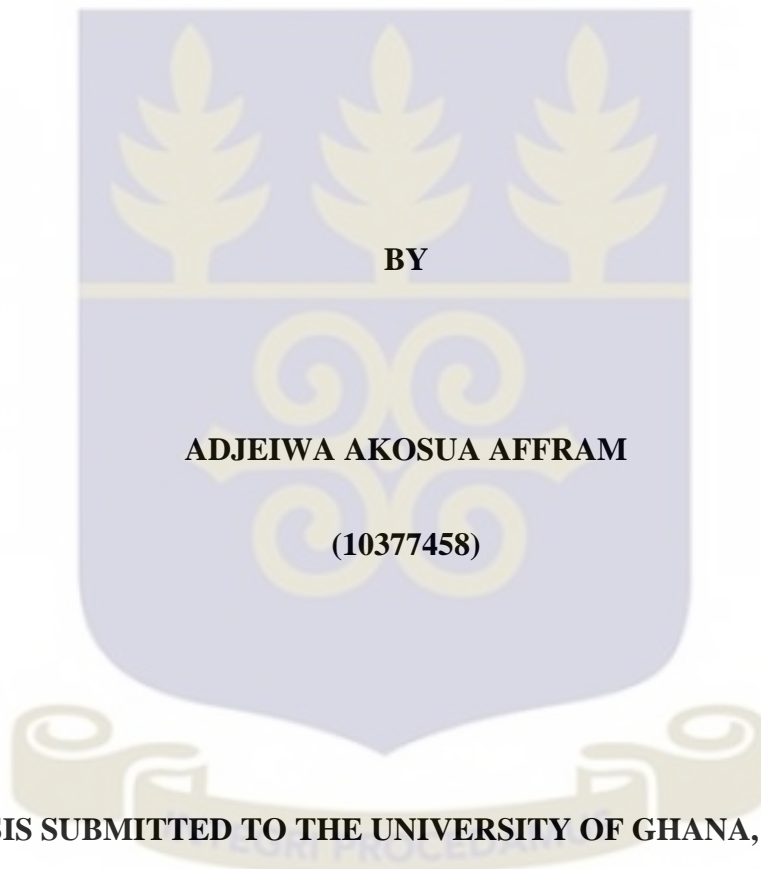


DEPARTMENT OF PSYCHOLOGY

UNIVERSITY OF GHANA, LEGON

STIGMA, SOCIAL SUPPORT AND SUBJECTIVE WELL-BEING OF PERSONS

WITH ALBINISM IN GHANA



**A THESIS SUBMITTED TO THE UNIVERSITY OF GHANA, LEGON IN
PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF
MPHIL CLINICAL PSYCHOLOGY DEGREE.**

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DECLARATION

I hereby declare that this research is conducted by me under the supervision of Dr Enoch Teye-Kwadjo and Dr Angela A. Gyasi-Gyamerah. This work has never been submitted to any other institution by anyone for any award. All references cited in this work have been duly acknowledged and I take full responsibility of any shortcomings associated with this work.

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DEDICATION

This work is dedicated to the albinism community in Ghana. Thank you for allowing me to share your experiences with others. To my father, in your tireless effort to introduce and expose me to the world through books, finally I too become an author.

ACKNOWLEDGEMENTS

I do not use these words loosely when I say this work could not have been done without Mr Kwame Andrews Daklo. Your constant enthusiasm and encouragement was what kept me going in the field. Thank you so much for your time and effort. To Dr Enoch Teye-Kwadjo for immediately saying yes when I brought up this somewhat unusual topic and for telling me “oh yes! It’s doable”. Your faith in me gave me the courage to embark on this journey. To Dr Angela. A. Gyasi-Gyamerah, for showing such interest and always getting me feedback in the fastest possible time. Your direction kept me grounded. I owe you a great debt of gratitude, my supervisors. A student is only as good as her teachers. Finally, to Brigadier General R.Y. Affram, without your financial support this dream would have remained a dream. I am grateful for this team that made this daunting journey less frightening.

