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COLLEGE OF HUMANITIES

THE PSYCHOSOCIAL IMPACT OF SICKLE CELL DISEASE (SCD) ON PARTNERS
OF SCD PATIENTS

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DECLARATION

This is to certify that this thesis is the result of research carried out by Wilhelmina Efua Wilson towards the award of MPhil Clinical Psychology in the Department of Psychology, University of Ghana.

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DEDICATIONS

To my parents, Dr. and Mrs. J. B. Wilson, for their indefatigable support,

and

to Mr. Dike Kattah, whose experiences inspired this thesis.

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ABSTRACT

The purpose of this study was to investigate the psychosocial effects that partners of SCD patients experience as a result of their relationship with the patient. A convergent mixed methods approach was used to evaluate the experiences of 75 partners within the city of Accra, Ghana, in 8 psychosocial areas: caregiver burden, marital satisfaction, physical health, psychological wellbeing, social relationships, environmental wellbeing, quality of life, and stigma. Mechanisms of coping among the partners were also examined. Participants of the study commonly reported psychological stress, financial strain, social disruption and stigma among challenging effects of living with a person with SCD. Significant gender differences were found in psychological wellbeing and coping strategies, in accordance with existing literature. The results further indicate that spouses who were aware of the patient's sickle cell status before marriage had significantly less stressful experiences than those who were unaware. Being married for a greater number of years was also associated with significantly lower stress levels. Other findings of the study suggest significant effects of caregiver burden and marital satisfaction on the psychosocial wellbeing and quality of life of the study sample. Participants also showed a lack of comprehensive knowledge of SCD. The results of this study have valid implications for comprehensive management of SCD patients. Couple-oriented psychosocial and psychoeducational interventions may be valuable in improving the ability of spouses to cope with their challenges and with their roles as caregivers. The reciprocal effect will be improved psychosocial wellbeing and quality of life of the patients themselves.

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CHAPTER ONE

INTRODUCTION

This study is an investigation of the psychosocial effects experienced by spouses of people with Sickle Cell disease (SCD). SCD is an inherited disorder of the blood which is associated with high levels of morbidity and mortality (Anie et al., 2010; Gibbons et al., 2015). The disease is also associated with a complex range of psychological complications and widespread psychosocial effects (Anie, 2005; Anie et al, 2010; Adegoke & Kuteyi, 2012). SCD is globally widespread, and most prevalent in African countries like Ghana (WHO, 2006).

Research studies on the psychosocial effects of chronic diseases like SCD on patients' partners have indicated a wide range of profoundly negative effects (Baanders & Heijmans, 2007; Rees et al., 2001). Partners are reported to experience effects such as worsened physical and psychosocial wellbeing, and reduced quality of life (Baanders & Heijmans, 2007; Eriksson et al., 2017; Rahmani et al., 2018; Rees et al., 2001). Studies on the psychosocial dimensions of various diseases have been influential in developing couple-oriented psychosocial interventions specific to these diseases (Martire et al., 2010). Due to differences in the effects of specific disease characteristics, the results of studies on the effects on one disease cannot be easily generalised to others (Baanders et al., 2007). The intent of this study, therefore, is to generate information specific to the psychosocial effects of SCD on patient's partners; information that will be relevant to couple-oriented psychosocial interventions in the management of SCD. This chapter presents an overview of SCD, and discusses the background and aims of this study.

1.1 Sickle Cell Disease and its Effects

SCD refers to a group of genetic blood disorders, all of which are caused by the abnormal haemoglobin gene, known as haemoglobin S (hgb S) (Anie & Green, 2015; Edwards et al., 2005). The disease occurs when an individual inherits either two of the variant gene hgb S (one from each parent), or one hgb S from one parent and another variant haemoglobin gene, e.g. haemoglobin C or haemoglobin beta-thalassemia, from the other parent (Anie & Green, 2015). The resulting haemoglobinopathies, thus, include sickle cell anaemia (hgb SS), which is the most common, sickle cell disease (hgb SC), and sickle-beta-thalassemia. The disease persists throughout the lifetime of affected individuals and requires careful management. SCD is well known as a cause of significant debilitation, as well as high levels of morbidity and mortality (American Society of Haematology (ASH), 2016; Edwards et al., 2005; Gibbons et al., 2015).

SCD is a globally widespread disease which afflicts up to 100 million people worldwide (Adegoke & Kuteyi, 2012). The disease predominantly affects people originating from malaria-prone areas like Africa, owing to the fact that the sickle cell gene evolved as a mutation resistant to malaria (Anie & Green, 2015; Anie et al., 2010). In the African Region, the disease is identified as the most common genetic disorder of clinical and epidemiological importance (World Health Organisation (WHO), 2010; Dennis-Antwi et al., 2008).

About 300,000 children are estimated to be born globally with SCD every year (WHO, 2006). Most of these children are born in Africa (WHO, 2006). The global prevalence of SCD is, however, projected to rise to more than 400,000 births over the next few decades. This rise has been ascribed to the improved survival of SCD births in the areas of high prevalence, as well as to population migration from low income countries to high income

countries (Piel et al., 2013). In Ghana, up to 2% of the population is born with SCD every year, and about 25% to 30% of Ghanaians are carriers of the disease (Ohene-Frempong et al., 2008). A carrier is an individual who inherits a single abnormal haemoglobin gene in addition to a normal haemoglobin gene. Carriers, therefore, are those with haemoglobin genotypes such as AS or AC. Such individuals have no symptoms of the disease, and are described as carrying the ‘Sickle Cell Trait’.

SCD causes many lifelong complications that can make every stage of life very challenging for the sufferer (ASH, 2016). Typical clinical syndromes of the disease include anaemia, vaso-occlusive crises (bone and muscle pain caused by blockages in the blood vessels), increased vulnerability to infection, tissue damage, and organ damage (ASH, 2016; Anie & Green, 2015; Anie et al., 2010; Edwards et al., 2005). The most frequently reported complication of the disease, however, is pain (ASH, 2016; Anie & Green, 2015, Adegbola et al., 2012; Edwards et al., 2005). The prominence of pain in SCD is captured in the types of names given to the disease in certain West African cultures (Anie et al., 2010). For example, in Ghana, SCD is named ‘Ahotutuo’ by the Twi speaking people, a term which can be literally translated as ‘body biting’, ‘body chewing’ or ‘beaten up’ in English (Anie et al., 2010). Similarly, the disease is referred to as ‘chwechweechwee’ among the Gas and ‘nuidudui’ among the Ewes (Konotey-Ahulu, 1996). The alliteration of letters in these names appears to capture the persistent nature of SCD pain (Anie et al., 2010). SCD pain may not be present at all times, however, patients experience frequent pain crises throughout their lifetime, and often require hospitalisation (ASH, 2016).

Research on the psychological and social effects of SCD has further shown significantly negative effects on the psychosocial functioning of sufferers. Patients often experience psychological complications, with anxiety, depression and loneliness among the most

commonly reported psychiatric symptoms (Anie, 2005; Anie et al, 2010; Asnani et al, 2010). Neuropsychological impairments have also been reported (Ampomah et al., 2015; Vichinsky et al., 2010). Factors like the chronic nature of the disease, the pain involved, and the need for frequent hospitalisation, have been identified as major contributors to distress and disability among patients (Anie, 2005; Edwards et al., 2005; Imhonde et al., 2013; Wonkam et al., 2014b). Sufferers of the disease often report significant limitations in their daily activities and in the fulfilment of their roles and responsibilities (ASH, 2016; Adegbola et al., 2012). This further leads to disruptions in life, work and education limitations, and difficulties in interpersonal relationships are also commonly reported experiences (ASH, 2016). SCD patients are often stigmatised (Marsh et al., 2011; WHO, 2010), a problem which can have significant effects on the psychological and social functioning of individuals. Individuals are reported to experience difficulties in the areas of general public perceptions and attitudes, education, employment and emotional issues (Anie et al., 2010).

Reciprocally, the psychiatric disturbances that SCD patients experience help to maintain the cycle of pain and debilitation that are characteristic of the disease (Edwards et al., 2005). Edwards and colleagues (2005) thus, assert that “like many other illnesses that possess a substantial chronic pain component, SCD is better conceptualized as a disease with psychosocial as well as physiological complications”. The importance of multidisciplinary teams of well-trained medical and non-medical professionals in the comprehensive management of SCD is strongly emphasized (Dennis-Antwi et al., 2008; Edwards et al., 2005).

1.2 Background to the Study

Research studies on the effects of chronic diseases like SCD consistently show that a chronic physical disease not only affects the chronically ill person directly, but also significant others who live with and care for the patient (Golics et al., 2013). The reports are of overwhelmingly negative physical and psychosocial impacts on the families and significant others, sometimes to an even greater extent than the impact on the patients themselves (Dobbie & Mellor, 2008; Rees et al., 2001). Effects like worsened physical health, increased stress, anxiety and depression, personal life strain, financial strain, impaired social and family life, and decrease in marital or relationship satisfaction are commonly reported (Baanders & Heijmans, 2007; Dobbie & Mellor, 2008; Lim & Zebrack, 2004; Rees et al., 2001).

Chronically ill patients often depend on family members and significant others for their self and medical care needs (de-Graft Aikins, Unwin et al., 2010). This can have significant negative effects on family members, resulting in conflict, changes in the quality of the relationship between patient and caregiver, marital discord and partner abandonment (de-Graft Aikins, Unwin, et al., 2010; Glantz et al., 2009). SCD research has mirrored these findings. Studies have examined the impact on family caregivers of SCD patients (parents, siblings, and the impact on the family unit as a whole) and have brought to light profoundly negative psychosocial effects (Anie et al., 2010; Ohaeri & Shokunbi 2002; Wonkam et al., 2014a). Reports indicate a significant financial burden on families, disruption in daily family interactions, disruption in the lives of primary caregivers, and marital disharmony among parents of children with SCD (Adegoke et al., 2012; Assimadi et al., 2000; Imhonde et al., 2013, Wonkam et al., 2014a). Family caregivers of SCD patients generally experience a reduced quality of life, negative effects on mood, sleep, physical health and cognitive functioning (Van Den Tweel et al., 2008). Research reports further indicate that along with

the stigma experienced by the patient, associative stigma can affect family caregivers and significant others (Marsh et al., 2011).

The importance of focusing on family caregivers and significant others is also clearly outlined in existing literature. Family members who become distressed are unable to care for the patients optimally (Holmes & Deb, 2003). Their decreased physical and psychological health, therefore, can negatively affect the health and wellbeing of the patient (Lim & Zebrack, 2004). These reports have led to several investigations on the negative impact of chronic illnesses on caregivers and the subsequent effects on the health of the patient. Such studies are instrumental, not only in informing interventions that improve the wellbeing of family members and significant others, but also in providing more successful interventions in the management of the patient (Golics et al., 2013).

The effect of chronic illness on partners (or spouses), whose relationship with the patient has been found to have more profound effects on the health of the patient, is the focus of much recent research. Partners are reported to experience greater levels of caregiver burden than other primary caregivers (Akpınar & Yurtsever, 2018; Rees et al., 2001). This is because they spend more time in the role as caregivers, and often have less social support (Meier et al, 2011; Rees et al., 2001). Spouses are also believed to have the greatest effect on the patient's health as there are greater opportunities for support provision and for interpersonal conflict in the marital relationship (Martire et al., 2004). Findings further indicate that the effect of chronic illness on a partner does not only result from the burden of caregiving, but is also determined by the type of disease, its nature, and other specific disease characteristics (Baanders & Heijmans, 2007).

Investigating the partner's experience in the management of any chronic illness has many advantages. Primarily, it leads to improved care and support for the partners, who may be experiencing greater levels of distress than the patients themselves. This further enables them to care for the patient better. Studies on the effects of specific diseases have also led to the development of psychosocial interventions that include spouses (Martire et al., 2004; Martire et al; 2010). These interventions are reported to yield significant positive effects on depression in patients, on marital functioning, and on pain symptoms (Martire et al., 2004; Martire et al., 2010). On the whole, they were found to be more effective than interventions that only focused on the patient. In some cases, including spouses in such psychosocial interventions even led to reduced patient mortality (Martire et al., 2004).

1.3 Statement of the Problem

Research studies on the effects of chronic illnesses on partners and marital relationships have investigated the effects of diseases like Cancer, Alzheimer's disease, Arthritis, Cardiovascular disease, and Diabetes (Baanders & Heijmans, 2007; Martire et al., 2004, 2010). As specific disease characteristics have been shown to have different effects, generalizations cannot be made from one disease to another (Baanders et al, 2007). Studies on specific diseases have, therefore, informed appropriate psychosocial interventions in the management of these diseases. There is, however, little empirical information on the effects of SCD on spouses, and at the time of conducting this study, no studies were found specifically investigating the impact of SCD on the healthy partner. This study hopes to address this gap. While the initial interest in the study stemmed from folk accounts of marital disharmony and distress among couples in which one partner has SCD, a review of the existing literature consolidated the relevance of such a study.

The existing literature reiterates the negative effects of a chronic illness on the health and well-being of the healthy partner, and the consequential negative effect on the partner's ability to provide adequate care and support to the chronically ill patient. The importance of a marital relationship to the health of both individuals involved is also clearly chronicled in the existing literature (Anderson & Keating, 2017; Glantz et al., 2009, Martire et al., 2018). Chronic illnesses have, however, been shown to have negative effects on marital relationships (Glantz et al., 2009, McInnes 2003; Rolland, 1994). As has been shown with other chronic diseases, psychosocial interventions that target both the spouse and the patient are, thus, of great importance. Considering, especially, that marriage is a life-long commitment, such interventions are valuable to maintaining marital harmony, sound health and good quality of life among chronically ill patients and their spouses. With regards to SCD, however, there is very little empirical information on the effects of the disease on marriages or on spousal caregivers; information that is necessary in the development of such interventions. An investigation of the nature and extent of difficulty that spouses of SCD patients experience, thus, represents a first step towards psychosocial interventions geared towards improving health and quality of life levels among both SCD patients and their spouses, as has been the case with other chronic ailments.

Another important consideration is the fact that SCD is a global health challenge, though predominantly prevalent in Africa (WHO 2010, Anie et al., 2010). In Ghana, as well, it is one of the more prevalent chronic conditions, with prevalence rates of between 20% - 30% of the population (WHO, 2010). The management and control of the disease are, thus, of substantial importance. An upsurge in multidisciplinary research is necessary to providing insights that enhance the knowledge and understanding of the disease (de-Graft Aikins et al., 2010). The results of this study will, thus, enhance an understanding of the complete burden

of the disease, and aid in the development of appropriate interventions for the comprehensive management of the disease. The knowledge generated from this study will be relevant to the development of appropriate strategies to support the spouses in their roles as caregivers. Primarily, the insights generated will help cater to the needs of the spouses themselves; it will provide an understanding of the areas in which they experience psychosocial stresses and inform appropriate interventions to support them. The study will have the secondary advantage of unearthing common problems that threaten marital quality and stability among SCD patients and their spouses. Such information will also enhance the knowledge-base and efficacy of couple-oriented psychosocial interventions. Considering the importance of a spouse's health and wellbeing, and of the quality of the marriage, to the health of the patient, the study will make a significant contribution to the comprehensive care and management of the patient.

1.4 Purpose Statement

The intent of this study was to investigate the psychosocial experiences of SCD on spouses of SCD patients in a Ghanaian setting. The study sought to explore effects of the disease in eight domains: the experience of caregiver burden, marital satisfaction among spouses of SCD patients, physical health, psychological wellbeing, social relationships (also referred to as social wellbeing in this study), environmental wellbeing, overall quality of life, and the experience of SCD-related stigma. The study also sought to highlight the mechanisms of coping among spouses of SCD patients. The importance of assessing coping mechanisms among individuals is highlighted in a paper by Brasileiro and colleagues (2016); identifying the coping styles of individuals allows healthcare professionals to aid them in improving their ability to cope more effectively with the effects of a disease (Brasileiro et al., 2016). Gender differences in the psychosocial effects of SCD and coping, as well as the effects of other

factors like the spouse's level of education, the number of years married and an awareness of the patient's sickle cell status before marriage were also explored in this study.

A mixed methods approach was used in the study. Mixed methods studies have the advantage of providing a more comprehensive understanding of a research problem through the integration of both quantitative and qualitative forms of data (Creswell, 2013). They also have the advantage of drawing of the strengths of both qualitative and quantitative approaches (Tariq & Woodman, 2013). This makes them better suited for answering more complex research questions, such as those related to health interventions (Tariq & Woodman, 2013). In such health-related research studies, therefore, using a mixed methods approach allows the researcher to gain a more complete understanding of issues and to 'hear the voice' of participants (Guetterman et al., 2015). This was the rationale behind the choice of a mixed methods approach to this current study. In order to gain a comprehensive understanding of the experiences of spouses of SCD patients it was considered important to derive numerical indications of the level and prevalence of psychosocial effects experienced, as well as to 'hear' participants' narrations of their lived experiences. The convergent mixed methods design, in particular, was found well-suited to the intents and time-frame of this study. In this method, both qualitative and quantitative data are collected and analysed concurrently, and then merged (Creswell, 2013). An important advantage of this design, which further informed its selection for use in this study is its use of both forms of data to confirm, cross-validate or corroborate the research findings. This quality of the convergent design helps ensure that a clear, accurate, and more comprehensive understanding of the results is obtained.

This study examines the following questions:

- What is the experience of persons married to SCD patients? In what areas and to what extent do they experience an impact?
- What is the effect on the marital relationship?
- How do spouses of SCD patients cope with the challenges associated with their partnership with an SCD patient?
- Do factors like demographic differences and an awareness of the patient's sickle cell status prior to marriage affect the psychosocial experiences of spouses of SCD patients?

1.5 Aims of the Study

This study seeks to investigate the psychological and social experiences of partners of SCD patients as a result of their relationship with the patient. To realise this aim, the following objectives were set:

1. To examine the experience of caregiver burden among spouses of SCD patients
2. To determine the impact of SCD on the Quality of Life (QOL) of a patient's spouse
3. To determine the effect of SCD on marital satisfaction
4. To highlight mechanisms of coping among spouses of SCD patients
5. To examine the experience of SCD- related stigma among spouses of SCD patients
6. To explore the effects of demographic differences (sex, level of education, and duration of marriage) on the psychosocial experiences of spouses of SCD patients.
7. To investigate the effects of an awareness of the patient's SCD status prior to marriage on the psychosocial experiences of spouses of SCD patients.

1.6 Hypotheses

In relation to the aims of the study, the following hypotheses were proposed:

1. There will be significant differences in psychosocial experience between male and female participants
2. There will be significant differences in coping strategies among male and female participants
3. The spouse's level of education will have a significant effect on the psychosocial effects experienced
4. A significant relationship will be found between the years of marriage and the psychosocial experiences of the spouse
5. An awareness of the patient's sickle cell status before marriage will have a significant effect on the psychosocial experiences of the spouse

1.7 Relevance of the Study

This study aims at generating socio-culturally relevant information regarding the difficulties faced by spouses of SCD patients in Ghana, which may be valuable to the development of effective holistic psychosocial and educational interventions in the management of SCD patients in Ghana. The study also hopes to elucidate specific areas that need to be targeted by educational and counselling programs that can assist spouses in their role as caregivers. Dobbie & Mellor (2008) argue that more emphasis should be given to such medical conditions in training programmes for psychologists. Information derived from this study may, therefore, be useful to the training of healthcare professionals, including Clinical and Health Psychologists, who will be involved in the management of these patients. Ultimately, information derived from the study will aid in improving the quality of life of the spouses, the

quality of their relationship with the patient, and subsequently, the quality of life of the patient as well.

The importance of such psychosocial investigations into the impact of chronic illness extends even beyond the needs of individuals. De-graft Aikins (2007) for instance, argues that chronic diseases pose a significant public health problem in Ghana due to the complexities of their causal factors and consequences. The biomedical model, however, plays a predominant role in research and interventions (Danquah et al., 2001; de-Graft Aikins, 2007). The African continent as a whole faces significant challenges in chronic disease research, practice and policy (de-Graft Aikins, Unwin, et al., 2010). Again, healthcare delivery and training programs still prioritise infectious diseases. There is, therefore, an urgent need for data and insights from multidisciplinary research for the development of socio-culturally appropriate chronic disease interventions (de-Graft Aikins et al., 2010). This study hopes to make a significant contribution towards this need.

1.8 Operational Definitions

This section explains the major terms and concepts referred to in this study with the definitions adopted for the purposes of the study.

Spouses/Partners of SCD Patients: The words ‘Spouse’ and ‘Partner’ are used interchangeably to refer to any individual (18 years or above) who is in a marital relationship with a person living with SCD. All recognisable forms of marriage in Ghana (legal, customary, Christian, or Islamic) were included (Marriages Act, 1884-1985 CAP. 127). Common Law marriages, which also occur frequently in Ghana, were also included. It is for this reason that the word ‘partners’ is interchanged with ‘spouses’ in this paper.

Psychosocial Impact: For the purposes of this paper, this term refers to the psychological and social experiences of spouses/partners of SCD patients as a result of living with an SCD patient. Experiences in the following psychosocial areas were considered in this study: Caregiver Burden, Marital Satisfaction, Physical Health, Psychological Wellbeing, Social Wellbeing, Environmental Wellbeing, overall Quality of life, and the experience of associated stigma.

Stigma: For the purposes of this study, stigma is considered to be any form of discrimination, shame, or negative attitude that spouses experience as a result of their relationship with an SCD patient. Examples are derogatory comments, mockery or advice against the relationship with the patient. The experience of SCD-related stigma is explored through the qualitative interviews in this study.

1.9 Summary

Chronic illnesses refer to those that are long-lasting in nature, persisting over a significant portion of an individual's life. Sickle Cell Disease (SCD) is a typical example of chronic illnesses. The disease is a genetic disorder of the blood that occurs when an individual inherits abnormal haemoglobin genes from both parents. It has been identified as the commonest haemoglobin disorder in man (Dos Santos et al., 2013; Gibbons et al., 2015). The disease is associated with high levels of morbidity and mortality, and currently, has no universal cure (Anie et al., 2010; Gibbons et al., 2015).

