UNIVERSITY OF GHANA

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THE ROLE OF SELF-COMPASSION ON PAIN, STIGMA AND PSYCHOLOGICAL WELL-BEING AMONG SICKLE CELL PATIENTS IN ACCRA

BY

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DECLARATION

I hereby state this is the result of my independent research and a true reflection of the result, and that no portion of it has been submitted for the award of any other degree by any other person or myself in this institution or any other institution.

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DEDICATION

This work is dedicated to the sickle cell community and advocacy groups in Ghana.

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ABSTRACT

Sickle cell disease is a blood disorder caused by a genetic mutation. It is a major public health concern in Africa with over 200,000 newborns each year. It has been shown to affect about 80% of people in Sub-Saharan Africa and affects 15,000 newborn babies. This study explored the role of self-compassion on pain, stigma and psychological well-being among people living with sickle cell disease. One hundred and thirty-eight (46 males, 92 females; *M* = 30.99) people living with sickle cell disease were sampled from two advocacy non-governmental organizations in Accra, to determine the relationship between self-compassion, psychological well-being, pain and stigma and the moderating role of self-compassion on the relationship between pain, stigma and psychological well-being and lastly the predictive factor of some demographics on pain. A multiple regression analysis revealed a significant positive relationship between self-compassion and psychological well-being. Self-compassion had a significantly negative relationship with stigma and pain. Furthermore, a multiple regression analysis showed that age, educational level and gender did not uniquely predict pain in sickle cell disease. A moderation analysis revealed that self-compassion did not moderate the relationship between pain and psychological well-being, as well as stigma and psychological well-being. This suggests that self-compassion may not buffer the pains and stigma in sickle cell disease but may help with the negative implications or stressors associated with the pains and stigma associated with the disease. These findings have important implications for clinicians and the management of sickle cell disease.

CHAPTER ONE

INTRODUCTION

Background of the Study

Genetic illnesses are extremely common, with an estimated 7 million or more babies born with a congenital genetic defect each year (Modell & Darlison, 2008). Sickle cell disease is a blood disorder caused by a genetic mutation. “Sickle cell disease (SCD) is a non-communicable condition which affects hemoglobin”; an iron-rich “protein in red blood cells that transport oxygen to the cells throughout the body” (Beard, 2001, p. 570). It is a set of blood related disorders that has effect on the lives and well-being of many persons worldwide (Ola et al., 2016; Piel et al., 2013; Yusuf et al., 2011). It has been identified as the most common life-threatening genetic illness among persons of African ancestry, as well as those from the Middle East, Mediterranean basin and the Indian subcontinent (Piel et al., 2013). Sickle-cell disease is an umbrella term for the many different genotypes that lead to certain symptoms, with Sickle-Cell Anemia (SCA) being the most common form. Those who are homozygous for the βS gene will suffer from chronic anemia, frequent pain episodes, and organ damage, while those who are heterozygous for the βS gene will merely have the trait but not the disease. The most common forms of SCD are HbSC (sickle cell hemoglobin C disease), HbSB (sickle cell hemoglobin B disease) thalassemia, HbSS (sickle cell hemoglobin S disease), and HbSE (sickle cell hemoglobin E disease). It is a huge public health concern in Africa, with over 200,000 newborns each year (Asare et al., 2018). Some studies have shown that, around 80% of people with sickle cell disease are born in Sub-Saharan Africa (Diallo, 2002; Grosse et al., 2011).

In Ghana, sickle cell disease affects roughly 15, 000 newborn babies (Asare et al., 2018). Sickle cell disease can have many negative effects on the body, such as extreme pain, a lack of healthy red blood cells, frequent infections, and damage to the organs. It is a profoundly serious condition that causes a lot of suffering and even death (Ababio et al., 2016). Sickling crisis is characterized by episodes of red blood cells forming into a sickle shape, which blocks off capillaries and prevents organs from receiving enough blood, causing intense pain. Factors such as dehydration, infection, fever, cold temperatures, and inadequate oxygen levels can initiate a crisis. The expenses associated with regular crises, medical bills, financial strain, and premature death can damage relationships within a family and make it difficult for them to find adequate social support to help manage the psychological weight of sickle cell disease (Edwin et al., 2011; Tusuubira et al., 2018). The repeated crises often result in children missing school and adults missing work, which can lead to students dropping out of school and adults losing their jobs (Edwin et al., 2011). This is combined with the regular stigmatization and prejudice people with SCD experience in Ghana, creating feelings of being disconnected from both families and communities.

Chronic pain in sickle cell disease refers to discomfort that occurs most days of the year and can last for more than six months. These pains usually begin in childhood and become more common as you get older (Osunkwo et al., 2020). A majority of people with sickle cell disease (95%) experience pain on the majority of their days, with almost a third feeling discomfort on almost all of them by the time they reach adulthood (Smith et al., 2008). Pain is one of the most commonly reported at emergency departments and the most complicated symptoms that leads to hospitalization in sickle cell patients (Ababio et al., 2016; Sims et al., 2021; Tsao et al., 2014). The pain they suffer has far-reaching effects for the patient; it is often accompanied by psychological illnesses such as depression and anxiety, stigmatization and worry (Dampier et al., 2017). Sleep hygiene, numerous somatic symptoms, and chronic exhaustion are all problems that patients with SCD face, all of which lower their quality of life (Dampier et al., 2017).

Aside the pain, stigma has been identified as a major health issue among sickle cell patients (Bulgin et al., 2018). People's physical functionality, everyday roles, general health perception, and social function have all been impacted by stigma (Adeyemo et al., 2015). People with sickle cell disease have been found to experience increased stress when faced with stigmatization. This has resulted in them being labelled as drug seekers, leading to delayed medical care in healthcare providers and emergency departments not believing their complaints about pain (Cole, 2007). When it comes to reporting their disease and health status, people with sickle cell disease experience some worry. As a result, people with sickle cell disease tend to be selective in their disclosures, which can be detrimental in some cases (Bulgin et al., 2018).

Stigma is a type of labeling that has negative implications for the stigmatized person. Health-related stigma occurs when an individual is subjected to some sort of discrimination or profound devaluation because of their health status. Because of a health condition, the individual is devalued, judged, or socially disqualified (Weiss et al., 2006). People in the family, the general public, and medical professionals have all been observed to display a negative attitude towards those who suffer from Sickle cell disease (Scambler, 2009). The negative or discriminating views that an individual enduring certain circumstances encounters lead to public stigma. Public stigma affects the majority of sickle cell patients, leading to self-stigma, which has been found to be particularly detrimental to the well-being of these patients (Corrigan & Rao, 2013). People who are stigmatized are less likely to seek help, especially in times of hardship, and are more likely to engage in unhealthy behaviors (Centers for Disease Control and Prevention, 2019). Stigma restricts people, especially those from marginalized groups, and is a major source of stress for these people, such as those with SCD (Buser et al., 2021; Major et al., 2018). Research by Buser et al. (2021) indicated that individuals are disinclined to form ties with those who have sickle cell disease. People have the perception that these people are going to die early and not live for long therefore, there is no need to befriend or be in any meaningful relationship with them. Due to the stigma associated with the disease, it was shown that some of them struggle to find a partner to settle with, they find it difficult to disclose their status to people and find it difficult to disclose to their employers as well (Buser et al., 2021).

Bio-medics have made significant contributions to alleviating aches associated with SCD by developing medications to reduce or relieve the pain. Although these medications help patients, they are linked to several negative side effects and addictions. To reduce the side effects associated with pain medication and prevent patient’s dependence on them, some researchers have recommended psychological therapies. Psychological interventions have also been shown to be useful in helping persons with SCD manage their suffering (Asnani et al., 2019; Oliveira et al., 2017). Psychological interventions can add up to bio-medical treatments to make treatments more comprehensive and this can help lead to the well-being of these individuals.

Among the several types of coping mechanism, self-compassion has been identified as an effective means of dealing with stressful life events (Allen & Leary, 2010; Chan et al., 2020; Hilbert et al., 2015; Neff & Germer, 2017). Self-compassion is a coping technique in which a person is kind and gentle to himself or herself. During tough times, it is important to be gentle and forgiving of oneself instead of being overly critical. Remembering that everyone makes mistakes is part of the human experience, not just something that happens to you. Allow yourself to feel your feelings without trying to push them away or become overwhelmed by them (Neff, 2011). People who practice self-compassion have been found to experience more joy, contentment, and drive, in addition to having healthier relationships and physical health, while also dealing with fewer feelings of anxiety and depression (Neff, 2011). Self-compassion involves treating yourself with the same level of understanding and support that you would give to a friend who is going through a challenging time. Self-compassion has three components and they are; self-kindness vs. self-judgment, common humanity vs. isolation, and mindfulness vs. over-identification (Neff, 2011). People should be taught to show themselves kindness, support and empathy when they are in difficulties, make mistakes or feel as though they are not good enough, rather than being hard on themselves. Greater emotional equanimity is obtained when reality is accepted with sympathy and kindness. People are taught that struggle and obstacles are part of the human experience, and that we all face challenges at some point in our lives, not just those who are experiencing them. Self-compassion requires teaching others to see that everyone is dealing with their own set of problems. Self-compassion necessitates a balanced attitude to our negative emotions, one that does not repress or exaggerate them. Non-judgmental behavior is instilled in people.

Self-compassion can be a trait or a state. Trait self-compassion is defined as an individual having or displaying attributes or aspects of self-compassion, such as patterns or features of kindness to oneself and not being critical of oneself that can generalize across circumstances and remain steady over time or in debilitating situations (Neff, 2011; Rashid et al.,2021). The traits might be inherited through a parent or family member, or they can be learned from the society in which the individual grew up.

Self-compassion becomes a state when individuals begin to display the attributes outwardly; state self-compassion is when an individual begins to respond and act in stressful situations (Breines & Chen, 2013; Neff, 2022). The individual begins to externalize his or her self-compassion features, making it visible for others to observe and know that the individual is self-compassionate. When they are in stressful situations, they take proactive actions by demonstrating self-compassion (Neff, 2003). They are the qualities, habits, or features of a person in a certain scenario at a specific point in their life or in a disagreeable mood. To be able to demonstrate state self-compassion, a person must already possess the traits, features, or attributes that a self-compassionate person must possess, resulting in the person expressing or implementing such elements as part of their existence. These individuals exhibit or tend to be compassionate to themselves in their everyday struggles when confronted with difficult events. It is possible that an individual with the trait of self-compassion has all these characteristics but cannot show them in debilitating situations. However, self-compassion must be a personality attribute before it can be expressed in a debilitating situation, which will then become a state when manifested.

It has been proven that self-compassionate people are happier, and that self-compassion fosters positive emotions, particularly soothing, warm, and safe feelings (Neff, 2003). Self-compassion is useful not only in stressful situations but also in everyday life. When people with sickle cell disease in pains are self-compassionate, they can help themselves manage their pains. When they are in those debilitating moments, they can become kind and gentle to themselves. Having the quality of self-compassion in them might act as a buffer for them in those situations, allowing them to become more independent and less reliant on others and, in some cases, drugs, which can lead to addiction (Misurya et al., 2020). Individuals stigmatized by the conditions or pains they face as sickle cell disease patients are more likely to be affected and blame themselves. These feelings of exhaustion and pain can lower one's quality of life, cause self-doubt, lower one's self-esteem, and prevent them from finishing personal tasks due to fear of being judged by others, emphasized the importance of using self-compassion as a tool to combat and manage psychological issues in individuals (Hamilton et al., 2004).

Problem Statement

Sickle cell disease is a major health concern and comes with its unique challenges and burdens that individuals living with such condition needs to adjust to (Achieng et al., 2018). It has been found that pains and stigma experienced by individuals with SCD greatly affects their psychological well-being (Bulgin & Jenerette, 2018; Buser et al., 2021; Collier, 2018; Poku et al., 2020; Topcu, 2018). To help the individual cope and manage the pains and stigma associated with the disease, bio medics have made great contributions and brought about some treatment's options (Makani et al., 2017; Mulunda-a-Mulunda & Ingwen, 2020). Although such treatments are good, they come with its side effects and they do not make treatments comprehensive. To make treatments more comprehensive, it is important to employ some psychological interventions (Ball & Balogh, 2016; Balogh et al., 2015; Pinnock et al., 2021).

