family/community support systems) of the primary caregiver. Knowledge gained from this study may be useful in assisting psychologists and other mental health professionals work collaboratively with primary caregivers to mitigate some of the challenges associated with raising their children with intellectual disability. Moreover, the findings from the study will be valuable in culturally sensitive counselling and educational interventions aimed at addressing the needs of primary caregivers of children with intellectual disability in a culturally sensitive manner. To address these concerns, specific hypotheses were proposed on the basis of previous research.
Figure 2.1: Conceptual Model of Stress mediating Primary caregiver and Psychological health; Africentric worldview (values) moderating the relationship between Stress and Psychological health

Figure 2.1 depicts a conceptual model describing the relationship between predictor, moderator, and outcome variables. Africentric worldview serves as a moderator in the relationship between stress and psychological health. The various domains describe the key variables that affect primary caregivers’ psychological health. The arrows between the domains represent the interactions in one or both directions between the various domains. The column on the left side of the model depicts primary caregivers of a child with intellectual disability predicting stress and the stress leading to psychological health. The column on the right represents the psychological health of primary caregivers. The column in the middle represents Africentric values serving as moderators between stress and psychological health.
Statement of Hypotheses

1. Primary caregivers of children with intellectual disability will have higher levels of stress and poor psychological health compared to primary caregivers of children with sickle cell disease and healthy controls.

2a. Africentric worldview will moderate the relationship between stress and psychological health.

2b. Spirituality will moderate the relationship between stress and psychological health outcomes (e.g. depression and anxiety).

2c. Communalism will moderate the relationship between stress and psychological health outcomes (e.g. depression and anxiety).

3. Africentric worldview will predict Africultural coping strategies.

Definition of Terms

*Intellectual Disability.* A broad term referring to a group of disabilities that originate before age 18 and characterized by significant limitations in intellectual functioning, learning, communication, problem solving, and adaptive behaviour (APA, 2013; AAIDD, 2009).

*Primary Caregiver.* Primary caregiver refers to a person who provides the majority of unpaid care (e.g. physical care, emotional support, household tasks) for kin or friends suffering from a variety of illnesses and disabilities (e.g. Alzheimer’s patients, terminally ill, disabled children) (Pearce, 2005). In this study, primary caregivers refer to the mothers, fathers, grandparents, guardians of children with intellectual disability who serve as parental figures and assume primary responsibility for their care and maintenance.
Stress. Stress can be defined as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (Lazarus & Folkman, 1984, p.354). In the current study, primary caregiving stress refers to the perceived stress of the primary caregiver in reaction to the demands of caregiving and not having adequate coping resources to handle it.

Africentric Worldview. Africentric worldview is “the worldview of people of African descent” and consists of the values, beliefs, and behaviour of people of African heritage (Belgrave & Allison, 2006, p. 28). In the current study, Africentric values measured were spirituality, communalism, intuition, sensitivity, orality, and respect for elders.

Spirituality. Spirituality refers to having faith in a higher being as well as valuing religious practices (Schiele, 2000).

Communalism. Communalism refers to valuing the support of significant others (family, friends, community) as well as providing support for others (Boyd-Franklin, 2003).

Intuition. Intuition refers to one’s ability to rely on his or her “inner voice”.

Sensitivity. Sensitivity refers to one’s emotional wellbeing linked to the wellbeing of others (Boykin & Ellison, 1995).

Orality. Orality refers to the preference for oral instruction to written instruction (Jones, 2003).

Respect for Elders. Respect for elders refer to giving respect to elders in the form of seeking advice and caring for their health needs (Turner, 1991).

Africultural Coping. According to Utsey et al. (2000), an Africultural coping style deals with ‘efforts to maintain a sense of harmony and balance within the physical, metaphysical, collective/communal and spiritual, psychological realms of existence’. In
the current study, Africultural coping strategies include spiritual, collective, cognitive, and ritual coping.

*Psychological Health.* In the current study, psychological health was assessed using the Brief Symptom Inventory which measures mental and physical symptoms associated with psychological distress as depression, anxiety, somatization, obsession-compulsion, interpersonal sensitivity, hostility, phobic anxiety, paranoid ideation, and psychoticism. Higher scores on the measure represent poor psychological health and lower scores represent better psychological health.
CHAPTER THREE
METHODOLOGY

Introduction

This chapter provides a detailed methodological information for the current study. The design of the study, study setting, participants, sample size, sampling technique, measures for data collection, procedure, and data analysis are presented. A detailed description of the research measures and their psychometric properties are also provided.

Research Design

The study utilized the mixed methods approach for collecting and analyzing data. Both quantitative and qualitative methods were “mixed” in a single study to provide a better understanding of the experiences of primary caregivers of children with intellectual disability. According to Creswell (2007), the mixed methods approach is a procedure for collecting, analyzing, and “mixing” both quantitative and qualitative data at some stage of the research process within a single study to understand a research problem completely. The rationale for using this approach is that, it allows findings to be confirmed, cross-validated, and corroborated within a single study (Creswell, 2003).

A quantitative approach involves inquiry into a problem by testing a theory comprising variables and measured with numbers which are statistically analyzed (Creswell, 2003). This method has strengths of producing accurate data that is usually generalized to a larger population (Patton, 2002). However, it is limited in its inability to produce detailed information on human behaviour, attitudes, and motivation (Gorard, 2003). The qualitative approach involves inquiry into a problem by building a holistic picture based on in-depth information from participants. Examples of qualitative methods include; interviews, focus groups, observation, and case studies.
One advantage of the qualitative approach involves providing detailed and rich insights into the phenomenon under study. However, qualitative data makes generalization difficult as sample is not selected randomly.

Recent empirical literature is emphasizing the use of both quantitative and qualitative methods instead of relying exclusively on either of the methods (Ivankova, Creswell, & Plano Clark, 2007). Combining both methods has a potential of defusing the problems of one method and strengthening the benefits of both methods for optimum results (Creswell & Plano Clark, 2007). Nevertheless, this model has a number of limitations. It is challenging and requires great effort to adequately capture a phenomenon with two separate methods (Creswell & Plano Clark, 2007; Foss & Ellefsen, 2002). It is also difficult comparing the results of two analyses from different data sets (Creswell & Plano Clark, 2007).

There are four different procedures for using a mixed methods approach (Ivankova et al., 2007). They are the explanatory mixed methods design which involves using a quantitative method followed by a qualitative method in a study; exploratory mixed methods design involves using a qualitative method followed by a quantitative method in a study; the embedded mixed methods design involves conducting both quantitative and qualitative phases of a study together and at the same time, and concurrent triangulation mixed methods design entails carrying out both quantitative and qualitative phases of a study at the same time but separately.

The current study utilized the concurrent triangulation mixed methods design (Creswell & Plano Clark, 2007) where both quantitative and qualitative data were collected at the same time and aimed at obtaining a holistic view of a particular phenomenon by studying it from different perspectives (Kopola & Suzuki, 1999). In this design, both quantitative and qualitative phases are given equal importance, such that data collection for both phases are done simultaneously, analysis
of both data sets are done separately, and references are drawn from both for a better comprehension of the problem (Kopola & Suzuki, 1999). Morse (2003) suggested a notation system for mixed methods strategies which best described the design as “QUAN + QUAL” strategy. The plus signifies that the two approaches are used concurrently, and the capitalization means that both methods are assigned equal importance.

A visual presentation of concurrent triangulation mixed method is presented in Figure 3.1 below:

![Visual Model of Concurrent Triangulation Mixed Method Design](http://ugspace.ug.edu.gh)

**Figure 3.1.** Visual model of concurrent triangulation mixed method design employed in the current study (adapted from Creswell & Plano Clark, 2007).

This figure shows the data collection methods, materials and analysis of the quantitative and qualitative phases of the study.
Study Setting

The current study was conducted in Accra metropolis, one of the ten districts of the Greater Accra region of Ghana. Ghana is located in West Africa and positioned above the equator. It is bordered by the Gulf of Guinea to the south, Togo to the east, Côte d’Ivoire to the west, and Burkina Faso to the north. The size of Ghana is about 238,537 square kilometers with a current population of 24,658,823 million (Ghana Statistical Services (GSS), 2012). The country is divided into 10 regions and 170 districts. There are three main religions in Ghana, namely: Christianity, Islam, and Traditional. However, Christianity is the majority with 71%; followed by Islam with 18%; Traditional with 5%, and another 6% are not affiliated to any religion (Ghana Statistical Services (GSS), 2012).

Accra metropolis is the capital city of Ghana. Accra shares boundaries with the Gulf of Guinea and four other municipals including La-dade Kotopon from the East and Ga West municipal, Ga-Central municipal, and Ga-South municipal assembly from the south. Accra has an estimated population of about 2,070,463 million (Ghana Statistical Services (GSS), 2012). Accra is the most developed and urbanized city in Ghana and as such attracts lots of migrants from the other parts of the country (Ghana Statistical Services (GSS), 2012).

Accra has a number of institutions that provide services for children with intellectual disability and which are patronized by people from other parts of the country. Three Special schools for children with intellectual disability and three schools for typically developing children were randomly selected to take part in the study. All the schools are located in Dzorwulu, Cantoments, and Kokomlemle, all suburbs of Accra. The health institution where primary caregivers of children with sickle cell disease were selected was the Korle-Bu teaching hospital also located in Accra.
These institutions were selected to ensure that a wider area is covered and that the sample was representative of the population in Accra. Participants resided in different geographical locations in Accra. Participants were from different socio-economic and ethnic backgrounds. Moreover, Accra served as the central point to generate the data on primary caregivers of children with intellectual disability since it allowed for greater access to them.

**Methods for Study One (Quantitative Phase)**

**Participants**

Two hundred (200) primary caregivers were contacted through the various Special Schools in the Accra Metropolis to take part in the study but a total of 160 primary caregivers voluntarily participated in the quantitative study, with a response rate of eighty percent (80%).

**Description of participants.** There were 55 (34%) primary caregivers of children with intellectual disability, 50 (31%) primary caregivers of children with sickle cell disease, and 55 (34%) primary caregivers of typically developing children serving as the healthy control group. Majority of the primary caregivers were females (n=45, 82%) and the males were (n=10, 18%) for primary caregivers of children with intellectual disability; females (n=39, 78%) and the males were (n=11, 22%) for sickle cell disease; and females (n=48, 87%) and the males were (n=7, 13%) for the healthy control group. The average age of primary caregivers of children with intellectual disability, sickle cell disease, and healthy controls were 41.45 (SD=7.01); 40.10 (SD=8.25), and 40.11 (SD=8.13) respectively. The sample of children in the study had a mean age of 8.13 (2.11) for children with intellectual disability; 7.82 (2.15) for children with sickle cell disease, and 7.69 (SD=2.27) for the healthy controls. The average number of years in school for primary caregivers of children with intellectual disability was 13.93(SD=2.20); 12.44 (SD=2.04) for sickle cell disease caregivers and 13.69 (SD=2.09) for healthy controls.
With regards to marital status, majority of the primary caregivers were married (n=38, 69.1%), single (n=13, 24%), divorced (n=3, 6%), and widowed (n=1, 2%) for primary caregivers of children with intellectual disability; The married were (n=43, 86%), single (n=2, 4%), divorced (n=5, 10%), and widowed (n=0, 0.0%) for sickle cell disease, and married (n=39, 71%), single (n=12, 22%), divorced (n=3, 6%) 10.0%), and widowed (n=1, 2%) for the healthy controls. Among primary caregivers of children with intellectual disability; (n=33, 60%) were formally employed, self-employed (n=17, 31%), and unemployed (n=5, 9%). Among primary caregivers of children with sickle cell disease; (n=9, 18%) were formally employed, (n=32, 64%) were self-employed, and (n= 9, 18%) were unemployed. Among primary caregivers of typically developing children or healthy controls; (n=26, 47%) were formally employed, (n=19, 35%) were self-employed, and (n=10, 18%) were unemployed. Thirty-three (60%) of the children have autism, twenty-two (40%) have Down syndrome, and 50 (100%) have sickle cell disease. These figures are presented in the Table 3.1 below;

Table 3.1: Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Caregiver characteristics</th>
<th>Type of Caregiver</th>
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<tbody>
<tr>
<td></td>
<td>ID N=55</td>
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<td>Female</td>
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<tr>
<td>Divorced</td>
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<tr>
<td>Widowed</td>
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<tr>
<td>Employment status:</td>
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</tr>
<tr>
<td>Islam</td>
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<td>Traditional/oth.</td>
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Table 3.1 (Continued): Demographic Characteristics of Participants

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</thead>
<tbody>
<tr>
<td></td>
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<td>SCD N=50</td>
<td>HC N=55</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
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<td>7.42</td>
<td>2.52</td>
<td>7.49</td>
</tr>
<tr>
<td>No. of years in education</td>
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<td>12.44</td>
<td>2.04</td>
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</tr>
<tr>
<td>Age of child (in years)</td>
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<td>2.11</td>
<td>7.82</td>
<td>2.15</td>
<td>7.69</td>
</tr>
<tr>
<td>Age of caregiver</td>
<td>41.45</td>
<td>7.01</td>
<td>40.10</td>
<td>8.25</td>
<td>40.11</td>
</tr>
</tbody>
</table>

Note: ID=Intellectual disability; SCD=Sickle cell disease; HC=Healthy controls; SD=Standard Deviation

**Sampling Technique**

Participants were selected with a non-probability purposive sampling. This sampling technique was chosen to obtain suitable participants who could give firsthand information regarding their experiences as primary caregivers (Munhall, 2000). Purposive sampling also ensured that the results from the study could be applied to the population under study since the main objective of a purposive sample is to produce a sample that can be logically assumed to be representative of the population (Lavrakas, 2008).

Primary caregivers of children with intellectual disability were identified as having a child diagnosed with intellectual disability by a professional (Psychologist/Psychiatrist/Pediatrician) based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria, and confirmed with the records of the three Special Schools (New Horizon Special School, Autism Awareness Training Center, and Dzorwulu Special School) in the Accra metropolis. Primary caregivers of children with chronic conditions (i.e. sickle cell disease) were selected from the Child Health Department of the Korle-Bu Teaching Hospital in the Accra metropolis. Primary caregivers of children without intellectual disability were recruited through the regular schools within the
same vicinity of the Special Schools on convenience basis. Children without intellectual disability were identified through their teachers’ observation in terms of their functioning in all areas of development in the past six months.

**Sample Size Determination**

The sample size for the study was based on recommendations for sample size for regression models Green (1991). According to Green (1991), $N > 50 + 8m$ (m is the number of independent variables) for testing multiple correlations and $N > 104 + m$ for testing individual predictors. This measurement was based on the assumption of a medium sized relationship. Therefore, based on the inclusion of thirteen independent variables (i.e. including subscales of all measures) in the current study, 154 respondents would be needed to test the multiple correlation and 117 respondents would be needed to test for individual predictors. Cohen (1992) also proposed that for multiple regression analysis, a sample size of 112 would be sufficient to have a medium effect size and power of .80. Therefore this study’s sample size of 160 participants is appropriate for an adequate effect size.

**Inclusion and Exclusion criteria**

**Inclusion criteria**

1. Primary caregivers of children with intellectual disability should have at least one child with a primary diagnosis of any of the intellectual disability (Down syndrome and autism) by a professional (Psychologist/Psychiatrist/Paediatrician) using the criteria spelt out in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).

2. Primary caregiver should be involved in the primary care of the child.
3. The primary caregivers’ child was to be between the ages of 5 and 12 years. The age range of 5 to 12 was settled on to narrow the focus, decrease the variance, and allow for a moderate effect size among variables being measured.

4. The child was supposed to attend a Special school because he or she has been identified and diagnosed as intellectually disabled.

5. The primary caregiver needed to reside with the child (even if it is during vacation).

6. Primary caregivers were to be between the ages of 18 and 70 years old.

   Primary caregivers of children without intellectual disability and those of children with sickle cell disease were also required to satisfy the inclusion criteria.

**Exclusion criteria**

1. Primary caregivers of children above 12 years were excluded from the study. This is because studies have shown that variations exist in the experiences of primary caregivers of children and primary caregivers of adolescents with intellectual disability vary (e.g. Fitzgerald, Birkbeck, & Matthews, 2002).

2. Primary caregivers of children with intellectual disability who were mostly cared for outside the home were excluded from the study.

3. Primary caregivers who had chronic condition themselves were excluded from the study, as this may influence their psychological health.

**Measures**

In the quantitative study, standardized self-report measures were used with their reliability and validity established before collecting data. The independent variables of the study were the demographic characteristics of the primary caregivers, stress, and Africentric values. The dependent variables were Africultural coping and psychological health. Relationships among these
variables were assessed and analyzed to determine their impact on psychological health of primary caregivers. Standardized self-report measures including Brief Symptom Inventory (BSI) (Derogatis, 1993); Parenting Stress Index-Short Form (PSI-SF; Abidin, 1995); Belgrave Africentric Worldview Scale (Belgrave et al., 1997), Africultural Coping Systems Inventory (Utsey et al., 2000) were used to elicit information on Primary Caregiving Stress, Africentric Worldview, Africultural Coping, and Psychological health. All the measures are presented in Appendix A to E.

Demographic information (Appendix A). A personal data sheet was designed to obtain demographic information from the participants who were mainly primary caregivers. Questions assessed gender, age, marital status, employment, education, religion, duration of care, and condition of the child. The demographic data can be found in Appendix A.

Psychological Health (BSI; Derogatis & Melisaratos, 1983) (Appendix B). The Brief Symptom Inventory (BSI- Derogatis & Melisaratos (1983; Appendix B) was used to assess primary caregivers’ psychological health. The measure consists of 53 items covering nine symptom dimensions: Somatization (“Pains in the heart or chest”), Obsessive-Compulsive (“Feeling blocked in getting things done”), Interpersonal Sensitivity (“Your feelings being easily hurt”), Depression (“Feeling lonely”), Anxiety (“Suddenly scared for no reason”), Hostility (“Temper outbursts that you could not control”), Phobic anxiety (“Feeling afraid in open spaces”), Paranoid ideation (“Feeling that most people cannot be trusted”), and Psychoticism (“Feeling lonely even when you are with people”); and three global indices of distress: Global Severity Index, Positive Symptom Distress Index, and Positive Symptom Total. Respondents rank each item on a 5-point scale ranging from 0 (not at all) to 4 (extremely) to measure the amount by which certain problems have caused distress in the past seven days.
The BSI-53 was designed to obtain the psychological health status from both primary care and community populations. The authors report good internal consistency for the nine dimensions, ranging from 0.71 on Psychoticism to 0.85 on Depression. Test-retest reliability for the nine symptom dimensions ranges from 0.68 (Somatization) to .91 (Phobic Anxiety), and for the three Global Indices from 0.87 (PSDI) to 0.90 (GSI). Scores are calculated by finding the average for each subscale and the Global Severity Index was used as a measure of overall psychological distress, which consists of a total weighted score obtained by the total score of all symptom dimensions of the BSI divided by the number of completed items.

The Global Severity Index was used for primary analyses in the current study and the subscales were analyzed for other exploratory purposes. Higher scores indicate higher psychological distress and lower scores indicate lower psychological distress. In the current sample, the BSI was found to have an alpha reliability of 0.96 for the 53 items. Reliability of the other dimensions are Depression (α =.93); Anxiety (α =.91); Somatization (α =.79); Obsession (α =.95); Interpersonal Sensitivity (α =.95); Hostility (α =.82); Phobic Anxiety (α =.81); Paranoid Ideation (α =.83); and Psychoticism (α =.81).

Parenting Stress (PSI-SF; Abidin, 1995) (Appendix C). Primary caregiving stress was measured using the PSI-SF (Abidin, 1995) The PSI-SF contains 36 statements and three subscales: parental distress (PD), parent-child dysfunctional interaction (P-CDI), and difficulty of child (DC). Scores range from 36 to 180, suggesting the general levels of stress experienced in the parenting role as a function of the three subscales. Each PSI-SF subscale consists of 12 questions. The PD subscale denotes the level of distress as a result of personal factors associated with the demands of child rearing. Examples of statements within this subscale include “I feel alone and without friends.” The P-CDI subscale measures parents’ dissatisfaction with the interactions with their
child. Examples of statements within this subscale include “My child smiles much less than I expected.” The DC subscale measures/assesses the parents’ perception of their child’s self-regulatory skills. Examples of statements within this subscale include, “I feel my child is very moody and easily upset.”

The PSI-SF is scored on a 5-point Likert scale, ranging from 1 (strongly agree) to 5 (strongly disagree). The scale was scored by reordering the items so that $5 = 1$, $4 = 2$, $3 = 3$, $2 = 4$, and $1=5$. To determine the subscale (PD, P-CDI, or DC) scores and total stress scores, all subscales were summed, with the overall score indicating the total level of stress. In the analysis, the higher the total score, the higher the level of stress and the lower the total score, the lower the amount of stress. It is also important to note that the total score on the PSI-SF reflects the stress associated with parenting, the parent child interaction, and the child. Test-retest reliability coefficients of the PSI-SF have been reported as 0.84, 0.85, 0.68, and 0.78 for total stress, parenting distress (PD), parent–child dysfunctional interaction (P-CDI), and difficulty of child (DC) respectively (Abidin, 1995). In the current study, the total stress (PSI-SF) was found to have an alpha reliability for total PSI-SF for PD ($\alpha = .91$), for P-CDI ($\alpha = .93$), and for DC ($\alpha = .92$).

*Africentric Worldview (BAWS; Belgrave, 2005) (Appendix D).* Africentric worldview was assessed with the Belgrave Africentric worldview scale. This scale consists of 23 items that can be subdivided into six factors of Spirituality, Intuition, Sensitivity, Communalism, Respect for Elders, and Orality. It was developed by Belgrave (2005) to assess Africentric values of African Americans. Questions such as ‘my successful achievements are due to the support of significant others’; ‘I can tell when a close friend is in trouble or feels bad’ are found on the scale. Responses were scored on a 5-point Likert scale. Higher scores indicated strong Africentric cultural values and lower scores indicated weak Africentric cultural values. Cronbach’s alpha for the scale is .63.
In the current study, the Africentric worldview scale was found to have an alpha reliability of .85. For Spirituality (α=.81), Communalism (α =.84), Sensitivity (α =0.60), Intuition (α=.81), Respect for Elders (α=.54), and Orality (α =.80).

_Africultural Coping (ACSI; Utsey et al., 2000) (Appendix E)._ Africultural coping strategies was assessed with the Africultural Coping System Inventory (Utsey et al., 2000). It is a 30 item scale used to measure the culture-specific coping strategies (Africultural coping) of participants during stressful situations. The scale consists of two sections. The first section requires respondents to think of a recent stressful event and write a brief description of it. In the second section, respondents answer the 30 items representing four coping style subscales: spiritual coping (“Left matters in God’s hands”), cognitive/emotional debriefing (“I found other things to keep me busy”), collective coping (“Got a group of family or friends together to help with the problem”), and ritual coping (“Use a cross or other object for its special powers in dealing with the problem”). This coping measure is aimed for use among adults of African descent and who are able to read minimally at a seventh-grade level. The Africultural Coping System Inventory is rated on a 4-point Likert-type scale (0 = does not apply or did not use, 1 = used a little, 2 = used a lot, and 3 = used a great deal).

The four subscales are scored by summing the item responses for each subscale. Scores for the four distinct culture-specific coping preferences (Spiritual Coping, Cognitive/emotional debriefing, Collective Coping, and Ritual Coping) are derived by summing items across each of the subscales (Utsey et al., 2000). High subscale scores indicate greater use of that coping strategy in response to stressful situations. Utsey et al. (2000) reported Cronbach’s alphas of 0.82 for cognitive-emotional debriefing, 0.76 for spiritual-centered coping, and 0.78 for collective centered coping. In the current study, the ACSI was found to have an alpha reliability (α =0.87), for
Cognitive-emotional debriefing (α=0.75), Spiritual coping (α=0.86), Collective coping (α=0.72), and Ritual coping (α=0.80).

**Pilot on Study Measures**

A pilot study was conducted on the various measures to determine their reliabilities. The alpha reliability obtained for the Brief Symptom Inventory was 0.85 which was quite consistent with the original internal consistency of .81. Three items on the scale were restructured to give a clearer understanding to participants since the researcher discovered that respondents could not understand them very well. An item like ‘Feeling blue’ was presented as ‘Feeling sad’. Secondly, an item like ‘Hot or cold spells’ was presented as ‘Feeling Hot or cold sometimes’. Lastly, an item like ‘Feeling very self-conscious with others’ was presented as ‘Feeling aware when you are with others’. On the Belgrave’s Africentric Worldview Scale (BAWS), the reliability coefficient obtained was .80. The alpha reliability obtained for the Africultural Coping Systems Inventory (ACSI) was .92 and the alpha reliability for the Parenting Stress Index (PSI-SF) was .90.

**Procedure**

Participants were recruited by obtaining permission from the authorities of the various institutions to conduct the study. With the assistance of the administrators in the various institutions, participants were informed to take part in the study. Primary caregivers who met the inclusion criteria received a packet including a letter introducing the principal investigator, the research, informed consent form (Appendix G), a demographic survey, the Brief Symptom Inventory (BSI), the Parenting Stress Index-Short Form (PSI-SF), the Belgrave Africentric Worldview Scale (BAWS), and the Africultural Coping Systems Inventory (ACSI). Anonymity of all participants was assured as names of primary caregivers and children were not obtained throughout the data collection process.
With the help of undergraduate research assistants, the questions and what was expected of primary caregivers in completing the questionnaires were explained to participants. Participants who could not read and write were assisted in answering the questions. The researcher and the research assistants also followed up to the homes of participants who could not respond to the questionnaires immediately and assisted them in responding to questions. Participants completed the questionnaires within approximately 50 minutes and they were collected back. Institutions which participated in the study and the participants received tokens as appreciation.

**Data Cleaning**

After the data collection, all data were cleaned, coded, and uploaded into Statistical Package for the Social Sciences 20.0 for analyses. The first section of the analysis explored the differences in socio-demographic variables, frequencies, means, standard deviations, analysis of normal distribution of the variables, descriptive analysis and correlation matrix among key study variables associated with the sample of primary caregivers of children with intellectual disability, sickle cell disease, and healthy controls.

**Data Analysis**

Analyses of all hypotheses were mainly done using advanced parametric statistical tests comprising Multivariate Analysis of Variance (MANOVA) and Hierarchical regression analysis. Parametric tests make assumptions about ratio or interval scale of measurement, normality of distribution, skewness, kurtosis, homogeneity of variances, and independent errors/residuals. These assumptions warrant that the samples used in a study have the same characteristics as the population of concern; in that the study could have both internal and external validity. Thus, the assumptions place constraints on the interpretation of research findings and strengthen inferences drawn about the population on the basis of samples.
Summary

This chapter outlined the research design of the study, participants, sampling technique, measures for data collection, procedure for data collection, data collection methods, and data analyses used in the study one (quantitative phase). A concurrent triangulation study design, comprising quantitative and qualitative approaches was used because it was considered to produce a detailed and varied data set. In the next two sections, results and discussion for study one (quantitative phase) will be presented.

