

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

**HEALTH BELIEF, SOCIAL SUPPORT, AND PSYCHOLOGICAL  
WELLBEING AS PREDICTORS OF TREATMENT COMPLIANCE: A  
STUDY AMONG CAREGIVERS OF SICKLE CELL AND ACUTELY ILL  
CHILDREN**

The crest of the University of Ghana is a shield-shaped emblem. The top section is a smaller shield containing three golden, downward-pointing arrowheads. Below this is a horizontal golden line. The main body of the shield is a larger shield with a golden, ornate scrollwork design. At the bottom of the shield is a golden banner with the Latin motto 'INTEGRI PROFERAMUS'.

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**THIS THESIS/DISSERTATION IS SUBMITTED TO THE UNIVERSITY  
OF GHANA, LEGON IN PARTIAL FULFILLMENT OF THE  
REQUIREMENT FOR THE AWARD OF MPhil CLINICAL  
PSYCHOLOGY DEGREE**

**JULY 2015**

*Health Belief, Social Support, and Psychological Wellbeing as Predictors of Treatment Compliance*

**DECLARATION**

I hereby declare that this research is conducted by me under the supervision of Professor Charity S. Akotia and Dr. Adote Anum. 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 for any shortcomings associated with this work.

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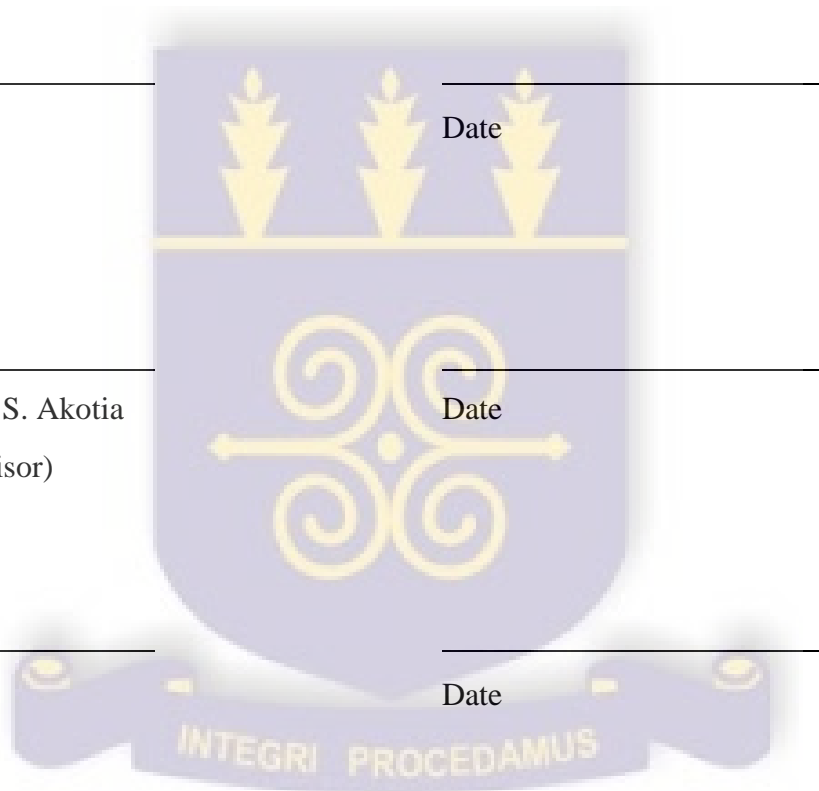
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*Health Belief, Social Support, and Psychological Wellbeing as Predictors of Treatment Compliance*

**ABSTRACT**

Caregivers of children with sickle cell disease experience psychological and physical challenges that affect their role as a caregiver. The aim of the study was to find out whether health belief, psychological wellbeing, social support, and some selected demographic variables influence the compliance of caregivers on the treatment of their children. Using a cross sectional survey method, 200 participants (100 caregivers of sickle cell children and 100 caregivers of acutely ill children) were purposively selected for the study. Using behavioural measure of health belief (CHBMS), psychological wellbeing (RSPW), and social support (MSPSS), and medication adherence (MAQ), data was collected. The results showed that caregivers of sickle cell children obtained significantly higher scores than caregivers of acutely ill children on medication adherence questionnaire. Standard multiple regression showed that health belief and social support of caregivers significantly predicted their compliance to their children's treatment. Psychological wellbeing however did not predict treatment compliance. Multiple regression analysis showed that the influence of caregivers' health belief on their compliance to their children's treatment was mediated by their psychological wellbeing. However, psychological wellbeing did not mediate the influence of social support on the treatment compliance. Multiple hierarchical regression analysis showed that age and number of children moderated the relationship between psychological wellbeing and treatment compliance in all caregivers. However, they did not moderate the relationship between health belief and treatment compliance, and between social support and treatment compliance in both sickle cell and acutely ill groups of caregivers. Similar influence was found between psychological wellbeing and treatment compliance in both the sickle cell and the acute illness groups. These results have clinical implication for sickle cell management and research into psychological studies involving caregivers of children with sickle cell disease.

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**DEDICATION**

To Felicia Akoto, whose yearnings for higher heights for her children kept me awake through all these years, and to Samuel Kofi Owusu, a brother whose support and encouragement continues to strengthen me to pursue the best there is.



*Health Belief, Social Support, and Psychological Wellbeing as Predictors of Treatment Compliance*

**ACKNOWLEDGEMENTS**

I am forever indebted to my creator, Elohim, and his son Jesus Christ, for the wisdom, knowledge, goodness, and mercies that I enjoyed under the wings of love. I believe that was all I needed through this time and beyond. I am eternally grateful.

I am humbly grateful to Prof. Charity Akotia and Dr. Adote Anum for their guidance and directives, patience and time, that they devoted to me from the beginning to the end of this thesis work. Thank you Prof. and Dr.

My gratitude also goes to the Departments of Child Health and Polyclinic of the Komfo Anokye Teaching Hospital (KATH) for their support, particularly Dr. Osei Akoto and Dr. Spangenberg and their teams, during my data collection. I am also grateful to members of the Psychiatric Unit (KATH) for their constant support throughout my studies, particularly Prof. Yaw Osei, Prof. Appiah Poku, and Dr. Donnir. Thank you.

I am grateful to the Child Development Study (CDS) team for the support throughout my study. I am grateful.

The following individuals are acknowledged for their diverse support rendered to me: Ramseyer (intern – Psych unit, KATH), Saida, Fanny, Shirley, Timah, and Godfred (National Service Persons). My gratitude also goes to my course mates, Miezah and Docia for their encouragements and technical support.

My deepest gratitude to Ms. Elizabeth Sarfo, for her constant encouragement and support.

Finally, I am also thankful to my siblings and the entire family for their unwavering support, as always.

God bless all of you.

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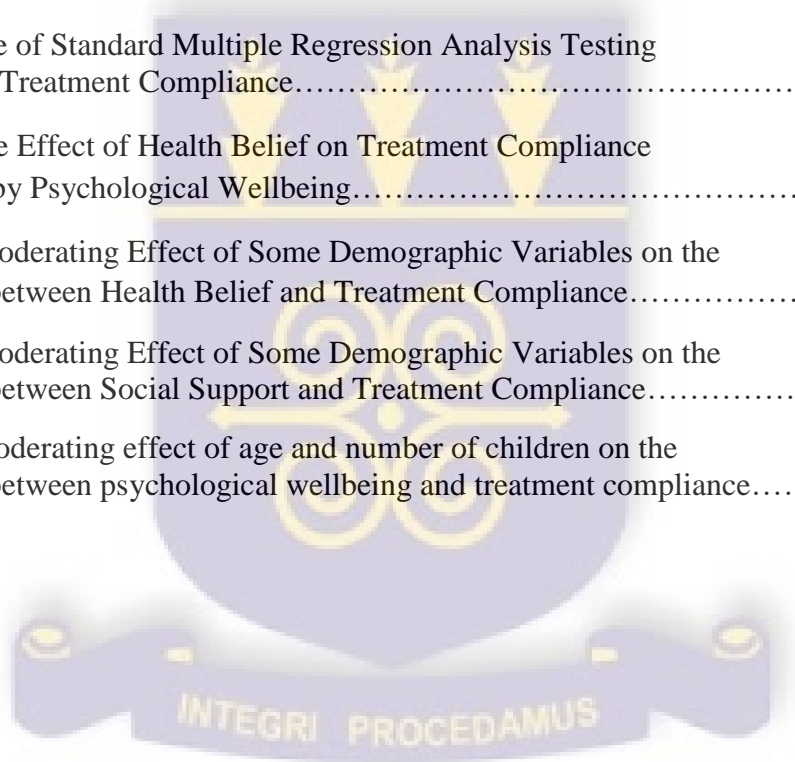
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**LIST OF ABBREVIATIONS**

AIDS -	Acquired Immune Deficiency Syndrome
ART -	Antiretroviral Therapy
CHBMS -	Champion's Health Belief Model Scale
CHRPE -	Committee on Human Research, Publication, and Ethics
CPAP -	Continuous Positive Airway Pressure
DDMA -	Discrepancies in Decision-Making Autonomy
ECH -	Ethics Committee for Humanities
GSS -	Ghana Statistical Service
HIV -	Human Immune Virus
ICS -	Inhaled Corticosteroids
IDDM -	Insulin-Dependent Diabetes Mellitus
KATH -	Komfo Anokye Teaching Hospital
KNUST -	Kwame Nkrumah University of Science and Technology
MAQ -	Morisky's 8-Item Medication Adherence Questionnaire
MSPSS -	Multidimensional Scale of Perceived Social Support
OSA -	Obstructive Sleep Apnoea
PSOM -	Positive State of Mind
RDU -	Research Development Unit
RSPW -	Ryff's Scale of Psychological Wellbeing
SCD -	Sickle Cell Disease
UG -	University Of Ghana
WHO -	World Health Organization

## CHAPTER ONE

### INTRODUCTION

#### **Background of the Study**

Sickle Cell Disease (SCD) is a non-communicable disease that is known to be one of the most prevalent genetic disease. Worldwide, it is the most commonly encountered genetic disorder, afflicting a quarter of a million newborns in the Sub-Saharan Africa alone (Kirkham, 2011; Hassell, 2010). It is a hemoglobinopathy with a genetic etiology understood to be caused by an autosomal recessive gene that is most severely expressed in those who are homozygous (Kirkham, 2011). It is characterized by the presence of hemoglobin S (HbS) and one other abnormal hemoglobin. The homozygous state results in an abnormal hemoglobin that is prone to polymer formation under cellular deoxygenation. The polymerized hemoglobin reduces red blood cell deformability and causes ‘sickling’ of erythrocytes within capillaries and end-arterioles. The resulting microcirculatory obstruction gives rise to vaso-occlusive crises that may occur repeatedly in the presence of certain triggers. The most common complications associated with the disease are crisis ranging from vaso-occlusive pain, recurrent severe anemia, organ damage, acute chest syndrome, and leg ulcer (Brown, Okereke, Lagunju, Orimadegun, Ohaeri, Akinyinka, 2010). Other complications include spleen sequestration, infections, and priapism in males. These complications and their outcomes are devastating to the sufferer and their loved ones, especially their caregivers who are closer to them. The complications are even more devastating when the sufferer is a child (Merluzzi, Philip, Dominic, & Heitzmann, 2011).

The history of SCD is testimonial to its slow and torturous approach to its management over the years. For the few decades after its identification, its pathophysiology of pain and anemia was unknown. This made its treatment predominantly supportive care. Advances however have

been made in understanding its pathophysiology since 1949 and now adequate literature and clinical programs are available in the management of the condition. However, this has not changed much in the domestic care that is given to patients with the condition. There is still evidence of burden on the caregivers of patient with SCD (Brown et al., 2010; Modi, Crosby, Guilfoyle, Lemanek, Witherspoon, Mitchell, 2009)

### **Burden of Care of SCD**

According to the World Health Organization (WHO), 5.2% of the world's population and over 7% of pregnant women carry an abnormal hemoglobin gene (Modell & Darlison, 2008). In Ghana, some studies report a prevalence carrier rate of 30% in the general population with a 2% rate in newborns (e.g., Ohene-Frempong, Oduro, Tetteh, & Nkrumah, 2008).

Researchers worldwide over the years have looked into this phenomenon of caregiving for chronic disorders, evaluating a number of possible influences on the various conditions. This interest has been strengthened by the fact that the caregivers' role, which is known to pose challenges both physically and mentally, affects the professional, family, and marital roles as well as daily activities of individuals that assumes them. (Ennis & Corry, 2014). Caregiving role comes with some incentives such as role satisfaction, maintenance of dignity, respect and others. However, it has been observed that it may represent a vulnerability to non-adherence to medication. As challenging as the care of patients with SCD is, specific care given to children with the condition come with its additional challenges.

Parenting a child with SCD has been described by Sales (2003) as a burden. This burden can be classified as objective and subjective. The objective burden includes day-to-day management of the illness, the effect on other aspects of life and financial consequences. The emotional distress caregivers experience when dealing with their ill child can be classified as a subjective burden (Sales, 2003). Confronting the pain of their child during vaso-occlusive crisis is emotionally upsetting for parents (Ievers-Landis, Brown, Drotar, Bunke, Lambert,

Walker, 2001). Vaso-occlusive crises and hospital visits interfere with work commitments and planned activities of caregivers and other family members. Financial consequences may arise as a result of travel expenses for trips to the hospital (Callery, 1997) and a poor health status of a child has been associated with reduced maternal or paternal employment (Kuhlthau, Perrin, 2001). Caregivers may have difficulty accepting the child's diagnosis and prognosis, and may experience anxiety about the child's future well-being, both in the short and long term.

Caring for a child with SCD poses extra demands, both in health and wellbeing, with daily emotional challenges which include constant fear of their children's hospitalization, possible death, separation anxiety, loss of control over their lives and helplessness (Brown et. al., 2010). Caregivers of children with SCD have to administer medication daily (e.g. antibiotic prophylaxis and folic acid ), promote behavior that minimizes pain episodes and act appropriately when symptoms arise by giving scheduled analgesics and plenty of fluids in the case of a painful crisis (Ievers-Landis et al., 2001; Moskowitz, Butensky, Harmatz, Vichinsky, Heyman, Acree, Wrubel, Wilson, Folkman, 2007).

In Ghana, like many other countries, children living with SCD are mostly cared for by their parents or by people who are closely related to them (Okraqu, Ofori-Atta, Danquah, Ekem, & Acquaye, 2009). This is quite common in the care of chronic diseases and illness in general. It is further reported that in many cultures, care of children and ill family members invariably falls on mothers or female family members (Atkin & Ahmad, 2000). However, the availability of support may come as a relief for these caregivers. Nukunya (2003) observed that the collectivistic nature of Ghanaian society make it easier for support to be rendered from other family members like siblings, grandparents, aunts and uncles, nephews and nieces, and cousins. Several challenges affecting the health and wellbeing of the caregiver may include the discipline of the child and frustration associated with the daily administration of routine drugs, regular hospital visits and hospitalizations which interferes with planned commitments and

financial consequences as well as the health promotion that will minimize crises (Brown et al., 2010; Sales, 2003). Some caregivers may even face rejection and blame from the child as being the cause of the disease after knowing that the disease is a genetic one (Okroku, et. al. 2009). Going through these challenges as a caregiver generally affects physical as well as psychological wellbeing and consequently, compliance with the treatment for the child living with SCD.

### **Beliefs and Adherence to Treatment**

Cramer et al. (2008) defined medication compliance as “the extent to which a patient acts in accordance with the prescribed interval and dose of a dosing regimen” (p. 46). In relation to this study, medication compliance is the caregivers’ adherence to the recommendations made by the physician with respect to timing, dosage, and frequency of medication to be taken by the child. For a child with SCD, compliance to treatment is key to survival. This key fact may be influenced by other factors that include the belief that the caregiver have about the condition. Health belief is the conviction that an individual has about a health condition that affects him or her. The knowledge of the severity of SCD alone does not adequately predict adherence to treatment. According to the health belief model propounded by Rosenstock (1974) as cited in Abbott, Dodd, and Webb (1996), “patients’ perceptions of the illness as serious, feeling of susceptibility, a belief that the treatment is beneficial, and a motivation or concern for one’s health should theoretically predict adherence rather than clinically assessed disease severity” (p. 1233).

In the Ghanaian society, similar to that of other parts of Africa, there is a belief that SCD is a spiritual disease, which results from curses (Anie, Egunjobi, & Akinyandu, 2010; Danquah, 2008). For that matter, caregivers of children with SCD seek spiritual remedies rather than orthodox treatment (Dennis-Antwi, Lorraine, Hiles, & Dyson, 2011; Anie et al, 2010). It is the belief that children with SCD have a considerable potential of dying (Goffman, 1968) so the

caregivers are likely to neglect the treatment regimen, regarding it as a waste of time. This general belief encourages the caregivers to discount these children (Sweeting & Gilhooly, 1997) as non-existent, patiently waiting for the day of his or her death (Denis-Antwi et al. 2011). Over the years, through education and religious influence from different religious groups, compliance to medication has been expected to improve. Even though there has been a steady improvement, cases of non-compliance on the part of caregivers persist (Brown et al., 2010). Children's adherence to medical treatment is mostly dependent on the knowledge and the health beliefs that the parent or the caregiver has about the particular medical condition (Brown et al., 2010).