Research on the psychosocial dimensions of chronic diseases like SCD have indicated widespread effects, not only on the patients themselves, but also on all who live with and care for the patient (Baanders & Heijmans, 2007; Golics et al., 2013; Wittenberg et al., 2013). Some studies even suggest that informal caregivers - family members and significant others

suffer a greater extent of physical, psychological and social consequences than the patients (Dobbie & Mellor, 2008; Rees et al., 2001). Spouses of people living with chronic illnesses represent one category of caregivers whose experiences have been focused on to a large extent in research studies. Research studies consistently demonstrate a profoundly negative impact on spouses, physically, psychologically, and socially (Baanders & Heijmans, 2007; Eriksson et al., 2017; Rahmani et al., 2018; Rees et al., 2001).

Studies have investigated the impact of specific diseases like cancer, stroke, diabetes and arthritis (Anderson & Keaton, 2017; Li & Loke, 2014; Wilson et al., 2018) on spouses of patients with these diseases. Disease-specific characteristics have been shown to have an effect on the nature of its impact (Baanders and Heijmans, 2007; Wittenberg et al., 2013). The results of studies on the effects of one disease can, thus, not be easily generalised to another. The nature of the care-giving relationship (e.g. spousal caregivers or adult-child caregivers), can also have an effect on the nature of the impact (Oldenkamp et al., 2016; Wittenberg et al., 2013). It is, therefore, important to consider the type of relationship between the caregiver and the patient in studying the effects of the disease. Studies on the impact of diseases have many advantages. They enhance knowledge and understanding of the complete burden of chronic disease, and help to improve medical decisions (Wittenberg et al., 2013). They also promote an understanding of the effects of chronic illness on the quality of significant others, so that appropriate interventions can be developed to cater to their needs (Golics et al., 2013). Considering that family members and significant others are critical to successful patient care, providing them with the relevant support services is, again, important to comprehensive patient management.

The findings of existing research of the profound negative impact of chronic diseases on spouses, and the critical role they play in patient management, influenced the object of this

research study. This study focuses on the experiences spouses of SCD patients – an area that has so far, received little research attention. Similar to the objectives of existing studies on the psychosocial impact of diseases, this study hopes to generate information that will be useful to the development of couple-oriented psychosocial interventions in SCD management.

CHAPTER TWO

LITERATURE REVIEW

Chronic diseases persist through a significant portion of an individual's life; in some cases, as with SCD, the disease is present throughout the individual's entire lifespan. Such diseases are often progressive (Baanders & Heijmans, 2007; de Ridder et al., 2008), and affect the ability of the affected individual to function normally (de Ridder et al., 2008). Due to their nature, chronic diseases require varying levels of ongoing adjustment (physically, psychologically, and socially) not only in the life of the patient, but also family members and significant others. A plethora of research exists on the diverse effects of chronic diseases like SCD, Cancer and Diabetes, and the findings consistently demonstrate that the overarching effect on patients and on families and significant others is complex and profoundly negative (de-Graft Aikins et al., 2010, Dobbie & Mellor, 2008). This literature review looks at the pattern of research on SCD and its impacts and portrays it as a reflection of the general trend of research on the various impacts of chronic illness. This comparison highlights the need for studies on the effects of illness on healthy partners and the efficacy of couple-based interventions for chronic diseases such as SCD. The existing research further depicts a reciprocal relationship: the negative impact of the patient's illness on the caregiver's health and wellbeing compromises his/her ability to adequately care for and support the patient (Holmes & Deb, 2003). The health and wellbeing of the patient is, thus, negatively affected (Lim & Zebrack, 2004). This reciprocal relationship is captured in the theoretical foundations of this study, which further affirm the significance of focussing on the patient's spouse. This chapter first discusses the theoretical foundations of the study. A review of the related literature is then presented.

2.1 Theoretical Foundations

This study has as its principal objective to highlight the psychosocial difficulties experienced by partners of SCD patients. The main reasons for this objective lie in the well-established fact that a chronic physical illness not only impacts the lives and wellbeing of the patients themselves (Golics et al., 2013; Wittenberg et al., 2013). Family members, loved ones, and all others who live with and care for the patient also experience an impact, which is sometimes to an even greater extent than the impact on the patient (Dobbie & Mellor, 2008). Family members and loved ones, in turn, have been shown to have the capacity to greatly influence the patient's health and wellbeing (Golics et al., 2013). When loved ones experience compromises in their wellbeing, therefore, there is the risk of a reciprocal negative effective effect on the patient's health (Golics et al., 2013).

Spouses, who are patients' most important caregivers, have been found to bear a significant psychosocial impact (Meier et al., 2011). They also, however, wield the most significant impact on the patient's health and wellbeing (Martire et al., 2004). Spouses are, therefore, critically important to a chronically ill patient's health and management. The importance of focussing on the wellbeing of spouses or partners of patients who have chronic ailments like SCD is implicit. Other chronic illnesses like cancer, diabetes, etc., have been shown to exert profound negative impacts on spouses, in varied psychosocial domains (Pitcealhy & Maguire, 2003; Li & Loke, 2014; Wilson et al., 2018). The spouses' distress thereby has a significant potential to affect the patient's own health and wellbeing. Focussing on the spouse as well in the management of a chronic illness primarily offers the opportunity to help relieve the distress that they experience and to improve their quality of life. It also offers the opportunity to improve the quality of the marriage, and the spouse is placed in a better position to take up the responsibilities brought on by the patient's illness and limitations. The

reciprocal positive effect on the health of the patient is another advantage. Overall, it leads to improved quality of life, psychosocial wellbeing and overall health of the patient as well.

Two major themes were identified from reports of existing research: the reciprocity that governs the overall impact of chronic diseases, and the importance of sound social support systems, both formal and informal, to a patient's wellbeing. These themes are fundamental to the purpose of this research study as they explain the need to address the stressful effects of a chronic illness on spouses, which can have reciprocal negative effects on the patient. The importance of studies such as this one to the augmentation of both formal and informal social support systems further drives the purpose of this study. The insight from studies like this one may strengthen healthcare systems (formal social support systems) by providing valuable information towards the management of chronic diseases. The ability of the spouse to cope with the challenges associated with the relationship with the patient can also be strengthened significantly through psychosocial interventions. This will, in turn, augment their ability to provide informal support to the patient.

The choice of a theoretical framework for this study was informed by a consideration of these themes. The Self-determination Theory (SDT) by Deci and Ryan (2000) and the Social Cognitive Theory (Bandura, 1986) are two theories of human behaviour that emphasize the influence of environmental factors on the behaviour of individuals. The basic tenets of these two theories were found applicable in conceptualising this study. Bandura's Social Cognitive Theory focuses on the reciprocal nature of interactions between individuals and factors in their environment. The theory has widespread applications in health management, and suitably reflects the basis of this study. The SDT by Deci & Ryan (2000) is a contemporary theory of motivation in human behaviour, which also focuses on the importance of environmental factors in shaping human behaviour. The SDT shows that regulating

environmental factors can be valuable in promoting positive health behaviour. These theories are discussed further in the following subsections.

2.1.1 The Self-Determination Theory (SDT; Ryan & Deci, 2000)

The concept of self-determination, as a psychological construct, refers to the process by which individuals take intentional, conscious decisions based on their own will (Hui & Tsang, 2012). The fundamental focus of the Self-determination Theory by Deci and Ryan (2000) is self-determined behaviour and the social and cultural conditions that promote it (Ryan, 2009). The theory is based on the premise that human beings are inherently active and growth-oriented organisms who have an intrinsic tendency to seek personal growth and development (Hui & Tsang, 2012; Ryan, 2009). This intrinsic tendency is referred to as Intrinsic Motivation (Ryan, 2009). The theory postulates that the development of these positive tendencies, however, depends on the kind of support they obtain from their environment (Hui & Tsang, 2012). An individual's intrinsic growth tendencies require "specific supports and nutriments" from one's social environment (Ryan, 2009). External influences such as social and cultural factors, therefore, have the potential to promote or to reduce an individual's sense of initiative or self-determination, in addition to their wellbeing and behaviour (Ryan & Deci, 2000). Improving support systems in the patient's environment is thus, important to promoting self-determined health-related behaviour and wellbeing.

The concepts of the SDT have found widespread application to processes of health behaviour change (Ng et al., 2012; Ryan et al., 2008). The promotion and maintenance of self-determined behaviour have been shown to be crucial in the care and management of patients (Ryan et al., 2008). The application of the SDT to health improvement and maintenance is specifically concerned with processes by which the patient acquires motivation to initiate and

maintain positive health-related behavior (Ryan et al., 2008). The theory is, thus, suitably applied to healthcare interventions and programs tailored toward health-behaviour change in chronically ill patients. A study by Williams and colleagues (2004) for instance, applies the SDT in interventions tailored towards the improvement of glycemic control among patients with type 2 diabetes.

Managing SCD requires active self-regulation and self-management by the patient. Interventions that augment self-determined behavior among SCD patients are, thus, important. As the SDT postulates, external or environmental influences play a vital role in determining a person's intrinsic motivation towards self-determined behavior (Ryan & Deci, 2000). With this in mind, this study targets two significant factors of an SCD patient's environment – the marital relationship and healthcare professionals.

Considering the significance of the marital relationship to health, a patient's spouse can be considered as one of the most significant factors in a patient's environment. The spouse represents an environmental factor that has critically significant potential to promote or undermine the patient's inherent tendency towards self-determined behavior. The ultimate aim of this study is to target spouses of SCD patients in psychosocial interventions tailored towards the patient's management. The first step towards the attainment of this goal is the investigation of areas of difficulty or distress among spouses which need to be focused on in such psychosocial interventions. This is the step that this study takes. With the insights that this study provides, couple-oriented psychosocial interventions can more effectively influence positive changes in marital relationships towards the improvement of the patient's wellbeing. In the same vein, the study targets health professionals, such as clinical psychologists, who may be tasked with the development of appropriate strategies towards improving the patient's psychosocial wellbeing. The information generated from this study

may be relevant to the training of clinical psychologists and other healthcare professionals in this regard.

2.1.2 The Social Cognitive Theory (Albert Bandura, 1986)

Bandura's Social Cognitive theory views human behaviour as the result of a dynamic and reciprocal interaction among their behaviour, their personal characteristics and environmental influences. Bandura refers to this model of causation as a "triadic reciprocal determinism" (Bandura 1989). Behaviour, personal factors and environmental influences all operate as interacting determinants that influence each other bi-directionally (Bandura, 1989). Personal characteristics include cognitive, emotional, and biological factors - thoughts, feelings, beliefs, expectations, goals, etc. Environmental influences include family members, friends, and colleagues, and other factors external to the individual that can affect his/her behaviour. The behaviour refers to the individual's skills and actions. The concept of reciprocal determinism therefore suggests that individuals function as a result of the dynamic and bi-directional interaction among these factors (Lang, 2005).

The Social Cognitive Theory has been shown to be relevant to health behaviour programs and has been used in providing the basis for intervention strategies. The concept of self-regulation in health behaviour change, for instance, is based on the Social Cognition theory (Ryan and Sawin, 2009). Self-regulation refers to self-management processes that enhance a person's ability to manage a chronic illness. It includes processes such as self-monitoring and reflective thinking, planning and action, and management of physical, emotional and cognitive responses (Ryan and Sawin, 2009). The management of chronic health conditions thus leads to the improvement of health outcomes and quality of life for the individuals and their families (Ryan and Sawin, 2009). Applying the concept of reciprocal determinism, self-

regulation processes are the personal factors; improvements in the individual's ability to manage the illness represent the behaviour change, and the family that is also affected represents environmental factors.

The theory may thus, also be applied to this study. The personal characteristics of a patient with SCD (the cognitive, biological and psychological factors), his/her health behaviours and the healthy spouse (an environmental factor) exert a dynamic and reciprocal interaction on each other. Improving the quality of life of the spouse, would lead to improvements in the patient's cognitive, psychological and biological factors, thus leading to enhancements in his/her self-regulation and health behaviours. The ultimate result, therefore, is improved health, quality life, and subsequently, quality of marriage, for patient and spouse.

2.1.3 Critique of Theories

The aim of a theoretical framework is to provide an explanation of the problem, purpose, significance and research questions of a research study (Grant & Osanloo, 2014). The selected theories that form a study's theoretical foundations serve as a rationale and support for the aims of the study (Grant & Osanloo, 2014). The theories selected for this particular research study are, thus, evaluated in view of the general aims of a theoretical framework.

The similarity between the SDT and the Social Cognitive Theory is the focus on the importance of environmental factors in determining the health, behaviour and wellbeing of individuals. The SDT emphasizes the role of social and environmental factors in motivating positive, self-determined behaviour in an individual (Ryan 2009). Similarly, the Social Cognitive Theory highlights the reciprocal nature of interactions between an individual and his/her environment (Bandura, 1989). In the field of healthcare and patient management, for instance, the SDT explains how managing social and environmental influences through

appropriate interventions can augment a patient's intrinsic motivation towards positive health behaviour (Ng et al., 2012; Ryan et al., 2008). The concept of reciprocity, on which the Social Cognitive Theory is based, also highlights the importance of addressing societal and environmental influences in patient management, as they have direct effects on the health and wellbeing of the patient.

Based on the fundamental premises of these two theories, this study highlights the need to regulate social and environmental influences in order to improve the health and wellbeing of SCD patients. In particular, the study focuses on the patient's partner as a significant environmental factor. The rationale for the study lies in the premise that managing important environmental factors can have significant positive effects on the health behaviour and overall health and wellbeing of the patient. Improving the quality of a marriage as well as the ability of a spouse to care for the patient can have reciprocal significant positive effects on the patient's psychosocial wellbeing. This positive psychosocial wellbeing will in turn, augment the patient's intrinsic tendency for positive health behaviour.

2.1.4 Conceptual Framework

The purpose of this study is to take the first step towards the development of appropriate psychosocial interventions that target the spouse and the marital relationship. This is to investigate the psychosocial issues or challenges that spouses face in their relationship with the SCD patient and in their role as caregivers. Figure 1 shows the conceptual framework for this study, based on the theoretical underpinnings discussed:

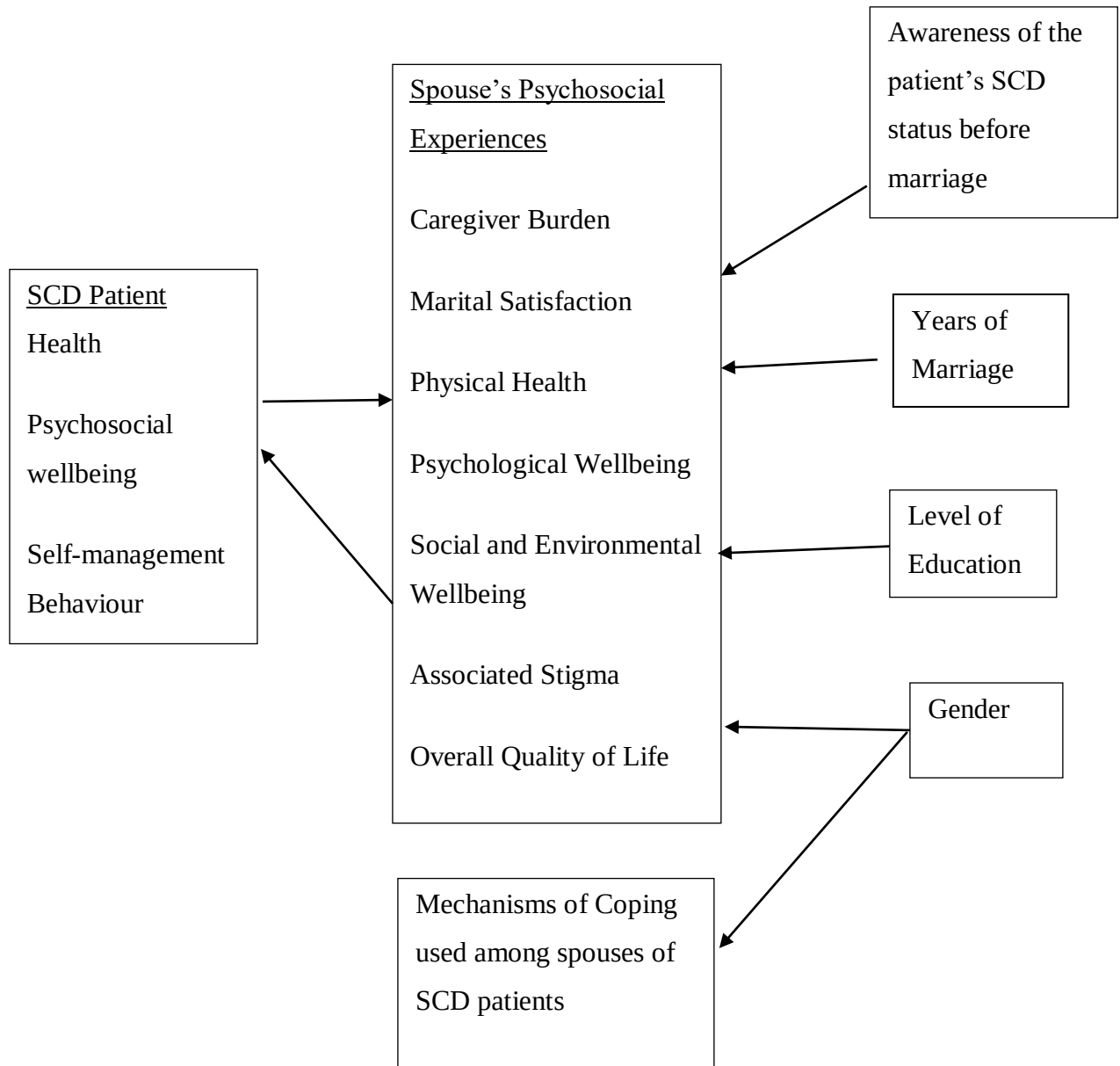


Figure 1: Conceptual Framework

A review of the existing literature on the impact of chronic diseases like SCD further explains the reciprocal nature of the effects of such diseases on significant informal caregivers like spouses. The important role of the spouse as an important environmental factor in influencing the health and wellbeing of the patient is also evinced. The existing literature is reviewed in the following sections.

2.2 The Impact of Chronic Diseases

Chronic diseases are associated with high levels of morbidity and mortality and exhibit significant prevalence levels across the world. In fact, Sub-Saharan Africa is the only region in the world in which infectious diseases still outnumber chronic diseases as a cause of death (de-Graft Aikins et al., 2010). All the same, the African continent bears a significant portion of the world's chronic disease burden (de-Graft Aikins et al., 2010). In Ghana, like in the rest of the continent, the “chronic disease epidemic” poses significant public health and developmental challenges (de-Graft Aikins, 2007). De-Graft Aikins and colleagues (2010) highlight the significant challenges that the African continent faces in chronic disease research, practice and policy. They emphasize that in order to understand and respond to the multifaceted roots and consequences of chronic diseases, it is necessary for interventions and policies to be properly informed by multidisciplinary models of research – biomedical and social science (de-Graft Aikins, 2007; de-Graft Aikins, Unwin, et al., 2010; de-Graft Aikins, Boynton, & Atanga, 2010).

This need for a multidisciplinary approach to the management of chronic diseases is stressed by many. Danquah and Amobire (2001) accentuate the adequacy of the biopsychosocial model in comprehensive chronic disease management; a model that views disease as occurring as a result of multiple factors comprising biological, psychological and social

dimensions which produce multiple effects. The required interdisciplinary approach to diagnosis and treatment must therefore comprise a team made up of physicians, nurses, nutritionists, clinical psychologists, environmental officers, social workers, etc. (Danquah & Amobire, 2001).

Clinical Psychologists play an integral role in the management of chronic diseases like SCD as the stressful effects of these diseases have a marked impact on the psychological health of patients, family members and significant others alike. Dobbie & Mellor (2008) argue that the implications for psychological practice cannot be overemphasized, and that it is imperative that more emphasis be given to chronic illness and its impacts in training programmes for psychologists.

The existing literature on the impact of chronic diseases seems to follow a certain trend. A significant portion of the research focuses on the patients themselves, with the initial focus on the physiological and biomedical dimensions of the disease. With time, the attention shifted to the immense psychological and social effects that are characteristic of living with chronic illness. One important finding of the research is that these psychosocial effects further impact on the patient's ability to adapt to and manage the illness, thus resulting in a reciprocal effect.

With further research came the realisation that the psychosocial effects of chronic disease not only impact the patient, but also family caregivers and significant others. Even those who may not identify themselves as carers but live with or spend time with the patient may still be greatly affected (Baanders & Heijmans, 2007; Golics et al., 2013). In investigating the effects of a patient's illness on families, the existing research has focused on parents (with a larger focus on mothers), spouses or partners, siblings, and the family unit as a whole. Family members have been shown to experience multiple, widespread effects, and the overall impact

is profound (Dobbie & Mellor, 2008; Golics et al., 2013; Lim & Zebrack, 2004). Effects on physical and psychological well-being, social life, and overall quality of life are well documented. Family caregivers, for instance, commonly report physical exhaustion and worsened physical health (Lim & Zebrack, 2004). Social problems such as disruptions in social life, impaired family relationships and increased financial strain are also common (Golics et al., 2013, Lim & Zebrack, 2004, Holmes & Deb, 2003).

A significant portion of the existing literature focuses on the profound effects on the psychological well-being of family members. Caregivers are often mentally exhausted, overwhelmed, and feel isolated because they lack support, training, information and a ‘sympathetic ear’ (Lim & Zebrack, 2004). Increased psychological stress and distress levels, depression and anxiety among families are also common findings (Dobbie & Mellor, 2008, Holmes & Deb, 2003). A study by Golics and colleagues (2013) investigating the impact of a patient’s illness on family members portrays the effects on the different facets of family life. While sixty-seven percent of participants reported a negative impact on their sleep and health, fifty-two percent described disruptions in their work and study. Sixty-nine percent (69%) of the participants reported impaired family relationships, due to effects like increased stress and tension, and up to 91% of the participants experienced a negative effect on their day-to-day living as a result of having a chronically ill relative. The significant impact of chronic disease on families was reported by 51% of the participants. The results of the study show the magnitude of the psychological impact of chronic illness on family members, as 92% of the participants reported being emotionally affected. Worry, guilt, anger and frustration were among the common effects.