Results for Study One (Quantitative Phase)

Introduction

This section presents the quantitative analysis and discussion. A potential mechanism by which Africentric worldview influence psychological health of primary caregivers of children with intellectual disability in Ghana was examined. Specifically, the moderating roles of spirituality and communalism on the influence of stress on psychological health of primary caregivers of children with intellectual disability were examined. Two main types of analyses were carried out. The first analysis involved preliminary analyses including: descriptive, bivariate correlations, and Multivariate Analysis of Variance (MANOVA). The second analysis involved Hierarchical regression analyses to test the hypotheses of the study.

Preliminary Analyses

In order to assess the accuracy of the data, normal distribution, reliability estimates, normality, and homogeneity were tested for key study variables. Based on the results of the preliminary analysis, the data met the underlying assumptions for the statistical analysis to be
carried out in the study. Descriptive statistics including frequencies, means, standard deviations, and correlational analyses were computed to support the interpretation of results. Correlational analyses were also computed between demographic variables and scores on the independent, moderators, and dependent variables to examine for possible significant relationships.

Further, skewness and kurtosis was within the acceptable range of ±2 (Tabachnick & Fidell, 2007) for Brief symptom inventory (BSI) and its subscales, Parenting Stress Index Short-Form (PSI-SF), Africentric worldview except for respect for elders and orality subscales were positively skewed, and Africultural coping and it subscales. Means, standard deviations, and tests for normality of the study variables can be found in Table 3.2-3.5.

Table 3.2: *Summary of Means, Standard Deviation, Skewness, Kurtosis and Cronbach Alpha (α) for Psychological Health and its Subscales (N=160)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Skewness</th>
<th>Kurtosis</th>
<th>Cronbach α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological health</td>
<td>1.59</td>
<td>.88</td>
<td>.20</td>
<td>-1.41</td>
<td>.96</td>
</tr>
<tr>
<td>Depression</td>
<td>1.65</td>
<td>1.16</td>
<td>.40</td>
<td>-1.15</td>
<td>.93</td>
</tr>
<tr>
<td>Anxiety</td>
<td>1.89</td>
<td>1.09</td>
<td>.15</td>
<td>-1.45</td>
<td>.91</td>
</tr>
<tr>
<td>Somatization</td>
<td>1.52</td>
<td>.90</td>
<td>.12</td>
<td>.97</td>
<td>.79</td>
</tr>
<tr>
<td>Obsession</td>
<td>1.85</td>
<td>1.13</td>
<td>.26</td>
<td>-1.31</td>
<td>.95</td>
</tr>
<tr>
<td>Interpersonal sensitivity</td>
<td>1.89</td>
<td>.93</td>
<td>.07</td>
<td>-1.38</td>
<td>.95</td>
</tr>
<tr>
<td>Hostility</td>
<td>1.35</td>
<td>.88</td>
<td>.32</td>
<td>-1.12</td>
<td>.82</td>
</tr>
<tr>
<td>Phobic anxiety</td>
<td>1.14</td>
<td>.91</td>
<td>.53</td>
<td>-.92</td>
<td>.81</td>
</tr>
<tr>
<td>Paranoid ideation</td>
<td>1.89</td>
<td>1.06</td>
<td>.20</td>
<td>-1.14</td>
<td>.83</td>
</tr>
<tr>
<td>Psychoticism</td>
<td>1.18</td>
<td>.92</td>
<td>.47</td>
<td>-.98</td>
<td>.81</td>
</tr>
</tbody>
</table>

SD= Standard Deviation
Table 3.3: Summary of Means, Standard Deviation, Skewness, Kurtosis and Cronbach Alpha (α) for Caregivers’ Stress and its Subscales (N=160)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Skewness</th>
<th>Kurtosis</th>
<th>Cronbach α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregivers’ stress (PSF-SF)</td>
<td>113.54</td>
<td>29.90</td>
<td>.28</td>
<td>-1.04</td>
<td>.96</td>
</tr>
<tr>
<td>Parental Distress</td>
<td>38.09</td>
<td>10.36</td>
<td>.13</td>
<td>-.64</td>
<td>.91</td>
</tr>
<tr>
<td>Parent-Child Dysfunctional Int.</td>
<td>36.41</td>
<td>11.51</td>
<td>.24</td>
<td>-1.08</td>
<td>.93</td>
</tr>
<tr>
<td>Difficulty of Child</td>
<td>39.03</td>
<td>10.74</td>
<td>.09</td>
<td>-1.16</td>
<td>.92</td>
</tr>
</tbody>
</table>

*SD=Standard Deviation*

Table 3.4: Summary of Means, Standard Deviation, Skewness, Kurtosis and Cronbach Alpha (α) for Africentric Worldview and its Subscales (N=160)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Skewness</th>
<th>Kurtosis</th>
<th>Cronbach α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Africentric values</td>
<td>76.64</td>
<td>8.09</td>
<td>-1.01</td>
<td>.93</td>
<td>.85</td>
</tr>
<tr>
<td>Spirituality</td>
<td>21.34</td>
<td>4.11</td>
<td>-1.27</td>
<td>.64</td>
<td>.81</td>
</tr>
<tr>
<td>Communalism</td>
<td>13.38</td>
<td>1.81</td>
<td>-1.01</td>
<td>.86</td>
<td>.84</td>
</tr>
<tr>
<td>Sensitivity</td>
<td>16.34</td>
<td>2.67</td>
<td>-1.31</td>
<td>1.51</td>
<td>.60</td>
</tr>
<tr>
<td>Intuition</td>
<td>8.13</td>
<td>1.77</td>
<td>-1.04</td>
<td>1.01</td>
<td>.81</td>
</tr>
<tr>
<td>Respect for elders</td>
<td>8.91</td>
<td>1.34</td>
<td>-1.74</td>
<td>5.10</td>
<td>.54</td>
</tr>
<tr>
<td>Orality</td>
<td>8.54</td>
<td>1.34</td>
<td>-1.75</td>
<td>5.38</td>
<td>.80</td>
</tr>
</tbody>
</table>

*SD= Standard Deviation*
Table 3.5: *Summary of Means, Standard Deviation, Skewness, Kurtosis and Cronbach Alpha (α)*

for Africultural Coping and its Subscales (N=160)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>SD</th>
<th>Skewness</th>
<th>Kurtosis</th>
<th>Cronbach α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Africultural coping</td>
<td>44.56</td>
<td>13.96</td>
<td>.30</td>
<td>-.24</td>
<td>.87</td>
</tr>
<tr>
<td>Cog/emotional</td>
<td>15.38</td>
<td>6.09</td>
<td>.74</td>
<td>-.02</td>
<td>.75</td>
</tr>
<tr>
<td>Spiritual-centered</td>
<td>15.27</td>
<td>5.11</td>
<td>-.05</td>
<td>-.81</td>
<td>.86</td>
</tr>
<tr>
<td>Collective coping</td>
<td>12.13</td>
<td>4.39</td>
<td>.48</td>
<td>-.59</td>
<td>.72</td>
</tr>
<tr>
<td>Ritual coping</td>
<td>1.78</td>
<td>2.42</td>
<td>1.16</td>
<td>.18</td>
<td>.80</td>
</tr>
</tbody>
</table>

*SD= Standard Deviation; Cog/emotional=Cognitive emotional debriefing*

**Correlations of Study Variables**

Pearson correlations were also computed to examine the relationship between demographic variables and key study variables. The variables entered into the analysis included: age of primary caregiver, age of child, number of years in school, and duration of caregiving, Psychological health (GSI), Parenting stress (PSI-SF), Africentric worldview (BAWS), and Africultural coping (ACSI). Significant coefficients were observed; Psychological health positively correlated with age of primary caregiver (r=.34, p<01); age of child (r=.25, p<01); and an inverse relationship with number of years in school (r=-.159, p<05). Further, Stress positively correlated with age of primary caregiver (r=.29, p<01); age of child (r=.17, p<05); number of years in school (r=-.16, p<01). Africentric worldview and Africultural coping were only significantly related with age of primary caregiver (r=-.19, p<05).

Correlations were also conducted on the interrelationships among all key study variables including Psychological health, Stress, Africentric worldview, and Africultural coping, and their
subscales. This was done to establish the concern for multicollinearity in the main analysis. All correlation analyses were tested at the .01 and .05 α level, two-tailed.

**Association between Primary Caregivers’ Stress and Psychological Health**

Primary caregiving stress and subscales correlated significantly with psychological health and all its subscales. The direction of the relationship is positive, indicating that as primary caregiving stress increases, psychological health (e.g. depression, anxiety) also tends to increase. For instance, as parental distress increased, depression also increased (r = .69, p < .01).

**Table 3.6: Correlation between Primary Caregiver’s Stress and Psychological Health (PH) and its subscales**

<table>
<thead>
<tr>
<th></th>
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<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Stress</td>
<td>.79**</td>
<td>.78**</td>
<td>.77**</td>
<td>.73**</td>
<td>.65**</td>
<td>.63**</td>
<td>.57**</td>
<td>.70**</td>
<td>.64**</td>
<td>.65**</td>
</tr>
<tr>
<td>PD</td>
<td>.65**</td>
<td>.69**</td>
<td>.67**</td>
<td>.65**</td>
<td>.50**</td>
<td>.46**</td>
<td>.43**</td>
<td>.55**</td>
<td>.49**</td>
<td>.53**</td>
</tr>
<tr>
<td>P-CDI</td>
<td>.66**</td>
<td>.69**</td>
<td>.68**</td>
<td>.66**</td>
<td>.64**</td>
<td>.63**</td>
<td>.54**</td>
<td>.68**</td>
<td>.63**</td>
<td>.62**</td>
</tr>
<tr>
<td>DC</td>
<td>.67**</td>
<td>.77**</td>
<td>.77**</td>
<td>.69**</td>
<td>.65**</td>
<td>.63**</td>
<td>.58**</td>
<td>.68**</td>
<td>.64**</td>
<td>.63**</td>
</tr>
</tbody>
</table>

n= 160, GSI=Global Severity Index; *Denotes significance at the 0.01 level (p < .01), PH = Psychological Health; Dep = depression; Anx. = Anxiety; Soma = somatization, Obsess = obsessive compulsion, Int-sen = interpersonal sensitivity; P/anx = Phobic anxiety, P/ideation = paranoid ideation, Psychot. = Psychoticism

**Association between Africentric Worldview and Psychological Health**

There was a modest, statistically significant, negative correlation between total Africentric worldview and Psychological health (r = -.39, p < .01), suggesting an inverse relationship between Africentric worldview and psychological health symptoms. Examination of the subscales of Africentric worldview revealed that spirituality and sensitivity related significantly with all subscales of Psychological health.
Table 3.7: Correlation between Africentric Worldview and Psychological Health (GSI)

<table>
<thead>
<tr>
<th>Source</th>
<th>Total Africen.</th>
<th>Spirituality</th>
<th>Communalism</th>
<th>Sensitivity</th>
<th>Intuition</th>
<th>Respect</th>
<th>Orality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total PH(GSI)</td>
<td>-.39**</td>
<td>-.45**</td>
<td>-.25**</td>
<td>-.25**</td>
<td>.01</td>
<td>-.14*</td>
<td>-.02</td>
</tr>
<tr>
<td>Depression</td>
<td>-.40**</td>
<td>-.47**</td>
<td>-.26**</td>
<td>-.21**</td>
<td>-.01</td>
<td>-.17*</td>
<td>-.05</td>
</tr>
<tr>
<td>Anxiety</td>
<td>-.42**</td>
<td>-.43**</td>
<td>-.28**</td>
<td>-.25**</td>
<td>-.05</td>
<td>-.16*</td>
<td>-.12</td>
</tr>
<tr>
<td>Somatization</td>
<td>-.41**</td>
<td>-.42**</td>
<td>-.36**</td>
<td>-.19**</td>
<td>-.04</td>
<td>-.17*</td>
<td>-.11</td>
</tr>
<tr>
<td>Obsession</td>
<td>-.27**</td>
<td>-.31**</td>
<td>-.14*</td>
<td>-.21**</td>
<td>.01</td>
<td>-.10</td>
<td>.05</td>
</tr>
<tr>
<td>Int. Sen.</td>
<td>-.23**</td>
<td>-.29**</td>
<td>-.15</td>
<td>-.14*</td>
<td>.06</td>
<td>-.11</td>
<td>-.00</td>
</tr>
<tr>
<td>Hostility</td>
<td>-.34**</td>
<td>-.37**</td>
<td>-.20**</td>
<td>-.25**</td>
<td>-.02</td>
<td>-.15*</td>
<td>-.00</td>
</tr>
<tr>
<td>Phobic anxiety</td>
<td>-.35**</td>
<td>-.45**</td>
<td>-.18*</td>
<td>-.21**</td>
<td>.01</td>
<td>-.08</td>
<td>-.01</td>
</tr>
<tr>
<td>P/ ideation</td>
<td>-.34**</td>
<td>-.32**</td>
<td>-.15*</td>
<td>-.20**</td>
<td>.12</td>
<td>-.02</td>
<td>.04</td>
</tr>
<tr>
<td>Psychoticism</td>
<td>-.32**</td>
<td>-.42**</td>
<td>-.16*</td>
<td>-.20**</td>
<td>.05</td>
<td>-.07</td>
<td>.01</td>
</tr>
</tbody>
</table>

*= p<.05, **= p<.01, PH=Psychological health or GSI (Global Severity Index)

The relationship between Stress and Africentric worldview revealed stress related negatively with total Africentric worldview ($r = -.45, p<.01$). Results for the subscales revealed that spirituality, communalism, and respect for elders also related significantly though modestly with stress subscales for the primary caregivers. For instance, there was an inverse relationship between spirituality and parenting distress (PD) ($r = -.47, p<.01$), parent-child dysfunctional interaction (P-CDI) ($r = -.46, p<.01$), and difficulty of child (DC) ($r = -.45, p<.01$).

Table 3.8: Correlation between Primary Caregiver’s Stress and Africentric Worldview and its subscales

<table>
<thead>
<tr>
<th>Source</th>
<th>Total Africen.</th>
<th>Spirituality</th>
<th>Communalism</th>
<th>Sensitivity</th>
<th>Intuition</th>
<th>Respect</th>
<th>Orality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Stress</td>
<td>-.47**</td>
<td>-.50**</td>
<td>-.37**</td>
<td>-.15*</td>
<td>-.05</td>
<td>-.20*</td>
<td>.03</td>
</tr>
<tr>
<td>PD</td>
<td>-.41**</td>
<td>-.47**</td>
<td>-.35**</td>
<td>-.10</td>
<td>-.07</td>
<td>-.17*</td>
<td>-.14*</td>
</tr>
<tr>
<td>P-CDI</td>
<td>-.42**</td>
<td>-.46**</td>
<td>-.36**</td>
<td>-.14*</td>
<td>-.06</td>
<td>-.22**</td>
<td>-.08</td>
</tr>
<tr>
<td>DC</td>
<td>-.40**</td>
<td>-.45**</td>
<td>-.30**</td>
<td>-.18*</td>
<td>-.01</td>
<td>-.15*</td>
<td>-.10</td>
</tr>
</tbody>
</table>

n= 160, *= p<.05, **= p<.01 PD=Parental distress; P-CDI=Parent Child Dysfunctional Interaction; DC=Difficulty of Child
Association between Africentric Worldview and Africultural Coping

A modest, statistically significant positive correlation was observed between total Africentric worldview and total Africultural coping (r = .33, p < .01), suggesting a direct relationship between Africentric worldview and Africultural coping strategies. The only dimensions that showed significant relationships but weak positive relationships were spirituality and cognitive coping (r = .19, p < .05), collective coping (r = .18, p < .05). Sensitivity related positively with cognitive coping (r = .20, p < .05), and intuition related with spiritual coping (r = .21, p < .01) but communalism did not relate with any of the coping strategies. The rest of the relationships did not reach statistical significance. There were no problems of multicollinearity.

See Table 3.9 for the zero order correlation matrix for the key study variables.

Table 3.9: Correlation between Africentric worldview and Africultural coping

<table>
<thead>
<tr>
<th>Source</th>
<th>Total Africen.</th>
<th>Spirituality</th>
<th>Communal</th>
<th>Sensitivity</th>
<th>Intuition</th>
<th>Respect</th>
<th>Orality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Coping</td>
<td>.33**</td>
<td>.21**</td>
<td>.11</td>
<td>.16*</td>
<td>.06</td>
<td>.16*</td>
<td>.08</td>
</tr>
<tr>
<td>Cognitive</td>
<td>.20**</td>
<td>.19*</td>
<td>.12</td>
<td>.20**</td>
<td>.03</td>
<td>.01</td>
<td>.05</td>
</tr>
<tr>
<td>Spiritual</td>
<td>.07</td>
<td>-.08*</td>
<td>.09</td>
<td>.11</td>
<td>.21**</td>
<td>-.04</td>
<td>.09</td>
</tr>
<tr>
<td>Collective</td>
<td>.18*</td>
<td>.18*</td>
<td>.06</td>
<td>.21</td>
<td>-.01</td>
<td>.03</td>
<td>-.03</td>
</tr>
<tr>
<td>Ritual</td>
<td>-.09</td>
<td>-.14</td>
<td>-.02</td>
<td>-.02</td>
<td>.01</td>
<td>-.06</td>
<td>.01</td>
</tr>
</tbody>
</table>

n= 160, * = p<.05, ** = p<.01

Differences between Demographics and Study Variables

Preliminary multivariate analysis of variance (MANOVAs) were conducted to determine if significant difference exist between demographic variables and the key study variables (Psychological health, Africentric worldview, Africultural coping, and Stress). The following demographic variables were included in the analyses: gender, marital status, employment status,
and religious denomination. The previously mentioned demographic variables were entered as the independent variables and the total scores of key variables and their subscales were entered as the dependent variables. Using Bonferroni adjusted to .01 level of alpha, the analysis revealed no significant differences for gender ($\lambda = .93; F (9, 124) = 1.02, p > .05$; partial $\eta^2 = .07$); marital status ($\lambda = .82; F (27,362) = .96, p > .05$; partial $\eta^2 = .66$), but there was significant difference by religious denomination ($\lambda = .65; F (27, 362) = 2.13, p > .01$; partial $\eta^2 = .13$) and employment ($\lambda = .80; F (18, 248) = 1.63, p < .05$; partial $\eta^2 = .15$) on psychological health.

Additionally, there was no significant difference by gender ($\lambda = .97; F (3, 130) = 1.16, p > .05$; partial $\eta^2 = .03$); marital status ($\lambda = .96; F (9, 316) = .65, p > .05$; partial $\eta^2 = .02$); and employment status ($\lambda = .91; F (6, 260) = 1.9, p > .05$; partial $\eta^2 = .04$); religious denomination ($\lambda = .92; F (9, 316) = 1.23, p > .05$; partial $\eta^2 = .03$) on stress. In a similar vein, there was no significant difference by gender ($\lambda = .96; F (6, 127) = .83, p > .05$; partial $\eta^2 = .04$), marital status ($\lambda = .85; F (18, 359) = .85, p > .05$; partial $\eta^2 = .05$); religion ($\lambda = .87; F (18, 359) = 1.03, p > .05$; partial $\eta^2 = .05$) but there was significant difference for employment status ($\lambda = .83; F (12, 254) = 2.04, p < .05$; partial $\eta^2 = .09$) on Africentric worldview. For Africultural coping, no significant difference were found for gender ($\lambda = .95; F (4, 129) = 1.73, p > .05$; partial $\eta^2 = .05$); marital status ($\lambda = .94; F (12, 341) = .64, p > .05$; partial $\eta^2 = .02$); employment status ($\lambda = .94; F (8, 258) = 1.04, p > .05$; partial $\eta^2 = .03$) and religious denomination ($\lambda = .87; F (12, 341) = 1.49, p > .05$; partial $\eta^2 = .04$).

To further assess for any significant differences between type of primary caregiver and primary caregivers stress, psychological health, Africentric worldview, and Africultural coping among the three groups of primary caregivers, four separate multivariate analyses of variance (MANOVA) were conducted. The first MANOVA included type of primary caregiver as the independent variable and subscales of the Parenting Stress Index-Short Form subscales (Primary
caregiver stress measure) as the dependent variables. The second MANOVA included type of primary caregiver as the independent variables and scores on the Brief Symptom Inventory subscales (Psychological health measure) as the dependent variables.

The first one-way MANOVA revealed significant main effect for type of primary caregiver as related to all subscales of primary caregiving stress, Wilks’ $\lambda=.21$, $F_{(6, 310)} =60.87$, $p<.01$, $\eta^2=.52$. At the univariate level, F tests results revealed significant differences on primary caregiver stress among the three groups of primary caregivers on Parental Distress (PD) $F_{(2,157)} =85.64$, $p<.01$, $\eta^2=.52$; Parent-Child Dysfunctional Interaction (PCDI), $F_{(2,157)} =165.27$, $p<.01$, $\eta^2=.68$; and Difficulty of Child (DC), $F_{(2,157)} =177.98$, $p<.01$, $\eta^2=.69$.

When the results for the dependent variables were considered separately, post-hoc comparisons, using Tukey HSD revealed significant differences for type of primary caregiver for stress ($\lambda = 56.11$, $p<.01$). An inspection of the mean scores indicated that primary caregivers of children with intellectual disability (ID=A) had significantly higher levels of stress on PD (M=47.60, SD=6.44; $p<.01$); P-CDI (M= 48.89, SD= 5.58; $p<.01$) and DC (M=51.09, SD=4.54; $p<.01$) than primary caregivers of children with sickle cell disease (SCD=B) and healthy controls (HC=C). This is represented by (A>B; A>C; B>C) in Table 3.10 below. In addition, primary caregivers of children with sickle cell disease (SCD) reported significantly higher scores on PD ($p<.01$); P-CDI ($p<.01$), and DC ($p<.01$) than the healthy controls (HC). This is represented by (B>C)* in Table 3.10. Results of these analyses are summarized in Table 3.10.
Table 3.10: Multivariate Analysis of Variance for Primary Caregiver Stress among Three Groups of Primary Caregivers

<table>
<thead>
<tr>
<th>Source</th>
<th>Caregivers</th>
<th>Caregivers</th>
<th>Caregivers</th>
<th>df</th>
<th>F</th>
<th>Tukey HSD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ID (A)</td>
<td>SCD (B)</td>
<td>HC (C)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>N=55</td>
<td>N=50</td>
<td>N=55</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td>47.60(6.44)</td>
<td>36.84(9.71)</td>
<td>29.73(4.90)</td>
<td>2, 157</td>
<td>85.64*</td>
<td>(A&gt;B)<em>,(A&gt;C)</em>,(B&gt;C)*</td>
</tr>
<tr>
<td>P-CDI</td>
<td>48.89(5.58)</td>
<td>33.46(8.86)</td>
<td>26.61(4.81)</td>
<td>2, 157</td>
<td>165.27*</td>
<td>(A&gt;B)<em>,(A&gt;C)</em>,(B&gt;C)*</td>
</tr>
<tr>
<td>DC</td>
<td>51.09(4.54)</td>
<td>35.08(7.51)</td>
<td>30.56(5.67)</td>
<td>2, 157</td>
<td>177.98*</td>
<td>(A&gt;B)<em>,(A&gt;C)</em>,(B&gt;C)*</td>
</tr>
</tbody>
</table>

*= p<.01 ID=Intellectual Disability; SCD=Sickle Cell Disease; HC=Healthy Controls; PD=Parental Distress; P-CDI=Parent Child Dysfunctional Interaction; DC=Difficulty of Child. A=Primary caregiver of children with ID; B=Primary caregivers of children with SCD; C=Healthy Controls.

The second one-way MANOVA revealed significant multivariate main effect for type of primary caregiver as related to psychological health, Wilks’ $\lambda$=.09, $F_{(18, 298)}$=40.08, $p<.01$, partial $\eta^2$=.60. Univariate effects for primary caregivers psychological health showed an overall significant difference among the three groups on somatization, $F_{(2,157)}$=119.98, $p<.01$, $\eta^2$=.52; obsession, $F_{(2,157)}$=159.00, $p<.01$, $\eta^2$=.67; interpersonal sensitivity, $F_{(2,157)}$=124.97, $p<.01$, $\eta^2$=.61; depression $F_{(2,157)}$=200.58, $p<.01$, $\eta^2$=.72; anxiety $F_{(2,157)}$=221.28, $p<.01$, $\eta^2$=.74; hostility, $F_{(2,157)}$=90.93, $p<.01$, $\eta^2$=.54; paranoid ideation, $F_{(2,157)}$=131.01, $p<.01$, $\eta^2$=.63; phobic anxiety, $F_{(2,157)}$=203.13, $p<.01$, $\eta^2$=.72; and psychoticism, $F_{(2,157)}$=140.75, $p<.01$, $\eta^2$=.64.

Post-hoc comparisons, using Tukey HSD for all nine dimensions of psychological health revealed that primary caregivers of children with intellectual disability (ID=A) had significantly poor psychological health than those of children with sickle cell disease (SCD=B) and those of healthy controls (HC=C) ($\lambda$ = 41.83, $p < .01$). This is represented by (A>B; A>C; B>C). However, primary caregivers of children with sickle cell disease (SCD) only significantly differed from
healthy controls (HC) on only two dimensions including: somatization (B>C; \( p < .01 \)) and anxiety (B>C; \( p < .01 \)), where primary caregivers of children with sickle cell disease (SCD) had higher scores than the healthy controls (HC). On all the other seven dimensions, primary caregivers of children with sickle cell disease (SCD) were not significantly different from the healthy controls (HC). These outcomes mean that primary caregivers of children with intellectual disability (ID) were more distressed than primary caregivers of children with sickle cell disease (SCD) and Healthy controls (HC). Results of these analyses are summarized in Table 3.11.

