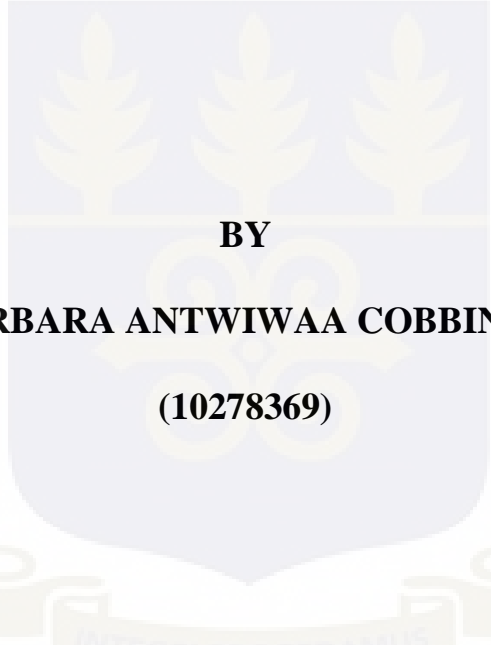


**DEPARTMENT OF PSYCHOLOGY
UNIVERSITY OF GHANA, LEGON**

**Stigmatization and Psychological Wellbeing of Primary
Caregivers of Children with Developmental Disabilities in
Ghana.**



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**THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA,
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Declaration

I hereby declare that this research is conducted by me under the supervision of Prof. C. C. Mate-Kole and Prof. J. Y. Opoku. This work has never been submitted to any other institution by anyone for any award. All references cited in this work have been duly acknowledged and I take full responsibility of any shortcomings associated with this work.

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Dedication

I dedicate this paper to God, the Cobbinah family, David Pinkrah and all primary caregivers who participated in the study.



Acknowledgement

I am most grateful to God for His mercies, favour and strength granted me throughout this research and indeed my entire masters' programme.

My heartfelt thanks to Prof. C. C. Mate-Kole and Prof. J. Y. Opoku, my supervisors, for their patience, constructive criticisms and positive interventions by which this study was conducted successfully.

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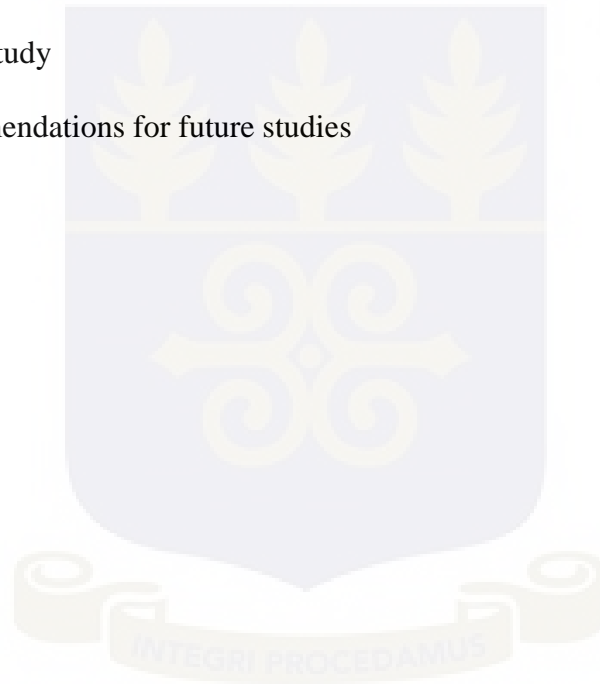
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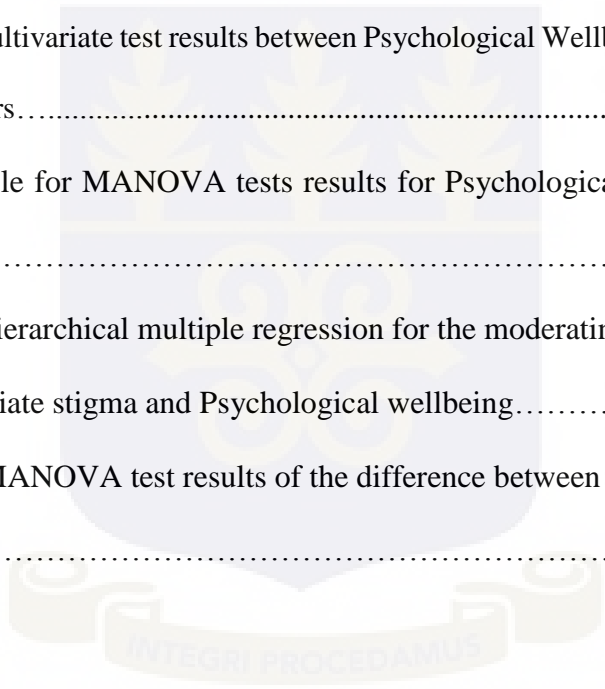
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List of Abbreviations

AACT Autism Awareness Care and Training

ACSI Africultural Coping Systems Inventory

ADHD Attention Deficits Hyperactive Disorder

APA American Psychological Association

ASD Autistic Spectrum Disorders

ASS Affiliate Stigma Scale

CDD Childhood Disintegrative Disorder

DD Developmental Disability

PDD Pervasive Developmental Disorder

RPWB Ryff scales of Psychological Well-being



Abstract

Ghana is a country with strong cultural and religious beliefs. These beliefs tend to foster stigmatization and discrimination of the disabled and their primary caregivers within society.

Developmentally disabled children, like those having other disabilities, are the most affected by stigmatization of their primary caregivers. The present study examined the effect of stigmatization on the psychological wellbeing of primary caregivers of developmentally disabled children. Sixty- nine primary caregivers of children with developmental disabilities in the Accra Metropolis were purposively selected for the study. A cross-sectional survey research design was used in assessing affiliate stigma, psychological wellbeing and the method of coping among primary caregivers.

Results of the study revealed that primary caregivers who have high affiliate stigma, experience poorer psychological wellbeing. It was also observed that married primary caregivers have better environmental mastery and personal growth than unmarried caregivers. Also Africultural Coping predicted psychological wellbeing and affiliate stigma. There was no significant difference between males and females on measures of psychological wellbeing. Furthermore there was no significant relationship established between educational background and psychological wellbeing. Results therefore imply that stigma reduction interventions which involve a consideration of primary caregiver's marital status, and also the use of Cognitive/Emotional Debriefing, Spiritual Centered coping, Collective coping and Ritual-Centered coping, would help improve the psychological wellbeing of primary caregivers.

CHAPTER ONE

Introduction

Background of Study

Definition of disability

Disability is generally defined as any limitation that is caused by impairment. In Ghana, there are diverse views of the definition of disability. It is usually defined to imply physical and/or sensory disabilities only (Reynolds, 2010).

According to the 2006 Disability Act of Ghana, a person with disability is one who has “a physical, mental or sensory impairment including a visual, hearing or speech functional disability which gives rise to physical, cultural or social barriers that substantially, limits one or more of the major life activities of the individual” (Stickney, Nathan & Oye-Lithur, 2007).

Developmental disability

Developmental disability is a disability that is manifested by a person from birth to twenty-two years, which constitutes a substantial disability to the affected individual, and is attributable to mental retardation or related to neurological conditions. Such conditions result in impairment of general intellectual functioning and/or adaptive behaviour (Developmental Disability Resource Centre, 2015).

Based on the above definition, developmental disabilities begin during the developmental period of an individual’s life and may cause a physical, learning, language and /or behavioural impairment. Developmental disabilities also usually last throughout an individual’s lifetime.

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Developmental disabilities have many causes including genetic or chromosomal abnormalities, prenatal exposure to chemical substances such as alcohol, preterm birth and certain viral infections during pregnancy.

According to Solarsh and Hofman (2006), developmental disabilities are disorders of the developing nervous system that manifest during infancy or childhood as developmental delay or as limitations of function in one or multiple domains, including cognition, motor performance, vision, hearing and speech, and behaviour. The variable nature, extent and timing of the disorders in the developing nervous system make their clinical expression different from one individual to another, both in severity and in relative effect on the different areas of function.

Some examples of developmental disabilities include; Attention deficit hyperactivity disorder (ADHD), Autism Spectrum Disorders, Cerebral Palsy, Intellectual disabilities, Fetal Alcohol Spectrum Disorders, Fragile X syndrome, Down syndrome and Rett syndrome.

Prevalence rate of developmental disability

It is not precisely known how many people have developmental disabilities. Indeed even trustworthy sources of information report data that appear contradictory. This challenge is due to the rapidly changing face of developmental disabilities brought on by the discovery and addition of new disabilities.

Nevertheless, prevalence rates on developmental disabilities in developing countries are inadequate and mostly outdated due to methodological problems, and limited financial and technical resources that preclude comprehensive population-based studies of developmental disabilities (Simeonsson, 2000). In western countries on the other hand, prevalence rates are

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more current and reliable. This is due to the use of technology and easy access to logistics for a prevalence determination exercise.

Durkin et al. (1994) conducted a survey to determine the prevalence rate in Jamaica using a 2-phase survey. It was discussed that 31 of every 1000 children suffer from developmental disabilities.

In Africa, prevalence is difficult to determine due to the existence of superstitious beliefs and therefore, stigma surrounding developmental diseases. Cases are hardly reported in health institutions. In some cases, individuals with developmental disability are kept hidden from the public. Therefore prevalence rates do not reflect the reality on the ground. Solarsh and Hofman (2006), point out the fact that difficulty in Africa to gather data on incidence of developmental disabilities is due to economic challenges. They furthermore stated that in low-income countries, estimates of the frequency of developmental disabilities invariably come from cross-sectional surveys which are relatively cost effective.

A review of prevalence of developmental disability in sub-Saharan Africa reveals that most of the prevalence studies were conducted in South Africa. The prevalence rates for all categories of developmental disability in these studies varied from eleven (11), to sixty (60), per thousand children.

In Ghana, according to the Ghana Statistical Service (2012), seven hundred and thirty-seven thousand, seven hundred and forty three individuals have some form of disability, representing 3% of the total population. Of this number, one hundred and twelve thousand, eighty-two individuals were reported as having intellectual disability representing 15% of the disabled population in Ghana. Apart from intellectual disability, no other developmental disability was

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mentioned in the report. This reflects the absence of adequate knowledge on developmental disability in Ghana.

Despite such alarming rates of reported cases, compared to the developed world, not enough information on developmental disability and its effects exist. With regards to research, there is very little published data on developmental disability. Most of these, however, focus on the developmentally disabled individuals. Primary caregiver focused research in Ghana is scanty. Therefore though primary caregivers struggle with stigmatization and its effects, research seems silent on these issues.

Stigmatization

Stigmatization associated with disability is a global social problem and this is reflected in the research conducted in varying countries and cultures (Chiu, Yang, Wong, Li & Li, 2013; Datta & Russell, 2002; Shobana & Saravanan, 2014).

Stigma is conceptualized by Corrigan (2000) as a set of prejudicial attitudes, stereotypes, discriminatory behaviours and biased social structures endorsed by a sizeable group about a discredited subgroup.

Mickelson (2001) described stigma as a complex construct that includes public, self, and structural components. It directly affects people with disabilities, as well as their support system, provider network, and community resources. In view of this definition, it is clear that stigma does not only affect individuals with one form of disability or the other but also their caregivers as well.

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Mak and Cheung (2008) conducted a study which defined affiliate stigma as the self-stigma and corresponding psychological responses of the associates of discredited or directly stigmatized individuals. As a result of their close affiliation to a stigmatized individual, caregivers, family members and friends may be personally affected by public stigma that prevails in the society.

Mak and Cheung (2008) argued that based on these cognitive and affective effects of affiliate stigma, caregivers might react behaviourally by concealing their status from others, withdrawing from social relations, or even alienating themselves from the disabled individuals. Such attitudes also directly or indirectly affect the development of disabled individuals. According to Baffoe (2013), prejudice and stigma ultimately lead to the denial of rights and resources that are afforded to all citizens.

Stigma develops. It goes through affective, **behavioural** and cognitive stages. According to Link and Phelan (2001), stigma involves the processes of labelling, stereotyping, separation, emotional reactions, status loss and discrimination in a power situation

One growing trend in explaining stigma is the acknowledgement of structural factors in the development and persistence of stigmatization (Link & Phelan, 2001). Social structures empower and privilege some people, often at the expense of others. Power differences are essential for the production and maintenance of stigma (Parker & Aggleton, 2003). Therefore with the existence of power structures within society, stigma is reinforced. For example, experiences of stigmatization are more likely among people who live in poverty (Jones, Weil, Coreil, & Shoush, 2004) or who lack social capital. Other cultural determined factors such as the degree to which people are held responsible for life outcomes are also important (Crandall & Moriarty, 1995). Therefore, developing better measures of important variations in social structures and investigating the impact of societal structures is vital to understanding and eliminating stigma.

Developmental disability and superstition

Public attitudes and beliefs on disabilities in Africa are often based on fear and misunderstanding, and therefore stereotype individuals with disabilities exposing them to prejudice and discrimination (Baffoe, 2013).

In Ghana, stigmatization still remains a major challenge in helping integrate developmentally disabled persons into society. Developmental disability in Ghana is generally connected to superstitious beliefs. Munyi (2012) suggests that diversifications in perception of persons with disabilities exist in Ghana as they do in other places in Africa. In Ghana, the general attitudes in many communities towards children with developmental disabilities is that they are “children of the rivers and forests” and were in the past returned to the forests or rivers under the disguise of helping them return to where they came from (Avoke, 2002; Botts & Owusu, 2013). Also, it was considered a bad omen to relate to a person with any form of developmental disability (Nukunya, 2003). Furthermore, developmental disabilities rendered sufferers “abnormal” and “useless” in society (Yekple, 2014).

Such beliefs are presently still accepted and internalized by the general population including potential primary caregivers of individuals with disability. Such labels cause and sustain the stigmatization of individuals suffering from such disabilities as well as their caregivers.

Affiliate stigma in the Ghanaian society is heightened due to the existence of strong cultural beliefs that throw a negative light on disability (Yekple, 2014). These beliefs are usually accepted and internalized by individuals long before they find themselves in the primary caregiver status. Therefore primary caregivers experience both public and internalized stigma (Chiu, Yang, Wong, Li & Li, 2013).

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Although in recent times, developmental disability has become a more familiar phenomenon across all socio-economic backgrounds and more people are beginning to understand and accept the existence of such disabilities due to the gradual increase in research work (Avoke 2002; Botts & Owusu, 2013; Yekple, 2014), there is more room for improvement in terms of awareness, education and the offer of social and financial assistance for the developmentally disabled. Stigma associated with developmental diseases still exists. Therefore more research, education and awareness is necessary to help eradicate the stigma and to integrate the developmentally disabled into society.

Problem Statement

Cultural beliefs in conjunction with fear of the “abnormal” tend to fuel stigma and therefore discrimination surrounding disability in Ghana. These cultural beliefs throw a negative light on disability and therefore enhance stigmatization of individuals with disability in Ghana (Yekple, 2014). People with disability are often feared or disregarded. According to Botts and Owusu (2013), there are many derogatory terms generally used for people with intellectual disability among the different tribal languages in Ghana. For instance the *Ewes* refer to them as “asotowo” which means idiot or fool, the *Gas* call them “bullus” meaning reduced mental ability and the *Akans*, “nea wanyin agya n’adwen ho” which implies a feeble minded individual.

As established previously, this stigma is not limited to disabled individuals but extends also to their primary caregivers as well. Caregiver-focused research is necessary because individuals with disabilities, especially children, are fundamentally dependent on others for development and adjustment into society. Like individuals with other forms of disability, children with developmental disabilities are often dependent upon primary caregivers to meet their needs. Coupled with care giving tasks which are generally burdensome, most caregivers experience

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stigma which increases the propensity to experience psychological ill health (Plant & Sanders, 2006). Primary caregivers experience poor psychological wellbeing because of the stigma they encounter in carrying out their responsibilities towards their wards (Weiss & Lunsky, 2011; Mac-Donald & Hastings, 2010). They are often regarded as being cursed for something done in the past either by themselves or a family member.

Unfortunately the needs and challenges of primary caregivers of developmentally disabled children in Ghana are generally relegated to the background.

In an attempt to avoid psychological distress, some primary caregivers make decisions that eventually hinder the rights of the developmentally disabled child.

Odoom and van Weelen (2011) stated that some primary caregivers in an attempt to avoid stigma, isolate their developmentally disabled children. In this way the child's right and freedom of association or movement is restricted and denied.

Also affiliate stigma experienced by primary caregivers poses a threat to the education of developmentally disabled children. Some primary caregivers are not able to send their disabled children through mainstream education as a result of stigmatization and since special education for their children is relatively expensive, most primary caregivers just leave their wards at home(Anthony, 2009).

Only a few functional support networks exist for primary caregivers of disabled children. Most of these support networks are formed only within the confines of a special needs school. Therefore primary caregivers who cannot afford to take their wards to these schools usually do not have the opportunity of being part of a support group. They therefore suffer poor psychological health due to abandonment by family and society (Sarpong, 2012). According to

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Mickelson (2009), most stigmatized primary caregivers perceive lack of support and negative relationships with other family members. Due to the fear of stigmatization, most family members, who are a major source of support for primary caregivers of developmentally disabled children, tend to withdraw or stay away. Some also stigmatize primary caregivers by blaming them for having developmentally disabled children.

In conclusion, affiliate stigma leads to self-blame and low self esteem in primary caregivers. Aside that it can prevent primary caregivers from seeking help. It is therefore important to investigate and understand the impact of stigmatization on the psychological wellbeing of primary caregivers and to provide possible solutions.