The effect on psychological adjustment is another key finding of research. It has been shown that chronic illness usually requires ongoing adaptation on the part of the individual (Dobbie

& Mellor, 2008, de Ridder et al., 2008) and in a likely manner, the family (Dobbie & Mellor, 2008). The extent to which the individual diagnosed with the chronic illness copes with the diagnosis, and their ability to adjust to physical, emotional and social challenges will impact on the adjustment and coping abilities of their family members (Dobbie & Mellor, 2008). Overall, families and loved ones of chronically ill patients experience a reduced quality of life (Golics et al., 2013, Lim & Zebrack, 2004). The impact that chronic illness has on an individual, however, may vary dramatically from person to person (Dobbie & Mellor, 2008). It is, thus, important to remember that chronic illness is not synonymous with poor psychological adjustment or psychological disorders (Dobbie & Mellor, 2008).

Specific characteristics of the caregiver, such as age, gender, level of education and the type of relationship with the patient, have been shown in previous studies to influence the caregiving experience. Gender differences in the experience of caregiving distress, for example, have been shown to be a significant factor. The reports indicate that female carers tend to exhibit higher levels of burden and distress than males (Akpinar & Yurtsever, 2018; Madivalkar et al, 2018; Poysti et al., 2012). This finding has been attributed to reasons such as the fact that the caregiving role is often naturally ascribed to women, and they are often expected to fulfil the role without preparation or knowledge (Papastravou et al., 2007). Women also tend to receive less social support in their role as carers than men (Papastravou et al., 2007). Papastravou and colleague, 2007, for instance, observed while conducting their research that when the caregiver was male, there was always another member of the family nearby to help and support. Male caregivers also tend to receive more informal support than females (Papastravou et al., 2007). Gender differences in the coping strategies used among family caregivers has also been shown to influence the differences in caregiving experiences.

Women reportedly use less effective coping strategies such as emotional coping strategies than men, which may explain their higher levels of distress (Papastravou et al., 2007).

The caregiver's level of education has also been shown to influence the caregiving experiences. Studies indicate that higher levels of education are associated with lower levels of caregiver distress (Akpinar et al., 2018, Madivalkar et al., 2018; Papastravou et al., 2007). Carers with higher levels of education tend to receive higher remuneration, leading to lower levels of burden (Papastravou et al., 2007). Higher levels of education among family members also allows them better access to information, and gives them the ability to use the information obtained more effectively (Akpinar et al., 2018). Education, again, influences the coping strategies adopted, and thus lead to less distress and better quality of life among caregivers (Akpinar et al., 2018).

Research interests on the psychosocial impacts of chronic diseases further narrow down to the impact on spouses or partners specifically. Spouses, like mothers, have been found to experience greater burden and levels of distress than other family caregivers, owing to the fact that they spend more time in the caregiving role (Akpinar et al., 2018; McInnes et al., 2003; Rees et al., 2001). Studies have explored the effects of various chronic diseases (including cancer, diabetes, asthma and arthritis) on the health and well-being of a healthy partner. As with the wider research on the impact on families and loved ones, these research studies consistently demonstrate profound effects on the physical and psychological health, as well as on the quality of life of partners.

The following section of this review explores further the existing research on the impact of illness on healthy partners and the need for couple-based interventions in the management of chronic illness.

2.3 Psychosocial Effects of Chronic Diseases on Partners

As earlier indicated, previous research on health-related quality of life focused almost exclusively on patients, but increasing attention is now being paid to the impact of chronic diseases on family caregivers and significant others (Rees et al., 2001). Much of the attention has been focused on the effects on the health and quality of life of partners or spouses. This is due to certain realisations. Primarily, it has been recognised that partners often become carers and they inevitably spend more time in the care-giving role than other primary caregivers (McInnes et al., 2003; Rees et al., 2001). In fact, the partner is often the patient's most important caregiver, and the most looked to for support (Li & Loke, 2014; Meier et al., 2011). It has also been shown that partners often have less social support and this may contribute to the experience of a greater care-giving burden than other carers (Eriksson et al., 2017; Meier et al., 2011; Rahmani et al., 2018; Rees et al., 2001). Research reports further indicate that the effect of chronic illness can be significant, irrespective of an involvement in care-giving (Baanders & Heijmans, 2007; Golics et al., 2013). Baanders & Heijmans (2007) for instance, argue against the initial viewpoint that the impact of a patient's chronic illness on a healthy partner results directly from the consequences and burden of care-giving. Instead, they assert that there are certain manifestations of chronic illness that may not necessarily lead to increased care-giving but may cause disruptions in the partner's life. Factors like the unpredictability of the patient's condition or the anticipation of possibly bad days may cause partners to put their own needs aside or to reorganize their lives in advance, and may hinder personal achievements (Baanders et al., 2007). The patient's illness symptoms, negative mood, and need for emotional support or physical assistance have also been shown to be physically, emotionally, and financially taxing (Martire et al, 2004; Lim & Zebrack, 2004). Findings, therefore, indicate that living with a person with chronic illness can

cause significant problems for healthy partners, for reasons that clearly go beyond the burden of care-giving (Baanders & Heijmans, 2007).

High levels of partner morbidity are prevalent findings in research studies on the impact of chronic illness. Even more important is the indication that there is a tendency for the quality of life of partners to be worse than that of the patients themselves (Rees et al., 2001). Partners have been shown to experience a complex range of effects including worsened physical health, an increased risk of psychological problems, and impaired social functioning. In a 2001 review of existing research on the impact of chronic illness on partners, Rees and colleagues found that partners reported numerous difficulties. These included: fear of the future, depression and/or anxiety, deterioration in the marital relationship and sex life, concerns about suffering of the patient, physical and mental exhaustion, social disruption – either through looking after the patient or through the unwillingness to go out alone, and financial difficulties (due to expense of care, or due to the inability of the patient or the partner to continue working).

Recent studies have mirrored these findings. In a qualitative study of the experiences of partners living with chronically ill persons by Eriksson and colleagues (2017), for instance, partners reported experiencing many challenges in their daily lives in relation to factors such as inadequate social support and the need to adapt to constant changes and an uncertain future. This had an impact on both their physical and psychological health, and they expressed the need for more assistance from the health care sector. The authors conclude with the all-important recommendation for formal care providers (i.e. healthcare professionals, including clinical psychologists) to acknowledge partners' needs, develop evidence-based assessment guidelines, and provide efficient support to partners with a chronically ill spouse (Eriksson et al., 2017). Rahmani and colleagues (2018) also found that due to a lack of

adequate supportive resources, female caregivers of husbands with severe (chronic) mental illness experienced emotional exhaustion and psychological distress, leading to emotional detachment over time. The conclusions in this study also emphasize the need to pay close attention to spousal caregivers' own mental health, and to provide adequate information, education and supportive resources to facilitate their transition to care giving roles (Rahmani et al., 2018).

The potential challenge that chronic illnesses pose to partners in their daily lives is again underscored in a study by Wilson and colleagues (2018) who show that spouses of patients with knee osteoarthritis experienced marital tension on days when they perceived the patient to be in significant pain. They stress, again, the need to examine both patient and partner's experience of the patient's pain, and its significance for daily marital functioning. Research findings over time, therefore, have consistently emphasized the need to pay attention to the experiences and needs of partners of chronically ill patients, in order to provide adequate support to them (Wilson et al., 2018).

The importance of marital functioning to health is well established in research literature. Higher marital quality is associated with increased psychological and physical health (Anderson & Keating, 2017; Martire et al., 2018), and negative marital interactions have been shown to exert a huge impact on the health of both patient and partner. Chronic illnesses have a devastating effect on marital relationships (Glantz et al., 2009; McInnes 2003; Rolland 1994). Apart from the decrease in their physical, psychological and social well-being, spouses also often report a decreased satisfaction in their relationship with the patient (Martire et al, 2010). Sexual dissatisfaction is also a commonly reported effect. Owing to a number of biological and psychological illness-related factors, chronically ill patients may experience alterations in sexual desire, capacity, and activity, leading to a limitation or

cessation of sexual relations (McInnes, 2003). An unsatisfactory sexual relationship, however, can further precipitate significant emotional crises in a healthy partner (McInnes, 2003). Subsequently, chronic illnesses can often lead to marital discord, separation, divorce, or partner abandonment (Glantz et al., 2009).

The adverse effect of spousal conflict on the physiology and health of the patient is also well established in the existing literature (Glantz et al., 2009; Martire et al., 2010; Wanik & Kulik, 2011). Considering the significant role that a spouse plays in a patient's ability to cope successfully (Meier et al., 2011; Martire et al., 2010; Lim & Zebrack, 2004), it stands to reason that the strongest links between chronic illness and family relationships have been most often found in the marital relationship (Martire et al, 2004). Due to the distressing effects of the patient's illness spouses may wane in their ability to be supportive with time, and may become increasingly critical and controlling (Martire et al., 2010). Factors such as marital conflict, spouse criticism, and expectations and beliefs regarding the disease have consistently been found to have profound effects on the management of chronic illness (Martire et al, 2018; Wanik & Kulik, 2011). Recognition of this reciprocal effect on the health and wellbeing of both patient and spouse has, therefore, precipitated more research on the impact of illness on the partner. Studies have tried to determine how specific disease characteristics affect a healthy partner, in which particular domains of life they are affected, and to what extent.

The importance of these studies on the impact of chronic illnesses on the partner can, thus, not be overemphasized. The information they derive leads to increased support for partners, aimed at helping to relieve them of their distress, and to improve their quality of life. Improving the partner's quality of life enables them to care for the patient better, and further improves the quality of their relationship with the patient. The subsequent result is improved

patient health and quality of life. Partner quality of life studies have been instrumental in the development of psychosocial interventions that include spouses in the management of chronic diseases. In a review of couple-oriented psychosocial interventions in diseases like cancer, arthritis, cardiovascular disease, chronic pain, HIV, and Type 2 diabetes, for instance, Martire and colleagues (2010) found that such interventions yielded significant positive effects on depression in patients, on marital functioning, and on pain symptoms. Such interventions were on the whole, more efficacious than regular patient care or psychosocial interventions that focused only on the patient. An earlier analysis of the benefits of including family members and significant others in psychosocial interventions for chronic illness, for instance, also showed that including spouses even reduced patient mortality in some cases (Martire et al., 2004). Regan and others (2012) reviewed similar couple-oriented interventions specifically related to cancer, and found significant improvements in couple communication, psychological distress, and relationship functioning, as well as in coping and reduced distress levels. Ultimately, partner quality of life evaluations lead to a more holistic approach to the management of chronic illnesses.

The existing literature further suggests that demographic characteristics such as a partner's gender may influence the impact of a chronic disease experienced by the partner. Studies indicate that female partners of chronically ill patients exhibit higher levels of distress than males (Poysti et al., 2012; Savundranayagam et al., 2011). Reasons for this finding have been attributed to the fact that wives have been found to exhibit greater willingness to commit to the relationship when the men are affected by chronic illness (Glantz et al., 2009). Women have also been found to adopt a more comprehensive caregiving role than men (Poysit et al., 2012). Another possible reason for the gender difference in distress levels is the fact that female caregivers have been found to be more likely to take a negative view of the patient's

illness and impact on their lives (Pitceathly & Maguire, 2003). Differences in coping strategies used between male and female carers further explains the differences in caregiving experiences. Women have been found to adopt more emotional coping strategies than men, which may be less effective in coping with the burden of care (Papastravou et al., 2007). Other less effective coping mechanisms such as avoidance coping have also been reported among female caregivers in previous studies (Papastravou et al., 2007).

SCD research has mirrored the general research trend on chronic diseases, except where spouses or partners are concerned. Whilst the initial focus was on the physiological dimensions, studies have, over time, highlighted diverse psychosocial effects of the disease both on patients and on their families. These studies have further shown the reciprocal effect that psychosocial distress has on the health of the patient. A review of the existing literature reveals very little information on the effects of the disease on a patient's spouse, or the effects on a marital relationship. The existing literature on the psychosocial impact of the disease is further examined in the next section.

2.4 The Psychosocial Effects of SCD

Research on the psychological and social effects of SCD evinces similar themes to those portrayed by general chronic disease research, such as the complex range of psychological and social effects on patients, which require close attention by varied healthcare professionals. The significant impact on the physical and psychological well-being of family members, caregivers, and significant others is also portrayed. A review of these themes is significant to this paper, as it helps better understand the potential impact on a spouse.

2.4.1 Psychological and Social Problems associated with SCD

Since the decade of the 1980s, there has been an upsurge of research focusing on the psychosocial aspects of SCD (Ohaeri & Shokunbi, 2002). The disease has been associated with several psychological and social difficulties, which may even have a more profound impact on the life of the sufferer than the pain crises itself (Okraku et al., 2008). Psychological complications are frequent co-morbidities of SCD, both in children and in adults (Anie et al., 2005). Among the psychiatric symptoms often presented by SCD patients, depression and anxiety are the most common (Alao et al., 2003; Anie et al., 2005; Edwards et al., 2005; Unal & Ozlem Kutuk, 2011). In a review of literature Anie (2005) identifies social withdrawal, aggression and poor relationships among commonly experienced psychological problems. Asnani and colleagues (2010) further found increased levels of loneliness co-existing with depression among SCD patients. Studies on the neuropsychological dimension of SCD also show that cognitive impairments frequently occur among SCD sufferers (Ampomah et al., 2015; Vichinsky et al., 2010). Persons living with the disease generally report a reduced overall quality of life (Mann-jiles & Morris, 2009; Santos & Gomes, 2013; Owotomo, 2016) .

Whilst the excruciating pain involved has been cited as one of the main causes of stress and anxiety, the distress that persons with SCD experience can also be attributed to the difficulties they face in social life (Adegbola et al., 2012; Wonkam et al., 2014b). The debilitating nature of the disease often leads to disruptions in daily activities, work and education limitations, and difficulties in interpersonal relationships (ASH, 2016). Patients have expressed worry about the long term effects of the disease and cumulative effects of sickle cell treatments (United States Food and Drugs Administration (FDA), 2014). Fears of dying early, fears of getting pregnant, and concerns over the ability to finish school and start

a career or family in addition to living with the long-term social and emotional impacts of the disease, are also common concerns among SCD patients (FDA, 2014). Other factors like the need for frequent hospitalisation, financial difficulties due to high unemployment levels, work limitations and the cost of disease management, as well as the effects of social attitudes to the disease have also been identified as possible contributors to the psychosocial burden of the disease (Anie et al., 2010; Edwards et al., 2005).

Stigma is a frequent experience of SCD sufferers (WHO, 2010). A study by Anie and colleagues (2010) on the psychosocial impact of SCD in a Nigerian population, for instance, found that the society in general exhibited a negative perception of SCD through its attitudes. A large proportion of the study's participants attributed this to limited awareness of SCD in the society. This is supported by the results of a study by Abioye-Kuteyi and colleagues (2009), who found that the majority of local government workers in Nigeria had poor knowledge of SCD. The authors, therefore, stress the need for the development of SCD education programmes for patients and the public.

Coping constitutes one of the most recurring themes in SCD research. Psychological problems among SCD sufferers have been associated with inappropriate coping strategies, or difficulties coping with the associated pain and symptoms of SCD (Anie, 2005). Studies indicate that the majority of patients have significant difficulty coping with their condition. 85.9% of adult patients in a study by Wonkam and others (2014b) in Cameroon, for example, reported moderate to severe difficulty living with SCD. Patients who were married indicated less difficulty coping than unmarried individuals (Wonkam et al., 2014b). It has, however, also been indicated that people with SCD exhibit different levels of the ability to cope, which has a direct effect on psychosocial functioning (Anie et al., 2010). Whilst some cope relatively well, attend school or work, and are active physically and socially, others are

unable to cope adequately, and lead more limited and secluded lives (Anie et al., 2010). Psychological interventions are effective ways of improving coping ability, and hence the psychosocial functioning, of individuals (Okraku et al., 2008).

The importance of psychological interventions in the management of SCD is evident, in light of the significant impact of the disease on the psychological and social wellbeing of patients. A consistent recommendation of studies of this psychosocial impact is that more emphasis be placed on the role of non-medical professionals, such as Clinical Psychologists, in the management of SCD. Studies have further indicated the efficacy of psychological interventions in SCD management. Cognitive behavioural interventions have, for instance, been reported to be effective in pain reduction and alleviation of mood problems (Anie, 2005; Edwards et al., 2005). A study by Okraku and colleagues (2008) also evidenced the effectiveness of psycho-education in improving knowledge and coping among adult SCD patients in Ghana. Studies on the effectiveness of psychological interventions in SCD, however, are limited and the need for well-designed assessments of the effectiveness of specific interventions in sickle cell disease has been identified (Anie & Green, 2015).

2.4.2 Psychosocial Effects of SCD on Family Caregivers

From the decade of the 1980s, there has been an upsurge of research focusing on the psychosocial aspects of SCD (Ohaeri & Shokunbi, 2002). A significant portion of the studies focuses on the impact on family caregivers. The attention has mainly been on parents (particularly mothers), siblings, and the family as a whole unit. Research results portray a significant negative impact on the psychological and social wellbeing of individual family members, on routine family activities and family interactions, and on family finances.

Research studies on the impact of SCD on caregivers have primarily looked at parents, with greater attention on the impact on mothers, who are more often the primary caregivers. Caring for a child with SCD has been shown to place a significant burden on parents. Research results indicate effects on psychological wellbeing, and financial difficulties. Parental relationships may also be affected, and having a child with SCD can lead to increased marital conflict and higher divorce rates (Habeeb et al., 2015). A study by Assimadi and others (2000) on the impact of SCD on families in Togo, for instance, found that parents were disturbed, with 82.5% experiencing insomnia, 76.7% feeling frustrated, 73.5% fearing the loss of the child, and 65% experiencing financial difficulties. The study further found that having a child with SCD led to the separation of seven out of twenty-six couples (26.9%). These findings are supported by the results of recent studies. Parents have expressed difficulties living with a child with SCD, and report harbouring fears of sickness and infection in the child, fear of crises at the wrong time and of hospital admission, and fear of having another child with SCD (Wonkam et al., 2014a). In a study by Brown and others (2010) in Nigeria, 26.8% of parents admitted feeling depressed, while 14.9% felt sorrowful and cried frequently. Another 4.5% of parents in this study felt that caring for a child with SCD had led to marital disharmony, and although majority of the parents preferred caring for the child themselves, 7.5% of them would rather have the child kept in an institution (Brown et al., 2010).

Mothers, in particular, have been shown to experience significantly high levels of psychosocial impairment (Tunde-Ayinmode, 2007). Many exhibit depressive symptoms and report that caring for their affected child placed limitations on their daily activities and their livelihood (Marsh et al., 2011; Moskowitz et al., 2007; Tunde-Ayinmode, 2007; Unal & Ozlem Kutuk, 2011). This could be attributed to the amount of time spent caring for the child

(Moskowitz et al., 2007; Tunde-Ayinmode, 2007). Negative effects on mood, sleep and cognitive function have been found (Van Den Tweel et al., 2008). Marital adjustment problems have also been indicated (Unal & Özlem Kütük, 2011). In a qualitative study by Marsh and colleagues (2011), mothers of children with SCD in a rural part of Kenya recount their experiences of blame and stigma. In one community, for instance, SCD in a child was attributed to ‘bad spirits’ in the mother, with fathers sometimes even refusing to be tested (Marsh et al., 2011). Mothers in this study also attested to the effects that caring for the affected child had on their independent livelihood (Marsh et al., 2011). One mother, for instance, explained that her childcare responsibilities prevented her from seeking financial independence (Marsh et al., 2011). Generally, female caregivers of SCD children experience a reduced quality of life (Van Den Tweel et al., 2008).

Financial distress was one of the most commonly reported problems among caregivers of SCD patients. This may be attributed to factors like the cost of hospital care which, with SCD is exacerbated by frequent hospitalisations. The effect on a caregiver’s ability to work is another significant factor. In a study conducted in the United States of America, Brandow and others (2008) illustrate that a single episode of pain crises in a child with SCD can result in missed work days for the caregiver. The majority of participants in a study by Wonkam and colleagues (2014a) in Cameroon agreed that caring for a child with SCD, moderately or severely, inhibited their job performance. Virtually all the participants in this study (98%) had lost at least 1 working day per month (Wonkam et al., 2014a). Multiple absences from work subsequently create the risk of unemployment in caregivers (Brandow et al., 2008). Missed work and potential unemployment ultimately have an impact on socioeconomic status which is crucial to the welfare of the entire family (Brandow et al., 2008).

Having a family member with SCD can have negative effects on family interactions and daily routines (Habeeb et al., 2015; Wonkam et al., 2014a; Adegoke & Kuteyi, 2012; Ohaeri & Shokunbi, 2002). Disharmony among family members and disruptions in family routines are frequently cited themes in studies on the negative impact of the disease. Adegoke and Kuteyi (2012) showed that families in Nigeria experienced moderate to severe disruption in day-to-day interactions within the family to the extent that 12.4% frequently quarrelled due to the child's illness. The study further showed that caregivers had a tendency to neglect other family members because they were caring for the affected child (Adegoke & Kuteyi, 2012). 50% of mothers in another study, also reported ignoring the rest of the family because of the ill child (Tunde-Ayinmode, 2007). Daily family routines such as going to church or to the market, or recreational activities within the home may also be disturbed by the child's behaviour or by the demands of the child's healthcare (Adegoke & Kuteyi, 2012). 26.9% of participants in Brown and others (2010) also stated that caring for the children's illness caused a general atmosphere of tension or hostility, with disagreements or quarrels among family members 22.4% of the families.

How families cope with the care of a child with SCD has been often used in research studies as an index of psychosocial burden. The results indicate varying levels of the ability to cope. In most of the studies reviewed, majority of families indicated little or no difficulty coping, with few others showing moderate to severe difficulty (Habeeb et al., 2015; Brown et al., 2010; Ohaeri & Shokunbi, 2002). In this regard, results of Wonkam and colleagues (2014a) differed as the majority of participants (88.3 %) experienced moderate to severe difficulty coping with SCD.