Table 3.11: Multivariate Analysis of Variance for Psychological Health among Three Groups of Primary Caregivers

<table>
<thead>
<tr>
<th>Source</th>
<th>Caregivers ID (A) M (SD)</th>
<th>Caregivers SCD (B) M (SD)</th>
<th>Caregivers HC (C) M (SD)</th>
<th>df</th>
<th>F</th>
<th>Tukey HSD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Psychological health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Somatizat.</td>
<td>2.37 (.40)</td>
<td>1.52 (.79)</td>
<td>.68 (.47)</td>
<td>2, 157</td>
<td>119.98*</td>
</tr>
<tr>
<td></td>
<td>Obsession</td>
<td>3.13 (.55)</td>
<td>1.19 (.76)</td>
<td>1.17 (.65)</td>
<td>2, 157</td>
<td>159.00*</td>
</tr>
<tr>
<td></td>
<td>Interpersonal</td>
<td>2.89 (.33)</td>
<td>1.39 (.76)</td>
<td>1.35 (.59)</td>
<td>2, 157</td>
<td>124.97*</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>3.00 (.57)</td>
<td>1.08 (.59)</td>
<td>.82 (.59)</td>
<td>2, 157</td>
<td>200.58*</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td>3.11 (.39)</td>
<td>1.67 (.77)</td>
<td>.88 (.48)</td>
<td>2, 157</td>
<td>221.28*</td>
</tr>
<tr>
<td></td>
<td>Hostility</td>
<td>2.24 (.47)</td>
<td>.91 (.75)</td>
<td>.87 (.57)</td>
<td>2, 157</td>
<td>90.93*</td>
</tr>
<tr>
<td></td>
<td>Phobic anxiety</td>
<td>2.22 (.54)</td>
<td>.65 (.51)</td>
<td>.54 (.39)</td>
<td>2, 157</td>
<td>203.13*</td>
</tr>
<tr>
<td></td>
<td>Paranoid id.</td>
<td>3.05 (.51)</td>
<td>1.41 (.86)</td>
<td>1.19 (.56)</td>
<td>2, 157</td>
<td>131.01*</td>
</tr>
<tr>
<td></td>
<td>Psychoticism</td>
<td>2.20 (.57)</td>
<td>.68 (.54)</td>
<td>.62 (.56)</td>
<td>2, 157</td>
<td>140.75*</td>
</tr>
</tbody>
</table>

* = \( p < .01 \) ID=Intellectual Disability; SCD=Sickle Cell Disease; HC=Healthy Controls; Somatizat.=Somatization A=Primary caregiver of children with ID; B=Primary caregivers of children with SCD; C=Healthy Controls.
The third and fourth MANOVA’s were conducted with Type of primary caregiver entered as the independent variable and Africentric worldview and Africultural coping were entered as the dependent variables separately. Significant multivariate main effect for type of primary caregiver as related to Africentric worldview, Wilks’ ($\lambda = 6.70$, $p < .01$) and Africultural coping ($\lambda = 13.22$, $p < .01$). There was significant difference for type of primary caregiver on Africentric worldviews and Africultural coping. Results of these analyses are summarized in Table 3.12 and 3.13 respectively.

Table 3.12: Multivariate Analysis of Variance for Africentric worldview among Three Groups of Primary Caregivers

<table>
<thead>
<tr>
<th>Source</th>
<th>Caregivers ID</th>
<th>Caregivers SC</th>
<th>Caregivers HC</th>
<th>df</th>
<th>F</th>
<th>Tukey HSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total BAWS</td>
<td>71.76 (.93)</td>
<td>75.92 (.97)</td>
<td>82.18 (.93)</td>
<td>2, 157</td>
<td>32.09*</td>
<td>(A&lt;B)<em>; (A&lt;C)</em>; (B&lt;C)*</td>
</tr>
<tr>
<td>Spirituality</td>
<td>18.65(4.91)</td>
<td>21.42(3.04)</td>
<td>23.96(1.70)</td>
<td>2, 157</td>
<td>31.83*</td>
<td>(A&lt;B)<em>; (A&lt;C)</em>; (B&lt;C)*</td>
</tr>
<tr>
<td>Communalism</td>
<td>12.72(2.01)</td>
<td>13.00(1.74)</td>
<td>14.40(1.12)</td>
<td>2, 157</td>
<td>16.19*</td>
<td>(A&lt;C)<em>; (B&lt;C)</em></td>
</tr>
<tr>
<td>Sensitivity</td>
<td>15.40(3.29)</td>
<td>16.44(2.54)</td>
<td>17.18(1.62)</td>
<td>2, 157</td>
<td>6.62*</td>
<td>(A&lt;C)*</td>
</tr>
<tr>
<td>Intuition</td>
<td>8.04(7.86)</td>
<td>7.86(2.23)</td>
<td>8.47(2.00)</td>
<td>2, 157</td>
<td>1.70</td>
<td>N/A</td>
</tr>
<tr>
<td>Respect for elders</td>
<td>8.51(1.60)</td>
<td>8.76(1.33)</td>
<td>9.44(.79)</td>
<td>2, 157</td>
<td>7.66*</td>
<td>(A&lt;C)*</td>
</tr>
<tr>
<td>Orality</td>
<td>8.45(1.52)</td>
<td>8.44(1.46)</td>
<td>8.73(.99)</td>
<td>2, 157</td>
<td>.79</td>
<td>N/A</td>
</tr>
</tbody>
</table>

*= p<.01; BAWS=Belgrave Africentric worldview Scale

Differences on Africentric values showed significance total Africentric worldview F (2,157) =32.09, p<.01, spirituality F (2,157) =31.83, p<.01, communalism F (2,157) =16.19, p<.01, sensitivity F (2,157) =7.62, p <.01 and respect for elders F (2,157) =6.66, p <.01 but not on Intuition F (2,157) =1.70, p >.01 and Orality F (2,157) =0.79, p >01] and the total Africentric values score F (2,157) =2.64, p>.01 among the three groups of primary caregivers. Post-hoc comparisons, using Tukey HSD revealed that healthy controls (HC) had higher Africentric values than primary caregivers of children with intellectual disability (ID) and primary caregivers of children with sickle cell (SC).
However, sickle cell (SC) group did not significantly differ from the healthy controls (HC) on the four significant dimensions.

For Africultural coping, there were significant differences between the groups on cognitive-emotional coping $F_{(2,157)} = 42.58, p < .01$, spiritual coping $F_{(2,157)} = 15.21, p < .01$ and collective coping $F_{(2,157)} = 12.97, p < .01$, but not ritual coping $F_{(2,157)} = .13, p > .01$. Comparisons revealed that primary caregivers of children with intellectual disability (ID) had lower Africultural coping strategies than primary caregivers of sickle cell (SC) and healthy controls (HC). This implies that primary caregivers of children with intellectual disability (ID) less often use Africultural coping strategies compared with primary caregivers of children without disabilities (HC) and primary caregivers of children with sickle cell (SC). But there was no significant difference on cognitive, spiritual and collective coping between primary caregivers of children with sickle cell (SC) and healthy controls (HC). This is presented in Table 3.13.

Table 3.13: Multivariate Analysis of Variance for Africultural coping among Three Groups of Primary Caregivers

<table>
<thead>
<tr>
<th>Source</th>
<th>Caregivers ID $N=55$ (A) M (SD)</th>
<th>Caregivers SC $N=50$ (B) M (SD)</th>
<th>Caregivers HC $N=55$ (C) M (SD)</th>
<th>df</th>
<th>F</th>
<th>Tukey HSD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Afr. coping</td>
<td>33.47(14.29)</td>
<td>52.22(14.31)</td>
<td>45.07(12.06)</td>
<td>2, 157</td>
<td>25.69*</td>
<td>(A&lt;B)<em>, (A&lt;C)</em></td>
</tr>
<tr>
<td>Cognitive-emot.</td>
<td>10.40(2.88)</td>
<td>17.82(4.20)</td>
<td>18.13(6.82)</td>
<td>2, 157</td>
<td>42.58*</td>
<td>(A&lt;B)<em>, (A&lt;C)</em></td>
</tr>
<tr>
<td>Spiritual</td>
<td>12.60(4.94)</td>
<td>17.96(4.28)</td>
<td>15.85(4.84)</td>
<td>2, 157</td>
<td>15.21*</td>
<td>(A&lt;B)<em>, (A&lt;C)</em></td>
</tr>
<tr>
<td>Collective</td>
<td>9.31(3.46)</td>
<td>13.74(3.32)</td>
<td>13.49(4.72)</td>
<td>2, 157</td>
<td>12.97*</td>
<td>(A&lt;B)<em>, (A&lt;C)</em></td>
</tr>
<tr>
<td>Ritual</td>
<td>1.91(2.68)</td>
<td>1.78(2.48)</td>
<td>1.67(2.11)</td>
<td>2, 157</td>
<td>.13</td>
<td>N/A</td>
</tr>
</tbody>
</table>

*= p < .01, Afri. coping=Africultural coping, Cognitive-emot=Cognitive emotional debriefing
Test of Hypotheses

Hierarchical regression analyses were the main statistical tests used in analyzing the proposed hypotheses. An advantage of using the hierarchical regression is that it allows for the extraction of as much causal inference as the data will allow (Cohen & Cohen, 1983).

Hypothesis 1

Hypothesis one stated that primary caregivers of children with intellectual disability will have higher levels of stress and poor psychological health (e.g. depression, anxiety) compared to primary caregivers of children with sickle cell disease and healthy controls.

To test the mediator effects of stress on the relationship between type of primary caregiver and psychological health, steps proposed by Baron and Kenny (1986) were followed. First, the predictor variable must correlate with the outcome variable. This is achieved by using Y as the outcome variable in a regression equation and X as a predictor. This step establishes that there is an effect that may be mediated (Path c’). Secondly, predictor variable (X) must correlate with the mediator (M) (Path A’). This step involves treating the mediator (M) as if it were an outcome variable and X as a predictor.

The third step involves showing that the mediator affects the initial or original outcome variable (Path c’). This is achieved by using the initial outcome variable (Y) as the criterion variable and the initial (X) and mediator (M) as predictors in the regression equation. Because the mediator cannot simply be correlated with the outcome variable, the mediator and the outcome may be correlated because they are both caused by the predictor variable. Therefore, the predictor variable must be controlled in establishing the effect of the mediator on the outcome (Baron & Kenny, 1986). The final step in this process attempts to establish that the mediating variable completely
mediates the predictor-outcome relationship. The effect of the predictor variable on the outcome variable controlling for the mediating variable must significantly reduce.

![Diagram of stress as a mediating variable between primary caregiver and psychological health.](image)

**Figure 3.2:** Stress as a mediating variable between primary caregiver and psychological health.

The above figure shows how being a primary caregiver predicts stress and stress in turn predicts psychological health. Moreover, it shows whether stress explains the relationship between being a primary caregiver and psychological health.

In testing this hypothesis, three hierarchical regression analyses were performed controlling for the effects of demographic variables (age of primary caregiver and number of years in school of the caregiver). In the light of the significant correlations between age of primary caregivers and number of years in school of the primary caregiver with key study variables, they were included in the analysis. This hypothesis was partially supported.

In the first regression analysis, the predictor variables were demographic variables, dummy coded primary caregivers (e.g. ID dummy: ID=1; SCD=0; HC=0. Control dummy: ID=1; SCD=1; HC=0) and psychological health was the outcome variable. The results were as follows for demographics for Step 1 $F(2,157) = 12.05, p<.01; R^2=.13$, significant individual predictors were age of primary caregiver ($\beta =.33, p<.01$) but number of years in school was not a significant predictor
of psychological health ($\beta = -0.14, p = 0.06$). For Step 2, significant individual predictors were the caregiver dummies $F(2, 155) = 237.85, p < 0.05; R^2 = 0.86, p < 0.01$. For ID dummy ($\beta = 0.85, p < 0.01$). This indicates that primary caregivers of children with intellectual disability experience higher psychological distress than the controls. For the control dummy ($\beta = 0.12, p < 0.01$), primary caregivers of children with intellectual disability and sickle cell disease experience higher psychological distress than healthy controls. When both dummies were entered into the model, they explained a significant amount of variance in the psychological health ($\Delta R^2 = 0.73, p < 0.01$). These results indicate that Path c’ was significant. Table 3.14 below shows the predictions:

Table 3.14: Hierarchical Regression Predicting Psychological Health from Primary caregiver ($N=160$)

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>B</th>
<th>SEB</th>
<th>$\beta$</th>
<th>t</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>Age of caregiver</td>
<td>0.04</td>
<td>0.01</td>
<td>0.33</td>
<td>4.42*</td>
<td>0.13**</td>
<td>0.13**</td>
</tr>
<tr>
<td></td>
<td>Number of years in school</td>
<td>-0.05</td>
<td>0.03</td>
<td>-0.14</td>
<td>-1.90</td>
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<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>Age of caregiver</td>
<td>0.00</td>
<td>0.00</td>
<td>0.00</td>
<td>0.08</td>
<td>0.86**</td>
<td>0.73**</td>
</tr>
<tr>
<td></td>
<td>Number of years in school</td>
<td>-0.03</td>
<td>0.01</td>
<td>-0.08</td>
<td>-2.66*</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>ID dummy</td>
<td>1.56</td>
<td>0.07</td>
<td>0.85</td>
<td>22.78**</td>
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</tr>
<tr>
<td></td>
<td>Control dummy</td>
<td>0.23</td>
<td>0.07</td>
<td>0.12</td>
<td>3.34**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**$p < 0.01$, *$p < 0.05$**

A supplementary analysis was performed on demographic variables and dummy coded primary caregivers as predictors and the subscales of psychological health as the criterion variables. Results revealed that for Anxiety and somatization subscales, both primary caregiver
dummies predicted them. **Anxiety**: $F_{(2,155)}=113.98, p<.01, R^2=.75$. ID dummy ($\beta=.63, p<.01$) and the control dummy ($\beta=.31, p<.01$). Table 4.14a below shows the prediction of anxiety from primary caregiver:

Table 3.14a: *Hierarchical Regression Predicting Anxiety from Primary caregiver (N=160)*

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>B</th>
<th>SEB</th>
<th>$\beta$</th>
<th>T</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>Age of care giver</td>
<td>.04</td>
<td>.01</td>
<td>.31</td>
<td>4.17**</td>
<td>.14**</td>
<td>.14**</td>
</tr>
<tr>
<td></td>
<td>Number of years in school</td>
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<td>.03</td>
<td>-.20</td>
<td>-2.64*</td>
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<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>Age of care giver</td>
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<td>.02</td>
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<td>.75**</td>
<td>.61**</td>
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<tr>
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<td>Number of years in school</td>
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<td>.02</td>
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<td>-2.19*</td>
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<td>.63</td>
<td>12.67**</td>
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</tr>
<tr>
<td></td>
<td>Control dummy</td>
<td>.72</td>
<td>.11</td>
<td>.31</td>
<td>6.28**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**p<.01, *p<.05

**Somatization:** $F_{(2,155)}=68.94, p<.01, R^2=.64, p<.01$. For ID dummy ($\beta=.43, p<.01$) and control dummy ($\beta=.38, p<.01$). However, on the other subscales, only the ID dummy was still a significant predictor, the control dummy was not.

Obsession, $F_{(2,155)}=80.30, p<.01, R^2=.68, p<.01$. For ID dummy ($\beta=.83, p<.01$) and control dummy ($\beta=-.02, p=.76$). Depression, $F_{(2,155)}=127.45, p<.01, R^2=.77$. For the ID dummy ($\beta=.80, p<.01$) and the control dummy ($\beta=.03, p=.57$). Interpersonal sensitivity, $F_{(2,155)}=63.98, p<.01, R^2=.62, p<.01$. For ID dummy ($\beta=.81, p<.01$) and control dummy ($\beta=-.00, p=.95$). Hostility, $F_{(2,155)}=45.28, p<.01, R^2=.54, p<.01$. For ID dummy ($\beta=.74, p<.01$) and control dummy ($\beta=.01, p=.92$). Phobic anxiety, $F_{(2,155)}=100.76, p<.01, R^2=.72, p<.01$. For ID dummy ($\beta=.83, p<.01$) and control dummy ($\beta=.06, p=.25$). Paranoid ideation $F_{(2,155)}=64.69, p<.01, R^2=.63, p<.01$. For the ID dummy ($\beta=.74, p<.01$) and for control dummy ($\beta=.10, p=.16$). Psychoticism, F
\( F(2, 155) = 70.86, p<01, R^2=.65, p<.01. \) For ID dummy \((\beta=.80, p<.01)\) and control dummy \((\beta=.05, p=.38)\). The results indicates that primary caregivers of children with intellectual disability scored higher on the subscales than the controls.

In order to test whether Path ‘A’ was significant, that is whether primary caregiver predicts stress, two steps of regression were performed. In Step 1, the demographic variable, age of primary caregivers and number of years in school were the predictor variables. Results showed: \( F(2,157) = 8.93, p<.01, R^2=.07; \) whiles stress scores increased with increasing age of primary caregiver \((\beta= .28, p<.05.)\), it decreases with number of years in school \((\beta= -.14, p=.06)\) indicating that number of years in school was no longer a significant predictor so it was left out of further analyses. In the second regression, the predictor variable was dummy coded primary caregiver and stress served as the criterion variable. In Step 2, dummy caregiver was the predictor variable. Results showed that dummy coded ID primary caregiver and Control dummy yielded significant main effects, \( F(2,155) =115.48, p<.01; R^2=.75. \) For ID dummy \((\beta= .69, p<.01)\) and for the control dummy \((\beta= .28, p<.01)\). Both dummies explained a significant amount of variance in stress \((\Delta R^2 =.65, p<.01). \) Thus, primary caregivers of children with intellectual disability predict stress compared to the controls. Additionally, primary caregivers of children with ID and sickle cell disease experience higher stress than the healthy controls, indicating Path A as significant. This can be found in Table 3.15.
Table 3.15: Hierarchical Regression Predicting Stress from Primary caregiver (N=160)

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>B</th>
<th>SEB</th>
<th>β</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
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<td>Step 1</td>
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<td>.28</td>
<td>.28</td>
<td>3.67**</td>
<td>.10**</td>
<td>.10**</td>
</tr>
<tr>
<td></td>
<td>Number of years in school</td>
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<td>.93</td>
<td>-.14</td>
<td>-1.90</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>Age of caregiver</td>
<td>-.09</td>
<td>.16</td>
<td>-.03</td>
<td>-.60</td>
<td>.74**</td>
<td>.65**</td>
</tr>
<tr>
<td></td>
<td>Number of years in school</td>
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<td>.52</td>
<td>-.05</td>
<td>-1.16</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ID dummy</td>
<td>43.14</td>
<td>3.12</td>
<td>.69</td>
<td>13.84**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Control Dummy</td>
<td>17.39</td>
<td>3.11</td>
<td>.28</td>
<td>5.62**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**p<.01, *p<.05

A supplementary analysis was conducted on subscales of stress that could be accounted for by the demographic variables and the type of primary caregiver. Results showed that ID dummy and control dummy predicts parenting distress (PD) \(F_{(2, 155)} = 42.62, p<.01, R^2 = .52\). For ID dummy (β=.50, \(p<.01\)). Thus, primary caregivers of children with intellectual disability experience higher parenting distress than the controls. For control dummy (β=.31, \(p<.01\)). This also means that primary caregivers of children with intellectual disability and sickle cell report high parenting distress than healthy controls. When both dummies were entered into the model, they explained a significant amount of variance in stress (ΔR² = .44, \(p<.01\)).

The same observation was made on Parent-child dysfunctional interaction (P-CDI), the results were; \(F_{(2, 155)} = 82.94, p<.01, R^2 = .68\). For ID dummy (β=.66, \(p<.01\)). Thus primary caregivers of children with intellectual disability experience higher levels of parent child dysfunctional interaction than the controls. For control dummy (β=.28, \(p<.01\)). They both explained a significant amount of variance in parent child dysfunctional interaction (ΔR² = .61, \(p<.01\)). Difficulty of child was found to be predicted by the dummy primary caregiver and the results were; \(F_{(2, 155)} = 89.04, p<.01, R^2 = .70\). For ID dummy (β=.72, \(p<.01\)). Thus, primary
caregivers of children with intellectual disability experience higher stress from difficult behaviour of the child than the controls. For control dummy ($\beta = .18, p < .01$). Primary caregivers of children with intellectual disability and sickle cell experience higher levels of stress from the child’s difficult behaviour than the healthy controls. When both dummies were entered into the model, they explained a significant amount of variance in difficulty of child subscale of stress ($\Delta R^2 = .59, p < .01$).

In the third mediation step, psychological health was entered as the outcome variable, Age of primary caregiver, caregiver dummies, and stress were entered as predictor variables. The results were as follows: Total stress did not predict psychological health $F (3, 155) = 225.01, p < .01, R^2 = .86, p < .01, (\beta = .13, p = .89)$. Significant predictors were ID dummy ($\beta = .83, p < .01$), control dummy ($\beta = .15, p < .01$). Because caregiver dummies are still significant predictors of the outcome variable, complete mediation did not occur. This can be found in Table 3.16 below:

Table 3.16: Hierarchical Regression Predicting Psychological Health from Primary Caregiver and Stress

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>B</th>
<th>SEB</th>
<th>$\beta$</th>
<th>t</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>Age of caregiver</td>
<td>.04</td>
<td>.01</td>
<td>.34</td>
<td>4.5**</td>
<td>.11*</td>
<td>.11*</td>
</tr>
<tr>
<td>Step 2</td>
<td>Age of caregiver</td>
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<td>.00</td>
<td>.00</td>
<td>1.14</td>
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<td>.74**</td>
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<td>ID dummy</td>
<td>1.52</td>
<td>.10</td>
<td>.83</td>
<td>14.76**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Control dummy</td>
<td>.28</td>
<td>.07</td>
<td>.15</td>
<td>3.72**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stress</td>
<td>.00</td>
<td>.00</td>
<td>.01</td>
<td>1.13</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**p < .01, *p < .05

However, an examination of the subscales of psychological health and subscales of stress revealed the occurrence of partial mediation.
Anxiety:  Stress subscales Parental distress (PD) ($\beta=.16$, $p<.05$), Parent-child dysfunctional interaction (PCDI) ($\beta=-.25$, $p<.01$), and Difficulty of child (DC) ($\beta=.20$, $p<.01$) predicted anxiety in the presence of caregiver dummy. Both ID dummy and control dummy were still significant. ID dummy ($\beta=.56$, $p<0.05$) and control dummy ($\beta=.32$, $p<0.01$) predicted anxiety. Thus, primary caregivers of children with intellectual disability predicted anxiety compared to all other groups. Similarly, primary caregivers of children with a condition predicted anxiety compared to the healthy controls. Together, they explained a significant amount of variance in anxiety ($\Delta R^2=.66$, $p<.01$). A partial mediation occurred in this situation. For instance, the strength of the ID dummy $\beta$ was reduced from .63 to .56 (See Table 3.14a) and the $\beta$ under anxiety. This suggest that stress explains the relationship between being a primary caregiver and anxiety. This can be found in Table 3.16a below:

Table 3.16a:  Hierarchical Regression Predicting Anxiety from Primary Caregiver and Stress  
($N=160$)

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>B</th>
<th>SEB</th>
<th>$\beta$</th>
<th>T</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>Age of care giver</td>
<td>.04</td>
<td>.01</td>
<td>.32</td>
<td>4.23**</td>
<td>.10**</td>
<td>.10**</td>
</tr>
<tr>
<td>Step 2</td>
<td>Age of care giver</td>
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<td>.01</td>
<td>.01</td>
<td>.18</td>
<td>.77**</td>
<td>.66**</td>
</tr>
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<td>ID dummy</td>
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<td>.18</td>
<td>.56</td>
<td>7.13**</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Control dummy</td>
<td>.74</td>
<td>.12</td>
<td>.32</td>
<td>6.28**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Parental Distress</td>
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<td>.01</td>
<td>.16</td>
<td>2.21*</td>
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<tr>
<td></td>
<td>Parent-Child Dysfunctional Interaction</td>
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<td>.01</td>
<td>-.25</td>
<td>-2.91**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Difficulty of Child</td>
<td>.02</td>
<td>.01</td>
<td>.20</td>
<td>2.73*</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**$p<.01$, *$p<.05$
**Somatization:** PD was a significant predictor ($\beta=.18, p<.05$). Both caregiver dummies were also significant. For ID dummy ($\beta=.23, p<.01$) and the control dummy ($\beta=.36, p<.01$). Together, they explained a significant amount of variance in somatization ($\Delta R^2=.51, p<.01$). Thus, partial mediation of stress occurred for both dummies. This is presented in Table 1 (Appendix).

**Depression:** PD ($\beta=.25, p<.01$); PCDI ($\beta=-.18, p<.05$, and DC ($\beta=.16, p<.05$) predicted depression. In this situation, ID dummy still predicted depression ($\beta=.65, p<.05$), however, control dummy was not significant ($\beta=.04, p=.42$). Both explained a significant amount of variance in depression ($\Delta R^2=.64, p<.01$). While partial mediation occurred for primary caregivers of children with intellectual disability (ID dummy), complete mediation occurred for the control dummy where stress explained the relationship between being a caregivers of a child with a disease condition, either intellectual disability or sickle cell and depression. This is presented in Table 2 (Appendix).

**Interpersonal sensitivity:** PD ($\beta=-.24, p<.01$) was a significant predictor and only ID was significant predictor ($\beta=.78, p<.01$) of interpersonal sensitivity. A partial mediation occurred for the ID dummy but a complete mediation occurred for the control dummy ($\beta=.04, p=.50$). This is presented in Table 3 (Appendix).

None of the stress subscales predicted psychological health subscales including obsession, hostility, phobic anxiety, paranoid ideation, and psychoticism. However, ID dummy predicted obsession ($\beta=.86, p<.01$) but the control dummy was not significant ($\beta=.04, p>.05$). ID dummy significantly predicted hostility ($\beta=.84, p<.01$) but control dummy was not significant ($\beta=.07, p=.31$). ID dummy predicted phobic anxiety ($\beta=.88, p<.01$) but control dummy did not ($\beta=.08, p=.17$). ID dummy predicted psychoticism ($\beta=.89, p<.01$) but control dummy did not ($\beta=.07, p=.31$). However, both ID dummy ($\beta=.77, p<.01$) and control dummy ($\beta=.13, p<.05$) predicted
paranoid ideation. For these subscales, no mediation occurred, however, with the ID dummy still predicting the subscales shows that being a primary caregiver of a child with intellectual disability accounts for a significant amount of variance in psychological health.

The occurrence of partial mediations and complete mediations in some of the variables primary caregiver, stress, and psychological health met the assumptions of mediation outlined by Baron and Kenny (1986). The Sobel test was applied to test for the partial mediation. Results of the Sobel test ($z=1.98$, $p<.05$) suggest that stress partially explains the relationship between being a primary caregiver of a child with intellectual disability and some psychological health outcomes (e.g. Anxiety, somatization, depression, and interpersonal sensitivity).

An additional analysis was performed to compare only primary caregivers of children with intellectual disability to primary caregivers of children with sickle cell disease on stress and psychological health.

On psychological health, after controlling for demographic variables, age of primary caregiver $F_{(1, 103)} = 10.35$, $R^2 = .09$, $p<.05$, $\beta = .30$, $p<.05$; primary caregivers of children with intellectual disability scored high on psychological health symptoms than primary caregivers of children with sickle cell disease $F_{(1, 102)} = 250.77$, $p<.01$, $R^2 = .83$, $\beta = .91$, $p<.01$. They also differed on all the psychological health subscales. Primary caregivers of children with intellectual disability contributed a significant amount of variance in psychological health ($\Delta R^2 = .74$, $p<.01$). An analysis of the subscales revealed that primary caregivers of children with intellectual disability scored higher on them than primary caregivers of children with sickle cell disease. This is presented in Table 4 (Appendix).