Aim of Study

The current study aims at investigating the effect of affiliate stigma on the psychological wellbeing of primary care-givers of developmentally disabled children and how the use of Africultural coping affects the impact of affiliate stigma on psychological wellbeing.

Objectives of Study

To assess the relationship between affiliate stigma and psychological wellbeing of primary caregivers of developmentally disabled children.

To determine the impact of a primary caregiver's marital status on psychological wellbeing.

To determine the effect of educational background of primary caregivers on psychological wellbeing.

To determine the effect of Africultural coping on the relationship between affiliate stigma and psychological wellbeing of primary caregivers.

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To explore gender differences in the effect of stigma on psychological wellbeing of primary caregivers of developmentally disabled children.

Relevance of Study

This study primarily seeks to investigate the effect of affiliate stigma on the psychological wellbeing of primary caregivers of developmentally disabled children.

Specifically it will provide a better understanding into the extent of psychological distress experienced by primary care-givers due to the stigma associated with caring for a developmentally challenged child in Ghana. This is necessary because, in addressing stigma effects, attention is usually given to the disabled and very little to their primary caregivers despite the fact that most disabled individuals in society, especially children, depend on their caregivers. This research addresses the psychological impact of stigmatization on primary caregivers of developmentally disabled children in Ghana and therefore serves as a helpful step in eliminating this stigma.

The research could serve as reliable data source in advocating against developmental disability related stigma in society. Information from this study could help in policy formation aimed at supporting disabled individuals and their caregivers. Investigating the moderating roles of social support and socio-economic status will be useful in drafting primary caregiver sensitive policies.

Furthermore results would enhance psychological practice. Investigating the extent to which afri-cultural coping helps in reducing the effects of stigmatization, would provide information that will be useful for counseling purposes.

Finally, this research will add to the limited existing literature on stigma associated with caring for a developmentally disabled child in Ghana. It will provide a Ghanaian perspective by

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revealing the cultural variation in the intensity and nature of developmental disorder stigma and its effect on the psychological wellbeing of primary care-givers.



CHAPTER TWO

Literature Review

Introduction

This chapter presents a review of some theoretical underpinnings of the factors that affect the psychological wellbeing of primary caregivers of children with developmental disabilities. The review examines theory relating to stigmatization of primary caregivers of developmentally disabled children and their psychological well-being. Using Goffman's theory of social stigma, identity threat model of stigma and the attribution theory, this section also explains primary caregivers' perceived stigma and their attitude towards intellectual disability. This chapter also reviews related studies in relation to the theories mentioned above. Lastly, the hypotheses and conceptual framework has also been presented in this section.

Theoretical Framework

Stigmatization occurs on societal, interpersonal, and individual levels. Studies of attitudes towards developmental disability, have considered societal influences such as stigma as a major factor to negative attitudes towards developmental disability. Stigma is an important consideration, because of its deleterious effect on families of children with disabilities (Fong, 2005; Skinner & Weisner, 2007). Many theories and models have been proposed with the aim of explaining stigma, its causes and effects.

Theory of Social Stigma

Among the influential models that have sought to explain the dynamics of stigmatization is the Theory of Social Stigma propounded by Goffman (1963, 1968). It is one of the earliest theories on stigma. This theory defines stigma as 'the situation' of the individual who is disqualified from

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full social acceptance and any attribute that is deeply discrediting. A key element of stigma, according to Goffman (1963, 1968), is that the bearer must have some sort of concern for what others think, and must also internalize the social norms to which they fail to conform. In this way, stigma is considered as both psychological and sociological.

Goffman (1963, 1968) defines three primary typologies of stigma: ‘abominations of the body’ (physical disabilities); ‘blemishes of individual character’ (‘moral’ failings); and ‘tribal stigma’ (race, religion, ethnicity). Examples of stigma according to Goffman’s (1963, 1968) theory include everything from visible or overt disfigurements/disabilities. Examples include being born without a nose or having had a limb amputated to covert characteristics such as urinary stricture, divorce, or homosexuality, which are more easily hidden.

Goffman’s (1963, 1968) theory and its applicability have been severely criticized by many modern researchers. Amongst these is Perez (2014), who criticized Goffman’s (1963, 1968) “Management of Spoiled Identity” theory. In Perez’ paper, it was pointed out that rather than focusing solely on the stigmatized ‘attribute’, it is more important to understand the social relationships that transform a simple characteristic into full blown stigma. In other words, there is a need for a ‘language of relationships’, which moves beyond the individual and emphasizes on the socially-contingent nature of stigmas. Another criticism of the theory is that it is contradictory in nature. Goffman (1963, 1968) indicated that stigmas are in some ways contextual and relational. In other words, a characteristic that attracts negative attention and discrimination in one circumstance may be positive or normative in a different circumstance. Nevertheless, he also emphasized the fact that certain characteristics are viewed so negatively that, in a particular sociocultural milieu they will always be considered abnormal and ‘deviant’

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no matter the circumstance. Despite these criticisms, Goffman's (1963, 1968) theory is of obvious importance to stigma literature and cannot be ignored.

Since the formulation of this theory, other models have been proposed to further conceptualize and explain the dynamics of stigma.

Identity Threat Model of Stigma

Another model that has been most significant in explaining the effect of stigma on individuals and their caregivers is the Identity Threat Model of Stigma (Major & O'Brien, 2005).

This model posits that situational cues, collective representations of one's stigma status, and personal beliefs and motives shape appraisals of the significance of stigma-relevant situations for well-being. According to Major and O'Brien (2005), a threat to identity results when stigma-relevant stressors are appraised as potentially harmful to one's social identity and as exceeding one's coping resources. Identity threat therefore creates involuntary stress responses and motivates attempts at threat reduction through coping strategies.

Their model further proposed that stress responses and coping efforts affect important outcomes such as self-esteem, academic achievement and health.

This model assumes that possessing a consensually devalued social identity (a stigma) increases one's exposure to potentially stressful (identity-threatening) situations.

Attribution theory

Attribution theory has been used to explain the stigmatization of disabilities, especially mental disabilities. According to Weiner (1993), attribution explains people's reactions to disabilities; in that both negative and positive reactions towards disability are based on the causative factors.

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Persons, who are seen as not having control over their disabilities because of the biological or physical cause, are shown positive and more helpful behaviours as opposed to persons whose disabilities are recognized as caused by themselves and who have control over what happens to them (Boysen & Vogel, 2008). Attitudes towards disability in Ghana suggest they are more negative (Quinn, 2007), because of the belief that intellectual disability is inflicted upon people by their own wrong doing and curses (Slikker, 2009).

Slikker posited that family members and individuals with disability felt stigmatized in the society because most people have the belief that the causative factors were more likely to emanate from the individuals with disability and their family members. Corrigan (2000) in explaining the relationship between stigma and attribution theory, also assented to the fact that people's reaction to disability depends on the interpretation of the symptoms of the disability. When the symptom is seen as uncontrollable, the person is not deemed responsible and therefore not stigmatized. This is also true for those perceived as having control over their symptoms. The general attitudes in many communities towards children with disabilities are negative because disability is generally considered an offence against gods, atonement for sins of family and ancestors. Thus, some persons with disabilities are ostracized, and excluded from the mainstream community (Avoke, 2010).

Review of Related Literature

Understanding Stigmatization

Stigma is a term which dates back to the Greeks who cut or burned marks into the skin of criminals, slaves, and traitors in order to identify them as tainted or immoral people that should be avoided (Goffman, 1963 as cited in Bos, Pryor, Reeder & Stutterheim, 2013). In recent times however, it is a known fact that stigma is beyond a physical mark on an individual. Stigma is defined as “any attribute that discredits or disqualifies a person from full social acceptance” (Dale, Smith, Norlin & Chess, 2006, p.81).

Beginning with Goffman's (1963) study in the early 1960s, the concept of stigma has become an important concern for sociologists, psychologists and researchers who work in the area of health and illness. Among the various disorders that have been considered in terms of their stigmatizing effects are bipolar disorder (Perlick, Miklowitz, Link, Perlick, Struening, Kaczynski, Gonzalez, Manning, Wolff & Rosenheck, 2007), mental health (Nyarko, Barke & Klecha, 2010; Corrigan, 2000) and recently, HIV/AIDs (Omosanya, Elegbede, Agboola, Isinkaye & Omopariola, 2013).

Corrigan (2000) conceptualized stigma as a set of prejudicial attitudes, stereotypes, discriminatory behaviours and biased social structures endorsed by a sizeable group about a discredited subgroup. This conceptualization reveals stigma as involving attitudes, beliefs and behaviour.

Mickelson (2001) considered stigma as a complex construct that includes public, self, and structural components. He argued that stigma directly affects people with disabilities, as well as their support system, provider network, and community resources. Therefore, not only are the disabled individuals stigmatized, their care givers face stigmatization by association. As a result,

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stigmatized individuals encounter problems in obtaining access to some community resources such as the opportunity of being enrolled in mainstream education.

These definitions share the assumption that people who are stigmatized have or are believed to have an attribute that marks them as different and portrays them as devalued in the eyes of others. According to Major and O'Brien (2005), stigmatizing marks may be visible or invisible, controllable or uncontrollable, and linked to appearance (e.g., a physical deformity), behaviour (e.g. child abuser), or group membership (e.g. African American). Notably, stigma is relationship and context-specific, that is, it does not reside in the person but in a social context.

Most definitions of stigma comprise two basic components, namely, the recognition of difference and devaluation (Dovidio, Major, & Crocker, 2000). Also, stigma occurs through social interactions. As such, stigma is not considered to reside in the person but rather in the social context (Crocker, Major, & Steele, 1998; Hebl & Dovidio, 2005).

Stigmatization can be overt. It can manifest as aversion to interaction, avoidance, social rejection, discounting, discrediting, dehumanization, and depersonalization of others (Dovidio *et al.*, 2000; Herek, 1999).

Stigma can also be subtle. For example, stigma can arise as non-verbal expressions of discomfort (e.g. a lack of eye contact) that result in tensed social interactions between stigmatized and non-stigmatized individuals (Hebl, Tickle & Heatherton, 2000).

From a social psychological perspective, stigmatization may have a number of functions (Phelan, Link & Dovidio, 2008). The first function is that of exploitation and domination. People with more power may stigmatize others with less power in order to maintain inequalities between groups. Another function is social norm enforcement, that is, keeping people in. The threat of

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stigmatization is thought to encourage deviants to conform to in-group norms. A final function is disease avoidance that involves keeping people away. From an evolutionary perspective, social exclusion of deviants provided protection against infectious diseases and thus contributed to survival (Kurzban & Leary, 2001; *Phelan et al.*, 2008).

Types of stigma

Pryor and Reeder (2011) articulated a conceptual model that seeks to bring greater clarity to the current but diverse literature on stigma. Building on previous theories (Corrigan, 2004; Herek, 2007), this model depicted four dynamically interrelated manifestations of stigma.

Public Stigma

The first type of stigma they conceptualized is public stigma. This stigma represents people's social and psychological reactions to someone they perceive to have a stigmatized condition. Public stigma comprises the cognitive, affective, and behavioural reactions of those who stigmatize (perceivers).

The origin of stigmatization lies in the cognitive representations that people (perceivers) hold regarding those who possess the stigmatized condition (targets). These cognitive representations or features of a stigmatized condition can trigger negative emotional and behavioural reactions (Dijker & Koomen, 2003). One such representation is the onset controllability for the stigmatized condition. High levels of attributed personal responsibility for the onset of the deviant condition evoke anger and stigmatizing behaviour as would be the case of a smoker who gets lung cancer, whereas low levels of personal responsibility yield feelings of sympathy and greater tendencies to provide help, which would more likely be with a woman who receives a diagnosis of breast cancer. Another representation is the perceived severity of the condition.

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High levels of perceived severity evoke both anxiety and sympathy on the part of perceivers (Crandall & Moriarty, 1995; Feldman & Crandall, 2007; Van Alphen, Dijker, Bos, Van den Borne & Curfs, 2012) and the occurrence of both emotions simultaneously can yield emotional ambivalence and awkward interactions (Dijker & Koomen, 2003; Hebl, Tickle, & Heatherton, 2000). This is often seen with conditions perceived to be fatal or severely disabling, for example, being in a wheelchair. Another similar feature is the perceived dangerousness of the condition. Perceived dangerousness elicits fear and avoidance in perceivers (Bos, Kok & Dijker, 2001; Feldman & Crandall, 2007). For example, people with mental illness have often been perceived to be unpredictable and dangerous and subsequently stigmatized. Lastly, perceptions of norm violation are positively related to anger and social exclusion, and negatively related to sympathy (Dijker & Koomen, 2003). Perceptions of norm violation have played a fundamental role in the stigmatization of people with HIV as traditionally HIV has been associated with promiscuity, prostitution, homosexuality, and intravenous drug use, all of which have, at some time, been or are still considered as deviant behaviour

Self Stigma

The second type of stigma in Pryor and Reeder's (2011) model is self-stigma. Self-stigma shows the social and psychological impact of having a stigma. It includes both the apprehension of being exposed to stigmatization and the potential internalization of the negative beliefs and feelings associated with the stigmatized condition.

Numerous studies have shown that stigma has negative consequences for the psychological wellbeing of stigmatized individuals (Meyer, 2003; Stutterheim, Pryor, Bos, Hoogendijk, Muris & Schaalma, 2009). Self-stigma can result from an awareness of public stigma, as people with stigmatized conditions are keenly aware of the social devaluation connected with their condition.

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Like public stigma, self-stigma has cognitive, affective, and behavioural components (Mak & Cheung 2010), and operates at both the explicit and at the implicit levels (Rusch, Corrigan, Todd, & Bodenhausen, 2010).

Public stigma impacts the self in three ways. Firstly through enacted stigma, which is the negative treatment of a person possessing a stigmatized condition, secondly through felt stigma, which is the experience or anticipation of stigmatization on the part of the person with a stigmatized condition; and thirdly through internalized stigma, which is the reduction of self-worth and accompanying psychological distress experienced by people with a stigmatized condition (Herek, 2007; 2009).

A fundamental dimension of stigmas concerns the degree to which they can be concealed. People who choose to seem 'normal' by hiding their stigma nevertheless remain 'discreditable' as long as the potential that the stigma can be revealed remains. Therefore concerns regarding who to tell and the fear of being discovered are significant sources of psychological distress among those who conceal their stigmatized condition (Pachankis, 2007). Examples include people who could potentially be stigmatized as a result of their concealed sexual orientation or socioeconomic status. While people who voluntarily disclose their stigmatized status (i.e. are open or out of the closet) or those who have a visible stigma (e.g. a deviant ethnicity, an obvious physical disability, etc.) do not experience the anxiety of "disclosure concerns," they still endure the potential of continually being 'discredited' in the eyes of others (Stutterheim, Bos, Pryor, Brands, Liebrechts & Schaalma, 2011).

Stigmatized individuals can attempt to mitigate the negative psychological and social impact of stigmatization (e.g. depression, anxiety, isolation, reduced social network, limited social support) by employing a variety of coping strategies. Some coping strategies are geared to altering the

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relationship between the stigmatized individuals and their environment (problem-focused coping), whereas other strategies seek to regulate negative emotions (emotion-focused coping). Problem-focused coping strategies can target the self, the situation, or others, and include strategies such as selective disclosure, compensating for the stigma during social interactions by, for example, being particularly outgoing, avoiding situations where stigmatization is likely (i.e. disengagement), affiliating oneself with others who share one's stigmatized condition, seeking social support, and activism. Furthermore emotion-focused strategies include downward social comparison, external attributions for the stigmatizing behaviour of others to, for example, ignorance, denial or prejudice minimization, distraction, positive reappraisal of experiences of stigmatization, and detaching oneself from one's stigmatized identity (Major & O'Brien, 2005; Miller & Kaiser, 2001).

Stigma by Association

The third type of stigma they postulated is stigma by association. This type of stigma is analogous to Goffman's (1963) courtesy stigma and entails social and psychological reactions to people associated with a stigmatized person, for example family and friends as well as people's reactions to being associated with a stigmatized person. According to Pryor et al., (2012), stigma sometimes extends to other individuals or things because they have a relation with the stigmatized. This type of stigma is known as stigma by association (Mehta & Farina, 1988) or courtesy stigma (Goffman, 1963). Stigma by association or courtesy stigma is when other people are regarded "as having spoilt their identity because they share a web of affiliation with the stigmatized". Stigma by association results from the affiliation that one has with a person already being stigmatized; and this happens through physical, biographical or relational role (Birenbaum, 2010). Courtesy stigma or stigma by association includes the emotions and beliefs of those

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surrounding the stigmatized person, including family members and professionals (Larson & Corrigan, 2008; Rusch, Angermeyer, & Corrigan, 2005). Family members of people with intellectual disability feel stigmatized for the reason that, they are associated with the intellectually disabled person and secondly being associated with the cause if the cause is perceived as a curse or a punishment of evil-doing. The effects of stigma-by-association are especially powerful because they are likely to persist after even a single exposure. Risen and Gilovich (2007) found that the mere association of a rare group member with a rare behaviour is sufficient to produce a link with the stigmatized and set the stage for more elaborate stereotyping. Pontikes, Negro and Rao (2010), confirmed this in their study that, the mere association of a person to an already stigmatized or would-be stigmatized member of a group was enough to cause the third person to also be stigmatized against.