In view of the significant impact of SCD on families, researchers consistently recommend giving social support to caregivers, for example in the form of financial assistance (e.g.

national medical insurance) and psychosocial interventions (such as self-help group programs and relief of psychological distress) (Habeeb et al., 2015; Brown et al., 2010; Ohaeri & Shokunbi, 2002).

2.4.3 The Effects of SCD on Marital Relationships

The literature search for related studies in this literature review brought up very little information on the experiences of people with SCD in their marriages, or the impact of the disease on marital relationships. The information found was culled from studies on other aspects of the psychosocial impact of SCD, not on marital relationships in particular. The findings of these studies, however, are indicative of difficulties SCD patients experience with regards to marital relationships.

In a study on the psychosocial stressors of adult SCD patients in Cameroon, for example, 16.9% of participants reported that having SCD caused significant marital disharmony, and 13.5% felt that they did not get enough help or support from their spouse (Wonkam et al., 2014b). Whilst the majority of participants in the study reported difficulty living with SCD, being married was found to be associated with less difficulty coping (Wonkam et al., 2014b). This is a confirmation of earlier findings that maintaining marital status is beneficial to coping with chronic illness (Glantz et al., 2009). A qualitative study on the socioeconomic and cultural impact of SCD in Nigeria (Owotomo, 2016) also sheds light on the difficulty that SCD patients experience in finding marital partners. The study shows how factors like societal beliefs and perceptions about SCD can inhibit marriage among SCD patients. For instance, a female SCD patient shared her experience of how men avoided relationships with her due to the fear of bearing a huge financial responsibility and the perception the SCD patients cannot excel in life (Owotomo, 2016). In one instance parents of an eligible partner

had even put a stop to her relationship with their son (Owotomo, 2016). The majority of participants in this study, however, indicated satisfaction with their relationship with their spouses (Owotomo, 2016). These studies do not focus on SCD in marriage specifically, but do highlight issues regarding marriage – such as stigma and marital conflict, that can affect the psychosocial wellbeing of patients.

Existing literature on the impact of SCD in marriage – the effects on marital relationships, the effects on partners and the experiences of patients themselves – is, evidently, inadequate. There are, however, obvious difficulties that could impact patients' lives and health, and thus, require attention. There is a clear need for more investigations into various aspects of SCD in marriage.

2.5 Summary

Research on the psychosocial impact of SCD has mirrored the general research trend on the effects of chronic diseases, except where the impact on the spouse is concerned. Earlier research on the impact of chronic ailments on spouses looked at the impact of diseases in general (Rees et al., 2001). As evidence for varying impacts of specific disease characteristics emerged, research studies focused on specific diseases like cancer and arthritis, diabetes, and mental illnesses like Schizophrenia (Li & Loke, 2014; Martire et al., 2018; Rahmani et al., 2018). It has further been shown that the impact of a chronic disease may be analyzed either on an individual level – from the separate points of view of patient and partner – or as a dyadic process that considers both partners' (patient and partner) mutual influence on each other, according to their ways of dealing with stress individually and in relation to each other (Meier et al., 2011). The literature search for this review brought up several studies on the impact of cancer on partners, and on couples and their coping, and on other diseases like

stroke, osteoarthritis, and schizophrenia. Little empirical information on the impact of SCD on partners or on couples, however, was found. SCD patients and their partners will, undoubtedly, also benefit from psychosocial interventions such as those described for cancer and other diseases. This study thus hopes to make a contribution towards this need. Maintaining married status during the course of any devastating medical illness is beneficial, and preventing partner abandonment should be possible (Glantz et al., 2009). The first step toward this goal, however, is identifying the risk factors for divorce and separation (Glantz et al., 2009). This is the step that this study hopes to take, by evaluating how and in what domains of life partners of SCD patients are affected, and to what extent.

CHAPTER THREE

METHODOLOGY

The primary aim of this study was to investigate the psychosocial challenges that partners of SCD patients experience as a result of their relationship with the patient. For the purposes of the study, partners' experiences were explored in the following domains: Caregiver burden, Marital Satisfaction, Physical Health, Psychological Wellbeing, Social Wellbeing, Environmental Wellbeing, Overall Quality of Life, and SCD-related Stigma. Mechanisms by which partners of SCD patients cope with their challenges were also explored. The object of this study was to use a mixed methods approach to gain a more comprehensive understanding of the experiences of spouses of SCD patients. The research design and the processes of obtaining and analysing data are presented in this chapter.

3.1 Research Design

To achieve the aims of the study, a convergent parallel mixed methods design was used. In this type of design, quantitative and qualitative data are collected concurrently, analysed separately, and then merged (Creswell, 2013). The aim of this type of design, to use the two methods to cross-validate or corroborate the research findings, was well-suited to the intent of this study.

The rationale for a quantitative component to the study lay in the objective to measure various indices that would provide an indication of the nature of the impact (the specific domains where an impact is experienced) as well as the extent of the distress experienced in that domain. To enrich the results of the study, however, it was considered important to elicit narratives from partners of SCD patients to provide a more comprehensive understanding of

their experiences. This was the rationale for the qualitative component of this research study. The qualitative interviews were purposed to further explore the lived experiences of spouses of SCD patients, the effects of the patient's illness on their marital satisfaction, and their ability to cope. The specific aim of the qualitative study, however, was to investigate experiences of SCD-related stigma among the participants, an objective which was not covered in the quantitative study.

Results from the two studies would further provide cross-validation for the findings of the research, as well as a more comprehensive understanding of the experiences of the participants.

3.2 Research Setting

The study was conducted within the Greater Accra Region, Ghana. The initial contact to participants was obtained at the SCD specialised clinics of the Korle-bu Teaching Hospital (KBTH). Interviews and questionnaires were administered at a time and location convenient to both participant and researcher, within the city of Accra.

3.3 Study Population

The targeted population for the study was spouses or partners of people living with SCD in Ghana. This included all individuals aged eighteen years or above, in marital relationships with SCD patients. This inclusion criterion was selected based on the fact that the legal age for marriage in Ghana is 18 years (Marriages Act, 1884-1985 CAP. 127). All forms of marriage legally recognised in Ghana – customary marriage, marriage by ordinance and Islamic law marriages (Marriages Act, 1884-1985 CAP. 127) – were included. Common Law marriages, which also occur frequently in Ghana, were also included. It is for this reason that

the word ‘partners’ is interchanged with ‘spouses’ in this paper. The study focused specifically on marital relationships, thus, individuals in courting relationships with SCD patients were excluded.

3.4 Quantitative Study

The main objective for this part of the study was to measure numerical indices of participants’ experiences in selected psychosocial areas to provide an indication of the levels of distress experienced. The areas targeted in the quantitative study were caregiver burden, marital satisfaction, physical health, psychological wellbeing, social wellbeing, environmental wellbeing, and general quality of life. This section discusses the methodology used in the quantitative part of the study – sampling procedures, participants, and procedures for data collection and analysis.

3.4.1 Sampling

Recruitment of participants for the quantitative part of the study was done over a period of 5 weeks. The techniques and procedures used are as follows:

Sampling Techniques

Participants for the Quantitative phase of the study were recruited by means of Purposive and Snowballing sampling methods. These two sampling techniques were selected due to perceived difficulties accessing the study population. The prevalence rate for SCD in Ghana is up to 30% of the Ghanaian population (WHO, 2010) and includes all SCD patients, both children and adults (married and unmarried). The population of married adult patients in the country was thus considered a limited population. Locating the spouses of this limited population, and obtaining an appropriate sample size, presented a challenge. Specialised

centres for treatment and management of the disease and Sickle Cell Associations were considered the best possible options for gaining contact with patients. The contact details of spouses, for those married, would then be accessed through the patients. This was the reasoning behind the use of Purposive Sampling. The specialised locations selected were the SCD Clinic, Ghana Institute of Clinical Genetics (KBTH)), the SCD Antenatal Clinic (Obstetrics and Gynaecology Department, KBTH), and the Sickle Life Organisation, Ghana (a SCD advocacy organisation which runs a SCD patient support group).

KBTH is one of very few hospitals in Ghana to run specialised SCD clinics. It was thus an appropriate location to gain access to patients (and spouses) from all over the country. In order to cater to the possible challenge of obtaining a sizeable sample at these locations, Snowballing was included as a complementary sampling method.

Sampling Procedure

It was necessary to obtain the approval of the authorities of the selected sampling locations. Copies of the Ethical Approval obtained for the study and the research proposal were, thus, sent to Heads of departments of the two specialised clinics at KBTH and to the CEO of the Sickle Life Organisation. Following a discussion with the CEO of the Sickle Life Organisation, information about the study was advertised on the organisation's social media platforms. Interested participants were asked to contact the researcher via phone or email. No interested participants, however, contacted the researcher from the organisation.

Recruitment of majority of the participants was done by engaging SCD patients at the two clinics and explaining the objectives of the study to them. Contact numbers to their spouses were then taken. The patients were also asked to inform their spouses about the study. The spouses were later contacted by telephone, and a convenient arrangement made for the study

to be conducted. Of about 117 spouses contacted, 75 were willing to participate in the study. This method of sampling yielded the majority of the study participants (89.3%). The remaining 10.7% of participants were recruited through snowballing. The interested participants were given an informed consent form, which detailed all relevant information about the study, and gave participants the option of participating in the in-depth interviews. Recruitment of participants for the qualitative study is discussed in further detail in section 3.5.1.

3.4.2 Participants for the Quantitative Study

A total of 75 participants were recruited for this part of the study. Demographic data collected on the sample included Age, Sex, Religion, Level of Education, the type of marriage they are in, and the duration of the marriage. Summaries of the socio-demographic characteristics of the sample are presented in Tables 1 and 2. Additional questions were added to the demographics page on the research questionnaire, to find out whether participants had knowledge of the patient's SCD status and of the disease before marriage. Statistics of the obtained data are also presented in Table 1.

The sample included 49 men (65.3%) and 26 women (34.7%). The proportion of male respondents (i.e. husbands of SCD patients), thus, was almost double that of female respondents (65.3% Males, 34.7% Females). This may be explained by the fact that one of the main data collection sites was the SCD Antenatal Clinic (KBTH). As the patients at this clinic are female, all participants obtained from this location were male. The mean age of participants was 39 years.

Table 1

Summary of Sample Demographic Characteristics

Variables		Frequency	Percentage
Sex	Female	26	34.7
	Male	49	65.3
Type of Marriage	Customary	26	34.7
	Common Law	18	24
	Christian	21	28
	Islamic	9	12
	Court Registration	1	1.3
Religion	Muslim	15	20
	Christian	59	78.7
	Traditionalist	1	1.3
Level of Education	No Formal Education	2	2.7
	Primary	6	8
	JHS	12	16
	SHS	15	20
	Tertiary	40	53.3
Awareness of	Aware	35	46.7
Patient's SCD Status	Not Aware	40	53.3

N=75

All of the types of marriage considered for the study were represented in the sample. 34.7% of respondents reported being in a Customary Marriage; 24% in Common Law Marriages;

28% in Christian Marriages; 12% in Islamic Marriages; and 1.3% in a Court Registration. The disproportion may be explained by the use of purposive and snowballing sampling techniques. The years of marriage refers to the number of years that a participant has been married to an SCD patient. The average duration of marriage in this study was 5 years.

The sample was also representative of the major religions practiced in Ghana – 78.7% were Christians, 20% are Muslims, and 1.3% Traditionalists. The majority of the participants in this study had acquired tertiary education (53.3%). 20% had completed senior high school, 16% had completed junior high, and 8% had only had primary education. 2.7% of the participants had had no formal education at all. Table 1 further indicates that a greater proportion of participants (53.3%) were not aware of their spouse's sickle cell status before marriage.

Table 2

Descriptive Statistics (Age and Years of Marriage) of the Sample

Variable (years)	<i>M</i>	<i>SD</i>	<i>N</i>
Age	39.15	6.81	75
Years of Marriage	5.37	3.48	75

3.4.3 Quantitative Data Collection

Quantitative data was collected by means of a research questionnaire which comprised pre-existing assessment tests that measure the psychosocial domains of interest to this study. The objectives for this part of the study were to measure indices of caregiver burden, marital satisfaction, physical health, psychological wellbeing, social wellbeing, environmental

wellbeing, and general quality of life. A research questionnaire was put together comprising pre-existing instruments which measure the selected psychosocial domains. The 12-item Zarit Burden Interview (Bedard et al., 2001) was used to measure Caregiver Burden among spouses of SCD patients, and the Index of Marital Satisfaction (Hudson, 2001) to evaluate the level of marital satisfaction among the spouses. Coping mechanisms among participants were assessed using the Brief COPE Inventory (Carver, 1997). The WHOQOL-BREF gives an indication of an individual's wellbeing in four separate domains (physical health, psychosocial health, social relationships, and environmental factors) as well as in index of the overall quality of life. This instrument was, thus, used to assess the corresponding study domains: Physical Health, Psychological Wellbeing, Social Wellbeing, Environmental Wellbeing and Overall Quality of Life. Participants were given the choice between self-administration of the research questionnaire and administration by a trained research assistant who could explain questions and instructions further. Majority of the questionnaires were administered to participants by trained research assistants, in the preferred language of the participant. Few participants chose to self-administer the questionnaires. Questionnaires were administered either over the telephone, or face-to-face, depending on the participant's preference. An online version of the questionnaire was also created and sent by email to participants who preferred this method. Details of the outcome measures included in the research questionnaire are presented below:

The Zarit Burden Interview – 12 Item Version (Bédard et al., 2001): This is an instrument that is designed to measure the extent to which a caregiver perceives his or her level of burden as a result of caring for a person with a particular diagnosis. It was originally developed to measure subjective burden among caregivers of dementia patients (Zarit, Reever & Bach-Peterson, 1980), but has since, been applied to different disease populations. Studies,

such as Braun and colleagues (2010), investigating the burden of spousal caregiving also found the ZBI valid and reliable. The revised version of the questionnaire contains 22 items. Shorter versions have been developed with 18 and 12 items. The 12 item version, which takes approximately 5 minutes to complete, was selected for the purposes of this paper. As the study includes a number of instruments, the shorter version was selected for considerations of time and length of the overall protocol. Answers to the questions are based on a 5-point Likert scale, ranging from never to nearly always present, with a total score range of 0 to 48. The interpretation of ZBI scores are as follows:

- 0-10: no to mild burden
- 10-20: mild to moderate burden
- >20: high burden

The ZBI has the advantage of being culturally neutral (Bedard et al., 2001). Hébert and colleagues (2000) also found no significant difference in the burden score according to the age, gender, living arrangement, marital status or employment status of the caregiver. The 12-item version has also shown to be a good indicator of caregiver burden. It has a high internal consistency with an overall Cronbach's alpha of 0.88 (Bédard et al., 2001).

The Index of Marital Satisfaction (IMS) (Walter W. Hudson, 1992): This is a 25-item instrument designed to measure the degree of the degree, severity, or magnitude of the problem that a spouse or partner has in a partner relationship (Hudson, 1992). The scale provides a measure the magnitude of marital discord or dissatisfaction that is felt or perceived. For the purposes of interpreting the IMS score, these two concepts (marital discord and marital dissatisfaction) are equated (Hudson, 1992). The instrument is based on a Likert scale, and it provides an overall numerical value. The higher the score the more dissatisfaction is indicated. While scores below 30 are considered indicative of satisfaction

with the relationship, scores above 30 are an indication of clinically significant problems. Individuals who obtain scores as high as 70 or higher are thought to be always experiencing severe distress, which suggests the possibility that some form of violence could be used as a means of dealing with problems in this area (Hudson, 1992).

The IMS scale has high reliability and validity, and consistently achieves an alpha value of 0.90 or larger and validity coefficients of 0.60 or greater (Hudson, 1992). An e.g. of the questions on the scale is, “I feel I should have never married my partner”. The IMS was considered relevant to the objective of investigating marital satisfaction in this study.

The Brief Coping Orientation to Problems Experienced Inventory (Brief COPE) (C.S. Carver, 1997): The Brief COPE is a shortened version of the Coping Orientation to Problems Experienced (COPE) inventory, which was developed by C. S. Carver (1997) to assess the different ways in which individuals respond when faced with stressful situations (Brasileiro et al., 2016). There are 28 items on the scale, and measurement is based on a four point Likert Scale. The instrument comprises 14 subscales, each of which assesses the degree to which a respondent utilizes a specific coping strategy (DeDios-Stern et al., 2017). The coping strategies assessed are: Self-distraction, Active coping, Denial, Substance use, Use of emotional support, Use of instrumental support, Behavioural disengagement, Venting, Positive reframing, Planning, Humour, Acceptance, Religion, and Self-blame. The inventory does not compute an overall coping index, only total scores for each subscale (Dedios-Stern et al., 2017; Carver, 1997). Higher scores on a subscale indicate an increased utilization of that specific coping strategy (DeDios-Stern et al., 2017). The instrument, therefore, indicates the specific mechanisms of coping most often employed among individuals in a study. It was, thus, well-suited to the objective of this study to highlight the mechanisms of coping used among spouses of SCD patients in relation to the psychosocial effects of the disease. An

added advantage of this scale is that its instructions and items are easily adaptable to any study. The Brief Copc has exhibited good internal consistency when applied to caregiver populations (DeDios-stern et al., 2017). The Cronbach's alpha found for each of the 14 subscales from the full COPE ranged from 0.54 to 0.90 (Brasileiro et al., 2016).

The World Health Organisation's Quality of Life Index (WHOQOL BREF): This is a cross-cultural quality of life assessment developed by the WHO in 1994 (The WHOQOL Group, 1996). It contains 26 items that measure an individual's perception of their quality of life in four domains: Physical Health, Psychological Well-being, Social Relationships and Environment. It derives specific domain scores as well as an overall quality of life score (The WHOQOL Group, 1996). This is one of the advantages of this instrument that make it applicable to this study. It allows for the investigation of the different areas or domains in which a patient's spouse experiences difficulties. The instrument was developed cross-culturally (The WHOQOL Group, 1996), therefore, it has the added advantage of deriving culturally relevant information. The WHOQOL-BREF has been shown to be a psychometrically valid and reliable quality of life instrument (Skevington, 2004; WHOQOL Group, 1998). The reliability statistics for the four domains of the instrument are as follows: Physical health (0.80), Psychological Wellbeing (0.76), Social Relationships (0.66), and Environmental wellbeing (0.80) (WHOQOL Group, 1998). The WHOQOL-BREF correlates at a Cronbach's alpha level of 0.90 with the longer version of the instrument, the WHOQOL-100 (WHOQOL Group, 1998).

3.4.4 Pilot Study

The pilot of the quantitative study was conducted on a sample of 15 participants, who were recruited from the SCD Clinic (KBTH) and the SCD Antenatal Clinic (KBTH) a week before

the main study was conducted. The main reason for the pilot study was the need to ascertain the suitability of the selected research instruments to the study population. With the exception of the WHOQOL-BREF which is cross-cultural and applicable to varied populations (WHOQOL Group, 1996), the selected quantitative instruments were developed in Western cultures, and have not been standardised to the Ghanaian population. Again, none of the selected instruments has been applied to a sample of spouses of SCD patients in particular. The pilot study thus provided a means of assessing the feasibility of using the selected scales on the chosen population. The pilot study also had the added advantage of evaluating the feasibility of the study protocol. Factors like the ease of accessing research participants, the length of the study protocol and the ability of participants to comprehend questions on the research instruments were evaluated in the pilot study. The derived reliability statistics are displayed in Table 3.

Table 3

Results of Reliability Testing (Cronbach's alpha) for the Selected Research Instruments

Scale	α	No. of Items
Zarit Burden Interview	.87	12
Index of Marital Satisfaction	.79	25
Brief COPE Inventory	.83	28
WHOQOL BREF	.80	26
N=15		

It may be observed from Table 3 that the pilot study derived reliability coefficients that were higher than 0.7 for all the selected scales. Following the assertion that alpha levels greater

than 0.7 can be deemed acceptable (Tavakol & Dennik, 2011) the selected scales were considered reliable and applicable to the selected research population.

The pilot study also revealed areas of the research questionnaire that were difficult for participants to fully understand, especially among participants who had difficulties with the English language. This prompted a re-training of research assistants to ensure that they could adequately explain terms and concepts to participants during data collection.

3.4.5 Quantitative Data Analysis

Quantitative data was analysed using the Statistical Package for Social Sciences Version 23 (IBM Corporation, 2016). Preliminary analytical procedures were initially computed, including tests of reliability and normality of data, and descriptive statistics of scores derived from the quantitative measures. The stated hypotheses for the study were then tested using parametric statistical tests. The assumptions behind the use of parametric tests were the normality of the sample data and the fact that all dependent variables considered in the five stated hypotheses were continuous variables, measured on interval or ratio scales. Details of hypothesis testing – variables considered and the choice of parametric test for each hypothesis - are presented below. For the purposes of the quantitative study, the psychosocial experiences of spouses were determined by assessing participants' scores in 7 psychosocial domains: caregiver burden, marital satisfaction, physical health, psychological wellbeing, social wellbeing, environmental wellbeing, and overall quality of life. In the stated hypotheses, therefore, “differences in psychosocial experiences” are determined by assessing the differences in all seven psychosocial domains.

Hypothesis 1: There will be significant differences in psychosocial experience between male and female participants

Hypothesis one was tested using the independent samples t-test. This test was selected based on the fact that the independent variable (gender) has two levels (male and female), and each dependent variable (i.e. each psychosocial domain) is measured on an interval scale.

Hypothesis 2: There will be significant differences in coping strategies between male and female participants.

This hypothesis was tested using the independent samples t-test. The independent variable (gender) was tested against each coping strategy, which represented the dependent variable. This independent t-test was chosen considering that the independent variable is nominal, with two levels, and that each of the dependent variables is each measured on an interval scale.

Hypothesis 3: The spouse's level of education will have a significant effect on the psychosocial effects experienced.

This hypothesis was tested using the One-Way ANOVA. The independent variable in this hypothesis (i.e. level of education) was measured at 5 levels (no formal education, primary, junior high school (JHS), senior high school (SHS), and tertiary). The selected psychosocial domains represented the dependent variables. Each dependent variable was measured on an interval scale.