On stress, after controlling for demographic variables, age of primary caregiver $F_{(1, 103)} = 7.00$, $R^2 = .06$, $p<.05$, $\beta = .25$, $p<.05$). Results revealed that primary caregivers of children with
intellectual disability scored higher on stress than primary caregivers of children with sickle cell disease $F_{(1, 102)} = 76.91, p<.01, R^2 = .60, p<.01, (\beta=.78, p<.01)$. They also differed on all the stress subscales. They contributed a significant amount of variance in stress ($\Delta R^2 = .54, p<.01$). This is presented in Table 5 (Appendix).

**Hypothesis 2a**

2a. Africentric worldview will moderate the relationship between stress and psychological health among primary caregivers of children with intellectual disability.

2b. Spirituality will moderate the relationship between stress and psychological health outcomes (i.e. depression and anxiety) among primary caregivers of children with intellectual disability.

2c. Communalism will moderate the relationship between stress and psychological health outcomes (i.e. depression and anxiety) among primary caregivers of children with intellectual disability.

To test for moderator effects in hypothesis two, recommendations stipulated by Frazier, Tix, & Baron (2004) for conducting hierarchical regression analyses for testing moderation were adopted. First, the independent and moderator variables were centered to reduce problems with multicollinearity (i.e. high correlations) among the variables in the regression analyses (Aiken & West, 1991). There were achieved by subtracting the mean value for a variable from each score for that variable. Interaction terms were created by multiplying the centered independent variables and centered moderator variables including all the subscales (Aiken & West, 1991; Frazier et al., 2004). In each of the regression analysis conducted, the variance accounted for by demographic variables including age of caregiver and number of years in school were controlled for and were
included as covariates because they were found to be related to the key study variables in the bivariate analyses.

Demographic variables were entered at the Step 1, the ID dummy (e.g. ID dummy; ID=1; SCD=0; HC; 0) was also controlled for by entering it at the Step 2, the main effects of stress and Africentric worldview were entered at Step 3, and the interaction terms at Step 4 of the hierarchical regression. Psychological health (subscales) was entered as the criterion variable. Significant change in $R^2$ for the interaction term indicates a significant moderator effect.

Hypothesis 2a, that Africentric worldview will moderate the relationship between stress and psychological health was not supported.

Results for Step 1 indicated that demographic variables, age of primary caregiver was a significant predictor of psychological health $F_{(1, 158)}=20.13, p<.01; R^2 = .11; \beta=.34, p<01$. The demographic variables accounted for a significant amount of variance in psychological health scores ($\Delta R^2 = .11, p<.01$). After controlling for demographic variables, ID dummy coded primary caregiver in Step 2 yielded significant main effects, $F_{(1, 157)}=402.01, p<.01; R^2 = .84, \beta=.91, p<.05$. It also explained a significant amount of variance in psychological health $\Delta R^2 = .72, p<.01$).

After controlling for demographic variables and the primary caregivers, stress and Africentric worldview in the Step 3 resulted in individual effects $F_{(2, 155)}=205.18, p<.01; R^2 = .84, p<.01$, significant main effect was found for stress ($\beta=.11, p<05$) but not for Africentric worldview ($\beta=.03, p=.41$).

Both Stress and Africentric worldview did not explain a significant amount of variance in psychological health ($\Delta R^2 = .01, p=.11$). Moreover, the interaction term of Stress x Africentric worldview revealed no significant moderating effects for psychological health $F_{(1, 154)}=164.80, p<.01; R^2 = .85, \beta = -.04, p = .25$. This suggests that Africentric worldview did not moderate the
relationship between stress and psychological health ($\Delta R^2 = .00, p > .25$). This result is presented in Table 3.17.

Table 3.17: **Hierarchical Regression Predicting Psychological Health from Stress and Africentric worldview** ($N=160$)

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>B</th>
<th>SEB</th>
<th>$\beta$</th>
<th>T</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
</tr>
</thead>
<tbody>
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<td>.12**</td>
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<td>.01</td>
<td>.34</td>
<td>.71**</td>
<td>.59**</td>
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<td>.04**</td>
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<tr>
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</tr>
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<td>Stress</td>
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<td>2.17*</td>
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</tbody>
</table>

Note: ** $p < .01$; * $p < .05$

Each of the psychological health subscales were explored. Africentric worldview explained significant variance in two subscales including, hostility ($\beta = -.17, p < .05, \Delta R^2 = .03, p < .01$) and psychoticism ($\beta = -.13, p < .01, \Delta R^2 = .02, p < .01$). Results on the subscales are presented (In Table 6 (Appendix).
Hypothesis 2 (b and c)

Separate hierarchical regression analyses were conducted for hypothesis 2b and 2c.

In hypothesis two (b) stated that spirituality will moderate the relationship between stress and psychological health outcomes (i.e. depression and anxiety) such that the relationship between stress and depression, anxiety will reduce for primary caregivers who report high levels of spirituality. This hypothesis was partially supported.

The interaction term of stress and spirituality did not moderate the relationship between stress and depression. Results for Step 1 indicated that demographic variables (i.e. age of primary caregiver) $F_{(1, 158)} = 21.58, p < .01; R^2 = .12; \beta = .35, p < .01$ was a significant predictor of depression. Similarly, the inclusion of ID dummy coded primary caregiver in Step 2 yielded significant main effects, $F_{(1, 157)} = 194.71, p < .01; R^2 = .71, \beta = .82, p < .01$. It explained a significant variance in depression ($\Delta R^2 = .59, p < .01$).

After controlling for the demographic variable and primary caregiver, stress and spirituality were entered in Step 3 and the results for individual main effects were $F_{(2, 155)} = 108.76, p < .01; R^2 = .74$, for stress ($\beta = .25, p < .01$) and spirituality ($\beta = -.05, p = .29$).

Both stress and spirituality explained a significant amount of variance in depression ($\Delta R^2 = .03, p < .05$). Additionally, after the interaction term of stress and spirituality was entered, no significant interaction effect of spirituality on the relationship between stress $F_{(1, 154)} = 87.24, p < .01, R^2 = .74, p < .01$. ($\beta = .05, p = .31$) and depression was found. This suggests that spirituality did not moderate the relationship between stress and depression ($\Delta R^2 = .00, p = .31$). This result is found in Table 3.18.
Table 3.18: Hierarchical Regression Analysis Predicting Depression from Parental Stress and Spirituality (N=160)

<table>
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<th>β</th>
<th>T</th>
<th>R²</th>
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*p<.05, **p < .01

On Anxiety, hierarchical regression analysis was performed to explore the incremental variance of a product term, including stress and spirituality on anxiety. The interaction term with stress and spirituality significantly predicted anxiety. Results for Step 1 indicated that the demographic variable (i.e. age of primary caregiver) significantly predicted anxiety $F_{(1, 158)} = 17.88, p<.01; R^2 = .10; \beta = .32, p<01$. Similarly, the inclusion of ID dummy coded primary caregiver (ID dummy) in Step 2 yielded significant main effects $F_{(1, 157)} = 147.19, p<.01; R^2 = .65, \beta = .79, p<.01$. 
After controlling for demographic variables and primary caregivers, stress and spirituality were entered in the Step 3 and resulted in significant individual effects $F_{(2,155)} = 84.25$, $p < .01$; $R^2 = .69$, $p < .01$, significant main effect was found for stress ($\beta = .32$, $p < .01$) but not spirituality ($\beta = -.02$, $p = .78$). They both explained a significant amount of variance in anxiety ($\Delta R^2 = .03$, $p < .01$). Additionally, after the interaction term of stress and spirituality were entered, significant interaction effect of spirituality on the relationship between stress and anxiety was found $F_{(1,154)} = 70.20$, $p < .01$; $R^2 = .70$, $p < .05$, $\beta = .12$, $p < .05$. The interaction term explained significant amount of variance in anxiety ($\Delta R^2 = .01$, $p < .05$). This result is presented in Table 3.19.

Table 3.19: *Hierarchical Regression Analysis Predicting Anxiety from Parental Stress and Spirituality (N=160)*

<table>
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<th>T</th>
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<th>$\Delta R^2$</th>
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<td>.10**</td>
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<td>.01</td>
<td>.04</td>
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<td>.55**</td>
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<td>.01</td>
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<td>.69**</td>
<td>.03**</td>
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</table>

*$p < .05$, **$p < .01$

Examination of the other subscales of psychological health revealed that spirituality also
Hypothesis 2 (c) stated that communalism will moderate the relationship between stress and psychological health outcomes (i.e. depression and anxiety). This hypothesis was not supported.

On depression, results showed significant main effects for stress but not communalism. However, after the interaction term of stress and communalism was entered in the model, results revealed no significant effects on depression. Results for Step 1 indicated that the demographic variables (i.e. age of primary caregiver $F_{(1, 158)}=21.58, p<.01; R^2 = .12, p<.01, \beta=.35, p<.01$) was a significant predictor of depression. It accounted for a significant amount of variance in depression ($\Delta R^2 = .12, p<.01$).

Similarly, the inclusion of ID dummy primary caregiver in Step 2 yielded significant main effects $F_{(1, 157)}=194.71, p<.01; R^2 = .71, p<.01, \beta=.82, p<.01$. The primary caregivers also explained a significant amount of variance in depression ($\Delta R^2 = .59, p<.01$).

Stress and communalism were entered in Step 3 and resulted in significant individual effects $F_{(2,155)}=107.94, p<.01; R^2 = .74, p<.01$, significant main effect was found for stress ($\beta=.28, p<.01$) but communalism was not a significant predictor of depression ($\beta=.02, p=.63$). However, they explained a significant amount of variance in depression ($\Delta R^2 = .02, p<.01$). After the interaction term of stress and communalism was entered, no significant interaction effect of communalism on the relationship between stress and depression was found, $F_{(1,154)}= 85.90, p<.01, R^2=.74, p<.01$. ($\beta=-.02, p=.71$). This suggests that communalism did not moderate or reduce the relationship between stress and depression ($\Delta R^2 =.00, p=.71$). Results are presented in Table 3.20.
Table 3.20: Hierarchical Regression Analysis Predicting Depression from Parental Stress and Communalism (N=160)

<table>
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<tr>
<th>Model</th>
<th>Predictors</th>
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<th>SEB</th>
<th>β</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
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<td>.59**</td>
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<td>.74**</td>
<td>.02**</td>
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<td>7.90**</td>
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</table>

*p<.05, **p<.01

On Anxiety, results showed that the interaction term of stress and communalism did not predict anxiety. Results for Step 1 indicated that demographic variables (i.e. age of primary caregiver) $F_{(1, 158)}=17.88$, $p<.01$; $R^2 = .10$, $p<.01$, $\beta=.32$, $p<.01$ was a significant predictor of anxiety. Similarly, the inclusion of ID dummy coded primary caregiver in Step 2 yielded significant main effects $F_{(1, 157)}=147.19$, $p<.01$; $R^2 = .65$, $\beta=.79$, $p<.01$. After controlling for demographic variables and primary caregiver, stress and communalism entered in the Step 3 resulted in significant individual effects $F_{(2, 155)}= 82.27$, $p<.01$; $R^2 = .69$, $p<.01$, significant main
effect was found for stress (β=.31, p<.01) but communalism was not a significant predictor of anxiety (β=-.02, p=.76). They both explained a significant amount of variance in anxiety (ΔR² =.03, p<.01). Additionally, after the interaction term of stress subscales and communalism were entered, significant interaction effect of communalism on the relationship between stress and anxiety F (1, 154) = 67.45, p<.01; R² = .69, β=.04, p=61 was found. This result is presented in Table 3.21.

Table 3.21: Hierarchical Regression Analysis Predicting Anxiety from Parental Stress and Communalism subscale of Africentric worldview (N=160)

<table>
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<th>β</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
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<td>.10**</td>
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<td>&lt; .05 **</td>
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*p<.05, **p<.01
Examination of the other subscales of psychological health revealed that communalism only moderated parenting distress (PD, $\beta=-.24$, $p<.05$); and parent child dysfunctional interaction (P-CDI, $\beta=.27$, $p<.05$) on only hostility, a subscale of psychological health. Interaction terms are presented in Table 8 (Appendix).

Supplementary analysis was performed on the rest of the subscales of Africentric worldview to determine their interaction with stress subscales and psychological health subscales. Results are as follows and tables can be found in Appendix.

**Depression.** Sensitivity moderated parenting distress and depression. Sensitivity also moderated parent child dysfunctional interaction (PCDI) and depression. Respect for elders also moderated PD and depression. Orality also moderated parent child dysfunctional interaction (PCDI), difficulty (DC) and depression. These results are presented in Table 9 (Appendix).

**Anxiety.** Sensitivity moderated parent child dysfunctional interaction (P-CDI) and anxiety. Orality also moderated parenting distress (PD), PCDI, and anxiety. Respect for elders also moderated (PD), DC and anxiety. Results are presented in Table 10 (Appendix).

**Hostility.** Orality moderated parenting distress (PD) and hostility. Results are presented in Table 11 (Appendix).

**Hypothesis 3:** Africentric worldview will predict the use of Africultural coping strategies.

This hypothesis was partially supported. Hierarchical regression was conducted to predict Africultural coping strategies (i.e. Spiritual centered coping) from the subscales of Africentric worldview. After controlling for demographic variable in Step 1, primary caregiver dummy (ID dummy) was entered into Step 2 and was significantly related to spiritual coping $F_{(1, 157)}=13.26$, $p<.01$, $R^2=.14$, $p<.01$, $\beta=-.58$, $p<.01$. It explained a significant variance in Spiritual coping ($\Delta R^2 =.13$, $p<.01$). Africentric values were entered at Step 3 and the results showed that Africentric
values predicted spiritual centered coping $F_{(6, 151)} = 9.31, p < .01; R^2 = .33$. Spirituality ($\beta = .39; p < .01$) and intuition subscales ($\beta = .30, p < .01$) predicted Spiritual centered coping. Communalism ($\beta = -.03, p > .05$), sensitivity ($\beta = .10, p > .05$), respect for elders ($\beta = -.16, p > .05$), and orality ($\beta = -.04, p > .05$) were not significant. These can be found in Table 3.22.

Table 3.22. Hierarchical Regression Predicting Spiritual coping from Africentric worldview ($N=160$)

<table>
<thead>
<tr>
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<th>$\beta$</th>
<th>t</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
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<td>.13**</td>
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</table>

* $p < .05$, ** $p < .01$

With regard to Collective coping, the demographic variables, age of primary caregiver was significantly related to Collective coping $F_{(1, 158)} = 6.64, p < .01; R^2 = .04, p < .05; (\beta = -.04, p < .05)$. For the primary caregiver, $F_{(1, 157)} = 22.08, p < .01; R^2 = .22, p < .01; (\beta = -.45, p < .01$. The subscales of Africentric worldview were not significantly related to Collective coping $F_{(6, 150)} = 6.15, p < .01; R^2 = .25, p > .01$. However, they collectively explained a significant amount of variance in Collective coping ($\Delta R^2 = .03, p > .05$). These can be found in Table 3.23.
Table 3.23: Hierarchical Regression Predicting Collective coping from Africentric worldview 
(N=160)

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>B</th>
<th>SEB</th>
<th>B</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>Age of care giver</td>
<td>-.11</td>
<td>.04</td>
<td>-.20</td>
<td>-2.58*</td>
<td>.04*</td>
<td>.04*</td>
</tr>
<tr>
<td>Step 2</td>
<td>Age of care giver</td>
<td>-.02</td>
<td>.04</td>
<td>-.04</td>
<td>-.52</td>
<td>.22**</td>
<td>.18**</td>
</tr>
<tr>
<td></td>
<td>ID dummy</td>
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<td>.70</td>
<td>-.45</td>
<td>-6.00*</td>
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<td></td>
</tr>
<tr>
<td>Step 3</td>
<td>Age of care giver</td>
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<td>.04</td>
<td>-.05</td>
<td>-.60</td>
<td>.25</td>
<td>.03</td>
</tr>
<tr>
<td></td>
<td>ID dummy</td>
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<td>.80</td>
<td>-.48</td>
<td>-5.59*</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Spirituality</td>
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<td>.09</td>
<td>-.08</td>
<td>-.93</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intuition</td>
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<td>.20</td>
<td>.01</td>
<td>.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sensitivity</td>
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<td>.13</td>
<td>.14</td>
<td>1.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Respect for Elders</td>
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<td>.30</td>
<td>-.04</td>
<td>-.48</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Communalism</td>
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<td>-.07</td>
<td>-.81</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Orality</td>
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<td>.25</td>
<td>-.04</td>
<td>-.46</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.05, **p<.01

Additionally, the subscales of Africentric worldview were also explored in their predictive relationship with Cognitive emotional debriefing coping and Ritual coping. The results showed that none of the subscales of Africentric worldview significantly related to cognitive and ritual coping. These can be found in Tables 3.24 and 3.25.
Table 3.24: *Hierarchical Regression Predicting Cognitive coping from Africentric worldview*  
(N=160)

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
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<th>B</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
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<td>-8.61**</td>
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<td>.03</td>
</tr>
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<td></td>
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<tr>
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<td>Intuition</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Sensitivity</td>
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<td>1.46</td>
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<tr>
<td></td>
<td>Respect for Elders</td>
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<tr>
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<td>Communalism</td>
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<td>-.01</td>
<td>-.15</td>
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<td></td>
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<tr>
<td></td>
<td>Orality</td>
<td>.08</td>
<td>.31</td>
<td>.02</td>
<td>.26</td>
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<td></td>
</tr>
</tbody>
</table>

*p<.05, **p<.01

Table 3.25: *Hierarchical regression Predicting Ritual coping from Africentric worldview (N=160)*

<table>
<thead>
<tr>
<th>Model</th>
<th>Predictors</th>
<th>B</th>
<th>SEB</th>
<th>B</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
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<td>.02</td>
<td>.19</td>
<td>.00</td>
<td>.00</td>
</tr>
<tr>
<td>Step 2</td>
<td>Age of care giver</td>
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<td>.03</td>
<td>.00</td>
<td>.03</td>
<td>.00</td>
<td>.00</td>
</tr>
<tr>
<td></td>
<td>ID dummy</td>
<td>.18</td>
<td>.43</td>
<td>.04</td>
<td>.42</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
<td>Age of care giver</td>
<td>.00</td>
<td>.03</td>
<td>.01</td>
<td>.07</td>
<td>.03</td>
<td>.02</td>
</tr>
<tr>
<td></td>
<td>ID dummy</td>
<td>-.23</td>
<td>.50</td>
<td>-.05</td>
<td>-.46</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Spirituality</td>
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<td>.06</td>
<td>-.17</td>
<td>-1.75</td>
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<td></td>
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<tr>
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<td>Intuition</td>
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<td>.12</td>
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</tr>
<tr>
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<td>Sensitivity</td>
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<td>.03</td>
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</table>
Summary of Quantitative Results

The current study utilized the following statistical analyses: Descriptive, correlations, MANOVA, and hierarchical regression. In the preliminary analysis, modest relationships were found between stress and psychological health symptoms, stress and Africentric worldview; Africentric worldview and psychological symptoms; and between Africentric worldview and Africultural coping. The rest of the analyses were based on MANOVA where primary caregivers of children with intellectual disability were found to have high stress and poor psychological health compared to primary caregivers of children with sickle cell disease and healthy controls. Additionally, primary caregivers of children with intellectual disability had low scores on Africentric values and Africultural coping compared to primary caregivers of children with sickle cell disease and healthy controls.

The current study found partial support for its hypotheses, utilizing hierarchical regression analysis. Firstly, stress partially mediated the relationship between being a primary caregiver of children with intellectual disability and psychological health outcomes (e.g. Anxiety, depression, somatization, and interpersonal sensitivity) compared to primary caregivers of children with sickle cell disease and healthy controls.
cell disease and healthy controls. This means that stress partially explains the relationship between being a primary caregiver of a child with intellectual disability and psychological health.

Secondly, Africentric worldview as a composite score did not moderate the relationship between stress and psychological health; however Africentric worldview moderated stress and some of the subscales of psychological health (i.e. hostility and psychoticism). This means that, in totality, Africentric worldview does not reduce the impact of stress on psychological health among primary caregivers of children with intellectual disability.

Thirdly, spirituality moderated the relationship between stress and anxiety but not depression. This finding illustrate the protective function of spirituality in the association between primary caregiving stress and anxiety. Fourthly, communalism did not moderate the relationship between stress and depression and anxiety. Therefore communalism did not serve as a protective mechanism in the relationship between stress and depression and anxiety.

Finally, spirituality and intuition subscales of the Africentric worldview predicted spiritual centered coping subscale of Africultural coping. All the other subscales of Africultural coping (i.e. collective, cognitive, and ritual coping) were not predicted by the subscales of Africentric worldview in the current sample.
Discussion for Study One (Quantitative Phase)

Introduction

This section provides an interpretative summary of the study’s findings in relation to the hypotheses on the stress and psychological health among primary caregivers of children with intellectual disability, alongside the utilization of Africentric values of coping and their relationship to previous studies. Specifically, the study predicted that spirituality and communalism will moderate the relationship between primary caregiving stress and psychological health outcomes (e.g. depression, anxiety). The study also investigated whether being a primary caregiver of a child with intellectual disability predicts stress and psychological health.

Three groups of primary caregivers, namely; primary caregivers of children with intellectual disability, sickle cell disease, and healthy controls were compared. The current study was guided by the Transactional model of stress and coping (Lazarus & Folkman, 1984) and the Africentric model (Azibo, 1996; Belgrave & Allison, 2006; Nobles, 1991). The Africentric model represent efforts to integrate cultural constructs into the Transactional model. The findings revealed both expected and unexpected results.

The first hypothesis stated that primary caregivers of children with intellectual disability will have higher levels of stress and poor psychological health compared to primary caregivers of children with sickle cell disease and healthy controls. This hypothesis was partially supported. Findings from the current study indicated that being a primary caregiver of a child with intellectual disability predicted psychological health and all it subscales including depression, anxiety, somatization, obsession, hostility, phobic anxiety, paranoid ideation, and psychoticism compared to primary caregivers of children with sickle cell disease and healthy controls. Similarly, primary caregivers of children with intellectual disability predicted stress compared to primary caregivers
of children with sickle cell disease and healthy controls. The results demonstrate that primary caregivers of children with intellectual disability experience high levels of stress and poor psychological health. This is consistent with findings from other studies indicating that primary caregivers of children with intellectual disability are at an increased risk for high levels of stress (Duarte et al., 2005; Gupta, 2007; Hung et al., 2010) and psychological distress (Estes et al., 2009; Olsson & Hwang, 2001).

The mediating effect of stress on the relationship between being a primary caregiver of a child with intellectual disability and psychological health was also examined. The findings revealed a lack of mediation of total stress in the relationship between primary caregiver and psychological health. This means that stress does not explain the relationship between the type of primary caregiver and psychological health. However, an examination of the subscales of stress revealed that, stress partially mediated the relationship between primary caregiver and psychological health subscales including anxiety, depression, somatization, and interpersonal sensitivity among primary caregivers of children with intellectual disability compared to primary caregivers of children with sickle cell disease and healthy controls.

One possible explanation for this mediating relationship is that primary caregivers of children with intellectual disability are more susceptible to stress which in turn affects their psychological health. This finding is consistent with studies that have found stress as a mediator of psychological health among parents of children with disabilities (e.g. Cramm & Nieboer, 2011; Jeffery, 2013; Whitson et al., 2011).

On the other subscales of psychological health, such as, obsession, hostility, phobic anxiety, paranoid ideation, and psychoticism, no mediation occurred. While being a primary caregiver of a child with intellectual disability was consistently a significant predictor, being a
primary caregiver of a child with a chronic disease condition was not a significant predictor of the stress subscales and psychological health. A plausible explanation for this finding could be that other factors apart from stress predict psychological health subscales among primary caregivers of children with chronic conditions.

To further compare primary caregivers of children with intellectual disability and primary caregivers of children with sickle cell disease on their prediction of stress and psychological health, an additional hierarchical regression analysis was conducted. Findings revealed that primary caregivers of children with intellectual disability predicted stress and psychological health compared to primary caregivers of children with sickle cell disease. This finding is consistent with previous studies reporting that primary caregivers of children with developmental disorders predicted stress compared to primary caregivers of children with chronic conditions (Gupta, 2007; Spratt et al., 2007). However, the finding is inconsistent with studies that have found similarities in stress among primary caregivers of children with intellectual disability and other chronic conditions (Hall et al., 2012; Nebbah, 2010).

In the second hypothesis 2 (a), Africentric worldview was predicted to moderate stress and psychological health of primary caregivers of children with intellectual disability. This hypothesis was not supported, as total Africentric worldview did not moderate the impact of stress on total psychological health. This result is consistent with studies emphasizing that adherence to Africentric values does not necessarily reduce or increase the effect of stress on psychological symptoms (Anderson, 2007; Jackson, 2008). However, this finding is inconsistent with findings from previous studies that have demonstrated that Africentric worldview is a significant moderator in the relationship between stress and psychological functioning (e.g. Neblett et al., 2010; Neblett & Carter, 2012; Wang et al., 2013).
An analysis of the subscales of psychological health revealed that Africentric worldview moderated the relationship between stress and hostility; stress and psychoticism among primary caregivers of children with intellectual disability compared to primary caregivers of children with sickle cell disease and healthy controls. This is a demonstration that among primary caregivers of children with intellectual disability, endorsing Africentric values reduced the impact of stress on hostility and psychoticism.

Hypothesis 2 (b) proposed that spirituality will moderate the relationship between stress and depression and anxiety. Findings from the hierarchical regression analysis revealed that spirituality moderated the relationship between stress and anxiety but not depression. The impact of stress on anxiety varied with the utilization of spiritual resources. Thus, while stress leads to psychological symptoms of anxiety, the strength of the effect depends on the level of spirituality. In the current study, as the level of spirituality increased, the effect of stress on anxiety decreased. However, those who had low spirituality, also had high stress and high anxiety. This means that the utilization of high levels of spirituality was beneficial to the current sample. This finding is consistent with findings from other studies highlighting that adherence to Africentric value of spirituality serve as a protective factor against psychological symptoms (Reutter, 2012; Smith III, 2012; Taylor et al., 2009). On the other hand, spirituality did not moderate the impact of stress on depression. This is consistent with studies which found no moderating effects of spirituality on depression (Jackson, 2008; Smith, 2003).

A closer look at the subscales of psychological health showed that spirituality moderated the relationship between parenting stress and paranoid ideation. This is an interesting finding bearing in mind that many Africans or Ghanaians have cultural beliefs involving a suspicion that having a child with intellectual disability is a result of a punishment for sins committed against
God or the gods (Anthony, 2009; Anum, 2011; Avoke, 2002). In the current study, as the levels of spirituality increased, the effect of the child’s condition on the parent’s paranoid ideation reduced. It could be that the primary caregivers’ belief and faith in God made them feel less suspicious of someone being responsible for their children’s condition.