TABLE OF CONTENTS

DECLARATION	i
DEDICATION	ii
ACKNOWLEDGEMENTS	iii
TABLE OF CONTENTS	iv
LIST OF TABLES	vii
LIST OF ABBREVIATIONS	viii
Abstract	ix
CHAPTER ONE	1
Introduction	1
Background to the study	1
Stigma	2
Social support.	4
Subjective well-being.	6
Statement of the Problem	8
Aims/Objectives	9
Relevance of the Study	9
CHAPTER TWO	11
Literature Review	11
Theoretical Framework	11
Biopsychosocial model	11
The transactional model of stress.....	11
Stress-buffer hypothesis.....	13
Review of Related Studies.....	16
Stigmatization of PWA.....	16
Awareness, knowledge and beliefs about albinism.	16
Effect of albinism on social relationships.....	19
Effect of albinism on personal relationships and employment.....	22
Well-being and Quality of life of PWA	24
Social support for PWA	26
Research Rationale	27
Hypotheses	28
CHAPTER THREE.....	30
Methodology	30

Participants	30
Sampling Procedure	30
Measures.....	31
The Impact of Skin Disease on Daily Life (ISDL).....	31
The Multidimensional Scale of Perceived Social Support (MSPSS).....	32
Personal Well-being Index (PWI).....	32
Data Collection Procedure.....	33
Design.....	35
Analytic Strategy.....	35
CHAPTER FOUR.....	37
Results.....	37
Preliminary Results	37
Demographic Characteristics of the Sample.....	37
Main Results.....	38
Hypothesis one.....	38
Hypothesis Two	39
Hypothesis Three	39
Hypothesis Four.....	40
Summary of results.....	40
CHAPTER FIVE.....	42
Discussion	42
Stigma and SWB	42
Social Support and SWB.....	44
Moderating role of social support	46
Gender differences in subjective well-being	50
Limitations and Recommendations of the Study	50
Conclusion and Implications	52
REFERENCES.....	55
APPENDIX	71

LIST OF FIGURES

Figure 1: Hypothesised Model	29
Figure 2: Observed Model	41

LIST OF TABLES

Table 1.....	37
Table 2.....	38
Table 3.....	39
Table 4.....	40

LIST OF ABBREVIATIONS

NOAH- National Organization for Albinism and Hypopigmentation

OCA- Oculocutaneous Albinism

GAPA- Ghana Association of Persons with Albinism

ISDL- Impact of Skin Disease on Daily Living

MSPSS- Multidimensional Scale of Perceived Social Support

PWA- Persons with Albinism

PWI- Personal Well-being Index

SWB- Subjective Well-being

Abstract

There are few empirical studies on the experiences of persons with albinism in Ghana. This study investigated the subjective well-being (SWB) of persons with albinism in selected Regions in Ghana. Participants ($N = 105$) were recruited via purposive and snowball sampling, and completed a survey questionnaire on social stigma, social support and subjective well-being. Results from Hierarchical Multiple regression indicated that there was a significant negative relationship between stigma and SWB. There was a significant positive relationship between social support and subjective well-being. Further, social support did not moderate the relationship between social stigma and subjective well-being. Besides, there were no gender differences in subjective well-being of persons with albinism. The implications of these results are discussed.

CHAPTER ONE

Introduction

Background to the study

Albinism is an inherited autosomal recessive gene that affects animals as well as humans of all races (National Organization for Albinism and Hypopigmentation [NOAH], 2014). In order for a person to be born with albinism, the autosomal recessive gene must be present in both parents. Persons with albinism (PWA) have little or no pigmentation in the eye, skin or hair, and have sensitive skin and poor vision (Braathen & Ingstad, 2006; Estrada-Hernández & Harper, 2007). There are two main types of albinism and these have many subtypes (Brocco, 2015). One of the two main types is Oculocutaneous Albinism (OCA), which affects the eyes, skin and hair of a person. The second type, Ocular albinism, affects the eyes only and is much less common (NOAH, 2014). In OCA, there is hypopigmentation of the skin, hair and eyes because there is little or no melanin production (Mabula et al., 2012). Currently, seven forms of OCA are recognized and some have other subtypes.

The pigment spectrum of OCA ranges from persons with no pigmentation at all to those with slight pigmentation with yellowish or brownish hair (NOAH, 2014). Type 1 OCA with subtype 1A (OCA1A) is the severest type of albinism with no melanin production at all. This type of albinism is extremely rare in black Africans (Kamaraj & Purohit, 2014; Kromberg et al., 2012). According to Kromberg et al.(2012), Type 2 OCA (OCA2) is the most common form of albinism in Sub-Saharan Africa. Type 3 OCA (OCA3) is a form of albinism that is more common among black Africans but rare in other races. It is also called Rufous OCA and individuals with this form of albinism have reddish-bronze skin colour as well as hair lighter than their skin colour, usually ginger coloured and blue or brown eyes (Kromberg et al., 2012).