Research has shown people associated with stigmatized individuals (e.g. family, friends, caregivers) are routinely devalued purely as a result of their connection with someone with a stigmatized condition (Hebl & Mannix, 2003; Neuberg, Smith, Hoffman, & Russell, 1994). This kind of devaluation seems to take place not only when there is a meaningful connection between a non-stigmatized and a stigmatized person (e.g. family relationships) but also when the connection is purely arbitrary; for example as a result of just proximity (Pryor, Reeder, & Monroe, 2012). Like public stigma and self-stigma, stigma by association comprises cognitive, affective, and behavioural aspects (Mak & Cheung, 2008).

Again, like public stigma and self-stigma, stigma by association entails dual processes. Explicit attitudes moderate the spread of stigma across companions with a meaningful relationship (e.g. a family member), whereas implicit attitudes moderate the spread of stigma when the connection is purely arbitrary as well as when the connection is more meaningful.

Structural stigma

Finally, structural stigma is defined as the “legitimatization and perpetuation of a stigmatized status by society’s institutions and ideological systems” (Pryor & Reeder, 2011). Accordingly, the four types of stigma are interrelated. However, public stigma -the consensual understanding that a social attribute is devalued - is considered to be at the core of the other three manifestations. Structural stigma refers to the ways in which societal ideologies and institutions perpetuate or exacerbate a stigmatized status (Corrigan & Lam, 2007). Recent literature on stigma acknowledge that stigma reproduces existing social inequalities and is perpetuated by hegemony and the exercise of social, economic, and political power (Campbell & Deacon, 2006; Link & Phelan, 2001; Parker & Aggleton, 2003; Scambler & Paoli, 2008). Societal structures promoting stigmatization vary cross-culturally and historically. As a result, the examination of structural stigma requires the examination of the social context in which that stigma occurs and the local knowledge systems that contribute to structural stigma (Foucault, 1977).

Attitude of primary caregivers towards children with developmental disabilities

Children are the pride of a family. The emotional preparation for expectant parents is usually shaped by a glamorous image of the baby, which is a kind of ego ideal. The discrepancy between the perfect child of their fantasy and the real child may be the cause for negative attitudes and parenting stress. Often a range of emotions, such as denial, guilt, blame, frustration, anger and despair, sweep through the parents as they are confronted by their children with disability (Bhan, 1995). Loss of hope for the ‘perfect child’ causes grief, and over time the feeling is heightened by loneliness, isolation, and exhaustion. Parents frequently over-protect their child and feel guilty that they are responsible for the child’s disability.

The parents of children with disabilities develop ‘chronic sorrow’ characterized by periodic

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recurrence of sadness, guilt, shock and pain (Wikler *et al.*, 1981). They are plagued by feelings of pessimism, hostility, and shame (Rangaswamy, 1989).

Denial, projection of blame, guilt, grief, withdrawal, rejection, and acceptance are some of the usual parental reactions (Drew *et al.*, 1984). Other primary caregivers also experience helplessness, feelings of inadequacy, anger, shock and guilt, whereas others go through periods of disbelief, depression, and self-blame. The close relatives like siblings also experience feelings of guilt, shame, and embarrassment (Frude, 1992)

One study that investigated attitudes of parents towards inclusion of their children with disability in a mainstream school was done by Elkins, van Kraayenoord and Jobling (2003). Their study was aimed at finding out parents' attitudes and opinions related to students with special needs in a regular school. Using a survey method, a sample of 354 parents was asked to give responses on a questionnaire. Results from this study found out that majority of parents showed positive attitudes towards the inclusion of their children into mainstream. This highlights the fact that parents and relatives will show positive attitudes towards inclusion of their wards.

Mbwilo, Smide and Aarts (2010) did a study to explore the factors that would influence family perspectives in providing care for persons with mental disability. The study employed qualitative methods to explore variables associated with family characteristics and factors associated with care-giving of a mentally disabled person in the family. The study was analyzed using thematic content analysis to categorize the data into meaningful phenomenon. The study found that family characteristics, lack of knowledge about the mental disability and health care resources were found to be associated with caring for children and adolescents with mental disabilities. Effects of the presence of mental disability in the family brought certain challenges associated with discriminations and interpersonal relationships problems. This study concluded that the lack of

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knowledge of the disability and the lack of social support affected the perception of family members with children and adolescents with mental disability.

A study by Chandramuki, Shastry and Vranda (2012) explored parental attitudes towards children with specific learning disabilities. The study sample comprised parents of 60 children with Specific Learning Disability (SLD). The attitudes of parents were assessed using the Parental Attitude Scale. Results showed differences in parental perceptions related to the gender of their children. Furthermore, parents experienced more anxiety, guilt, insecurity, emotional instability, self-pity and hopelessness when the child is male.

Stigma and psychological wellbeing

Assertions have been made that exposure to social discrimination and stigma affects the well-being and attitude of a person. Perceptions of stigma by association have been found to be related to lower self-esteem and psychological distress in those connected with stigmatized individuals (Struening, Perlick, Link, Hellman, Herman & Sirey, 2001; Mak & Kwok, 2010). Stuart (2005) argues that family members who feel or experience courtesy stigma, may experience it as fear, loss, lowered family esteem, shame, secrecy, distrust, anger, hopelessness and inability to cope.

Therefore, caregivers of disabled individuals practice defense mechanisms that aim at protecting individuals against stigma. People often try to hide their relationship to a stigmatized family member (Phelan, Bromet & Link, 1998) or encourage that member to hide his or her condition. Such concealment “advice” is detrimental to the psychological well being of the stigmatized family member (Stutterheim, 2009).

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A growing body of research suggests that primary caregivers of children with developmental disability suffer poor psychological health. Primary caregivers of developmentally disabled children, experience significantly higher levels of negative affect, marginally poorer psychological well-being, and significantly more somatic symptoms (Greenberg *et al.*, 2008). This suggests that primary caregivers of developmentally disabled children experience relatively poorer psychological wellbeing than individuals who are not primary caregivers of developmentally disabled children.

According to Mak and Cheung (2008), disabled individuals as well as their caregivers, both experience stigmatization. In their study, they argued that stigma does not only affect the discredited individuals but also individuals associated with the targeted individuals (e.g. family members, caregivers, friends and service providers).

Caregivers of developmentally disabled individuals have a negative assessment of their own wellbeing. In Werner and Shulman's (2013) study investigating the subjective wellbeing among family caregivers of individuals with developmental disabilities, it was revealed that subjective wellbeing of family caregivers was below the average normative level and that the strongest predictors of subjective wellbeing were caregivers' self-esteem, social support, positive meaning in care giving and affiliate stigma. Caregivers' feelings of low self-esteem predict negative psychological wellbeing while perception of reliable social support and positive reaction to care giving and affiliate stigma lead to positive subjective assessment of psychological wellbeing of primary caregivers. These findings therefore indicate the importance of supporting caregivers across their life-span in order to decrease stigma, improve social support and self-esteem and improve subjective wellbeing.

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A study by Chiu et al. (2013) on affiliate stigma of caregivers of children with intellectual disabilities showed that caregivers generally experience poorer psychological wellbeing than individuals who do not have the caregiver status. They further discovered that caregivers with better resources appeared to have coped better and had lower psychological distress, lower anxiety and a higher level of personal empowerment.

Perlick et al. (2007) argue that greater perceptions of stigma towards caregivers were associated with significantly higher levels of depressive symptoms. Findings from their studies suggested that in addition to posing a barrier to the recovery of people with developmental disabilities, stigma erodes the morale of the family members who help care for them.

Mothers of children with developmental disability have significant psychological problems that might worsen due to negative attitudes (stigma) towards their wards with developmental disability.

In the Ghanaian context, stigmatization may be unavoidable for primary caregivers of a developmentally disabled child. This is because disability of a person in Ghana is generally regarded as a taboo or a forbidden effect on a person and his family (Inclusion, 2011). Miller and Kaiser (2001) maintain that understanding the effect of stigma, gives room to explore its impact on psychological factors.

A study was conducted by Ostman and Kjellin (2002) to investigate psychological factors associated with stigma experienced by relatives of mentally ill patients. Using a semi-structured questionnaire, they interviewed 162 relatives of patients in acute wards following voluntary and compulsory admissions. Majority of relatives experienced mental health problems because they perceived stigma regardless of the characteristics of their mentally ill relatives. A majority of relatives experienced psychological distress associated with the stigma they perceived. Ten per

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cent had had suicidal thoughts and 18% wished death for their mentally ill relative.

Perkins, Holburn, Deaux, Flory and Vietze (2002), investigated mother-child relationship and self-esteem of typical children of mothers with intellectual disability with the aim to examine the emotional outcomes among them. They administered questionnaires to 36 participants (18 males, 18 females) who were between the ages of 9 and 17 years. The questionnaires assessed attachment style, caregiver style, perception of maternal stigma and self-esteem of the children. Children of mothers with intellectual disability were found to feel stigma associated with their mothers' disability and also felt stigmatized themselves and this had an effect on their attachment to their mothers and their self-esteem.

A qualitative study of Ghanaian families of people with disabilities was done by Anum (2011). This study explored the experiences of Ghanaian families with a disabled child. Employing qualitative techniques such as semi-structured interviews, participant observation and narrative analysis, the researcher explored experiences of four families with disabled children in the Dangme West District. The study's findings showed that families of disabled children experience stigma, strain on family relationships and lack institutional support most likely because they experience stigma. One explanation that was given to why families, especially the mothers who are the primary caregivers, felt stigmatized was the cultural explanations of disability in the Ghanaian context. This perception of stigma was also found as one of the causes of the strains in intra-family and inter-family relationships.

Marital status and psychological wellbeing of primary caregivers

Studies have supported the fact that the existence of a support network for primary caregivers of developmentally disabled children experiencing stigma, improves their psychological wellbeing or reduces the negative impact of stigma on their psychological wellbeing.

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According to Benson (2012), perceived support has an effect on the psychological health of primary caregivers of developmentally disabled children. Findings suggest that network emotional support contribute to increased mothers' perception of support which, in turn, reduces depressed mood and increases wellbeing.

In a study by Markey (2015), it was shown that marital status of caregiver had a significant predictive value for both anxiety and expressive symptoms. Specifically, people who are divorced, separated, or widowed may experience chronic stressors relating to their marital situation thereby resulting in magnified negative effects on psychological wellbeing. This is supported by Harley, Almond, Han, Burton and Schonwetter's (2003) study which revealed that as a result of the overload of pressures, divorced, separated or widowed primary caregivers may be more vulnerable to developing a psychological disorder.

They also indicated that the additional support married individuals obtain from their spouses makes them more likely to experience better psychological wellbeing.

Mickelson (2009) reported that perceived stigma is consistently related to less perceived support availability from respondents' parents (i.e. the child's grandparents), more negative interactions with spouse and grandparents, and increased depressive symptoms. The implications are that the more primary caregivers perceive themselves as being stigmatized, the more negative their relationships with significant others become. Due to a break down in social support primary care givers therefore experience increased depressive symptoms which is an indication of psychological ill health.

Socio- economic differences in psychological wellbeing of caregivers

Studies have shown that differences in socio-economic status of individuals present differences in experiences in psychological wellbeing. Some studies show that a relationship exists between socio-economic status and well-being of caregivers. According to Stelzer *et al.*, (2004), lower socioeconomic status has a strong correlation with both the status of having a child with disability and poorer well-being. Also, low socio-economic status has a detrimental effect on family and child outcomes and that little variation in outcomes is found at moderate to high levels of socio economic status (Hudson, 2005).

Carter *et al.* (2008) reported that caregivers who had at least a high school education reported better quality of life and lower psychological distress than those with lower educational levels.

However, not all studies show a significant relationship between educational level and psychological wellbeing. In a study by Markey (2015), educational level had no significant effect on the psychological wellbeing of caregivers.

Gender differences in psychological wellbeing of caregivers

Gender is a second factor that may be associated with variability in the effect of having a disabled child. A large body of research has suggested that women bear a greater care giving burden than men and that women experience poorer psychological health in relation to stigma associated with their developmentally disabled children. Women not only spend more time caring for other family members, but they tend to also experience greater depression, poorer well-being, and worse physical health outcomes than men in caregiving roles, although these differences are often small in magnitude (Pinquart & Sorensen, 2006).

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Despite much interest in gender differences in the consequences of care giving, few studies have examined whether mothers and fathers are differentially affected by the experience of parenting a disabled child. Some research suggests that mothers of children with mental retardation provide greater hours of support and perceive greater burden than fathers (Pruchno & Patrick, 1999), yet other studies report that mothers and fathers experience similar levels of subjective burden and depressive symptoms (Essex & Seltzer, 1999). Seltzer et al. (2001) found that mothers of children with developmental disabilities experience a greater decrease in their hours of employment and job stability than fathers when compared to parents with a non-disabled child, but they found no gender differences in psychological or physical well-being.

Less attention has been paid to the well-being of fathers. The available evidence suggests that the association between parenting a child with intellectual disability and lower well-being is much less pronounced among fathers and fathers typically report lower levels of psychological distress than their spouses (Emerson *et al.*, 2010; Gerstein *et al.*, 2009; MacDonald & Hastings, 2010; Olsson & Hwang, 2001; Saloviita *et al.*, 2003).

Stigma in Ghana: Culture and superstition.

In Ghana, cultural and belief systems have strong influences on the conceptualization of developmental disability and these go a long way to affect the birth, acceptance and integration of children with such conditions into society (Yekple, 2014).

Taboos and belief systems in Ghana cause stigmatization of developmentally disabled children and their caregivers. Nukunya (2003) reported that in some Ghanaian traditional cultures, it is believed that meeting a disabled child early in the morning spells doom for the rest of the day. He further reported that pregnant women are also admonished to stay away from such children

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due to the belief that they would give birth to children with similar disabilities. These beliefs have negative implications on the wellbeing of developmentally disabled children in the Ghanaian society.

According to Avoke (2001a), in Ghana, the general attitude in many communities towards children with developmental disabilities is that they are “children of the rivers and forests” and were in the past returned to the forests or rivers under the disguise of helping them return to where they came from.

Often, within the Ghanaian society, people result to labeling developmentally disabled children in negative and demeaning ways. Studies indicate that children with developmental disability are regarded as feeble-minded, incapable, and just burdens on society (Russel & Malhotra, 2002; as cited in Gibilisco, 2010). Such negative labels can have damaging effects on the lives of children with disability and their primary caregivers as well.

According to Yekple (2004), negative labels and the stigma attached to developmental disability often lead to the concealment of children by parents in order to avoid the stigma and deep-rooted stereotype behaviours by the society.

Coping and psychological wellbeing of primary caregivers

A primary caregiver’s role places him or her in a unique position, in that though they are not directly stigmatized, they experience stigmatization by association or affiliate stigma which affects their psychological wellbeing. From reviewed literature, primary caregivers adopt various coping strategies in order to reduce or remove the effects of stigma on their psychological wellbeing.

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For both mothers and fathers, a variety of coping strategies have been reported to be related to parental well-being (Baker, Blacher & Olsson 2005; Glidden, Billings, & Jobe, 2006; Glidden & Natcher, 2009; Hassall & Rose, 2005; MacDonald, Hastings, & Fitzsimons, 2010; Nachshen & Minnes, 2005; Oelofsen & Richardson, 2006; Olsson, 2008; Olsson et al., 2008; Paczkowski & Baker, 2008; Van der Veek, Kraaij, & Garnefski, 2009). The majority of parents with children with developmental disabilities employ a variety of coping strategies to deal with the demands facing them (Glidden & Natcher, 2009; Lee, 2009). A larger repertoire of and greater use of coping strategies are related to increased well-being (Taanila, Syrjälä, Kokkonen, & Järvelin, 2002). Mothers tend to use coping strategies more frequently than fathers. This could possibly be as a consequence of mothers taking more responsibility for child care (Saloviita et al., 2003). The use of active or problem-focused coping strategies which emphasize efforts to seek social support, actively solve the problem, and positive reappraisal, appear to be recorded more frequently than other strategies and to be associated with more positive parental well-being (Glidden, Billings & Jobe, 2006; Kim, Greenberg, Seltzer, & Krauss, 2003; Paczkowski & Baker, 2008; Van der Veek et al., 2009).

In a study by Al-Yagon (2015), investigated how the emotional resources (low anxiety/avoidant attachment, low negative affect, and high positive affect) of parents may explain the differences in their coping resources (active/avoidance coping with child-related problem, sense of coherence). Four-hundred and ten (410) parents were sampled for the study comprising of 107 parents of children with developmental disability and 98 parents of typically developing children. It was observed that parental emotional resources contributed to coping resources, although differed partially between the groups of parents.

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An experimental study conducted by Gammon & Rose (1991), aimed at examining the effectiveness of the Coping Skills Training Program (CSTP) involved training in problem solving, achieving personal goals, interpersonal skills training, and cognitive restructuring- all presented in a group treatment format. Results showed the importance of teaching parents to set realistic, behaviourally measurable goals and also increased attention to the development of support networks. It was further demonstrated that a behavioural approach to skills acquisition can make a significant contribution to parents who daily face situations which they may not be prepared for.

Caring for a developmentally disabled child is a challenging experience especially with the attendant stigma associated with it. Primary caregivers therefore need to use positive coping interventions that would help them withstand stigma and improve their wellbeing.

In conclusion, several studies have been done to understand the dynamics of stigma in families of the developmentally disabled. Cultural explanation given to stigma is based on the knowledge an individual has about the norm of society. A combination of the above explanations provides a better understanding of how stigma operates in the society, especially against children with developmental disability and their primary caregivers.