Hypothesis 2 (c) stated that communalism will moderate the relationship between stress and anxiety and depression. This hypothesis was not supported. Specifically, communalism was not found to affect the strength of the relationship between stress and anxiety and depression. In the current study, communalism was thought to function like family and community support systems protecting primary caregivers from anxiety, depression, and stress. These findings were unexpected given the communal nature of the African and the Ghanaian culture where people are more inclined to support and be supported by other members of the family and society in times of adversity (Gyekye, 2003; Jones, 2007, Mashego, 2005; Taylor et al., 2001).

One interesting finding on communalism that is worth mentioning was its ability to moderate the relationship between parenting stress and hostility, a dimension of psychological health. Hostility is characterized by hostile thoughts, behaviours, and feelings, and having typical urges for annoyance and irritability. Thus, for communalism to impact the relationship between stress and hostility suggests that once primary caregivers receive support from family and society in raising their children, their inclination towards irritability reduces. This finding is novel and complement existing literature on the psychological health of primary caregivers of children with intellectual disability.

It should be noted that in each of the hierarchical multiple regression analyses conducted to test moderating effects of Africentric values, only stress emerged as a predictor of depression,
anxiety, and other subscales of the psychological health. Africentric values did not predict psychological health in the current sample. Moreover, the inability to determine moderating effects in some of the investigated relationships makes it challenging to determine whether the incidence of stressful events increases greater utilization of Africentric values or whether the use of these values increases the intensity of stressful events. Nevertheless, the predictive nature of stress in the development of psychological health symptoms deserves further research consideration in terms of the moderating and mediating factors that reduce the strength of the relationship between stress and psychological health.

The third hypothesis stated that Africentric values will predict Africultural coping strategies. This hypothesis was also partially supported by the data. Spirituality and intuition subscales of the Africentric worldview predicted only the spiritual centered coping subscale of Africultural coping. None of the Africentric values predicted the collective, cognitive, and ritual centered coping strategies. The findings of the current study indicate that spirituality of Ghanaian primary caregivers of children with intellectual disability predicted their use of spiritual coping strategies. This is consistent with findings from studies which have reported that among primary caregivers, spirituality predicts the adoption of spiritual coping behaviours (Anderson, 2006; Laurence-Webb & Okundaye, 2007). However, Conner (2003) did not find Africentric values to predict spiritual coping.

The other Africentric values did not predict any of the Africultural coping strategies, leaving it unclear as to the exact relationship between Africentric worldview and Africultural coping. There is also a possibility that primary caregivers of children with intellectual disability utilize other coping styles that are not Africentric in nature but based on Western values of individualism that were not assessed in the current study. According to Green (2007), assessing
the coping behaviours of people of African descent only with African centered measures may not suffice as that would not guarantee an appropriate option for research. Further utilization of these measures in future research may yield different results.

The current study also examined the other subscales of the Africentric worldview unlike previous studies that have only examined the Africentric worldview in totality. Some of subscales of the Africentric worldview including sensitivity were found to have significant moderating effects on the relationship between the subscales of stress and psychological health.

Sensitivity moderated the relationship between parenting stress and depression and anxiety among primary caregivers of children with intellectual disability. Sensitivity means concern for the needs of others and it is also linked to one’s emotional well-being (Boykin & Ellison, cited in Belgrave & Allison, 2006). Therefore, this African value needs to be given attention in that parents should be encouraged to show concern for their children and others, thereby enhancing their own psychological functioning.

Another remarkable finding that emerged from the current study was the predictive effects of some demographic variables on psychological health. For example, age of primary caregiver was positively associated with stress and psychological health symptoms-primary caregivers of children with intellectual disability experienced higher levels of depression than younger caregivers. Additionally, a negative relationship existed between parents’ educational level and depression and anxiety. As the number of years in school increased, depression and anxiety decreased. Possible reasons that could be raised for these findings are that, older primary caregivers may find it more difficult to deal with the demands of caregiving as they age. Moreover, societal and parental expectations of independence in the child as the child ages puts enormous pressure
on primary caregivers as the presence of intellectual disability hampers the child’s development and independence.

With regards to the number of years in school, the reason for the negative relationship with depression and anxiety could be that as a primary caregivers become more educated, they become less vulnerable to depression and anxiety tendencies associated with raising a child with intellectual disability. The knowledge parents acquire about the children’s condition makes them more relaxed about the children’s condition and what the future holds for them.

The findings of the current study corroborates results from literature that primary caregivers of children with intellectual disability experience higher levels of stress and poor psychological health.

The unexpected results from the use of Africentric and Africultural measures could be attributed to the fact that these measures have not been used extensively. Specifically, these measures have not been used among primary caregivers of children with intellectual disability. It could be that these measures are not appropriate for this population considering the stigma associated with having a child with intellectual disability.

Despite these findings, results are framed in a context that emphasizes the relevance of cultural coping factors such as spirituality and communalism (family and community support systems) pertinent to Ghanaian primary caregivers of children with intellectual disability. Greater use of these coping strategies should be encouraged as they have the potential of mitigating psychological distress (Jones, 2003; Maris, 2010; Utsey et al., 2000). Findings of study one are summarized in Figure 3.3.
Figure 3.3. Revised model showing Stress mediating Primary caregiver of a Child with Intellectual Disability and Anxiety; Spirituality moderates the relationship between Stress and Anxiety (Study One).
CHAPTER FOUR

Methods for Study Two (Qualitative Phase)

Introduction

The purpose of the qualitative phase was to complement the quantitative phase by exploring the unique experiences of primary caregivers of children with intellectual disability and how they cope in the Ghanaian cultural context. Additionally, this phase of the study allowed for elaboration of how African cultural values impact coping among primary caregivers of children with intellectual disability. Research has shown that cultural values are complex and cannot be explained by just quantitative measures (Segall, Lonner, & Berry, 1998). Though, many Africentric scholars acknowledge the usefulness of the quantitative approach, they suggest that qualitative methods are effective in unearthing the rich experiences of people and it is more consistent with the oral tradition value of Africans (e.g. Asante, 1990; Schiele, 2000).

Participants

Participants in this phase of the study comprised primary caregivers of children with intellectual disability which is the specific group of interest to the study. Eleven (11) participants, mainly mothers were recruited out of the fifty-five (55) primary caregivers of children with intellectual disability for the study. These participants met the criteria for the study and also expressed willingness to participate in an audio-recorded interview for the qualitative phase. Participants were asked to complete an anonymous personal data form designed to capture their demographic data (e.g. age, gender, employment status, marital status, age of child, etc.) and that of their children. Participants ranged in age from 38-63 years with average age of 47 years and the children’s ages ranged from 5 to 12 years. Seven (7) were married, two (2) were divorced, and two
(2) were widowed. Five (5) of the primary caregivers were formally employed, four (4) were self-employed, and two (2) were unemployed. There were seven (7) male and four (4) female children. Six (6) children had autism and five (5) had Down syndrome. See Table 4.1 for demographic characteristics of participants.

Table 4.1: Demographic Characteristics of Participants

<table>
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<th>#</th>
<th>Name*</th>
<th>Gender of caregiver</th>
<th>Age of caregiver</th>
<th>Marital status</th>
<th>Employment status</th>
<th>Gender of child</th>
<th>Age of child</th>
<th>Type of disability</th>
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<td>4</td>
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<td>53</td>
<td>Married</td>
<td>Formal</td>
<td>Male</td>
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<td>Down syndrome</td>
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<td>Formal</td>
<td>Female</td>
<td>12</td>
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</tr>
<tr>
<td>7</td>
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<td>Male</td>
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<td>Autism</td>
</tr>
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</table>

*Note: pseudo names were used throughout the study*
**Sampling Technique**

Participants were purposively selected to participate in the study. Research has shown that purposive sample provides the appropriate participants who could give appropriate information for a study (Munhall, 2000).

**Sample Size Determination**

In contrast to quantitative research where the sample size is determined by having a number of subjects that will reach statistical significance or an adequate effect size, in qualitative research, determining the adequacy of a sample size is not based on any formal criteria. Different recommendations are made by different authors. For example, Morse (2000) asserted that determining a sample size for qualitative study depends on several factors including, the topic for the study, the scope, the quality of data, amount of information obtained from each of the participants, design of the study, and the number of interviews per respondent. Earlier, Creswell (1998) and Morse (1994) recommended that when the purpose of the study is to explore the unique experience of a particular group of people, at least 5-25 interviews and 6 interviews respectively is adequate to achieve theoretical saturation.

Theoretical saturation refers to the point at which no new information or additional themes are observed from the data (e.g. Bernard, 2000; Glaser & Strauss, 1967). In the current study, using eleven (11) participants is consistent with the recommendations made by Creswell (1998) and Morse (1994).

**Inclusion and Exclusion criteria**

**Inclusion criteria**

1. Primary caregivers of children with intellectual disability should have at least one child with a primary diagnosis of any of the intellectual disability (Down syndrome and autism)
by a professional Psychologist/Psychiatrist/Paediatrician) using the criteria spelt out in the Diagnostic and Statistical Manual of mental disorders (DSM-IV).

2. Primary caregiver should be involved in the care of the child.

3. The child should be between the ages of 5 and 12 years.

4. Primary caregivers should have consented to be interviewed with audio tape.

5. Primary caregivers were required to speak English or Akan languages.

Exclusion criteria

1. Primary caregivers who were unwilling to share their experiences were taken as unwillingness to participate in the study.

2. Primary caregivers with other languages apart from English and Akan (because of translation difficulties).

3. Primary caregivers of other conditions aside from intellectual disability.

4. Primary caregivers of children younger than 5 years and older than 12 years with intellectual disability.

5. Primary caregivers who did not give their consent were not to take part in the study.

6. Primary caregivers with a child living and mainly cared for outside the home.

Aims of the Study

Main Aim

To provide insight into the experiences of primary caregivers caring for their children with intellectual disability in the Ghanaian cultural context.

Specific Aims

1. To explore the impact of caring for an intellectually disabled child on primary caregivers.
2. To explore the coping strategies of primary caregivers of children with intellectual disability in the Ghanaian cultural context.

Research Questions

1. What are the experiences of primary caregivers in raising a child with intellectual disability?

2. What are the coping strategies utilized by Ghanaian primary caregivers of children with intellectual disability?

Measures

*Semi-structured interview schedule.* A semi-structured interview schedule with a set of open-ended questions was used to elicit information on the stress and coping experiences of primary caregivers in the Ghanaian context. The interview protocol was designed based on questions in the quantitative survey to explore the impact of raising a child with intellectual disability and the coping strategies utilized by primary caregivers in the Ghanaian cultural context.

Ten (10) items were in the interview protocol. Some of the questions include: *How did you feel when you first found out of the diagnosis of your child? How do people in society react to you and your child? What coping strategies do you use in dealing with stress associated with caring for your child”? How did you know about your child’s disability?*

Probes such as (“Please describe your feelings” and “How does your belief in God and support from your family help you through this situation”?)) were introduced to seek more clarifications of primary caregivers’ experience. According to Creswell (2002), probing may be used to obtain information, clarify a point, or expand on ideas. Field notes on the experiences of primary caregivers were also made during each interview to serve as an audit trail (Koch & Harrington, 1998). The interview protocol can be found in Appendix F.
Procedure for Data Collection

Participants were contacted and informed of the nature of the study. After the initial contacts were made, eleven (11) participants agreed voluntarily. Reasons ascribed to the unwillingness of other primary caregivers to participate in the study were lack of time and not being comfortable with the audio recording. Participants who expressed interest in participating in the interview were contacted by the researcher through a telephone call to schedule a meeting at their own time and convenience, and which did not compromise confidentiality. Participants were given a brief description of the nature and purpose of the interview and they were also informed of their right to withdraw from the study if they so wish. Participants were assured of confidentiality and anonymity. Whereas some participants preferred to be interviewed in their homes, others preferred to be interviewed at the school premises.

The interview began with exchange of pleasantries between the researcher and the primary caregiver. Since the nature of qualitative interview are usually between strangers, research has shown that the interviewing process should begin with establishing rapport with participants since that allows for an openness of discussion between the interviewer and interviewee (Rubin & Rubin, 2005). Thereafter, the interviewer asked for demographic information (e.g. age, gender, type of disability, marital status and employment status). The interview began with a more general question (e.g. could you please share with me three most important things in your life?). This question was asked to enable the researcher get adequate information on whether raising the child forms an essential part of their life. The other questions in the interview followed through to the end.

During the interview, participants were given time to openly express themselves and also allowed to answer questions completely. However, care was taken so that participants did not veer off from the import of the question. Probes were also introduced to assist participants provide
detailed explanations and also help the researcher seek clarification from participants along the main questions (Rubin & Rubin, 2005). All eleven (11) interviews were digitally recorded and lasted for approximately 50 minutes depending on the depth of responses provided by participants.

A total of five hundred (500) minutes of data was recorded. Participants were also asked whether they had any additional information they wished to share about being a primary caregiver of a child with intellectual disability. Primary caregivers who participated in the interviews were given tokens for their participation. Participants were checked upon immediately after the interview to discuss any questions, concerns, or feelings they may have had about the interviewing experience. A summary of the analysis was later sent to participants for feedback and their responses were incorporated into the findings.

**Data Analysis**

The data was analyzed manually using thematic analysis to ensure that the researcher got familiar with the data. Braun and Clarke (2006) defines thematic analysis as a method that identifies, analyzes, and report themes within a data and goes beyond this by interpreting the themes. Unlike other methods, thematic analysis is not associated with pre-existing theoretical framework, and can be used across a range of qualitative approaches (Braun & Clarke, 2006). Research has shown that thematic analysis is the most fundamental method for qualitative analysis (Green & Thorogood, 2009). Braun and Clarke (2006) assert that in thematic analysis, the researcher plays a crucial role in analyzing and interpreting the information gathered.

*Steps of the Thematic Analysis.* Thematic analysis involves six main steps including transcribing, familiarization with the data, generating codes, and searching for themes, reviewing themes, defining themes and interpretation. In the current study, all interview recordings were transcribed verbatim. Two doctoral students with experience in qualitative research assisted in
transcribing the data. They had similar themes emerging from the interviews. The transcribed data were also reviewed by the researcher to ensure that all the details of the interview were captured accurately. According to Creswell and Miller (2000), having multiple reviewers ensure a reduction in bias as well as reliability in understanding the data. A total of seventy seven (77) pages of transcripts were generated. Firstly, the data was read thoroughly in order to get familiar with it and full understanding of the participants account (Lacey & Luff, 2001). Secondly, initial codes of interesting features of the data were generated in a systematic fashion across the entire data set. Different colours on the computer were used to code the data. Thirdly, similar or close meaning ideas were coded as units.

Fourthly, the coded ideas were collated into potential themes and broader themes. Themes were checked to determine whether they related to coded extracts in order to generate thematic map of analysis. The themes were then defined and named at the fifth step. Lastly, the significance of the themes to the entire data was established. This process was applied to all eleven transcripts and quotes from the transcripts were extracted to explain the themes. Words such as “hmmm”, “aaaahhh”, and “you know” were removed from the quotes, as well as words that were repeated unnecessarily to ensure clarity and brevity. A table of themes and subthemes as well as a thematic map were derived. Extracts from interviews were used to support themes and subthemes.

**Trustworthiness**

The aim of trustworthiness in a qualitative inquiry is to support the argument that the inquiry’s findings are “worth paying attention to” (Lincoln & Guba, 1985, p.290). Research has demonstrated that the qualitative method can enhance the trustworthiness of findings using the criteria proposed by Lincoln and Guba (1985) namely; credibility, dependability, transferability,
and confirmability. These methods correspond to the validity and reliability in quantitative research (Guba & Lincoln, 2000; Lincoln & Guba, 1985). The present study proved to be of significance to the primary caregivers as it provided a platform for them to express themselves on their feelings and experiences regarding having a child with an intellectual disability.

**Credibility.** Credibility refers to an evaluation of whether or not the research findings represent a “credible” conceptual interpretation of the data drawn from the participants’ original data (Lincoln & Guba, 1985, p.296). This is usually achieved by collaborating with participants from the beginning of the study to the dissemination of the findings. It is equivalent to internal validity in quantitative research. Credibility was established through peer debriefing and member checks which Guba and Lincoln (1989) regarded as ‘the single most critical technique for establishing credibility’. Peer debriefing was applied to the whole research process, including data analysis and findings to ensure a better understanding and interpretation of participants’ stories. For the current study, peer debriefing was conducted with two fellow doctoral students in order to provide feedback on findings as they developed.

**Dependability.** Dependability refers to the extent to which the same results of a study will be gotten if the study is repeated in the same context. It is equivalent to reliability in quantitative research. In order to address the issue of dependability in qualitative research, all the processes within the study should be reported in detail to ensure replication of the study in future (Mays & Pope, 2000). In the current study, dependability was confirmed by recording details of the research process in terms of the steps taken in recruiting participants, data collection, and data analysis—where the abstraction of themes were clearly outlined to allow others to conduct similar research.

**Transferability.** Transferability refers to the degree to which the results can be generalized or applied to other contexts similar to the research context (Lincoln & Guba, 1985). It is equivalent
to external validity in quantitative research. Since the sample of this study was not randomly selected and also limited in size, care was taken in generalizing results to the wider population of primary caregivers of children with intellectual disability. However, findings of the study can be used as a starting point for the development of theories and formulation of research questions to be tested in future qualitative studies among primary caregivers of children with intellectual disability.

**Confirmability.** Confirmability is a measure of how well the findings are supported by the data collected (Lincoln & Guba, 1985). It refers to the extent to which findings can be confirmed by another researcher. It is equivalent to objectivity in quantitative research. This was achieved in the current study by documenting the procedures for checking and rechecking the data with participants for confirmation of their information throughout the study. Confirmability was also achieved by maintaining an audit trail (Lincoln & Guba, 1985).

**Ethical Approval**

Ethical approval for both phases of the study was obtained from the Institutional Review Board at the Nuguchi Memorial Institute (IRB-NMI) (Appendix G), University of Ghana, Legon, Accra. Permission to conduct the study was obtained from the various Special schools (New Horizon Special School, Dzorwulu Special School and the Autism Awareness and Training Center) and the Korle-Bu teaching hospital. All ethical guidelines proposed by the American Psychological Association were strictly adhered to. Written informed consent was sought from all participants prior to responding to questionnaires and interview sessions. Participants were informed of the nature and purpose of the study. They were also told of their rights to continue with the interview or withdraw at any time if they wish (Appendix H). Participants were also assured of confidentiality and anonymity.
In the qualitative phase, participants were assured of confidentiality and anonymity by providing them with pseudo names created by the researcher and used throughout the study. At some point during the qualitative interview, some participants shed tears as long buried memories were evoked. Under such circumstances, participants were given time to cry and then were later asked if they were willing to continue the interview. In addition, the researcher emotionally supported the participants by encouraging them to stay strong.

**Storage of Data**

All information regarding the recordings and transcribed materials were kept under lock and to be destroyed after five years. Electronic versions of both quantitative and qualitative data were stored safely on the researcher’s laptop and with a password.

**Summary**

The research design, study setting, participants, sampling technique, measures for data collection, procedure for data collection and data analysis, ethical approval, and storage of data were discussed in this section. In the next two sections, results and discussion for study two (qualitative phase) is be presented.
Findings of Study Two (Qualitative Phase)

Introduction

This section presents findings of the qualitative phase of the study. The qualitative phase was conducted to compliment the findings of the quantitative phase and to increase an understanding of the stressful experiences of primary caregivers of children with intellectual disability and the coping strategies they adopt in the Ghanaian cultural context. Additionally, primary caregivers’ knowledge of condition and perceived cause of disability were explored to obtain a comprehension of those issues as well. Results from this phase are presented here in the form of major and sub-themes that emerged from the interviews.

Thematic analysis of the qualitative data yielded seven main themes that best captured the stress and coping experiences of primary caregivers of children with intellectual disability. Additionally, subthemes were detailed using relevant extracts from the transcripts. Based on the findings, interpretations are provided.

Emergent Themes

The analysis of the interviews revealed themes and subthemes associated with the experiences of primary caregivers of children with intellectual disability. The major themes were: (1) Psychological reactions; (2) Caregiving challenges; (3) Societal reactions; (4) Coping strategies; (5) Psychological functioning; (6) Knowledge of condition; and (7) Perceived cause of disability.

Themes and subthemes should not be viewed in isolation but grasped and understood in the whole experience of parenting a child with intellectual disability. Themes and sub themes are illustrated in Table 4. 2 and the thematic map in Figure 4. 1.
Table 4. 2: *Summary of Themes and Sub-themes identified from the qualitative study*

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological Reactions</td>
<td>• Sadness</td>
</tr>
<tr>
<td></td>
<td>• Worry about future</td>
</tr>
<tr>
<td></td>
<td>• Stress</td>
</tr>
<tr>
<td>Caregiving Challenges</td>
<td>• Employment Issues</td>
</tr>
<tr>
<td></td>
<td>• Demands of Caregiving</td>
</tr>
<tr>
<td>Societal Reactions</td>
<td>• Stigma</td>
</tr>
<tr>
<td></td>
<td>• Isolation</td>
</tr>
<tr>
<td>Coping Strategies</td>
<td>• Spiritual beliefs</td>
</tr>
<tr>
<td></td>
<td>• Hope</td>
</tr>
<tr>
<td></td>
<td>• Support</td>
</tr>
<tr>
<td>Psychological functioning</td>
<td>• Relief</td>
</tr>
<tr>
<td></td>
<td>• Strength</td>
</tr>
<tr>
<td>Knowledge of Condition</td>
<td>• Medical/psychological assessment</td>
</tr>
<tr>
<td></td>
<td>• Teacher Information</td>
</tr>
<tr>
<td></td>
<td>• Personal Knowledge</td>
</tr>
<tr>
<td>Perceived Cause of Disability</td>
<td>• Medical</td>
</tr>
<tr>
<td></td>
<td>• Spiritual</td>
</tr>
</tbody>
</table>
The thematic map above shows the major and sub-themes associated with the caregiving experiences of Ghanaian primary caregivers of children with intellectual disability. However, it is important to note that the themes are not entirely independent, but are interrelated in explaining the lived experiences of primary caregivers. The major and sub-themes addresses the research questions of stress and coping experiences of Ghanaian primary caregivers of children with intellectual disability.
**Theme 1: Psychological Reactions**

This broad theme describes the psychological reactions of primary caregivers upon realizing the child has a problem. Primary caregivers of children with intellectual disability unanimously reported of psychological reactions in the form of sadness, worry, and stress after they knew of their child’s condition. Under this broad theme, three (3) sub-themes were identified: sadness, worry about the future, and stress of having a child with intellectual disability. These are illustrated by statements from some primary caregivers;

**Sadness**

All primary caregivers described the experience of having a child with intellectual disability as very sad. They cried their hearts out in expressing grief for the loss of a perfect and healthy child they were expecting. This is illustrated by statements from some primary caregivers:

“That day I found out “I cried. I wasn’t happy at all because, I have two children and the first is a girl and even that I wanted a boy as my first child and so when I had this boy I was so excited because that is what I wanted but when they told me about this situation, I didn’t like it, I cried a lot” (Gessie).

“Well it was very painful and I cried. After her birth I decided not to give birth again and so it was really painful that my last child had to have such a condition” (Eve).

**Worry about the future**

Primary caregivers unanimously expressed worry about the child’s present and future situation. This is illustrated with the words of some primary caregivers:

“If you look at him now that he is almost eight years but there are so many things he cannot do for himself and so I worry about his future. What can he do for himself in future and
who will take care of him. In fact I really worry about my son. It is only God that can help him” (Enoma).

“I am very worried about his future because as at now he can’t talk, think or do anything for himself and so if God does not help him to get well and I die and leave him what will he do. Who will take care of him? I used to have house helps but they were all not treating him well in my absence so I decided to stop working and concentrate on his care so his future keeps me very worried, who will get such time for him” (Grandma).

**Stress**

Primary caregivers also described the stressful experience of having a child with intellectual disability. Particularly, they indicated that their stress stemmed from controlling behavioural problems of their children and daily hassles of parenting. Some views of some of the participants are expressed below:

“I feel very stressed, I have many things to do in my life but I have no time to do anything for myself. Everything is centered on my son’s welfare. I get very tired at the end of the day and most of the time I feel sick because I do not have any help” (Obenewa).

**Theme 2: Caregiving Challenges**

Raising children with intellectual disability involves a lot of challenges. Primary caregivers in the current study also reported of the many caregiving challenges they encountered in caregiving. Some primary caregivers indicated that they felt overwhelmed with the situation because they could not do anything for themselves and that their lives revolved just around their children.
Employment and financial issues emerged as part of the caregiving challenges in the current study. Caregiving challenges were thus put in two sub themes namely demands of caregiving and employment issues.

**Demands of caregiving**

“I go through a lot of daily problems. In the morning when we wake up, I wake him up and brush the teeth... brushing his teeth is difficult. I have to sing and crack jokes for him to laugh so that when he opens the mouth then I can brush. I have to bath him, dress him, feed him and virtually do everything for him. The issue is that he cannot do anything for himself so I have to help him out every time. After all these I have to take him to school myself” (Enoma).

“Problems, upon problems, I go through a lot of troubles associated with taking care of him... when I was delivering he had a problem with one of his hands and so he is very slow so I can’t do much for himself unless I do and though sometimes he can, he will not do it as I want it. I have to brush his teeth, bath, dress, and feed him. After all these I take him to school before I am able to go to work. It’s a lot of work” (Obenewa).

**Employment Issues**

“I have stopped working and devoted my time to taking care of him. I also go back to the school to pick him up and the distance between the house and the school is very far. My day is very hectic” (Enoma).

“Before the child came I was working but when he came his condition made me to stop working. The maids I had did not also treat him well as they gave him all kinds of
names especially when I am not around. My life now revolves around him alone and I sometimes feel sad” (Grandma).

“Growing up I had plans of working and having a fabulous career, but because of my daughter I had to come to terms with the fact that I will be a caregiver all my life. I cannot work like other women do” (Adessa).

The employment difficulties faced by primary caregivers led some of them to run into financial difficulties. Many families struggled to meet the basic needs of their child. Below are illustrated statements of some parents of children with intellectual disability:

‘It’s difficult providing his needs and even food because he eats a lot” (Gessie).

“Her fees, transport is all my burden and the father is taking care of the elderly ones” (Alice).

Theme 3: Societal Reactions

For all families in the current study, having a child with intellectual disability involves a transition to a new and often unwelcome identity in society. Throughout the study, primary caregivers demonstrated their awareness of societal attitudes which made them feel stigmatized and isolated.

Stigma

Almost all primary caregivers reported that the burden of care for their children with intellectual disability was further aggravated by unsympathetic comments from the general public which may be emanating from the cultural perceptions of disability in society. They faced rejection.
and derogatory comments which further fueled the stigma they experienced. This is illustrated in the following narratives by different mothers:

“If has been a real experience and a very difficult journey of having a child with special need. One day a certain woman who also sells some of the products we sell intentionally came here to insult me that I have given birth to a dog” (Leslie).