### **The Role of Social Support and Wellbeing of the Caregiver**

Caring for a child with chronic disease is highly demanding and has practical and emotional consequences (Sullivan-Bolyai, Sadler, Knafl, Gilliss, 2003; Murphy, Christian, Caplin, Young, 2007) and that the quality of care they receive may be affected by the caregivers' well-being. Like children with chronic disease, SCD children are dependent on the caregivers for additional care and monitoring of their health. Several studies found that 30-40% of the caregivers had symptoms of psychological distress (Brown et al. 2000; Thompson, Gil, Burbach, Keith, Kinney, 1993b; Ievers-Landis, Brown, Lambert, Hsu, Eckman, 1998; Hofmann, De Montalembert, Beauquier-Maccotta, de Villartay, Golse, 2007). It is important to address the caregivers' well-being and to identify needs for additional support, for both the health and well-being of the caregiver and the child (Midence, McManus, Fuggle, Davies, 1996).

Social support, as defined by Chisholm-Burns, Spivey, and Wilks (2009) is "a network of family, friends, neighbors, and community members, that is available in times of need to give psychological, physical and financial help" (p. 2). Gottlieb (2000) defined social support more broadly as the "process of interaction in relationships which improves coping, esteem,

belonging, and competence through actual or perceived exchanges of physical or psychosocial resources” (p. 28). The two definitions propose sources, type, as well as the influence of social support. Social support may be actual or perceived, and can take the form of physical, financial, or emotional support. When an individual experiences higher social support, they are likely to have higher psychological wellbeing (Asante 2012). People with SCD need social and psychological support from the family and significant others to provide strong foundation and relief (Okroku et al., 2009). This is not different from the needs of the caregivers since they are going through similar emotional challenge that the disease poses to their loved one.

Research suggest however that social support can benefit health by buffering stress, changing affective states, increasing self-efficacy, and influencing change in negative health behaviors (DiMatteo, 2004). With emphasis on the latter, this study focuses on the influence that social support from family, friends, and members of the caregivers’ community have on their compliance behaviour. When an individual experiences lowered psychological wellbeing, they are likely to engage in non-adherent behaviour. This is because lowered psychological wellbeing indicates lowered self-esteem, lack of motivation, lowered emotional wellbeing; depression, hopelessness and lowered psychomotor activities (Moskowitz et al. 2007). This lowered psychological wellbeing tends to affect the caregivers’ motivation to comply to the medication regimen of the child with SCD.

It has also been observed that adherence is higher when patients or caregivers have practical support available to them (DiMatteo, 2004). Family structural support, which includes marital status and living arrangements, is also positively associated with treatment adherence (Miller & DiMatteo, 2013). This social support serves as a protective factor for most people who are faced with various challenges in their lives, including chronic illness like SCD. The practical, emotional and financial support that comes from family member go a long way in aiding the

mothers, and for that matter, caregivers cope with the caring of the child (Atkin & Ahmad, 2000).

### **Statement of the Problem**

The treatment of SCD in Ghana over the years has experienced a steady improvement in the provision of the health care facilities. Continual adherence to treatment regimen remains key to the success of the management of the condition. However, the compliance of children with SCD to treatment is not entirely left to the child, but dependent largely on the caregivers of these children. Caregivers' social behaviour towards SCD is likely to be oriented by their perceived cause of the condition which might be a product of their specific social and cultural circumstance (Blaxter, 1983) lying with themselves, the natural world around them, the social world or the supernatural world (Helman, 2000). This does not mean that the caregiver is ignorant of medical issues surrounding SCD, but rather their knowledge may be embedded within deeper cultural belief about the health that is related to SCD (Dennis-Antwi et al., 2011). It is this belief in the spiritual etiology of chronic diseases that lead people into seeking spiritual remedies (de Graft-Aikins, Anum, Agyemang, Addo, & Ogedegbe, 2012; Dennis-Antwi, 2008) rather than adhering to medical treatment.

In addition to these beliefs, caregivers, mostly from poor backgrounds, see caring for a child with SCD as a great financial drain. In Ghana where access to healthcare service depends on the ability to pay (Dennis-Antwi et al, 2011), caregivers are faced with the enormous challenge to provide the optimal care. Cost of transportation to health centers for reviews, cost of adjustments in meals, cost of frequent hospitalization and major surgical procedures arising from crisis, which may include organ failures and others, may incur great financial burden on the caregivers. Even though a 2003 National Health Insurance Scheme exists, the poor in the country remain outside the scheme (Ghana Ministry of Health, 2015). This additional stress puts a strain on the wellbeing of the caregiver who is already stretched by their commitments

in their society. Unfortunately, the stigma attached to SCD may limit the social support that is needed to strengthen these caregivers cope with and adhere to the management plan for these children. Mothers will hide their child's condition or may regard SCD as a 'spoiled identity', just waiting for the child to die (Dennis-Antwi et al, 2011; Goffman, 1968) and therefore disregard the importance of complying with medical treatment.

This study therefore explores the health belief, psychological wellbeing and the social support of caregivers. In view of the exploration, the present study investigated the effect of health belief, social support, and psychological wellbeing of caregivers on their compliance to the treatment of their children with SCD.

### **Aims and Objectives**

This study seeks to find out whether health belief, psychological wellbeing, social support, and some selected demographic variables influence the compliance of caregivers on the treatment of children with SCD. Specifically, the study seeks to:

1. Examine the influence of health belief of the caregiver of children with SCD on their compliance to the treatment regimen of the children.
2. Examine the effect of social support of the caregivers on their compliance to the treatment of their children with SCD.
3. Investigate the effect of psychological wellbeing of caregivers on their treatment compliance of their children with SCD.
4. Find out if psychological wellbeing of caregivers plays a mediating role in the relationship between their health beliefs, social support, and their compliance to their children's treatment.
5. Find out if the any of the demographic characteristics of the caregivers' plays some moderating role in the relationship between their health belief, social support, psychological wellbeing, and their compliance to their children's treatment.

### **Relevance of the Study**

The treatment and management of SCD has been focused on the medical aspects neglecting the psychosocial challenges that confront sufferer. Medical practitioners tasked with the onus of management of children with SCD need information from findings of studies such as the present one in understanding the challenges and needs of the caregivers of these children. This will then help them to inculcate the caregivers in the management programme of the children, maximizing better treatment outcome.

Again, the findings will promote discussion for guidelines for first aid psychotherapy to the caregivers that are be found to be experiencing any emotional or psychological difficulty as they accompany the children for their periodic reviews. This will help in planning psychotherapeutic interventions that will target the population of the study in dealing with some of the neglected difficulties that are associated with the care of children with SCD.

The study will also help kindle the understanding of the Ghanaian society, particularly the health service providers; to recognize and appreciate some of the needs; both physical and psychological, and to offer help if it becomes necessary to these caregivers of children with SCD.

By making the results of this study available to policy makers, it will remind them of the need to include the needs of children with SCD and their primary caregivers when making policies.

## CHAPTER TWO

### LITERATURE REVIEW

This chapter focuses on the theories that guide the various variables and its relations to treatment compliance. It also consists of the review of available literature related to the relationships between the variables of this study. The hypothesis and the conceptual framework will also be presented in this chapter.

#### **Theoretical Framework**

Three psychological theories are employed to explain the relationship between the caregivers' beliefs about the child's condition, their psychological wellbeing, their perceived social support, and compliance to the treatment regimen of their children. Using the Rosenstock's (1974) Health Belief Model, the mechanism of the caregivers' belief system about the condition and its relationship to their adherence to the treatment of the children will be explained. The Theory of Planned Behavior (Ajzen, 1991) will also be employed to explain the caregivers' belief and psychological wellbeing and its relationship with their treatment compliance. The Rational Regulation Theory (Lakey & Orehek, 2011) will also be employed to explain the perceived support of caregivers and its relations to their psychological wellbeing and ultimately compliance to treatment.

#### **Health Belief Model (Rosenstock, 1974)**

The Health Belief Model is a psychological model that attempts to explain and predict health behaviors. This prediction is done through the assessment of individual's attitudes and beliefs. The core assumption of the model is based on the assumption that a person will take a health-related action if that person feels that a negative health condition or consequence can be avoided. Secondly, that the proposed action is effective in avoiding the negative health condition or consequence. Finally, that the individual is capable and confident in executing the

proposed action aimed at avoiding the negative health condition or consequence (Rosenstock, Strecher, Becker, 1988). The model was spelled out initially in terms of four main constructs that represents perceived threat and net benefit. These constructs are perceived susceptibility, perceived severity, perceived benefits, and perceived barriers.

In line with this study, perceived susceptibility is the extent to which caregivers believe they and others around them are likely to suffer from SCD. For example, do they believe that SCD is genetic or hereditary? Perceived severity or seriousness is the caregivers' perception of how serious SCD is, medically and socially. Perceived barrier is the caregiver's view of impediments to or the likely cost of complying with the child's SCD treatment. These may include resistance from the child, cost of treatment, knowledge of the caregivers and others that may facilitate or discourage compliance with treatment regimen of the child. Perceived benefit is the caregiver's view of the reward for complying with the child's SCD treatment, which may include absence of crisis, uninterrupted academic work of the child, uninterrupted social commitments of the caregivers, among others. In addition to these constructs, "cue to action" was added to cover the caregivers' readiness to comply with their child's treatment. Self-efficacy, which is the caregivers' capacity to comply, was also added to help in explaining habitual non-compliance. This theory has shown that it is effectiveness in predicting health behaviour (Carpenter, 2010). Affirmation of the model's theoretical cogency and appropriateness for use was based on Kelly, Mamon and Scott (1987) proposal that evaluating health belief using its component as a whole was predictive of compliance to treatment.

### **The Theory of Planned Behaviour (Ajzen, 1991)**

The Theory of Planned Behaviour, an extension of the Theory of Reasoned Action (Ajzen, 1985), is a theory that predicts deliberate behaviour, because behaviour can be deliberative and

planned. In the present study, compliance to treatment is considered as deliberate and planned behaviour. Ajzen and Fishbein (1980) formulated the Theory of Reasoned Action after years of research in attitude from the Expectancy Value Models (Fishbein & Ajzen, 1975), after trying to estimate the discrepancy between attitude and behavior. Ajzen (1991), after continual research into the subject, found that behavior appeared not to be 100% voluntary and under control, hence the inclusion of perceived behavioral control. Perceived behavioral control refers to individual's perceptions of their ability to perform a given behavior. Over the years, the theory has shown its effectiveness in explaining behaviour (Armitage & Conner, 2001).

In line with this study, the theory postulates that compliance as a behaviour is greatly determined by the attitude towards the treatment of SCD. These attitudes include specific ones toward compliance, which is the subjective norms (beliefs), and the perceived behavioral control. These variables are predictive of the caregivers' adherence behavior. As a general rule of this theory, the more favorable the subjective norm (health belief) and the perceived behavioral control (Social support and psychological wellbeing) are, the stronger the individual's intention to engage in a desired behaviour (comply with SCD treatment of their child).

### **Relational Regulation Theory (Lakey & Orehek, 2011)**

Relational regulation theory (RRT) is a social support theory designed to explain main effects hypothesis between perceived support and health, particularly mental health (Lakey & Orehek, 2011). The main effect hypothesis, which cannot be explained solely by the stress and coping theory, stipulates that social support is beneficial all the time, with people with high social support being in better health than people with low social support, regardless of stress (Lakey, 2010; Cohen, Wills, 1985). RRT hypothesizes that the link between perceived support and health comes from people regulating their emotions through ordinary conversations and shared

activities rather than through conversations on how to cope with stress. The content of these conversations and activities are mostly values that are shared by the community and the individual themselves. They may include cultural, religious or spiritual, and socioeconomic values of the individuals. In this study, caregivers' constant contact with family members, friends and other acquaintances have implications on their health and wellbeing. These contacts may result in practical help in caring for the child like payment of hospital bills, helping in the home care of the child, encouragement and shared experience from others close to the caregiver. This regulation of emotion is relational in that the support providers, conversation topics, and activities that help regulate emotion are primarily a matter of personal taste. This is supported by previous work showing that the largest part of perceived support is relational in nature (Lakey, 2010).

### **Review of related Literature**

Several researchers have suggested that compliance to treatment is essential in ensuring better treatment outcomes. Behavioural changes are fundamental in the treatment of chronic diseases since it is a lifelong activity. Compliance in short-term and self-administered therapies is higher than for long-term therapies. The reasons for such non-adherence behaviour in the chronic disease treatments may include simple forgetfulness, depression, uncertainty about the effectiveness of treatment, lack of knowledge about the consequences of poor adherence, poor social support, economic problems, and belief systems (McDonald, 2002; Hynes, 2002).

Some studies have suggested that treatment adherence can be maximized if particular attention is paid to some of these factors. Among these factors, the prevalent ones have been the health belief of the sufferer, the social support that the sufferer experience and the psychological wellbeing. Other factors including the age, socioeconomic status and education has been named

to play a part. Researchers have thus been studying these factors and its influence on compliance in chronic diseases.

### **Relationship between Health Belief and Treatment Adherence**

A number of personal characteristics influences compliance or adherence. Health belief being one of these has been the focus of many studies. For instance, Putman (2004) conducted a descriptive study among a sample of 102 rural asthmatic Appalachian adults aimed at investigating the influence of knowledge, health belief, attitude towards asthma, and the behavioural intention to adhere on their adherence to asthma treatment regimen. They found that health belief had a significantly positive correlation with adherence. Health belief explained about 16% of the variance in the adherence behaviour indicating that higher scores on health belief correspond with higher adherence. It was also found that age was significantly related to adherence to prescribed medication. The older the participant the more likely it was for the participant to adhere to prescribed medication.

Similarly Kelly, Mamon and Scott (1987) in their study, investigated a group of psychiatric outpatients. Their aim was to find out the relationship between health beliefs and medication compliance with antipsychotic drug regimens. They interviewed 107 outpatients discharged from two Veterans Administration Medical Centres. Serving as the organizing framework, the health belief model was used to explore the relationships among perceptions of illness severity, susceptibility, benefits, and barriers of treatment, cues to action, and medication compliance. They found that the components of the health belief model together was predictive of the medication compliance with a 20% explanation of its variance. The study supported the concept that patients hold identifiable patterns of health beliefs and attitudes and that the health belief framework functions best when utilized as an integrated model to examine compliance.

Mardanian Dehkordi (2013) investigating patients with hyperlipidemia, aimed to explore the relationship between health belief and medication adherence. Employing a correlational survey method, eighty-two (82) patients with hyperlipidemia who participated in the study provided information regarding their demographic characters, adherence to medications and health beliefs. Their Finding consistent with other studies such as Kelly et al (1987) and Putman (2004) showed that there was a significantly positive relationship between health beliefs and adherence to medications in patients with hyperlipidemia to the extent that high scores in health beliefs was related to increased adherence to medication. Recommended use of health belief as a whole was emphasized in the study as well.

In investigating similar relationship, Pourghaznein, Ghafari, Hasanzadeh, Chamanzari (2013) studied patients diagnosed with Type 2 diabetes. Their objective was to detect the relationship between health belief and medication adherence. Employing a correlation cross-sectional survey, 150 patients were included and were given a questionnaire that explored medication adherence and health beliefs. They found that a significantly positive correlation existed between medication adherence and subscales of perceived severity and perceived sensitivity. However, a significant negative relationship was found between medication adherence and perceived barriers. No significant relationship was found between perceived benefits and cues to action with medication adherence. However, the correlation between health belief as a whole and medication adherence was not assessed.

DiMatteo, Haskard and Williams (2007) in a meta-analysis, investigated the relationship between health belief, disease severity and patient adherence. The objective was to retrieve and analyze the correlation effect size and moderators of the relationship between adherence and patients' beliefs in disease threat, their objective disease severity, and their rated health status by either a physician, the patient, or a parent. Selecting published works between 1948 and

2005, 116 articles were included in the study. They found that perceived disease threat, which is a component of health belief, had a significantly positive correlation with adherence. This meant that higher health belief was associated with better adherence. More relevantly, they found that in children with less serious disease, the correlation between their caregivers' health belief and their adherence was negative. However, there was a positive correlation between caregivers' health belief and adherence in children with serious conditions. This indicates that caregivers of children with chronic conditions comply more to treatment regimens when their health belief is high.

Caution however has to be taken in drawing causal conclusions from this work because the findings were correlational. This relationship could also be because of some other variables that were not considered in the study, example the socioeconomic status, psychological wellbeing, social support, age, among others.

In a more related study, Olsen, Smith, Oei, and Douglas (2008) investigated the relationship between patients' health belief and adherence to continuous positive airway pressure (CPAP) therapy adherence for obstructive sleep apnea (OSA). The objective of the study was to investigate the health belief model constructs in the prediction of CPAP adherence early in the treatment of OSA. Employing an experimental method, 77 patients diagnosed with OSA were selected for a pretest and posttest. CPAP adherence was assessed at a 4-month follow-up. They found that patients have developed beliefs and expectations about OSA and CPAP even before they start CPAP treatment. These beliefs and expectations significantly and positively correlated with the patients' adherence to effective therapy. Health belief model constructs alone explained 21.8% of the variance in CPAP adherence.