It is clear, from reviewed literature that most studies conducted in Ghana on stigmatization and disabilities have focused on cultural beliefs, superstition and how these affect the quality of life of disabled individuals. Though it is evident that primary caregivers of the disabled in Ghana are equally stigmatized, not much research has been conducted on how stigma affects them and the coping mechanisms. Therefore more research is necessary to fill this gap in literature.

Rationale

Numerous studies have been conducted on stigma and developmental disability. Most of these studies however have been conducted in the Western countries. Such literature reveal the extent to which the psychological wellbeing of primary caregivers of developmentally disabled children have been investigated in other parts of the world (MacDonald & Hastings, 2010; Perlick, 2007; Plant & Sanders, 2007; Shobana & Saravanan, 2014).

In Ghana however, most published stigma studies do not aim at investigating the psychological effect of stigma. From literature review, stigma studies in Ghana generally aim at understanding the cultural, religious and social factors that cause or fuel existing stigma. This is reflected in the many research on how cultural beliefs and superstition impact on and enhance stigma in Ghana. Examples of such studies include Tradition and change in Ghana; Nukunya (2003) and Traditional practices and belief systems as factors influencing access and enrolment of children with intellectual disability in special schools in Ghana (Yekple, 2014). Research has shown that caregivers of the disabled equally experience some form of stigma which have an impact on their psychological health (Mak & Cheung, 2008; Ali, Hassiotos, Strydom, King, 2012; Werner & Shulman, 2013). Nevertheless, a large number of Ghanaian studies on stigma focus on the directly stigmatized or disabled individuals. Relatively insufficient knowledge exists on the effect of stigma on the psychological wellbeing of primary care-givers of individuals who suffer such disabilities in Ghana.

Based on the review of literature, it was also observed that of the few caregiver-focused studies that exist, most of the studies were qualitative in nature. Most of such studies, for example “The stigma of mental illness in Southern Ghana: Attitudes of the urban population and patients’ views”; Nyarko, Barke and Klecha (2010), employed the use of interviews and focus group

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discussions. Though these provide in-depth knowledge on the challenges primary caregivers face in carrying out their responsibilities, there is a need to have quantitative studies to verify and validate the results of qualitative studies.

This study therefore seeks to fill the gap within Ghanaian literature by providing quantitative information on the stigma felt by primary-care givers of developmentally disabled children and the impact on the psychological health of primary care-givers.

Statement of Hypotheses

Hypothesis 1: Affiliate stigma of primary caregivers will significantly predict psychological wellbeing.

Hypothesis 2: Married primary caregivers will have a significantly better psychological wellbeing than unmarried primary caregivers.

Hypothesis 3: Primary caregivers with higher educational background will have a significantly better psychological wellbeing than those with lower educational background.

Hypothesis 4: Africultural coping will moderate the relationship between affiliate stigma and psychological wellbeing.

Hypothesis 5: Africultural coping will have a significant negative relationship with affiliate stigma.

Hypothesis 6: Africultural coping will have a significant positive relationship with psychological wellbeing.

Hypothesis 7: Female primary caregivers will have a significant poorer psychological wellbeing than males.

Conceptual Framework

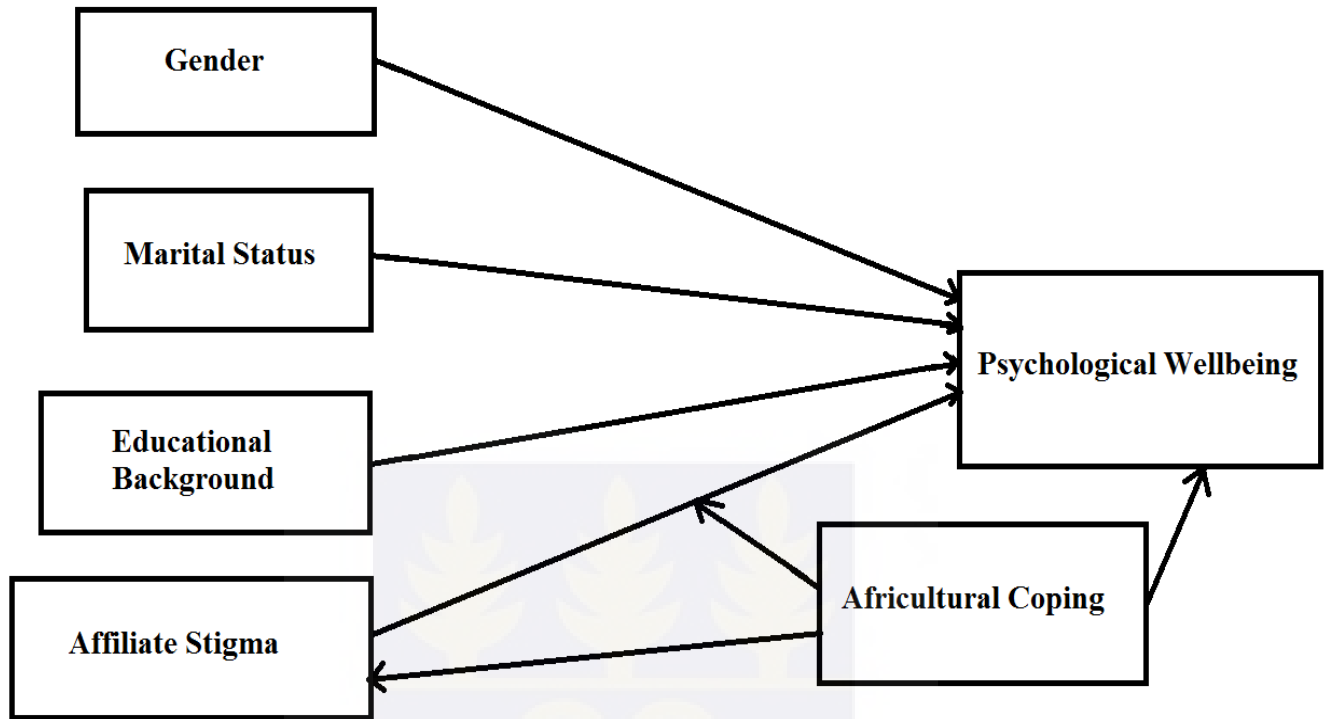


Fig 2.1: A schematic representation of the hypothesized relationship between stigmatization, psychological wellbeing and Africultural coping.

In the model above, gender, marital status, educational background, affiliate stigma and Africultural coping are hypothesized to be predictive factors of psychological wellbeing. Africultural coping is furthermore hypothesized to be a predictive factor of affiliate stigma as well as a moderating factor between affiliate stigma and psychological wellbeing.

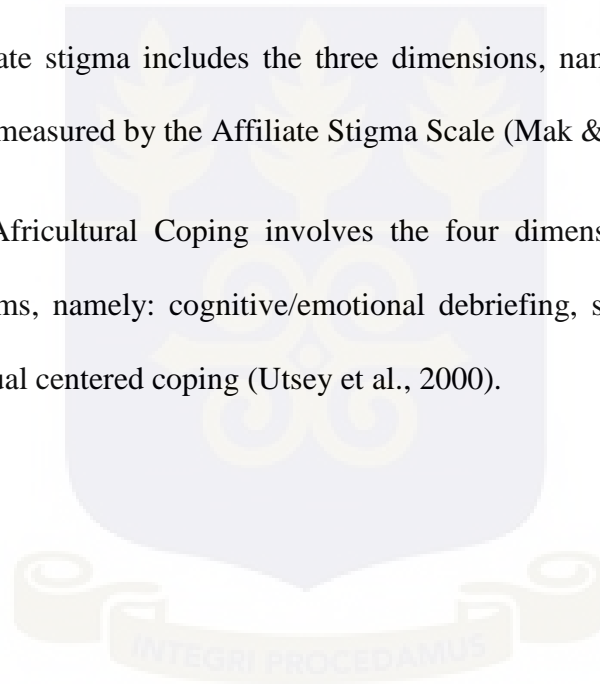
Operational Definition of Terms

Primary caregiver: In this study a primary caregiver is defined as a parent or relative who is primarily responsible for the developmentally disabled child (Datta, Russell & Cookemane, 2002).

Psychological well-being: This includes the six dimensions measured by Ryff Scales of Psychological Well-being, namely: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self acceptance (Ryff, 1995).

Affiliate Stigma: Affiliate stigma includes the three dimensions, namely: affective, cognitive and behavioural stigma, measured by the Affiliate Stigma Scale (Mak & Cheung, 2008).

Africultural Coping: Africultural Coping involves the four dimensions of the Africultural Coping Inventory Systems, namely: cognitive/emotional debriefing, spiritual centered coping, collective coping and ritual centered coping (Utsey et al., 2000).



CHAPTER THREE

Methodology

Introduction

This study investigated the effect of stigmatization and the use of aficultural coping on psychological wellbeing of primary caregivers. Under this section, the description of the target population, sample, sampling techniques, and research design used in the research are discussed. The chapter describes the instruments used for data collection and the scoring of the data, how the questionnaires in the study were piloted and the psychometric properties of the scales used reported. Finally, it describes the data collection procedure used in the study.

Research Setting and Population

This study was conducted in the Accra metropolis, the capital of Ghana found in the Greater Accra Region. It is located in the southern part of the country. The population for the study was primary caregivers of children with developmental disability admitted in special schools in the Accra metropolis; namely: Autism Awareness Care and Training, Dzorwulu Special School and New Horizon School. Persons with developmental disability in these special institutions were diagnosed by a qualified clinical psychologist or medical officer. The participating primary caregivers for this research were supposed to be living with the children during the last past year in the same house. The population also constituted people from different cultural backgrounds and religious affiliations across the country. New Horizon School and Autism Awareness Care and training (AACT) are private institutions. New Horizon admits persons with special needs of different categories ranging from Cerebral Palsy, Autism Spectrum Disorder (ASD), Learning Disabilities, Attention Deficit Hyperactive Disorder (ADHD) and mental retardation, AACT

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admits persons with Autistic Spectrum Disorders exclusively. Dzorwulu Special school; Dansoman branch, is a public school that also admits from a wide range of developmental disabilities.

Sample and Sampling Technique

Sixty-nine (69) participants were used in the study. It was ensured that these participants lived with the developmentally disabled child. The convenient sampling technique was used in selecting these participants. This sampling method implies that one must be available and willing to participate in the study (Babbie, 2005). This method was the best for the study because there is presently no data or information on primary caregivers of developmentally disabled children in Ghana. Therefore getting the primary caregivers through the special schools was the best option available.

Potential participants who did not live with their developmentally disabled child were not included in the study. Also primary caregivers of children older than 15 years were not included in the study.

To collect data for this study, questionnaires were administered by hand to the selected special needs schools. A total number of one hundred (100) questionnaires were distributed to primary caregivers who consented to take part in the research from the selected special needs schools. This number was used to ensure that, if there was a low response rate, the required sample size for the study of at least sixty -six (66) participants would still be achieved. This sample comprised primary caregivers of different demographic backgrounds in areas such as sex, age, educational background, occupation, marital status, type of developmental disability of child and number of years of care giving experience. Also details regarding the age, birth position and gender of the child were assessed. Out of total number of questionnaires administered, sixty-nine (N= 69) were completed and returned. All sixty-nine were used in analysis.

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The total number of sixty-nine (69) responses for the study was adequate because according to Stevens (1996), for social science research, about 15 respondents per predictor are needed for a reliable equation. Since there are four predictors in this study the minimum sample size according to Stevens' recommendation would be sixty (60). This implies that the acquired respondent number of 69 was adequate for the research.

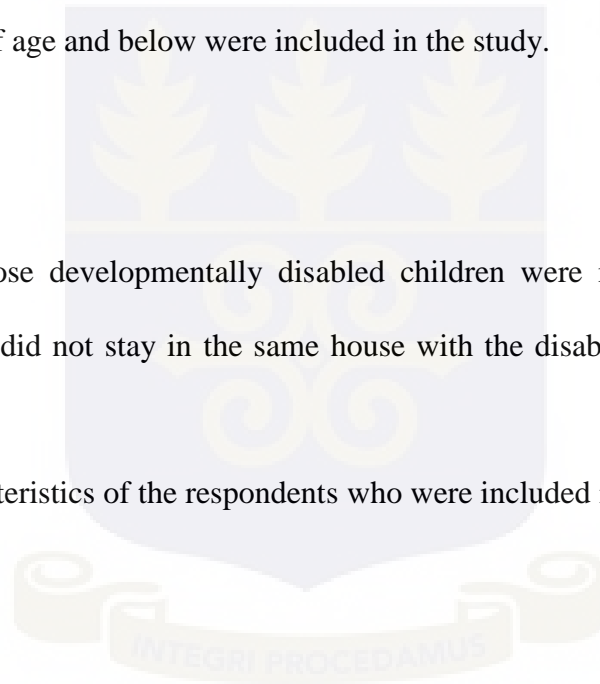
Inclusion Criteria

Participants whose children had been diagnosed with developmental disability and whose children were 15 years of age and below were included in the study.

Exclusion Criteria

Primary caregivers whose developmentally disabled children were more than 15 years and primary caregivers who did not stay in the same house with the disabled child were exempted from the study.

The demographic characteristics of the respondents who were included in the study are presented in Table 3.1.



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Table 3.1: *Demographic Characteristics of Respondents*

<i>Variable</i>	<i>Mean</i>	<i>Frequency</i>	<i>Percentage</i>
Sex			
Male		20	29.0
Female		49	71.0
Age of Respondent			
20-29		13	18.8
30-39		29	42.0
40-49		21	30.4
50-59		4	5.8
60 and above		2	2.9
Mean Age-Male	41.56		
Female	34.53		
Years of Education			
9 years	13.32	6	8.7
12 years		18	26.1
15 years		18	26.0
16 years		22	31.9
18 years		5	7.2
Marital Status			
Married		44	63.8
Divorced		4	5.8
Widowed		2	2.9
Separated		9	13.0
Single/Never married		10	14.5
Type of Disability			
Intellectual disability		11	15.9
Asperger's Syndrome		4	5.8
PDD		1	1.4
Autism disorder		17	24.6
CDD		3	4.3
ADHD		3	4.3
Cerebral Palsy		24	34.8
Down syndrome		6	8.7
Care giving Experience			
0-2years		22	31.9
3-5years		30	43.5
6-8years		10	14.5
9-11years		4	5.8
12-15years		3	4.3

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Table 3.1: *Demographic Characteristics of Respondents ctd.*

<i>Variable</i>	<i>Mean</i>	<i>Frequency</i>	<i>Percentage</i>
Religion			
Christianity		67	97.1
Islam		2	2.9
Living with Child			
Yes		69	100
No		0	0
Relationship with Child			
Father		19	27.5
Mother		46	66.7
Grandparents		3	4.3
Aunt		1	1.4
Care of Child-Who			
I/Myself		64	92.8
Other(Mother of child)		5	7.2
Occupation			
Business		15	21.7
Trader		8	11.6
Seamstress		7	10.1
Teacher		9	13.0
Secretary		6	8.7
Housewife		8	11.6
Accountant		4	5.8
Manager		11	15.9
Pensioner		2	2.9
Child's Age			
0-2years		22	31.9
3-5years		30	43.5
6-8years		9	13.0
9-11years		5	7.2
12-15years		3	4.3
Birth Position			
First		45	65.2
Second		15	21.7
Third		8	11.6
Fourth		1	1.4
Child's Gender			
Male		20	56.5
Female		49	43.5
Total		69	100

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As shown in Table 3.1, 29% of the participants were males whilst 71% were female. Also, 18.8% of the participants were aged between 20 and 29 years, 42% between the ages of 30 and 39, 30.4% between the ages of 40 and 49 and 5.8% between the ages of 50 and 59 years. Furthermore, 2.9% of the participants were 60 years and above. Regarding the educational level of participants, only 7.2% of participants had post graduate education whilst 8.7% had junior high school education. 10.1% of the participants had training college education, 15.9% polytechnic education whilst 26.1% had a senior high school education. The majority of participants representing 31.9%, were graduates. Analysis of marital status indicates that, 2.9% of the participants were widowed, 5.8% were divorced whilst 13% were separated from their spouse. Ten participants representing 14.5% were single or never married. Majority of the participants (63%) were married.

It was also observed that, majority (34.8%) of children of the participants suffered from Cerebral Palsy. Statistics also revealed that 24.6% of children of the participants had Autism disorder while 15.9% had intellectual disability. It was observed that 8.7% had Down syndrome, 5.8% had Asperger's Syndrome, 4.3% had Childhood Disintegrative Disorder, 4.3% had Attention Deficit Hyperactive Disorder whilst 1.4% had Pervasive Developmental Disorder. In terms of experience in care-giving, majority of the participants (43.5%) had between 3 years to 5 years experience, 31.9% had from birth of child to 2 years experience, 14.5% had 6 to 8 years of care giving experience, 5.8% had 9 to 11 years care-giving experience whilst 4.3% had between 12 and 15 years of care-giving experience. Analysis of participants' religion showed that majority (97.1%) were Christians with just 2.9% being of the Islamic religion. All participants as at the time of the study were living with the developmentally disabled child. The relationship of the primary caregiver to the child was also assessed. It was observed that 27.5% were fathers of the child, 66.7% mothers and 4.3% grandparents of the child. One participant, representing 1.4%,

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indicated that she was an aunt to the child. Also, majority of the participants (92.8%) reported being the main care takers of the child. It was further observed that 7.2% of the participants, mostly men, indicated that the mother of the child took more care of the child than they did. With regards to the occupation of the participant, most participants were into business representing 21.7%. Of the total number of respondents, 13% were teachers, 11.6% were traders and 11.6%, housewives. 15.9% indicated being in a management position, 5.8% were accountants and 10.1%, seamstresses. Six participants indicated being secretaries (8.7%) and two being pensioners (2.9%). The ages of the children ranged from 0-2years (31.9%), 3-5years (43.5%), 6-8years (13.0%), 9-11years (7.2%) to 12- 15years (4.3%). Majority of the children were males, representing 56.5% whilst thirty, representing 43.5% were females.