Aside from the traditional psychological intervention that are mostly used by therapists like the cognitive behavioral therapy (CBT), there are also other interventions, such as self-compassion, which have been shown in managing the impact of stressors on psychological well-being, pain and stigma. Self-compassion is one of such interventions that can be employed to help individuals cope with stress associated with the condition. Self-compassion can be seen as a type of emotion regulation which operates on an unconscious level, making a person more accepting and more tolerant of internal and external stressors (Svendsen et al., 2016). Trait self-compassion can help enhance the psychological well-being of SCD patients if they are investigated, applied, or developed. Some research has demonstrated that having a compassionate attitude towards oneself can enhance one's mental health (Khorami et al., 2016; Neff & Germer, 2017). Obese people, those with chronic pain, athletes, and others have all been proven to benefit from self-compassion (Hilbert et al., 2015; Ingstrup et al., 2017; Skinta et al., 2019). Self-compassion has been established to be an active coping mechanism which has been shown to help persons in coping or recovering quickly because the individual is involved in the treatment process; they are actively participating in their recovery(Allen & Leary, 2010; Gil et al., 1991).Research conducted in different populations, such as Macbeth and Gumley (2012), who found that self-compassion leads to improved psychological well-being, and Torrijos-Zarcero et al. (2021), who demonstrated that mindful self-compassion effectively managed chronic pain and reduced psychological disorders like depression symptoms, has provided evidence of the link between self-compassion and these variables. However, these studies were not conducted within the context of sickle cell disease.

People with SCD have recently received a lot of research attention in Ghana (Asare et al., 2018; Oluwole et al., 2020; Oppong et al., 2020; Sims et al., 2021). Among others, sickle cell research has included topics such as the burden of SCD on patients, SCD diagnostic patterns, cognitive functioning, and SCD prevalence (Asare et al., 2018; Oppong et al., 2020; Sims et al., 2021). However, truly little is understood about the connections between pain, stigma, mental health and self-compassion.

This necessitates research into the self-compassion variable in Ghana, which will provide insight into further research into the variable in the future. Once the variable has been proven to be useful in the real world, practitioners can use such techniques to assist people with sickle cell disease in managing their pains and the stigma that comes with the disease. Also, to effectively address the issue of stigma, pains and enhance their psychological well-being of patients with SCD in Ghana, psychosocial factors that affects their psychological well-being must be explored and investigated. This will serve as a road map to developing interventions using self-compassion to help people living with SCD. In Ghana, there is a paucity of research on self-compassion, particularly among people with sickle cell disease. Thus, this study seeks to explore the role of self-compassion among people with sickle cell disease.

Aims and Objectives

This research will investigate how self-compassion affects the experience of pain, stigma and psychological well-being in individuals with sickle cell disease living in Accra. The objectives are to;

- Assess the relationship between psychological well-being, pain and stigma.
- Examine the relationship between self-compassion, pain and stigma
- Test the moderating effect of self-compassion on pain, stigma and psychological well-being

Relevance of study

Theoretically, looking into the role of self-compassion on stigma, pain, and psychological well-being in people with sickle cell disease can provide useful information and help to direct future research in the subject.

In practice, the study will assist practitioners in the field in adapting another type of intervention and program to address the needs of people living with sickle cell disease in times of distress, as well as all stakeholders and policymakers in supporting these people emotionally, socially, and physically to help improve their well-being and increase their chances of survival. This will also help therapists provide appropriate services to enable persons with sickle cell disease to cope with the suffering they experience.

In summary, the study aims to de-emphasize the traditional biomedical-centered strategy and underline the importance of using a multidisciplinary biopsychosocial approach towards understanding sickle cell disease.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter includes an overview of the pertinent literature and theoretical underpinnings of the study. There is discussion of three key theories for this investigation. The review of relevant studies took a critical look at earlier studies on the factors related to sickle cell disease.

Theoretical Framework

The Psychological well-being theory, Seligman's wellbeing theory and Cognitive Appraisal theory were used to explain psychological wellbeing, self-compassion, stigma and pain.

1. Psychological Well-being Theory (PWBT; 1989, 2018)

The PWBT is rooted in social psychology, which draws on various psychological theories such as lifespan development, clinical approaches to personal growth, and mental health principles. These theories provide a broad outline of positive psychological functioning (Van Dierondonck et al., 2008). A significant resemblance is that the conditions are all expressed based on well-being as an alternative of ailment. Ryff (1989) described psychological well-being as the absence of distress and other psychological issues, having a positive perspective on oneself, mastery over one's own life, healthy connections with others, independence, feelings of growth and development, and a drive to make life meaningful. The Psychological Well-Being Theory (PWBT) moves away from the subjective view of psychological theory and adopts a more objective approach. It suggests that individuals form their opinions of life based on comparing themselves to others (social comparison processes), how they interpret feedback from important people in their lives (reflected appraisals), why certain events happened (attributional process), and how much importance they give to those occurrences (psychological centrality).

People with sickle cell disease often experience pain, stigma, and poor mental health (Ke et al., 2015; World Health Programme, 2016). As a result of this, they may compare their life experiences to others, pay attention to what others say about them, and attempt to discover the causes of their suffering. If they have a negative view of their situation, it can lead to a decrease in hope, depression, anxiety, and difficulty forming relationships. On the other hand, if they can maintain a positive outlook, it can help them achieve better psychological well-being and improved mental health. By applying the PWBT, this study sought to assess whether self-compassion could enhance the psychological well-being of individuals living with sickle cell disease.

2. Seligman's theory of well-being (Seligman, 2011)

Seligman's theory of well-being is based on the idea that for a person to have lasting happiness and well-being, there are five major components that need to be present. These five components are "positive emotions (P), Engagement (E), Positive Relationships (R), Meaning (M), Accomplishment/Achievement (A)" (PERMA model) (Seligman, 2011, p.12). Seligman (2011) indicated that each element of the PERMA plays an essential role to the attainment of individuals need and well-being not to follow these elements to an end but as an end.

Additionally, each aspect of the PERMA model had to be able to stand on its own and still link together with the other components. Seligman (2011) states that focusing on the five basic components of the PERMA model can lead to greater happiness and improved life circumstances. This suggests that individuals can achieve higher levels of satisfaction by maximizing positive emotions, increasing engagement in activities, building positive relationships with other people, having a sense of meaning and purpose, and striving for achievement. However, sickle cell patients who are in pain and experience stigma may not be able to focus enough on things that make them happy or devote time to forming relationships, as well as dealing with the feeling of not being viewed in the same way as healthy people. To improve their psychological wellbeing, it is important for these individuals to be kind to themselves and not be too critical of themselves during challenging times, such as when they are in pain or experiencing negative factors in society. This study aligns with this theory by investigating whether self-compassion can foster positive emotions, engagement in life despite the challenges posed by SCD, the strengthening of positive relationships, the search for meaning in their experiences, and the pursuit of accomplishment despite adversity. Through the lens of PERMA model, the study aims to elucidate whether self-compassion may enhance psychological well-being and overall quality of life for individuals with SCD, supporting the second the objective this research.

3. Cognitive Appraisal Theory (Fournier, 2018; Lazarus, 1982)

Cognitive appraisal theory proposes that people's personal interpretations of a situation will determine how they emotionally react to it. It works on how one interprets an event as positive or negative and what caused the situation (Fournier, 2018; Lazarus, 1982). All humans are not the same: we all have our personality; some can deal or cope with pressure situations and some cannot cope with them. Sickle cell is a genetic disease that affects a person's well-being, because these patients are stigmatized due to the public's perception against them and experience pains. Due to the stereotypical mindset about these people and the pain they go through, they are discriminated against and denied access to certain things like; job employment by some companies and certain activities for the fear that they may not be able to do and might fall sick in the cause of the event. Some of the patients may be able to cope in times of these and some may not be able to cope in these times which may affect their well-being. Stigma and pain can be major stressors; some peoplewho have been judged negatively by society feel the effects of this judgment to be very damaging,while others believe they can handle any potential damage caused by the public's negative opinion(Rüsch et al., 2009). These may have an impact on their well-being and self-esteem as individuals,as some may believe they are unimportant in society, while others may cope better since the understand how humans behave, understand the source of their pains and that, all humans are subjected to stressors in life.

This theory was applied to examine how self-compassion influences cognitive appraisals of pain and stigma, affecting emotional reactions and coping mechanisms. By doing so, we aim to test the moderating effect of self-compassion on the relationships between pain, stigma, and psychological well-being, as outlined in the third objective of this research.

Review of Related Studies

Stigma, Pain and Psychological Well-being

Martin et al. (2018) investigated the effects of health-related stigma on pain interference, social support, quality of life and hospital outcomes in sickle cell patients between the ages of 12 and 18. Through administering measures of stigma, pain interference, social support, quality of life and loneliness, the researchers found that elevated stigma was associated with higher pain interference, lower quality of life, higher loneliness and a heightened level of pain intensity during hospitalization. In this study, the researchers used an in-patient sample in completing the study. The in-patient sample may have been a more ill group, limiting the findings to other groups with SCD. Participants also completed measures during acute painful events, which could have influenced their pain perception. Lastly, the researchers used stigma measure developed for epileptic patients, this may not accurately reflect SCD experience of stigma.

In a similar study, Buser et al. (2021) explored the perception of stigmatization for adults with SCD in Kumasi, Ghana. In this qualitative study, 12 participants who were mostly females were assessed. Participants reported that, because of stigma, they were afraid and unwilling to disclose their status to people and they revealed feelings of isolated and receiving heavy criticisms and negative comments about their unhealthy body stature which leads to increase both physiological and emotional pains and in tend affect their well-being. This study did not focus on looking at any coping strategy for individuals living with sickle cell disease.

In Turkey, a survey was conducted of individuals with chronic joint pain to examine the relationship between pain, attitudes toward pain, and mental health. Results from this research, which looked at the connections between these factors, indicated that feelings about pain and the intensity of pain affect the psychological condition of people with long-term pain (Topcu, 2018). While this study provides insight into pain-related factors, it’s essential to consider the specificity of chronic joint pain and whether the findings can be directly applied to individuals with SCD who experience a different type of pain.

In a systematic review by Bulgin et al. (2018) to synthesize literature regarding health-related stigma in adolescents and adults living with sickle cell disease, twenty-seven articles from 2004-2017 were reviewed. It was shown that stigma hinders physiological and psychological well-being. Stigma impairs healthcare interaction and has a harmful social consequence. In a recent systematic review and meta-analysis by Rzeszutek et al. (2021), studies published within the five years period (2016-2020) were analyzed from databases such as Google Scholar, Scopus, Medline, and others to assess the relationship between HIV/AIDS stigma and psychological wellbeing of individuals living with HIV. After examining multiple articles, 64 were chosen for data review. The sample included 25,294 HIV-positive people, 10,682 females, 14,590 males and 22 of unspecified gender. The findings showed a negative and moderate link between stigma and wellbeing, which was further influenced by the ages of participants, being stronger among older adults. Variation in the association between stigma and wellbeing across studies was not explained by sociodemographic or clinical factors, publication year, or stigma measurement.

Self-compassion, Pain, Stigma and Psychological Well-Being

MacBeth and Gumley (2012) carried out a meta-analysis in which they examined 20 samples from 14 studies to evaluate the correlation between self-compassion and mental illness.

They found that having self-compassion leads to better mental health and fewer mental health issues. Gender distribution in this study was skewed with females being over 70 percent of the sample, this may limit the generalizability of the findings to the whole population.