There have been other researchers who focused on the relationship between health belief and adherence to treatment, but reported no significant relationship between the two variables. For

example, Steele et al (2001) in a study examined the association between two components of the health belief model (perceived vulnerability and barriers) and adherence to antiretroviral therapy (ART). The aim of the study was to find out if there was any relationship between health belief of caregivers or parents and their adherence to the treatment of their children with HIV. Thirty (30) parents/caregivers were recruited for the study. Using measures of perceived vulnerability, perceived barriers, and an objective measure of adherence, which included pill count, they did not find significant relationship between the aforementioned variables. It is important to note that the sample size was too small to be able to make inferences from it. In addition, assessing health belief in its components rather than as a whole may have accounted for the insignificant relationship.

Similarly, Miner, Alexander, Ewing, and Gerace (2013) did a study among caregivers of children diagnosed with epilepsy. They aimed at determining the association between adherence to prescribed antiepileptic medication and caregivers' beliefs about the medication. Using hundred (100) caregivers for the study, they found no significant relation between caregivers' belief and their adherence to antiepileptic medication. Nevertheless, 28% of the respondents reported complete adherence, the majority of caregivers perceived their child's medication was necessary to maintain good health. It must be noted however that other factors like socioeconomic status as well as education may have contributed to the insignificant relationship.

In another study, Armstrong, Duncan, Stokes, and Pereira (2014) focused on the caregivers of children who suffer from asthma. The objective of the study was to examine the associations of parenting stress and caregiver negative health beliefs with adherence to inhaled corticosteroids (ICS) medication in a sample of preschool-aged children. Forty-three (43) caregivers and their child with asthma, aged between 2 and 5 years were recruited for the study.

Pharmacy refill records were reviewed to measure medication adherence objectively. Using the paired samples t-test and Pearson's correlation coefficients, the researchers found that there was a significant negative association between caregiver negative health beliefs, and the objective measure of ICS adherence. This meant that caregivers who had high health beliefs were likely to be non-compliant with their child's treatment.

### **Psychological wellbeing and Medication adherence**

The treatment compliance has also been found to have a relationship with psychological wellbeing of caregivers and patients suffering from different kinds of conditions. For example, Wrubel, Moskowitz, Richards, Prakke, Acree, and Folkman (2005) in a qualitative study focused on the perspective of mothers in relation to pediatric adherence. They aimed at articulating what is involved in the daily life experience of giving or supervising a child's HIV medication in order to clarify what promotes or impedes adherence. Analysis of narrative responses of 71 maternal caregivers of children with HIV was conducted. They found four themes, which included mothers' attitudes and feelings related to adherence practices, the impact of the medications on adherence practices, interactions of mothers and children related to adherence practices, and developmental issues and responsibility for medication adherence. They found that adherence practices were impacted in a positive way by mothers' commitment to adherence, and in a negative way by feelings of stigma and guilt, by the effects of bereavement on children and by children adopting their mothers' attitudes about medications. The interactive process of giving medication was shaped by children's behavior, mothers' developmental expectations for children, and, for mothers with HIV, their adherence for themselves. The researchers however did not find that the wellbeing of the mothers was associated with the child's adherence or that of the mothers themselves. They found that pediatric adherence often came at a cost to the caregiver's wellbeing.

In a related quantitative study, Reis, Guerra, and Lencastre (2013) sampled 197 outpatients diagnosed with HIV/AIDS attending the Infectology service and on antiretroviral medication for a 6-month period. Their objective was to analyze the relationship between treatment adherence and subjective well-being. They found that there is a positive correlation between therapeutic adherence and positive affect as well as between adherence and satisfaction with life among patient of HIV/AIDS.

Similar to Reis et al (2013), Petróczi, Hawkins, Jones and Naughton (2010) in an observational study, focused on the adherence of HIV patients to exercise programmes. They aimed at presenting an analysis of HIV patients with known physical and psychological characteristics exploring associations with non-compliance of prescribed exercise regimen. Twenty-two (22) participants consisting of 11 males and 11 females patients were included in the study. Prior-to-treatment differences in perceived physical, functional, and psychological well-being exist between adherent and non-adherent patients. They found that perceived wellbeing had a significantly positive relation with the prescribed exercise regimen. This means that patients with higher perceived wellbeing are likely to adhere to the prescribed exercise regimen.

### **Social Support and Treatment Compliance**

A number of studies has also expounded on the link between social support and treatment compliance of patients with chronic conditions and the caregivers of such patients. Boas, Foss, De Freitas and Pace (2012) in a cross-sectional and quantitative study analyzed the relationship between social support, adherence to non-pharmacological treatment (diet and physical exercise) and pharmacological treatments (insulin and/or oral anti-diabetic medication) and clinical and metabolic control. Through validated instruments for the Brazilian population, data was gathered from one hundred and sixty-two (162) type 2 diabetes mellitus patients. They

found that social support had a significantly positive correlation with treatment adherence. However, social support may make such an impact if it is coming from a particular source.

In a similar research in adherence among diabetes patients, Lewandowski and Drotar (2007) for example studied the relationship between caregivers' social support and adherence to medical treatment of adolescents with type 1 diabetes. The objective of the study was to investigate the relationship between mother-reported spousal support and social network support, and mother-adolescent diabetes-related conflict, discrepancies in decision-making autonomy (DDMA), and adolescent adherence to diabetes treatment. Fifty-one (51) mothers of adolescents with insulin-dependent diabetes mellitus (IDDM) completed self-report measures of social support, diabetes-related conflict, and adolescent autonomy for diabetes care. They found that mother-reported spousal support had a significantly positive correlation with adherence to treatment in their child, indicating that, higher levels of mother-reported spousal support were associated with greater adherence to treatment.

Similarly, Houston, Osborn, Lyons, Masvawure, and Raja (2015) on perceived social support from peer facilitators in an HIV treatment adherence intervention examined participants' perceptions in terms of the social support from peer facilitators in a hospital-based intervention. The aim of the study was to examine this source of social support and to describe how four defined types of social support affect adherence of participants, sexual safety, and coping behaviours. Content analysis was conducted with reference to four types of social support (instrumental, informational, emotional, and affiliation) on exit interviews with 11 participants enrolled in the intervention that targeted African-American patients living with HIV/AIDS. They found that perceived informational support from peer facilitators with regard to adherence had greater impact and credibility amongst participants than the same type of support from medical providers. Informational support was cited most frequently with regard to influencing

adherence and sexual safety behaviours; whereas perceived emotional support was cited primarily with helping, participants cope with HIV. Even though the sample was small, it has been demonstrated that the type of social support is relevant when it comes to achieving optimal treatment adherence.

Again, Van Dam, Van Der Horst, Knoop, Ryckman, Crebolder, and Van Den Borne (2005) conducted a review on social support in diabetes patient, through a computerized systematic search in Medline, the Cochrane Library, PsychINFO, and Embase files. They found that different forms of social support were reported to have positive correlation with treatment outcome. These included group consultations, Internet or telephone-based peer support, and social support groups. However, there was no significant correlation between improved diabetes control and classic forms of support, e.g. from spouse, family and friends. They concluded that this review supports the hypothesis that specific social support interventions affect patient self-care and diabetes outcomes.

Similar to the work of Van Dam et al (2005), Scheurer, Choudhry, Swanton, Matlin and Shrank (2012) aiming to evaluate the association between social support and medication adherence, reviewed study articles published before November 2010 in peer-reviewed, healthcare related journals. This was done using PubMed, EMBASE, and Web of Science, and search terms related to social support and adherence, yielding 5331 articles. Fifty (50) studies were included in the final analysis. A greater degree of practical support was most consistently associated with greater adherence to medication. Structural or emotional support did not yield a significant association with adherence. However, most studies were limited in size and design, and substantial variability in designs and outcome measurement prohibited pooling of results, necessitating qualitative evaluation of the studies.

In a more related study Raphael, Butler, Rattler, Kowalkowski, Mueller, and Giordano (2013) focused on the psychological factors that affect adherence behaviour of children with SCD. They aimed at examining the psychological characteristics of social support, motivation, and parental information and how they affect the utilization of health care among SCD children. Using a cross sectional survey design, they included one hundred and fifty (150) parents of SCD children receiving care at a SCD center in the study. They found that there was a significantly positive relation between satisfaction with social support and routine hematology clinic visits. This means that children of parents reporting higher satisfaction with social supports had higher odds of 2 or more routine hematology visits in the 12 months prior to the study. Even though the researchers did not focus on medication intake as adherence, routine visits to the SCD center may represent medication refills and other checks that are essential in managing SCD. Similar findings were found in Ahrari, Moshki and Bahrami (2014) study investigated the relationship between social support and adherence to dietary and fluid restriction in hemodialysis patients in Iran. Using 237 hemodialysis patients, they found that there were significantly negative correlations between social support and non-adherence to fluid and dietary regimens, indicating that the more a patient receives social support, the less likely they will be involved in non-adherent behaviour.

In some studies, it has been found that this relationship is mediated by some other factors, particularly psychological wellbeing. For example, Gonzalez et al (2004) in examining the potential mechanisms for the relationship between social support and better medication adherence among illness groups found that some aspects of psychological wellbeing, specifically positive state of mind (PSOM) and depression were mediators of this relationship. They examined the relationships between these variables among HIV positive men who have sex with men and women on highly active antiretroviral therapy. Analyses of the data showed

that greater social support and PSOM related to better adherence whereas higher depression scores related to non-adherence. PSOM partially mediated the relationship between social support and adherence. They concluded that PSOM might be an important mechanism through which social support is related to better medication adherence.

### **Demographic characteristics and Treatment compliance**

Some studies have made relevant findings on the influence of some demographic variables and its effect on treatment compliance. For example, Putman's (2004) study aimed at investigating the influence of health belief, knowledge, attitudes and intention to adhere to treatment in 102 adult asthmatic patients, found that age was positively correlated significantly with adherence. This indicated that the older a participant, the likely he, or she would adhere to prescribed medication for asthma. Pourghaznein (2013) found similar results when studying relationship between health belief and adherence among type 2 diabetes patients. Others like Olsen et al (2008) studying the predictability of the HBM in predicting adherence, found that there was no significant relationship between age and adherence. Similarly, Miller et al (1987) found no significant relationship between age and adherence.

Assessing similar associations in the relationship between social support and treatment compliance, Ahrari, Moshki, and Bahrami (2014) study aimed at investigating the relationship of social support and adherence to dietary and fluid restriction in hemodialysis patients, found that increase in age was associated with adherence to dietary and fluid restrictions. Asante (2012) in a study aimed at investigating the association between age, gender, social support, and psychological wellbeing of patients with HIV, found significantly negative correlation between age and social support. However, there was no significant correlation between age and all the components of psychological wellbeing measured in the study.

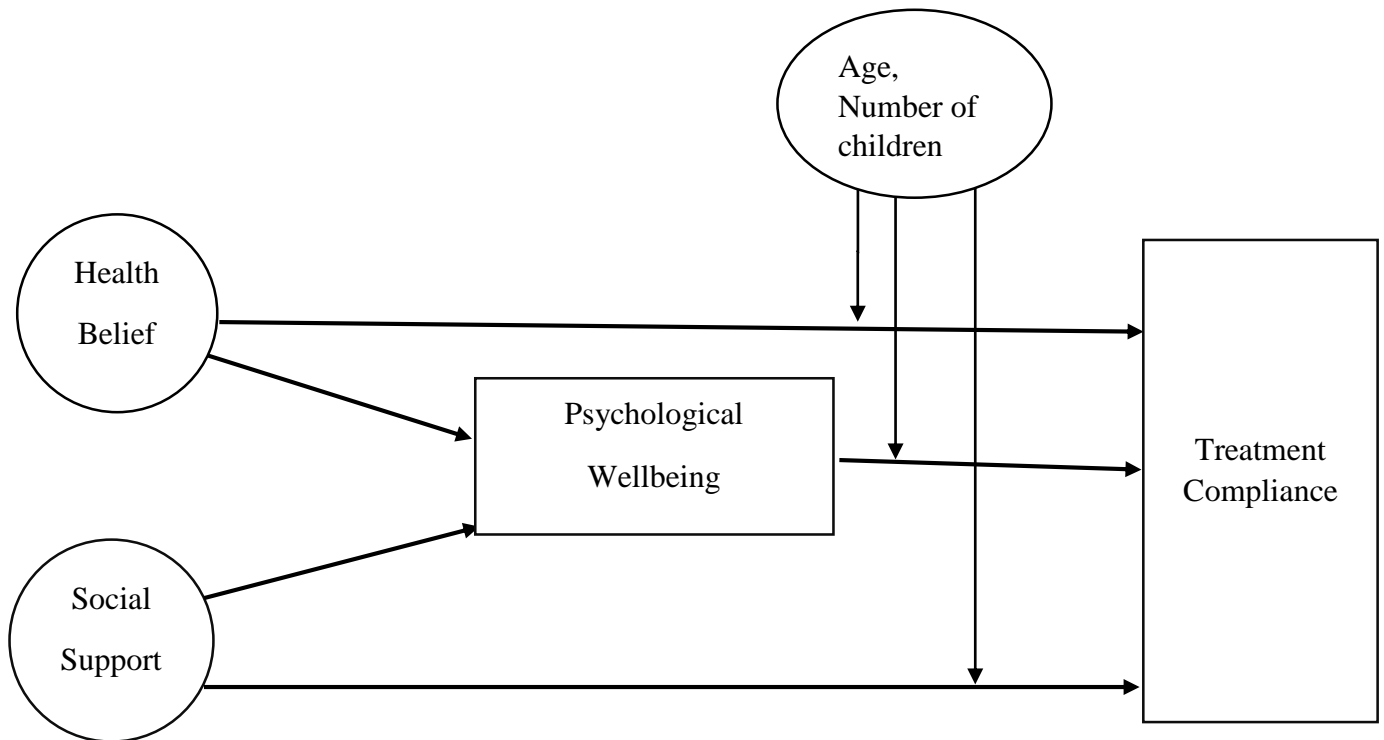
Pourghaznein (2013) again found that there was a significantly negative correlation between number of children and treatment compliance, in a study evaluating health belief and adherence in diabetes patients. It indicated that people with more children to take care of are more likely to be non-compliant with treatment. Bitaraes, Oliveira and Viana (2008) in their study aimed at assessing compliance in caregivers of SCD children in Brazil, found that there was no association between the number of children under the care of caregivers and their compliance to antibiotic prophylaxis treatment of their children.

### **Statement of Hypothesis**

- Hypothesis 1: Health belief of caregivers will predict their compliance to their children's treatment.
- Hypothesis 2: Social support of caregivers will predict their compliance to their children's treatment.
- Hypothesis 3: Psychological wellbeing will mediate the relationship between health belief and compliance to treatment.
- Hypothesis 4: Psychological wellbeing will mediate the relationship between social support and compliance to treatment.
- Hypothesis 5a: Age of caregiver and number of children will moderated the relationship between caregivers' health belief and their compliance to treatment.
- Hypothesis 5b: Age of caregiver and number of children will moderated the relationship between caregivers' social support and compliance to treatment.
- Hypothesis 5c: Age of caregiver and number of children will moderated the relationship between caregivers' psychological wellbeing and compliance to treatment.

Figure 1:

## Conceptual Framework



The above model illustrated in Figure 1, health belief, social support and psychological wellbeing are hypothesized to be predictive factors of treatment compliance, which is the dependent variable. However, psychological wellbeing is hypothesized to mediate the relationship between health belief and treatment compliance on one hand, and the relationship between social support and treatment compliance on the other. Age of the caregiver and number of children of the caregiver are hypothesized to be moderating factors between the three main independent variable and treatment compliance, the dependent variable.

### Operational Definition of Terms

**Caregiver:** A mother, father, sibling, grandparent, uncle, aunt, or a step parent who is responsible for taking care of a child with SCD or acute conditions.

**Health belief:** It includes six components that is measured by the modified Champion's Health Belief Model Scale (Perceived susceptibility, perceived severity, perceived benefits, perceived barrier, cues to action and self-efficacy)

**Social support:** It is the index of the three dimensions as measured by the Multi-dimensional Scale of Perceived Social Support (Family, Friend, and Significant others).

**Psychological wellbeing:** it includes six dimensions as measured by Ryff's Scale of Psychological Wellbeing (autonomy, environmental mastery, personal growth, positive relations, purpose in life, and self-acceptance)

**Compliance to treatment:** the caregiver's active commitment in the child's adherence to medication regimens as measured by Morisky's 8-item Medication Adherence Questionnaire.

**Chronicity of the condition:** the seriousness of the child's condition classified into chronic illness (i. e. SCD) and acute illness. In addition, the basis for the two groups of the study.

## **CHAPTER THREE**

### **METHODOLOGY**

This chapter discusses the research method employed in the investigation of effect of health beliefs, psychological wellbeing, and social support in predicting treatment compliance of caregivers of children with SCD and acutely ill children. It introduces the research setting and population, which include the description of the research setting, the characteristics of the population of the study. It also focuses on the sample and the sampling techniques employed in the study. The design of the research is also discussed in this chapter. In addition to these, the chapter also describes the data collection technique used as well as the description of the data collection instruments, inclusion and exclusion criteria, the pilot study, ethical considerations as well as a description of the data analysis tool that was used.