The total population of individuals with OCA in Africa is unknown since the incidence and prevalence of albinism varies between and within countries (Mcbride, 2014). The prevalence rate in Zimbabwe for example is 1 in 4,182 and within Zimbabwe, 1 in 1000 among the Tonga ethnic group, which is four times higher than that for the country as a whole (Lund, Puri, Durham-pierre, King, & Brilliant, 1997). In Tanzania, there is an estimated population of PWA at about 170,000 (Thuku, 2011 cited in Ikuomola, 2015a), while in Nigeria and South Africa, the estimated prevalence rate is 1:1100 and 1:3900 respectively . Statistically, Africa seems to record the highest prevalence of people born with albinism (Ikuomola, 2015a). According to Kromberg et al. (2012), albinism is the most common recessively inherited disorder in Africa followed by sickle-cell anemia. Despite this, there appears to be no information on the prevalence rate of albinism in Ghana since no data seems to exist to provide the numbers.

Due to the obvious difference in skin pigmentation from that of the majority of the population, PWA in Africa are stigmatized and treated differently from others in the society (Baker & Lund, 2017; Brocco, 2016; Phatoli, Bila, & Ross, 2015). A majority of the research on PWA in Africa find that although they are treated differently, they are most often treated with love and compassion by their families (Braathen & Ingstad, 2006; Brocco, 2016). However, Baker, Lund, Nyathi, and Taylor (2010) described instances where PWA were killed or left to die by their families because of the stigma they carry.

Stigma. The earliest definition of stigma originated from Greek culture where the term stigma was used to describe a mark placed on an individual signifying his or her deviance from the norm (Goffman, 1963). Stigma has been described as an attribute prescribed to a person as a mark to show that his/her social identity is a deviation in the society he or she finds himself/herself in, therefore reducing that person "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 12; Crocker, Major, &

Steele,1998). Definitions of stigma assume that stigmatized individuals have, or are believed to have, an attribute that marks them as different therefore leading to devaluation in the eyes of those that do not bear the mark (Major & Brien, 2005). Stigma today is not a physical mark but rather a discrediting social difference leading to a spoiled social identity (Bos, Pryor, Reeder, & Stutterheim, 2013; Link & Phelan, 2001).

Stigma is rooted in social relationships because it is a social phenomenon that is shaped by the culture and structure of society. Research reveals that stigma exists when the relationship between attributes (a discrediting mark) and stereotypes converges (Goffman, 1963; Link & Phelan, 2001; Pescosolido & Martin, 2015). Link and Phelan (2001) used the term 'label' in place of 'attributes' because the latter implies truth while the former leaves the validity of the label an open question. Human beings select features or 'marks' that differ from what they know and are used to and then label these differences that later lead to stereotyping. Labeling provides the justification for devaluing, mistreating, and excluding people. This is because the labels set them apart from the norm and link them to characteristics considered undesirable, and with this the rationale for stigmatization is constructed and justified (Link & Phelan, 2001; Major & Brien, 2005; Pescosolido & Martin, 2015).

Stigma can cause prejudice and discrimination and hence stigma has been linked to many negative consequences like depression, anxiety and low self-esteem (Corrigan, 2004; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Ritsher & Phelan, 2004). Studies in Ghana and abroad have revealed that stigmatization leads to low levels of psychological well-being and life satisfaction (Asante, Meyer-Weitz, & Petersen, 2015; Markowitz, 1998; Porter, Brennan-ing, Burr, Dugan, & Karpiak, 2017; Tawiah, Adongo, & Aikins, 2015).

According to Major and Brien (2005), there is the assumption that stigmatized individuals internalize the negative view of them held by the society. However, when it comes to self-esteem for example, empirical evidence does not support the prediction that members of stigmatized groups should have low self-esteem (Crocker & Major, 1989). Some individuals who are stigmatized adopt an empowerment model rather than a coping model when dealing with stigma. They therefore reject the labels given to them by others when they perceive such labels as carrying an unrealistic and negative stereotype (Camp, Finlay, & Lyons, 2002; Shih, 2004). The ability to deal successfully or unsuccessfully with stigma is strongly related to many other variables like social support (Galvin, Davis, Banks, & Bing, 2008) and subjective well-being (Diener, 1984; Diener & Ryan, 2008). Social support has been shown to act as a buffer to psychological distress such as stigma (Łakuta, Marcinkiewicz, Bergler-czop, & Brzezińska-wcisło, 2017; Li, Lee, Thammawijaya, Jiraphongsa, & Rotheram-Borus, 2009; Vyavaharkar et al., 2014) and is known to positively influence psychological well-being (Akwei, 2015; Asante, 2012; Glozah, 2013; Wilson & Somhlaba, 2016).