Hypothesis 4: There will be a significant relationship between the years of marriage and the psychosocial experiences of the spouse

Considering that both the independent and the dependent variables in this hypothesis are continuous variables, the statistical test used was the Pearson Correlation Coefficient Test.

Hypothesis 5: An awareness of the patient's sickle cell status before marriage will have a significant effect on the psychosocial experiences of the spouse

The statistical test chosen here was the MANOVA. In this hypothesis, the independent variable (awareness of patient's sickle cell status before marriage) was measured on a nominal scale at two levels (aware and not aware). This was tested against each of the selected psychosocial domains, measured on an interval scale.

3.5 Qualitative Study

The qualitative part of this study involved one-on-one in-depth interviews with interested participants, with the aim of eliciting the lived experiences of spouses of SCD patients. In accordance with convergent mixed methods designs, sampling, data collection and data analysis in the qualitative study were done concurrently with the quantitative study procedures. The specific methods used in the qualitative part of the study are presented in this section.

3.5.1 Sampling

The sample used in the qualitative part of the study was recruited alongside the recruitment of participants for the quantitative study. As previously discussed, Purposive and Snowballing methods were primarily used in recruiting participants for the study. Respondents for the qualitative interviews in particular were then recruited by Self-selection. A self-selected

sample is one in which the inclusion of sample units depends on whether the units themselves agree or decline to participate in the sample (Lavrakas, 2008). In this study, self-selection was done via the informed consent forms. All the participants who had expressed willingness to participate in the study were recruited for the quantitative study and given informed consent forms to sign. The forms provided in-depth information about both quantitative and qualitative components of the study, and gave participants the option of participating in the qualitative interviews as well. Interested participants indicated their willingness to participate in the qualitative study via a checkbox provided on the forms. The proposed sample size for the in-depth interviews was 10, thus participants were no longer recruited for the qualitative study when this number was reached. Demographic details of the respondents obtained are given in the following section.

3.5.2 Participants of the Qualitative Study

A total of 10 participants were included in the in-depth interviews. The sample included 7 males and 3 females. 20% of participants in the sample were in Islamic marriages, 30% in Christian marriages, and 50% in customary marriages. 80% of the participants were Christian, and 20% were Muslims. Majority of the participants (20%) had had a tertiary education while the rest had secondary education. With regards to the awareness of the patient's sickle cell status before marriage, 60% were aware and 40% were not aware. Table 4 shows the detailed profile of the respondents.

Table 4

Detailed Profile of Respondents in the Qualitative Study

Respondent's I.D	Sex	Age (years)	Type of Marriage	Years of marriage	Level of Education	Religion	Awareness
R.1	F	39	Islamic	11	Secondary	Muslim	Not aware
R.2	M	43	Christian	9	Tertiary	Christian	Aware
R.3	M	37	Customary	8	Secondary	Christian	Not aware
R.4	F	38	Customary	5	Tertiary	Christian	Aware
R.5	M	51	Customary	12	Tertiary	Christian	Not aware
R.6	M	38	Christian	7	Tertiary	Christian	Aware
R.7	M	46	Christian	8	Tertiary	Christian	Aware
R.8	M	48	Islamic	9	Tertiary	Muslim	Aware
R.9	F	33	Christian	5	Tertiary	Christian	Not aware
R.10	M	53	Customary	14	Tertiary	Christian	Aware

Note. *Awareness* refers to the awareness of the patient's sickle cell status prior to marriage.

3.5.3 Qualitative Data Collection

One-on-one in-depth interviews were chosen as the method of inquiry in the qualitative study. This method of interviewing was chosen for two main reasons: to allow participants the opportunity to talk more openly about their experiences, and to for reasons of confidentiality, owing to the sensitive nature of the issues discussed. The objective of the qualitative study was to further explore the psychosocial experiences of spouses of SCD patients to enrich the results of the quantitative study. A semi-structured interview guide was, thus, developed including open-ended questions that inquired about participants' experiences

in relation to their partnership with an SCD patient. The qualitative study had an additional specific objective, which was to explore the experience of SCD-related stigma among spouses of SCD patients. Specific questions were, therefore, included about stigma. The interview guide provided the advantage of consistency in the questions asked, and prevented the interviewers from missing or forgetting to ask important questions. The semi-structured interview guide comprised 10 main questions. Additional questions (5) were included to probe further about specific areas where an effect may have been experienced. Examples of questions on the guide are shown in Table 5. A convenient time and location for the interview was arranged with participants who had indicated interest in the qualitative study. Ten (10) interviews were conducted, each lasting an average of 20 minutes. Field notes were taken during the interviews with the consent of the participants, and the narratives properly constructed later.

Table 5

Examples of Qualitative Interview Questions

-
- What has been your experience, being married to a person with SCD?
 - What do you think has been the effect of your partner's illness on your marriage?
 - In what specific ways has your marriage suffered due to your partner's SCD?
 - Have your finances suffered? How?
 - Has your sex life been affected? How?
 - Have you experienced any form of stigma because you are married to a person with SCD? E.g. demeaning or derogatory comments, people trying to prevent your marriage to a person with SCD, etc.
 - How do you cope with the difficulties arising from your relationship with a person with SCD?
-

3.5.4 Qualitative Data Analysis

Findings of the qualitative study were analysed by Thematic Analysis, using an inductive approach. Thematic Analysis refers to the process of identifying patterns within qualitative data, that are important or interesting, and that say something about an issue (Maguire & Delahunt, 2017). This analytical method has the advantage of being flexible because it is not tied to a particular theoretical perspective; it is thus easily applicable to different contexts (Maguire & Delahunt, 2017). This study adopted an inductive approach to deriving themes. With this approach, theme analysis is driven by the data itself, instead of by the research questions (Maguire & Delahunt, 2017). This approach was preferred as a method of discovering new and unexpected themes.

Of several different methods of thematic analysis, this study chose to follow Braun & Clarke's (2006) six-step framework. This method is recognised as one of the most influential approaches, as it offers a clear and easily applicable framework to thematic analysis (Maguire & Delahunt, 2017). The six step approach developed by Braun & Clarke (2006) is as follows: (1) becoming familiar with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining the themes, and (6) writing up the results (Maguire & Delahunt, 2017). This step-by-step approach was found easily applicable to this study and followed accordingly. As a first step, the narratives from the interviews were properly typed out and then read over in order to become familiar with the data. Initial codes were then derived, and themes generated. The generated themes were then reviewed and re-organised into global themes and subthemes. Themes and subthemes were clearly defined, and the results presented in a table.

In order to enhance the trustworthiness of the data obtained, methods of Investigator Triangulation and Persistent Observation were put in place. Investigator Triangulation is a method of ensuring credibility of qualitative data by involving two or more researchers in the organizational aspects and analytical procedures of the study (Korstjens & Moser, 2018). This study involved two researchers in the organisational aspects, as well as in the coding, analysis and interpretation decisions to enhance credibility. Persistent Observation also helps improve credibility through detailed examination of the data to identify the relevant elements (Korstjens & Moser, 2018). The data obtained in this study was thoroughly examined and re-examined, to ensure that the insights obtained, codes developed and themes generated were accurate.

3.6 Data Integration

Results of the quantitative and qualitative studies were interpreted separately, and merged in the discussion section.

3.7 Ethical Considerations

Ethical Clearance

Ethical approval for the study was obtained from the Ethics Committee from the Humanities (ECH), University of Ghana (Appendix A).

Informed Consent

The objectives of the study were clearly explained to all participants, and enrolment was done only on voluntary basis. Trained research assistants reviewed an Informed Consent form with all participants. Participants were required to sign the informed consent form.

Participants were duly informed of their right to withdraw from the study at any time, and for whatever reason, without any negative consequences. They were also assured of the confidential treatment of their responses. No names were attached to the questionnaires. Each participant was instead assigned a research identification number that could be used to identify their responses in the event of a withdrawal. Only persons directly involved in the research process, i.e., the student researcher, supervisors, and research assistants had access to the questionnaires.

Participants were also informed of the sensitive nature of some of the topics included in the questionnaires and the interview. They were accorded the option to take a break or to terminate the research process if they experienced discomfort. The option of obtaining counselling and psychological support from a qualified clinical psychologist was also given.

CHAPTER FOUR

RESULTS

This study used a convergent parallel mixed methods design to investigate the nature of the psychosocial impact that partners of SCD patients experience as a result of their relationship with the patient. Data collection in the quantitative and qualitative studies was done concurrently, and the obtained data analysed separately. The results of the analysis of both quantitative and qualitative data are presented in this chapter. Quantitative analysis results are presented in section 4.1, and qualitative findings in section 4.2.

4.1 Results of Quantitative Data Analysis

Quantitative data analysis consisted of preliminary analytical procedures and hypothesis testing. Preliminary analysis of the data involved tests of reliability and normality of the sample data, as well as descriptive statistical procedures to summarize participants' responses on the research instruments. Results of these procedures are presented in section 4.1.1. Section 4.1.2 presents the results of hypothesis testing. Further analysis of the sample data revealed other findings that were considered significant to the purpose of this study. These findings are presented in section 4.1.3.

4.1.1 Preliminary Analysis

Reliability and Normality of Sample Data

Tests for the reliability and normality of the sample data were first conducted to assess the suitability of the obtained data for the use of parametric tests. Results of reliability testing are presented in Table 6. For all the selected quantitative research instruments, a Cronbach's alpha of more than 0.7 was derived. Based on the assumption that an alpha level greater than

0.7 is an indication of good reliability (Tavakol & Dennick, 2011) the obtained data was considered reliable.

Table 6

Reliability Statistics of Sample Data

Scale	α	No. of Items
1. Zarit Burden Interview (ZBI)	.78	12
2. Index of Marital Satisfaction (IMS)	.81	25
3. Brief COPE Inventory	.89	28
4. WHOQOL (BREF)	.75	26

N = 75

The normality of the sample data was then tested to assess its suitability for parametric testing. Normality testing was done using skewness and kurtosis measures. The results are presented in Table 7.

Table 7

Skewness and Kurtosis Measures of the Sample Data

Scale	Skewness	Kurtosis
1. Caregiver Burden	-.77	.20
2. Index of Marital Satisfaction	.06	-.46
3. Brief Cope Inventory	-1.20	.41
4. WHO Quality of Life	.01	-.64

N=75

From Table 7 it may be observed that all the obtained skewness and kurtosis scores fall within the range +2 to -2, which is acceptable for the sample size (Kim, 2013). This indicates that the sample data can be assumed to be consistent with the normal distribution; an assumption that is required for the use of parametric tests.

Descriptive Statistics

Descriptive statistics were computed on the data obtained to show the distribution of scores on the outcome measures. Table 8 presents summaries of scores in the psychosocial domains tested in the quantitative study. Table 9 presents summaries of scores on the coping inventory.

Table 8

Summary of the Distribution of Scores on Outcome Measures

Variable	Min.	Max.	<i>M</i>	<i>SD</i>
Caregiver Burden	5.04	41.04	15.38	8.27
Index of Marital Satisfaction	0.00	74.00	27.20	17.37
Physical Health	25.00	82.10	58.28	11.45
Psychological Wellbeing	20.80	91.70	69.06	16.67
Social Relationships	16.70	100.00	61.67	17.43
Environmental Wellbeing	25.00	90.60	57.76	13.63
Overall Quality of Life	4.00	10.00	7.39	1.52

N=75

Participants of the quantitative study reported average scores of 15.38 on the Caregiver Burden scale and 27.20 on the Index of Marital Satisfaction (IMS) scale. These scores indicate mild to moderate levels of Caregiver burden and general marital satisfaction among majority of spouses of SCD patients. The maximum score on the IMS scale (74.00) is an indication of high levels of distress. It gives an indication of clinically significant scores among a minority of the participants. Average scores on all domains of the WHOQOL scale were above 50, indicating relatively high levels of physical health, psychological, social and environmental wellbeing among spouses of SCD patients. The mean Quality of Life score (7.38) also indicates relatively high quality of life among participants.

Table 9 presents Coping Mechanisms among partners of SCD patients, in order of extent to which the specific mechanisms are used. Higher mean values indicate mechanisms which are used to a greater extent. From the table, therefore, it can be observed that the mechanisms of Coping that are used the most among partners of SCD patients are Planning, Active Coping, Acceptance, Positive Refraining, and Religion. Substance Use was the least used among participants.

Table 9

Coping Strategies used among the sample of Spouses of SCD Patients

Coping Mechanism	<i>M</i>	<i>SD</i>
Planning	6.28	1.78
Active Coping	6.20	1.33
Acceptance	6.05	1.64
Positive Refraining	5.99	1.66
Religion	5.83	1.72
Use of Instrumental Support	5.41	1.75
Use of Emotional Support	5.35	1.56
Self-Distraction	4.29	2.12
Venting	3.51	1.98
Denial	3.28	1.88
Behavioural Disengagement	3.21	1.51
Self-Blame	3.08	1.75
Humour	2.93	1.28
Substance Use	2.57	1.04

N=75

4.1.2 Results of Hypothesis Testing

Hypothesis 1: There will be significant differences in psychosocial experience between male and female participants

An independent samples t-test was conducted to compare males and females on the selected psychosocial domains. The results indicate a significant difference in psychological wellbeing between males and females at the .05 level of significance: [t (73) = -2.10, p=0.04]. Results of the test are summarized in Table 10. The table shows that with regards to psychological wellbeing, the mean value reported by male participants (71.94) was higher than the mean for female participants (63.63). The results of this test indicate, therefore, that the psychological wellbeing of male participants in this study was significantly higher than that of female participants. Hypothesis 1 was, thus, supported. There were no significant differences with respect to the other psychosocial areas (caregiver burden, marital satisfaction, physical health, social wellbeing, environmental wellbeing or overall quality of life).

Table 10

Results of Independent Samples T-Test on Gender Differences in Psychosocial Experience

Outcome	Gender				<i>T</i>	df	<i>P</i>
	Males		Females				
	(n=49)		(n=26)				
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
CB	14.38	7.33	17.28	9.67	1.46	73	0.15
IMS	25.08	16.22	31.19	19.03	1.46	73	1.15
PHYS	59.77	11.05	55.49	11.89	-1.56	73	0.12
PSYCH	71.94	16.47	63.63	15.97	-2.10	73	0.04*
SOC	64.46	17.57	56.42	16.21	-1.94	73	0.06
ENV	59.07	13.06	55.31	14.59	-1.14	73	0.26
QOL	7.53	1.56	7.12	1.45	-1.13	73	0.26

*Significant at $p < 0.05$ Note. CB=Caregiver Burden, IMS=Index of Marital Satisfaction Score, PHYS=Physical Health, PSYCH=Psychological Wellbeing, SOC=Social Wellbeing, ENV=Environmental Wellbeing, QOL= Quality of Life

Hypothesis 2: There will be significant differences in coping strategies between males and females

An independent samples t-test was conducted to assess differences between male and female participants in coping strategies used at the 0.05 level of significance. Significant results were observed between male and female participants in three coping domains: self-distraction, denial, and self-blame. Results of the test are summarized in Table 11.

Table 11

Summary of Results of Independent t-test on Gender differences in Coping Strategy

Coping Strategy	Gender				<i>T</i>	df	<i>P</i>
	Males		Females				
	(n=49)		(n=26)				
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Self-distraction	3.88	2.03	5.08	2.10	-2.41	73.00	0.02*
Active Coping	6.35	1.27	5.92	1.41	1.33	73.00	0.19
Denial	2.88	1.68	4.04	2.03	-2.65	73.00	0.01*
Substance Use	2.61	1.12	2.50	0.91	0.44	73.00	0.66
Emotional Support	5.27	1.52	5.50	1.61	-0.62	73.00	0.54
Instrumental Support	5.39	1.69	5.46	1.88	-0.17	73.00	0.86
BD	3.02	1.55	3.58	1.39	-1.53	73.00	0.13
Venting	3.22	1.76	4.04	2.29	-1.72	73.00	0.09
Positive Refraining	6.16	1.59	5.65	1.77	1.27	73.00	0.21
Planning	6.27	1.71	6.31	1.10	-0.10	73.00	0.92
Humour	2.94	1.22	2.92	1.41	0.05	73.00	0.96
Acceptance	6.22	1.46	5.73	1.91	1.25	73.00	0.22
Religion	5.63	1.45	6.19	2.12	-1.35	73.00	0.18
Self-blame	2.71	1.50	3.77	2.01	-2.36	40.19	0.02*

Note. B D = Behavioural Disengagement *Significant at $p < 0.05$

Table 11 shows significant differences in the extent to which male and female participants utilized Self-distraction as a coping mechanism [$t(73) = 2.42, p = 0.02$]. Significant differences were also found in the use of Denial as a coping mechanism [$t(73) = 2.65, p = 0.01$], and with Self-Blame [$t(73) = 2.42, p = 0.02$]. With all three mechanisms of coping, females reported higher mean values, indicating greater reliance on these coping strategies than men. Results of the test on all other coping domains were not significant.

Hypothesis 3: The spouse's level of education will have a significant effect on the psychosocial effects experienced

A One-way ANOVA was conducted to compare the effect of the spouses' level of education on the selected psychosocial domains. No significant results were observed at the 0.05 level of significance. Hypothesis 3 was, therefore, not supported. Results of this test are presented in Table F1 (Appendix F).

Hypothesis 4: A significant relationship will be found between the years of marriage and the psychosocial experiences of the spouse

Hypothesis 4 was tested using the Pearson Product Moment Correlation Test. Results of the test indicate a significant positive relationship between years of marriage and environmental wellbeing at the 0.05 level of significance [$r(75) = 0.21, p=0.04$]. This indicates that longer years of marriage are associated with increased Environmental Wellbeing. Hypothesis 4 was, therefore, supported. The results are shown in Table 12. No significant relationships were found between years of marriage and other psychosocial domains.

Table 12

Correlations among Years of Marriage and Psychosocial Experiences

	1	2	3	4	5	6	7	8
1. Years of marriage								
2. Caregiver Burden	.13							
3. Index of marital satisfaction	-.09	.67						
4. Physical health	.15	-.34	-.31					
5. Psychological Wellbeing	.00	-.68	-.54	.68				
6. Social Relationships	.05	-.55	-.54	.69	.76			
7. Environmental Wellbeing	.21*	-.36	-.45	.69	.68	.75		
8. Quality of life	.14	-.38	-.39	.58	.68	.59	.69	

* Correlation is significant at $p < 0.05$

Hypothesis 5: An awareness of the patient's sickle cell status before marriage will have a significant effect on the psychosocial experiences of the spouse

A one-way MANOVA was conducted to assess the effect of an awareness of the patient's sickle cell status on the psychosocial experiences of the spouse. Results of the test indicate statistically significant differences in three psychosocial domains: Caregiver Burden, Psychological Health and Social Relationships. Table 13 summarizes the results of this test.

Table 13

Summary of One-way MANOVA Results for the Effect of an Awareness of the Patient's Sickle Cell Status before Marriage on Psychosocial Experiences

	Aware	Unaware	F	df	P	η^2
Outcome	(n=40)	(n=35)				
	M (SD)	M (SD)				
CB	13.04 (6.35)	17.45 (9.22)	5.72	1	0.02*	0.07
IMS	27.20 (14.14)	27.20 (19.97)	0.00	1	1.00	0.00
PHYS	59.90 (10.40)	56.87 (12.25)	1.31	1	0.26	0.19
PSYCH	76.32 (13.05)	62.71 (17.04)	14.75	1	0.00*	0.17
SOC	67.39(15.82)	56.67 (17.41)	7.70	1	0.01*	0.10
ENV	59.47 (11.60)	56.27 (15.18)	1.03	1	0.31	0.14
QOL	7.69 (1.23)	7.13 (1.71)	2.58	1	0.11	0.03

Note. N=75 *Significant at $p < 0.05$

CB=Caregiver Burden, IMS=Index of Marital Satisfaction, PHYS=Physical Health, PSYCH=Psychological Wellbeing, SOC=Social Wellbeing, ENV=Environmental Wellbeing, QOL=Quality of Life

Results of the one-way MANOVA indicated significant differences in psychosocial experiences between spouses who were aware of the patient's sickle cell status before marriage and those who were not aware: [$F_{(67)} = 4.97$, $p < 0.01$, Pillai's Trace = 0.34, Partial Eta Squared = 0.34, observed power = 0.99]. Hypothesis 4 was, therefore, supported. Following the significance of the overall test, a Bonferroni Post-Hoc was conducted.

Table 13 shows differences in psychosocial impact among spouses who were aware of the patient's SCD status before marriage and spouses who were not aware in three domains:

Caregiver Burden [$F_{(1)} = 5.72, p = .02, \eta^2 = .07$], Psychological Wellbeing [$F_{(1)} = 14.75, p < .01, \eta^2 = .17$], and Social Relationships [$F_{(1)} = 7.70, p = .01, \eta^2 = .10$].

With respect to Caregiver Burden, the mean score of partners of SCD patients who were not aware of the patient's sickle cell status before marriage (mean value of 17.45) was significantly higher than that of those who were aware of the patient's sickle cell status before marriage (mean value of 13.04). The test results, therefore, indicate that partners of SCD patients who were not aware of the patient's status before marriage experienced significantly greater Caregiver Burden than those who were aware.

With respect to Psychological Wellbeing, partners who were aware of the patient's sickle cell status before marriage show a higher mean score (mean score of 76.32) than partners who were not aware (mean score of 62.71). This result indicates that partners who were aware experienced significantly higher Psychological Wellbeing than those who were unaware.

With regards to Social Wellbeing, partners who were aware had a higher mean score of 67.39. The mean value for partners who were unaware was 56.67. This suggests that partners of SCD patients who were aware of the patient's sickle cell status before marriage experienced significantly higher Social Wellbeing than those who were not aware.

The data, therefore, supports the hypothesis that an awareness of the patient's sickle cell status prior to marriage will have a significant effect on the psychosocial experiences of the spouse.