#### **Research Setting and Population**

The study was conducted in the Ashanti Region of Ghana specifically in Kumasi. Geographically the third largest region in the country, it occupies approximately 24,500 square kilometers of the land surface of Ghana. In terms of population, it is the second largest in the country with a population of about 4,780,380 inhabitants (Ghana Statistical Services, 2011).

Komfo Anokye Teaching Hospital was selected for the study. The pediatric sickle cell clinic of the hospital caters for patients of the northern and some other parts of the southern sectors of Ghana. The cultural and religious backgrounds of patients who attend clinic at the pediatric clinic are also representative of the population of the country, making the clinic suitable for this study.

**Sample**

The sample for the study was selected from the pediatric SCD OPD and the pediatric clinic of the Polyclinic. Bearing the characteristics of the population, and the researcher employing multiple regression as the analysis tool as well as the used of standardized instruments for data collection, the size of the sample was arrived at with the formula (Sample size =  $104 + m$ ). This is a recommendation by Tabachnick and Fidell (2007), where  $m$  represents the number of independent variables in the study. With the three main independent variables and the various demographic variables, the formula yielded a sample size of 114. According to Leedy and Ormond (2001), “larger samples are needed for heterogeneous populations while a smaller sample is needed for homogeneous population” (p. 221). The sample was made up of parents, siblings, grandparents and other relatives. A sample of two hundred (200) participants was selected. For this study being a comparison study, one hundred (100) participants represented the SCD caregivers’ group and the other hundred (100) represented the acutely ill group. This grouping is based on the chronicity of the medical condition.

**Sampling Technique**

Non-probability sampling techniques were used to select participants for the study for practical reasons. The researcher was interested in the caregivers of children with sickle cell disease and acute conditions. This made it difficult to employ probability sampling techniques expected to have been used in this study. The purposive sampling technique was used with an interest in caregivers of children with SCD and acute illness. With the research setting being a hospital, the convenience sampling technique was then used to select participants for the study.

**Inclusion criteria**

Caregivers caring for a child with SCD or other acute conditions between the ages 1-13 years were included. The caregiver themselves must be above the age of 18 years. The caregiver

must either be a parent to the child, related to the child or be a legal guardian of the child. The caregiver should have been living with the child for at least a year in the same household prior to the study and be responsible for the day to day care, including hospital visits and enforcement of treatment regimens.

### **Exclusion Criteria**

Caregivers of children with SCD and other chronic comorbid conditions were excluded as participants of this study. Caregivers suffering from a chronic disease were also excluded, as it might be a confounding variable. Caregivers of children below the age of 1 years and above the age of 16 years and those who are less than 18 year or above 60 years were also excluded.

### **Demographic Characteristics**

The distribution of demographic characteristics indicate that the caregivers' age ranged from 18years to 49 years [ $M = 34.72$ ,  $SD = 6.80$ ]. The age of the children of the caregivers ranged from 1 year and 16 years [ $M = 4.98$ ,  $SD = 3.81$ ]. In addition, the number of children under the caregivers' care ranged from 0 to 7 [ $M = 2.81$ ,  $SD = 1.60$ ]. There were 32 males (13 sickle cell group, 19 acutely ill group) and 168 females (87 sickle cell group, 81 acutely ill group) caregivers in the study. Table 1 illustrates the demographic characteristics of the participants.

Table 1:

## Demographic Characteristics of Participants

Demographic Variable	Characteristics	Sickle Cell Group	Acutely Ill Group	Total
Sex	Male	13	19	32
	Female	87	81	168
Marital Status	Married	78	91	169
	Single	13	4	17
	Separated	0	0	0
	Divorced	2	0	2
	Co-habiting	4	5	9
	Widowed	3	0	3
	Educational Level	None	5	5
	Primary	10	9	19
	JHS	39	38	77
	SHS	30	15	45
	Tertiary	16	33	49
	Religion	Christian	81	91
Child's Genotype	Muslim	18	9	27
	Tradition	1	0	1
	SS	40		40
Income	SC	46		46
	SF	14		14
	<GHC 250	46	58	104
	250 – 499	39	18	57
	500 – 999	10	10	20
Relationship To Child	1000 – 1500	1	14	15
	>1500	4	0	4
	Mother	81	85	166
	Father	12	12	24
	Other relatives	7	3	9

**Measures**

Questionnaires consisting of five (5) sections were used to gather data for the study. The first section consists of questions on demographic information. The second section consists of Champion's Health Belief Model Scale that was used to measure participants' health beliefs. The Ryff's Scale of Psychological Wellbeing was used to measure of the caregivers' psychological wellbeing. The Multi-dimensional Scale of Perceived Social Support was

employed to measure perceived social support. To measure participants' compliance to their children's treatment, the Morisky's 8-item Medication Adherence Questionnaire was employed in the last section.

### ***Demographic Data***

Information gathered on demographic characteristics include age, sex of the caregiver, educational level, marital status, religion, number of children of the caregiver, sex of the child, age of the child, income, and relationship to the child.

### ***Champion's Health Belief Model Scale – CHBMS (Champion, 1997)***

The CHBMS is a multi-dimensional scale that assesses health beliefs. It was originally developed by Champion in 1993, revised in 1997 and again in 1999 to assess beliefs towards breast cancer screening. The instrument was developed based on the health belief model (Rosenstock, 1974). It contains sixty-one (61) items with eight (8) subscales. Components of the instrument that fit the measure of health beliefs on SCD was employed and these include perceived susceptibility, perceived severity, perceived benefit, perceived barrier, self-efficacy and cue to action. The original scale reported internal consistency of these subscales ranging between .83 and .91 (Champion, Skinner, & Menon, 2005; Champion & Scott, 1997)

In this study, the scale has been adopted with some modifications and the word "Breast cancer" was replaced with "sickle cell disease". There are 32 items in the scale with items allocated to take the measure of perceived susceptibility (4 items), perceived severity (7 items), perceived benefits (6 items), perceived barriers (6 items), cue to action (7 items), and self-efficacy (2 items). Items on the instrument include "the thought of sickle cell disease scares me," and "sickle cell disease hurts one's life and loved ones." The response options for each item a Likert format ranging from 1 to 5, with 5 being "strongly agree" and 1 being "strongly disagree." See appendix C for a copy of the scale.

***Ryff's Scale of Psychological Well-Being- RSPW (Ryff, 1989b)***

This is a multidimensional scale designed by Ryff (1989b) to measure six theoretically motivated constructs of psychological wellbeing. It contains items that measure six dimensions of wellbeing. These are autonomy – independence and self-determination; environmental mastery – the ability to manage one's life; personal growth – being open to new experiences; positive relations with others – having satisfying high quality relationships; purpose in life – believing that one's life is meaningful; and self-acceptance – a positive attitude towards oneself and one's past life (Ryff & Keyes, 1995).

The scale was originally validated on a sample of 321 well-educated, socially connected, financially comfortable, and physically healthy men and women (Ryff 1989a). In that study, a 20- item scale was used for each of the six constructs, with approximately equal numbers of positively and negatively worded items. The internal consistency coefficients were quite high (between 0.86 and 0.93) and the test-retest reliability coefficients for a subsample of the participants over a six week period were high (0.81- 0.88). Ryff and Keyes (1995) in a study found that the shortened scale correlated from 0.70 to 0.89 with a 20-item parent scale.

The 42-item version of the scales was employed in this study to measure the wellbeing of the primary caregivers. The response format for all RPWB items was on a six (6) point Likert scale, ranging from strongly disagree, moderately disagree, slightly disagree, slightly agree, moderately agree, and strongly agree. Twenty (20) items comprised positive items while 22 had negative items. All the subscales have 7 items each measuring the construct that they represent. The scale had items like “in general, I feel I am in charge of the situation in which I live”, “I have a sense of direction and purpose in life”, and “my decisions are not usually influenced by what everyone else is doing”. Prior to analysis, items with negative content were reverse scored so that high values indicated better psychological well-being. A score on the

instrument represented a participant's psychological wellbeing. This scale was chosen because it had reported good internal consistencies in previous study in measure psychological wellbeing.

***Multi-dimensional Scale of Perceived Social Support – MSPSS (Zimet, Dahlem, Zimet & Farley, 1988)***

The Multi-Dimensional Scale of Perceived Social Support (MSPSS) is a self-report subjective measure that measures mainly three dimensions of social support. It is a 12-item instrument that measures three sources of social support; family, friends, and significant others. Response is on a 1-7 Likert scales ranging from very strongly disagree to very strongly agree. Originally a 24-item scale on a 1-5 Likert scale, results from various pilot study led to the revised and current version of the scale. In the study by Zimet et al (1988), the scale reported internal consistency of .87, .85, and .91 for family, friends, and significant others respectively. It reported an alpha of .88 for the scale in total. Items on the scale include “There is a special person with whom I can share my joys and sorrows”, “My family really tries to help me”, “I can count on my friends when things go wrong”, and others. This scale was employed for this study for its consistency in predicting social support in previous study. There have been a number of studies done to establish the psychometric properties of this scale. For instance, Canty-Mitchell and Zimet (2000) investigated the MSPSS with a sample of urban adolescents and found internal reliability estimates of .93 for the total score and .91, .89, and .91 for the Family, Friends, and Significant Others subscales respectively. Factor analysis of the MSPSS with their sample confirmed the three-factor structure of the measure. In addition, Edwards (2004) investigated the psychometric properties of the scale and found the internal reliability of the total scale to be .86, with the subscales being .88, .90, and .61 for Family, Friends, and Significant Others respectively. In this study there were no changes made to the scale.

***Medication Adherence Questionnaire - MAQ (Morisky, Green & Levine, 1986)***

The MAQ is a self-report measure of medication adherence. It contained 8 items enquiring about activities relating to adherence. Each item measures a specific medication-taking behavior and not a determinant of adherence behavior. Response categories are “Yes” and “No” indicating 1 and 2 respectively for each item and a 5-point Likert response for the last item. Response on items ranged from 0 to 1, such that a total score of 0 represents higher adherence, a total score between 1 and 3 represents medium adherence and a total score between 4 and 8 represents low adherence. Morisky et al. (1986) reported a Cronbach alpha of .71.

For this study, the items in the scale were retained except for substitutions of some words to suit the caregiver’s response. For instance, “Do you sometimes forget to give your child his/her medicine?” and “Did you give your child all his/her medicines yesterday?” All items were also reversed scored so that higher score represent good adherence

**Pilot Study**

The pilot study was done to test the applicability and internal consistency of the items of the selected instruments for the study before the commencement of the actual data collection. To make sure that the participants for the pilot study were from the same population, it was conducted in the Poly Clinic of the Komfo Anokye Teaching Hospital in the Kumasi. Twenty-one (21) caregivers of children with various kinds of acute conditions were recruited into the pilot study. The ages of the participants were between 25 years and 48 years with a mean age of 35.90 years. These caregivers were taking care of children between ages 1 and 6 children in their household with 3.14 as the mean number of children they are caring for in addition to the child with the acute condition. The mean age of the children with the acute condition was 4.05 years. The scales on the questionnaire were translated into Twi and back translated into English to ensure its applicability. Changes were made to some of the items to suit the understanding of the participants of the study.

After the administration of the instruments, reliability coefficients were established for the instruments. The modified Champion’s Health Belief Model Scale recorded an alpha of .78; the Ryff’s Scale of Psychological Wellbeing had an alpha of .92; the Multi-dimensional Scale Perceived Social Support had an alpha of .87; and the Morisky 8-item Medication Adherence Questionnaire had an alpha of .52. According to Nunnally and Berstein (1994), a scale is

considered accepted if it attains an alpha of above .50 for research however, it is ideal for a scale to have an alpha of .70 and above, for statistical strength. Therefore, these alpha scores suggest that the instruments are reliable for use for this study. The Cronbach alphas for the subscales are presented below in Table 2.

Table 2:

Internal Reliability Coefficients of the Instruments and Their Subscales

Instrument	Subscale	Cronbach Alpha ( $\alpha$ )
CHBMS		<b>.78</b>
	Perceived susceptibility	.80
	Perceived severity	.93
	Perceived benefit	.86
	Perceived barrier	.79
	Cue to action	.76
	Self-efficacy	.76
RSPW		<b>.92</b>
	Autonomy	.84
	Environmental mastery	.75
	Personal growth	.78
	Positive relations	.84
	Purpose in life	.85
	Self-acceptance	.82
MSPSS		<b>.87</b>
	Family	.80
	Friends	.87
	Significant others	.92
MAQ		<b>.52</b>

## Design

The research design employed in this study is the cross sectional design. This design was chosen for the features it possessed. These features include reliance on existing differences rather than change following an intervention as seen in experiments, no time dimension, and that participants are grouped based on existing difference rather than random allocation (Hall, 2008). This study sought to establish a predictive relationship between psychological characteristics of the population; health belief, psychological wellbeing, their social support,

and their adherence to the medication regimen of their children with sickle cell disease and acutely ill children.

### **Procedure**

This study received approval from the Ethics Committee for Humanities (ECH) of the University of Ghana. An introductory letter was obtained from the Department of Psychology of the University of Ghana to the two hospital directorates of the Komfo Anokye Teaching Hospital (KATH) where the study was conducted. On approval from the directorates, permission was obtained from the Research and Development Unit (RDU) of KATH through the Child Health Directorate and the Poly Clinic Directorate for the collection of data from the pediatric sickle cell clinic and the pediatric polyclinic respectively. An additional approval was obtained from the Committee on Human Research, Publication, and Ethics (CHRPE) of the Kwame Nkrumah University of Science and Technology (KNUST) and KATH, under whose jurisdiction the study was being conducted.

With a consent form design under the requirements of ECH and CHRPE, participants were then recruited at the sickle cell clinic and the pediatric clinic to participate in the study. The purpose and the objective of the study, found within the consent form were explained to them and those that agreed to be part of the study gave their consent by completing the form. This was done in accordance with the research requirement of ECH as well as CHRPE.

The researcher and research assistants who have been trained in the administration of the scales on the questionnaire by the researcher then administered the coded questionnaire containing a section for collecting demographic information, Health Belief Model scale, psychological wellbeing scale, perceived social support scale, and medication adherence questionnaire to each participant. Instructions on each section were explained to participants to understand what was expected of them before they start the section. Confidentiality of the

information given by the participants was assured and the questionnaire was then collected for scoring and data entry for subsequent analysis.

## CHAPTER FOUR

### RESULTS

The primary purpose of this study was to find out whether the interaction between health belief, social support, and psychological wellbeing of the caregivers play a role in the management and treatment of children with SCD and other acute illness. Health belief, psychological wellbeing, and social support were examined as predictors of compliance to treatment. Psychological wellbeing was however examined as mediating the relationship between health belief, social support, and treatment compliance. Demographic characteristics which included age of the caregiver, relation to the child, marital status, income, sex, educational level, and religion was examined as moderating the relationship between the predictors and treatment compliance of the caregivers. Five hypothesis were tested using a series of regression analyses, which is in line with the aims and objectives of the study.

#### **Preliminary analyses**

Preliminary analyses were presented in four sections, which include the analysis of the normal distribution of the variables, descriptive statistics, reliability analysis, and the computations of the Pearson correlations among the variables of the study. The normality of the data obtained for the study was verified. The analysis as illustrated in table 1 below revealed that the variables for the study were all normally distributed. Normality test for the kurtosis and Skewness revealed no challenges with all scales used for the analyses having a value ranging between  $\pm 1$ . All variables were therefore cleared to be used in the analyses. Table 3 below illustrates the results of the mean, standard deviation, kurtosis, Skewness, and internal consistencies.

Table 3:

Mean scores, Standard Deviation, Normality, and Internal Consistency of the Major Scales.

Instrument	Mean	SD	Skewness	Kurtosis	Cronbach's Alpha
CHBMS	96.23	9.06	-.15	-.37	.71
RSPW	191.97	20.88	-.57	-.34	.85
MSPSS	58.71	13.97	-.17	-.93	.86
MAQ	12.76	1.83	.46	-.77	.52

Note:  $N = 200$ ; CHBMS = Champion's Health Belief Model Scale; RSPW = Ryff's Scale of Psychological Wellbeing; MSPSS = Multidimensional Scale of Perceived Social Support; MAQ = Medication Adherence Questionnaire.

As illustrated in table 3 above, the reliability coefficients reported for the health belief model scale, psychological wellbeing scale and the social support scale were .71, .85 and .86 respectively. The medication adherence questionnaire however reported a reliability coefficient of .51. The correlation between the various variables used in the study was also analyzed. The results are presented in Table 4 below.