“Even in the family when you are giving meaningful contribution they say this woman she doesn’t understand anything because she has a special child. I had an issue with a cousin of mine, when I told her that if I have a child with special needs does it mean I don’t have sense.” (Gessie).

One parent reported that the doctors she consulted did not tell her of the child’s diagnosis because of stigmatization in society. She stated this as:

“Though we had several consultations, they didn’t tell us what the condition was because they said they did not want to label her” (Adessa).

Parents also reported of remarks made about their children. Sometimes the child was told terrible words because of his/her disability:

“One day at church he urinated on himself and one woman said, ‘an old boy like you why should you urinate on yourself but I got bored about it and told her that the child has a problem. There is also woman at church who tells everybody who comes to the church for the first time about my grandsons condition but one day I confronted her and told her that instead of telling people about the child she should pray for him” (Grandma).
Isolation

Primary caregivers experienced isolation due to the negative attitudes from family and community towards to them. They reported feeling isolated as a result of the way they were stared at in society. Some parents put it in this way:

“I don’t have friends because of my son….to avoid people staring at us we usually do not go out to many places unless he is going to school and even that I struggle to get enough money to board taxi” (Obenewa).

“People stare a lot and when some people see us the way they look at us it is as if we are not human beings. The last time the father took us to a restaurant and the drinks we bought, he poured all away and everyone was staring. Because of some of these reactions we hardly go out” (Enoma).

Primary caregivers also indicated how they felt about the societal attitudes in the form of stigmatization and discrimination they and their children were subjected to and this is illustrated by:

“I feel very sad sometimes and I must confess that it is a very trying moment. As if we requested for the condition from God. It takes a lot of strength and power from God to go through societal reactions and comments” (Adessa).

“Sometimes I feel down, I feel sad because we did not ask for this but we have so if you see us and you make negative comments I don’t know what you want us to do” (Samuela).

Interestingly, some primary caregivers were not much affected by societal reactions as some of them were willing to forgive people who made negative comments about them. The
primary caregivers’ unique response to these situations may be related more to the personality of the parent as opposed to their child’s intellectual disability:

“Those who say good things I thank them but those who say bad things I only pray for them that God should forgive them because it is not my fault to have a child with disability” (Leslie).

**Theme 4: Coping Strategies**

Despite the problems that primary caregivers encountered with raising a child with intellectual disability, they also reported a variety of coping strategies to deal with their problems. During the interview, it became evident that primary caregivers possessed coping strategies such as their spiritual beliefs, hope, family and community supports which helped them to adapt to their new life.

**Spiritual beliefs**

Many of the primary caregivers reported several spiritual practices they used in coping including; meaning of having a child with intellectual disability, surrendering everything to God, prayers, singing, reading the bible, engaging in church activities, and perceiving their role as a God given responsibility. This is illustrated by statements from parents.

“I believe children are gifts from God and he knows why we had this child. Parents should not lose hope because for me now my daughter can do certain things for herself” (Eve).

“I am a strong believer in God so the only thing I know is that God gave her to us and he knows why he gave her to us” I believe I was chosen by God to have a child with a disability. My daughter had to come to the world but through me. Sometimes I ask God, “Why me” and a friend
once said ‘why not you’. I believe God wanted this child to come in to the world and he had to choose me. I believe it is a calling (Adessa).

Some parents also talked about total surrender of their situation to God. Usually when people realize that they do not have the resources needed to deal with their situation. However, they know that by surrendering all to God, God is all powerful and cares about their circumstances. For the primary caregiver, surrendering to God was a way of coping with their situation;

“I just leave things in the hands of God. It’s only God who can help me. I pray and I just relax and take my mind off things” (Meryl).

“Sometimes I feel like I am in charge and can carry all the burdens alone... But there comes a point where you realize that it is only by the grace of God that you can survive.... God has a plan for us and it is that which sustains me” “The ways of God cannot be understood and so I have taken it like that” “God knows we can face this battle that is why He has given us the child” (Enoma).

In addition to believing that their child is God sent and surrendering everything to God, the participants perceived prayer as a channel for communicating with God. This is illustrated by a statement from a parent:

“I usually do prayers and understanding and knowing the lord you serve, knowing what he can do for me encourages me... “I mostly pray for direction and I always go to the church programmes in order to feel relieved” the prayers do help but most often though we pray and all but just the thought of being in this state is a great worry. “I think in very situation things happen to us and you ask God ‘why me’ but I think the first thing to do is to accept it so you know how to handle it” (Samuela).
“I pray a lot, I’m not able to go to church because of him and as a member of the women’s group, they come to pray and share God’s word with us” ... I pray a lot and read my bible when I am distressed. ... I’m not able to go for church meetings but they come here sometimes to brief me on what is going on in the church since I’m not able to frequent church. These things make me feel alive again (Grandma).

Moreover, some primary caregivers made reference to church attendance as a place of refuge and that going to church and getting involved in activities relieved them of their stress. The extract below illustrates this:

“Anytime I go to church there is a sister at church who has been very helpful. Sometimes when I need help with food she gives us rice since she sells rice. She has really been helpful” (Gessie).

“I’m a Presbyterian...so the church support us sometimes with one or two things especially those of us with children like this. Also I have one lady who when I go to church we do chat about her and she advises me on how to handle her and prays with us as well” (Eve).

Others also used singing and reading the bible as coping resources which is also embedded in their spiritual beliefs. This is illustrated by an extract from the text:

“Well normally I like singing, so when I’m sad I start singing and praising God for how far he has brought me and my child. I know God will make a way where there seem to be no way...He will touch my daughter and she will be whole just like the woman in the bible” (Alice).

“I usually sing and thank God for everything. I am a member of Women’s Aglow so I pray a lot and it relieves me knowing that God is in control of my life. I believe only God knows why he gave me my son...he knows why...maybe he knows I can take care of him better so I know he will see me through” (Obenewa).
The spiritual nature of these primary caregivers were so pervasive that they believed having a child with intellectual disability was a God given responsibility. This is shown by statements from some parents:

“I have given birth to him, God knows why he gave him to me and he knows I can handle him that is why I have always been there for him. I believe it is God’s will that I had this child because maybe he knows I can take care of him” (Gessie).

“When I look at my child I know one day God will do something great for me through my child. I feel I am responsible for him and if I take good care of him God will bless me. In fact the child has brought lots of blessings to this family” (Enoma).

“I think that this work is for me to do”. I believe that God had a purpose for this life” (Adessa).

On the contrary, some primary caregivers felt frustrated by God and their own spiritual beliefs because they felt they had not been treated fairly by God who had given them such a child. Besides, the church did not always serve as a haven of refuge for the sick and vulnerable. The extract below highlight this dichotomy and is illustrated by a statement from a primary caregiver:

“I am not able to pray because the moment I open my mouth I start crying” “I ask ‘oh God why me’, why should this happen to me. What I have done to deserve this” “why do I have to go through this problem” (Leslie).

“One day at church he urinated on himself and one woman said, ‘an old boy like you why should you urinate on yourself but I got bored about it and told her that the child has a problem. There is also woman at church who tells everybody who comes to the church for the first time
about my grandsons condition but one day I confronted her and told her that instead of telling people about the child she should pray for him” (Grandma).

Hope

Primary caregivers were hopeful of the future of the children and interestingly their hope hinged on their spirituality that God has a purpose for the child in their lives. Though, parents in this study were very conscious of the limitations of their children, they also expressed hope in the midst of despair. This was stated in the words of some parents:

“There is hope for the future because since she started school she has really improved and I’m so thankful to God that we did not abandon her”. With all the difficulties, I still feel very responsible for her because she is my child and the first one and so I feel I have to give her the best education so that she can also be somebody in future. I also love her very much because out of all my kids she is always around me and inspires me a lot” (Adessa).

“I will tell parents who have just discovered this to be patient and accept their children because they do not know what will become of them. They should not give up because there is hope (Samuela).

Support

Primary caregivers expressed mixed reactions about support they received from family, friends, community, professionals and these contributed significantly to their psychological functioning. Some of the primary caregivers reported of the limitations in the support they got from family and friends. Some primary caregivers were not very convinced of the support from family, friends, and the community. These are found in statements below:
"The family is not helping. After the father passed away, the father's family are also not helping, one time we met one of his sisters, who said that they know about my situation but... we also have children and unfortunately my parents have also passed so I really do not have anybody who is providing support for us" (Gessie).

"I don’t get support from anyone because everybody thinks that times are hard so each one for himself God for us all. I only rely on God and my children" (Meryl).

Although several primary caregivers reported on the limitations in the support from family and friends, others were grateful of the little support they received. Some of the reports are found in the statements below:

"My husband helps a lot, days when I’m not able to take her to school, he does it and even at home he helps with taking care of the home. He is very supportive. "I cannot pinpoint somebody but a group, my mother, husband. They get very helpful sometimes” (Adessa).

'I have a good friend in Kumasi whom I usually call when I’m stressed. For the family, it is once a while you get some support in terms of visitation. Sometimes if I have to go for a course they come in but not all the time. At church too, there is one Sunday school teacher who supports us, help my daughter to fit into her class at church and protects her from children who might be rude to her” (Samuela).

Other primary caregivers also reported of the support they received from their children’s school in terms of organizing educational programmes for them and encouraging them to hold on. However there were also mixed reactions. This is illustrated by:

"The school also helps a lot because they organize programmes for us on how to handle our children and how to cope. They encourage us anytime we are sad that everything will be well”

"The school also helps a lot because they organize programmes for us on how to handle our
children and how to cope. They encourage us anytime we are sad that everything will be well” (Enoma).

“Sometimes I call the teachers or doctor friends of mine and ask how do I go about this or that” (Samuela).

On the contrary, other primary caregivers raised issues of being maltreated by health professionals who sometimes reacted very negatively to them.

‘She urinated on herself one time and a nurse shouted at her ‘how can a big girl like you urinate on yourself’ I think that was extreme coming from a health professional” (Adessa).

From the above illustrations, it could be realized that the spiritual beliefs, hope, and support served as coping resources for parents of children with intellectual disability. For parents in this study, their spiritual beliefs emerged as a very vital coping resource in making sense of their children’s disability and also to their survival.

Theme 5: Psychological functioning

Primary caregivers also reported that they felt a sense of relief and strength from their spiritual beliefs and support they received. The theme was put in two sub themes namely, relief and strength.

Relief

Some parents described that they felt very relieved and relaxed when they utilized their spiritual beliefs and support they received from others. This is illustrated in the words of some parents as:
“As a Christian mother, I’m not able to go for meetings but they come here sometimes to brief me on what is going on in the church since I’m not able to frequent church. These things make me feel alive again” (Grandma).

“I realized that when I pray and believe that God has taken care of my problem, I feel relieved and....as if the problem is no more...I...don’t feel stressed any more” (Meryl).

**Strength**

Some parents also expressed a sense of strength from the coping strategies they utilized. Special reference was made to prayers as a source of strength and comfort to stay positive in dealing with raising their children.

“I pray, I read my bible. One day, I felt sad and started singing “what a friend we have in Jesus” I think that was the day I really listened to the words of that song” and it really strengthened me because I got to know that I have a friend in Jesus who came to die to save me and that through all my trials he will see me through”. “It is prayers that are carrying me on. Together with my husband we continue to commit our lives unto God that he gives us the strength to carry on” (Adessa).

“Usually I feel sad and depressed but as soon as I pray, I feel God’s presence with me and it strengthens me move on in life” (Meryl).

*Other findings from qualitative data*

**Theme 6: Knowledge of Condition**

This major theme describes the various ways through which primary caregivers got to know about their children’s condition. Primary caregivers reported on their knowledge of the child’s condition from three (3) sources including medical/psychological consultation, teacher
information, and their personal knowledge. From the data analysis, it was realized that many of the primary caregivers reported of getting to know it through the hospital. A few of them also mentioned the role of the child’s teacher and observing physical features of the child. This was stated as;

**Medical/psychological consultation**

“As he was growing, as at age 6 months he had to sit, crawl and all but he couldn’t and so I got alarmed and took him to the hospital again. After series of assessments, they told me that my child had a problem with the brain” (Enoma).

“They sent us to the assessment center at Achimota for us to go through series of tests and it was there that I was informed that my child has a disability called Down syndrome. So we brought the report back to the school and then they admitted him on that condition and since then he has been here” (Obenewa).

**Teacher information**

“Teachers started complaining that when they teach the child she does not get it and in the words of one teacher, ‘your child when we say this, she will sitting down and looking at us. She does not say anything and will be sitting down looking at us’ (Eve).

**Personal knowledge**

Interestingly, some parents indicated that they suspected something was wrong with their children’s development. This was due to the physical features of the child and also delays in development, especially physical features and toilet training abilities

“I think some few days after birth... I know their features and their pace of development” (Adjo).
From the narratives above, it seems that parents’ knowledge of the child’s condition varied along medical assessments and personal knowledge respectively. In the case of Eve, her child’s behaviour in school was something that had happened at home before, but repeating such behaviours in school seemed to suggest a real problem exists with her child.

**Theme 7: Perceived Cause of Disability**

Primary caregivers were asked what they thought was the cause of their child’s disability. Majority of them were not sure what could have caused the condition. However, some parents reported that they got to know of their child’s condition at the hospital. Additionally, almost all primary caregivers recounted the spiritual nature of having a child with intellectual disability. From their responses, their perceived cause of disability were put into two subthemes namely, medical and spiritual.

**Medical**

Many of them recounted what they were told by doctors and nurses about the cause of the child’s condition, as related to the age of child birth or the child having convulsions.

“*After we were discharged we went for review after two weeks and I met a white doctor who said because I was over 40 years, that could be a contributing factor. So it was there that I knew it*” (Samuela).

“*I was told he had Convulsions throughout the night. So I think it is the lack of oxygen and the series of convulsions that caused the disease. In fact my child had convulsions till age seven when I was given drug to stop it*” (Gessie).
Spiritual

Other primary caregivers perceived their child’s disability as spiritual in nature, though many of them claimed they did not believe in the existing evil connotation people ascribe to disability in Ghana. Regardless, they still talked about it but placing emphasis on the fact that they attributed it more to their Christian faith in God than to the traditional beliefs of curse and punishment from the gods. This is illustrated in statements from some parents:

“We are in Africa and so sometimes I hear a lot of things concerning spirituality in terms of children with intellectual disability being children of the rivers or what and also you hear people say that they are going to ‘escort them’ and then they leave them to their fate at river banks. But as I said I am a strong believer in God so I do not think that my child is a river child. The only thing I know is that God gave her to us and he knows why he gave her to us” (Adessa).

“As for that one I don’t know because all I know is that the creation of God is wonderful so I cannot really tell what caused it. The ways of God cannot be understood and so I have taken it like that” (Enoma).

Summary of Qualitative Findings

The qualitative phase was conducted to provide support to the quantitative findings, as well as build our understanding of the stress, coping, and psychological health of primary caregivers of children with intellectual disability in Ghana. Findings of the qualitative phase of this study illuminate the constant struggle faced by primary caregivers of children with intellectual disability. Having a child with intellectual disability affects all aspects of the primary caregiver’s life. Once primary caregivers were aware of the child’s condition, they started thinking of what they perceived to be the cause of their children’s disability, and they expressed their emotional feelings,
societal reactions, caregiving challenges, coping strategies and the impact on their well-being. Of significant importance is the coping strategies they adopted, including their spiritual beliefs, hope, and support.

Regardless of the enormous challenges faced by primary caregivers, they also remained strong in raising their children. Primary caregivers in the current study reported on their overwhelming reliance on their faith to cope with the challenges associated with having a child with intellectual disability. This reiterates the point made by some researchers that people of African descent prefer coping strategies associated with their spiritual worldview. For example, most Africans are spiritual or religious in nature, and it is these spiritual beliefs that provide a sense of relief and strength in times of distress.

Additionally, the analysis revealed mixed reactions on support from family, formal or professionals, and the entire society. Though, some primary caregivers reported of some amount of support from family, friends, and other formal supports, largely, others also reported lack of support from these sources. Therefore, it behooves on the family, society, and other professionals involved with families of children with intellectual disability to improve on their sensitivity and empathy to primary caregivers and their children with intellectual disability.
Discussion for Study Two (Qualitative Phase)

Introduction

The qualitative phase explored the stress and coping experiences of primary caregivers raising children with intellectual disability in the Ghanaian cultural context. Additionally, primary caregivers’ knowledge of condition and perceived cause of disability were also explored to increase our understanding of those issues as well. The qualitative phase was conducted to compliment the findings of the quantitative study.

Primary caregivers reported of psychological reactions they experienced after they knew of their child’s condition also emerged from the study. They expressed emotionally distressing feelings, fears, and worry about the condition of the child and what the future holds for them. These reactions are consistent with finding from other studies on psychological functioning of parents of children with intellectual disability (Ambikile & Outwater, 2012; Cramm & Nieboer, 2011).

Moreover, challenges associated with caregiving were also reported by primary caregivers in the current study. Almost all primary caregivers reported that their daily routine activities in the form of feeding, bathing, and assisting the child in all activities, was overwhelming because they could not do anything for themselves and that their lives revolved just around their children. Many children with intellectual disability are not able to take care of themselves, or perform behaviours that are expected of other children of their age with normal development. Thus, the birth of a child with intellectual disability bring unexpected demands and challenges to parents, for which they are often not prepared. This is consistent with previous studies which assert that parents experienced heightened stress because of the daily hassles associated with caring for their children (Pisula, 2007; Plant & Sanders, 2007).
Employment and financial issues emerged as part of caregiving challenges in the current study. Many primary caregivers reported that they could not work as they wanted because they had to care for the child. Specifically, one critical consequence of having a child with intellectual disability is the reduced or inability to get employed as they spend a greater amount of time caring for the child (Ambikile & Outwater, 2012; Olsson & Hwang, 2008). For instance one primary caregiver recounted that she is not able to do anything for herself because of the presence of the child, she takes him to school and brings him back home, thereby causing her to stop work in order to devote all her time to the child. These employment problems resulted in financial difficulties for many primary caregivers. Primary caregivers felt burdened because they had to provide everything for the child which they would not provide under normal circumstances would not be provided for a child without intellectual disability. Primary caregivers had to send their children to Special schools with high school fees and privately transported to school due to inconveniences and their own safety.

In another development, almost all primary caregivers in the current study talked about being stigmatized in society (Anum, 2011; Ambikile & Outwater, 2012). Primary caregivers raised their children within the cultural context of a powerful influence of traditional beliefs that devalue people with disabilities (Anum, 2011; Avoke, 2002; Baffoe, 2013) and this caused them to feel emotionally burdened (Anum, 2011; Green, 2007). Moreover, primary caregivers narrated not going out with children or getting involved in activities in the community as they perceived that to attract negative comments and stares from the public.

Despite the problems that primary caregivers encountered with raising a child with intellectual disability, they also reported a variety of coping strategies to deal with their problems. Some of the coping strategies highlighted were spiritual beliefs and family/community support
systems which were noted as essential to their psychological functioning. Many of the primary caregivers identified themselves as Christians and reported several spiritual practices they used in coping including; meaning of having a child with intellectual disability, surrendering everything to God, prayers, singing, reading the bible, engaging in church activities, and perceiving their role as a God given responsibility.

Hope was also adopted as a coping strategy by primary caregivers in the current study. Primary caregivers were hopeful of the future of the children and interestingly their hope hinged on their spirituality that God has a purpose for the child in their lives. This assertion is consistent with findings where spirituality has been found as a source of hope and optimism (Ciarrocchi et al., 2008; Durà-Vilà et al., 2010). This is a confirmation of the spiritual nature of people of African descent (Ani, 1990; Gyekye, 2003; Utsey et al., 2000).

Another coping strategy identified in the current study was Ghanaian primary caregivers utilizing family, community, and professional support systems in adjusting to their problems. Support from family and friends proved to be necessary because it indirectly implied acceptance of the primary caregiver and the child by the family and other members of society, thereby making them more comfortable. In the current study, primary caregivers reported receiving some support from their spouses or siblings, and grandparents of the child. Further, some parents indicated that they received formal support from the child’s school in terms of organizing programmes on how to care and cope with their children.

On the other hand, it was also obvious from the current study that family and community support systems was limited for some primary caregivers. Some primary caregivers were not very convinced of the support from family, friends, and the community and this is supported by findings from other studies (Edwardraj et al., 2010; Gupta et al., 2012), where parents of children with
intellectual disability received little support from family and society. In fact, according to some primary caregivers, the fact that they had children with intellectual disability made them to be perceived as outcasts in the family.

As evidenced from the comments of primary caregivers, coping strategies were found to contribute significantly to their psychological functioning. Primary caregivers reported that they felt a sense of relief and strength from their spiritual beliefs and support they received. For many of the primary caregivers, the faith they reposed in God strengthened them through the challenges. These findings are consistent with existing literature among parents of children with disabilities, where spiritual beliefs have been found to promote better mental health (Durà-Vilà et al., 2010; Marshal et al., 2003; Tarakeshwar & Pargament 2001). It is clear that primary caregivers in this study explained their circumstances to a greater degree in terms of their spirituality and would appreciate more acceptance and support from the religious community.

Primary caregivers reported on their knowledge of the child’s condition from various sources including medical/psychological consultation, teacher information, and their personal knowledge. While some reported of medical and psychological knowledge of their children’s condition, others also reported of getting the information from their children’s teacher. Personal knowledge was also reported as a source of knowledge of the child’s condition.

Attributions about the perceived cause of the child’s disability was reported as either medical or spiritual in nature. Many of them reported that information given to them by doctors indicated that the child’s condition was related to their age of getting pregnant or convulsions in the child. However, all primary caregivers referred to spiritual understandings of intellectual disability. This was perhaps influenced by how disability is interpreted in the Ghanaian cultural
context. In Ghana, having a child with intellectual disability is attributed to punishment from the gods (Avoke, 2002).

In conclusion, the findings of the qualitative phase of this study indicated that primary caregivers of children with intellectual disability faced challenges in raising their children. They reported on their heir psychological reactions to raising a child with intellectual disability, societal reactions, coping strategies, psychological functioning, source of information on the child’s condition, and perceived cause of the condition. Regardless of some variability that existed among primary caregivers in terms of their spiritual beliefs and the support they received from family and society, majority of the primary caregivers in this study focused on the brighter side of their lives. This is a confirmation of emerging literature that having a child with intellectual disability is not an entirely gloomy situation but a source of strength (Durà-Vilà et al., 2010; Hastings et al., 2002).
CHAPTER FIVE

General Discussion

The purpose of this chapter is to integrate and discuss the findings of both the quantitative and qualitative studies and relate them to previous research. The concurrent mixed methods design was utilized in the current study. Owing to the cross-sectional nature of the quantitative study and its inadequacy to determine causality among study variables, a qualitative study was conducted concurrently on a small sample of the primary caregivers of children with intellectual disability to provide a detailed and holistic picture of the stress and coping experiences of primary caregivers of children with intellectual disability in the Ghanaian cultural context. This design was selected because it allows for findings to be confirmed and corroborated in a single study (Creswell, 2003).

The first phase of the study utilized the quantitative method. The quantitative phase sought to explore the potential influence of Africentric worldview (African cultural values) on stress, coping, and psychological health among primary caregivers of children with intellectual disability. The quantitative data were analyzed using MANOVA and hierarchical regression analysis. Although, this study did not examine all the quantitative variables qualitatively, some of the findings from both quantitative and qualitative phases converge to provide preliminary evidence about the psychological health of primary caregivers raising children with intellectual disability.

Results from the quantitative study showed that being a primary caregiver of a child with intellectual disability predict higher stress which also leads to poor psychological health. Therefore, raising children with intellectual disability impact negatively on the psychological health of primary caregivers. This finding tend to resonate with the wider literature which have consistently reported that primary caregivers of children with intellectual disability predict higher levels of psychological distress (Azeem et al., 2013; Bayat et al., 2011; Estes et al., 2009; Norlin
& Broberg, 2013). Gallagher and Whiteley (2012) reported that parents of children with intellectual disability scored higher on their physical health symptoms than healthy controls.

The disabling and permanent nature of intellectual disability unlike other conditions predict the higher stress levels and impairments in the psychological health of primary caregivers of children with intellectual disability. For example, Davis and Carter (2008) reported that impaired social relatedness in children with autism was related to overall parent stress and parent-child interactions. However, other studies did not find the child’s condition to predict parent’s psychological health (Baker et al., 2005; Mitchell & Hauser-Cram, 2008; Resch et al., 2012).

Another possible reason that could be advanced for the high levels of stress and poor psychological health among primary caregivers of children with intellectual disability is the behavioural characteristics of the child which often do not complement the role of the primary caregiver (Duarte et al., 2005; Tomanik et al., 2004). Caring for a child with intellectual disability demands lots of time and resources from the primary caregiver as the child is not able to do much for him or herself (Daire et al., 2011; Hastings & Brown 2002).

Moreover, the physical features of children with intellectual disability are usually visible than other chronic conditions, contributing to the stigma and social isolation felt by primary caregivers. This situation may have increased the stress levels of primary caregivers. Most primary caregivers describe having a child with intellectual disability as very stressful (Gray, 2002).

However, this finding is inconsistent with other studies that have demonstrated that the child’s disability had no relationship with parents’ stress (Khamis, 2007; Mitchell & Hauser-Cram, 2008; Patenaude, 2011). Among Ghanaian primary caregivers, Nebbah (2010) did not find differences in stress levels among primary caregivers of children with mental retardation, chronic conditions, and healthy controls. The results of the quantitative study provide substantial evidence
that being a primary caregiver of a child with intellectual disability relates to particular parental outcomes including stress and poor psychological health. Therefore, understanding the associations among these variables would facilitate the design of appropriate intervention programmes aimed at reducing distress associated with caregiving.

In a similar manner, findings from the qualitative phase corroborated the quantitative results by providing additional evidence of negative emotional disturbances associated with having a child with intellectual disability. Primary caregivers reported that when they were told about their children’s condition, they were saddened and traumatized by the news. The grief of primary caregivers was as a result of the fact that their expectations of a normal and perfect child were dashed. This is consistent with existing literature on the negative psychological reactions of parents of children with intellectual disability (Ambikile & Outwater, 2012; Cramm & Nieboer, 2011).

One major stress for most primary caregivers was their worry about the child’s future. Primary caregivers were concerned about the child’s inability to be independent, inability to interact with others, communicate with others, care for themselves, find a job, and have their own families without constantly depending on others. This finding is consistent with studies that have shown that the primary concern for most parents of children with disabilities is the future of the child and the stressful experience of having a child with intellectual disability (Duarte et al., 2005; Hung et al., 2010; Pisula, 2007).