Research Design

In exploring the relationships between variables (affiliate stigma, psychological well-being, and Africultural coping), predictive correlational design was used for the study. A cross-sectional survey design was used because participants were drawn from varying backgrounds, different educational levels, experience, age, sex and disability suffered by child at one point in time. The study investigated the predictive effects of gender, marital status, educational background and Africultural coping on psychological wellbeing. The effect of Africultural coping on affiliate stigma as well as its moderating effect on the relationship between affiliate stigma and psychological wellbeing was also investigated.

The cross-sectional survey design was suitable as this study sought to establish relationships between research variables by sampling a cross-section of the caregiver population. Data collection was conducted once with the use of questionnaires. This proved ideal due to time and financial constraints.

Materials/ Instruments

Questionnaires were used to gather data on the variables in the study. Specifically, data was gathered on the following variables; affiliate stigma (main independent variable), Africultural coping (moderating variable), and psychological well-being (dependent variable). Demographic information on marital status, gender and educational background were also collected.

The instruments used in this study included; Affiliate Stigma Scale (ASS), the Ryff scales of Psychological Well-being (RPWB), Africultural Coping Systems Inventory (ACSI) and a self-designed demographic questionnaire.

Questionnaires and surveys are probably the most widely used research tools within the social sciences (Breakwell, Hammond & Fife-Schaw, 1995). Questionnaires are limited by the fact that respondents must be able to read the questions and respond to them. They are however still appropriate for this research because, surveys are available for researchers to collect original data, directly observing, analyzing and describing a large population (Babbie, 2004). In addition, surveys are also good at measuring behaviours, attitudes and orientations (Newell, 1993) such as employee innovative behaviour. Their low cost, minimal resource requirements and potentially large sample-capturing abilities make them an attractive research method for academics and practitioners. Questionnaires do not require as much effort from the questioner as verbal or telephone surveys, and often they have standardized answers that make it simple to compile data.

Demographic Data

This part of the questionnaire applied self-designed questions to gather information about the characteristics of participants such as age, gender, educational level, marital status, type of disability suffered by their child and caregiver experience.

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Affiliate Stigma Scale (ASS; Mak & Cheung, 2008)

The ASS was developed by Mak and Cheung (2008) in order to provide a quantitative instrument with which affiliate stigma can be compared across different condition.

The Affiliate Stigma Scale (ASS) is a twenty-two item (22-item), 4- point likert scale that is used to assess the internalized stigma of affiliates of stigmatized individuals. It comprises three dimensions; namely Affective stigma (e.g. “I feel inferior because of my child with developmental disability”, “I feel emotionally disturbed because I have a child with developmental disability”, 7 items, median alpha = 0.67); Cognitive stigma (e.g. “My reputation is damaged because I have a child with developmental disability”, “people’s attitude towards me turns sour when I am with my child”, 7 items, median alpha = 0.70) and Behavioural stigma (e.g. “I avoid communicating with my child”, “ I dare not tell others that I have a child with developmental disability”, 8 items, median alpha = 0.69). Each item has four options scored from 1 (strongly disagree) to 4 (strongly agree). The minimum and maximum possible scores are 22 and 88 respectively. A higher total score indicates a higher level of affiliate stigma. The scale has a Cronbach’s alpha (α) of .95. Affiliate stigma was shown to be associated with greater subjective care giver burden and lower perceived benefits of care giving. The ASS has been used in many studies to determine affiliate stigma of caregivers (e.g. Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables; Werner & Shulman, 2013)

Ryff Scales of Psychological Wellbeing (PWB; Ryff, 1989)

The Ryff Scales of Psychological Wellbeing (PWB) was initially designed by Ryff (1989) based on a theoretical model of psychological well-being that encompasses six distinct dimensions of wellness. These dimensions included autonomy (the extent to which individuals view themselves as being independent and able to resist social pressures), environmental mastery (the extent to

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which individuals feel in control of and able to act in the environment), personal growth (the extent to which individuals have a sense of continued development and self-improvement), positive relations with others (the extent to which individuals have satisfying, trusting relationships with other people), purpose in life and self acceptance (the extent to which individuals hold beliefs that give life meaning). The scale originally consists of 84 items and has a Cronbach's alpha (α) of .90.

The 18-item short form, developed by Ryff and Keyes (1995) was used in this study. The short form similarly consists of the six dimensions of autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self acceptance. The PWB- short form has three items per dimension and has a Cronbach's alpha of 0.89. The scale has both positively and negatively phrased items. Specifically, items 1, 4, 5, 8, 15, 16, 17, and 18 were reverse coded. Responses to each statement was scored using a 6-point Likert-like scale with one (1) indicating strong disagreement and five (6) indicating strong agreement. The minimum and maximum possible scores are 18 and 108 respectively. A higher total score will indicate a higher psychological wellbeing.

Africultural Coping Systems Inventory (ACSI; Utsey *et al.*, 2000)

The ACSI (Utsey *et al.*, 2000) is a 30-item self-report measure of the unique coping behaviours employed by African Americans during stressful encounters with the environment. The ACSI is grounded in an African-centered conceptual frame-work and consists of the following dimensions or subscales: Cognitive/Emotional Debriefing (11 items; e.g. "Sought out people I thought would make me laugh"), Spiritual-Centered Coping (8 items; e.g. "Read passage from a daily meditation book"), Collective Coping (8 items; e.g. "Got a group of family and friends together to help with the problem"), and Ritual-Centered Coping (3 items; e.g. "Burned incense

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for strength or guidance in dealing with the problem”). It measures culture-specific coping strategies used in stressful situations. The Cognitive/Emotional Debriefing subscale has a Cronbach’s alpha of 0.80, Spiritual-Centered Coping, 0.79, Collective Coping, 0.71 and Ritual Centered coping, 0.75. The ACSI is a four- point likert type instrument with a scale of 0 (did not use), 1 (used a little), 2 (used a lot) and 3 (Used a great deal). The lowest and highest possible scores are 0 and 66 respectively. A higher score reveals the frequency with which a participant used aficultural coping systems to manage stressful experiences. In order to establish the concurrent validity of the ACSI, Pearson product-moment correlation coefficients were computed between its subscales and the subscales of the Ways of Coping Questionnaire- WCQ (Folkman & Lazarus, 1985).

The problem-focused subscale of the WCQ was positively and significantly correlated with the ACSI’s Spiritual-Centered Coping and Collective Coping subscales.

There was also a positive and significant relationship between the WCQ’s Detachment subscale and the ACSI’s Cognitive/Emotional Debriefing subscale. The Seeking Social Support subscale of the WCQ was positively and significantly correlated with all of the ACSI’s subscales except the Ritual-Centered Coping subscale.

The Pilot Study

According to Baker (1994), a pilot study is the pre-testing or “trying out” of a particular research instrument. Teijlingen van, Rennie, Hundley and Graham (2001) also assert that, one of the advantages of conducting a pilot study is that, it might give advance warning about where the main research project could fail, where research protocols may not be followed, or whether proposed methods or instruments are inappropriate or too complicated. A pilot study can reveal deficiencies in the design of a proposed experiment or procedure and these can then be addressed before time and resources are expended on large scale studies. However, Polit, Beck and Hungler (2001) conceptualized pilot studies to be feasibility studies which are small scale versions or trial runs, done in preparation for a major study.

In view of the aforementioned reasons, an initial pilot test was conducted before the main data collection. A pilot study helps to establish the procedures and parameters, clarify instructions, determine the appropriate levels of the independent variable, and also determine the reliability and validity of the variables. A pilot study was also conducted to assess the appropriateness of the various measures on a Ghanaian population so as to address any cross-cultural validity of the measures if the need be since all the scales were used in the western parts of the world with different cultural perspectives. The scales that were piloted included:

Affiliate Stigma Inventory, Ryff Scales of Psychological Well-being and Africultural Coping Inventory. The pilot study was conducted within the Accra Metropolis using primary caregivers of children with developmental disability. Twenty-seven (27) primary caregivers of children with developmental disability were conveniently selected to participate in the pilot study. The ages of the participants were between 27 years to 65years. All the questionnaires were administered to participants.

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The sample included males and females with different educational backgrounds, marital status and years of experience in care-giving. They were also primary caregivers of children with different developmental disabilities. In all, participants did not express difficulty in responding to the items on all the scales. Reliability analysis produced acceptable values for all the scales. The reliability analysis (Cronbach's α) of the data obtained yielded the following results.

A Cronbach's alpha value of 0.76 was observed for Affiliate Stigma as a whole construct, while the sub-dimensions of affective, cognitive and behavioural stigma recorded Cronbach's alpha values of 0.85, 0.79 and 0.56 respectively.

Sub dimensions of Ryff Scale of Psychological Well-Being; Environmental Mastery, Personal growth, Positive relations with others, Purpose in life, Self acceptance and Autonomy yielded Cronbach's alphas of .40, .25, .41, .48, .16 and .24 respectively. Overall Cronbach's alpha value of Ryff Scales of Psychological Well-Being was 0.72. This value indicated that the Ryff Scales of Psychological wellbeing, based on the pilot study, had internal consistency and therefore was a reliable measure of psychological wellbeing for this study.

The Africultural Coping Inventory recorded a Cronbach's alpha of 0.72. This reliability value of 0.72 suggests that the Africultural Coping Inventory was a reliable scale for the study.

All the scales were found to be reliable for the study and could be used for the main study.

Procedure

In order to ensure a satisfactory response rate to the survey, the following steps were adopted in the study.

In the first place, approval for this study was obtained from the Ethics Committee for Humanities (ECH) of the University of Ghana. A verbal pre-survey consent was then sought from the heads and administrators of the selected schools to announce the intention of using their institution for the study and ask for their assistance and cooperation.

Introductory letters were then obtained from the Department of Psychology, University of Ghana and sent to the selected special schools that consented to take part in the study, purposely to seek formal consent to use their institution for the study. On approval, the various special schools were used as a means of getting in touch with the prospective participants. Those who consented were given the self-report questionnaires to respond to. The questionnaires contained clear instructions on how to fill them correctly. Notwithstanding, the researcher elaborated more on the instructions before handing over the questionnaires to the respondents. Though the explanation of the objectives of the research to participants may influence the responses of the participants, it is necessary because, it is ethical of researchers to be honest (Babbie, 1998). All respondents were required to complete questionnaires on affiliate stigma, psychological wellbeing and aficultural coping.

To assure respondents of confidentiality, respondents were told not to write their names anywhere on the questionnaire since that information were not needed. In anticipation that the primary caregivers may be busy at the time the researcher meets them, participants were given about a week to respond to the questionnaires after which the researcher went back for them. The time needed to respond fully to a questionnaire was however about ten to fifteen minutes. The

duration for the data collection was about seven (7) weeks. Data collection started in the first week of May 2015 and ended in the third week of June, 2015. After data had been collected, it was then scored and coded for statistical analysis.

Ethical Considerations

It is possible that, although a research study is feasible on practical grounds (the design is sound, the research question is specific and appropriate methods are available for its investigation), it remains unacceptable due to its ethical implications. It is important that a researcher investigates these implications prior to embarking on a research work. Moreover, social research must take into consideration the ethical conduct of the research and this process must start at the research planning stage through the recruitment and selection of research participants. It also includes ethical considerations during the conduct and reporting of the research (Aguinis & Henle, 2002).

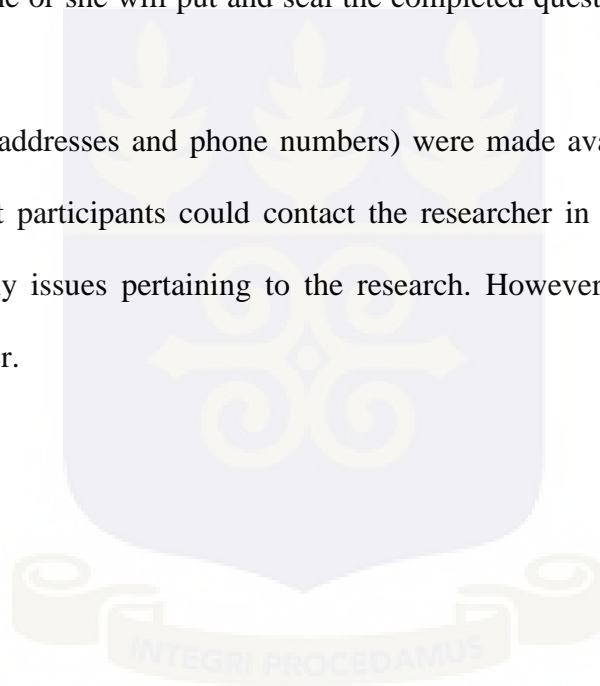
In the American Psychological Association (APA, 2002) Ethical Code, certain ethical considerations are to be considered when psychologists are building their professional and scientific work. It is therefore deemed necessary to go in accordance with these ethical principles governing the use of human participants for research purpose. The Ethical Code as stipulated by APA is intended to provide specific standards to cover most situations encountered by psychologists. The main purpose of the Ethical Code is the welfare and protection of individuals and groups with whom psychologists work and the education of students, members, and the public regarding ethical standards of the discipline.

All the ethical principles stipulated by the APA's Ethical Code were taken into consideration in this research. First of all, in every school used in this research, permission was sought from the school authorities and their assistance sought in administering the questionnaire where necessary. Also, the purpose of the study was explained to participants, both in words and in writing and

their consent was sought. Specific instructions regarding the purpose of the study and voluntary participation in the research were clearly spelt out on the questionnaire. Also, it was explained to participants that there was no foreseen risk, discomfort or adverse effect should they participate or decline to participate in the research.

Also, nobody was induced to participate in the study. To ensure confidentiality and anonymity of responses, participants were instructed not to write their names on the questionnaires or mark the questionnaire in ways that would reveal their identity. In addition, each participant was given an envelope into which he or she will put and seal the completed questionnaire before returning it.

Finally, contacts (email addresses and phone numbers) were made available to participants on the questionnaire so that participants could contact the researcher in case they wanted to ask question(s) or clarify any issues pertaining to the research. However, no such contacts were received by the researcher.



CHAPTER FOUR

Results

Introduction

The purpose of this study was to examine the impact of having a developmentally disabled child on the psychological wellbeing of primary caregivers. Affiliate stigma, marital status, gender and educational background were investigated as predictors of psychological wellbeing. Furthermore, the effect on Africultural coping on psychological wellbeing, and affiliate stigma as well its moderating effect on the relationship between affiliate stigma and psychological wellbeing were also examined. In accordance with the aim and objectives, seven (7) hypotheses were tested. Hypothesis 1 was analyzed with linear regression analysis. Hypotheses 5 and 6 were analyzed using correlational analysis. In analyzing Hypotheses 2, 3 and 7, the one-way multivariate analysis of variance (MANOVA) was used. The moderating effect of africultural coping on the relationship between affiliate stigma and psychological wellbeing, in hypothesis four, was analyzed with a hierarchical regression analysis.

Preliminary Analyses

Preliminary analyses involved four main sections. These included analysis of the normal distribution of the variables, descriptive statistical analysis of demographic variables, reliability analysis and computing the Pearson correlations among the variables of the study. First, the normality of the data obtained for the study was verified. The analysis revealed that all the study variables were normally distributed (Table 4.1). According to Tabachnick and Fidell (2006), a variable is normal when the value for skewness and kurtosis range between ± 1 . All the variables were accordingly used in the analysis.

Table 4.1: Means, Standard Deviation, Skewness, Kurtosis and Internal consistency (Cronbach's alpha) of the various instruments or measures used.

	<i>Means</i>	<i>Std. Deviation</i>	<i>Skewness</i>	<i>Kurtosis</i>	<i>Alpha</i>
Affiliate StigmaScale(ASS)	56.68	12.52	-0.26	-0.90	0.94
ASS.. Affective	19.78	4.75	-0.32	-1.11	0.89
ASS..Cognitive	18.09	4.12	-0.45	-0.95	0.81
ASS.. Behavioral	18.81	4.94	0.19	-0.91	0.89
Ryff Scales of Psychological Wellbeing (RPWB)	64.52	15.80	-0.05	-0.48	0.91
RPWB...Autonomy	11.09	3.18	-0.39	-0.50	0.59
RPBW..Environmental Mastery	9.96	3.36	-0.13	-0.87	0.72
RPBW..Personal Growth	11.46	2.72	-0.06	-0.17	0.51
RPBW.. Positive Relations	10.59	2.95	-0.12	-0.90	0.52
RPBW.. Purpose in life	11.03	2.63	-0.03	-0.13	0.10
RPBW... Self acceptance	10.39	3.72	-0.15	-0.73	0.73
Africultural..Coping	41.97	10.92	-0.24	-0.47	0.83
Systems Inventory(ACSI)					
ACSI..Cognitive/Emotional	19.86	10.15	4.49	29.74	0.75
Debriefing	13.36	3.82	-0.29	-0.39	0.69
ACSI..SpiritualCenterd	12.19	4.52	-0.10	-0.14	0.66
ACSI..Collective					
ACSI...Ritual-Centered	1.07	1.59	2.08	5.01	0.67

ASS: Affiliate Stigma Scale, RPWB: Ryff Scales of Psychological Wellbeing, ACSI: Affiliate Coping Systems Inventory.