Similarly, Zessin et al. (2015) carried out a meta-analysis, combining 79 samples with 16,416 participants. This research was focused on the correlation between self-compassion and various aspects of well-being; the findings indicated that people who practice self-compassion have higher levels of cognitive and psychological well-being. This meta-analytical study was unable to shed insight into the development of the relationship between self-compassion and well-being in the context of specific critical life events like an individual experiencing stress or any challenging life event.

In 2013, Hall and colleagues conducted a research project to analyze the correlation between self-compassion and physical and mental health. One hundred and eighty-two college students took part in the study, completing a self-compassion scale consisting of three parts. Results showed that individuals with higher levels of self-compassion reported fewer physical symptoms. Allen et al. (2012) also looked at how self-compassion impacted the connection between subjective well-being and physical health among elderly people. One hundred and thirty-two individuals aged 67 to 90 answered a survey regarding their physical health, self-compassion and subjective wellbeing. The results indicated that self-compassion is linked to better overall health.

Torrijos- Zarcero et al. (2021) conducted a randomized controlled trial to compare mindful self-compassion intervention and cognitive behavioral therapy on relevant clinical chronic pains. Participants were grouped into two being either mindful self-compassion or cognitive behavioral therapy. Both interventional meetings took place once a week for eight weeks and had no more than 20 participants in each group. The mindful self-compassion group consisted of sixty-one participants, whiles the cognitive behavioral therapy group had sixty-two members. It was established that mindfulness-based self-compassion was effective than cognitive behavioral group in managing chronic pains and was again had greater effect on depression symptoms.

Lanzaro et al. (2021) examines scientific literature from inception to April 2020 using four electronic search databases: Psych INFO, EMBASE, the Cochrane library, and Medline. Two essential questions, which together identified 16 studies, were the basis of the study. The first question focused on compassion-based psychological interventions and how they affect pain outcomes. The first question identified seven studies with a total sample of 253 participants that included adult patients with chronic pain. In the second question, nine studies with 1,430 participants in different cross-sectional studies on the relationship between self-compassion and outcomes related to pain were assessed. It was shown that compassion-related interventions are beneficial for people living with chronic pains. However, neither the efficacy of the compassion-based interventions nor the relationship between self-compassion and pain outcomes could be established.

A study was conducted on 1,158 overweight and obese Germans to investigate self-compassion as a tool to counter self-stigma (Hilbert et al., 2015). Structural equation modelling was used and adjusted for sociodemographic factors to assess self-compassion's role in physical and mental health, including BMI. Questionnaires were used to collect data. The results showed that self-compassion had the potential to buffer the harmful effects of self-stigma on wellbeing, reducing the association by one-third in terms of depression, somatic symptoms, and quality of life. However, self-compassion did not have any effect on the association between self-stigma and BMI as it was not related to BMI.

A survey of 401 individuals who identify as gay, lesbian, or bisexual from Hong Kong, China, was conducted using a questionnaire. It was designed to measure their connection to self-stigma, the process of it, anxiety, depression, loneliness, and social separation. The findings indicated that people with higher levels of self-compassion were less likely to have a positive link between stigma stress and the six psychological issues, compared to those with lower levels of self-compassion (Chan et al., 2022).

Self-compassion as a Moderator

Kyeong (2013) examined the moderating role of self-compassion in the link between academic burn-out and mental health among Cyber University students in Korea, with 350 counseling psychology students as participants. It was shown that self-compassion moderated the relationship between academic burnout and psychological well-being and between academic burnout and depression. Participants who part took the study were enrolled in counselling psychology course. These participants are more likely exposed to self-compassion as students of psychology, which may have influenced their personhood. As a result, generalizing these findings to a diverse sample may not hold.

Philips and Hine (2021) conducted a meta-analysis of 94 peer-reviewed articles to explore the association between self-compassion, physical health, and healthy behaviors. Their results suggested a causal effect of self-compassion on positive health outcomes but showed no significant impact on young people's physical health. They also found that multi-session self-compassion interventions had more substantial effects than single sessions.

Similarly, Eccles et al. (2022) studied the relations between self-compassion, stigma, and psychological distress among 130 individuals living with Parkinson's disease. The results showed that there was a connection between self-compassion, experienced and felt stigma, depression, anxiety, and stress, yet no moderation was seen in the association between experienced stigma and distress by self-compassion. To investigate the correlation between self-compassion and self-reported stress reactivity and to determine the significance of the association with several types of stress reactivity, Helminen et al. (2021) sampled 145 undergraduates in an introductory psychology course. With total stress reactivity as the dependent variable, self-compassion significantly explained the variance. As a moderator of the relationship between current and total stress reactivity, self-compassion was barely significant.

A study by Heath et al. (2018) to examine whether having compassion for oneself lessened the tendency for people to internalize the stigma associated with seeking psychological help. Three hundred and sixty-nine undergraduate students who participated in the study completed questionnaires on self-compassion, anticipated self-stigma, and perceived public stigma. They found that self-compassion provides psychological resilience, and helps protect people from the negative effects of public stigma on their self-esteem.

Age, Education, Gender, Pain and Stigma

In a research project that focused on elderly Ghanaians, it was found that women experienced more chronic back pain and arthritis/joints pain than men. Women with only primary education had a 36.2% prevalence rate of chronic back pain and 15.8% chronic arthritis/joints pain, while men in the same situation had prevalence rates of 29.0% and 9.8% respectively (Nakua et al., 2015)

Additionally, in a meta-analytic study by Lautenbacher et al. (2017), it was established that pain threshold increases with age; aging decreases pain sensitivity for lower pain intensity. This study reviewed more than 70 articles from various search bases like pub med, Google scholar and psych info. They looked at 31 studies on pain threshold and 9 studies that assessed pain tolerance threshold.

Furthermore, a study conducted by Boggero et al. (2015) revealed that pain intensity affects the relationship between age and pain interference; elderly people who experienced higher levels of pain reported less interference with their daily activities than younger individuals. The data was collected from 508 people aged 18-78 suffering from chronic orofacial pain, who had all been assessed between 2008 and 2012. This suggests that older people can manage psychological well-being despite pain and continue to carry out daily tasks.

In a Pakistani study, 38 patients with major depressive disorder were selected for the study from various government sector hospitals using a questionnaire to measure discrimination and stigma. The study examined the gender differences when it comes to the level of discrimination and stigma experienced by people with major depressive disorder. It was established that both men and women endure a remarkably high amount of associated stigma and discrimination. However, women when compared to men face a higher level of internalized stigma, this can be attributed to the patriarchy society in Pakistan, which allows for greater tolerance of men's problems than women's (Khan et al., 2015).

In their systematic review and meta-analytic study on the "correlates of stigma for patients with cancer: a systematic review and meta-analysis", Huang et al. (2021) sampled 31 studies that involved a total of 7114 participants, their study search used online research-based search engines like PubMed, Web of Science et cetera to look for information on their topic that included patients living with cancer who is 18 years or above, stigma and others. Their findings showed there were higher cancer stigma scores associated with being a male.

In a secondary study, data was collected from 74,051 individuals from the 2010-2017 national health interview survey among adults aged 30-49 in the USA for 15 years. The relationship between pain and education were established. It was shown that greater levels of educational attainment are associated with less pain; adults with higher level of educations report less pain. High school dropouts have 30% higher odds of reporting pain, while college graduates have about 30% lower odds (Zajacova et al., 2020).

Singh et al. (2008) studied the influence of gender and age on the results of a knee arthroplasty. They sent a pain questionnaire to patients who had undergone either a primary or revision TKA between 1996 and 2004 via mail two and five years after the surgery. Results showed that women reported more moderate to severe pain than men, even when preoperative pain and age were considered. Specifically, more women and fewer people aged 61 to 70 reported moderates to severe pain two years after primary TKA.

Amertil et al. (2021) studied how factors like, uncertainty, self-efficacy and self-management are connected to the number of emergency hospital visits made by adult sickle cell patients in Ghana annually. A purposive and convenience sample of 85 adults from a sickle cell clinic was used. Employment, marital status, and gender affected self-management. Living situation and education impacted the level of uncertainty related to the illness. Education and living situation, however, had no influence on self-efficacy. Those with family support and employment had better self-management, while those with higher education and living with their family had decreased illness uncertainty.

Studies in Ghana

In their study to explore the diagnostic pattern of sickle cell disease in Ghana, Sims and colleagues (2021) asked parents how their children's SCD was first diagnosed. Using secondary data and a questionnaire survey of 354 parents who reported on behalf of their children. It was shown that 74% of children under the age of 18 are diagnosed by the age of four, due to majority of them experiencing pain crises. Most of them were diagnosed when they were 15 or older. During the newborn period, just 5.5% of them were diagnosed with SCD. Two-thirds were diagnosed in a hospital or emergency department setting during a pain crisis. Since most of these children did not receive early diagnoses, they might not have received all the care they needed to manage their pain sooner and might not have understood their pain crisis difficulties. It would be better to investigate the significance and function of self-compassion in how they manage their lives during the disease-related crisis. Whether this self-compassion psychological therapy, in which a person demonstrates kindness toward oneself during difficult circumstances, might support and aid those people who learn about their crises later in life as well.

At the Ghana Institute of Clinical Genetics, Asare et al. (2018) conducted research to describe the burden of sickle cell disease and identify prevalent consequences. All patient folders and records were reviewed retrospectively in two-years. There were more clinical visits in January and May to late July, according to the statistics. A majority of the 20,788 clinic visits made by SCD patients were by those with HBSS (61%), followed by HBSC. These visits were mostly for specialist care, with obstetrics, gynecology, orthopedic and ophthalmology clinics being the most popular. Avascular necrosis, retinopathy, and priapism were among the consequences identified, all of which contributed to their pain crisis. In Ghana, we primarily experience the rainy and dry seasons during the study's specified months. This could imply that the weather or climatic changes during this time affect sickle cell patients and lead to more frequent hospital visits because of their crises intensifying during this time. Self-compassion must be researched to see if it can benefit those with sickle cell disease, as it has been shown to be beneficial for people in stressful situations (Neff, 2003). If it is deemed effective, it can assist patients in managing stressful situations without always rushing to the hospital, but it can also provide them with first aid before they see doctors or other medical professionals because it has been established that some health professionals even perceive people living with drugs as drug seekers (Singh et al., 2016).

In a study by Ababio and colleagues (2016), 294 patients with sickle cell disease and 624 healthy controls were surveyed for their demographic information, pain degree, and frequency. Data was analyzed using Group Pad Prism and EPI Info software and showed that 94.4% of the sickle cell population experienced nociceptive pain and the remainder experienced neuropathic pain. This pain was associated with a fear of mobility in participants. As it has been established in this study, pain is a common problem with the general SCD population especially nociceptive pains, it is necessary to evaluate whether these population can cope better with psychological variable like the self-compassion. It would be of need to assess whether state or trait self-compassion in individuals would help or serve as a buffer when an individual is in the stressful moments of pain. Exploring self-compassion among individuals living with sickle cell disease can help future studies employ an interventional study to help these individuals cope better as psychological therapies has been known to help people cope better in debilitating moments (Anie & Green, 2005; Chen et al., 2017).

Poku, Caress and Kirk (2020) in Ghana, investigated the ways adolescents coping with SCD handled and dealt with fatigue. The research was carried out in two SCD medical centers located in the Volta area of Ghana. Twenty- four participants participated in this qualitative narrative and picture elicitation interview. It was shown that adolescents were stigmatized due to their level of fatigue and this was a major daily threat to normalcy. It was then again shown that adolescents deliberately isolated socially from people to manage information and impression about their status.

Oppong and colleagues (2020) conducted a cross-sectional survey with 938 children aged 1-12 years in the Volta region of Ghana to analyze the occurrence of sickle cell disorder and malaria. The results indicated that those who had sickle cell screening were 16.0%, with an overall prevalence of 2.0%. Also, there was a strong correlation between sickle cell disorder, sub-microscopic parasitemia infection, and anemia.