Additionally, caregiving challenges, employment and financial issues, and societal reactions were expressed by most primary caregivers. The qualitative phase also revealed primary caregivers knowledge of their children’s condition and perceived causes of intellectual disability. Primary caregivers reported on the challenges associated with caregiving which came in the form
of demands of caregiving or daily hassles, employment and financial issues. Many primary caregivers expressed being burdened because they had to provide everything for the child and dedicate a greater part of the time and day to care for the child which they would not provide under normal circumstances for a child without intellectual disability, as evidenced in other studies (Hartley et al., 2005; Plant & Sanders, 2007; McNally & Mannan, 2013).

Many primary caregivers also recounted that the presence of the child affected their work activities. They complained of their inability to work because no job would employ them and allow them to have a break for their child after school. Others who owned their businesses also faced losses because they did not have enough time to attend to their customers, hence losing their customers. Some primary caregivers also reported quitting their jobs to care for their children full-time, while others struggled to balance employment and caregiving duties. According to the parents, all these conditions significantly affected their finances. This is consistent with research reporting that the high cost of caring for children with intellectual disability causes considerable stress to parents (Ambikile & Outwater, 2012; Olsson & Hwang, 2008).

Furthermore, primary caregivers also expressed concern about societal reactions to their children and themselves. In many societies throughout the world, primary caregivers are expected to have perfect children and they are blamed when they have a child with any kind of disability (Avoke, 2002; Gray, 2002; McNally & Mannan, 2013). In Ghana, research has shown that primary caregivers of children with intellectual disability experience more discrimination and isolation (Anum, 2011; Avoke, 2002; Hervie, 2013).

Consequently, many primary caregivers reported that they preferred limiting themselves to their homes and not often visit relatives since even relatives constantly reminded them of having
a child with intellectual disability, which is a curse. Some primary caregivers reported they could no longer go out to public programmes and activities because of the possible reactions from people and how to manage their child’s conduct in public. This is consistent with previous findings where the attitudes of society usually cause parents to feel isolated and withdraw from social activities (Jamison, 2011; Kermanshashi et al., 2008; McNally & Mannan, 2013). Some primary caregivers in the current study made claims to the effect that discrimination from society propelled some parents of children with intellectual disability to send their children to the river side to be taken care of by the gods. In their own description, they referred to this act as “ye ko gya no kwan” (meaning they are going to escort the children).

Furthermore, primary caregivers reported feeling bad and sad about the treatment meted out to them in society. Most of them indicated that they had not asked for the condition so they did not understand why they should be treated that way. In relating this finding to other studies, there is an argument that the emotional distress experienced by parents of children with intellectual disability may be related to the intensity of the stigma they experience and not necessarily the nature of the child’s condition (Gray, 2003; Green, 2007; Shin & Crittenden, 2003). However, comments from some of the primary caregivers revealed that in order not to feel bad about societal reactions, they made efforts to show society how much they love their children and which they believe will prevent others from being rude. One parent recounted that “More often we treat her well and show her lots of love and so it does not give other people the chance to be mean, they get to know that she is very special to us”. This is consistent with the findings by Govender (2002) where parents accepted and loved their children with mental retardation despite the negative attitudes of society. Findings from the qualitative phase provided greater understanding into the
lived experiences of primary caregivers of children with intellectual disability beyond what could be provided exclusively by the quantitative phase of the study.

An additional remarkable point of convergence that is worth stating is the coping strategies utilized by primary caregivers of children with intellectual disability. Primary caregivers were able to appraise their situation as a challenge and not something that has brought their world to an end. In both phases of the study, the significance of spirituality as a coping strategy was strongly demonstrated by primary caregivers. In the quantitative phase, parents were found to use more of their spirituality as they experienced stress and anxiety. Higher levels of spirituality actually reduced the anxiety they experienced in caregiving. In the prevailing literature, spirituality has been identified as a crucial factor that influenced the way primary caregivers appraise their stressful situations as opportunities for growth (Dura Vila et al., 2010; Jegatheesan et al., 2010; Marshal et al., 2003). Generally, previous findings have found spirituality to positively impact parental distress (Allen & Marshall, 2010; Poston & Turnbull, 2004; Tarakeshwar & Pargament, 2001). The quantitative results indicating that spirituality buffered the relationship between stress and psychological health is very significant given that copious research touts the importance of spirituality among people of African descent (Houltberg et al., 2011; Reutter, 2012; Watlington & Murphey, 2006) and particularly among Ghanaians (Bonsu et al., 2014; Gyekye, 2003; Schreoder et al., 2011).

Similarly, in the qualitative study, responses from primary caregivers showed that majority of them relied more on their spiritual faith in God to make sense of their experiences and cope with raising their children. Primary caregivers submitted all their problems to God and hoped to be given strength by God to go through. Majority of primary caregivers indicated that their children were given to them by God because He knows they can take care of the child. Other
primary caregivers also surrendered their problems to God believing that in His own time he will make things better. Primary caregivers reported that the child was a special gift from God which brought blessing and favour to the family. These findings are consistent with and further supported those studies that have reported spirituality as a coping mechanism that helped primary caregivers understand their children’s disability and accept their situation as part of God’s purpose for their lives (Durà-Vilà et al., 2010; Jegatheesan et al., 2010; Skinner et al., 2001). Recent studies in Ghana have demonstrated primary caregiver’s strong reliance on their spiritual faith to cope with raising their children with intellectual disability (Hervie, 2013; Nebbah, 2010). This finding corroborate findings on other populations of African descent, where spiritual beliefs and practices were used to cope with stressful events (Anderson, 2006; Hartley et al., 2005; Laurence-Webb & Okundaye, 2007).

In addition, most primary caregivers reported that they constantly prayed, read the bible, sung, and attended church activities to help them cope. They strongly believed that as they prayed and read the bible, a miracle would occur in their lives and their children would be healed. Through prayer, they believed they could reach out to God who is ready to grant them his divine blessings and guidance. This is consistent with studies where primary caregivers described various spiritual coping mechanisms that helped them endure stress, including prayer, contact with church leadership and members, meditation, religious television and music (Allen & Marshall, 2010; Anderson, 2006; McNally & Mannan, 2013).

However, one intriguing aspect of the qualitative interview was that one primary caregiver did not consider her spirituality, especially prayer, as an effective coping strategy. Indeed she indicated that she did not pray because anytime she attempted to pray, she ended up crying. Some primary caregivers also stated that the religious community or the church did not provide
support but was rather a source of stress. This is consistent with findings where the church did not provide support and acceptance for parents and their children (Speraw, 2006). Primary caregivers yearned for support from the church but were disappointed at the negative attitude of some church members. Moreover, spiritual activities such as prayers and reading the scriptures did not play a significant role in the interpretation of the child’s disability among parents of disabled children (Parker et al., 2011).

It is quite clear from the discussion that findings from both studies highlighted the impact of spirituality in helping primary caregivers cope with the stress in their lives. Among Ghanaian primary caregivers of children with intellectual disability, studies have reported that parents are more inclined to put their faith in God for solutions to their problems (Hervie, 2013; Nebbah, 2010). The emphasis given to their spirituality is a reflection of spirituality as a fundamental dimension of the Africentric worldview which aids in the interpretation and coping with stressful events (Ani, 1990; Gyekye, 2003; Utsey et al., 2000).

Moreover, the qualitative phase provides new evidence of the positive aspects of having a child with intellectual disability in the Ghanaian context. Hope was identified as an important coping strategy among primary caregivers. Although primary caregivers expressed sadness for their child’s condition, they were hopeful of the future for their lives and that of their children. Primary caregivers felt a revival of hope that things will get better especially when the child achieved a developmental milestone. Kausar et al. (2003) reported how parents of children with developmental disabilities were hopeful of their child’s future and this hope influenced interpretation of their lives and also provided them with strengths to cope. It is clear that primary caregivers in this study explained their circumstances to a greater degree in terms of their
spirituality. Thus, spirituality as a coping strategy should be encouraged to improve the psychological health of primary caregivers of children with intellectual disability.

Another point of convergence in both phases of the study was the lack of adequate social support from family and the community. The quantitative results did not find a moderating effect of communalism (family and community support systems) on both depression and anxiety. The findings are consistent with studies that have shown that among primary caregivers of children with special needs, social networks did not affect the relationship between caregiver strain and wellbeing (Munsell et al., 2012). Furthermore, some studies have indicated that family and social support systems may not always function as expected to reduce the emotional burden of parents (Ambikile & Outwater, 2012; Edwardraj et al. 2010; Gallagher & Whiteley, 2012; Plumb, 2011).

A plausible reason for communal values not moderating the relationship between stress and anxiety, depression in the current sample of Ghanaian primary caregivers of children with intellectual disability, could lie in the stigmatizing nature of having a child with intellectual disability. This is confirmed by studies that have indicated that the fear of stigma resulted in less support being received from family and society (Aldersey, 2012; Hartley et al., 2005). Thus, communalism (family and community support systems) may not have reduced the negative impact of stress on primary caregivers’ psychological health because of family and community’s reluctance to intervene in helping primary caregivers raise their children with intellectual disability.

There are even indications of family and social support increasing stress for parents of children with intellectual disability (Green, 2003; Plumb, 2011) or not having any relationship with parenting stress (Peer, 2011). In similar collectivist cultures like India, parents reported higher
levels of emotional burden and lacked support from family and society (Edwardraj et al., 2010; Gupta et al., 2012; Pal et al., 2005). Another possible explanation for this finding may be that primary caregivers may be seeking support from family, friends, and the community, but these sources of support are not fitted out to provide the appropriate guidance and informational support as it relates to finding formal sources of service for primary caregivers and their children.

Similarly, in the qualitative study, majority of the primary caregivers reported the general lack of support from family and society because of their children. They described that their extended family and the community had become distanced from them due to their child’s disability. The mere fact that they had children with intellectual disability made them to be perceived as outcasts in the family and not even allowed to take part in decision making. Also, in the qualitative study, some parents reported lack of support, insensitivity, and respect from health professionals. This is consistent with an assertion made by McConkey et al. (2008) that parents of children with disabilities are often frustrated by the lack of support from professionals associated with children with disabilities.

Findings from both phases showed minimal support for communal values of family and community support systems and provide evidence of the gradual erosion of the communal value system of Africans. Though the extended family system in the African culture functions to provide communal support for families in times of stress, where problems are owned and shared by everyone in society (Boyd-Franklin, 2003; Daly et al., 1995; Gyekye, 2003), this trend seems to be eroding as many community and extended family members do not share in the problems of others members and therefore may not provide adequate support for primary caregivers and their children with intellectual disability (Ambikile & Outwater, 2012; Hartley et al., 2005).
Besides, due to modernization and urbanization, many family members are living far apart from each other and may have difficulty providing financial and emotional support for one another in times of difficulty. Madukwe and Madukwe (2010) asserted that factors such as poverty, wars, HIV, westernization, and globalization may be causing the destruction of the once cherished values of communal living in Africa.

The extended family system is rapidly being replaced with the nuclear family system where members are just concerned with the care of immediate family (Apt, 1995; Oppong, 1981). In today’s African family, informal support is weakening and it seems that the saying that “each one for himself God for us all” is the order of the day in contrast to “everyone is the brother’s keeper”. This finding is also suggestive of the fact that raising children is no longer the responsibility of the whole community as previously acclaimed in literature (Gyekye, 2003; Mbiti, 1977; Turner, 1991). Parents of children with intellectual disability do not feel understood or supported by their own family and friends (Ambikile & Outwater, 2012).

However, a minor point of divergence occurred in the qualitative phase of the study where a few of the primary caregivers reported being appreciative of the support they received from their spouses, siblings, grandparents of the child, church, and the school. Siblings, spouses, and grandparents offered emotional support when primary caregivers were sad or overwhelmed and helped with the daily hassles associated with care giving. Support from the child’s school came in the form of organizing programmes on how to care and cope with their children.

Generally, the ability of families with intellectually disabled children to feel supported and accepted as described in the interviews enabled the primary caregivers to continue with their lives and not live in the shadow of their children’s disability. These relationships became a great source
of strength and played an important role in adaptive coping. Previous studies have identified family and social support as a protective factors against psychological distress (Dunn et al., 2001; Ha et al., 2011; Mashego, 2005; McNally & Mannan, 2013).

In Ghana, some studies have also asserted that practical and emotional support from members of the family and the community helped primary caregivers cope with raising the child (Anum, 2011; Hervie, 2013). In some African countries like Tanzania and South Africa, the presence of family and social supports helped primary caregivers cope with the stress of raising a child with intellectual disability (Aldersey, 2012; Mashego, 2005; McNally & Mannan, 2013). Two recent studies in Ghana, Anum (2011) and Hervie (2013) reported of the beneficial effects of family and social support for primary caregivers of children with intellectual disability. Research has shown that support from both informal and formal sources improve the lives of families’ of children with intellectual disability (Hastings & Johnson, 2001; McNally & Mannan, 2013).

During the analysis of the qualitative data, other findings that were identified were the primary caregiver’s source of knowledge of the child’s condition and the perceived cause of the disability. These findings are worthy of note as they may inform future research on how best to provide information regarding intellectual disability to primary caregivers. Regarding knowledge of the child’s condition, some of them reported that they took their children to the hospital to get information on what was wrong with the child, especially when they realized the child was not achieving the normal developmental milestones.

Other primary caregivers also indicated that they got to know their child had a problem with their mental abilities through an alert from their teachers on the child’s performance in school, and others also knew it just through their own personal knowledge. A few of the primary caregivers reported of the features of the child as indicators of intellectual disability.
The qualitative findings also highlighted primary caregivers’ attributions about the cause of the child’s disability. The two main causes identified by primary caregivers were medical and spiritual causes. Whilst some of them reported that they were informed about their child’s condition by doctors and nurses, as related to their age of child birth or the child having convulsions, almost all primary caregivers referred to their spiritual understandings of intellectual disability. This was perhaps influenced by how disability is interpreted in the Ghanaian cultural context. In Ghana, having a child with intellectual disability is attributed to punishment from the gods (Avoke, 2002). In the current study, majority of the primary caregivers appeared not sure of the cause of the child’s condition and this could have been an indication of their external attribution of events that happen in their lives, a typical characteristic of people of African descent (Mashego, 2005).

However, majority of them stated that, they did not attribute their child’s condition to the gods but to the will of God, consistent with their Christian religion as asserted by previous studies (Croot et al., 2008; Hervie, 2013; Jegatheesan et al., 2010). Thus, the current study revealed a blend of African and Western worldviews on the cause of disability consistent with other studies (Andin, 2008; Croot et al., 2012; Kaur, 2011).

Summary of Study One and Two

The current study is among emergent quantitative and qualitative studies demonstrating the impact of raising a child with intellectual disability and the possible influence of their cultural values on the coping strategies they adopt. In the quantitative phase of the study, analyses revealed primary caregivers’ stresses associated with raising a child with intellectual disability and how that affected their psychological health. In the qualitative phase, primary caregivers reported their real challenges such as their psychological reactions, including stress, worry about the future, and stress
associated with raising their children. They also reported of caregiving challenges on demands of care, financial problems, employment issues, societal reactions, coping strategies, and psychological functioning in caring for their children with intellectual disability. Additional findings discovered were how they knew about the child’s condition and the perceived cause of disability. Spiritual belief in God was evident in coping and reducing the emotional burden of primary caregivers. Majority of them though, consistently talked about their complete reliance on God for help. Relative to support from family and community, primary caregivers experienced a combination of both negative and positive support. Findings from both phases of the study were discussed in relation to other studies, especially studies conducted in African contexts. Combining the results for both quantitative and qualitative studies provided a complete and holistic understanding of how existing information on Africentric values such as spirituality and family and community support systems influence the psychological health of primary caregivers of children with intellectual disability.

One significant issue that should be noted is that, in the qualitative study, when primary caregivers were asked to share anything that they had not been asked in the interview, most of them mentioned the need for more social and financial support from family, society, government and non-governmental agencies to traverse the difficult situation they find themselves. Largely, the spiritual faith of primary caregivers provided them comfort and support in their grief. Whilst the quantitative results inform us about the relationships among stress, Africentric values of coping, and psychological health, the qualitative results supported some of the findings and further provide a deeper understanding of the experiences of primary caregivers of children with intellectual disability in the Ghanaian cultural context. The quantitative and qualitative studies are presented in a model in Figure 5.1.
**Stressors**
Primary caregiving stress

**Psychological reactions:** *sadness, worry about the future and stress*

**Caregiving challenges:** *demands of caregiving, employment and financial issues*

**Societal reactions:** *stigma and social isolation*

**Knowledge of condition:** *medical assessment, teacher information, and personal knowledge*

**Perceived cause of disability:** *medical and spiritual*

**Coping strategies:** 
spirituality, and communalism (family and community support systems)

**Coping strategies:** 
spirituality, support, and hope

**Psychological health/functioning**

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**Quantitative findings** —— **Qualitative findings**

**Figure 5.1. An integrated model of the Quantitative and Qualitative findings**
Limitations of the study

This study encountered some limitations. The purposive sampling and the limited sample size of both studies make generalization difficult. A more representative and larger sample size could increase the generalizability of the results and increase the power to detect significant relationships.

Moreover, majority of participants were female who also identified themselves as Christians and this limits the ability to generalize findings to male primary caregivers and non-Christians. Given the dearth of research on experiences of fathers, understanding these perspectives from a paternal point of view is an important perspective to explore as well.

The study setting, Accra metropolitan area, limits the study to an urban area to the exclusion of rural Ghana. Probably, primary caregivers living in rural Ghana could have had different experiences. Also, the participants of the current study were relatively homogenous with respect to their demographics and had their children attending special schools. Thus, the findings cannot be generalized to primary caregivers whose children for whatever reason are not attending Special Schools.

Another limitation was the potential of responses to be affected by social desirability. In the quantitative phase, the use of self-report measures may have limited the researcher’s ability to accurately capture the experiences of primary caregivers. In the qualitative phase of the study, participants may have overstated or understated their experiences.

Further, a methodological limitation was observed in the current study. It is possible that some of the measures used in the quantitative phase could not adequately capture the exact nature of what participants were trying to communicate. Specifically, the Belgrave’s Africentric Worldview Scale and the Africultural Coping Systems Inventory (Utsey et al., 2000) have often
been employed in racial discrimination studies but not primary caregiving studies. Though these measures are among the few ones exploring culture-related coping among people of African descent, future studies should validate these measures, along with other measures among different samples of the Ghanaian population. In the qualitative phase, although probes were introduced to allow for detailed investigation, being an inexperienced interviewer, opportunities for further clarifications into the experiences of primary caregivers may not have been captured during the interviewing process.

Administration of the measures in the quantitative phase may also have negatively impacted the results of this study as the length of the measures may have led to fatigue among participants. Nevertheless, the experiences captured in the findings may help provide a full description of the collective issues confronted by this population.

**Implications**

Findings from both quantitative and qualitative investigations provide a comprehensive understanding of the experiences of primary caregivers of children with intellectual disability and has implications for clinical practice, future research, policy, and knowledge.

**Implications for clinical practice**

The current study has created a greater awareness of the high levels of distress in Ghanaian primary caregivers of children with intellectual disability, and which needs to be addressed by mental health professionals. Primary caregivers need to be emotionally strong to provide better care for their children.

Additionally, the study has highlighted the strengths of some African cultural values including spirituality and family/community support systems as effective coping strategies among primary caregivers of children with intellectual disability. Mental health professionals, irrespective
of their personal orientation, should be cognizant of the worldview of primary caregivers of children with intellectual disability and be open to incorporate them in the design of intervention programmes, and to enable primary caregivers perceive their situation as manageable. The multicultural guidelines of the American Psychological Association (2003) highlight the need to expand psychological literature to consider the cultural dimensions of people’s experience.

Religious groups should be educated on the experiences of families of children with intellectual disability. Queener and Martin (2001) emphasized the importance of cooperation between mental health professionals and the Church in improving the mental health of African Americans.

Support groups should be established for families raising children with intellectual disability to allow them share information, learn more about their child’s condition, and provide opportunities for building relationships as this may help reduce their burden.

**Implications for policy**

Findings of the current study has implications for implementation of services and policies for families and their children with intellectual disability, ensuring that their perspectives are considered in any intervention processes.

Currently, there exist no institutional mechanism for assisting primary caregivers of children with intellectual disability in Ghana. This trend is potentially harmful as psychological health of primary caregivers is linked to the health of their children. Policy makers attempting to design and implement more inclusive disability policies are encouraged to formulate policies that require the Social Welfare Department and the Ministry of Gender, Children, and Social Protection to provide mental health assessment to primary caregivers of children with intellectual disability.
Advocacy groups for primary caregivers of children with intellectual disability should promote awareness and knowledge on intellectual disability, parents’ stress associated with having a child with intellectual disability, and the influential nature of African cultural values especially spirituality as a useful coping strategy.

It should be noted that in the qualitative study, when primary caregivers were asked to share anything that they had not been asked in the interview, most of them mentioned the need for adequate social and financial support to deal with their situation. Policies should be directed at providing financial support for primary caregivers to educate their children and support themselves. These provisions would go a long way to enhance the mental health of primary caregivers.

Additionally, government and non-governmental organizations should establish respite care services to strengthen or increase access to support within the family and society. This is essential as it will provide primary caregivers a break for themselves to focus on their own health. Respite care services might help assist primary caregivers in meeting the demands of personal, family, social, employment life, and ultimately mitigate their distress. According to Chan and Sigafoos (2001) respite care services served to reduce short term stress for mothers and had positive effect on mothers of younger children with developmental disabilities.

The findings of this study recommend that the entire society be educated by government and non-governmental agencies in charge of people with disabilities on causes of intellectual disabilities, experiences of primary caregivers, and the need to show love and concern for these families. Health care professionals should also have a welcoming attitude that enables them interact with parents and their children in a more friendly and effective way.
Recommendations for future research

The present study provides an initial step in understanding the relevance of Africentric values in coping with the stress associated with having a child with intellectual disability in Ghana. Based on a cultural theoretical framework that recognizes the role of cultural values (i.e. spirituality, communal values) in coping and psychological functioning, it would be empirically relevant to further examine these variables in addition to other culturally relevant coping strategies which would be helpful in informing intervention programmes aimed at promoting the psychological health of primary caregivers of children with intellectual disability.

Though many significant effects of Africentric values were not observed in the quantitative phase, future studies should continue to utilize the Africentric measures to strengthen their utility and validity in the Ghanaian population.

Moreover, the current study focused on interactions among variables and their predictive values, rather than simply the main effects. Future research should further explore both the moderation and mediation roles of Africentric values, stress, and Africultural coping strategies. Frazier, Tix, and Baron (2004) asserted that a specific research field becomes empirically innovative when moderation/mediation analyses are utilized to explain and/or describe the relationship between any given variables.

Another potential avenue for future investigation lies in primary caregivers’ reaction towards professional support which was found to be mixed in the qualitative study. More research is needed on the nature and benefits of professional supports and to determine the ways to increase positive interactions between parents of children with disabilities and the professionals they rely upon for support.
A further exploration of participants other individualized coping strategies is warranted, since the current study reported only one significant interacting effects of Africentric values. Greer (2007) asserted that the limited number of cultural coping measures makes it imperative to add other coping measures not designed for cultural specific groups in order to improve their cultural relevance.

Further qualitative work should be done using the Africentric worldview as a framework. The themes that emerged from the qualitative phase should be further explored. One of the themes that emerged from the qualitative phase indicated that most primary caregivers reported experiencing stigmatization in society. It would be beneficial to adopt a family strength-based approach to understand how primary caregivers deal with the stigma and to initiate programmes to help families rely on their unique strengths to manage or reduce stigma to the barest minimum.

Additionally, some positive aspects of raising a child with intellectual disability which is currently being given attention in the wider literature on families of children with intellectual disability also emerged from the qualitative phase. For instance, primary caregivers articulated hope as one way of coping with raising their children. Research should commence on hope as a coping strategy in parents of children with intellectual disability as it is beneficial to their wellbeing.

Finally, a longitudinal study would be beneficial in determining whether any changes in stress, African cultural values, Africultural coping, and psychological health occur over an extended period of time among primary caregivers of children with intellectual disability. This would provide a clearer image of how an Africentric worldview influences psychological health.
Contributions to Knowledge

Findings of this study has implications for psychological education. The study attempted to improve the knowledge base of Africentric values as effective coping strategies.

Knowledge gained from this study may prepare future psychologists and counselors to address cultural values, especially issues of spirituality with their clients. The study revealed the importance of spirituality to the health of primary caregivers. The strength-based approach was underscored in the current study as to how spirituality and communalism provided strengths for primary caregivers in coping with the stress associated with caregiving.

Moreover, mental health professionals should be trained to be aware and sensitive to the cultural and spiritual beliefs of families of children with intellectual disability. By examining the role of spirituality in the lives of primary caregivers, other sources of support (i.e. church members, prayers, pastors etc.) may be identified. Training programmes should be reoriented to include the effectiveness of cultural values that propel families to cope with problems associated with the management of their children with intellectual disability.

Although findings of this study might not be generalizable to all primary caregivers of children with intellectual disability, it may be useful in teaching psychology students about the impact of Africentric values in the lives of primary caregivers of children with intellectual disability. Additionally, findings from this study may help teachers of psychology to incorporate culturally sensitive practices that include Africentric values, thereby enhancing the cultural competence of future psychologists and counselors. For example, studies (e.g. Post & Wade, 2009) have shown that spiritual-based psychotherapy require specialized training, which does not currently exist at adequate levels in Ghanaian institutions of Psychology. Therefore, the current
knowledge base regarding spiritual resources should be incorporated into curriculum and clinical practicums.

The current study also expanded on the transactional model by emphasizing the importance of culturally-specific coping strategies in the form of Africentric values of spirituality and communalism on psychological health of Ghanaian primary caregivers of children with intellectual disability.

Although, much empirical support was not found for Africentric values predicting psychological health, the values remain very relevant to the coping needs of primary caregivers. Therefore, future studies should continue to explore culturally sensitive theoretical models that incorporate Africentric values of spirituality, family support, and interdependence among primary caregivers of children with intellectual disability in Ghana.

Conclusion

The current research makes a valuable contribution to the limited research on stress, coping, and psychological health among primary caregivers of children with intellectual disability from an African cultural perspective. The study confirmed the added challenges associated with having a child with intellectual disability. Some of the issues identified in both studies provide researchers, mental health professionals, and policy makers in Ghana a more thorough understanding of the experiences of primary caregivers of children with intellectual disability and the essential steps they can take to improve the psychological health of primary caregivers and their children.

The use of a mixed methods design was a unique strength of this study in examining the protective role of some African cultural values of coping on the stressful experiences of primary
caregivers of children with intellectual disability. As hypothesized, the quantitative analyses revealed that stress explained the relationship between being a primary caregiver of a child with intellectual disability and psychological health (i.e. anxiety, depression, and somatization). Expectedly, spirituality moderated the relationship between stress and anxiety. On the contrary, communalism failed to moderate the relationship between stress and anxiety and depression. Additionally, spirituality and intuition predicted spiritual coping.