It is observed that the variables in this study were all normally distributed. Affiliate Stigma showed a skewness value of -0.26 and a kurtosis of -0.90. Psychological wellbeing showed a skewness value of -0.05 and kurtosis of -0.48. Africultural coping had a skewness value of -0.24 and kurtosis of -0.47. The instruments used in the study; namely Affiliate Stigma Scales, Ryff Scales of Psychological Wellbeing and Africultural Coping Inventory were all reliable with alpha values of 0.94, 0.91 and 0.83 respectively.

Correlation analyses were done to detect relationships amongst study variables. The results are shown in Table 4.2.



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Table 4.2: *Pearson-Product Moment correlations between study variables*

	1	2	3	4	5	6	7	8	9	10	11	12	13
1 AS1	-												
2 AS2	.757**	-											
3 AS3	.676**	.779**	-										
4 PW1	-.321**	-.463**	-.517**	-									
5 PW2	-.430**	-.555**	-.491**	.732**	-								
6 PW3	-.545**	-.525**	-.582**	.646**	.713**	-							
7 PW4	-.484**	-.587**	-.630**	.637**	.653**	.685**	-						
8 PW5	-.349**	-.423**	-.507**	.592**	.414**	.663**	.627**	-					
9 PW6	-.499**	-.597**	-.590**	.766**	.787**	.677**	.749**	.563**	-				
10 AC1	-.316**	-.287*	-.278*	.004	.209	.110	.143	-.099	.126	-			
11 AC2	-.162	-.197	-.295*	-.064	.017	.044	.086	-.124	.064	.316**	-		
12 AC3	-.355	-.298*	-.354**	-.009	.106	.088	.248*	-.024	.219	.318**	.595**	-	
13 AC4	-.200	-.118	-.275*	-.042	-.035	-.008	.138	.084	.084	.189	.044	.219	-

Note: AS1 = Affective, AS2 = Cognitive, AS3 = Behavioral, PW1 = Autonomy, PW2 = Environmental Mastery, PW3 = Personal Growth, PW4 = Positive Relations with Others, PW5 = Purpose in life, PW6 = Self Acceptance, AC1 = Cognitive and Emotional Debriefing, AC2 = Spiritual Centered coping, AC3 = Collective coping, AC4 = Ritual Centered coping; * $p < .05$, ** $p < .01$.

From Table 4.2, it is observed that all sub-dimensions of Affiliate stigma correlated significantly with all sub-scales of Psychological Wellbeing. This therefore indicates that higher values of affiliate stigma correlated with lower values of psychological wellbeing. Based on this, it was concluded that primary caregivers with higher affiliate stigma were observed to have lower psychological wellbeing.

Again it was observed that Cognitive/Emotional Debriefing had significant negative correlations with affective affiliate stigma ($r = -.316, p < .01$), cognitive affiliate stigma ($r = -.287, p < .05$) and behavioural affiliate stigma ($r = -.278, p < .05$). It is therefore implied that a primary caregiver's use of Cognitive/Emotional Debriefing as a coping mechanism would reduce Affiliate Stigma experienced.

It was further observed that Spiritual Centered coping had a significant negative correlation with Behavioural affiliate stigma ($r = -.295, p < .05$), indicating that the use of Spiritual Centered coping would reduce the behavioral affiliate stigma of primary caregivers.

From the correlational analysis, it can be observed that Collective coping correlated negatively with both Cognitive affiliate stigma ($r = -.298, p < .05$) and Behavioral affiliate stigma ($r = -.355, p < .01$).

It could therefore be explained that the use of Collective coping reduces both cognitive affiliate stigma and behavioural affiliate stigma of participants. Correlations between Africultural coping and Psychological wellbeing revealed a positive correlation between Collective coping and Positive relations with others ($r = .248, p < .05$). This correlation implies that the use of collective coping interventions will improve primary caregivers' relations with others. Finally, Ritual centered coping was found to have a negative correlation with Behavioural affiliate stigma

($r = -.275, p < .05$). This implied that the use of Ritual centered coping reduced the Behavioural affiliate stigma of primary caregivers.

Hypothesis Testing

Seven hypotheses were formulated in this study. Hypothesis 1 was analyzed using linear regression analysis. The one-way multivariate analysis of variance (MANOVA) was used in analyzing Hypotheses 2, 3 and 7. Correlational analysis was used in analyzing hypotheses 5 and 6. Moderating effect of aficultural coping on the relationship between affiliate stigma and psychological wellbeing, in hypothesis 4, was analyzed using a hierarchical regression analysis.

Regression analyses were conducted to test the general model that certain independent variables accounted for variance in the dependent variable (psychological well-being). Also the hierarchical regression was conducted to test the moderation effects of some variables between the independent variables and dependent variable relationship. The dependent variable (psychological wellbeing) constituted a composite score of six variables, namely: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self acceptance. The independent variables in this study were affiliate stigma, socio-economic status and gender. Below are the hypotheses examined in the study.

Hypothesis 1: Affiliate stigma of primary caregivers will significantly predict psychological wellbeing.

Hypothesis 2: Married primary caregivers will have a significantly better psychological wellbeing than unmarried primary caregivers.

Hypothesis 3: Primary caregivers with higher educational background will have a significantly better psychological wellbeing than those with lower educational background.

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Hypothesis 4: Africultural coping will moderate the relationship between affiliate stigma and psychological wellbeing.

Hypothesis 5: Africultural coping will have a significantly negative relationship with affiliate stigma.

Hypothesis 6: Africultural coping will have a significant positive relationship with psychological wellbeing.

Hypothesis 7: Female primary caregivers will have a significantly poorer psychological wellbeing than males.

Hypothesis 1

One of the major aims of this study was to examine the extent to which affiliate stigma explained variance in psychological well-being. Consequently, it was predicted that “Affiliate stigma of primary caregivers will significantly predict psychological wellbeing.” To test this hypothesis, a linear regression analysis was conducted. Affiliate stigma was entered as a predictor of psychological well-being, which is the dependent variable. The results showed that affiliate stigma significantly predicts psychological well-being ($\beta = -.715, p < .01$). Furthermore, analyses of the subscales of affiliate stigma showed that behavioural affiliate stigma significantly predicted psychological wellbeing. The results from the regression analysis showed that affiliate stigma accounted for a significant variance in the psychological well-being, thus the hypothesis was supported. The results are presented in Table 4.3 below.

Table 4.3: Summary of Simple Regression for hypothesis one.

<i>Model</i>		<i>B</i>	<i>Std. Error</i>	β	<i>Sig.</i>
1	(Constant)	110.541	6.784		.000
	Affective	-.069	.476	-.021	.885
	Cognitive	-1.084	.646	-.283	.098
	Behavioral	-1.331	.478	-.416	.007**
	Affiliate Stigma	-.903	.126	-.715	.000**

Note: $R^2 = .448$, ** $p < .01$

Hypothesis 2

A one-way multivariate analysis of variance was conducted to test the hypothesis that married primary caregivers will have a significantly better psychological wellbeing than unmarried primary caregivers. Six dependent variables were used; namely autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance. The independent variable was marital status. The independent variable had two levels; married and unmarried. There were no statistically significant differences between married and unmarried participants on the combined dependent variables: $F(4,64) = 2.101$, $p = .066$; Wilks' Lambda=.831.

When the results for the dependent variables were considered separately, there were two differences that had statistical significance, using a Bonferroni adjusted alpha level of .025.

These two included Environmental Mastery: $F(4, 64) = 7.398$, $p = .008$, $\eta^2 = .099$ and Personal Growth: $F(4, 64) = 7.027$, $p = .010$, $\eta^2 = .095$. The results are shown in Table 4.4.

Table 4.4: *Summary of Multivariate test results of the difference between psychological wellbeing and marital status of primary caregivers*

<i>Variable</i>	<u><i>Married</i></u> <i>N=44</i>	<u><i>Unmarried</i></u> <i>N=25</i>	<i>F</i>	<i>df</i>	<i>p</i>	η^2
Auto.	11.32(3.07)	10.68(3.39)	.637	4, 64	.428	.009
Envtl.	10.75(2.83)	8.56(3.81)	7.398		.008**	.099
Psnl.grth	12.09(2.45)	10.36(2.87)	7.027		.010*	.095
PstvRela.	11.05(2.87)	9.80(2.99)	2.917		.092	.042
Pps/Life	11.27(2.44)	10.60(2.94)	1.040		.311	.015
SlfAcpt.	10.98(3.40)	9.36(4.09)	3.109		.082	.044

Note: $p= 0.025$, Bonferroni adjustment.

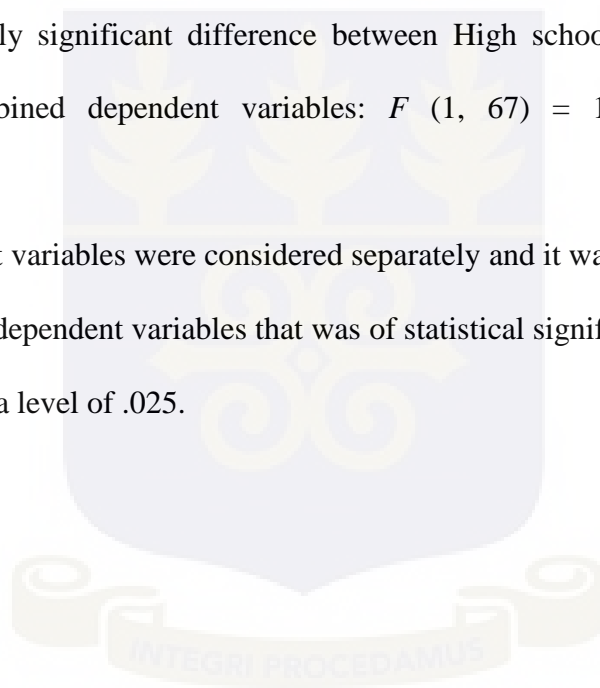
Auto: Autonomy, Envtl: Environmental Mastery, Psnl.grth: Personal Growth, PStvRela.: Positive Relations with others, Pps/Life: Purpose in life, SlfAcpt: Self-Acceptance.

Married participants were therefore found to have better environmental mastery and personal growth than unmarried participants.

Hypothesis 3

In order to test the hypothesis that primary caregivers with higher educational background will have a significantly better psychological wellbeing than those with lower educational background, a one-way multivariate analysis of variance was used. Six dependent variables were imputed, namely: autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance. The independent variable in the analysis was educational background which was in two levels; High School and Tertiary levels of education. There was no statistically significant difference between High school and Tertiary levels of education on the combined dependent variables: $F(1, 67) = 1.644, p = .150$; Wilks' Lambda=.863.

Results for the dependent variables were considered separately and it was observed that there was no difference in the dependent variables that was of statistical significance, using a Bonferroni adjusted alpha level of .025.



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Table 4.5: Summary table for MANOVA test results for psychological wellbeing and educational background.

Variable	<u>High School</u> n=22	<u>Tertiary</u> n=47	F	df	p	η^2
PW1	10.77(2.52)	11.23(3.47)	.31	1,67	.579	.005
PW2	9.23(3.00)	10.30(3.50)	1.53		.220	.022
PW3	10.45(2.11)	11.94(2.83)	4.69		.034	.065
PW4	10.22(2.81)	10.77(3.03)	.495		.484	.007
PW5	10.95(1.89)	11.06(2.94)	.025		.874	.000
PW6	9.45(3.17)	10.83(3.90)	2.082		.154	.030

Note: p= .025, Bonferroni adjustment.

PW1 = Autonomy, PW2 = Environmental Mastery, PW3 = Personal Growth, PW4 = Positive Relations with Others, PW5 = Purpose in life, PW6 = Self Acceptance

Hypothesis 4

The fourth hypothesis states Africultural coping as a moderating factor to the relationship between affiliate stigma and psychological wellbeing. The hypothesis was investigated using a hierarchical multiple regression. The dependent variable (DV) in this analysis was psychological well-being while the independent variable (IV) was affiliate stigma. The moderating effect of africultural coping on the relationship between affiliate stigma and psychological wellbeing was determined.

In the first step of the hierarchical regression, the sub dimensions of affiliate stigma were entered. The results showed that there was a significant R^2 , $F(3, 65) = 18.223$, $R^2 = .457$, $p < .05$. The subscales of the moderator (Africultural coping) were then entered into the second step. The results showed there was a significant R^2 , $F(7, 61) = 8.96$, $R^2 = .507$, $p < .05$. The interaction effects of Affiliate stigma, psychological wellbeing and Africultural coping were also checked in the third step. Results revealed that there was a significant change, $F(10, 58) = 417.701$, $R^2 = .986$, $p < .05$.

As indicated in Table 4.6 below, none of the sub-dimensions of Africultural coping however significantly moderated the relationship between affiliate stigma and psychological wellbeing (Cognitive/Emotional Debriefing: $\beta = .12$, $p > .05$, Spiritual Centered Coping: $\beta = .02$, $p > .05$, Collective Coping: $\beta = .01$, $p > .05$, Ritual Centered Coping: $\beta = -.13$, $p > .05$). Therefore the fourth hypothesis was not supported. Furthermore, with reference to Table 4.6, significant interaction effects were observed between Affiliate stigma and Africultural coping ($\beta = -.36$, $p < .05$), and also between Psychological wellbeing and Africultural coping ($\beta = 1.22$, $p < .01$).

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Table 4.6: Summary of Hierarchical multiple regression for the moderating factor of Africultural coping, between Affiliate stigma and Psychological well-being

Model		B	Std. Error	β	Sig.
1	AStig.	-.07	.48	-.02	.885
	CStig.	-1.08	.65	-.28	.098
	BStig.	-1.33	.48	-.42	.007**
2	AStig.	-.14	.11	-.53	.774
	CStig.	-.89	.14	-.04	.175
	BStig.	-1.73	1.12	.06	.001**
	CED	-.07	2.52	.12	.049
	SC	-.78	2.56	.02	.116
	CC	0.03	.42	.01	.946
	RC	-1.26	.97	-.13	.200
3	AStig.	.65	.32	.20	.046*
	CStig.	.33	.42	.09	.435
	BStig.	-.67	.30	-.21	.027*
	CED	-.24	.09	-.16	.010*
	SC	-1.09	.30	-.26	.001**
	CC	-1.04	.33	-.30	.003**
	RC	-1.39	.52	-.14	.009**
	ASxAC	-.01	.004	-.36	.030*
	PWxAC	.02	.001	1.22	.000**

Note: $\Delta R^2 = .457$; ($p < .05$) for step 1; $\Delta R^2 = .502$, ($p > .05$) for step 2; $\Delta R^2 = .879$, ($p < .05$) for step 3. ** $p < .01$, * $p < .05$.

AStig. = Affective Affiliate Stigma, CStig. = Cognitive Affiliate Sigma, BStig. = Behavioral Affiliate Stigma. CED = Cognitive/Emotional debriefing, SC= Spiritual Centered Coping, CC= Collective Coping, RC= Ritual Centered Coping, ASxAC = Interaction effect between Affiliate stigma and Africultural Coping, PWxAC = Interaction effect between psychological Wellbeing and Africultural Coping.

Hypothesis 5

Hypothesis five states that Africultural coping will have a significantly negative relationship with Affective affiliate stigma. This hypothesis was analyzed using Pearson- product moment correlation analysis. As shown in Table 4.2 above, results revealed that Cognitive/Emotional Debriefing had a significant negative correlation with Affective affiliate stigma ($r = -.316, p < .01$), Cognitive affiliate stigma ($r = -.287, p < .05$) and Behavioral affiliate stigma ($r = -.278, p < .05$). Based on this it is clear that a primary caregiver's use of Cognitive/Emotional Debriefing as a coping mechanism would reduce Affective, Cognitive and Behavioral affiliate stigma experienced.

It was further observed that Spiritual Centered coping had a significant negative correlation with Behavioral affiliate stigma ($r = -.295, p < .05$), indicating that the use of Spiritual Centered coping would reduce the behavioural affiliate stigma of primary caregivers.

From the results of the analysis in Table 4.2 above, it can be observed that Collective coping correlated negatively with both Cognitive Affiliate stigma ($r = -.298, p < .05$) and Behavioural Affiliate stigma ($r = -.355, p < .01$).

It could therefore be explained that the use of Collective coping reduces both Cognitive Affiliate stigma and Behavioral Affiliate stigma of participants. Finally, Ritual Centered coping was found to have a negative correlation with Behavioral Affiliate stigma ($r = -.275, p < .05$). This implied that the use of Ritual Centered coping reduced the Behavioural affiliate stigma of primary caregivers.

Hypothesis 6

Hypothesis six which states that Africultural coping will have a significant positive relationship with psychological wellbeing was also analyzed using Pearson- product moment correlation. The correlations between Africultural coping and Psychological wellbeing revealed a positive correlation between Collective coping and Positive relations with others ($r = .248, p < .05$). This correlation implies that the use of collective coping interventions will improve primary caregivers' relations with others. Results are shown in Table 4.3 above.

Hypothesis 7

The seventh hypothesis stated that there will be a significant gender difference in psychological wellbeing of primary caregivers. This was analyzed using a one-way multivariate analysis of variance (MANOVA). Six dependent variables were used; namely autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance. The independent variable in the analysis was gender which was in two levels; namely male and female. There was no statistically significant difference between males and females on the combined dependent variables: $F(1, 67) = 0.827, p = .572$; Wilks' Lambda=.886.