In another study done in Ghana, Oluwole et al. (2020) tested the potential for hydroxyurea to improve cognitive abilities in children with SCD over a period of one year or more. To do this, they conducted a cross-sectional survey of 58 children aged 5-13, 28 of whom were not taking hydroxyurea and 30 who were. After administering cognitive questionnaires, they found that those who had taken hydroxyurea had higher hemoglobin levels and scored significantly better on working memory tests than those who had not taken the drug.

In a different study by Emlet et al. (2015), it was found that adults aged 55 and over experienced significantly lower levels of overall and internalized HIV-related stigma than those under the age of 40.

Rationale of the Study

Although many studies have explored sickle cell disease and the stresses associated with the disease and some treatment plans in the bio medics, little have been done in the psychological aspect to look at treatment therapy that can help these individual's cope with the stresses associated with the disease and to help make treatment more comprehensive rather than depending on only the bio medics. Evidence has shown that using both psychological therapies and bio medics in helping people living with sickle cell disease would make treatment more comprehensive (Kamenov et al., 2017)

Also, most of the studies conducted in Ghana, have focused on looking at the diagnostic patterns of SCD, the burdens of sickle cell disease and variation in pain and clinical indices (Ababio et al., 2016; Asare et al., 2018; Poku et al., 2020; Sims et al., 2021). Leaving a gap of how individuals can cope with the stressors associated with sickle cell disease. This study seeks to close the research gap by finding out how self-compassion will help to reduce the stigma and pain associated with patients with SCD by high lightening the importance with patients being actively involved in their own care with appropriate intervention and practices with the stated variables. It is because of these gaps that this study seeks to study the role of self-compassion on pain, stigma and psychological wellbeing among people living with sickle cell disease. The study seeks to give credence to why it is important to look at the role of self-compassion to find out whether moderating self-compassion, a form of pain management on pain and stigma impact the patient with SCD.

Hypotheses

1. There will be significant positive relationship between self-compassion and psychological well being
2. There will be significant negative relationship between self-compassion and stigma
3. There will be a significant negative relationship between self-compassion and pain

4. There will be a significant negative relationship between pain and psychological well being
5. Self-compassion will moderate the relationship between pain and psychological well-being
6. Self-compassion will moderate the relationship between stigma and psychological well being
7. Age, educational background, and gender will predict pain

Conceptual Framework

Self-compassion is anticipated to have a significant relationship with pain, stigma, and psychological well-being. Self-compassion is expected to moderate the relationship between pain and psychological well-being and between stigma and psychological well-being. Lastly, it is expected that age, educational background or level and gender will contribute significantly to predicting pain or stigma.

The diagram in Figure 1 below provides a pictorial explanation or description of the expected outcome of the study.

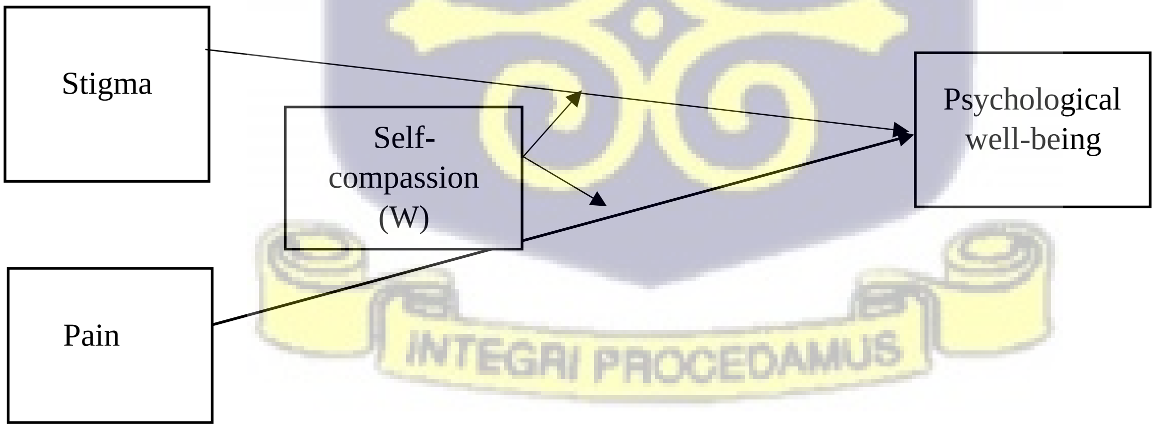

Figure 1 Conceptual model of self-compassion moderating the relationship between stigma, pain, and psychological well-being.

CHAPTER THREE

METHODOLOGY

Introduction

This chapter focuses on the plan for gathering data, such as the research setting, the sample involved, the methods used to select participants, the criteria for participation, the measures used to collect information, any ethical considerations and the steps taken to obtain the research data.

Research Design

The research was conducted using a cross-sectional quantitative design. Many variables, including age, gender, and marital status, and educational attainment, age of diagnosis, sickle cell status, and employment status were explored using the design. The design made it possible to quantify the variables in the study, understand and derive conclusions about correlations between the variables.

Research Settings

The data was collected via two non-governmental sickle cell social support advocacy groups in Ghana, specifically Accra. These two organizations promote awareness of sickle cell disease among the public, they provide education, offer support and advocacy for those living with sickle cell disease. These groups organize programs either in person or online to provide social support and other activities to support members living with the condition or the population. Also, they meet at least once a month to offer in person support or education to its members or the public. These groups have registered members who either learn more about the disease from their peers, professionals, and other specialists in the field, or provide testimonials about their problems to aid others and many other activities that would help individuals living with the disease and caregivers. Additionally, these organizations help screen those who have never had a screening for sickle cell disease. They also have genetic counselors who offer support to those who have just been diagnosed with sickle cell disease as well as any relevant additional aid to their members. They have medical laboratory scientists who helped in screening people, medical doctors, and other health professionals as part of their groups.

Sickle cell Association of Ghana (SCAG) is an umbrella body for sickle cell disease patient support groups in Ghana. The Korle-Bu Branch was contacted and used for this study. The core mission of SCAG is to make life better for individuals and families affected by SCD in Ghana. Since its inception, it has advocated for the rights of individuals living with SCD. Sickle cell association of Ghana, Korle-Bu branch has its meeting days on every last Thursday in the month to help educate its members about the disease, provide support for those in needs and have WhatsApp platform for members to share their experiences and any other things related to the disease on daily basis. SCAG have a team of health professionals including medical doctors, nurses, psychologists, laboratory scientist, social workers and other caregivers who are readily available to support any person living with sickle cell disease.

Sickle Life is a non-governmental advocacy group based in Korle-Bu, Accra-Ghana. The group has about 250 members on their support group and more followers on social media including Instagram, Facebook, and others since they provide education and support on this media as well. Their aim is to help the public make informed decisions about sickle cell disease through providing education and to ensure the wellbeing and good health for people living with sickle cell disease, their caregivers, and families. The group is prepared to offer a secure environment for people living with sickle cell disease to engage and learn about their condition with the help of trained and knowledgeable peer counselors, health professionals and others. The group embark on activities such as health screening, screening of sickle cell status, sensitization of public awareness on sickle cell disease, support for individuals living with sickle cell disease etc. The group also does screening, education, and advocacy at least once a month in a location chosen by its leadership. This is part of the group's initiative to raise awareness about sickle cell disease.

Social support has been seen to be beneficial for people living with chronic (Khatiwada et al., 2021; Yu et al., 2020) hence, selecting participants from these two groups in Greater Accra who provide social support and other services to individuals living with SCD.

Population, Sample and Sample Determination

The target population were people living with sickle cell disease and at least a member of a sickle cell social support group. The reason is that, it has been established that health staffs at the facilities stigmatize individuals living with sickle cell disease in times of their crisis as drug seeking (Bulgin et al., 2018; Jenerette et al., 2015). However, people receiving social support are more comfortable and tend to cope better in times of their crisis (Li et al., 2021; Ozbay et al., 2007). Hence, using those with a social support group or those not at the hospital but in their homes. 138 participants living with sickle cell disease were sampled for the study. The sample size was determined using a rule of the thumb suggested by Tabachnick and Fidell (2013). The rule of thumb states that the sample size (N) needed for any regression analysis should be equal to or exceed 50+8m, where 'm' equals the number of predictor variables. Based on this principle, m= 3 because there are 3 main predictors (stigma, self-compassion, and pain) in this study thus, the minimum size required would be 74. Therefore, the sample size of 138 was considered statistically adequate for this study.

Purposive, convenience and snowball sampling technique were used to select the sample from the population for the study. The participants were deliberately chosen based on their interest in and availability for the study. Due to the emphasis of gathering participants from these social support groups in Accra, the purposive sampling was adopted. Also, the convenience sampling was used to select members willing to engage in the study due to their willingness and availability. As members of these organizations had grown into friends and families, the snowballing technique was used as well. Consequently, when a person who agrees to participate in the study is done, the person helps to refer other members who are part of the social support group to us by either reaching out to them on the phone or give their contacts to us to inform them about the study. They helped us to reach out to other participants whom they know and would be interested to take part in the study since they all belong to the same social organizations and have become more or unless like a family.

Inclusion and Exclusion criteria

The study included all males and females living with sickle cell disease, who are 18 years or more and have been diagnosed of any of the three types of sickle cell disease hemoglobinopathy (e.g., Hemoglobin SS, SC, or sickle beta thalassemia plus). It excluded those experiencing severe pains and were not 18 years. People who were in excruciating pain at the time were not included in the survey because they might not have been in the proper state to respond to the questions. Again, people under the age of 18 were excluded to participate since, under law, they are considered minors (The Children's Act, 1998) and cannot offer their own consent; instead, their parents must consent on their behalf. It would have made data collection more complex and cost us some more money on airtime. We would have called two times to explain the study: first with the parents and with the child at different times. Since we collected data both online and in-person, participants under the age of 18 were not included because a parent or guardian may find it difficult or may not have brought their children to only take part in a study if their schedules may not permit and, students were in school at the time of data collection. Additionally, a guardian or adult helping a child complete an online survey may have had an influence on the child's opinions since some of them may not understand the questions (Wolthers, 2006) and would therefore, need the help of an elderly relative. Hence, only adult participants who are 18 years old were sampled.

Measures

Demographic data

Demographic questionnaire was used to collect information on respondents' age, gender, marital status, religion, educational level, employment status, sickle cell status, when diagnosed for sickle cell disease, how often pain is experienced due to sickle cell disease.

1. *Stigma (The Measure of Sickle Cell Stigma; Bediako et al., 2016).*

The Measure of Sickle Cell Stigma is an adult scale used to measure specific stigma associated with an adult living with sickle cell disease. Participants between 18 and 64 were used for the scale's development. It contains 11 items with a Cronbach alpha of .87 indicating very good internal consistency and have four subscales with Cronbach alpha for the four subscales ranged from .74 to .89 (Bediako et al., 2016); social/interpersonal rejection (3 items); internalized stigma

(3 items) items evaluate one's negative personal feelings of guilt related to having sickle cell disease; disclosure concerns (3 items) items evaluate the reluctance to disclose one's SCD status to others; and expected discrimination (2 items) evaluates the anticipated discrimination based on SCD status. Some of the items on the scale include; "As a rule, telling others I have sickle cell has been a mistake," "I feel that I'm not as good as others because I have sickle cell disease;" "I worry about being discriminated against because I have sickle cell." The response on the scale ranges from 1 (completely false) to 6 (completely true). Scoring high on the scale showed higher levels of stigma and scores were added up and averaged across all items to produce a global score. The current study recorded a Cronbach alpha for this scale to be .77.