Social support. Social support essentially refers to the many different help and care that people receive from others. There have been difficulties on how best to define social support. Albrecht and Adelman (1987) defined social support as a verbal and non-verbal communication between a receiver and a recipient that helps an individual reduce the uncertainty about a distressing situation. The reduction of uncertainty enhances the perception that the individual has control over his/her life experiences. According to this definition, social support helps people to feel protected in a situation where they feel vulnerable and not in control., Cohen (2004) defined social support as the provision of resources (psychological and material) from a person's social network that enhances an individual's ability to cope with stress.

Cohen, Underwood and Gottlieb (2000) attempted to define social support more broadly to include interactions of relationships which may result in actual or perceived resources exchanged to improve well-being. Social support is a multidimensional construct and is conceptualized and measured in different ways. Two main types of social support exist – actual/received and perceived social support. Actual social support is the support that people receive at the time of need. Perceived support refers to a person's belief that social support is available and will be provided when needed (Norris & Kaniasty, 1996). Perceived social support, however, predicts positive mental health while actual support has minimal effect on mental health (McDowell & Serovich, 2007). This is because, for a person to receive social support, the stressor must have already occurred. Therefore, the social support received is used as a resource to counterbalance the effect of the stressor. The belief that social support will be available gives people some comfort and armor against stressors. Thus, people with high perceived social support report positive mental health as opposed to persons receiving actual social support after the stressor has caused distress. The adequacy of social support relates directly to the type and severity of the stressor and a number of studies have shown social support to buffer stress. (Wills and Cohen, 1985; Zimet, Zimet, & Farley, 1988).

Further, social support is categorized into three main types; instrumental, informational, and emotional social support. Instrumental support is the material help provided to people who are in need of it such as money and gifts. Informational support on the other hand refers to the provision of information that is relevant to alleviating the effects of the current stressor. These are usually in the form of advice or guidance. Emotional support involves putting out feelings that convey empathy, reassurance, and trust. Emotional support also provides an outlet for individuals to express their emotions and vent (Cohen, 2004). Social support can influence an individual's ability to adjust and

live with an illness. It can also help raise the quality of life and subjective well-being of people as well as enable them to develop and use positive forms of coping (Abrefa-Gyan, Cornelius, & Okundaye, 2015; Prakesh, Kumar, & Shinha, 2014).

Subjective well-being. Psychologists have mainly been interested in negative emotional states until the rise of positive psychology, which encouraged the investigation of positive emotions and feelings of well-being (Linley et al., 2006; van Hoorn, 2007). Self-reports on how well life is going can give vital information on underlying emotional states. This interest led to the measurement of subjective well-being [SWB] (Proctor, 2014). Diener (1984) who defined it first introduced the term SWB as “an umbrella term used to describe the level of wellbeing people experience according to their subjective evaluations of their lives” (Diener & Ryan, 2009, p. 391). There is an affective and a cognitive component of SWB. The affective component is an individual’s balance between positive and negative feelings (hedonic balance). The cognitive component on the other hand is an individual’s life satisfaction (Schimmack, Radhakrishnan, Oishi, Dzokoto, & Ahadi, 2002). SWB is therefore commonly understood and measured through life satisfaction (Diener, 1984; Diener et al., 2016; Rojas, 2004) which is “the degree to which a person positively evaluates the overall quality of his/her life as a whole” (Veenhoven, 1996, p. 17). Life satisfaction together with indicators of mental and physical health, economic and social indicators, tell how well people thrive (Diener, Oishi, & Lucas, 2003; Veenhoven, 1996). Because life satisfaction is a cognitive component of SWB, it is not heavily influenced by temporary changes in life such as emotional states. A person’s measure of his or her life satisfaction is more stable than his measure of hedonic balance (Veenhoven, 1996). Life Satisfaction is considered not only to be the more stable component of SWB, but also the key indicator of positive SWB (Eid & Diener, 2004; Proctor, 2014).