Results for the dependent variables were considered separately and it was observed that there was no significant difference in the dependent variables, using a Bonferroni adjusted alpha level of .025.

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Table 4.7: Summary of the MANOVA test results of the difference between psychological wellbeing and gender.

Variable	<u>Male</u>	<u>Female</u>	F	df	p	η^2
	n=20	n= 49				
PW1	11.95(3.22)	10.73(3.13)	2.10	1, 67	.152	.03
PW2	10.80(3.60)	9.61 (3.23)	1.79		.185	.03
PW3	11.95(2.63)	11.27(2.63)	.90		.347	.01
PW4	11.20(2.63)	10.35(2.76)	1.19		.279	.02
PW5	10.95(3.17)	11.06(2.42)	.03		.875	.00
PW6	10.95(3.78)	10.16(3.71)	.63		.429	.01
AS1	18.55(3.78)	20.29(4.73)	1.92		.170	.03
AS2	17.10(4.20)	18.49(4.06)	1.63		.206	.02
AS3	18.25(4.12)	19.04(5.26)	.36		.550	.01
AC1	22.20(16.54)	18.90(5.87)	1.51		.223	.02
AC2	13.45(3.90)	13.33(3.83)	.02		.904	.00
AC3	12.25(4.29)	12.16(4.66)	.01		.943	.00
AC4	0.50(1.31)	0.89(1.76)	3.78		.056	.05

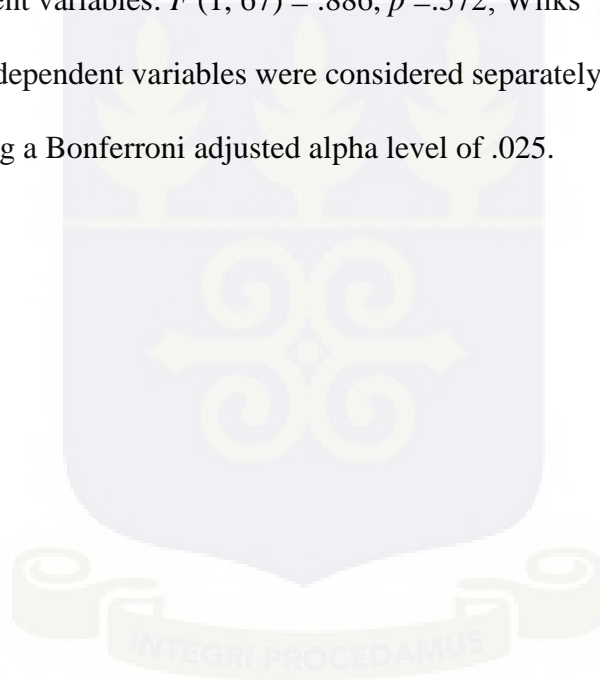
Note: $p= 0.025$, Bonferroni adjustment.

Note: AS1 = Affective, AS2 = Cognitive, AS3 = Behavioral, PW1 = Autonomy, PW2 = Environmental Mastery, PW3 = Personal Growth, PW4 = Positive Relations with Others, PW5 = Purpose in life, PW6 = Self Acceptance, AC1 = Cognitive and Emotional Debriefing, AC2 = Spiritual Centered coping, AC3 = Collective coping, AC4 = Ritual Centered coping.

Gender differences in affiliate stigma and afri-cultural coping.

The gender differences in affiliate stigma and afri-cultural coping were also examined. This was done using a multivariate analysis of variance (MANOVA). Cognitive/Emotional Debriefing, Spiritual coping, Collective Coping, Ritual Centered Coping, Affective Affiliate stigma, Cognitive Affiliate stigma and Behavioural Affiliate stigma were entered as dependent variables and gender as a fixed factor with two levels; male and female. The results as shown in Table 4.7 above, indicate that there was no statistically significant difference between males and females on the combined dependent variables: $F(1, 67) = .886, p = .572$; Wilks' Lambda=.827.

When the results for the dependent variables were considered separately, there was no significant difference observed, using a Bonferroni adjusted alpha level of .025.



Summary of the findings

Seven hypotheses were formulated to investigate the effect of stigmatization on the psychological wellbeing of primary caregivers of children with developmental disabilities. The predictive effect of affiliate stigma on psychological wellbeing was investigated. Furthermore effects of demographic variables such as marital status, educational background and gender on psychological wellbeing were also analyzed. The moderating effect of Africultural coping on the relationship between affiliate stigma and psychological wellbeing as well as the predictive effects of Africultural coping on affiliate stigma and psychological wellbeing were also analyzed using regression analyses.

The first hypothesis, stating that affiliate stigma of primary caregivers will predict psychological wellbeing was supported. A negative relationship was observed between affiliate stigma and psychological wellbeing. This indicated that primary caregivers with high affiliate stigma showed poorer psychological wellbeing. Furthermore married primary caregivers were observed to have a higher environmental mastery and personal growth than unmarried primary caregivers. It was also observed that Primary caregivers who used more Cognitive/Emotional Debriefing in coping showed less Affective affiliate stigma, Cognitive affiliate stigma and Behavioural affiliate stigma. Again, participants who used more Spiritual Centered coping showed lower Behavioural affiliate Stigma. It was further observed that participants who used more Collective coping, had lower Cognitive and Behavioral affiliate stigma. It also led to higher positive relations with others. A negative correlation was also observed between Ritual Centered coping and Behavioral Affiliate Stigma.

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No significant difference was observed in psychological wellbeing of participants based on gender and educational background. Finally, Africultural coping, based on the study, did not moderate the relationship between affiliate stigma and psychological wellbeing. Interaction effects were however observed between affiliate stigma, psychological wellbeing and africultural coping



CHAPTER FIVE

Discussion

Introduction

The aim of this study was to find out the impact of affiliate stigma on the psychological wellbeing of primary caregivers of developmentally disabled children and also to assess the moderating effect of Africultural coping on the relationship between affiliate stigma and psychological wellbeing. Affiliate stigma was investigated as a predictive factor of psychological wellbeing. Educational background, marital status and gender differences were also explored. The moderating effect of Africultural coping on the relationship between affiliate stigma and psychological wellbeing was also investigated. It was also of interest to investigate the effect of Africultural coping on affiliate stigma and psychological wellbeing. The results observed supported the first hypothesis that affiliate stigma is a predictive variable of psychological wellbeing. A negative relationship was observed between affiliate stigma and psychological wellbeing. This indicates that primary caregivers with high affiliate stigma showed poorer psychological wellbeing. Furthermore married primary caregivers were observed to have a higher environmental mastery and personal growth than unmarried primary caregivers. It was also observed that primary caregivers who used more Cognitive/Emotional Debriefing in coping showed less Affective affiliate stigma, Cognitive affiliate stigma and Behavioural affiliate stigma. Participants who used more Spiritual Centered coping were observed to show lower Behavioural Affiliate Stigma. Further observations revealed that participants, who used more of Collective coping, had lower Cognitive and Behavioural affiliate stigma. A negative correlation was also observed between Ritual Centered coping and Behavioural Affiliate Stigma. Another observation made was that Collective coping led to higher Positive Relations with others. It was

furthermore observed that married primary caregivers had better environmental mastery and personal growth than unmarried primary caregivers. No significant difference was observed in psychological wellbeing of participants of different gender and educational backgrounds. Finally, Africultural coping, based on the study, did not moderate the relationship between affiliate stigma and psychological wellbeing. Interaction effects were however observed between affiliate stigma, psychological wellbeing and Africultural coping

Relationship between affiliate stigma of primary caregivers and psychological well-being

One purpose of the study was to examine whether the stigma perceived by primary caregivers as a result of their association to children with developmental disabilities predicts their psychological well-being. In accordance with the hypothesis, affiliate stigma was found to predict some variance in the psychological well-being of primary caregivers of children with developmental disability. This finding suggests that the extent of affiliate stigma felt by primary caregivers can influence their psychological wellbeing. Affiliate stigma as measured in this study consisted of affective, cognitive and behavioural components. It was observed that primary caregivers who showed high affiliate stigma, also had low environmental mastery (eg: feelings of lack of control over one's situation), low autonomy (eg: being easily influenced by others), low personal growth (eg: unwillingness to make major improvements to one's life), low positive relations with others (eg: inability to form close relationships), low purpose in life (eg: living without any goal or aim) and low self-acceptance (eg: being disappointed with one's life) This finding is supported by Struening *et al.*, (2001). In their study, the perception of stigma by association was found to be related to lower self-esteem and psychological distress in those connected with disabled individuals

It was observed that for every increase in affiliate stigma, there was an equal decrease in psychological wellbeing. Therefore it can be explained, based on this study, that the more affiliate stigma perceived by primary caregivers, the lower their psychological wellbeing (Mak & Kwok, 2010).

From the study, it was observed that most of the primary caregivers were parents of the developmentally disabled children. Having such a bond with the child, the impact of stigma on their psychological wellbeing is heightened. Family members who feel or experience courtesy stigma, may experience it as fear, loss, lowered family esteem, shame, secrecy, distrust, anger, hopelessness and inability to cope (Stuart, 2005). Feeling that the child is “unwanted” or a “misfit” in society due to stigma affects the psychological wellbeing of the caregiver. Also, the feeling of guilt associated with cultural beliefs in Ghana, lowers the psychological wellbeing of primary caregivers. Some cultural beliefs regarding the cause of developmental disability blame the “misfortune” on a curse which was as a result of something evil done in one’s past or by one’s family.

The finding that affiliate stigma predicts psychological wellbeing of primary caregivers, supports Werner and Shulman’s (2013) study which investigated the subjective wellbeing among family caregivers of individuals with developmental disabilities. Their study showed that subjective wellbeing of family caregivers was below the average normative level and that affiliate stigma was among the strongest predictors of subjective wellbeing of caregivers.

Marital Status as a predictor of psychological wellbeing

In this study, the second hypothesis which stated that married primary caregivers will have a significantly better psychological wellbeing than unmarried ones was supported. It was found that married primary caregivers had a higher environmental mastery and personal growth than unmarried caregivers. This finding implies that married primary caregivers feel more in control over their lives and seek improvement and development in their lives more than unmarried caregivers. This finding supports previous studies, which indicate a significant relationship between marital status and psychological wellbeing. According to Markey (2015), marital status of a caregiver had a significant predictive value for both anxiety and expressive symptoms. Furthermore, caregivers who were divorced separated or widowed experienced chronic stressors which may lead to negative effects on psychological wellbeing (Benson, 2012).

Harley, Almond, Han, Burton and Schonwetter's (2003) study reveal that as a result of the overload of pressures, divorced, separated or widowed primary caregivers may be more vulnerable to developing a psychological disorder.

They also indicated that the additional support married individuals obtain from their spouses makes them more likely to experience better psychological wellbeing.

Educational background and psychological wellbeing

The third hypothesis stated that primary caregivers with higher educational background will have a significantly better psychological wellbeing than those with lower educational background. This hypothesis was not supported. There was no significant relationship found between educational background and psychological wellbeing. A primary caregiver's number of years of education had no significant impact on psychological wellbeing. This result could be due to

better understanding of developmental disabilities gained through educative meetings organized by the special needs schools. These meetings educate primary caregivers on developmental disabilities and therefore help reduce psychological distress experienced by caregivers. This finding is supported by Markey's (2015) study which showed that educational level had no significant effect on the psychological wellbeing of caregivers. In contrast, however, Carter *et al.*, (2008) in their study reported that caregivers who had at least a high school education reported better quality of life and lower psychological distress than those with lower educational levels.

Africultural coping and psychological wellbeing

In this study, Africultural coping was examined as a moderating variable in the predictive relationship between affiliate stigma and psychological wellbeing. The impact of using Africultural coping was also explored in this study. As a moderating variable, Africultural coping was proposed to serve as a buffer against the effect of affiliate stigma on psychological wellbeing. This coping strategy involves cognitive/emotional debriefing, spiritual-centered coping, collective coping and ritual-centered coping. This moderation effect was not observed. According to this study, using Africultural coping does not reduce or increase the effect of affiliate stigma on psychological wellbeing. However in analyzing the relationship between Africultural coping and affiliate stigma, and Africultural coping and psychological wellbeing, sub-dimensions of Africultural coping were found to correlate with affiliate stigma and positive relations with others. A negative correlation was observed between affiliate stigma and Africultural coping. This showed that, based on the data collected, the use of Africultural coping led to a reduction in participants' feeling of stigmatization, their stigmatized perceptions of themselves and stigma-influenced behaviour (MacDonald, Hastings, & Fitzsimons, 2010;

Nachshen & Minnes, 2005; Oelofsen & Richardson, 2006). Also it was found that Collective coping led to an increase in positive relations with others. This indicates that the more primary caregivers share their challenges and difficulties with family and friends, and seek support from them, the better their relationships with others and subsequently psychological wellbeing. These findings are consistent with previous literature which indicate the impact of coping on psychological wellbeing of primary caregivers (Baker et al., 2005; Glidden, Billings, & Jobe, 2006; Glidden & Natcher, 2009; Hassall & Rose, 2005). A study by Taanila, Syrjälä, Kokkonen, and Järvelin (2002) revealed that having a larger repertoire of and greater use of coping strategies are related to increased psychological well-being of primary caregivers.

Furthermore, the use of active or problem-focused coping strategies which emphasize efforts to seek social support, actively solve the problem, and positive reappraisal help in improving the psychological wellbeing of primary caregivers (Glidden *et al.*, 2006; Kim, Greenberg, Seltzer, & Krauss, 2003; Paczkowski & Baker, 2008; Van der Veek *et al.*, 2009).

Gender and psychological well-being

In this study, gender did not predict psychological wellbeing. No significant differences existed between male and female primary caregivers of children with developmental disabilities. This finding is contrary to the stated hypothesis that there will be a significant difference between male and female primary caregivers. The findings from Perlick *et. al.*, (2007)'s study confirms the findings that there is no significant difference between the psychological wellbeing of male and female primary caregivers. Also Essex and Seltzer (1999), in their study found no gender differences in psychological and physical wellbeing of primary caregivers of children with developmental disability. One possible reason for this observation could be because all the primary givers, whether male or female had experienced or participated in some kind of

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intervention and empowerment program use through their involvement in the special needs schools where their wards are being trained and educated. It is most likely this resulted in the differences in psychological wellbeing of male and female caregivers. The observation could also be explained by the change in the dynamics of gender roles within the Ghanaian society. Gender roles are more liberal with men carrying out feminine roles where necessary and vice versa. Due to this, the psychological distress brought on by caring for a developmentally disabled child is a shared experience for both male and female primary caregivers.

Observed conceptual frame-work

Findings from this study resulted in the conceptual frame-work.

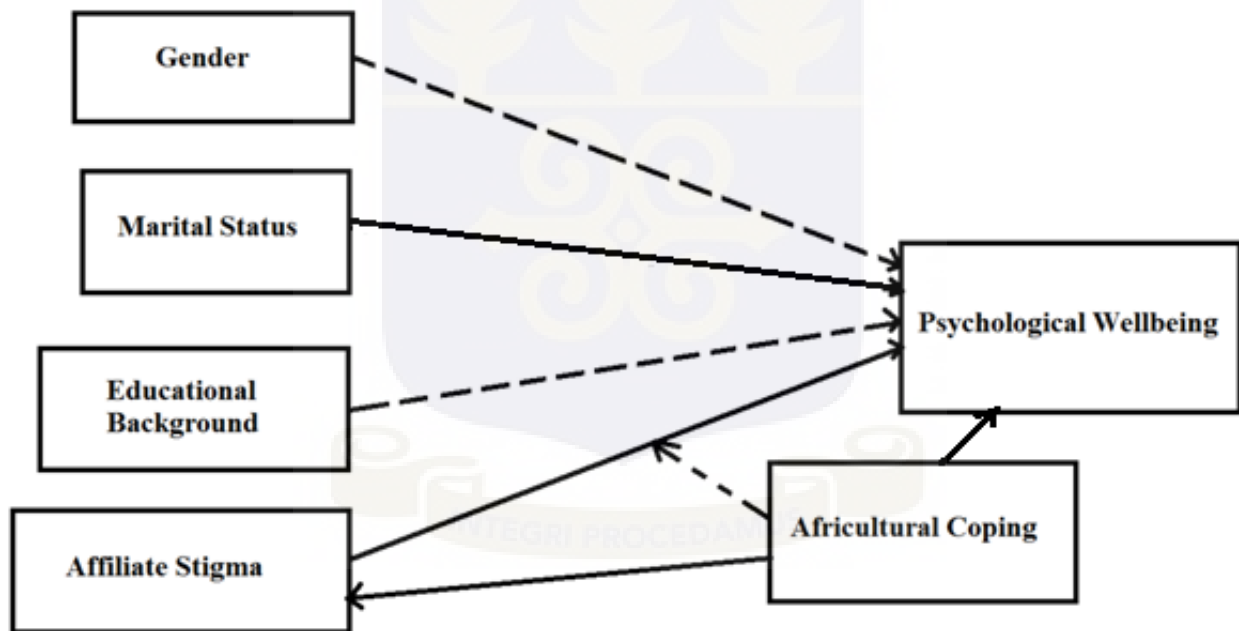


Fig. 5.1: A schematic representation of the observed relationship between stigmatization, psychological wellbeing and Africultural coping.