4.1.3 Other Findings

This section presents unexpected findings that were considered significant to the purpose of the study. A Pearson Correlation test was conducted to examine the relationships between caregiver burden and all domains of the quality of life assessment (physical health, psychological wellbeing, social relationships, environmental wellbeing and overall quality of life). From the results of this test, significant relationships between caregiver burden and marital satisfaction, and marital satisfaction and the quality of life domains were also observed. Results are presented in Table 14.

Table 14

Correlations among Caregiver Burden and other Psychosocial Variables

Variable	1	2	3	4	5	6	7
1. Caregiver Burden							
2. Index of Marital Satisfaction	.67*						
3. Physical Health	-.34*	-.31*					
4. Psychological Wellbeing	-.68*	-.54*	.68*				
5. Social Relationships	-.55*	-.54*	.69*	.76*			
6. Environmental Wellbeing	-.36*	-.45*	.69*	.68*	.75*		
7. Quality of Life	-.38*	-.39*	.58*	.68*	.59*	.69*	

* $p < 0.05$

Relationship between Caregiver Burden and Marital Satisfaction

The table indicates a significant positive relationship between caregiver burden and the index of marital satisfaction [$r_{(75)} = .67, p < .001$]. This shows a direct relationship between the

two measures. The index of marital satisfaction score is actually an indication of the degree of marital dissatisfaction an individual has with the marital relationship, thus higher index of marital satisfaction scores represent higher levels of marital dissatisfaction. The table therefore indicates that higher levels of caregiver burden among spouses of SCD patients are associated with higher levels of marital dissatisfaction.

Relationship between Caregiver Burden and Quality of Life Domains

Significant negative relationships are shown in the table between Caregiver Burden and each of the WHOQOL domains: between Caregiver Burden and Physical Health [$r_{(75)} = -.34$, $p = .003$]; Caregiver Burden and Psychological Health [$r_{(75)} = -.68$, $p < .001$]; Caregiver Burden and Social Relationships [$r_{(75)} = -.55$, $p < .001$]; Caregiver Burden and Environmental Wellbeing [$r_{(75)} = -.36$, $p = .002$]; Caregiver Burden and Quality of life [$r_{(75)} = -.38$, $p = .001$]. An inverse relationship is, therefore, indicated between Caregiver Burden and the Quality of life domains. Higher levels of Caregiver Burden, therefore, are associated with lower levels of Physical Health, Psychological Wellbeing, Social Relationships and Environmental Wellbeing.

Relationship between Marital Satisfaction and Quality of life Domains

The correlation study also shows significant relationships between marital satisfaction and quality of life among spouses of SCD patients. Direct negative relationships are indicated between the Index of Marital Satisfaction (IMS) and each of the quality of life domains. Relationships can be observed between IMS and Physical Health [$r_{(75)} = -.31$, $p = .003$], IMS and Psychological Wellbeing [$r_{(75)} = -.54$, $p < .001$], IMS and Social Wellbeing [$r_{(75)} = -.54$, $p < .001$]; IMS and Environmental Wellbeing [$r_{(75)} = -.45$, $p < .001$]; and IMS and Overall QOL [$r_{(75)} = -.39$, $p = .001$]. As previously noted, the index of marital satisfaction is a measure of

marital dissatisfaction. These relationships, therefore, indicate that the higher levels of marital dissatisfaction are associated with reduced physical health and psychological wellbeing, reduced satisfaction with social relationships, and lower environmental satisfaction.

4.2 Qualitative Findings

Qualitative data was analysed by thematic analysis, using a bottom-up or inductive approach. A total of six themes were identified, one of which was an unexpected finding. The derived themes were Psychosocial effects, Effects on the Marital Relationship, Coping Mechanisms, the experience of SCD-related Stigma, and Factors that affect the psychosocial experience of the spouse. The last theme, Inadequate Awareness of SCD among spouses of SCD patients, was an unexpected finding that was considered relevant to this research study. Psychosocial Effects including respondent's experiences regarding their psychological, social and environmental wellbeing. Recorded narratives pertained to effects such as stress and anxiety, disruptions in social relations and financial strain. Under Effects on the Marital Relationship, narratives relating to marital discord, lack of emotional fulfilment and deterioration in sexual relations were recorded. Derogatory comments and attitudes, and Negative societal perceptions constituted the subthemes under the Experience of SCD-related stigma. Mechanisms of coping reported among the study sample were coded, Coping Mechanisms, and subthemes under Factors affecting the psychosocial experience of the spouse included the awareness of the patient's SCD before marriage and the duration of marriage. These themes, and their corresponding subthemes, are presented in Table 15.

Table 15

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Sample Quotes
Psychosocial Effects	Stress	3	<i>"Well, I can say it's really challenging to be with someone with this illness" R.3</i> <i>"...the experience is a stressful one despite all the good efforts." R.5</i> <i>"...it's been stressful and unpredictable..." R. 6</i>
	Emotional Effects	3	<i>"...it has affected me psychologically. I felt sad about her pain sometimes....Again, as I said, her pain experience saddens me a lot" R.2</i> <i>"...sometimes I feel bad about how he feels weak sometimes." R.4</i> <i>"...Mostly at night she feels a lot of pains at her joints which sometimes affect my sleep.....her pains sometimes affect me emotionally" R.7</i>
	Fear of losing the patient	2	<i>Interviewer: "Have you ever been bothered by a fear of losing your partner?"</i> <i>Respondents: "Well, sometimes." R.3</i> <i>"Oh yeah. Virtually every day..." R.5</i>
	Anxiety	1	<i>"Personally, it has...made me worry more about the future.... worry about what support I can get should I become fully or partially incapacitated in any form." R.6</i>

Table 15 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Examples of Quotes
Psychosocial Effects (continued)	Disruptions in Social relations	2	<i>"...my friends don't normally visit me during the time the sickness gets severe."</i> R.1 <i>"...and moreover, family members not visiting me as well."</i> R. 3
	Limitations on Social life	5	<i>"...the kind of social life we used to have, like outings, etc., in the past has come to a certain limitation because of her illness."</i> R.2 <i>"...The kind of social life I used to have before marriage is not the same as now..."</i> R.5 <i>"...it has left us little to no room for a social life..."</i> R.6
	Financial Strain	5	<i>"...it's a little stressful for me because most of the moneys have been spent on medicines and other hospital bills. Sometimes I have to use my own money on the kids."</i> R.1 <i>"...I can say financially it has affected me a lot..."</i> R.3 <i>"...the bills too are another challenge. I have to spend more on my wife and the kid [child also has SCD]"</i> R.5
	Restraints on Personal Activities	4	<i>"....and also not having enough time to attend to other activities"</i> R.3 <i>".....the limitations [on] time to do other works. Sometimes I used to receive calls to come to the hospital when it gets worse."</i> R.5 <i>"...sometimes you don't get the full time for yourself."</i> R. 7

Table 15 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Examples of Quotes
Effects on the marital relationship	Deterioration in Sex life	7	<i>“and moreover, the attention that I need...it has affected my sex life and affection” R.1</i> <i>“Of course, my sex life is affected due to how severe the disease is”R.2</i> <i>“...a generally poor sex life as a result of the limitations brought by partner’s physical pain and general weakness”R.6</i>
	Lack of Emotional Fulfilment	2	<i>“...moreover, the attention that I need...” R.1</i> <i>“Personally, it has left me feeling not as emotionally fulfilled as I would want.” R6</i>
	Marital Discord	1	<i>“...frequent misunderstandings and an inability to fully understand and appreciate each other’s requirements...”R.6</i>
Experience of SCD-related Stigma	Derogatory comments and attitudes	3	<i>“sometimes my friends say I should forget about him” R.1</i> <i>“sometimes my very close friends mock me...”R.2</i> <i>“some of my friends and relatives tried to advise me not to marry him.....some of my friends look down upon me...”R4</i>
	Negative Perceptions of the society	4	<i>“...the main thing people used to say is that this illness can easily lead to death...This normally affects me as to whether to continue the relationship or not...” R.3</i> <i>“the stigma that SCD patient’s don’t live long really affects me...”R.4</i> <i>“She is a little disabled, and this made some of my relatives to prevent me from marrying her because they thought my children will be affected.” R8</i>

Table 15 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Examples of Quotes
Coping Mechanisms	Religious Coping	6	<i>“moreover, I make sure I pray as well” R.2</i> <i>“Also, my pastor has been supporting me with prayers too” R.4</i> <i>“But with prayers I have more hope that the situation will get better” R.5</i>
	Social Support	6	<i>“I do have some little support from friends with money to help me solve some these challenges” R.3</i> <i>“... sometimes I used to get support from some of my relatives....” R.5</i> <i>“I do go out to friends and sometimes the counsellors to advise me.” R.10</i>
	Self-distraction	2	<i>“.... But sometimes I tried to engage in certain activities to forget about some of the pains...” R.2</i> <i>“...going out with friends if possible and other activities that may temporarily distract me...” R.6</i>
	Substance use	2	<i>“...Sometime I tried to forget about it by drinking etc.” R.5</i> <i>“Coping mechanisms include smoking...” R.6</i>
	Positive Refraining	2	<i>“...I see to it to make the best out of the situation....” R.3</i> <i>“...I have been making the situation look better than before.” R.7</i>

Table 15 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Examples of Quotes
Factors that affect the psychosocial effect on the spouse	Awareness of patient's SCD before Marriage	5	".... For me since I am aware of the status as a 'carrier', it wasn't much stressful for me." R2 "Yes, my husband told me.... I haven't been affected much by his illness." R4 "Yes [aware]...you can still manage the situation if you really understand some of the difficulties about SCD." R8
	Duration of Marriage	3	"...But I think for a very long time with her it's OK...." R.3 "I have lived long with him so am used to it..." R.1 "First I was bothered but now...the situation is getting better." R8
Inadequate Awareness of SCD among spouses of SCD patients		4	"I never had much knowledge about SCD so I don't really know the main consequences associated with it. But some of my relatives told me it's a serious illness, but my husband told me he is just a carrier, i.e., SC." R1 "...I know she's just a carrier..." R.2 "Not many of my relatives know he is an SCD patient, and even, he is just a carrier..." R 9

4.3 Summary of Findings

The results of the quantitative study on 75 partners of SCD patients indicate the experience of a mild to moderate level of Caregiver Burden among participants. On average, the participants recorded satisfaction with their marital relationships, although some participants recorded clinically significant levels of distress. With regards to the WHO Quality of Life domains, participants' average scores indicated general satisfaction with their Physical Health, Psychological Wellbeing, Social Relationships, and Environmental Wellbeing. The overall Quality of Life of the sample was also high. Of the Coping mechanisms assessed, Planning, Active Coping, Acceptance, Positive Refraining and Religion, were used to a greater extent among participants. Humour and Substance Use were employed to the least extent.

Results of hypothesis testing also indicate significant differences in psychological wellbeing among male and female participants, with females reporting lower levels of psychological wellbeing. Gender differences were also found in the use of self-distraction, denial and self-blame as coping strategies. These strategies were used to a greater extent among females than among males. Findings further indicate that an awareness of the patient's Sickle Cell status before marriage had a significant effect on the psychosocial impact of the spouses. Differences in the impact were observed with regards to Caregiver Burden, Psychological Wellbeing, and Social Relationships. Longer years of marriage were also found to lead to lower levels of distress among participants. The spouse's level of education had no significant effect on the psychosocial impact of participants.

Other findings of this study indicate a significant relationship between caregiver burden and all domains of the WHO quality of life assessment. Increased levels of caregiver burden were

associated with decreased physical health and decreased psychological, social and environmental wellbeing. Increased caregiver burden was also associated with reduced quality of life among partners of SCD patients. A significant negative correlation was also found between caregiver burden and marital satisfaction. This indicates that increased caregiver burden leads to reduced marital satisfaction. Marital satisfaction was also found to correlate positively with physical health, psychological wellbeing, social wellbeing, environmental wellbeing and overall quality of life.

Thematic analysis of the qualitative findings generated a total of six themes. These included Psychosocial effects, Effects on the Marital Relationship, Coping Mechanisms, The Experience of SCD-related stigma, and Factors affecting the Psychosocial experience of the spouse. The sixth theme, Inadequate Awareness of SCD among Spouses of SCD patients, was an unexpected finding that was considered relevant to the purpose of this study.

Psychosocial effects reported in the qualitative interviews include emotional and psychological stress, and effects on spouses' social and environmental wellbeing (e.g. social disruption, financial strain and limitations on personal activities). The main effects on the marital relationship were deterioration in sexual relations and a lack of emotional fulfilment. Participants who reported marital disharmony were in the minority. Participants further reported experiencing stigma in the forms of derogatory comments and negative attitudes from relatives and members of their community. The mechanisms of coping most often used among respondents in the qualitative study were religious coping and social support. Self-distraction, Positive refraining and Substance Use were employed to a lesser extent. An awareness of the patient's sickle cell status before marriage and the longer years of marriage were identified as factors that led to lower levels of psychosocial distress among spouses of SCD patient.

CHAPTER FIVE

DISCUSSION

The current study involved a mixed methods approach to evaluate the psychosocial impact of SCD on partners of SCD patients. The experiences of the partners were evaluated in specific psychosocial domains: Caregiver Burden, Marital Satisfaction, Physical Health, Psychosocial Wellbeing, Social Wellbeing, Environmental Wellbeing, and Quality of Life. The study aimed at deriving indices of the partners' experiences in these domains via a quantitative study, and further exploring partners' experiences in a qualitative study. The qualitative study had an additional objective of exploring the experience of SCD-related stigma among partners of SCD patients. This study also assessed the coping strategies often used among spouses of SCD patients. Findings of the quantitative and qualitative studies are merged in this discussion to find answers to the study's original research questions.

The aims and objectives of the study were informed by existing research findings which indicate a profoundly negative impact of chronic illness on the patient's spouse. Studies have indicated a wide range of negative effects on spouses including worsened physical health and an increased risk for psychological disorders (Eriksson et al., 2017; Rahmani et al., 2018; Rees et al., 2001). Studies have also shown that differences in disease characteristics can lead to different psychosocial effects, indicating that research findings on one disease cannot be generalised to other diseases (Baanders and Heijmans, 2007). The nature of the caregiving relationship (e.g. spousal caregivers or adult-child caregivers) has also been found to affect the nature of the impact (Oldenkamp et al., 2016; Wittenberg et al., 2013). It is, therefore, important to consider the type of relationship between the caregiver and the patient in studying the effects of the disease (Oldenkamp et al., 2016; Wittenberg et al., 2013). The

purpose of this study, therefore, was to provide information specific to the effects of SCD on partners.

The findings of the study indicate that partners of SCD patients indeed experience widespread psychosocial effects due to their relationship with an SCD patient. Some of the reported effects were mild to moderate levels of caregiver burden, financial challenges and limitations on their social life. In this regard, the results of this study confirm the findings of previous studies. Contrary to the findings of existing literature, however, the results of this study do not indicate an overarching or profound negative impact. In spite of the challenges reported, partners of SCD patients in this study indicate overall satisfaction with their marital relationships and with their quality of life, physical health and psychosocial wellbeing. This result is attributed to the prevalence of adaptive coping mechanisms and strong social support systems found among the study participants. This divergent finding further prompted a discussion of the influence of culture on caregiving experiences, as it was noted that the previous studies reviewed were mainly conducted in Western cultures while the current study was conducted in an African context. The contrast between the findings of this study and those of the existing research was, thus, further explained. The findings are discussed further in this chapter, in relation to the aims and research questions of the study.

5.1 Psychosocial Effects of SCD on Partners

The primary aim of this study was to investigate the psychosocial effects experienced by spouses of SCD patients as a result of their relationship with an SCD patient. The questions that the study sought to examine, in relation to this specific aim, were, ‘What is the experience of persons married to SCD patients? In what areas and to what extent do they experience an impact?’ Findings of the qualitative study indicate that marriage to a person

with SCD is a challenging and sometimes stressful experience. Specific areas of psychosocial difficulty were caregiver burden, finances, personal life and social activities, psychological wellbeing, and societal perceptions. Quantitative assessments of the extent of the impact on the participants, however, indicate a general satisfaction with their marital relationships, psychosocial wellbeing and quality of life, in spite of the reported challenges. The suggestion given by these results, therefore, is that the spouses of SCD patients studied are able to cope effectively with their challenges. This is an indication that is confirmed by the assessment of coping strategies among the spouses. This section discusses the psychosocial effects on the spouse; coping among spouses of SCD patients is discussed in subsequent sections.

Caregiver Burden

Studies on caregiver burden have noted its significant role in the psychosocial distress experienced by spouses of people living with chronic diseases (Paschou et al., 2018; Savundranayagam et al., 2010). Caregiver burden refers to the type of stress or strain that is associated with the challenges of caring for chronically ill relatives (Buhse, 2008). It has been a major focus of research for several years, and has been defined as a multidimensional construct that has significant effects on caregivers physically, emotionally, and psychologically (Paschou et al., 2018; Savundranayagam et al., 2010). The results of this study confirm the research reports. Mild to moderate levels of caregiver burden were reported among partners of SCD patients in this study. An examination of the correlations among caregiver burden, psychosocial wellbeing and quality of life this study showed significant negative associations between caregiver burden and all domains of the WHO quality of life assessment. Increased levels of caregiver burden among spouses of SCD patients, therefore, can lead to reduced physical health and psychosocial wellbeing. Increased levels of caregiver burden can also lead to reduced partner quality of life.

A significant positive relationship was also found between caregiver burden and the index of marital satisfaction among spouses of SCD patients in this study. Higher indices of marital satisfaction on the IMS scale actually represent higher levels of marital dissatisfaction and discord (Hudson, 1992). The study results therefore indicate that increased levels of caregiver burden among spouses of SCD patients may, therefore, lead to increased marital disharmony and dissatisfaction among affected couples. This result confirms previous research findings on the adverse effects of caregiver burden on the quality of relationship between caregivers and care receivers (Savundranayagm et al., 2010). Previous research studies on gender differences in the experience of caregiver burden have yielded contradictory results (Poysti et al., 2012). Whiles majority of studies conclude that women experience more distress than men, several others report no significant differences (Poysti et al., 2012). In this study, no significant differences were found in levels of caregiver burden between wives and husbands of SCD patients.

Caregiver burden among spouses of SCD patients, thus, represents an area worthy of attention in psychosocial interventions in SCD management. Improving the ability of partners to cope with the burden of caregiving can, evidently, have a significant positive effect on their psychosocial wellbeing, quality of life, and marital satisfaction. Psychological interventions like psychoeducation, for instance, have been shown to be effective in reducing subjective burden of care among spousal caregivers (Savudranayagam et al., 2011). The correlations observed in this study further confirm the assertion by Paschou and colleagues (2018) that the identification of other factors such as quality of life and marital satisfaction is also important in the development of strategies that may burden spousal caregivers. Considering the potential reciprocal effect of the spouse's wellbeing on the health of the

patient, addressing the burden of caregiving and psychosocial wellbeing among partners of SCD patients can have significant positive effects on the patient's wellbeing as well.

Psychological Wellbeing

Chronic illnesses can have significant adverse effects of the psychological health of patient's partners (Dobbie & Mellor, 2008; Pitceathly & Maguire, 2003). The findings of this study indicate that the illness symptoms and incapacities of a person living with SCD exert psychological effects on the patient's partner. Thirty (30) % of the partners interviewed described living with an SCD patient as stressful, and another 30% reported feeling sad when the patient experienced painful episodes and weakness. One participant, for instance, reported concerning his wife: "her pain experience saddens me a lot". Another participant described: "Her pain sometimes affects me emotionally. Mostly at night she feels a lot of pain in her joints, which sometimes affects my sleep." The emotional stress of watching their partner go through the symptoms of the illness is reflected in these reports. 30% of the spouses expressed fear of losing the patient and worries about the future. The psychological challenges reported in this study mirror the results of existing literature studies (Baanders & Heijmans, 2007; Rees et al., 2001).

In spite of the psychological stress and difficulties reported, however, participants in the study indicated satisfactory levels of psychological wellbeing on the whole. This was indicated by the quantitative assessment of psychological wellbeing, which generated a relatively high average score. On the whole, the results, therefore, suggest that in spite of the difficulties associated with the patient's illness, partners of SCD patients are able to cope well psychologically. This result confirms an assertion by Pitceathly and Maguire (2003) in a study of the psychological impact of cancer on patient's partners that most partners cope

well. There is, however, an important minority that become highly distressed or develop an affective disorder. It is, therefore, important to consider that this indication of overarching positive psychological wellbeing among spouses of SCD patients is given by average scores. Psychosocial interventions involving spouses of SCD patients should, therefore, consider the possibility of highly distressed spouses who may be in the minority.

Social and Environmental Wellbeing

Social Wellbeing is defined, for the purposes of this study, as a state of balance and satisfaction with regards to social relationships and support, based on the conceptualization of this construct in the WHOQOL BREF (WHOQOL GROUP, 1996). An indication of the individual's overall social wellbeing was measured via the WHOQOL BREF Social Relationships domain. Similarly, Environmental Wellbeing was defined as an individual's satisfaction with environmental factors such as financial resources, participation in and opportunities for recreation (WHOQOL Group, 1996). This construct was also measured via the WHOQOL Environment domain. Questions regarding social and environmental wellbeing were also included in the qualitative interview. Participants in this study reported experiencing difficulties in these two domains. Challenges reported included limitations on social activities and social relationships, financial strain, and limitations on personal activities. Participants, for instance, reported that their partner's illness placed limitations on their social life as a couple. One participant, for instance, said, "...the kind of social life we used to have, like outings, etc., in the past has come to a certain limitation because of her illness" (R.2). Another reported that the illness had "...left [us] little to no room for a social life..." (R.6)

Other participants reported restraints on their interactions with friends and family members, for example, “...my friends don’t normally visit me during the time the sickness gets severe.” (R.1). 40% of participants also felt that their partner’s illness placed restraints on their personal activities and time to engage in other activities. As some participants reported, “...sometimes you don’t get the full time for yourself” (R.7); “....and also not having enough time to attend to other activities” (R.3).

For one female participant, the restraints on her ability to work contributed to the financial effects of the illness. She reported, “...for instance, if he didn’t go to work, that means that I have to close early from market which also affects my income....” (R.1). A strain on financial resources was one of the most prevalent challenges among participants. 50% of participants in the study had experienced financial challenges, due to reasons such the cost of the patient’s medical care, and limitations on the patient’s ability to work.