Table 4:  
Pearson's Product Moment correlations coefficients between the study's variables

Variables	1	2	3	4	5	6	7	8	9	10
1 Age of caregiver	-									
2 Group	.19**	-								
3 No. of children	.29**	.21**	-							
4 Marital Status	.21**	.22**	.28**	-						
5 Education	.07	.09	-.37**	.01	-					
6 Income	.11	.01	-.17*	.08	.32**	-				
7 Health belief	.08	.33**	.20**	.27**	.24**	.15*	-			
8 Psych. Wellbeing	-.02	-.10	-.18*	.03	.25**	.04	.18**	-		
9 Social support	-.15*	-.30**	-.22**	-.10	.17*	.12	-.01	.34**	-	
10 Treat. Compliance	-.09	-.64**	-.15*	-.15*	.01	.08	-.21**	.23**	.49**	-

Note: \* $p < .05$ , \*\* $p < .01$ ,  $N = 200$

Health belief was found to have a significantly negative correlation with treatment compliance [ $r = -0.21$ ,  $p = .003$ ], indicating that the higher the health belief of the caregiver, the more likely it is that they will not adhere to the medication of their children. Psychological wellbeing was found to have a significantly positive correlation with treatment compliance [ $r = 0.23$ ,  $p = .001$ ], indicating that the more caregivers feel psychologically healthy, the more they are likely to adhere to the medication of their children. Social support also had a significantly positive correlation with treatment compliance [ $r = 0.49$ ,  $p = .000$ ], showing that when caregivers enjoy a higher level of social support from all sources, they are likely to adhere to the medication

regimen of their children. Number of children under the care of caregivers was also found to have a significantly negative correlation with treatment compliance [ $r = -.154, p = .029$ ]. This indicates that caregivers with higher number of children are less likely to adhere to the medication regimen of their children. Marital status was dummy-coded and entered with married and cohabiting as reference point to indicate the presence of a partner. Marital status was found to have a significantly negative correlation with treatment compliance [ $r = -.15, p = .032$ ]. This indicates that caregivers with partners are less likely to comply with their children's treatment regimen. Group was coded with 1, being sickle cell group, and 2, being acutely ill group. Group was found to have a significantly negative correlation with treatment compliance [ $r = -.64, p = .000$ ]. This indicated that caregivers from the sickle cell group are more likely to be compliant with their children's treatment than caregivers from the acutely ill group. Further relationships are observed in the results of the testing of the stated hypotheses.

### **Hypothesis Testing**

Five hypotheses were tested in this study. The hypotheses one and two were tested using standard multiple regression analysis. Hypotheses three, four and five were tested using hierarchical multiple regression analysis. Mediating effect of psychological wellbeing in the relationship between health belief and social support, and the dependent variable was tested in hypotheses three and four. For hypothesis five, the moderating effects of demographic variables of age and number of children were tested on the relationship between the independent variables and the dependent variable. The dependent variable consisted of the index score of participants on the Morisky's 8-item Medication Adherence Questionnaire (MAQ). The independent variables in the study were health belief, psychological wellbeing, and social support. The health belief variable constituted a composite score of six variables; perceived susceptibility, perceived severity, perceived benefit, perceived barrier, cue to action

and self-efficacy. The psychological wellbeing variable also constituted a composite score six variables; autonomy, environmental mastery, personal growth, positive relations, purpose in life, and self-acceptance. The social support variable constituted a composite score from three major sources of support; family, friends and significant others. All participants of the study were measured on all the variables involved in the study. The participants were in two groups namely, sickle cell group and acutely ill group based on the chronicity of their children's condition.

### **Testing for the Predictors of Caregivers' Treatment Compliance**

In testing for the prediction of treatment compliance by health belief, social support and psychological wellbeing, standard multiple regression was conducted. All assumptions for conducting regression were examined before testing. The assumptions of normality, independence of error, homogeneity of variance, multicollinearity, and missingness of data were all met. To indicate the assumption of linearity, partial scatterplot of health belief, psychological wellbeing, and social support as the predictors, and the treatment compliance as the criterion, displayed points falling within an absolute value of two (2).

The health belief, social support, psychological wellbeing, age of caregiver, and number of children, were entered in a block as predictors and treatment compliance was entered as the criterion. The addition of age of caregivers, and number of children were based on their ability to predict treatment compliance in previous studies and a significant correlation with treatment compliance respectively.

### **Hypothesis One**

It was hypothesized that 'health belief of caregivers will predict their compliance to their children's treatment. The results of the regression analysis as illustrated in table 5 below showed that health belief predicted treatment compliance significantly [ $t_{(192)} = -3.65, \beta = -.23$ ,

$p = .000$ ]. Findings also showed that the model accounted for approximately 30% of the variance in treatment compliance [ $F_{(7, 194)} = 11.86, R^2 = .30, p = .000$ ]. This means that the hypothesis that “health belief of caregivers will predict their compliance to their children’s treatment” was supported. The result of the analysis is presented in table 5 below. However, with reference to table 7, health belief did not significantly predict treatment compliance in both the sickle cell group and the acutely ill group [ $t_{(98)} = -.40, \beta = -.04, p = ns$ ], [ $t_{(98)} = .50, \beta = .05, p = ns$ ] respectively.

Table 5:

Summary Table of Standard Multiple Regression Analysis Testing Predictors of Treatment Compliance

Model		B	SEB	$\beta$	$t$
<b>1</b>	Health belief	-.05	.01	-.23*	-3.65*
	Social support	.06	.01	.44*	6.80*
	Psychological wellbeing	.01	.01	.12	1.78
	Age of caregivers	-.002	.02	-.01	-.10
	Number of children	.02	.08	.01	.20
Model summary					
	$\Delta F$	11.86*			
	(df)	(194)			
	$\Delta R^2$	.30			
	Adj $R^2$	.27			
	$R^2$	.30			

Note: \*  $p < .001$

## Hypothesis Two

Social support of caregivers was hypothesized to predict their compliance to their children’s treatment. In testing this hypothesis, standard multiple regression analysis was again conducted, entering social support, health belief, psychological wellbeing, age of caregiver, and number of children as predictors and treatment compliance as the criterion. The results illustrated in table 5 above, revealed that social support predicted treatment compliance

significantly [ $t_{(194)} = 6.80, \beta = .44, p = .000$ ]. Findings show that the model accounted for approximately 30% of the variance in treatment compliance [ $F_{(7, 194)} = 11.86, R^2 = .30, p = .000$ ]. This indicates that the hypothesis that “social support of caregivers will predict their compliance to their children’s treatment” was supported.

### **Testing Mediation role of psychological wellbeing**

Psychological wellbeing of caregivers was hypothesized to be a mediating variable in the relationship between their health belief and their treatment compliance, and their social support and their treatment compliance.

In testing this mediation, multiple regression was employed. All assumptions for conducting regression analysis were examined before testing. Review of scatterplot of unstandardized residuals of predicted values showed a random display of points falling within an absolute value of two (2), indicating linearity. The bloxplot suggested a relatively normal distributional shape of residuals with no outliers. The Durbin-Watson statistic was computed to evaluate independence of error and was 1.58, which is considered acceptable indicating that the assumption of independent of error was met. The assumption of the homogeneity of variance was met when scatterplots of studentized residuals against predicted values and against values of the independent variables showed a relatively random display of points constant over the range of values of the independent variables. Tolerance and VIF were all in normal ranges (.809 and 1.236 respectively), indicating that the assumption of multicollinearity was met.

### **Hypothesis Three**

Multiple regression analysis was used to investigate the hypothesis that “psychological wellbeing will mediate the relationship between health belief and compliance to treatment”. As

table 4 illustrated, there was significant correlation between the health belief and treatment compliance [ $r = -0.21, p = .003$ ]. Therefore, mediation analysis was conducted.

As illustrated in table 6, results indicated that health belief was a significant predictor of psychological wellbeing, [ $t_{(197)} = 2.6092, \beta = .4201, p = .0098$ ] and that psychological wellbeing was a significant predictor of treatment compliance [ $t_{(197)} = 3.9693, \beta = .0237, p = .0001$ ]. These results support the mediational hypothesis. Health belief was a significant predictor of treatment compliance after controlling for psychological wellbeing, [ $t_{(197)} = -3.8096, \beta = -.0524, p = .0002$ ] consistent with partial mediation. Without adjusting for psychological wellbeing, health belief significantly predicted treatment compliance [ $t_{(197)} = -3.0277, \beta = -.0424, p = .0028$ ]. Approximately 12% of the variance in treatment compliance was accounted for by the predictors [ $F_{(2, 197)} = 12.8029, R^2 = .12, p = .000$ ]. Using the Sobel test for indirect effect, health belief significantly predicted treatment compliance through psychological wellbeing [ $z = 2.1875, \beta = .0100, p = .0287$ ]. These results show that caregivers' health beliefs was associated with approximately 1/100 points higher treatment compliance scores as mediated by psychological wellbeing. Therefore, the hypothesis that 'psychological wellbeing will mediate the relationship between health belief and treatment compliance' was supported.

Table 6;

Summary of the Effect of Health Belief on Treatment Compliance as Mediated by Psychological Wellbeing.

Effect	$\beta$	SE	$t$	$z$
Effect of HB on PWB	.4201*	.1610	2.6092*	
Effect of PWB on TC	.0237*	.0060	3.9693*	
Adjusting for PWB, effect of HB on TC	-.0524*	.0137	-3.8096*	
Without adjusting for PWB, effect of HB on TC	-.0424*	.0140	-3.0277*	
Indirect effect of HB on TC through PWB	.0100**	.0045		2.1875**
F	12.8029****			
R <sup>2</sup>	.1150			
Adj R (df1), (df2)	.1060 (2), (197)			

Note: HB = Health belief, PWB = psychological wellbeing, TC = treatment compliance. \*  $p < .01$ , \*\*  $p < .05$ , \*\*\*  $p < .001$

#### **Hypothesis Four**

Psychological wellbeing was hypothesized to mediate the relationship between social support and treatment compliance. Multiple regression analysis was again employed to investigate this hypothesis. Table 4 shows that there is a significant correlation between social support and treatment compliance [ $r = .49$ ,  $p = .000$ ], therefore permitting mediation analysis to be conducted.

Results from the analysis as illustrated in appendix H, show that social support significantly predicted psychological wellbeing [ $t_{(197)} = 4.9980, \beta = .5001, p = 000$ ], but psychological wellbeing was not a significant predictor of treatment compliance [ $t_{(197)} = 1.0383, \beta = .0060, p = .3004$ ]. After controlling for psychological wellbeing, social support significantly predicted treatment compliance [ $t_{(197)} = 7.0143, \beta = .0605, p = 000$ ]. Social support predicted treatment compliance significantly, without controlling for psychological wellbeing [ $t_{(197)} = 7.8109, \beta = .0635, p = .000$ ]. These results do not support the hypothesis for mediation; therefore, there was no need to run further analysis for mediation. The results showed that the hypothesis that “psychological wellbeing will mediate the relationship between social support and treatment compliance” was not supported. This indicates that social support of caregivers which is significantly associated with their treatment compliance score does not change significantly as mediated by psychological wellbeing. (See results table in appendix H).

### **Testing Moderation**

In order to test the moderation effect of age of caregivers and number of children in the relationship between health belief, psychological wellbeing, social support, and treatment compliance, the assumptions for conducting regression analysis was examined. The assumptions of normality, linearity, independence of error, and homogeneity of variance were met before testing. The independent variables and the demographic variables were standardized to prevent any problems associated with multicollinearity.

Hierarchical regression analysis was therefore employed to examine the moderation effect of age of caregiver and number of children of caregivers, on the relationship between health belief and treatment compliance, social support and treatment compliance, and also psychological wellbeing and treatment compliance.

**Hypothesis Five (a)**

To determine whether caregivers' demographic characteristics significantly moderate the relationship between health belief and treatment compliance, hierarchical multiple regression was employed. With treatment compliance as the dependent variable, health belief was entered into the first block. The age of the caregiver and number of children were added in the second block and the third block contained the interaction of each of the demographic variable and health belief. The result of the analysis is presented below in Table 7.

Table 7;

Summary of Moderating Effect of Some Demographic Variables on the Relationship between Health Belief and Treatment Compliance.

Variables	Treatment compliance								
	Sickle cell			Acute illness			All caregivers		
	$\Delta R^2$	$\beta$	<i>t</i>	$\Delta R^2$	$\beta$	<i>t</i>	$\Delta R^2$	$\beta$	<i>t</i>
<i>Step 1</i>	.002			.003			.04		
HB		-.04	-.40		.05	.50		-.21*	-3.03*
<i>Step 2</i>	.003			.007			.02		
Age of Caregiver		.05	.41		.08	.83		-.05	-.63
No. of Children		-.07	-.54		-.007	-.07		-.11	-1.42
<i>Step 3</i>	.05			.02			.01		
HB*age Of Caregiver		-.16	-1.15		-.19	-1.32		-.13	-1.55
HB*No. of Children		-.13	-.97		.04	.30		.08	.93
<i>n</i>	100			100			200		

Note: \* $p < .01$ , HB = health belief, Step 3 Summary:  $\Delta F = 2.71$ ,  $R^2 = .06$ , ( $df$ ) = (94) for sickle cell group,  $\Delta F = .90$ ,  $R^2 = .03$ , ( $df$ ) = (94) for acutely ill group, and  $\Delta F = 1.22$ ,  $R^2 = .07$ , ( $df$ ) = (194) for all caregivers.

As observed in Table 7 above, no significant prediction was made on treatment compliance by the interaction of the moderators and health belief, [ $t_{(194)} = -1.55$ ,  $\beta = -.13$ ,  $p = .123$ ] and [ $t_{(194)} = .93$ ,  $\beta = .08$ ,  $p = .356$ ] for age and number of children respectively. The interaction between the moderators and health belief did not significantly account for the variance in treatment compliance [ $F_{(2,194)} = 1.22$ ,  $R^2 = .07$ ,  $p = .298$ ]. Therefore the hypothesis that “age of the caregiver and number of children will moderate the relationship between caregivers' health

beliefs and their compliance to treatment” was not supported, indicating that demographic characteristics of caregivers does not have influence in how well they will comply with their children’s treatment in terms of their health belief. Similarly, there was no moderating effect of the demographic variables observed in the sickle cell group, [ $t_{(194)} = -1.15, \beta = -.16, p = .253$ ], [ $t_{(194)} = -.13, \beta = -.97, p = .335$ ] and the acute illness group [ $t_{(194)} = -1.32, \beta = -.19, p = .189$ ], [ $t_{(194)} = .30, \beta = .04, p = .764$ ] for age and number of children respectively.

### Hypothesis Five (b)

This hypothesis is stated, as “age of caregiver and number of children will moderate the relationship between caregivers’ social support and their compliance to treatment”. To determine this, hierarchical multiple regression was employed. Social support was entered in the first block, with the demographic variables in the second block and the interaction of each of the demographic variables with health belief in the third block. The results are presented in table 8 below.

Table 8:

Summary of Moderating Effect of Some Demographic Variables on the Relationship between Social Support and Treatment Compliance.

Variables	<i>Treatment compliance</i>								
	Sickle cell			Acute illness			<i>All caregivers</i>		
	$\Delta R^2$	$\beta$	$t$	$\Delta R^2$	$\beta$	$t$	$\Delta R^2$	$\beta$	$t$
<i>Step 1</i>	.16			.16			.24		
SS		.40*	4.34*		.40*	4.34		.49*	7.81*
<i>Step 2</i>	.01			.01			.002		
Age of Caregiver		.13	1.15		.08	.89		-.01	-.07
No. of Children		-.07	-.63		.09	.92		-.05	-.71
<i>Step 3</i>	.01			.03			.01		
SS*age of Caregiver		-.13	-1.05		-.15	-1.24		-.10	-1.47
SS*No. Of Children		-.03	.26		-.17	-1.49		-.04	-.65
<i>n</i>	100			100			200		

Note: \* $p < .001$ , SS = Social support, Step 3 Summary:  $\Delta F = .58, R^2 = .18, (df) = (94)$  for sickle cell group,  $\Delta F = 1.69, R^2 = .20, (df) = (94)$  for acutely ill group, and  $\Delta F = 1.65, R^2 = .25, (df) = (194)$  for all caregivers.

In table 8 above, there was no significant prediction in the treatment compliance by the interaction of the moderators and social support in all the caregivers, [ $t_{(194)} = -1.47, \beta = -.10, p = .142$ ], [ $t_{(194)} = -.65, \beta = -1.47, p = .520$ ] for age and number of children respectively. Moreover, the interactions between the moderators and social support did not significantly account for the variance in treatment compliance [ $F_{(2, 194)} = 1.65, R^2 = .25, p = .193$ ]. Therefore the hypothesis that ‘age of caregiver and number of children, will moderate the relationship between caregivers’ social support and their compliance to treatment’ was not supported by the data, indicating that demographic characteristics of the caregivers have no influence in how well they comply with their children’s treatment in terms of their social support. Assessing the same relationship among the caregivers of children with sickle cell and those with acute illness yielded similar results. None of the interactions of the demographic variables with social support significantly account for variance in treatment compliance.

### **Hypothesis Five (c)**

This hypothesis states “age of caregiver and number of children will moderate the relationship between caregivers’ psychological wellbeing and their compliance to treatment”. A hierarchical multiple regression was employed to test this hypothesis. In following the steps proposed by Baron and Kenny (1986), the psychological wellbeing was entered into the first block, with the demographic variables in the second block. The third contained the interaction of each of the demographic variables and psychological wellbeing. Beta scores were obtained for the variable and the results are presented in Table 9 below.

Table 9:

Summary of moderating effect of age and number of children on the relationship between psychological wellbeing and treatment compliance.