In the qualitative study, primary caregivers reported on their psychological reactions, caregiving challenges, societal reactions, psychological functioning, knowledge of the child’s condition, and perceived cause of disability. However, the study revealed primary caregivers’ reliance on their spirituality as coping strategy, with a minimal support for the protective role of support from family and friends on primary caregivers’ health. A strong desire for support and interaction with family members and the community existed among primary caregivers. Primary caregivers confirmed that support from spouses, family members, and friends were very valuable to them. Hope was also identified as a coping strategy. In both phases of the study, spirituality appeared to be the most adaptive strategy for primary caregivers of children with intellectual disability in Ghana.

This study has implications for clinical practice, research, policy, and psychological education. This study proposes that attempts at addressing the coping behaviours of primary caregivers of children with intellectual disability should focus on the cultural values of the people especially in African societies. The communal nature of African societies makes it imperative to look beyond the individual and have an adequate understanding of their coping behaviours. Culture affects the health behaviours of people in several ways (Kuo, 2010; Lam & Zane, 2004; Utsey et al., 2000). Among people of African descent, culture carry important consequences with regards
to their preference for cultural factors as significant coping resources (Belgrave & Allison, 2006; Constantine & Blackmon, 2002; Neblett et al., 2010; Utsey et al., 2000).

Therefore, policies aimed at assisting primary caregivers cope with their situation should be well situated within the cultural context of the people. Findings from the current study could prepare psychologists and counselors to develop and provide targeted interventions that recognize the importance of cultural values of their clients. Primary caregivers should be encouraged to utilize their Africentric values of spirituality and communalism in coping with stress associated with raising their children. This study serves as an inspiration for more culture-based research on stress and coping experiences of primary caregivers of children with intellectual disability.

Given the available literature and the results of this study, it is hoped that this study will stimulate discussions among families, community, health care professionals, government, and non-governmental organizations on how to establish effective programmes to improve the lives of primary caregivers and their children with intellectual disability.
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## APPENDICES

### LIST OF TABLES

**Table 1: Hierarchical regression predicting Somatization from Primary caregiver and Stress (N=160)**

<table>
<thead>
<tr>
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*p<.05, *p<.05

**Table 2: Hierarchical regression predicting Depression from Primary caregiver and Stress (N=160)**

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Table 3: Hierarchical regression predicting Interpersonal Sensitivity from Primary caregiver and Stress (N=160)

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*p<.05, *p<.05

Table 4: Hierarchical regression Prediction Psychological health from Primary caregiver (N=110)

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Table 6: Hierarchical Regression predicting Psychological health subscales from Stress x Africentric worldview (N=160)

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<td>Stress*Afri</td>
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<td>.14</td>
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Table 8: Regression Predicting Hostility from Parental Stress (subscales) and Communalism (N=160)

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<tr>
<th>Model</th>
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<th>β</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
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<td>.00</td>
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<td>.02*</td>
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<td>Psychoticism Stress</td>
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<td></td>
<td>Afri</td>
<td>.00</td>
<td>.01</td>
<td>.03</td>
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<tr>
<td></td>
<td>Stress × Afri</td>
<td>.00</td>
<td>.00</td>
<td>-.13**</td>
<td>.66**</td>
<td>.02**</td>
<td></td>
</tr>
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</table>

*p<.05, *p<.05; Afri=Africentric worldview. Significant interactions are in bold

Table 7: Regression Predicting Paranoid ideation from Parental Stress (subscales) and Spirituality (N=160)

<table>
<thead>
<tr>
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<th>β</th>
<th>t</th>
<th>R²</th>
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<td>.65*</td>
<td>.02*</td>
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</table>

*p<.05, *p<.05

Table 8: Regression Predicting Hostility from Parental Stress (subscales) and Communalism (N=160)

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<tr>
<th>Model</th>
<th>Predictors</th>
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<th>β</th>
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<th>R²</th>
<th>ΔR²</th>
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<td>.56*</td>
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<td>PCDI x Com</td>
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<td>2.41*</td>
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*p<.05, *p<.05
Table 9: Regression Predicting Depression from Parental Stress (subscales) and Africentric worldview subscale (Sensitivity and Orality) (N=160)

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<tr>
<th>Model</th>
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<th>SEB</th>
<th>β</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
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<td>PCDI x Sensitivity</td>
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<td>.21</td>
<td>1.97*</td>
<td>.79*</td>
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<td>PD x RES</td>
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<td>.01</td>
<td>.28</td>
<td>2.68*</td>
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<td></td>
<td>PCDI x Orality</td>
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<td>.01</td>
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<td>DC x Orality</td>
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<td>.01</td>
<td>-.18</td>
<td>-2.32*</td>
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*p<.05, *p<.05
Table 10: Hierarchical Regression Analysis Predicting Anxiety from Parental Stress (subscales) and Sensitivity and Orality subscale of Africentric worldview (N=160)

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<th>R²</th>
<th>ΔR²</th>
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</tr>
<tr>
<td></td>
<td>PCDI x Sensitivity</td>
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<td>.00</td>
<td>.25</td>
<td>2.17*</td>
<td>.75*</td>
<td>.04*</td>
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<td>PD x RES</td>
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<td>2.44*</td>
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<td>DC x RES</td>
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<td>.01</td>
<td>-.23</td>
<td>-2.17*</td>
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<td></td>
<td>PD x Orality</td>
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<td>.01</td>
<td>-.23</td>
<td>-2.43*</td>
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<td></td>
<td>PCDI x Orality</td>
<td>.02</td>
<td>.01</td>
<td>.20</td>
<td>1.97*</td>
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*p<.05, *p<.05

Table 11: Hierarchical Regression Analysis Hostility from Parental Stress (subscales) and Orality subscale of Africentric worldview (N=160)

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<th>Predictors</th>
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<th>SEB</th>
<th>β</th>
<th>t</th>
<th>R²</th>
<th>ΔR²</th>
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</thead>
<tbody>
<tr>
<td>Step 4</td>
<td>Interaction</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>PD x Orality</td>
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<td>.01</td>
<td>-.25</td>
<td>-2.12*</td>
<td>.61*</td>
<td>.07*</td>
</tr>
</tbody>
</table>

*p<.05, *p<.05
APPENDIX A

SECTION A: Demographic Data

Please tick or make a mark in the box that most appropriately answers the question.

Gender   Male [  ]                                                                     Female [  ]

Your Age       [   ]                                                                   Age of your Child [   ]

Marital Status:           Single [  ]             Married [   ]          Divorced [   ]     Widowed [  ]

Employment Status:    Employed [  ]      Self-employed [ ]        Unemployed [  ]

Educational Level:     Tertiary [  ]     Junior high school [ ] Senior high school [  ]     Middle School
[  ]     Other Specify__________________

Religious Background:   Christianity [  ] Islam [ ]    Traditional [ ]   Other (Specify) ______

Relationship to the child:  Father [   ]   Mother [   ]   Grandparent [   ] Other (Specify) _______

How long have you been caring for the child? _________________ years.

Are you paid for your work as a primary caregiver? Yes [ ]              No [   ]

Do you get help from other people?                Yes [  ] No [  ]

Have any of your children been diagnosed with any developmental/intellectual disability by a
doctor, psychologist or mental health professional? Yes [ ]   No [ ].

Please specify the type of disability__________________
APPENDIX B

Brief Symptom Inventory (BSI)

SECTION B: Directions: Below is a list of problems people sometimes have. Please read each one carefully and tick the best answer that describes how much that problem has distressed or bothered you during the past 7 days including today. Do not skip any items. If you change your mind, erase your first mark carefully and then fill in your new choice.

HOW MUCH WERE YOU DISTRESSED BY

<table>
<thead>
<tr>
<th>SITUATION</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Nervousness or shakiness inside</td>
<td></td>
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<tr>
<td>2. Faintness or dizziness</td>
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<tr>
<td>3. The idea that someone else can control your thoughts</td>
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<tr>
<td>4. Feeling others are to blame for most of your troubles</td>
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<tr>
<td>5. Trouble remembering things</td>
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<td>6. Feeling easily annoyed or irritated</td>
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<td>7. Pains in the heart or chest</td>
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<td>8. Feeling afraid in open spaces</td>
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<tr>
<td>9. Thoughts of ending your life</td>
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<tr>
<td>10. Feeling that most people cannot be trusted</td>
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<td>11. Poor appetite</td>
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<td>12.</td>
<td>Suddenly scared for no reason</td>
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<tr>
<td>13.</td>
<td>Temper outbursts that you could not control</td>
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<tr>
<td>14.</td>
<td>Feeling lonely even when you are with people</td>
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<tr>
<td>15.</td>
<td>Feeling blocked in getting things done</td>
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<tr>
<td>16.</td>
<td>Feeling lonely</td>
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<td>17.</td>
<td>Feeling sad</td>
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<td>18.</td>
<td>Feeling no interest in things</td>
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<td>19.</td>
<td>Feeling fearful</td>
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<td>20.</td>
<td>Your feelings being easily hurt</td>
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<tr>
<td>21.</td>
<td>Feeling that people are unfriendly or dislike you</td>
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<tr>
<td>22.</td>
<td>Feeling inferior to others</td>
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<tr>
<td>23.</td>
<td>Nausea or upset stomach</td>
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<td>24.</td>
<td>Feeling that you are watched or talked about by others</td>
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<tr>
<td>25.</td>
<td>Trouble falling asleep</td>
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<tr>
<td>26.</td>
<td>Having to check and double check what you do</td>
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<tr>
<td>27.</td>
<td>Difficulty making decisions</td>
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<tr>
<td>28.</td>
<td>Feeling afraid to travel on buses or trains</td>
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<td>29.</td>
<td>Trouble with breathing</td>
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<td>30.</td>
<td>Feeling Hot or cold sometimes</td>
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<td>31. Avoiding certain things, places, or activities because they frighten you</td>
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<td>32. Your mind going blank</td>
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<td>33. Numbness or tingling in parts of your body</td>
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<tr>
<td>34. The idea that you should be punished for your sins</td>
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<td>35. Feeling hopeless about the future</td>
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<td>36. Trouble concentrating</td>
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<td>37. Feeling weak in parts of your body</td>
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<td>38. Feeling tensed up</td>
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<td>39. Thoughts of death or dying</td>
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<td>40. Having urges to beat, injure, or harm someone</td>
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<td>41. Having urges to break things</td>
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<td>42. Feeling aware when you are with others</td>
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<td>43. Feeling uneasy among people</td>
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<td>44. Never feeling close to another person</td>
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<td>45. Feel panicky</td>
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<td>46. Getting into frequent arguments</td>
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<td>47. Feeling nervous when you are left alone</td>
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<td>48. Others not giving you proper praise</td>
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<td><strong>49. Feeling so restless you couldn’t sit still</strong></td>
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<td><strong>50. Feelings of worthlessness</strong></td>
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<tr>
<td><strong>51. Feeling that people will take advantage of you if you let them</strong></td>
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<tr>
<td><strong>52. Feeling of guilt</strong></td>
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<tr>
<td><strong>53. The idea that something is wrong with your mind</strong></td>
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</tbody>
</table>
APPENDIX C

Parenting Stress Index-Short Form (PSI-SF)

Instruction: Read the statement carefully and TICK the response that best represents your opinion.

<table>
<thead>
<tr>
<th>ITEM</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Not Sure</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I often have the feeling that I cannot handle things very well.</td>
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<tr>
<td>2. I find myself giving up more of my life to meet my children’s needs than I ever expected.</td>
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<tr>
<td>3. I feel trapped by my responsibilities as a parent.</td>
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<tr>
<td>4. Since having this child, I have been unable to do new and different things.</td>
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<tr>
<td>5. Since having a child, I feel that I am almost never able to do things that I like to do.</td>
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<td>6. I am unhappy with the last purchase of clothing I made for myself.</td>
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<tr>
<td>7. There are quite a few things that bother me about my life.</td>
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<tr>
<td>8. Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).</td>
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<tr>
<td>9. I feel alone and without friends</td>
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<td>10. When I go to a party, I usually expect not to enjoy myself.</td>
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<tr>
<td>11. I am not as interested in people as I used to be.</td>
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<td>12. I don’t enjoy things as I used to.</td>
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<tr>
<td>13. My child rarely does things for me that make me feel good.</td>
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<tr>
<td>14. Sometimes I feel my child doesn’t like me and doesn’t</td>
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<tr>
<td>15. My child smiles at me much less than I expected.</td>
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<tr>
<td>16. When I do things for my child, I get the feeling that my efforts are not appreciated very much.</td>
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<td>17. When playing, my child doesn’t often giggle or laugh.</td>
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<td>18. My child doesn’t seem to learn as quickly as most children.</td>
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<tr>
<td>19. My child doesn’t seem to smile as much as most children.</td>
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<tr>
<td>20. My child is not able to do as much as I expected.</td>
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<tr>
<td>21. It takes a long time and it is very hard for my child to get used to new things.</td>
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<td>22. For the next statement, choose your response from the choices “1” to “5” below. I feel that I am:</td>
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<tr>
<td></td>
<td>not very good at being a parent</td>
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<tr>
<td></td>
<td>a person who has some trouble being a parent</td>
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<tr>
<td></td>
<td>an average parent</td>
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<td></td>
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<tr>
<td></td>
<td>a better than average parent</td>
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<tr>
<td></td>
<td>a very good parent</td>
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<tr>
<td>23. I expected to have closed and warmer feelings for my child than I do and this bothers me.</td>
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<tr>
<td>24. Sometimes my child does things that bother me just to be mean.</td>
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<tr>
<td>25. My child seems to cry or fuss more often than most children.</td>
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<tr>
<td>26. My child generally wakes up in the bad mood.</td>
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<tr>
<td>27. I feel that my child is very moody and easily upset.</td>
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</tbody>
</table>
28. My child does a few things which bother me a great deal.

29. My child reacts very strongly when something happens that my child doesn’t like.

30. My child gets upset easily over the smallest things.

31. My child’s sleeping or eating schedule was much harder to establish than I expected.

32. *For the next statement, choose your response from the choices “1” to “5” below.*

I have found that getting my child to do something or stop doing something is:

1. much harder than I expected.
2. somewhat harder than I expected
3. about as hard as I expected
4. somewhat easier than expected
5. much easier than I expected.

33. *For the next statement, choose your response from the choices “10+” to “1-3” below.*

Think carefully and count the number of things which your child does that bother you. For example:

- dawdles
- refuses to listen
- overactive
- cries
- interrupts
- fights
- whines etc.

34. There are some things my child does that really bother me a lot.
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<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>35. My child turned out to be more of a problem than I had expected.</td>
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<tr>
<td>36. My child makes more demands on me than most children.</td>
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</table>
APPENDIX D

Belgrave Africentric Worldview Scale (BAWS)

SECTION D: Below is a list of situations describing you perceive the world and your relations with others. Please tick the response that applies to you

<table>
<thead>
<tr>
<th>SITUATION</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I perform better on oral rather than written tasks.</td>
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<tr>
<td>2. When greeting someone, I prefer verbal acknowledgements (rather than a nod or hand wave).</td>
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<tr>
<td>3. I feel that sometimes I do things 'Just because it feels right&quot;.</td>
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<tr>
<td>4. I listen to my inner voice.</td>
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<tr>
<td>5. I am likely to rely on my inner voice.</td>
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<tr>
<td>6. I have to see something to believe it</td>
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<tr>
<td>7. I can tell when a close friend is in trouble or feels bad.</td>
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<tr>
<td>8. Attending churches, mosques, or other</td>
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</tbody>
</table>
places of worship are important to me.

9. I meditate and engage in other acts of faith.

10. I believe in a spiritual force or power.

11. When stressed, I put my faith in a higher being.

12. When I hear music I respond actively to it.

13. When speaking I am likely to use body language and hand gestures.


15. When things don’t work out, I try to see the positive side.

16. People should be judged on who they are rather than material achievements.

17. It is expected that the elderly will be cared for by younger generations.

18. Older members of my family are relied on for advice/guidance.

19. It is not unusual for me to call close
<p>| | | | |</p>
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<thead>
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</thead>
<tbody>
<tr>
<td>family friends “uncle, aunt, etc.”</td>
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<td></td>
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</tr>
<tr>
<td><strong>20.</strong> The ultimate value of a person is in his or her service to others.</td>
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<tr>
<td><strong>21.</strong> My successful achievements are due to the support of significant others.</td>
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<tr>
<td><strong>22.</strong> I usually arrive at meetings, classes, work etc before or at the exact specified time</td>
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<tr>
<td><strong>23.</strong> Remembering the past is as important as preparing for the future</td>
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</table>
APPENDIX E

Agricultural Coping System Inventory (ACSI)

SECTION E: Please respond to the following statements about how you respond to stressful situations using the scale below.

Think of a stressful situation you experienced within the past week or so. Write a brief description of that situation.
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Now, respond to the following statements about how you responded to the stressful situation using the scale below.

<table>
<thead>
<tr>
<th>ITEM</th>
<th>Does not apply</th>
<th>Used a little</th>
<th>Used a lot</th>
<th>Used a great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pray that things would work themselves out.</td>
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</tr>
<tr>
<td>2. Get a group of family or friends together to help with the problem.</td>
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<tr>
<td>3. Share your feelings with a friend or family member.</td>
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<tr>
<td>4. Remember what a parent (or other relative) once said about dealing with these kinds of situations.</td>
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<tr>
<td>5. Try to forget about the situation.</td>
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<tr>
<td>6. Go to church, mosque (or other religious meeting) to get help from the group.</td>
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<tr>
<td>7. Think of all the struggles Africans/Ghanaians have to endure, which give you strength to deal with the situation.</td>
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<tr>
<td>8. To keep from thinking about the situation, you find other things to keep you busy.</td>
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</table>

239
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</thead>
<tbody>
<tr>
<td>9.</td>
<td>Seek advice about how to handle the situation from an older person in your family or community.</td>
</tr>
<tr>
<td>10.</td>
<td>Read a scripture from the Bible (or similar book) for comfort and/or guidance.</td>
</tr>
<tr>
<td>11.</td>
<td>Ask for suggestions on how to deal with the situation during a meeting of your organization or club.</td>
</tr>
<tr>
<td>12.</td>
<td>Try to convince yourself that it was not bad.</td>
</tr>
<tr>
<td>13.</td>
<td>Ask someone to pray for you.</td>
</tr>
<tr>
<td>14.</td>
<td>Spend more time than usual during group activities.</td>
</tr>
<tr>
<td>15.</td>
<td>Hope that things would get better with time.</td>
</tr>
<tr>
<td>17.</td>
<td>Spend more time than usual doing things with family and friends.</td>
</tr>
<tr>
<td>18.</td>
<td>Try to remove yourself from the situation.</td>
</tr>
<tr>
<td>19.</td>
<td>Seek out people you thought would make you laugh.</td>
</tr>
<tr>
<td>20.</td>
<td>Get dressed up in my best clothing.</td>
</tr>
<tr>
<td>21.</td>
<td>Ask for blessings from a spiritual or religious person.</td>
</tr>
<tr>
<td>22.</td>
<td>Help others with their problems.</td>
</tr>
<tr>
<td>23.</td>
<td>Lit a candle for strength or guidance in dealing with the problem.</td>
</tr>
<tr>
<td>24.</td>
<td>Seek emotional support from family and friends.</td>
</tr>
<tr>
<td>25.</td>
<td>Burn incense for strength or guidance in dealing with the problem.</td>
</tr>
<tr>
<td>26.</td>
<td>Attend a social event (dance, party, movie) to reduce stress caused by the situation.</td>
</tr>
<tr>
<td>27.</td>
<td>Sing a song to yourself to help reduce the stress.</td>
</tr>
<tr>
<td>28.</td>
<td>Use a cross or other object for its special powers in dealing with the problem.</td>
</tr>
<tr>
<td>29.</td>
<td>Find yourself watching more comedy shows on television.</td>
</tr>
<tr>
<td>30.</td>
<td>Leave matters in God’s hands.</td>
</tr>
</tbody>
</table>
APPENDIX F

Interview Guide (Qualitative phase)

Participants were asked about their gender, age, marital status, employment status, gender of child, age of child and type of disability.

Demographic Data

1. Gender…
2. Age of primary caregiver…
3. Marital status…….
4. Employment Status……..5. Gender of child…
5. Age of child…
6. Type of disability: …..

1. Could you please share with me three most important things in your life? Probes: How would you describe your relationship with God and your family?
2. How did you know that your child had a disability?
3. How did you feel when you first found out of your child’s condition? Please describe your feelings?
4. What do you think is the cause of your child’s disability? Probe. Any other cause?
5. What are some of your worries and concerns about your child’s disability and his/her future?
6. What motivates you to accept and care for your child?
   Probes: What would you tell other parents’ who finds out their child has a disability?
7. How do people in society react to you and your child?
a. How do you feel when people make comments people make about your child's disability?

8. Do you get stressed because of your role as a parent of a child with disability?
   a. Probes: What are some of the daily hassles you go through in dealing with your child’s disability?
   b. What is the most difficult situation you have found yourself in dealing with your child’s disability?
   c. How do you feel about the amount of time you spend taking care of your child?

9. What coping strategies do you use in dealing with stress associated with caring for your child?
   Probes: How does your belief in God and your family help you through this situation? Do you have any specific person you turn to for support?
   b. Which one, your spirituality or family do you mostly use in dealing with stress?
   c. How well do the coping strategies you have described help to reduce your stress?

10. Is there any other issue you would want to share with me?
APPENDIX G

INFORMED CONSENT FOR PRIMARY CAREGIVERS

Title of Study: Examination of the Relationship between Africentric worldview and Psychological well-being among Primary Caregivers of Children with Intellectual disability in Ghana

Principal Supervisor: Prof. C. Mate-Kole
University of Ghana, Department of Psychology

(0274) 323-154

Purpose:
You are being asked to be in a research study examining the impact of culture-specific coping style has on stress experienced by caregivers of children with intellectual disability. You are being asked to participate because you have been identified as a parent of a child with intellectual disability. This study is being conducted as part of a PHD programme in the Department of Psychology, University of Ghana, Legon.

Study Procedures:
If you decide to participate in this study you will be asked to complete a total of 6 questionnaires. Each questionnaire measures a different variable associated with the study. The estimated total time to complete all the questionnaires provided is 50 minutes. Your participation in this study is a one-time occurrence. You will not be asked for further participation in the future. A packet is enclosed that includes all of the following in addition to this information sheet:

1) Demographic Questionnaire
2) Questionnaire measuring Parenting Stress
3) Questionnaire determining Africentric worldview
4) Questionnaire measuring Africultural Coping
5) Questionnaire measuring Psychological health
6) Interview guide for Qualitative phase

Benefits:
As a participant in this research study, the researcher intends to conduct a seminar for you on coping strategies and how to use them to your benefit and that of your child. The information you would provide may also benefit other people now or in the future.
Risks: There are no known risks for participating in this study.

Costs: There will be no costs to you for participation in this research study.

Compensation: You will not be paid for taking part in this study but you would benefit from the seminar by the researcher. You would get more information about your child’s condition, increased knowledge about cultural values and wellbeing of parents of children diagnosed with intellectual disability.

Confidentiality: All information collected about you during the course of this study will be kept without any identifiers.

Voluntary Participation/Withdrawal: Taking part in this study is voluntary. You are free to not answer any questions or withdraw at any time.

Questions: If you have any questions about this study now or in the future, you may contact Mabel Oti-Boadi. Call the following phone number: (020) 2698-309.

If you are unable to contact the researcher, or if you want to talk to someone other than the researcher, you may also call (0274) 323-154 to ask questions or voice concerns.

Participation:
By completing the enclosed questionnaires you are agreeing to participate in this study
PSYC 2/33/02

June 11, 2012

The Executive Secretary
The Institutional Review Board
Noguchi Memorial Institute for Medical Research
University of Ghana
Legon

Dear Sir or Madam,

REQUEST FOR ETHICAL CLEARANCE
MRS. MABEL OTI-BOADI
10046009

The above-named is a Ph.D student at the Department of Psychology, University of Ghana, Legon.

In partial fulfillment of the award of the Ph.D degree programme, Mrs. Oti-Boadi has to write and submit an original thesis on the topic “Examination of the Relationship between Africentric Worldview and Psychological Well-Being among Primary Caregivers of Children with Intellectual Disability in Ghana.”

To enable her proceed with her work, she needs ethical approval/clearance from your outfit to enable her collect data on Primary Caregivers.

The proposal has been read by the Head of Department and has been approved by the Department as worthy of consideration.

Find attached the Research Proposal for your assessment.

We would be glad if she is granted the ethical approval.

Yours faithfully,

Dr. B. Ampensah
Head of Department
NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979

Institutional Review Board
Post Office Box L.G 581
Legon, Accra
Ghana

Phone: +233-302-916438 (Direct)
+233-289-522574
Fax: +233-302-502182/5113202
E-mail: nirb@noguchi.mimcom.org
Telex No: 2556 UGI. GH

My Ref: No: DF.22
Your Ref, No:

4th July, 2012

Ethical Clearance

Federalwide Assurance FWA 00001824
IRB 00001276
NMIMR-IRB CPN 103/11-12
IORG 0000908

On 4th July, 2012, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL: Examination of the Relationship between Africentric Worldview and Psychological Well-being among Primary Caregivers of Children with Intellectual disability in Ghana

Principal Investigator: Mabel Oti-Boadi, Mrs (PhD Candidate)

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 3rd July, 2013. You are to submit annual reports for continuing review.

Signature of Chairman:..............................
Rev. Dr. Samuel Ayeet-Nyampong
(NMIMR – IRB, Chairman)

cc: Professor Alexander K. Nyarko
Director, Noguchi Memorial Institute
for Medical Research, University of Ghana, Legon
ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824

NMIMR-IRB CPN 103/11-12 amend. 2014

IRB 00001276

IORG 0000908

On 5th March 2014, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting conducted continuing review and approved the amendment to your protocol titled:

TITLE OF PROTOCOL: Examination of the relationship between Africentric worldview and psychological well-being among primary caregivers of children with intellectual disability in Ghana

PRINCIPAL INVESTIGATOR: Mrs. Mabel Oti-Boadi

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 4th March, 2015. You are to submit annual reports for continuing review.

Signature of Chair: 

Mrs. Chris Dadzie
(NMIMR - IRB, Chair)

cc: Professor Kwadwo Koran
Director, Noguchi Memorial Institute for Medical Research, University of Ghana, Legon
ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824

NMIMR-IRB CPN 103/11-12 revd. 2015

IRB 00001276

IORG 0000908

6th May, 2015

On 6th May 2015, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting conducted continuing review and renewed your protocol titled:

TITLE OF PROTOCOL: Examination of the relationship between Africentric Worldview and psychological well-being among primary caregivers of children with intellectual disability in Ghana

PRINCIPAL INVESTIGATOR: Mabel Oti-Boadi, PhD

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 5th May, 2016. You are to submit annual reports for continuing review.

Signature of Chair: .........................................

Mrs. Chris Dadzie
(NMIMR – IRB, Chair)

cc: Professor Kwadwo Koram
    Director, Noguchi Memorial Institute
    for Medical Research, University of Ghana, Legon