2. *Psychological well-being (PWS; Ryff, 1995, 2014)*

The psychological well-being scale (PWS; Ryff, 1995, 2014) is a self-report instrument that consist of 18 items to measure the well-being of a person. It has six subscales and the subscales are; the environmental mastery growth subscale, the personal growth, the positive relations with others, the purpose in life and the self-acceptance. These various subscales contain three items each. Items on the scale include but not limited to; "I feel I am in charge of the situation in which I live," "I have confidence in my opinions, even if they are contrary to the general consensus," "I think it is important to have new experiences that challenge how you think about yourself and the world," etc. The response rate for the items is from strongly agree (1) to strongly disagree (7). Some of the items were reversed scored and higher score after summing the items mean higher psychological wellbeing while lower scores indicate lower psychological wellbeing. It has been reported to have a Cronbach alpha of 0.88, with subscales alphas ranging from 0.72 to 0.88 except autonomy which has Cronbach alpha of 0.57 (Lee et al., 2019) with a Cronbach alpha for current study to be .71.

3. *Pain (The short-form McGill Pain Questionnaire; Melzack, 1987)*

The short-form McGill Pain questionnaire is used to test for pain. The scale has 15 descriptors with 11of them being sensory and the remaining 4 being affective. The first 11 items address the sensory dimension of pain, or the intensity of the pain, and its last four items address the affective dimension of pain, or how the pain impacts the person. Some of the items include; "What does your pain feel like; throbbing, shooting etc." It is rated on an intensity scale of 0 to 3, severe is the highest rating, (0 showing no pain, 1 being mild and 2 being moderate). The point values for responses to the 15 questions were summed. Sub scores for the sensory and affective dimensions are added. There is a visual analogue scale for pain and a final question about pain intensity. Higher scores usually describe a worsening of the subjective perception of pain. The scale is found to have a Cronbach's alpha of .93 (Mehdizadeh et al., 2020) and the current study had a Cronbach alpha of .92.

4. *Trait Self-compassion (The self-compassion scale-short form; Raes et al., 2011)*

The self-compassion scale-short form (SCS-SF; Raes et al., 2011) is a 12-item self-report instrument that assesses a person's level of compassion towards themselves. The items were reported on a 5-point response scale from 1 (almost never) to 5 (almost always), and participants were asked to rate how frequently they act in the manners that were indicated). It has 6 subscales; self-judgment, Isolation, self-kindness, over-identification, mindfulness, self-kindness, and common humanity. The scale has an internal consistency (Cronbach's alpha ≥ 0.86). Some of the items include; "when I fail at something important to me, I become consumed by feelings of inadequacy" etc. All the items from the "self-judgment, Isolation and Overidentification" subscales were reversed coded. A total score is generated by adding each item on the scale and averaging them; higher scores indicate greater self-compassion. The Cronbach alpha for this study was .73.

Procedure for data collection

Permission was obtained from two sickle cell social support and advocacy groups in Accra, Ghana: Sickle Cell Association of Ghana and Sickle Life Association. These groups both provide social support, education and other counselling services for members living with sickle cell disease and care-givers. We submitted request letters and a copy of the study proposal to the leaders. The leaders suggested that we use shorter versions of the various scales. This is because they felt the long versions of the scales, we provided would be tiresome for their members. After permission was granted, the leaders advertised the study on their various WhatsApp platforms and announced to the members willing to take part in the survey to privately message the researcher or come for their meeting. The researcher got the contacts of all who were interested in the survey and called them.

The study was conducted in three forms. Some of the participants filled the questionnaire in person at their meeting hours or a favorable location for the participants. Others completed the questionnaire on Google forms. Lastly, some were called on the phone and the questions were read and explained to them to answer. These three approaches were adopted because some participants reported that the mainly cold and rainy weather prevented them from attending in-person meetings.

Data was collected between August 4 and October, 10, 2022, which is a rainy season. Most of them said they were cold, others reported busy and therefore, prevented them from coming to the meeting or meeting the researcher to fill the questions in person. The researcher had to resort to sending the Google link created for the survey to the participants who could use the internet, read, and write. In-person questionnaire completion was only possible for 50 of the participants during three meeting sessions by both groups. Some meeting days were cancelled by Sickle Cell Association of Ghana due to weather conditions and rains.

Prospective participants were sent frequent daily reminders and announcements on their WhatsApp pages for those who want to take part send a private message to us online or in person. The researcher and assistant attended meetings hosted by the Sickle Cell Association Ghana, during which participants filled out the questionnaires. Interested participants unable to attend meetings were asked to give a convenient day to meet the researcher to fill it. Again, we attended meetings of Sickle Life Association which is organized once in a month. Participants present and willing to take part in the study were given questionnaires to help complete it.

A link was provided to participants who completed questionnaires online. Eighty of the participants took part using the link online. At any point when filling out the questionnaire, participants had the option to leave the study without any penalty by closing the browser tab. There was no set time limit for completing the questionnaire, which participants may do anywhere convenient to them.

Some of the participants who consented to participate in the study but were unable to come because of rain, weather, and other issues were called, and they did the survey over the phone. They gave responses after the researcher read to them the questionnaires and options. This method was used mostly for people without smart phones, who had trouble using the internet, and those who could not read or understand English on their own without assistance. Five of the participants participated in the study using this method.

Ethical considerations

Ethical approval and clearance were obtained from the Ethics committee for Humanities of the University of Ghana (protocol number: ECH334/21-22). The aim of the study was explained to prospective participants and those agreed to take part in the study signed a consent form. Participants could withdraw from the study if they did not want to continue. Participants were reminded of confidentiality and anonymity; however, 4 declined to participate due to personal reasons, while others refused to show up despite having made a promise to do so. Also, three of the participants who agreed to participate in the study online by answering the questions on the Google form refuse to answer them after the link was sent to them, they also refused to reply or answer the researchers' texts or calls, so the researcher ignored and did not force them to participate in the study. Two of the respondents could not complete the questionnaires with the complain that it had too many items. The research was conducted in accordance with the standards and principles regarding the conduct of research with human participants in the APA code of conduct (2016).

CHAPTER FOUR

RESULTS

Introduction

This chapter presents the results obtained from the data analysis. The first part of this chapter focuses on the preliminary analysis, descriptive and demographic variables, the other sections present inferential statistics. Seven hypotheses were tested using regression statistics.

Preliminary Analysis

The SPSS statistical software package (v21) was used to analyze the data, and the SPSS macro process (v4.1) (Hayes, 2022) was also used to analyze the moderated hypothesis. The data distribution was checked for normality using parametric tests (Table 2**)**. Skewness cut off values were ≤ ± 1 and kurtosis cut-off values were ≤ ± 2. These are considered acceptable for the parametric analysis (Bryne, 2013; George, 2011; Hair et al., 2010). There were no scale items removed from the data analysis because all items were normally distributed. The participants' demographic characteristics were described using descriptive analysis (Table 1).

Table 3 summarizes the intercorrelation among the main study variables. To test the hypothesized associations among the variables. The moderator was entered into the W moderator space for further analysis after the DV was first entered into the Y category, the IV into the X category, and the hypothesis into the PROCESS macro in SPSS. Using p <.05 or better, the statistical significance of the model was tested. The sample characteristics of all study participants are presented in Table 1 and intercorrelations among study variables in Table 3.

Table 1

Sample characteristics of study sample (N= 138)

Characteristic	Frequency	Percentage (%)
Sex		
Male	46	33.3
Female	92	66.7
Marital status		
Single	101	73.2
Cohabiting	4	2.9
Married	31	22.5
Divorced	2	1.4
Religion		
Christian	124	89.9
Muslim	12	8.7
Other	2	1.4
Educational level		
Tertiary	104	75.4
Secondary	20	14.5
Basic	14	10.1
Employment status		
Employed	65	47.1
Unemployed	16	11.6
Self-employed	31	22.5
Student	26	18.8
Sickle cell status		
SS	97	70.3
AS	3	2.2
SC	38	27.5
Age of sickle cell diagnosis		
Newborn/infancy (birth-5 years)	68	49.3
Childhood (6 to 12 years)	42	30.4
Adolescent (13 years to 18 years)	14	10.1
Adulthood (19 and above)	14	10.1
Frequency of pains		
Rarely	29	21.0
Sometimes	56	40.6
Mostly	26	18.8

Frequently	27	19.6
Mean Age (SD); min-max	30.99 (8.44); 18-65	

The characteristics of the 138 participants are summarized in Table 2. The average age of the respondents was 30.99 (8.44), with a minimum age of 18 and a maximum age of 68. There were 92 female participants (67%) and 46 male participants (33.3%). A large proportion of them (73.2%) were single, with 22.5% married, 2.9% cohabiting, and 1.4% divorced.

There were 89.9% of the sample being Christians, 8.7% of them Muslims and 1.4% belongs to others which were not stated. The sample had 75.4% having tertiary education with 47.1% employed and 70.3% with the SS sickle cell type. Most of the participants were diagnosed of sickle cell at infancy (49.3%, n= 68), childhood (30.4%, n= 42) and during adolescence and adulthood (10.1%, n= 14) each.

Table 2

Means, standard deviations, range, skewness and kurtosis and reliability of psychological wellbeing, self-compassion, stigma, and pain scales.

Variable	*N*	*Minimum*	*Maximum*	*Mean*	*SD*	*Skewness*	*Kurtosis*	*Alpha* (α)
PWB	138	42	126	94.06	14.18	-.29	1.36	.71
SELF COM	138	8.50	28.00	19.54	3.30	-.19	.61	.73
PAIN	138	.00	50.00	24.46	11.94	-.18	-.65	.92
STIGMA	138	11.00	57.00	33.05	10.72	.19	-.57	.77

PWB=Psychological wellbeing; SELF COM= Self compassion

Table 3

Intercorrelations among study variables [Self-Compassion, Stigma, Pain, and Psychological Wellbeing]

Variable	1	2	3	4
1. Psychological wellbeing	-			
2. Self-compassion	.534**	-		
3. Stigma	-.41**	-.37**	-	
4. Pain	-.48**	-.21**	.34**	-

Note. ** $p < 0.01$ *two-tailed*, *$p < 0.05$ *two-tailed.*

Correlational analysis above shows that self-compassion is negatively correlated with stigma and pain. Furthermore, self-compassion positively correlated to psychological well-being. Also, pain and psychological well-being had a significant negative correlation. There was a significant positive correlation between stigma and pain.

Hypotheses Testing

To test for the seven hypotheses in the study, standard multiple regression analysis was performed for hypothesis 1, 2,3 and 4, with psychological well-being as the dependent variable and self-compassion, pain, and stigma as the independent variables (Result can be seen in Table 4 below). Hypotheses 5 and 6 were tested using Process macro for moderation whereby self-compassion was entered as a moderator for the relationship between pain and psychological well-being and stigma and psychological well-being (Results can be seen in Table 5 and 6 below).

A standard multiple regression was performed for hypothesis 7 with pain as the dependent variable and age, educational background, and gender as the predictor variables (Result can be seen in Table 7 below).

Table 4

Regression analysis of self-compassion, pain, stigma, and psychological well-being

Variables	B	SE	Β	*t*	*p*
Constant	76.62	7.76		9.88	.000
Self-compassion	1.74	.30	.40	5.78	.000
Stigma	-.20	.10	-.15	-2.11	.04
Pain	-.40	.08	-.34	-4.87	.000

Note. DV= psychological well-being. R^2*= .44*

Multiple regression analysis was used to determine the relationship between self-compassion, pain, stigma, and psychological well-being. The overall regression model shows that self-compassion, stigma, and pain accounted for the prediction of the variance in psychological well-being (R^2=.44, F (3, 134) = 35.07, p= .000). The results showed that self-compassion (β=.40, *p*= .000) had a predictive relationship with psychological well-being, stigma (β= -.15, *p*= .037) had a predictive relationship with psychological well-being and pain (β= -.34, *p*= .000) had a predictive relationship with psychological well-being. This suggests that there is a relationship between self-compassion, pain, stigma, and psychological well-being as expected. The result can be observed in Table 4.

Moderation Analysis (Hypotheses 5 & 6)

Moderation analysis was conducted using Haye's (2022) PROCESS macro v4.1. The hypotheses 5 and 6 that self-compassion will moderate the relationships between pain, stigma and psychological wellbeing were tested. The recommended bias-corrected bootstrap confidence interval of 5,000 was used (Hayes, 2022).