Variables	Treatment compliance								
	Sickle cell			Acute illness			All caregivers		
	$\Delta R^2$	$\beta$	$t$	$\Delta R^2$	$B$	$t$	$\Delta R^2$	$\beta$	$t$
<i>Step 1</i>	.001			.16			.05		
PWB		.03	.31		.40**	4.34**		.22**	3.22
<i>Step 2</i>	.01			.01			.02		
age Of Caregiver		.06	.48		.02	.25		-.06	-.80
No. Of Children		-.08	-.66		.12	1.22		-.10	-1.38
<i>Step 3</i>	.017			.001			.03		
PWB*age f Caregiver		-.12	-.89		-.03	-.33		-.17*	-2.31*
PWB*No. of Children		-.03	-.18		-.02	-.17		.16*	2.13*
<i>n</i>	100			100			200		

Note: \* $p < .05$ , \*\* $p < .001$ , Step 3 Summary:  $\Delta F = .84$ ,  $R^2 = .02$ , (df) = (94) for sickle cell group,  $\Delta F = .08$ ,  $R^2 = .18$ , (df) = (94) for acutely ill group, and  $\Delta F = 3.58^*$ ,  $R^2 = .10^*$ , (df) = (194) for all caregivers.

In table 9 above, the interaction between psychological wellbeing and the moderators significantly predicted treatment compliance in all caregivers, [ $t_{(194)} = -2.31$ ,  $\beta = -.17$ ,  $p = .022$ ] and [ $t_{(194)} = 2.13$ ,  $\beta = .16$ ,  $p = .034$ ] for age and number of children respectively. The interaction between psychological wellbeing and the moderators significantly accounted for 10% of the variance in treatment compliance [ $F_{(2, 194)} = 3.58$ ,  $R^2 = .10$ ,  $p = .03$ ]. Therefore, the hypothesis that “age of caregiver and number of children will moderate the relationship between caregivers’ psychological wellbeing and their compliance to treatment” was supported by the data, indicating that age and number of children of caregivers have an influence in how well they will comply with their children’s treatment in terms of their psychological wellbeing. However, there was no significant prediction of treatment compliance by the interaction of the moderators and psychological wellbeing in sickle cell group [ $t_{(194)} = -.89$ ,  $\beta = -.12$ ,  $p = .376$ ], [ $t_{(194)} = -.18$ ,  $\beta = -.03$ ,  $p = .860$ ] for age and number of children respectively. A similar

relationship was observed in the acute illness group [ $t_{(194)} = -.33, \beta = -.03, p = .745$ ], [ $t_{(194)} = -.17, \beta = -.02, p = .866$ ] for age and number of children respectively.

### **Summary of Results**

This study tested five main hypotheses to find out the influence of psychological factors of health belief, social support, and psychological wellbeing on caregivers' compliance to their children's treatment. The summary of the findings are as follows:

Health belief of caregivers negatively influenced their compliance to their children's treatment.

Social support experienced by the caregivers had a positive influence on their compliance to the treatment of their children.

The influence of caregivers' health belief on their compliance to their children's treatment was mediated by their psychological wellbeing.

The influence of social support of caregivers on their treatment compliance was not mediated by their psychological wellbeing.

Age and number of children of caregivers does not have an influence on how well caregivers will comply with their children's treatment in terms of their health belief and social support in all caregivers groups. Similar relationship was observed in the sickle cell and the acute illness groups in terms of health belief and social support. However, age and number of children had a significant influence in the relationship between psychological wellbeing and treatment compliance in all caregivers. These demographic characteristics however did not have any influence on how well caregivers complied with their children's treatment in terms of psychological wellbeing in both the sickle cell and the acute illness group.

## CHAPTER FIVE

### DISCUSSION

This study was set to examine the extent to which health beliefs, psychological wellbeing, social support and some selected demographic characteristics influence the treatment compliance given by caregivers of SCD children. It was also aimed at finding out if the psychological wellbeing of caregivers plays a mediating role in the relationship between their health belief and social support as predictors and their compliance to their children's treatment regimen. The study also examined if some selected demographic characteristics of caregivers have any moderating role to play in the relationship between health belief, social support, psychological wellbeing, and their compliance to their children's treatment.

In this chapter, discussions on the findings derived from the study are presented. In addition to this, the general implications of the study to clinical work as well as research and the necessary recommendations for general care of children with SCD are also discussed. The chapter finally ends with the summary and conclusion of the study.

#### **Health belief and treatment compliance of caregivers**

One of the major objectives of the study was to find out whether health belief of caregivers will predict their compliance to treatment regimen of their children. Health belief significantly predicted some variance in the caregivers' treatment compliance. This finding is consistent with a great deal of past research in health belief and adherence which show that health belief is predictive of adherence behaviour (e. g. Kelly et al., 1987; Mardanian Dehkordi, 2013; Pourghaznein et al., 2013; Putman 2004). However, there were some differences in the nature of the predictions between this study and the previous ones. For example, in this study, we found the association between treatment compliance and health belief to be negative while others have found the relationship to be positive (e.g. Pourghaznein et al., 2013; Putman, 2004).

This may have been because in Putman's (2004) study for example, observational study design was employed without the use of a standardized instrument for the measure of health belief. Pourghaznein et al. (2013) who employed the use of a standardized instrument investigated relationships between compliance and components of health belief. They found varying relationships between these components of health belief and compliance, without assessing health belief as a whole. Others studies (e.g. Mardanian Dehkordi, 2013; Olsen et al., 2008) employing different instruments for assessing health belief and compliance, may have accounted for the difference in the nature of the predictions. It is likely that the difference may be because of the instrument and nature of coding of the health belief that was employed in the present study.

The health belief model (Rosenstock, 1974) postulate that the likelihood of a person engaging in a recommended healthy behaviour is determined by the possibility of avoiding a negative health condition or consequence, effectiveness of the healthy behaviour in avoiding the negative consequence, and the capability of the person in engaging in the healthy behaviour that is recommended. The model proposes that if a person does not have these perceptions, the person is likely to desist from the recommended healthy behaviour. In this study, the caregivers showed higher levels of health belief but exhibited low levels of compliance to their child's medication regimen.

One probable explanation for this finding may be that the Ghanaian society is known to be highly religious, with sufferers of chronic diseases perceiving the etiology of the condition as spiritual (De Graft-Aikins et al., 2012; Dennis-Antwi, 2008); believing that it is a curse or being caused by their enemies through witchcraft. Even though the orthodox medical forms of treatment at the hospital are made available to them, they may still prefer to go to the traditional healers or priests for remedies for SCD. In most cases, they would only use the hospital

treatment as a second option to the traditional treatment forms. Periodic hospital visits would be adhered to, but the medication given would not be sufficiently taken.

It may also be that health care professionals at the hospitals do not educate the patient and their caregivers enough about the dangers of using alternative forms of treatment for the condition. The caregivers may then consider these forms of treatments that are already available in their communities.

The present study also investigated the possibility that psychological wellbeing will mediate the relationship between health belief and compliance to treatment. The results of the study revealed that health belief of caregivers' prediction of their compliance to their children's treatment was partially mediated by their psychological wellbeing. Consistent with previous studies (e.g. Wrubel et al., 2005; Reis et al., 2013), psychological wellbeing was found to play a significant role in adherence to treatment. Psychological wellbeing has been evaluated in previous studies as an outcome of stress and disease. In this study, it was viewed as a predictor of healthy behaviour that is aimed at better treatment outcome.

In line with the theory of planned behaviour (Ajzen, 1991), compliance as a healthy behaviour is determined by attitudes, in the form of beliefs and wellbeing. Caregivers of SCD children are expected to be stressed, depressed and less motivated to engage in healthy behaviour. If these caregivers had positive health belief, then they are likely to engage in recommended health behaviours like compliance to their child's treatment regimen. Therefore, caregivers' positive psychological wellbeing that may have resulted from their health belief may have enforced their compliance to their child's treatment.

Age and number of children were also examined as moderators of the relationship between health belief and treatment compliance. Findings showed that the caregivers' age did not

moderate the relationship between compliance and health belief. This means that age did not have any influence in how well caregivers will comply because of their health belief. This was consistent with previous literature on health belief and adherence to treatment (e.g. Miller et al., 1987; Olsen et al., 2008). This might have been because mass media in the form of radio and television has made it possible to share information with everybody regardless of age. The work of health educators on radio and television may have influence the caregivers' understanding of the condition or even motivated them to comply with the treatment of their children. Therefore, younger caregivers and the older ones may have improved their knowledge of SCD through the mass media, and this may have affected the relationship between their belief and their compliance the way it did.

Number of children of caregivers was also hypothesized to have an influence in the relationship between health belief and treatment compliance of caregivers. This was not supported by the data. This was consistent with previous studies on compliance of caregivers of SCD children (e.g. Bitaraes et al., 2008). A probable explanation may be that in this study, the average number of children under the care of a caregiver was 3. The 2010 National Population Census revealed Kumasi metropolis in the Ashanti region recording an average household size of 4 (Ghana Statistical Service, 2013). This means that the average number of children in a household may be 2. Therefore, caregivers dealing with an extra child in the household may not have affected the relationship between their belief and their compliance significantly but might be affecting other relationship. This may be because Ghanaian society, being a collectivistic one (Gyekye, 1996; Nukunya, 2003), sees mothers taking care of their children and the children of other members of the extended family; cousin's children, sibling's children or siblings themselves. Therefore, even though number of children may have a positive

correlation with compliance in this study, it may not affect the relationship between health belief and compliance significantly.

### **Social support and treatment compliance of caregivers**

As part of the aims of this study, social support was hypothesized to have an influence on the caregivers' compliance to their children's treatment. Confirming the hypothesis, the findings of this study showed that social support correlated positively and predicted significant variance in treatment compliance of caregivers. This indicates that caregivers who score high on social support scale are likely to comply with the treatment regimen of their children. The finding of this study supports previous studies in the relationship between social support and compliance to treatment (e.g. Boas et al., 2012; Lewandowski & Drotar, 2007; Houston et al., 2015; Raphael et al., 2013). SCD management is a tedious one that requires much dedication from the caregiver in order to achieve the necessary health outcome of the child. Caregivers therefore need all the support that is available to them to be able to cope with the daily care of the children.

In Gyekye's (1996) view, the Ghanaian society is more collectivistic, emphasizing communalism and brotherliness; therefore, caregivers are likely to receive support from family members, friends, and acquaintances when going through such challenges. However, the effectiveness of the available support may depend on its helpfulness or otherwise. The theory of relational regulation emphasizes the successful regulation of emotions through ordinary conversation and shared activities as the link between social support and health (Lakey & Orehek, 2011). Sharing others experience with SCD and other chronic diseases may give the caregivers the confidence to stay compliant with their children's medication regimen and treatment as a whole. The findings in this study may have been influenced by this.

In addition to this, it was hypothesized that the relationship between social support and treatment compliance is mediated by psychological wellbeing. This hypothesis was not confirmed by the data. This is inconsistent with previous literature in social support and treatment compliance (e.g. Gonzalez et al., 2004). The possible explanation may be the differences between this study and the previous one. For example, Gonzalez et al (2004) examined two aspects of psychological wellbeing, which included positive state of mind (PSOM) and depression. Both mediated the relationship but in opposite direction. However, in this study psychological wellbeing was evaluated with its entire components as a unit. This might have led to the results of this study.

Moreover, in explaining the results of this study from the perspective of the relational regulation, we can surmise that the influence of social support on healthy behaviour is dependent on the quality of the support. This quality is what is known to fuel the individual's wellbeing through the ordinary conversations and shared activities. Caregivers may have experienced support but the quality that was missing might have accounted for the result in this study.

Age and number of children of the caregiver was hypothesized to be moderating factors in the relationship between social support and compliance to the children's treatment. The results showed that caregivers' age did not moderate the relationship between social support and treatment compliance of the caregivers. This finding did not provide support for previous studies on this relationship (e.g. Ahrari et al., 2014; Houston et al., 2015). A possible explanation could be the type of social support that was assessed. For example, Houston et al. (2015) investigated social support from only peer facilitators. This means that the source of support was from individuals that were the same age group of the patient, making the participants age relevant. In the previous study, support from the medical providers was found

to possess relatively less influence on the participant's compliance. However, in the present study, all the sources of social support were assessed, regardless of age. The relational regulation theory emphasizes the importance of shared activities and conversations as a link between support and health (Lakey & Orehek, 2011). This is easily facilitated when the giver of the support and the receiver of it are similar in age. Therefore, caregivers of children with SCD receiving support from family, friends, and other people, who may or may not be of the same age group may have accounted for the insignificant influence of age in the relationship between social support and compliance.

The results also show that number of children did not moderate the relationship between social support and treatment compliance. The relational regulation theory again postulates that the presence of other people to share activities and conversations with have the ability to improve the health of individuals (Lakey & Orehek, 2011). The present study did not assess the presence of other children that needed special care but rather presence of other children. Therefore the presence of the other children, who may be healthy may have neutralize the burden that it is expected to be present. This might have accounted for the results in the present study. The interaction of number of children and social support therefore may not affect compliance in caregivers as expected.

### **Psychological wellbeing and treatment compliance**

As part of the objective of this study, it was hypothesized that age and number of children of the caregivers will influence the relationship between psychological wellbeing and treatment compliance. Age was found to influence the relationship between psychological wellbeing and compliance of caregivers. This finding did not support previous studies on this relationship (e.g. Calvetti, Giovelli, Gauer, De Moraes, 2014). This finding presumes that age is an important factor in the psychological wellbeing of caregivers of children. As indicated by the

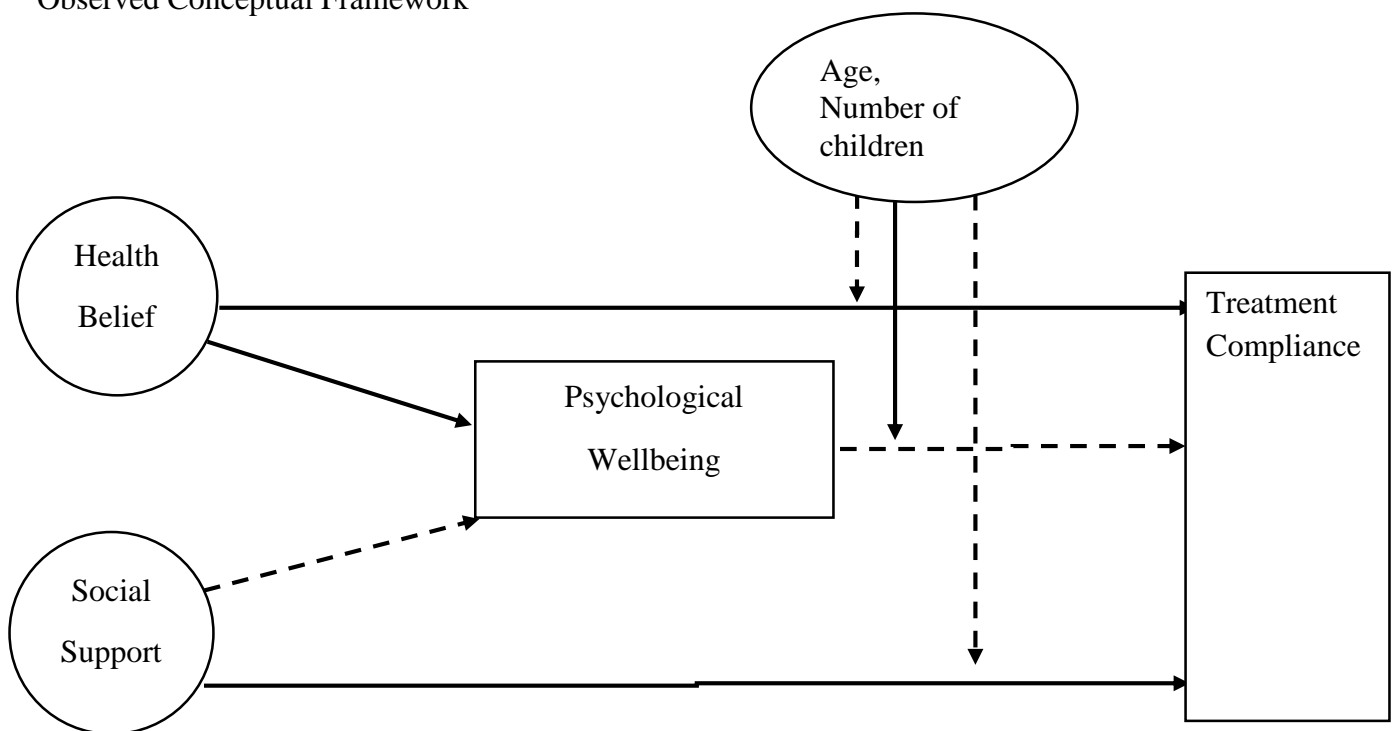
theory of planned behaviour (Ajzen, 1991), age and other shared demographic characteristics coupled with psychological wellbeing affects perceived behaviour control, that in turn influences the likelihood of performing a healthy behaviour. It was noticed that most caregivers in this study reported that they do not receive help from other family members because they are older and expected to be independent. Younger caregivers however were reporting support from family and friends. This support, which is known to improve psychological wellbeing, is influenced by age. This may have been the reason for the negative prediction of compliance as seen in the study.

Number of children was also found to influence the relationship between psychological wellbeing and treatment compliance. This was consistent with previous studies on adherence and wellbeing (e.g. Reis et al., 2013). A probable explanation to this may be that caregivers see the presence of their other children as a source of motivation to comply with the medication regimen of the child with SCD. Other children in the household may mean extra hands for the care of the child. The realization that the caregiver is not alone will influence their wellbeing and this may have affected their compliance to treatment. This may have been the reason for the positive prediction of compliance by the interaction of psychological wellbeing and number of children.