The effects on social activities and environmental factors found in this study mirror the findings of existing studies (Baanders et al., 2007; Rees et al., 2001). The quantitative measures of Social and Environmental Wellbeing derive relatively high average score, indicating satisfactory wellbeing with relation to social relationships and environmental factors. This gives the impression that the spouses in this study are able to cope well with the social and environmental stressed they encounter as a result of their marriage to a person with SCD.

Quality of Life

Similar to the reports of sound physical health, psychological wellbeing, social relationships and environmental wellbeing, spouses of SCD patients in this study showed good levels of quality of life. This result, again, suggests that the spouses are able to cope adequately with

the challenges associated with their marital relationship. Narratives of some of the respondents in the qualitative interviews also indicate an overall sense of wellbeing among majority of the participants, in spite of the challenges presented by their relationship with an SCD patient. One male participant, for example, said, *“I don’t think the experience with my wife having such illness is much different from any other person. But sometimes you don’t get the full time for yourself. Mostly at night she feels a lot of pains at her joint which sometimes affect my sleep. But I think the experience is normal”* (R.7). The findings of this study, therefore, contradict existing research findings on the quality of life of partners of people with chronic diseases. The existing research indicates reduced quality of life levels among partners of chronic disease patients (Meier et al., 2011; Golics et al., 2013). A review by Rees and colleagues (2001) suggests that the psychosocial impact on partners sometimes leads to an even worse quality of life than that of patients themselves. The satisfactory quality of life of this sample, again, provides an indication of sound coping abilities among the participants.

The Experience of SCD-Related Stigma

The experience of Stigma among spouses of SCD patients was assessed through the qualitative interviews. 70% of the participants had experienced some form of stigma in the form of remarks and attitudes from friends and members of the society. Examples are, *““sometimes my friends say I should forget about him”* (R.1); *“some of my friends and relatives tried to advise me not to marry him.....some of my friends look down upon me”*(R4).

The assessment of stigma in the study further revealed some mistaken perceptions and beliefs of the Ghanaian society about SCD. For example, one male participant reported, *“she is a little disabled, and this made some of my relatives [try] to prevent me from marrying her because they thought my children will be affected”*(R8). This finding is consistent with

results of existing studies. In a study of the psychosocial impact of SCD within a Nigerian population, Anie and colleagues (2010) found a generally negative perception of SCD, which was attributed to limited awareness of the disease. Abioye-Kuteyi and colleagues (2009) also reported a poor knowledge of SCD among government workers in Nigeria. The lack of adequate awareness of SCD is another emerging theme in the qualitative component of this study, exhibited by the spouses of SCD patients. Coupled with the negative attitudes and perceptions displayed by members of society, a general lack of adequate awareness of the disease in the society is indicated. This theme is discussed further in subsequent sections.

5.2 The Effect on the Marital Relationship

The second research question for this study sought to specifically examine the effect of SCD on marital relationships. The quantitative and qualitative data provide an answer to this question. Of the effects of SCD on marital relationship, deterioration in sex life was the most prevalent effect, reported by 70% of spouses in this study. Both male and female participants expressed a lack of satisfaction with the levels of intimacy and affection in the relationship, due to the patient's illness. Participants reported experiencing feelings of loneliness and lack of emotional fulfilment as a result. For example, *"...and moreover, the attention that I need...it has affected my sex life and affection"* (R.1). Other participants reported, *"Of course, my sex life is affected due to how severe the disease is"* (R.2). *"Personally, it has left me feeling not as emotionally fulfilled as I would want"* (R.6). This finding is consistent with McInnes (2003), who indicated that the patient's biological and psychological illness-related factors could result in changes in their sexual desire, capacity, and activity, leading to a limitation or cessation of sexual relations. An unsatisfactory sexual relationship could eventually cause emotional problems for the partner (McInnes 2003). Chronic illnesses,

therefore, can often result in unsatisfactory marital relationships, which can lead to marital discord, separation, divorce, or partner abandonment (Glantz et al., 2009).

In spite of the challenges reported however, participants of this study indicate a general level of satisfaction with respect to their marital relationships. A relatively low index of marital satisfaction score (27.20) was obtained in the quantitative study. This is an indication of general satisfaction, as scores below 30 are considered indicative of overall marital satisfaction (Hudson 1992). Participants in the qualitative study who felt that the disease led to marital discord were in the minority (10%). The responses of some participants in the qualitative interviews, when asked what they felt the effect on their marriage was, also give an indication of general satisfaction in spite of the challenges. One participant, for instance, said, “I don’t think my wife having such an illness is much different from any other person...” (R.7). Another participant reported, “I think on our marriage it’s not much an effect...” (R10). Again, the impression gained is that participants are able to cope effectively with the challenges met, hence the sense of satisfactory wellbeing. An examination of coping strategies among the spouses of SCD patients in this study (discussed in the next section) confirms this indication.

Further findings in this study attest to the significance of marital health to the overall wellbeing of both patient and partner (Martire et al, 2010; Meier et al., 2011). Results of this study indicate that increased marital dissatisfaction among spouses of SCD patients lead to reduced physical health, psychosocial wellbeing and quality of life of the spouses. Reciprocally, reduced wellbeing among spouses can lead to negative effects on the patient’s wellbeing and quality of life. In view of this finding, this study stresses the recommendation by Glantz and colleagues (2009) that healthcare providers be especially sensitive to early suggestions of marital disharmony among couples affected by chronic illness. Early

identification and psychosocial intervention have the potential to improve quality of life and quality of care, and reduce the incidence of separation and divorce (Glantz et al., 2009). Although majority of the spouses of SCD patients in this study reported overall satisfaction with their marital relationships, a critical look at the distribution of scores shows that a minority of the participants reported clinically significant levels of marital dissatisfaction. A minority of participants in the qualitative studies also reported that the effects of the disease led to marital discord. This finding further validates the assertion by Pitceathly and Maguire (2003) that although a majority of partners of chronically ill patients cope well, an important minority become highly distressed, and may even develop an affective disorder. Spousal caregivers are also more at risk of developing psychiatric morbidity when there are relationship difficulties with the patient (Pitceathly & Maguire, 2003). The importance of evaluating marital satisfaction in psychosocial interventions in SCD management can, therefore, not be overemphasized. Apart from addressing the overall health, wellbeing and quality of life of spouses, such interventions also address patient health and quality of life.

5.3 Mechanisms of Coping among Spouses of SCD Patients

One of the aims of the study was to assess mechanisms of coping among spouses of SCD patients, in relation to the question, ‘How do spouses of SCD patients cope with the challenges associated with their partnership with an SCD patient?’ Coping was considered in this study as the ways by which individuals respond to the stress and difficulties they experience as a result of their partnership with an SCD patient. Results of the quantitative assessment indicate that the majority of partners of SCD patients used adaptive coping methods. The major forms of coping used among spouses of SCD patients were Planning, Active Coping, Acceptance, Positive Refraining, and Religion. Self-Distraction and the use

of Emotional Support were also used to lesser extent. The least used method of coping was substance use.

These coping mechanisms further emerged in the qualitative interviews. The most prevalent forms of coping reported in the qualitative interviews were Religion (reported by 60% of the participants) and the use of Social support (also reported by 60% of participants). Participants, for instance, reported obtaining forms of financial and emotional support from family members and friends, and for pastors. Positive refraining and Self-distraction were also reported by respondent of the qualitative interview, and only 20% of the participants admitted to the use of substances (alcohol and smoking). It can be observed, therefore, that adaptive coping strategies were more prevalent among participants. Moreover, strong social support systems are indicated among the spouses in this study. Existing studies have previously indicated the importance of coping and social support to the adaptation to chronic illness (Schreurs & de Ridder, 1997). Similarly, research reports indicate that a lack of adequate social support contributes significantly to high distress levels among spouses of patients with chronic illnesses (Eriksson et al., 2017; Meier et al., 2011; Rahmani et al., 2018). The presence of strong coping mechanisms and social support systems among the study participants can thus explain the high levels of wellbeing recorded, in spite of the challenges they face in their marriages to SCD patients. The importance of social support in coping among spouses of chronically ill patients is, thus, further validated by the results of this study.

5.4 Factors that affect the psychosocial experiences of spouses of SCD patients

Further objectives of this study were to examine the effects of factors like gender differences, years of marriage, and an awareness of the patient's sickle cell status before marriage.

Significant differences were found between male and female participants in psychological wellbeing, and in the use of self-distraction, denial and self-blame as mechanisms of coping. The results further indicate that longer years or duration of marriage are associated with lower levels of distress. Spouses who were aware of the patient's sickle cell status before marriage also reported lower levels of psychosocial distress. These findings are further discussed in the following subsections.

5.4.1 Gender Differences in Psychosocial Experiences and in Coping Strategies

Most studies on gender differences in the impact on chronic illness on spouses indicate that women (i.e. wives of chronically ill partners) exhibit higher levels of distress than men (husbands) (Poysti et al., 2012; Savundranayagam et al., 2011). These differences have been attributed to reasons like the finding that wives are more willing to commit to the relationship when the men are affected by chronic illness (Glantz et al., 2009). Men and women have also been found to approach their caregiving roles differently, with women taking a more comprehensive role (Poysit et al., 2012). This study sought to evaluate these differences among spouses of SCD patients. The study further assessed gender differences in coping strategies.

Results of the study show significant differences in psychological wellbeing between male and female spouses of SCD patients. Male participants exhibited higher levels of psychological wellbeing than female participants. This finding supports the research reports of a greater negative impact on female spousal caregivers. In particular, this finding reflects the research results of by Pitceathly and Maguire (2003) which found a greater psychological impact of cancer on wives of affected male patients. Female caregivers were found to be

more likely to take a negative view of the patient's illness and impact on their lives (Pitceathly & Maguire, 2003).

With respect to the mechanisms of coping among spouses of SCD patients, wives were found to use Self-distraction, Denial and Self-blame to a significantly greater extent than husbands of SCD patients. The use of denial and self-blame, in particular, to cope with stressful situations has been associated with greater risk of distress (Nipp et al., 2016). The use of denial and self-blame to a greater extent among female participants, thus, explains their lower levels of psychological wellbeing. The findings on gender differences in coping, thus, buttress the reports of higher levels of distress among wives of chronically ill patients. The findings further indicate that it is important to assess coping strategies among spouses of SCD patients in developing interventions that are tailored to their unique needs.

5.4.2 The Effect of An Awareness of The Patient's Sickle Cell Status Prior to Marriage

This study explored the effects of an awareness of the patient's sickle cell status before marriage on the overall psychosocial experience of the spouse. Results of the quantitative study indicated significant differences in psychosocial impact between spouses who were aware of the patient's sickle cell status prior to marriage and spouses who were not aware. Significant differences were found in the experience of Caregiver Burden, and in their Psychological and Social Wellbeing. Spouses who were aware of the patient's status before marriage experienced significantly less caregiver burden, and significantly higher levels of psychological and social wellbeing. This finding is corroborated by the results of the qualitative study. Participants who had prior knowledge of the patient's sickle cell status before marriage expressed lower levels of stress. For example, "*For me since [I] am aware of [her] status, it wasn't much stressful for me.*" (R.2). The experiences of spouses who were

aware obviously contrasted those of participants who had no prior knowledge of the patient's sickle cell status.

This finding has valid implications for psychosocial interventions in the management of SCD patients. Considering the proportion of the study's participants who were unaware of the patient's sickle cell status before marriage (40% in the quantitative study and 40% in the qualitative study as well), it is evident that many patients avoid disclosing their status. As previous studies suggest, stigma and negative societal perceptions cause significant challenges in the pursuit of marital partners among SCD patients (Owotomo, 2016). This could present a reason for the patient's lack of disclosure. It is however, evidently important for patients to inform potential spouses of their sickle cell status before marriage. Psychosocial interventions may be effective in sensitizing patients to the need to disclose their status to potential spouses, and in improving their ability to cope with possible negative attitudes. Pre-marital counselling programs tailored specifically to SCD patients and their partners are also recommended to provide psychoeducation and awareness to prepare partners for the potential challenges of the relationship.

5.4.3 The Effect of the Years of Marriage on the Psychosocial Impact on Partners

The years of marriage, in this study, refers to the number of years the individual has been married to an SCD patient. The study sought to explore the effect of this variable on the psychosocial experiences of the spouse – that is, whether or not the length of time spent in the marital relationship made any difference to the psychosocial impact experienced. Results of both qualitative and quantitative studies indicate that longer years married are associated with a lesser impact. Examples of narrations to this effect are: *“I have lived long with him so [I] am used to it”* (R.1); *“First, I felt uncomfortable, but that was before we got married, and*

with time I was able to cope well” (R.2); “It wasn’t easy for me from the beginning....But I think [after] a long time with her it’s ok”(R.3). The longer the duration of the marriage, therefore, the easier it is for spouses to cope with the patient’s illness. The results of the quantitative study, however, only indicate a significant effect with regards to environmental factors like financial resources and the opportunities to participate in recreational activities, indicating that the longer an individual is married to a person with SCD, the greater his/her environmental wellbeing. This result was ascribed to limitations in the quantitative approach in generating more comprehensive results.

5.5 Inadequate Awareness of SCD among Partners of SCD Patients

A general lack of adequate knowledge of SCD was observed among partners of SCD patients in the qualitative interviews. This was an unexpected finding. It was noted that a significant number of participants referred to some patients as “carriers”, particularly those with genotype SC. Examples of quotes are: *“I never had much knowledge about SCD so I don’t really know the main consequences associated with it. But some of my relatives told me it’s a serious illness, but my husband told me he is just a carrier, i.e., SC” (R1); “For me since [I] am aware of the status as a carrier, it wasn’t much stressful for me....”(R.2); “Not many of my relatives know he is an SCD patient, and even he is just a carrier” (R. 9).* These narrations are an obvious lack in the understanding of the disease. Considering the critical role of a spouse in the life of a patient, it is essential that appropriate educational interventions be developed for spouses. The need for adequate education of spouses to aid them in their roles as caregivers, emphasized by Rahmani and colleagues (2018) is confirmed in this study.

5.6 Cultural Influences on Coping among Spouses of SCD Patients

As has previously been emphasized, the existing studies on the impact of chronic diseases on healthy spouses consistently convey a profoundly negative impact on areas such as health, finances and social life. Whilst the findings of the current study do show that partners of SCD patients experience similar negative effects, the indication given is, however, not of an overarching negative impact. Instead, the participants of this study indicate overall satisfaction with their marital relationships and with their quality of life, physical health and psychosocial wellbeing, in spite of the stresses and challenges reported. This divergent finding may be attributed to the prevalence of adaptive coping mechanisms and strong social support systems found among the study participants, as discussed in the previous sections. Considering that the previous studies reviewed were mainly conducted in Western cultures, whilst the current study was conducted in an African setting, the divergent results in this study are further indicative of the influence of culture on the coping ability and experiences of informal caregivers – a theme that is well established in research literature.

Research reports consistently indicate that caregiving experiences differ significantly among ethnic groups, due to the influence of cultural norms and values (Pharr et al., 2014). Pharr and colleagues, 2014, for instance, found that in collectivist cultures such as the one in which this study was conducted, ideals like familism and filial piety contribute to cultural perceptions that sustain caregiving responsibilities. Among caregivers from more individualistic western cultures, on the other hand, caregiving was not naturally embedded in cultural values, and was thus more likely to be experienced as an unexpected disruption (Pharr et al, 2014). The discrepancy between the results of this study and those of existing studies may, thus, be explained by the differences in the norms and values of the different cultural settings. In the

collectivist cultural setting of the current study, cultural ideals and perceptions could contribute to the expression of less distress among the spousal caregivers.

The influence of cultural norms and values on caregiving further validate the attribution of the study results to the existing of adaptive coping mechanisms and strong social support systems among the study sample. Coping style and social support have been identified as important coping resources that are influenced by cultural values (Knight & Sayegh, 2010). Knight and Sayegh (2010) assert that there may be dissimilar coping styles among different cultural entities, as well as differing meanings for social support, and varying ways of expressing emotional distress, all contributing to different experiences of caregiving. The importance of the cultural context in which research studies are conducted can, thus, not be overemphasized.

5.7 Conclusions

This study highlighted the psychosocial experiences of partners of SCD patients in a Ghanaian setting. Findings of the study provide an indication of an overall sense of balance or wellbeing among participants, in spite of obvious challenges. An assessment of areas of difficulty revealed mild to moderate levels of caregiver burden, financial strain, emotional stress, and experiences of SCD-related stigma. Mechanisms of coping among partners of SCD patients in this study were largely adaptive, and included active coping, positive refraining and religious coping. Only a small minority of the participants used alcohol or smoking as means of coping with their challenges. Findings of the study also suggested the presence of strong social support systems among partners of SCD patients.

To a large extent, the results of this extent mirrored previous research findings on the psychosocial impact of chronic diseases on partners. Similar to the findings in a review by

Rees and colleagues (2001), partners in this study reported financial difficulties (mainly due to medical expenses), a deterioration in sex life, and social disruption. Previous studies, however, indicate high levels of distress, an overall low quality of life, and a decreased satisfaction in the marital relationship among spouses of people with chronic diseases (Rahmani et al., 2018; Martire et al., 2010; Rees et al., 2001). Studies also found a lack of adequate social support among partners of chronically ill patients (Meier et al., 2011; Eriksson et al., 2017; Rahmani et al., 2018). In contrast, the results of this study suggest a general sense of balance and wellbeing among the partners of SCD patients, in spite of the challenges experienced. The indication given is of sound ability of the participants in this study to cope with their challenges. This suggestion was supported by the general use of adaptive coping mechanisms exhibited by majority of the participants. Moreover, participants reported strong social support systems, which have consistently been shown to play an important role in the adjustment and coping of spouses of people chronic diseases (Rahmani et al., 2018; Eriksson et al., 2017). The contrast between the findings of this study and previous studies is, thus, explained. Existing studies have shown that a lack of adequate supportive systems contribute immensely to the reduced quality of life and increased distress among spouses of chronically ill patients (Rahmani et al, 2018; Eriksson et al, 2017). These studies have, therefore, advocated for the improvement of social support systems in their specific settings.

Coping ability and social support are identified as important coping resources that are influenced by cultural norms and values (Knight & Sayegh, 2010). Cultural values are also important in shaping perceptions that can significantly influence the caregiving experience (Pharr et al, 2014). The discrepancy between the results of this study and those of previous

studies is, thus, indicative of the influence of cultural norms and values on the experience of caregivers.

The negative effects of the patient's illness on the psychological, social and environmental wellbeing of the spouse indicated by the results of this study further allude to the theoretical premises of the study. The Self-Determination Theory by Deci and Ryan (2000) and the Social Cognitive Theory by Bandura (1986) both highlight the need to focus on environmental factors (such as the spouse) as well in health behaviour management by emphasizing the reciprocal relationship between individuals and environmental factors. It is, therefore, necessary to focus on such environmental factors as well in the management of chronic diseases. This study represents a first step in focussing on the spouse, as an environmental factor in the comprehensive management of SCD. The insights derived from this study will aid in the development of interventions that will relieve distress among spouses of SCD patients, leading to better care and support and improved quality of life for the patients, as shown by the theoretical framework.

The ultimate goal of this study, therefore, was to provide socio-culturally relevant information that can be tailored towards couple-oriented psychosocial interventions in SCD management. The areas of psychosocial difficulty shown in this study may, thus, be used as a basis in counselling programs for spouses of SCD patients. Caregiver burden has been shown to be significant among this population, and to play a critical role in their psychosocial wellbeing. Thus, psychosocial interventions for these spouses should give substantial consideration to this domain. Psychoeducational interventions, for instance, have been shown to be effective resources for reducing the burden on spousal caregivers (Savudranayagm et al., 2011). The overall effect on the marital relationship was also shown to be critically important. Marital satisfaction was found to be significantly related to the psychosocial

wellbeing and quality of life of the spouse. Dissatisfaction with the marriage or increased levels of marital disharmony, therefore, can lead to significantly negative effects on the wellbeing and quality of life of the spouse, and reciprocally, on the patient. Couple-oriented psychosocial interventions will be valuable in helping couples maintain or improve the quality of their marital relationships.

The findings of this study further indicate the important role of the spouse's awareness of the patient's sickle cell status prior to marriage. Partners who were aware of the patient's status before marriage reported significantly lower caregiver burden, and significantly higher psychological and social wellbeing. This is an area that is of critical importance to psychosocial interventions in SCD management. The majority of spouses in this study had had no knowledge of the patient's status before marriage. This is an indication that many SCD patients avoid disclosing their sickling status. Counselling and psychoeducation programs may, hereby, play a significant role in a number of ways in sensitizing patients to the importance of opening up to potential partners about their status. Patient education on the benefits of their disclosure to the health and wellbeing of their partners, and the reciprocal effects on their own health will have valuable effects. Counselling programs may also be effective in reducing patient's fear of stigma or other issues that inhibit their ability to disclose their sickling status. Participants of this study also exhibited a lack of proper awareness of the disease. Psychoeducation programs will, thus, also be effective in increasing the understanding of the disease and its effects among people married to SCD patients. This will have the added advantage of augmenting their coping abilities and enlightening them about more effective ways of helping their partners to manage their symptoms. The recommendation by Rahmani and colleagues (2018) that there is a need to provide adequate

information and education among spouses to facilitate their transition to caregiving roles is thus validated.

This study, therefore, recommends the development of couple-oriented psychosocial interventions in SCD management which focus on improving the knowledge, coping abilities and psychosocial wellbeing of both patients and their partners. In addition to psychoeducation, these programs should also include psychological interventions for couples who may be experiencing distress. Basing such interventions on the concept of reciprocity can lead to significant improvements in marital quality, coping ability and psychosocial wellbeing among both patients and spouses.

5.8 Limitations of the Study

Sample Size

A total of 75 participants were included in the quantitative part of this study. A larger sample size, however, may have contributed to greater statistical significance. The sample for this study was collected within a five week period. Considering the difficulties accessing the study population, a greater time frame should have been allocated to sampling, to allow a bigger sample to be collected.