Table 5

Results of moderation analysis examining the moderating effect of self-compassion on the relationship between pain and psychological wellbeing.

Variables	B	SE	*t*	*p*
Constant	94.19	.95 [92.31, 96.06]	99.34	.000
Pain	-.45	.08 [-.61, -.30]	-5.66	.000
Self-compassion	1.93	.29 [1.36, 2.50]	6.68	.000
Self-compassion * Pain	.02	.02 [-.03,.06]	.65	.512

Note. R^2 = .42. *a. dependent variable: psychological wellbeing; upper and lower confidence interval in parenthesis*

The regression model was statistically significant F (3, 134) =32.76, *p* = .000. The variance explained in psychological wellbeing was 42%. It can be observed that pain (B= -.45) and self-compassion (B=1.93) made statistically significant contribution to explaining the variance in psychological wellbeing. The hypothesis tested the moderating role of self-compassion on the relationship between pain and psychological wellbeing. The results showed a non-significant interaction between self-compassion and pain on psychological wellbeing (B=.02, t = .65, p = .512), thus hypothesis 5 was not supported. The interaction between self-compassion and pain did not explain the variance in psychological wellbeing (R^2 change= .0019, F-change (1, 134) = .43, p = .512). This means that self-compassion did not moderate the relationship between pain and psychological wellbeing in people living with sickle cell disease. The result can be observed from Table 5.

Table 6

Results of moderation analysis examining the moderating effect of self-compassion on the relationship between stigma and psychological wellbeing.

Variables	B	SE	*T*	*p*
Constant	93.99	1.06 [91.90, 96.08]	89.10	.000
Stigma	-.34	.10 [-.54, -.14]	-3.34	.001
Self-compassion	1.91	.33 [1.26, 2.55]	5.86	.000
Stigma* Self-compassion	-.01	.03 [-.06, .05]	-.19	.852

Note.R^2*= .34; a. dependent variable= psychological wellbeing; upper and lower confidence interval in parenthesis*

The regression model was statistically significant (F (3, 134) =23.09, p= .000). The variance explained in psychological wellbeing (34%). It can be observed that stigma (B = -.34) and self-compassion (B =1.91) made statistically significant contribution to explaining the variance in psychological wellbeing. The hypothesis tested the moderating role of self-compassion on the relationship between stigma and psychological wellbeing. The results showed a non-significant interaction between self-compassion and stigma on psychological wellbeing (B =.03, *t* = -.19, *p* = .852), hypothesis 6 was therefore not supported. The interaction between self-compassion and stigma did not explain the variance in psychological wellbeing (R^2 change= .000, F-change (1, 134) = .04, *p* = .85). This means that self-compassion did not moderate the relationship between stigma and psychological wellbeing in people living with sickle cell disease. The result can be observed from Table 6.

Table 7

Results of multiple regression showing age, educational background and gender predicting pain in sickle cell disease

Variables	B	SE	Β	*t*	*p*
Constant	30.36	4.16		4.84	.000
Gender	.73	2.28	-.03	.32	.75
Age	-.23	.13	-.16	-1.81	.07
Educational background	.70	1.61	.04	.43	.67

Note. a. Dependent variable: Pain; R^2*= .024;* educational background (1= tertiary, 2= secondary, 3= basic); gender (1= male, 0= female)

Multiple regression analysis was used to determine if age, educational background, and gender predict pain in sickle cell disease. The overall regression model shows that age, educational background, and gender did not account for the prediction of the variance in pain outcome

(R^2=.024, F (3, 134) = 1.10, p = .35) Moreover, the results also showed that age does not predict pain (β=-.16, p = .07), educational background do not predict pain (β=04, p =.67), and lastly, gender does not predict pain (β=-.03, p = .75). This suggests that age, gender, and educational background do not play any pivotal role in predicting sickle cell pain. The result can be observed from Table 7.

Summary of Results

The study tested seven hypotheses to examine the role of self-compassion on sickle cell pain, stigma, and their psychological wellbeing. The findings of the present study are summarized below:

1. There was statistically significant positive relationship between self-compassion and psychological wellbeing
2. There was statistically significant negative relationship between stigma, pain, and psychological well-being
3. There was a statistically significant negative relationship between self-compassion, pain, and stigma.
4. Self-compassion did not moderate the relationship between pain and psychological well-being
5. Self-compassion did not moderate the relationship between stigma and psychological well-being
6. Age, educational level, and gender were not predictors of pain in sickle cell disease.

Observed Model

The diagram in Figure 2 below provides a pictorial explanation or description of the observed outcome of the study.

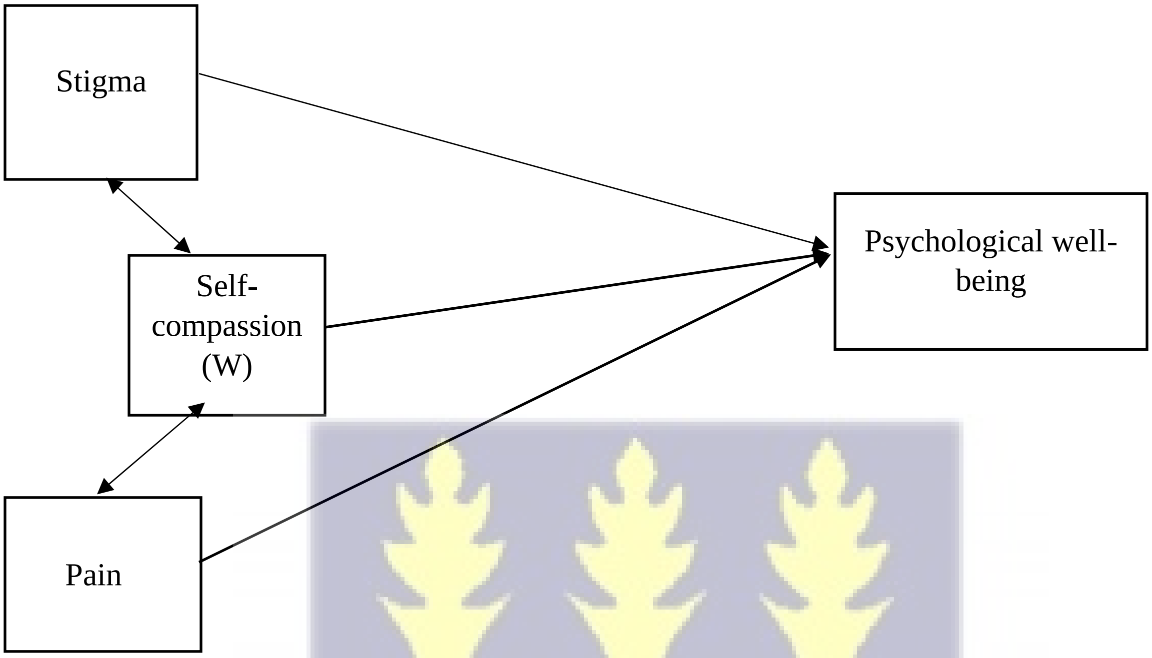

Figure 2 Observed model of the relationship between stigma, pain, self-compassion and psychological well-being as relates to persons with SCD.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter discusses the findings of this study and makes references to existing literature on self-compassion among people living with Sickle Cell Disease. In all, seven hypotheses were tested, four of which were supported, while the remaining three were rejected. Contextual explanations for different outcomes and contradictory results are provided in discussing the key findings. The theoretical and practical implications of the findings are also discussed, along with recommendations for future research and clinical practice. The chapter concludes with limitations, recommendations, and a conclusion.

Pain and stigma in sickle cell disease is a major public health concern due to the complications associated with it. It is essential to investigate the impact of psychological variables that can assist the individual in dealing with the pains and stressors associated with the disease. The purpose of this study was to investigate the role of self-compassion on pain and stigma among individuals living with sickle cell disease.

Discussion of Findings

Self-compassion, Pain, Stigma, and Psychological Well-being

Results from a regression analysis revealed that self-compassion, stigma, and pain were contributing factors of psychological well-being in people living with sickle cell disease. Self-compassion was found to have a significant positive relationship with psychological well-being, but it was also found to be significantly and negatively correlated with stigma and pain. Pain had a significant inverse relationship with psychological well-being and a significant positive relationship with stigma. The results supported the first hypothesis, which stated that there is a significant positive relationship between self-compassion and psychological well-being. Participants who reported higher levels of self-compassion were more likely to report higher levels of psychological well-being. The findings from this study are consistent with previous research works, such as that of MacBeth and Gumley (2012) who found in a meta-analytic study that self-compassion is significantly associated with better well-being and less psychopathology. Self-compassion maybe bi-directional, for instance, it has been shown that children who received warm and supportive childhood have higher self-compassion (Kelly & Dupasquier, 2016; Temel & Atalay, 2018). Hence, having interpersonal well-being can increase an individual's level of self-compassion. Similarly, Zessin et al. (2015) found that self-compassion is significantly associated with better cognitive well-being and better psychological well-being after conducting a study to examine the relationship between self-compassion and different forms of well-being. Hall et al. (2013) also established that self-compassion is associated with less physical symptoms. Finally, the present findings confirm the study by Allen et al. (2012) that self-compassion is associated with better general health. These studies and the current finding suggest that when a person is self-compassionate, their overall health and well-being may improve. This is because self-compassion entails the individual positively relating to themselves, which does not involve self-judgmental or social comparisons, but compassion for oneself. In any stressful event or situation, the individual becomes kind to himself or herself; the individual develops a sense of common humanity and becomes mindful rather than overidentification (Neff, 2009). Self-compassionate individuals in distress become aware of what they are experiencing in the present moment in such a clear and balanced manner that, they do not ignore or ruminate on disliked aspects of themselves or their lives. These may go a long way toward enhancing or improving people's general health or well-being during stressful events or moments. It could be understood that higher levels of self-compassion is associated to emotional resilience and a lower likelihood of engaging in coping behaviors linked to poorer mental health and wellbeing (Krieger et al., 2013; Leary et al., 2007).

Furthermore, the result indicated that higher levels of self-compassion could be beneficial to individuals who experience stigma and pains associated with sickle cell disease. This finding corroborates with previous findings (Chan et al., 2020; Hilbert, 2015). Eccles et al. (2022) and Edwards et al. (2019) found that higher self-compassion is associated with lower levels of stigma and improve negative impact of chronic pain on important areas of life. Additionally, Heath et al. (2018) found that self-compassion reduces the negative effects of perceived public stigma on anticipated self-stigma, providing psychological resilience.

People living with sickle cell disease are most often overwhelmed by the disease's uncertainties such as the pains, stigmas, and other stressors (Bulgin, 2018; Buser, 2021). This may trigger negative emotions and thereby leading to increasing pains or increasing the stigma's associated with the disease. However, when an individual is self-compassionate, the likelihood that this individual will ruminate on the stressors associated with the disease is low, and thus this individual may have control on these stressors. Individuals who are self-compassionate may see all humans as having a common problem and, as a result, would acknowledge the stigmas and pains they are experiencing rather than being self-judgmental towards themselves. Even though these self-compassionate individuals would feel the enacted stigma and may cause self-stigma at some point, they may acknowledge and recognize that everyone has a problem and we are all not perfect, thereby influencing the individual's self.

It was revealed in this study that pain has a significant negative relationship with psychological well-being. This shows that higher levels of pain may decrease a person's psychological wellbeing. This study is consistent with previous studies that showed that pain is correlated with psychological wellbeing (Larsson et al., 2019; Topcu, 2018). Living with pain can have an impact on one's mood and outlook, which in turn can influence one's perception of pain (Finan & Garland, 2015; Peters, 2015). Pain increases the risk of developing mood and anxiety disorders, and it can make a person feel depressed, hopeless, and anxious as they ruminate on their pain condition. Pain can have a significant impact on a person's psychological well-being. It can cause a person to be concerned about the possibility of pain flare-ups while out in public, or it can make a person feel too irritable or exhausted to go all out. Any of these can cause a person to isolate, which can have a negative impact on the individual's psychological well-being by causing depression, which can exacerbate the individual's pains. Furthermore, pains may cause misunderstandings of a person and may cause people to reject the individual, making the person feel left out of activities; it may also affect the individual's sleeping pattern at night due to physical discomfort, all of which leads to psychological distressing or lowering the psychological well-being of the person (Leary, 2022; Zhai et al., 2018).