The observed relationships between the variables are presented below in figure 2.

Figure 2:

Observed Conceptual Framework



In the model above, health belief is predictive of treatment compliance, indicating that health belief of caregivers is directly related to compliance to their children's treatment. Social support is predictive of treatment compliance, indicating that social support of caregivers is directly related to compliance of caregivers to their children's treatment. Psychological wellbeing partially mediated the relationship between health belief and treatment compliance. However, psychological wellbeing does not mediate the relationship between social support and treatment compliance. Age and number of children do not moderate the relationship between health belief and treatment compliance, social support and treatment compliance, and psychological wellbeing and treatment compliance.

**Implications of Findings for research and clinical practice**

Our findings indicated a significant amount of burden on caregivers. It is normal to focus on patients of SCD but it would be prudent to be mindful of the effects of care of SCD on the caregiver. This is not out of place, earlier studies both in Ghana and outside have shown that caring for people with chronic diseases have an enormous effects on the caregiver (Asante, 2012; Dennis-Antwi et al., 2011; Ennis & Corry, 2014; Wrubel et al., 2005)

It is also important to pay attention to the belief systems of the caregiver as we found that a strong relationship between beliefs and treatment compliance. Also, health belief of the caregivers have been found to predict compliance of the caregivers, indicating that family members who are responsible for the care of the child should be exposed to extensive psycho-education into the condition to facilitate compliance. The content of the psycho-education should be structured in such a way that it takes into consideration the caregivers' belief systems thereby strengthening their understanding of the condition.

Future research should consider investigating treatment outcomes in addition to compliance to be able to discuss the effectiveness of caregivers' compliance. Coping as a psychological variable should also be examined to ascertain its effect on the relationships understudied in the study. The assessment of treatment compliance should include hospital visits, pill counts, medication refills, and actual medication taking.

**Limitations of the Study**

The use of the cross-sectional design in this study prevents inferences of causal relationship to be made among the variable that were understudied. In addition, the sample size of 200 reduces the generalization of the findings of this study. Questionnaires used in the study could not give room for further response that is necessary for important elements to be assessed. For example, elements like coping, treatment outcome, religiosity and others could give more information

about the caregiver characteristics that affect the child's treatment. In addition, explanations of terminologies on the questionnaire that may not have been understood clearly by caregivers may have affected the response to the scales.

### **Conclusion**

SCD is the most common hemoglobinopathy that affects people of the sub-Saharan African descent. Living with SCD is associated with many challenges that include crisis associated with the condition, the stigma that surrounds the disease and the general disability that the disease presents. Compliance to the child's treatment regimen has been noted as essential in the successful management of the condition. This is likely to be affected by caregivers' factors as health belief, psychological wellbeing, and social support.

This study therefore investigated the extent to which these caregiver characteristics affect the treatment compliance of the child. The outcome of the study showed that health belief, and social support significantly predicted treatment compliance of caregivers in children with the disease. Psychological wellbeing did not significantly predict treatment compliance.

However, psychological wellbeing significantly mediated the relationship between health belief and treatment compliance. Psychological wellbeing did not mediate the relationship between social support and treatment compliance of the caregivers.

Age and number of children under the care of the caregivers did not moderate the relationships between health belief and treatment compliance, and social support and treatment compliance respectively. However, age and number of children had a significant influence on how well caregiver comply with their children's treatment in terms of psychological wellbeing in all caregiver group. There was no moderating effect of age and number of children in the

relationship between psychological wellbeing and treatment compliance in the sickle cell and the acute illness group.

In summary, the outcome of this study serves as basis for further research in the area of psychological health of caregivers of SCD children and its relation to compliance, as there are fewer studies conducted in Ghana. This study has demonstrated that the psychological variables such as health belief, social support, and psychological wellbeing directly or interactively affect the caregivers' compliance to the treatment of their children. In-depth clinical assessment of these factors is however essential for management.

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**APPENDICES**

## Appendix A:

Consent Form for Participants of the Study.



UNIVERSITY OF GHANA



Official Use only Protocol number
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OFFICE OF RESEARCH, INNOVATION, AND DEVELOPMENT

**Ethics Committee for Humanities (ECH)****PROTOCOL CONSENT FORM**

Section A- BACKGROUND INFORMATION
--------------------------------------

Title of Study:	TO Health Belief, Social Support, and Psychological Wellbeing as Predictors of Treatment Compliance: A Study among Caregivers of Sickle Cell and Acutely Ill Children
Principal Investigator:	Daniel Fordjour
Certified Protocol Number	

Section B- CONSENT TO PARTICIPATE IN RESEARCH
--

**General Information about Research**

- The study seeks to examine the health belief, social support, and psychological wellbeing of caregivers and how these factors influence the caregivers' willingness and readiness to seek help, and to explore the consequences of the interaction of these areas of their lives on the management and treatment of their children who are living with sickle cell disease and acute conditions.
- The study is expected last run from May 15 to June 15, 2014. This is the expected duration for data collection from the research participants in the study.
- Participants will be expected to respond to four scales on a questionnaire designed for the study. The questionnaire will consist of Champion's Health Belief Model Scale (CHBMS), Multidimensional Scale of Perceived Social Support (MSPSS), Ryff's Scales of Psychological Wellbeing (RSPW), Morisky's Medication Adherence

Questionnaire (MAQ), and a section for demographic information. Specific guidelines and instructions are provided before the commencement of each of the scales.

### **Benefits/Risk of the study**

There are no specific risks and benefits associated with the participation in this study to the participants. However, findings from this study will help build up knowledge about the role beliefs, social support, and psychological wellbeing of caregivers, particularly parents, play in their bid to comply with treatment of their children who are sickle cell patients.

### **Confidentiality**

- Participants will **NOT** be required to state their names, telephone or mobile numbers, postal or residential address on the questionnaires only questions like age, sex, and ethnicity among others will be required of them which will not directly or indirectly indicated their identity. All records and data collected will be filed and kept in a filing system and locked up to protect the identity of participants and their views on the variables being tested.
- Aside from the principal investigator, her two supervisors may have direct access the research records at any particular time thus signing or thumb printing this written consent form, participants or their representatives are authorizing such access.

### **Compensation**

- Participants will be given a pen, which will used be to answer the questionnaire, and subsequently kept by the participants. In addition to this, participants who may need psychotherapeutic assistance will be given if it becomes necessary. This is only to show appreciation for participation.

### **Withdrawal from Study**

- Participation is voluntary and participants may withdraw at any time without Penalty.
- As the principal researcher, I assure that any participant will not be adversely affected if he/she declines to participate or later stops participating.
- Participant 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.
- Participation will be terminated when and if a participant indicates the will to withdraw from the study under any circumstances and/or reasons pertinent to the participant.

### **Contact for Additional Information**

- For further information about the study, contact Prof Charity S. Akotia, Department of Psychology, Faculty of Social Sciences, University of Ghana. She can be contacted on 020 812 7695 and at [sakotia@libr.ug.edu.gh](mailto:sakotia@libr.ug.edu.gh)

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 B:  
Demographic Page of the Questionnaire of the Study

Study ID.....

## UNIVERSITY OF GHANA

**Health Belief, Social Support, and Psychological Wellbeing as Predictors of Treatment Compliance: A Study among Caregivers of Sickle Cell and Acutely Ill Children**

This study is being conducted as part of the fulfillment for the award of Master of Philosophy in Psychology. The focus of the study is to find out the relationship between **health belief, social support, and psychological wellbeing of primary care givers** of children with Sickle Cell Disease and those with acute medical conditions and their **compliance to treatment**. The outcome of the study will help in identifying new ways of helping primary caregivers cope with the care of the children and improve on their compliance to treatment.

For this reason, the researcher is grateful for your participation in the study. You will be required to respond to the following items aimed at gathering information on the aforementioned constructs above. Your participation is voluntary and that decision to withdraw from the research will not be met with any resistance.

This questionnaire is in 5 sections; a. Demographics section, b. health belief model section, c. social support section, d. psychological wellbeing section, and e. Medication adherence rating scale section. Instructions will be giving at the beginning of every section before responding.

**Section A: Demographic Information**

Please fill in the information require, and circle the option applicable to you, where necessary.

Age: .....

Sex: MaleFemale

No. of Children: .....

Genotype: .....

Marital Status:

MarriedSingleSeparatedDivorcedCo-habiting

Educational Level:

NonePrimaryJHSSHSTertiary

Sex of Child:

MaleFemale

Age of Child: .....

Religion:

ChristianMuslimOther, Specify .....

Child's genotype:

SSSCOther,specify.....

Income:

 < GHC 250 GHC 250 – GHC 499 GHC 500 – GHC 999 GHC 1000 – GHC 1500 > GHC 1500Relation to Child: MotherFatherUncleAuntSibling

## Appendix C:

## Champion's Health belief Model Scale for the Sickle Cell group.

Listed below are a number of statements describing sets of beliefs. Please read each statement carefully and on the 1-5 scale adjacent, circle the number that tells how much you think each statement is typical of you

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Agree</b>
1.	There is a good possibility that my child will develop infections	1	2	3	4	5
2.	I worry a lot about sickle cell disease	1	2	3	4	5
3.	It is very likely that all my children are at risk for sickle cell disease.	1	2	3	4	5
4.	My child's physical health makes it more likely that he/she will get sickle cell complications.	1	2	3	4	5
5.	The thought of sickle cell disease scares me	1	2	3	4	5
6.	When I think of someone having sickle cell disease, I think that his/her academics and career is in danger	1	2	3	4	5
7.	When I think about sickle cell disease, my heart beats faster	1	2	3	4	5
8.	How one feels about themselves would change, if one has sickle cell disease	1	2	3	4	5
9.	Problems one would experience with sickle cell disease would last a long time	1	2	3	4	5
10.	Sickle cell is a hopeless disease	1	2	3	4	5
11.	Sickle cell disease hurts one's life and love ones	1	2	3	4	5
12.	Going for checkups would make my child feel good	1	2	3	4	5
13.	Having regular checkups would decrease my child's chances of dying from sickle cell crisis.	1	2	3	4	5
14.	If I take my child for checkups, I will decrease his/her chances of needing major treatment as a result of sickle cell disease complications.	1	2	3	4	5
15.	Regular checkups for my child will help me find out possible complications early.	1	2	3	4	5
16.	Having regular checkups would protect my child from other complications of sickle cell disease	1	2	3	4	5
17.	If I take my child for regular check-ups, I would not worry as much about the sickle cell disease.	1	2	3	4	5

18.	I do not like to talk about sickle cell disease.	1	2	3	4	5
19.	Taking my child for regular checkups makes me worry about sickle cell disease	1	2	3	4	5
20.	Taking my child for regular reviews for sickle cell disease is embarrassing to me.	1	2	3	4	5
21.	The reviews at the hospitals take too much time	1	2	3	4	5
22.	Taking my child for the reviews at the hospitals is unpleasant.	1	2	3	4	5
23.	Check-ups and reviews of sickle cell disease cost too much money	1	2	3	4	5
24.	I want to find health problems early	1	2	3	4	5
25.	Having good health is important to me and my child	1	2	3	4	5
26.	I search for new information to improve my child's health	1	2	3	4	5
27.	I feel it is important to carry out activities that will improve my child's health	1	2	3	4	5
28.	I know how to get regular check-ups for complications of sickle cell disease	1	2	3	4	5
29.	I make sure my child eats a well-balanced diet.	1	2	3	4	5
30.	I always follow medical orders because I believe they will benefit my child's state of health	1	2	3	4	5
31.	I can recognize normal and abnormal changes in my child's health	1	2	3	4	5
32.	I feel confident that I can manage the sickle cell crisis of my child if I am given the directives.	1	2	3	4	5

## Appendix D:

## Champion's Health belief Model Scale for the Acutely Ill group

Listed below are a number of statements describing sets of beliefs. Please read each statement carefully and on the 1-5 scale adjacent, circle the number that tells how much you think each statement is typical of you

		<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Agree</b>
1.	There is a good possibility that my child will get well.	1	2	3	4	5
2.	I worry a lot about my child's sickness.	1	2	3	4	5
3.	It is very likely that all my children are at risk for sicknesses.	1	2	3	4	5
4.	My child's physical health makes it more likely that he/she will get sick.	1	2	3	4	5
5.	The thought of illness scares me	1	2	3	4	5
6.	When I think of someone being ill, I think that his/her academics and career is in danger	1	2	3	4	5
7.	When I think about illness, my heart beats faster	1	2	3	4	5
8.	How one feels about themselves would change, if one were sick.	1	2	3	4	5
9.	Problems one would experience with any sickness would last a long time	1	2	3	4	5
10.	Being sick is a hopeless thing	1	2	3	4	5
11.	Being sick hurts one's life and loved ones.	1	2	3	4	5
12.	Going for checkups would make my child feel good	1	2	3	4	5
13.	Having regular checkups would decrease my child's chances of dying from sickness.	1	2	3	4	5
14.	If I take my child for checkups, I will decrease his/her chances of needing major treatment as a result of sickness complications.	1	2	3	4	5
15.	Regular checkups for my child will help me find out possible complications early.	1	2	3	4	5
16.	Having regular checkups would protect my child from other complications of sickness	1	2	3	4	5
17.	If I take my child for regular check-ups, I wouldn't worry as much about sicknesses.	1	2	3	4	5

*Health Belief, Social Support, and Psychological Wellbeing as Predictors of Treatment Compliance*

18.	I do not like to talk about diseases.	1	2	3	4	5
19.	Taking my child for regular checkups makes me worry about diseases	1	2	3	4	5
20.	Taking my child for regular reviews is embarrassing to me.	1	2	3	4	5
21.	The reviews at the hospitals take too much time.	1	2	3	4	5
22.	Taking my child for the reviews at the hospital is unpleasant.	1	2	3	4	5
23.	Check-ups and reviews cost too much money	1	2	3	4	5
24.	I want to find health problems early	1	2	3	4	5
25.	Having good health is important to me and my child	1	2	3	4	5
26.	I search for new information to improve my child's health	1	2	3	4	5
27.	I feel it is important to carry out activities that will improve my child's health	1	2	3	4	5
28.	I know how to get regular check-ups for my child	1	2	3	4	5
29.	I make sure my child eats a well-balanced diet.	1	2	3	4	5
30.	I always follow medical orders because I believe they will benefit my child's state of health	1	2	3	4	5
31.	I can recognize normal and abnormal changes in my child's health	1	2	3	4	5
32.	I feel confident that I can manage illnesses of my child if I am given the directives.	1	2	3	4	5

## Appendix E:

## Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet &amp; Farley, 1988)

The set of statements are interested in the how you feel about some things. Read each statement carefully. Indicate how you feel about each statement.

Circle the “1” if you **Very Strongly Disagree**

Circle the “2” if you **Strongly Disagree**

Circle the “3” if you **Mildly Disagree**

Circle the “4” if you are **Neutral**

Circle the “5” if you **Mildly Agree**

Circle the “6” if you **Strongly Agree**

Circle the “7” if you **Very Strongly Agree**

1	There is a special person who is around when I am in need	1	2	3	4	5	6	7
2	There is a special person with whom I can share my joys and sorrows	1	2	3	4	5	6	7
3	My family really tries to help me.	1	2	3	4	5	6	7
4	I get the emotional help and support I need from my family	1	2	3	4	5	6	7
5	I have a special person who is a real source of comfort to me	1	2	3	4	5	6	7
6	My friends really try to help me	1	2	3	4	5	6	7
7	I can count on my friends when things go wrong	1	2	3	4	5	6	7
8	I can talk about my problems with my family	1	2	3	4	5	6	7
9	I have friends with whom I can share my joys and sorrows	1	2	3	4	5	6	7
10	There is a special person in my life who cares about my feelings	1	2	3	4	5	6	7
11	My family is willing to help me make decisions	1	2	3	4	5	6	7
12	I can talk about my problems with my friends	1	2	3	4	5	6	7

## Appendix F:

## RYFF'S SCALE OF PSYCHOLOGICAL WELLBEING

Please indicate your level of agreement to the following statements by circling the corresponding number, using a score range below.