Generalization of Study Results

This study was conducted within a Ghanaian population of spouses of SCD patients. In order to ensure that the results obtained could be generalised to the entire population, efforts were made to select appropriate sampling locations. KBTH is one of very few hospitals in Ghana to run specialised SCD clinics. The Ghana Institute of Clinical Genetics (Sickle Cell Clinic) and the Sickle Cell Antenatal Clinic at KBTH, were thus, appropriate locations to gain access

to patients and spouses from all over the country. The Purposive and Snowballing methods used in the recruitment of participants, however, did not ensure that the sample was adequately representative of participants from all different regions of Ghana. Considering the variations in culture and lifestyle among Ghanaians from different parts of the country, differences may exist in the experiences of spouses. For example, the experiences of the spouse of an SCD patient in a rural Ghanaian setting, may be significantly different from the experiences of one who is based in an urban setting, where lifestyles are more modernised and there is a greater influence of Western cultures. Using a quota sampling method, for example, may have resulted in a sample that was more representative of the study population.

Again, the selected clinics offer educational programs to patients to help improve their self-management behaviours. Patients who do not attend such clinics regularly (or do not attend clinic at all, such as those who patronise forms traditional medicine), may exhibit different health behaviours that can influence the psychosocial experience of the partner. Including samples from the different settings would, thus, have allowed for the evaluation of the effects of such differences in patient health behaviour. The obtained results would then provide a broader perspective and have a greater potential to be generalized.

Self-Selection Bias

The use of self-selection as the main method of recruiting participants for the qualitative interviews introduces issues of representativeness of the qualitative study sample, and again, of the generalizability of the results. Including additional methods of ensuring trustworthiness could help enhance the generalizability of the study results.

5.9 Recommendations for Future Research

Psychosocial interventions in SCD management will benefit from insights from more studies on the effects of the disease on partners and on marital relationships. This study has evinced the significance of culture and context to caregiving experiences. Including spouses from different cultural settings will further enrich research results on the impact of SCD on spouses, and enhance the potential of the results to be generalised. For instance, studies focused within Ghana may evaluate differences between the experiences of spouses in rural and those in urban settings. Differences in the experiences of spouses from different cultural regions of the country may also be evaluated.

Considering that SCD is a globally widespread disease, it would not only be interesting, but also beneficial to investigate the experiences of spouses of SCD patients from different cultural settings or from different countries. Comparing the experiences and coping strategies from such different samples will derive rich results on the influence of cultural values among spouses of SCD patients. This will further inform the tailoring of psychosocial interventions to the unique needs of individuals as, for example, more adaptive strategies can be incorporated into educational interventions.

A study that compares the experiences and perceptions of spouses to those of the patients themselves, with regards to the effect of SCD on the marital relationship, is also recommended. The results of such a study would be beneficial in developing couple-based psychosocial interventions in SCD management.

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APPENDICES

Appendix A Ethical Approval



UNIVERSITY OF GHANA ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

P. O. Box LG 74, Legon, Accra, Ghana

My Ref. No.....

15th December, 2017

Ms. Wilhelmina Efua Wilson
Department of Psychology
University of Ghana
Legon

Dear Ms. Wilson,

ECH 075/17-18: PSYCHOSOCIAL IMPACT OF SICKLE CELL DISEASE (SCD) ON PARTNERS OF SCD PATIENTS

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities for a full board review and the following actions taken subject to the conditions and explanation provided below:

Expiry Date:	12/06/18
On Agenda for:	Initial Submission
Date of Submission:	13/11/17
ECH Action:	Approved
Reporting:	Quarterly



Please accept my congratulations.

Yours Sincerely,

Rev. Prof. J. O. Y. Mante
ECH Chair

CC: Dr. Maxwell Asumeng, Department of Psychology, University of Ghana.

Appendix B Informed Consent Form

UNIVERSITY OF GHANA



Official Use only

Protocol number

Ethics Committee for Humanities (ECH)

PROTOCOL CONSENT FORM

**Section A- BACKGROUND
INFORMATION**

Title of Study: Psychosocial Impact of Sickle Cell Disease (SCD) on Partners of SCD Patients in Ghana	
Principal Investigator:	Wilhelmina Wilson
Certified Protocol Number	

Section B- CONSENT TO PARTICIPATE IN RESEARCH

General Information about Research

This is a study that examines on your personal experiences as a spouse/partner of a person living with Sickle Cell Disease (SCD). What the study hopes to achieve is to bring to light the difficulties and stresses that spouses of SCD patients experience as a result of their

relationship with the patient. The study will require you to answer three (3) questionnaires. This will take approximately 30 minutes. The questionnaires contain questions about the effects that your spouse's illness has had on you physically and psychologically, and the effects on your social life and finances. There are also questions about your marital relationship, and about the ways in which you cope with the difficulties presented by your relationship.

The study also involves a twenty (20) minute one-on-one interview with the researcher. In the interview, you will be asked to speak freely about your experiences in your marriage to a SCD person. The interview will be audio recorded with your consent. If you prefer not to have the audio recording, the researcher may take notes of the conversation. You will be asked at the end of the questionnaire period if you are willing to participate in the interview. You may decide not to participate in the interview, or to be interviewed at a later date.

Benefits/Risks of the study

The results of this study will be useful to counselling programs that will help reduce that distress that spouses go through. It will also help health professionals to better manage the psychological and social challenges which affect the health of the patients themselves.

The questionnaires coupled with the interview may be time consuming. Participants may therefore take a break at any time. Participants willing to participate in the interview may also opt to be interviewed at a later date. The topics included in the interview and questionnaires are of a sensitive nature, and participants may experience some stress or psychological distress as a result. Qualified Clinical Psychologists will therefore be at hand to offer counselling and psychological support.

Confidentiality

Each Participant will be assigned an identification number, which will be used to identify their questionnaires and interview recordings instead of their names. A record of the

participant's name and identification number will be stored on the principal investigator's computer so that if a participant decides to withdraw from the study, their responses can be correctly identified.

Only persons directly involved in the research (i.e. the student investigator, supervisors and research assistants) will have access to questionnaires and interview recordings. Thus by signing or thumb printing a written consent form, the participant or their representative is authorizing such access.

Compensation

Individuals who participate in the interview will be offered a drink (water and/or a soft drink) during the interview.

Withdrawal from Study

Participation in this study is voluntary, and you may withdraw or stop participating at any time, without any negative consequences. Please do indicate the circumstances and/or reasons for your withdrawal. In case any information becomes available that may be relevant to your willingness to participate or withdraw, you will be immediately informed.

Contact for Additional Information

For answers to any questions about this study, or in case of any form of distress related to your participation in this study, please contact:

1. Mina Efua Wilson
University of Ghana, Department of Psychology
Tel: 0242172074
Email: minaefuawilson@gmail.com

2. Prof. C. C. Mate-Kole
University of Ghana, Department of Psychology
Email: cmkole@ug.edu.gh

If you have any questions about your rights as a research participant in this study you may contact the Administrator of the Ethics Committee for Humanities, ISSER, University of Ghana at ech@isser.edu.gh / ech@ug.edu.gh or 00233- 303-933-866.

Section C- PARTICIPANT 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 Participant

Signature or mark of Participant

Date

If a participant cannot read and or understand 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 / Mark

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 C Research Questionnaire

Thank you for your participation in this research study. Please answer the questions below.

A. Personal Information

1. Age:
2. Sex: Male () Female ()
3. Religion: Christian () Muslim () Other (please specify)
4. Level of Education: No Formal Education () Primary () Junior High School () Senior High School () Tertiary ()
5. Occupation:
6. How long have you been married to a person with SCD?
7. Type of Marriage: Customary () Common Law Marriage ()
Christian () Islamic Marriage ()
Court Registration ()
8. Spouse's Sickle Cell Genotype: SS () SC () I don't know ()

Additional Questions

9. Were you aware of your spouse's Sickle Cell status before deciding to get married?
10. If not, please tell us briefly how you found out.....
.....
.
11. Did you have any knowledge of Sickle Cell Disease (SCD) prior to your marriage?
12. If so, please tell us how:
I have family members with SCD.....
I had friends with SCD before I met my spouse.....
I had heard /read about SCD.....

B. ZBI -12

Please read each of the following statements carefully and choose the answer that best reflects the way your spouse's illness (crises, as well as daily challenges and limitations) makes you feel

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always		
Do you feel...?		
1.	That because of the time you spend with your spouse that you don't have enough time for yourself?	
2.	Stressed between caring for your spouse and trying to meet other responsibilities (work/family?)	
3.	Angry when you are around your spouse?	
4.	That your spouse currently affects your relationship with family members or friends in a negative way?	
5.	Strained when you are around your spouse?	
6.	That your health has suffered because of your involvement with your spouse?	
7.	That you don't have as much privacy as you would like because of your spouse?	
8.	That your social life has suffered because you are caring for your spouse?	
9.	That you have lost control of your life due to your spouse's SCD status?	
10.	Uncertain about what to do about your spouse?	
11.	You should be doing more for your spouse?	
12.	You could do a better job in caring for your spouse?	

C. Index of Marital Satisfaction

This questionnaire is designed to measure the degree of satisfaction you have with your marriage. There are no right or wrong answers. Answer each item as carefully and as accurately as you can by placing a number beside each statement as follows.

1. Never
2. Rarely
3. Sometimes
4. Quite Frequently
5. Nearly Always

ITEM	ANSWER
1. I feel my partner is affectionate enough	
2. I feel that my partner treats me badly	
3. I feel that my partner really cares for me	
4. I feel that I would not choose the same partner if I had to do it over again	
5. I feel that I can trust my partner	
6. I feel that our relationship is breaking up	
7. I feel that my partner does not understand me	
8. I feel that our relationship is a good one	
9. I feel that ours is a very happy relationship	
10. I feel that our life together is dull	
11. I feel that we have a lot of fun together	
12. I feel that my partner does not confide in me	
13. I feel that ours is a very close relationship	
14. I feel that I cannot rely on my partner	
15. I feel that we do not have enough interest in common	
16. I feel that we manage arguments and disagreements very well	
17. I feel that we do a good job of managing our finances	
18. I feel that I should never have married my partner	
19. I feel that my partner and I get along very well together	
20. I feel that our relationship is stable	
21. My partner is a real comfort to me	
22. I feel that I no longer care for my partner	
23. I feel that the future looks bright for our relationship	
24. I feel that our relationship is empty	
25. I feel there is no excitement in our relationship	

D. Brief COPE Inventory

This questionnaire asks how you have been coping with the stressful experiences associated with your marriage to a person with SCD. To what extent do you rely on the items below to help you cope? Try to rate each of the items separately in your mind from the others. Make your answers as true for you as you can. Use the following choices:

1. Not at all
 2. Rarely
 3. Quite Frequently
 4. Nearly Always
-
1. I've been turning to work or other activities to take my mind off things.
 2. I've been concentrating my efforts on doing something about the situation I'm in.
 3. I've been saying to myself, "this isn't real."
 4. I've been using alcohol or other drugs to make myself feel better.
 5. I've been getting emotional support from others.
 6. I've been giving up trying to deal with it.
 7. I've been taking action to try to make the situation better.
 8. I've been refusing to believe that it has happened.
 9. I've been saying things to let my unpleasant feelings escape.
 10. I've been getting help and advice from other people.
 11. I've been using alcohol or other drugs to help me get through it.
 12. I've been trying to see it in a different light, to make it seem more positive.
 13. I've been criticizing myself.
 14. I've been trying to come up with a strategy about what to do.
 15. I've been getting comfort and understanding from someone.
 16. I've been giving up the attempt to cope.
 17. I've been looking for something good in what is happening.
 18. I've been making jokes about it.
 19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
 20. I've been accepting the reality of the fact that it has happened.
 21. I've been expressing my negative feelings.
 22. I've been trying to find comfort in my religion or spiritual beliefs.
 23. I've been trying to get advice or help from other people about what to do.
 24. I've been learning to live with it.
 25. I've been thinking hard about what steps to take.
 26. I've been blaming myself for things that happened.
 27. I've been praying or meditating.
 28. I've been making fun of the situation.

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Thank you for your support!!

Appendix D Qualitative Interview Guide

1. What has been your experience being married to a person with Sickle Cell Disease?
 - What has it been like being married to a person with Sickle Cell Disease?
2. How, in your opinion, have you been affected by your partner's Sickle Cell?
3. What do you think has been the effect of your partner's illness on your marriage?
4. What do you think has been the effect of the illness on your personal life?
 - In what specific ways are you affected by your partner's SCD?
 - In what specific ways has your marriage suffered due to your partner's SCD?
 - Have your finances suffered? How?
 - Has your sex life been affected? How?
5. Which aspects of your partner's illness have particularly affected you? E.g. frequent pain crises, daily limitations, etc.?
6. Have you been bothered by a fear of losing your partner?
7. Have you been affected in any way by the Stigma attached to SCD? E.g. demeaning or derogatory remarks, people trying to prevent your marriage to a person with SCD, etc.
8. How do you cope with the difficulties arising from your partnership with a SCD person?
9. What was your initial reaction when you found out that your spouse had SCD?
10. Did you find out before you got married?

Appendix E Results of Qualitative Interviews

Table E1 shows the results of thematic analysis of the qualitative data with all respondent quotes.

Table E1

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Sample Quotes
Psychosocial Effects	Stress	3	<i>"Well, I can say it's really challenging to be with someone with this illness" R.3</i> <i>"...the experience is a stressful one despite all the good efforts." R.5</i> <i>"...it's been stressful and unpredictable..." R. 6</i>
	Emotional Effects	3	<i>"...it has affected me psychologically. I felt sad about her pain sometimes.....Again, as I said, her pain experience saddens me a lot" R.2</i> <i>"...sometimes I feel bad about how he feels weak sometimes." R.4</i> <i>"...Mostly at night she feels a lot of pains at her joints which sometimes affect my sleep.....her pains sometimes affect me emotionally" R.7</i>
	Fear of losing the patient	2	<i>Interviewer: "Have you ever been bothered by a fear of losing your partner?"</i> <i>Respondents: "Well, sometimes." R.3</i> <i>"Oh yeah. Virtually every day..." R.5</i>
	Anxiety	1	<i>"Personally, it has...made me worry more about the future.... worry about what support I can get should I become fully or partially incapacitated in any form." R.6</i>

Table E1 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Quotes
Psychosocial Effects (continued)	Disruptions in Social relations	2	<i>"...my friends don't normally visit me during the time the sickness gets severe." R.1</i> <i>"...and moreover, family members not visiting me as well." R. 3</i>
	Limitations on Social life	4	<i>"...the kind of social life we used to have, like outings, etc, in the past has come to a certain limitation because of her illness." R.2</i> <i>"...The kind of social life I used to have before marriage is not the same as now..." R.5</i> <i>"...it has left us little to no room for a social life..." R.6</i> <i>"Sometimes my social life...I spend more times just with my wife to support [her]..." R10</i>
	Financial Strain	5	<i>"...it's a little stressful for me because most of the moneys have been spent on medicines and other hospital bills." R.1</i> <i>"...I can say financially it has affected me a lot..." R.3</i> <i>"...the bills too are another challenge. I have to spend more on my wife..." R.5</i> <i>"Because of her illness, some of her relatives come and stay.... I spend on them also which makes the situation a bit difficult for me." R8</i> <i>"I spend more time and money on her treatment so sure, financially it has affected me." R10</i>

Table E1 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Quotes
Psychosocial Effects (continued)	Restraints on Personal Activities	5	<i>“...for instance, if he didn’t go to work, that means that I have to close early from market which also affects my income....” R.1</i> <i>“....and also not having enough time to attend to other activities” R.3</i> <i>“.....the limitations [on] time to do other works. Sometimes I used to receive calls to come to the hospital when it gets worse.” R.5</i> <i>“...sometimes you don’t get the full time for yourself.” R.7</i> <i>“...I think I spend a lot of time on her instead of attending to something else.” R8</i>

Table E1 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Quotes
Effects on the marital relationship	Deterioration in Sex life	7	<i>“and moreover, the attention that I need...it has affected my sex life and affection” R.1</i> <i>“Of course, my sex life is affected due to how severe the disease is” R.2</i> <i>“...Of course, my sex life was affected due to how severe the illness is.” R.3</i> <i>“My sex life has been affected also because we don’t normally have enough time with each other...R.5</i> <i>“...a generally poor sex life as a result of the limitations brought by my partner’s physical pain and general weakness” R.6</i> <i>“...Well for my sex life I can say I was affected too.” R.8</i> <i>“my sex life has been affected because my wife hasn’t been virtually feeling well as always” R.10</i>
	Lack of Emotional Fulfilment	2	<i>“...moreover, the attention that I need...” R.1</i> <i>“Personally, it has left me feeling not as emotionally fulfilled as I would want.” R6</i>
	Marital Discord	1	<i>“...frequent misunderstandings and an inability to fully understand and appreciate each other’s requirements...”R.6</i>

Table E1 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Quotes
Experience of SCD-related Stigma	Derogatory comments and attitudes	3	<i>“sometimes my friends say I should forget about him” R.1</i> <i>“sometimes my very close friends mock me...”R.2</i> <i>“some of my friends and relatives tried to advise me not to marry him.....some of my friends look down upon me...”R4</i>
	Negative Perceptions of the society	4	<i>“...the main thing people used to say is that this illness can easily lead to death...This normally affects me as to whether to continue the relationship or not...” R.3</i> <i>“the stigma that SCD patient’s don’t live long really affects me...”R.4</i> <i>“She is a little disabled, and this made some of my relatives to prevent me from marrying her because they thought my children will be affected.” R8</i> <i>“Yeah, I have been affected by this stigma like losing my wife and that she may not live long, and some of the bad remarks made from people and even my colleagues.” R10</i>
Coping Mechanisms	Religious Coping	6	<i>“moreover, I make sure I pray as well” R.2“</i> <i>“...my pastor has been supporting me with prayers” R.4</i> <i>“But with prayers I have more hope that the situation will get better” R.5</i> <i>“.... I have been praying too...” R.8</i> <i>“...But I also pray to God to help solve the problem... R.1</i> <i>“ also having hope that God will help us” R.3</i>

Table E1 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Themes	Subthemes	Frequency	Quotes
Coping Mechanisms (continued)	Social Support	6	<i>"I do have some little support from friends with money..." R.3</i> <i>"For me, my mum has been advising me to stay strong and forget about the worries. Also, my pastor has been supporting me with prayers." R4</i> <i>"... sometimes I used to get support from some of my relatives...." R.5</i> <i>"I have a lot of hope from my pastor and other good friends to cope with the situation." R8</i> <i>"...taking hope from my mum as always." R9</i> <i>"I do go out to friends and sometimes the counsellors to advise me." R.10</i>
	Self-distraction	2	<i>".... But sometimes I tried to engage in certain activities to forget about some of the pains..." R.2</i> <i>"...going out with friends if possible and other activities that may temporarily distract me..." R.6</i>
	Substance use	2	<i>"...Sometime I tried to forget about it by drinking etc." R.5</i> <i>"Coping mechanism include smoking..." R.6</i>
	Positive Refraining	3	<i>"Well I was able to manage the situation" R.1</i> <i>"Also see to it to make the best out of the situation...." R.3</i> <i>"...I have been making the situation looks better than before." R.7</i>

Table E1 (continued)

Thematic Framework for the Psychosocial Impact of SCD on Partners of SCD Patients

Theme	Subtheme	Frequency	Examples of Quotes
Factors that affect the psychosocial experience of the partner	Awareness of patient's SCD before Marriage	5	".... For me since I am aware of the status as a 'carrier', it wasn't much stressful for me." R2 "Yes, my husband told me.... I haven't been affected much by his illness." R4 "Yes I was aware....I think the experience is normal" R7 "Yes [aware]...you can still manage the situation if you really understand some of the difficulties about SCD." R8 "I think on our marriage, it's not much an effect..." R10
	Duration of Marriage	2	"...But I think for a very long time with her it's OK...." R.3 "I have lived long with him so am used to it..." R.1 "First I was bothered but now...the situation is getting better." R8
Inadequate Awareness of SCD among spouses of SCD patients		4	"I never had much knowledge about SCD so I don't really know the main consequences associated with it. But some of my relatives told me it's a serious illness, but my husband told me he is just a carrier, i.e., SC." R1 "...I know she's just a carrier..." R.2 "....I learnt he is just a carrier...." R4 "Not many of my relatives know he is an SCD patient, and even, he is just a carrier..." R 9

Appendix F Results of Insignificant Hypothesis Tests

A One-way ANOVA was conducted to test the third hypothesis, which stated that, ‘*the spouse’s level of education will have a significant effect on the psychosocial effects experienced*’. No significant results were found at the 0.05 level of significance. Hypothesis 3 was, therefore, not supported by the study data. Results of the test are presented in Table F1.

Table F 1

Summary of a One-way ANOVA on the effects of Level of Education on Psychosocial Impact

Psychosocial Domain	Sum of Squares	df	Mean Square	F	p
Index of Marital Satisfaction					
Between Groups	741.67	4	185.42	0.60	0.66
Within Groups	21580.33	70	308.29		
Total	22322.00	74			
Caregiver Burden					
Between Groups	396.20	4	99.05	1.49	0.22
Within Groups	4663.03	70	66.62		
Total	5059.23	74			
Physical Health					
Between Groups	357.52	4	89.38	0.67	0.62
Within Groups	9347.33	70	133.53		
Total	9704.84	74			

Table F1 (continued)

Summary of a One-way ANOVA on the effects of Level of Education on Psychosocial Impact

Psychosocial Domain	Sum of Squares	df	Mean Square	F	p
Psychological Wellbeing					
Between Groups	1605.59	4	401.31	1.48	0.22
Within Groups	18969.86	70	270.91		
Total	20575.44	74			
Social Wellbeing					
Between Groups	2440.92	4	610.23	2.13	0.09
Within Groups	20049.79	70	286.43		
Total	22490.71	74			
Environment					
Between Groups	276.69	4	69.17	0.36	0.84
Within Groups	13469.14	70	192.42		
Total	13745.83	74			
Quality of life					
Between Groups	7.99	4	1.99	0.85	0.50
Within Groups	163.80	70	2.34		
Total	171.79	74			