The findings of this study showed that, there is a significant positive relationship between stigma and pain. This is showing that as stigma increases pain increases too. This is consistent with previous published works (Bean et al., 2022; Collier, 2018; Martin et al., 2018). From anecdotal evidence published in the work of Collier (2018), one person suffering from chronic pains is quoted to say "people look at me and other injured workers and they assume that we are all fixed, and they cannot understand why we are still having challenges", "We are deemed as complainers, malingerers and drug-seekers, it creates a lot of stigmas" (p. 204). These are the words of an individual experiencing chronic pain. The continued experience of pain frequently interferes with the performance of daily activities, which, according to Cooper, would lead to people stigmatizing a person going through such pains. Given that a person living with sickle cell has persistent pains that affect his or her productivity at work, people may begin to label him or her, resulting in the person being stigmatized, as Cooper mentioned, his employers and fellow colleagues do not understand him and these may lead to adding up to trigger the physical pains they experience. Also, because pains are not visible, people may believe those experiencing them are exaggerating, which contributes to stigma and tends to increase the pain or the pain increasing stigma the individual is experiencing, as it may trigger some stressors such as depression and anxiety, leading to an increase in the individual's pains and stigmas at the same time. Evidence published in the study of Bean et al. (2022) by a person experiencing pains says; “people at my work especially my manager cannot understand my pain because I am not in a cast or she cannot see what’s wrong with me so she often thinks I am making it up or making it worse than it is” (p. 1758). The effects of stigma can not only be experienced in a person's interactions with others, but it may also influence their physical and psychological state. People who suffer from chronic pain may internalize the stigma, believing negative statements about themselves that make them feel rejected or worthless. This tends to cause physical discomfort and can be described as "painful." Research has shown that there is a relationship between physical and social pain (Riva et al., 2014), also Eissenberger et al. (2006) found that increased exclusion experiences were linked to higher pain sensitivity and Bernstein (2012) found that social exclusion could significantly alter the physical pain relationship and sensitivity and again, Moayedi and Davis (2013) found perceived unpleasantness as an essential element of pain perception

According to the Cognitive appraisal theory (Fournier, 2018; Lazarus, 1982), individuals’ interpretation of the eliciting event and one’s bodily responses to it influenced the individual. People interpret events based on how they think about them, resulting in different emotions being elicited in response to the same eliciting event. According to the theory, some patients experiencing pain may be stigmatized because of what others say or think about them; however, some people may not be stigmatized if the same words are used on them while they are experiencing pain. Also, as stated in the evidence, the fact that their managers or coworkers do not understand them may not be a stigmatizing event, but rather a request for empathy, which these individuals may misinterpret them. However, the cognitive appraisal theory states that how you interpret events affects you, but others may interpret them differently, which may not be negative and thus will not affect them or lead to more stigma or pains. As a result, negatively interpreting situations may impact the individual's physical perception and sensitivity, which may contribute to the physical pain they are experiencing.

Self-compassion as a Moderator in Pain, Stigma and Psychological well-being in sickle cell disease

In assessing the role of self-compassion as a moderator in the relationship between pain and psychological well-being as well as the relationship between stigma and psychological well-being, it has been shown that self-compassion has a relationship with stigma, psychological well-being, and pain. However, contrary to expectations, results from the current study revealed that self-compassion did not moderate the relationship between stigma and psychological wellbeing as well as pain and psychological well-being.

Even though self-compassion was shown to have significant relationship with stigma, thus, higher self-compassion is related to lower stigma, a moderation analysis showed that self-compassion cannot serve as a buffer in the relationship between stigma and psychological wellbeing. This is consistent with previous study that showed that self-compassion could not moderate the connection between experienced stigma and distress (Eccles et al., 2022). Regardless of levels of self-compassion, the relationship between stigma and psychological well-being was not affected. The use of self-report may have impacted this result, as people with higher levels of self-compassion may perceive experiences of sickle cell disease related stigma differently, thus not affecting the relationship between stigma and psychological wellbeing.

Again, self-compassion did not moderate the relationship between pain and psychological well-being. As it was shown in the study, self-compassion had a significant relationship with pain, thus higher self-compassion relates to lower pain and higher self-compassion relates to higher psychological well-being. However, self-compassion did not buffer this relationship. This is partially consistent with a previous study by Lanzaro et al. (2021) who found compassion-related interventions are beneficial for people living with chronic pains but they could not establish the efficacy of the relationship with self-compassion and pain. Also, Lanzaro et al. (2021) found that self-compassion, however, was beneficial for people living with chronic pains, they could not establish that self-compassion weakened the physical pain these individuals are experiencing but was beneficial to them. It could be that the emotional pain associated with the chronic pain in these individuals were weakened as self-compassion has been established to build psychological resilience and therefore helps in managing emotional pains (Torrijos-Zarcero et al., 2021). This present finding is in contradiction to other previous studies which found self-compassion as a moderator in other populations (Allen et al., 2012; Hall et al., 2013; Kyeong, 2013; Torrijos-Zarcero et al., 2021).

Self-compassion could serve as a moderator in these previous studies due to the population in their samples. In the study of Hall et al. (2013), the authors looked at the relationship of self-compassion to physical symptoms and psychological well-being in college students and it was shown to be associated with less physical symptoms. The individual's physical symptoms may be covert, but the distress they are experiencing may be present, which the individual may not show due to the resilience he or she has built. It is also possible that these college students are only experiencing academic stressors such as burnout, which will pass. Unlike sickle cell pain, which is inherited and may live with it for the rest of their life, the individual may have to manage and adjust to the pains they experience. Also, Allen et al. (2012) assessed the role of self-compassion as a moderator of the relationship between perception of physical and subjective well-being in the elderly. Even though the elderly experience pain, assessing their perception may not be that self-compassion can alleviate pain. People's perception is that they are aware of something. It is possible that these people perceive and believe that being compassionate to themselves will reduce their pain, but this may not be the case because sickle cell pain is a physical condition that the individual experiences, even though it might help improve the individual's well-being. That does not rule out the possibility of the individual experiencing pain. Torrijos-Zarcero et al. (2021) compared self-compassion intervention and cognitive behavioral therapy on relevant clinical chronic pains and self-compassion was shown to be more effective than cognitive behavioral therapy in managing chronic pains. This does not mean that self-compassion may buffer or weakened the pain these individuals are experiencing or feeling. It may, however, help them manage their pains a little better than cognitive behavioral therapy.

The study demonstrates that self-compassion cannot influence the relationship between pain and psychological well-being. That is, self-compassion cannot eliminate pains; rather, it is beneficial and helps the individual as to how to manage the pain the individual is experiencing. This suggests that pain was not reduced to improve one's psychological well-being, regardless of self-compassion. This could be because sickle cell pain is a physical condition as well as an unpleasant physical and emotional state. A self-compassionate individual's physical pain symptoms can be reduced but not eliminated, especially in sickle cell pain, which can invade every aspect of the individual's life and is not only emotional pain but also physical nociceptive and neuropathic pain (Wang et al., 2010). An individual who is self-compassionate during a pain crisis may not necessarily work to reduce the pain the individual is experiencing; however, this individual may require the compassion of another person during those debilitating moments as well. People with sickle cell disease are born with this chronic pain and may experience it throughout their lives. This type of pain is unpredictable; it deforms blood cells and can get stuck in and block a person's blood vessel. When this occurs, oxygen-rich blood cannot reach key organs and tissues, resulting in a pain attack. The pain may be sharp, stabbing, intense or throbbing. Self-compassion cannot alleviate such pain; this is a physical chronic condition that is more biological in nature, attacking the individual's central nervous system and physical being. Sickle cell pain is a nociceptive and neuropathic physical pain that invades or intrudes on all aspects of a person's life; thus, self-compassion, which has been shown to help individuals in times of distress, cannot reduce the impact of the physical pain the person is experiencing. Self-compassion, on the other hand, can or may help the individual deal with the emotional stressors that influence the individuals to experience those physical pains that come with the disease. Individuals who are self-compassionate can or may deal with the emotional stressors that contribute to physical pains but not the physical pain itself.

Sociodemographic variables and pains in sickle cell disease

Results from regression analysis showed that age, educational background, and gender were not significant predictors of pain in sickle cell disease. This suggests that pain in sickle cell disease does not matter about age, one’s educational background or gender. This is consistent with the study by Rzeszutek et al. (2021) in which sociodemographic factors failed to explain the variance in the relationship between stigma and well-being. Even though pain has been shown to be more persistent in males than females living with sickle cell disease (Udezue & Girshab, 2004), this study shows that gender does not matter in sickle cell pain; all people with sickle cell disease experience pain, and gender cannot be used to predict pain. It is once again demonstrated that one's age and educational background have no bearing on the pains they experience. Since sickle cell pain is unpredictable and can affect anyone regardless of age, educational background, or gender. Evidence suggests that pain from sickle cell disease affects both children and adults, and that employment status has no bearing on pain. It has been suggested that employment status may be related to behavioral and social factors rather than poor health (Williams et al, 2018). A person's level of education, gender, or age cannot save them from pain because sickle cell pain is unpredictable due to its physical and biological nature, and some tissues in the body are also affected when it comes to this pain. As a result, a person's level of education, age, and gender have no direct effect on the level of pain experienced by someone living with sickle cell disease.

Implications for Research, Policy, and Clinical Practice

The findings have significant implications for future researchers, policymakers, and clinical practices.

Implication for Research

The findings have significant theoretical implications, particularly for sickle cell health professionals and scholars. The current study adds to the body of knowledge on self-compassion and pain management in sickle cell disease. According to the findings of this study, self-compassion, pain, and stigma are important determinants of well-being in people with sickle cell disease. The relationships between these variables provide a conceptual and theoretical framework for future research studies. This, in essence, calls for more research into the role of self-compassion in pain management in people with sickle cell disease, particularly the physical aspect of their pain, as well as an interventional study among individuals who experience chronic pain. Future studies could investigate some predictors of self-compassion to identify those who are vulnerable to low self-compassion and thus lower psychological well-being. Interventions aimed at increasing self-compassion may be beneficial for people living with sickle cell disease.

Implication for Clinical Practice

The findings of this study revealed that, self-compassion can help or be beneficial for people to deal with stressors associated with sickle cell disease that are not physical pain. It is important for health care providers to be aware of some additional things they can do to assist these individuals in managing the stressors they face. Health care providers can create a support system to help people living with sickle cell disease cope with stressors such as stigma and emotional pains that contribute to their pain crisis. For example, a person living with sickle cell disease who is financially burdened because of their condition can be trained to be self-compassionate to have the trait that will help him or her cope with the emotional pain that is contributing to the disease's physical pain crisis. Even though self-compassion cannot eliminate or reduce the health-related stigma and pain crisis in sickle cell patients, it can be used to train them to build resilience, which can help them manage and cope with these stressors and thereby increasing psychological well-being. Hence, Counselling services be promoted among people living with sickle cell disease to receive training in self-compassion. Clinicians should be guided that sickle cell pain does not matter about one’s employment status, level of education, age, or gender. These individuals all experience pains which cannot be accounted for by their social status. Clinicians and health-care workers dealing with sickle cell disease should keep in mind that pain is not determined by an individual's age, gender, or level of education. Everyone can experience a pain crisis, and they should not believe that their age or education level matter in their pain crisis.