Strongly disagree	Moderately disagree	Disagree	Agree	Moderately agree	Strongly agree
1	2	3	4	5	6

	Statements	1	2	3	4	5	6
1	I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.						
2	In general, I feel I am in charge of the situation in which I live.						
3	I am not interested in activities that will expand my horizons.						
4	Most people see me as loving and affectionate						
5	I live life one day at a time and don't really think about the future.						
6	When I look at the story of my life, I am pleased with how things have turned out.						
7	My decisions are not usually influenced by what everyone else is doing						
8	The demands of everyday life often get me down.						
9	I think it is important to have new experiences that challenge how you think about yourself and the world.						
10	Maintaining close relationships has been difficult and frustrating for me						
11	I have a sense of direction and purpose in life.						
12	In general, I feel confident and positive about myself.						
13	I tend to worry about what other people think of me.						
14	I do not fit very well with the people and the community around me.						
15	When I think about it, I haven't really improved much as a person over the years.						
16	I often feel lonely because I have few close friends with whom to share my concerns.						
17	My daily activities often seem trivial and unimportant to me.						
18	I feel like many of the people I know have gotten more out of life than I have.						
19	I tend to be influenced by people with strong opinions						

20	I am quite good at managing the many responsibilities of my daily life.						
21	I have the sense that I have developed a lot as a person over time.						
22	I enjoy personal and mutual conversations with family members or friends.						
23	I don't have a good sense of what it is I'm trying to accomplish in life.						
24	I like most aspects of my personality.						
25	I have confidence in my opinions, even if they are contrary to the consensus.						
26	I often feel overwhelmed by my responsibilities						
27	I do not enjoy being in new situations that require me to change my old familiar ways of doing things.						
28	People would describe me as a giving person, willing to share my time with others.						
29	I enjoy making plans for the future and working to make them a reality.						
30	In many ways, I feel disappointed about my achievements in life.						
31	It is difficult for me to voice my own opinions on controversial matters.						
32	I have difficulty arranging my life in a way that is satisfying to me.						
33	For me, life has been a continuous process of learning, changing, and growth.						
34	I have not experienced many warm and trusting relationships with others.						
35	Some people wander aimlessly through life, but I am not one of them						
36	My attitude about myself is probably not as positive as most people feel about themselves.						
37	I judge myself by what I think is important, not by the values of what others think is important.						
38	I have been able to build a home and a lifestyle for myself that is much to my liking.						
39	I gave up trying to make big improvements or changes in my life a long time ago.						
40	I know that I can trust my friends, and they know they can trust me.						
41	I sometimes feel as if I've done all there is to do in life.						
42	When I compare myself to friends and acquaintances, it makes me feel good about who I am.						

## Appendix G:

## Morisky 8-Item Medication Adherence Questionnaire

*Please indicate your agreement with the statement below on how well you follow your child's medication regimen.*

	Questions	Response	
		Yes	No
1	Do you sometimes forget to give your child his/her medicine?		
2	People sometimes miss taking their medicines for reasons other than forgetting. Thinking over the past 2 weeks, were there any days when you did not give your child his/her medicine.		
3	Have you cut back or stopped giving your child medicine without telling your doctor		
4	When you travel or leave home, do you sometimes forget to bring along your child's medicine?		
5	Did you give your child all his/her medicines yesterday?		
6	When you feel like your child's symptoms are under control, do you sometimes stop giving his/her medicine?		
7	Taking medicine every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your child's treatment plan?		
8	How often do you have difficulty remembering to give your child all his/her medicine? <input type="checkbox"/> A. Never/rarely <input type="checkbox"/> B. Once in a while <input type="checkbox"/> C. Sometimes <input type="checkbox"/> D. Usually <input type="checkbox"/> E. All the time		


Appendix H:

**Summary of the Effect of Social Support on Treatment Compliance as Mediated by Psychological Wellbeing**

<b>Effect</b>	<b><math>\beta</math></b>	<b>SE</b>	<b><i>t</i></b>	<b><i>z</i></b>
<b>SS on PWB</b>	.5001*	.1001	4.9980*	
<b>PWB on TC</b>	.0060 <sup>ns</sup>	.0058	1.0383 <sup>ns</sup>	
<b>c'</b>	.0605*	.0086	7.0143*	
<b>c</b>	.0635*	.0081	7.8109*	
<b>a × b</b>	.0030 <sup>ns</sup>	.0029		1.0217 <sup>ns</sup>
<b>Model summary</b>				
<b>F</b>	31.0560*			
<b>R<sup>2</sup></b>	.2397			
<b>Adj R</b>	.2320			
<b>(df1), (df2)</b>	(2), (197)			

Note: SS = Social support, PWB = psychological wellbeing, TC = treatment compliance, c' = adjusting for PWB HB on TC, c = without adjusting for PWB HB on TC, a×b = indirect effect of HB on TC through PW. \*  $p < .001$

Appendix I: Introductory Letter from the Department of Psychology, UG



**UNIVERSITY OF GHANA**  
**DEPARTMENT OF PSYCHOLOGY**  
Tel.: (233-0302) 500381 Ext. 3754/3310 P. O. Box LG 84, Legon - Ghana E-mail: [psychology@ug.edu.gh](mailto:psychology@ug.edu.gh)  
028 955 04 63

Our Ref. No.....

PSYC 2/33/01

April 22, 2014

The Administrator  
Ethics Committee for Humanities  
Institute of Statistical, Social and Economic Research (ISSER)  
University of Ghana  
Legon

Dear Sir/Madam,


**LETTER OF INTRODUCTION**  
**DANIEL FORDJOUR- ID NUMBER:10226001**

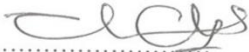
The above-named is an M.Phil in Clinical Psychology student in the Department of Psychology, University of Ghana, Legon.

As part of the requirement, Daniel Fordjour has to write and submit an original thesis. The title of his thesis is "**Health Belief, Health Seeking Behaviour and Psychological Wellbeing: Impact of Primary Care Giving of Children Living With Sickle Cell Disease on Treatment Compliance**". He is planning to conduct his study at the Okomfo Anokye Teaching Hospital, Sickle Cell Unit.

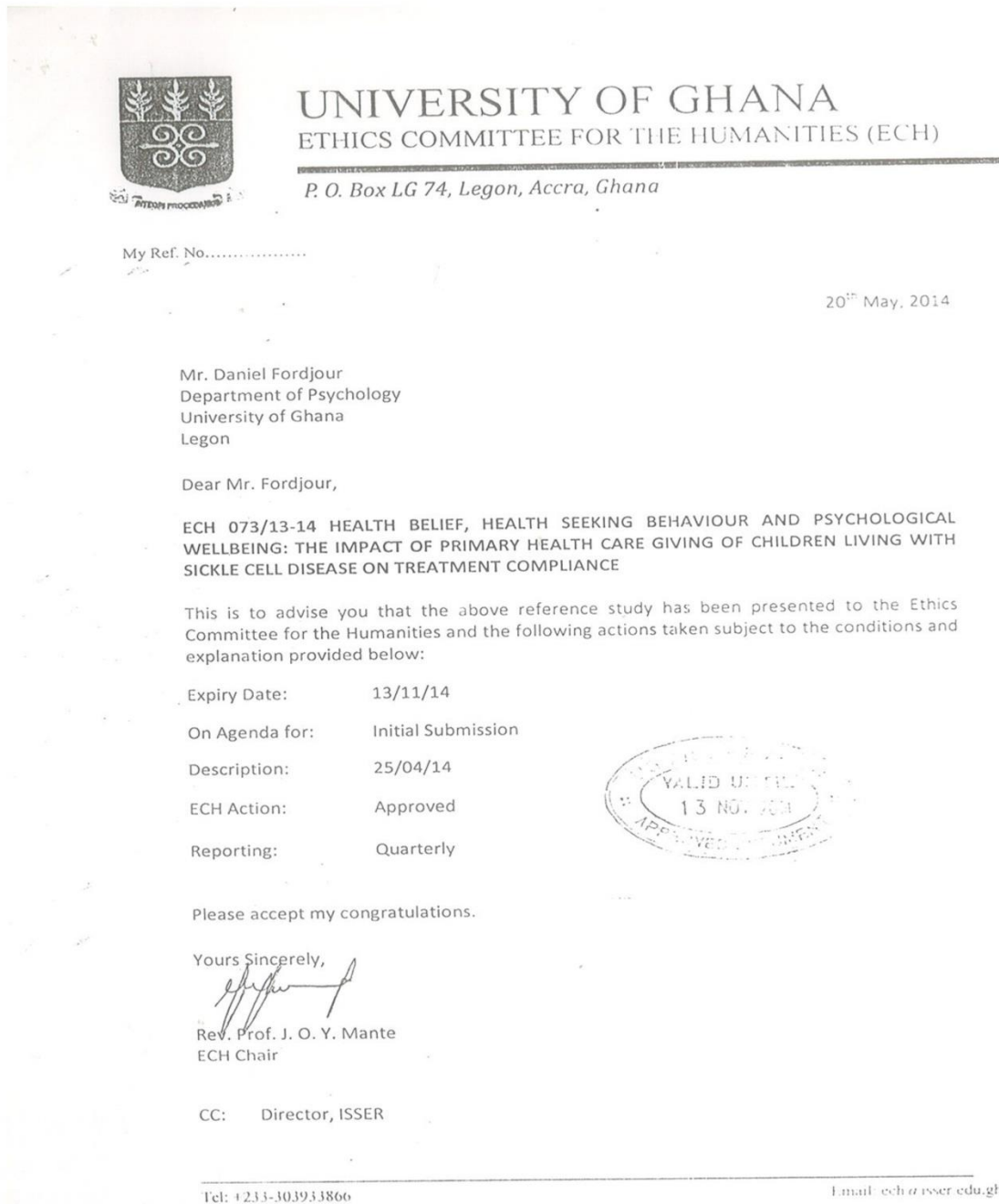
He is applying to your Board for institutional approval/clearance to enable him carry on with his Research Work. He has received approval from our department. Your assistance in reviewing his proposal is much appreciated.

Yours sincerely,



  
.....  
Prof. C.C. Mate-Kole  
(Head of Department)

  
.....  
Prof. Charity S. Akotia  
(Supervisor)

Appendix J: Ethical approval from ECH



Appendix K: Ethical Approval from CHRPE – KNUST, KATH.



KWAME NKURUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY  
**COLLEGE OF HEALTH SCIENCES**

SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL  
**COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS**

Our Ref: CHRPE/RC/253/14 16<sup>th</sup> September, 2014.

Mr. Daniel Fordjour  
Department of Psychology  
University of Ghana  
LEGON.

Dear Sir,

**ETHICS REVIEW COMMENTS – CONDITIONAL APPROVAL**

*Protocol Title: "Health Belief, Health Seeking Behaviour and Psychological Wellbeing; the Impact of Primary Care Giving of Children with Sickle Cell Disease on Treatment Compliance."*

Following an Expedited Review, your protocol was given a conditional approval subject to you addressing the following concerns/queries:

**On the CHRPE Form:**


Item 2.2: 1. The main objective in this study is not really clear. We cannot follow the main and specific objectives. We need more clarification.

Item 2.4: 1. Your study design is too scanty. Please elaborate.

Kindly make the necessary amendments and submit one copy each of all required documents to the CHRPE (Room 7 Block J, School of Medical Sciences, KNUST), along with a letter explaining the changes you have made to each document for consideration and approval. The date and reference number of this letter should be quoted in your letter.

Thank you Sir, for your application.

Yours faithfully,

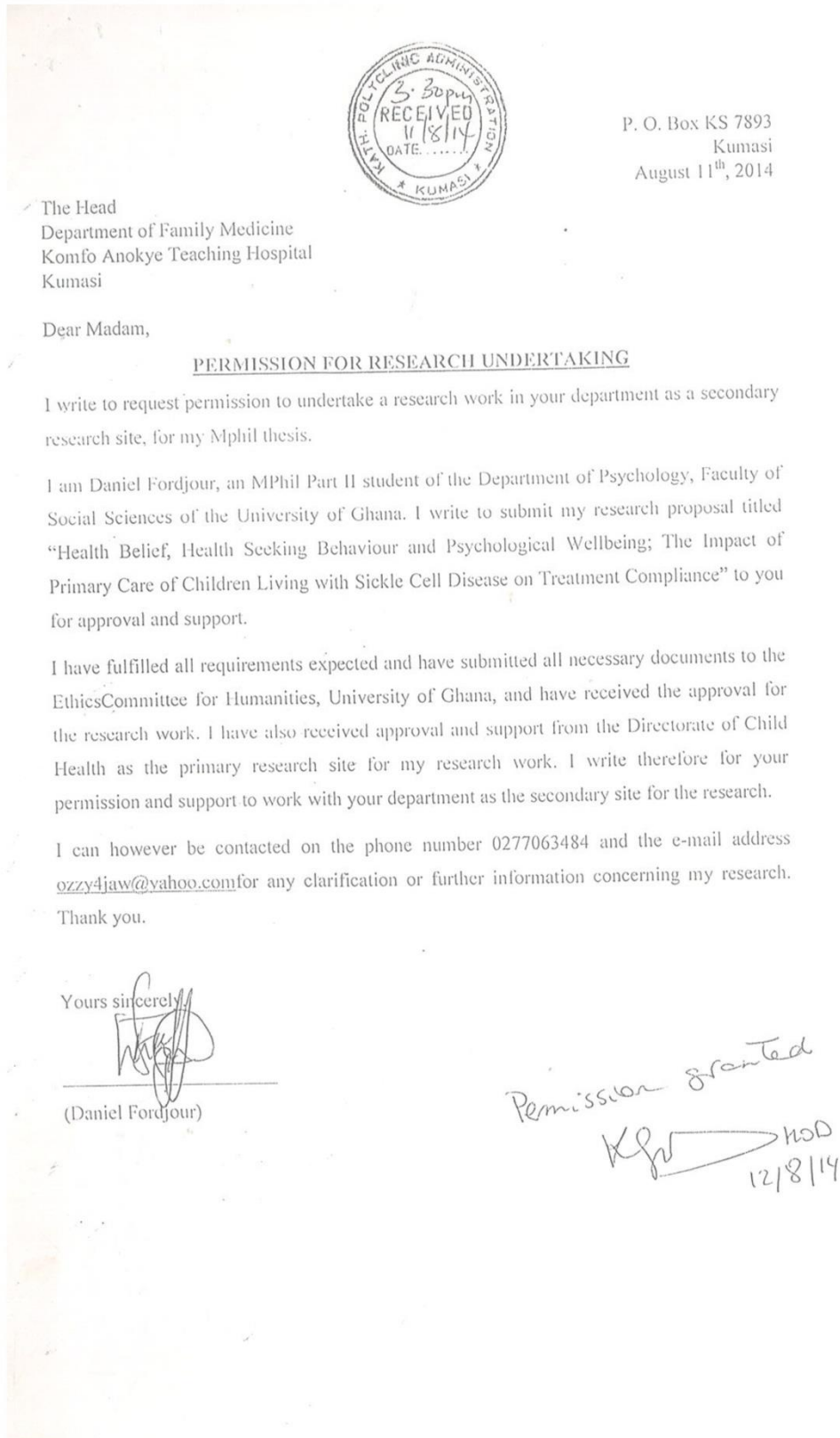
  
Osomfuor Prof. Sir J. W. Acheampong MD, FWACP  
**Chairman**

---

Room 7 Block J, School of Medical Sciences, KNUST, University Post Office, Kumasi, Ghana  
Phone: +233 3220 63248 Mobile: +233 20 5453785 Email: [chrpe.knust.kath@gmail.com](mailto:chrpe.knust.kath@gmail.com) / [chrpe@knust.edu.gh](mailto:chrpe@knust.edu.gh)

*Health Belief, Social Support, and Psychological Wellbeing as Predictors of Treatment Compliance*

Appendix L: Permission Letter from Polyclinic - KATH



Appendix M: Permission Letter from Child Health - KATH

**KOMFO ANOKYE  
TEACHING HOSPITAL**

Directorate of Child Health

Our Ref. No:.....

Your Ref. No:.....

**KATH**

P. O. Box 1934  
KUMASI - GHANA  
Tel: +233 - 3220-22301 - 4  
Fax: +233 - 3220 - 24654/24621  
Website: [www.kathhsp.org](http://www.kathhsp.org)

11<sup>TH</sup> AUGUST 2014

The Deputy Director  
Research and Development Unit  
KAH

Dear Sir

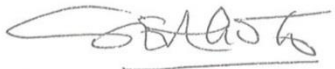
**LETTER OF SUPPORT: "HEALTH BELIEF, HEALTH SEEKING BEHAVIOUR AND PSYCHOLOGICAL WELLBEING; THE IMPACT OF PRIMARY CARE GIVING OF CHILDREN LIVING WITH SICKLE CELL DISEASE ON TREATMENT COMPLIANCE"**

I am writing in support of Mr. Daniel Fordjour, an MPhil Part 2 student in the Faculty of Social Sciences University of Ghana's application for registration and ethical clearance for the conduct of research on the above-mentioned topic.

He has sought permission to carry out the research work as titled above in our Directorate.


We have taken a look at the protocol and we are in support and therefore give permission of the Directorate for him to seek ethical clearance and subsequently proceed to carry out the study.

Yours faithfully,



**DR ALEX OSEI-AKOTO  
HEAD, SICKLE CELL CLINIC  
(for HOD-CHILD HEALTH)**

Appendix N: Approval from RDU – KATH



**KOMFO ANOKYE TEACHING HOSPITAL**  
**RESEARCH AND DEVELOPMENT UNIT (R & D)**  
***CERTIFICATE OF REGISTRATION***

REG. NO. RD/CR14/155

This is to certify that

Prof/Dr/Mrs/Mr/Ms. Daniel Fordjour  
has registered his/her proposed study titled Health belief, health seeking behaviour and psychological well being; the impact of primary care giving of children living with sickle cell disease on treatment compliance  
.....with the Research and Development Unit.

Date 13th August, 2014 A CENTRE OF EXCELLENCE

Name of issuing officer	Signature
<u>Raymond Atiemo Danso (Snr. Admin. Mgr)</u>	<u><i>radtinsch</i></u>

0570600  
Receipt No

\*\*This certificate does not constitute ethical clearance for the conduct of the study but proof of registration of study with KATH. Ethical clearance from the Committee of Human Research Publications and Ethics (CHRPE) is required to conduct the study