NB

- > : Non-predicting effects
- > : Predicting effect

In Figure 5.1, affiliate stigma is shown to predict psychological wellbeing. No significant differences were found in psychological wellbeing for gender, educational background. Also, Africultural coping did not moderate the relationship between affiliate stigma and psychological wellbeing. It was observed that there was a significant relationship between Africultural coping and affiliate stigma. Furthermore significant relationships were observed between Africultural coping and Affiliate stigma, Africultural coping and Psychological wellbeing, and Marital status and Psychological Wellbeing.

Implications of findings

The findings of this study have important implications for practice. The knowledge gained from this study and other previous research emphasized the importance of stigma as a significant source of psychological well-being (Dunn, 2003; Seltzer *et al.*, 1997).

These findings therefore indicate the importance of supporting caregivers in order to decrease stigma, improve social support and improve psychological wellbeing.

In order to enhance the psychological wellbeing of Primary caregivers and to enhance their performance in the care giving role, a stigma reduction approach must be used in planning interventions and policies. The use of Cognitive and Emotional Debriefing coping approach would be helpful in reducing affiliate stigma. Also, Spiritual centered coping is of importance in dealing with Behavioural aspects of Affiliate stigma such as primary caregivers' avoidance of contact with their wards, more especially due to the fact that in Ghana, spirituality plays an important role in everyday life (Avoke, 2001). Collective coping, was found to be a very important form of coping in dealing with Cognitive Affiliate stigma and Behavioural Affiliate stigma. Collective Coping was also found to be important in helping to increase primary caregivers' positive relative relations with others which consequently improve the psychological

wellbeing of primary caregivers. Furthermore, based on the observation that married primary caregivers had a higher environmental mastery and personal growth than the unmarried, it is necessary to focus attention on the marital status and challenges within a primary caregivers relational life in helping to improve their psychological wellbeing. Finally, because there was no significant difference between the psychological wellbeing of male and female primary caregivers, intervention program use for primary caregivers should target both male and female caregivers. In other words, though factors of poor psychological wellbeing may differ for both male and female primary caregivers, interventions must be designed to help both males and females to improve their psychological wellbeing.

Limitations of the current study

This study has its limitations which may have affected the general outcome and observations made.

One major limitation was primary caregivers' unwillingness to divulge information about their developmentally disabled child and their feelings concerning the situation due to the stigma attached to their condition. Also, though most participants were as honest as possible, the fear of seeming uncaring and hopeless restrained some participants from fully expressing their feelings concerning the conditions of their children.

Secondly, the small number of primary caregivers used in the study would make generalization of results to a larger population difficult. There were a total of sixty-nine (69) primary caregivers involved in this study. This included primary caregivers of children with the eight types of developmental disability identified within this study. The statistical power of the analyses was constrained by the small sample size, which also limited the number of predictors tested. For example, a larger sample size would have enabled exploration of the effects of different types of developmental disability on the psychological well being of primary caregivers of children with

developmental disabilities.

Again, due to the nature of the study, it was difficult to employ probability sampling strategies because there was no data on the number of families with persons with intellectual disabilities in Ghana or in the greater Accra Region, where the study took place.

The questionnaires used did not give room for further responses therefore it is likely that certain important elements of the study may have been overlooked. Future studies could incorporate open-ended questions within the questionnaires in order to elicit more information about the challenges of having a child with a particular type of developmental disability and to obtain a more detailed understanding of the affiliate stigma primary caregivers feel.

Furthermore, the homogeneity of the sample could affect the generalizability of findings. All participants had been contacted through special needs schools and therefore had received some forms of intervention services, which may also make it difficult to generalize to families who have not received similar services.

Finally, limitations exist in the interpretation of the direction of effects. Although the quality of the affiliate stigma was found to predict parental well-being, it is possible that the effects are in the reverse direction or that transactional, multidirectional processes are operating.

Suggestions and Recommendations for future studies

This research has identified the effects of stigma on the psychological well-being of siblings of persons with intellectual disability, with sibling relationship, type of intellectual disability and attitudes as serving as moderating effects. However, this study is not without limitations. The first limitation was the relatively small sample size used in the study. This affected the generalizability of the results. Future research should consider using a larger sample size.

Secondly, future studies should consider a mixed method approach where qualitative research

would give room for exploration of specific details concerning stigma perception and its impact in specific areas of their lives. A qualitative approach could also provide further explanation for observations made.

It is also suggested that the sample should be selected from other settings aside special needs schools where caregivers may go through intervention program use. This is to ensure that the sample is not overly homogeneous.

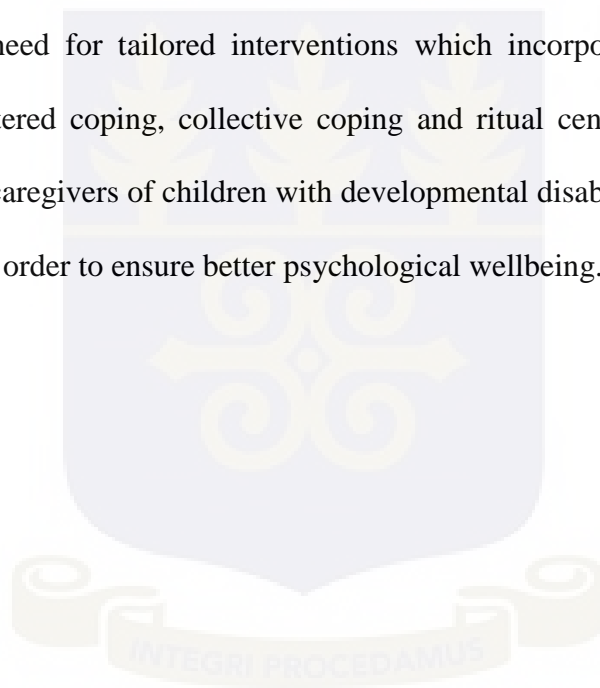
Conclusions

This research brings to fore new information about a relatively under researched area of primary caregivers of children with developmental disability in Ghana. Stigmatization is one of the major challenges that developmentally disabled children and their families face. This unfortunately can affect the attitudes and psychological well-being of primary care givers. This study examined affiliate stigma and its effect on psychological well-being of primary caregivers. Africultural coping was investigated both as a moderating variable and predictive variable of the affiliate stigma and psychological wellbeing. Differences in demographic variables such as marital status, gender and educational background were also investigated. It was hypothesized and confirmed that affiliate stigma significantly predicts psychological wellbeing of primary caregivers. Married primary caregivers were found to have better environmental mastery and personal growth than unmarried primary caregivers.

In contrast to what was hypothesized and previous literature, there were no gender differences in psychological wellbeing of primary caregivers, neither was there any difference in psychological wellbeing due to educational background. It was further observed that Africultural coping did not moderate the relationship between affiliate stigma and psychological wellbeing. However it predicted affiliate stigma and psychological wellbeing. Specifically, Cognitive/Emotional Debriefing was observed to lead to lower Affiliate stigma.

To conclude, results from this study reveal that primary caregivers in Ghana experience stigma which causes poor psychological wellbeing. It was also shown that primary caregivers who are married have better control of their environment or the everyday challenges that they face, and are more capable and motivated to making improvements to their lives than unmarried primary caregivers. The study furthermore showed that though Africultural coping did not reduce the effect of stigma on psychological wellbeing, it reduced affiliate stigma and improved primary caregivers' positive relations with others.

There is therefore the need for tailored interventions which incorporate cognitive/emotional debriefing, spiritual centered coping, collective coping and ritual centered coping in order to offer Ghanaian primary caregivers of children with developmental disabilities effective strategies in dealing with stigma in order to ensure better psychological wellbeing.



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APPENDICES

Appendix 1: Protocol Consent Form



UNIVERSITY OF GHANA



Official Use only Protocol number

OFFICE OF RESEARCH, INNOVATION AND DEVELOPMENT
Ethics Committee for Humanities (ECH)

PROTOCOL CONSENTFORM

Section A- BACKGROUND INFORMATION

Title of Study:	Stigmatization and Psychological Wellbeing of Primary Caregivers of Children with Developmental Disabilities in Ghana.
Principal Investigator:	Cobbinah Barbara Antwiwaa
Certified Protocol Number	10278369

Section B- CONSENT TO PARTICIPATE IN RESEARCH

General Information about Research

The purpose of the study is to find out how stigma associated with being the primary caregiver of a child with developmental disability in Ghana, affects the psychological condition and well-being of the primary caregiver.

The study will take about one hour to complete.

Each participant would be required to complete a self-report structured questionnaire including scales measuring psychological well-being, acculturation coping and affiliate stigma.

Benefits/Risk of the study

There are no anticipated risks or benefits involved in the study.

Confidentiality

Research data would be accessed by the researcher and research supervisors only. Also, data collected would be used only for research purposes.

Withdrawal from Study

- Participation in the study is voluntary and participants may withdraw at any time without penalty. The participant will not be adversely affected if he/she declines to participate or later stops participating in the study.
- Participant should be assured that he/she or the participant's legal representative will be informed in a timely manner if information becomes available that may be relevant to the participant's willingness to continue participation or withdraw.

Contact for Additional Information

In case of research-related injury, and for answers to any questions about the research, the researcher may be contacted.

- Name: Cobbinah Barbara Antwiwaa
Address: P. O. Box 30530; Accra
Phone number: +233262565597

Section C-VOLUNTEER AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and am willing to give consent for me, my child/ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

Name of Volunteer

Signature or mark of volunteer

Date

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

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

Name of witness

Signature of witness

Date

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

Name of Person who Obtained Consent

Signature of Person Who Obtained Consent

Date

Appendix 2: Socio-Demographic Information

Stigmatization and psychological wellbeing of primary care-givers of children with DD

Please answer all the questions as honestly as you can. Your responses will be kept in absolute confidence. Your personal information will not be associated with your responses and none of the information will be discussed with anyone.

1. Age: _____

2. Sex: Male Female

3. What is your religion?

a. Christianity

b. Muslim

c. Traditional

d. Others (specify): _____

5. Do you live with the child?

Yes No

6. What is your relationship with the child?

Father Mother Grandparent Other (specify)

7. Who takes care of the child most of the time?

I Others (specify) _____

8. What is your highest level of education?

a. No formal education b. Middle school c. JHS d. SHS g. Training college

Polytechnic h. Graduate f. Postgraduate g. Other, please specify

What is your occupation? If they own a business please state the type of business, e.g. trading/retailing, etc.

22. Marital Status

Married Divorced Widowed Separated Never married/ single

Number of years of child giving experience: _____

The following are questions about **your child with a disability**. Please respond as honestly as

Stigmatization and psychological wellbeing of primary care-givers of children with DD

possible.

11. Child's age: _____

12. Birth position of this child: _____

13. Child's gender: Male [] Female []

14. Disability of child (Please tick as many as apply.)

Intellectual disability []

Autism Spectrum Disorders: Asperger's Syndrome []

Pervasive Developmental Disorder, Not Otherwise Specified []

Autistic Disorder []

Rett Syndrome []

Childhood Disintegrative Disorder []

Attention Deficit Hyperactive Disorder []

Cerebral Palsy []

Down Syndrome []

Fragile X Syndrome []

Other : Please specify []



Appendix 3- Affiliate Stigma Scale

Stigmatization and psychological wellbeing of primary care-givers of children with DD

Instructions: Please consider your current status as the primary caregiver of a developmentally disabled child and your relationship with others due to this status. Indicate whether you strongly disagree, disagree, agree or strongly agree to the statements below.

It is requested that participant be as honest as possible. Participant should also be assured of complete confidentiality.

	Strongly disagree	Disagree	Agree	Strongly agree
1. I feel inferior because of my child with developmental disability.				
2. I feel emotionally disturbed because I have a child with developmental disability.				
3. The behaviour of _____ (Name of child with developmental disability) makes me feel embarrassed.				
4. I feel helpless for having a child with developmental disability.				
5. I feel sad because I have a child with developmental disability.				
6. I worry if other people would know I have a child with developmental disability.				
7. I am under great pressure because I have a child with developmental disability.				
8. Other people would discriminate against me if I am with _____ (name of child with developmental disability).				
9. My reputation is damaged because I have a child with developmental disability.				
Strongly Disagree	Disagree	Agree	Strongly Agree	
11. Having a child with developmental				

disability imposes a negative impact on me.				
12. Having a child with developmental disability makes me think that I am incompetent compared to other people.				
13. Having a child with developmental disability makes me think that I am inferior to others.				
14. Having a child with developmental disability makes me lose face.				
15. I avoid communicating with _____ (name of child with developmental disability).				
16. I dare not to tell others that I have a child with developmental disability.				
17. I reduce going out with _____ (name of child with developmental disability).				
18. Given that I have a child with developmental disability, I've cut down contacts with my friends and relatives.				
19. When I am with _____ (name of child with developmental disability), I especially keep a low profile.				
20. I've cut down the contacts with _____ (name of child with disability).				
21. I dare not to participate in activities related to _____ developmental disability lest other people would suspect that I have a child with developmental disability.				
22. Given that I have a child with developmental disability, I've cut down the contacts with my neighbors				

Appendix 4 : Ryff Scales of Psychological Wellbeing

Stigmatization and psychological wellbeing of primary care-givers of children with DD

The following set of statements deal with how you might feel about yourself and your life. Kindly reflect on how your primary caregiver role/parent role makes you feel about yourself and your life.

Circle the number that best describes the degree to which you agree or disagree with each statement.	Strongly Disagree	Disagree	Disagree Slightly	Agree Slightly	Agree	Strongly Agree
1. I tend to be influenced by people with strong opinions.	1	2	3	4	5	6
2. In general, I feel I am in charge of the situation in which I live.	1	2	3	4	5	6
3. I think it is important to have new experiences that challenge how you think about yourself and the world.	1	2	3	4	5	6
4. Maintaining close relationships has been difficult and frustrating for me.	1	2	3	4	5	6
5. I live life one day at a time and don't really think about the future.	1	2	3	4	5	6
6. When I look at the story of my life, I am pleased with how things have turned out.	1	2	3	4	5	6
7. I have confidence in my opinions, even if they are contrary to the general consensus.	1	2	3	4	5	6
8. The demands of everyday life often get me down.	1	2	3	4	5	6
9. For me, life has been a continuous process of learning, changing, and growth.	1	2	3	4	5	6
10. People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6
11. Some people wander aimlessly through life, but I am not one of them.	1	2	3	4	5	6
12. I like most aspects of my personality.	1	2	3	4	5	6
13. I judge myself by what I think is important, not by the values of what others think is important.	1	2	3	4	5	6
14. I am quite good at managing the many responsibilities of my daily life.	1	2	3	4	5	6
Circle the number that best describes the degree to which you agree or disagree with each	Strongly Disagree	Disagree	Disagree	Agree Slightly	Agree	Strongly Agree

statement.			Slightly			
15. I gave up trying to make big improvements or change in my life a long time ago.	1	2	3	4	5	6
16. I have not experienced many warm and trusting relationships with others.	1	2	3	4	5	6
17. I sometimes feel as if I've done all there is to do in life.	1	2	3	4	5	6
18. In many ways, I feel disappointed about my achievements in my life.	1	2	3	4	5	6



Appendix 5: Africultural Coping Systems Inventory

Stigmatization and psychological wellbeing of primary care-givers of children with DD

Instructions: Please consider the strategies you use in coping with stressful situations. Recall a stressful situation(s) that occurred. Rate each coping strategy by indicating whether you used it to cope with the stressful situation.

0 = Did not use 1 = Used a little 2 = Used a lot 3 = Used a great deal.

- _____ 1. I prayed that things would work themselves out.
- _____ 2. I got a group of family or friends together to help with the problem.
- _____ 3. I shared my feelings with a friend or family member.
- _____ 4. I remembered what a parent (or other relative) once said about dealing with these kinds of situations.
- _____ 5. I tried to forget about the situation.
- _____ 6. I went to church (or other religious meeting) to get help or support from the group.
- _____ 7. I thought of all the struggles Black people have had to endure and it gave me strength to deal with the situation.
- _____ 8. To keep from dealing with the situation, I found other things to keep me busy.
- _____ 9. I sought advice about how to handle the situation from an older person in my family or community.
- _____ 10. I read a scripture from the bible (or similar book) for comfort and/or guidance.
- _____ 11. I asked for suggestions on how to deal with the situation during a meeting of my organization or club.
- _____ 12. I tried to convince myself that it was not that bad.
- _____ 13. I asked someone to pray for me.
- _____ 14. I spent more time than usual doing group activities.
- _____ 15. I hoped that things would get better with time.
- _____ 16. I read a passage from a daily meditation book.
- _____ 17. I spent more time than usual doing more things with friends and family.

0 = Did not use, 1 = Used a little, 2 = Used a lot, 3 = Used a great deal.

Stigmatization and psychological wellbeing of primary care-givers of children with DD

- _____ 18. I tried to remove myself from the situation.
- _____ 19. I sought out people I thought would make me laugh.
- _____ 20. I got dressed up in my best clothing.
- _____ 21. I asked for blessings from a spiritual or religious person.
- _____ 22. I helped others with their problems.
- _____ 23. I lit a candle for strength or guidance in dealing with the problem.
- _____ 24. I sought emotional support from family and friends.
- _____ 25. I burned incense for strength or guidance in dealing with the problem.
- _____ 26. I attended a social event (dance, party, movie) to reduce stress caused by the situation.
- _____ 27. I sang a song to myself to help reduce the stress.
- _____ 28. I used a cross or other object for its special powers in dealing with the problem.
- _____ 29. I found myself watching more comedy shows on television.
- _____ 30. I left matters in God's hands.