Limitations of the Study

The cross-sectional design employed in the study precluded making causal inferences about the dependent and independent variables. All results interpretation and discussion were based on prior theory and literature and the research methodology used denies the opportunity to make causal inferences regarding the experiences of the population. That said, this study offers much insight on correlates of self-compassion among the sickle cell population in Ghana.

Another limitation was the volatility of the weather which prevented people from attending the social support meetings and potentially contributing to the study. This meant the researchers had to work with a smaller pool of participants. Furthermore, the use of non-probability sampling techniques prevented participants from being randomly sampled from the population. Participants were chosen subjectively based on the researchers’ judgment and the willingness of the participants, thus negatively affecting the representativeness of the sample for the population of persons with Sickle-cell Disease. Also, this study used people who are receiving social support in a group which they may differ from others who are not seeking such support.

Recommendations for Future Research

Although it was established in this study that, self-compassion is beneficial to people living with sickle cell disease, we recommend that future researchers conduct longitudinal and interventional study to monitor and understand whether self-compassion can help reduce the disease-related stigma and pain crisis the individuals experience eventually. This will provide in-depth knowledge about the role of self-compassion in sickle cell disease. Also, future quantitative researchers should use probability sampling techniques, which allow for the random selection of participants while ensuring that the sample is representative of the population. Finally, data collection for future studies should not take place during the rainy season or during cold weather. It must always be completed prior to the rainy season.

Conclusion

Sickle cell disease is a genetically inherited blood disorder associated with complications such as pain crisis, social stigma that leads to other distresses, cost, and other factors that affect the individual's well-being. Individuals living with sickle cell disease would be able to cope better if treatment and management of disease-related stressors become more holistic and comprehensive. Bio medics have contributed by developing drugs that help manage the physical and some emotional pains associated with the disease. This usually comes with some complications that affect clients who take the drugs even though they help them manage their disease. Other management activities, such as dehydration, relaxation, and a variety of other approaches, have been found to benefit people with sickle cell disease. Previous research has found a link between sickle cell disease management and psychological interventions.

Although self-compassion is important in the health outcomes of individuals' well-being in other populations such as Parkinson disease and other chronic pain and disease, there is a paucity of empirical findings in self-compassion as a tool to build resilience and cope in times of debilitating moment in people living with sickle cell disease. As a result, this study looked at the role of self-compassion in pain and stigma in people with sickle cell disease in Accra, Ghana. The findings revealed a significant relationship between self-compassion and psychological well-being; that is, higher self-compassion is associated with higher psychological well-being. It was once again demonstrated that self-compassion has a significant negative relationship with pain and stigma. Individuals with high self-compassion may experience less pain and stigma.

Furthermore, self-compassion, pain, and stigma were found to be significant predictors of psychological well-being in sickle cell patients. However, Self-compassion had no moderating effect on the link between stigma, pain, and psychological well-being. Therefore, self-compassion did not affect the association between pain and psychological well-being or the connection between stigma and psychological well-being.

Finally, it was found that age, gender, and educational levels of individuals living with sickle cell disease were not significant determinants or predictors of their pain.

The current findings suggest that self-compassion can be used to help manage some of the stressors associated with sickle cell disease. Self-compassion can benefit individuals experiencing pain and stigma by assisting them in managing stressors and coping through stressful situations. While it cannot eliminate the pain and stigma, it can assist in dealing with it, particularly with emotional and other stressors that can contribute to exacerbating those pains and stigmas and other stressors.

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APPENDICES

APPENDIX A: ETHICAL CLEARANCE

UNIVERSITY OF GHANA
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

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

My Ref. No…ECH 334 /21-22

August 4, 2022.

De-Graft Nana Agyei
Department of Psychology
University of Ghana
Legon

ETHICAL CLEARANCE
(ECH 334/ 21-22)

The protocol title below has been reviewed and approved by the ECH Committee.

TITLE OF PROTOCOL**: THE ROLE OF SELF-COMPASSION ON PAIN, STIGMA AND PSYCHOLOGICAL WELLBEING AMONG SICKLE CELL PATIENTS IN ACCRA**

PRINCIPAL INVESTIGATOR: **Mr. De-Graft Nana Agyei**

Please note that the final review report must be submitted to the Committee at the completion of the study. Your research records may be audited at any time during or after the implementation. Any modification of this research project must be submitted to ECH for review and approval prior to implementation.

Please report all serious adverse events related to this study to ECH within seven (7) days verbally and in writing within fourteen (14) days.

This certificate is valid till August 3, 2023. You are required to submit annual reports for continuing review.

Please accept my congratulations.

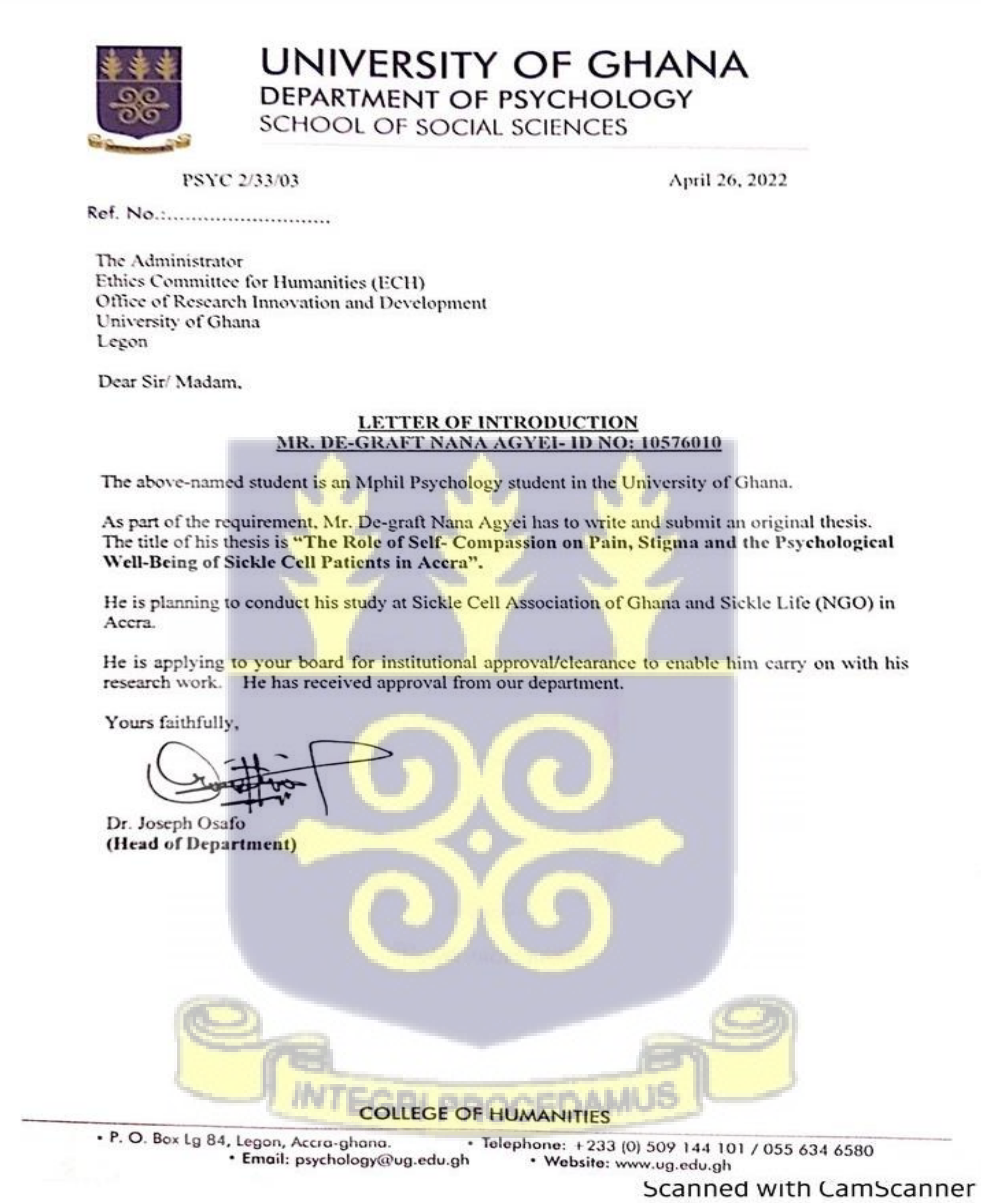
Yours Sincerely,

Professor C. Charles Mate-Kole ECH
Chair

Cc: Dr. Benjamin Amponsah, Department of Psychology, UG
Dr. Annabella Osei-Tutu, Department of Psychology, UG

Tel: +233-303933866 Email: ech@ug.edu.gh

APPENDIX B: INTRODUCTORY LETTER



UNIVERSITY OF GHANA
DEPARTMENT OF PSYCHOLOGY
SCHOOL OF SOCIAL SCIENCES

PSYC 2/33/03 April 26, 2022

Ref. No.:...........................

The Administrator
Ethics Committee for Humanities (ECH)
Office of Research Innovation and Development
University of Ghana
Legon

Dear Sir/ Madam,

LETTER OF INTRODUCTION
MR. DE-GRAFT NANA AGYEI- ID NO: 10576010

The above-named student is an Mphil Psychology student in the University of Ghana.

As part of the requirement, Mr. De-graft Nana Agyei has to write and submit an original thesis. The title of his thesis is **"The Role of Self- Compassion on Pain, Stigma and the Psychological Well-Being of Sickle Cell Patients in Accra".**

He is planning to conduct his study at Sickle Cell Association of Ghana and Sickle Life (NGO) in Accra.

He is applying to your board for institutional approval/clearance to enable him carry on with his research work. He has received approval from our department.

Yours faithfully,

Dr. Joseph Osafo
(Head of Department)

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APPENDIX C: CONSENT FORM

PROTOCOL CONSENT FORM

Section A- BACKGROUND INFORMATION

Title of Study:	The Role of Self-Compassion on Pain, Stigma and Psychological Well-being Among Sickle Cell Patients in Accra
Principal Investigator:	De-Graft Nana Agyei
Certified Protocol Number	

Section B– CONSENT TO PARTICIPATE IN RESEARCH

General Information about Research

This study is to find the role of self-compassion on pain, stigma and the psychological well-being of people living with sickle cell disease. Self-compassion is a coping technique whereby an individual treat himself or herself with kindness or gentle in times of distress.

This study will take about 25 to 40 minutes of your time. It is expected that each of the questionnaire takes about 10 minutes to complete. Therefore, the study duration would not exceed 40 minutes. Participants would have periodic breaks while completing the questionnaires. To reduce any type of fatigue, participants can choose to complete the questionnaires over two days, or they can take a five-minute break after fifteen minutes of sitting.
If you agree to be part of the study, you will be asked to fill some sets of questionnaires that assess the pains, stigma, self-compassion and the psychological well-being of people. You can choose to fill the questionnaire in-person or online via Google forms depending on what works best for you.

Benefits/Risks of the study

Your participation in this study may not benefit you directly, but it will help improve knowledge about the coping style of sickle cell patients and the findings may serve as a source of information for practitioners like psychologists use it to help people living with sickle cell in times of their distress. There are minimal risks associated with your participation in this study. I will take every precaution to ensure and maintain your safety and confidentiality.

Confidentiality

All information collected in this study would be treated with utmost confidentiality and will not be shared with anyone with the exception of my supervisors supervising me to do this work. I will not include any identifying information in the data collection phase.

Compensation

Participants would be compensated with 20.00 Ghana cedis airtime or cash upon successfully filling the questionnaire. Participants who do not complete all the questionnaires will not receive any amount.

Withdrawal from Study

Participation in this study is voluntary and participants can withdraw at any time without any consequences. If you feel uncomfortable and become disinterested in the study, you can withdraw or decline to continue participating in this research.

Contact for Additional Information

If you need further information about this research or need to contact someone about this research, please do not hesitate to contact me

De-Graft Nana Agyei; Department of Psychology, University of Ghana, Legon; degraftagyei87@gmail.com; Tel: +233 206002792

Your rights as a Participant

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@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 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