Individualistic cultures place more importance on emotions than collectivistic cultures therefore emotions are less salient in life-satisfaction judgments in collectivistic cultures (Schimmack et al., 2002). Hedonic balance has also been found to be a weaker predictor of SWB in collectivistic cultures than in individualistic cultures (Suh, Diener, Oishi, & Triandis, 1998). Life satisfaction can be measured using a single construct with multiple items. Each item taps from global life satisfaction and represents different variations of global life satisfaction. SWB can also be studied through the investigation of many specific life domains. The rationale underlying this approach is that a person's life can be measured as a general construct of many specific domains; and that life satisfaction can only be understood after an assessment of satisfaction with these domains of life (Mariano, 2004). According to Diener et al. (2016), life satisfaction relies on factors like health, income and the quality of one's work. Therefore, SWB cannot be truly measured by only one facet of this larger construct. To obtain a true measure of SWB, several components must be measured.

The information on gender and SWB is inconsistent with some studies reporting gender differences while others report no differences. According to Diener (1984) and van Hoorn (2007), women generally report higher SWB scores than men do. Al-Attayah and Nasser (2016) found that women reported higher SWB compared to men in a sample of university students in Qatar. However, Addai, Amanfu, and Opoku-Agyeman (2013) found no significant relationship between gender and happiness or satisfaction in life among Ghanaians. Sahu (2013) also did not find any gender differences among men and women while investigating SWB among a sample of adults in India.

There is no single determinant of SWB, however conditions necessary for high SWB include positive mental health and social relationships. Kapteyn, Smith, and Van Soest (2009) found social contacts and families to have the highest impact on life

satisfaction. Married people tend to rate their SWB higher than unmarried people (Diener, Gohum, Suh, & Oishi, 2000). However, a study by Addai, Opoku-Agyeman, and Amanfu (2015) in Ghana revealed that married persons reported low levels of happiness and satisfaction with life compared to unmarried respondents. Measures of SWB also predict social support. Addai, Amanfu and Opoku-Agyeman (2013) explored the predictors of SWB in Ghana measuring global happiness and life satisfaction. While Ghanaians reported high levels of happiness, they were relatively less satisfied with life. Ethnicity, religion, health, economic status, educational level and community engagement were predictors of happiness and life satisfaction among Ghanaians. Similar findings on ethnicity and religion on life satisfaction of Ghanaians were reported by Pokimica, Addai, and Takyi (2012).

Statement of the Problem

People who are different most often have their differences singled out, marked and labeled. These labels and marks are the stigma placed on people who appear to be different from what the society is used to. According to Markus and Kitayama (1991), people in collectivistic cultures (as African societies are described) encourage conformity. PWA stand out because of their skin colour, and this skin colour is the mark that may create a room for differential treatment by others.

There have been quite a number of studies on PWA in Africa but very little research on PWA in Ghana. Studies of PWA in Africa have focused on stigma, and slaughter and killings of PWA. A few studies investigate the quality of life of PWA with a further minority of those studies investigating the subjective aspect of this quality of life. This dearth in literature means that the unique experiences of persons living with albinism are unaccounted for in the general body of knowledge. Therefore, there is a need to investigate the unique experiences of this vulnerable population to find out if the Ghanaian

society view them favourably or unfavourably. Thus, this study sought to focus on subjective wellbeing, which is the subjective aspect of quality of life, while investigating social stigma experienced by persons with albinism as well as the social support they receive. In this regard, the questions that ought to be asked are:

1. Do PWA in Ghana suffer stigma at the hands of others just like those in other African countries because of their skin difference?
2. Do PWA receive social support and if they do, does it buffer their experiences of stigma leading to improved subjective well-being?

Aims/Objectives

The main aim of this study is to investigate the experiences of PWA. The specific objectives are to:

1. Investigate stigma experienced by PWA in Ghana.
2. Determine the level of perceived social support of PWA in Ghana.
3. Assess the SWB of PWA in Ghana.
4. Determine the influence of social support on the relationship between stigma and SWB.

Relevance of the Study

It is expected that this study will provide insight into the experiences of PWA in Ghana. Little is known about the psychological well-being of persons in this population and it is expected that this study will help bridge this gap by promoting public awareness of this health condition through presentations at seminars and conferences. It is also expected that this study will contribute to the areas of clinical psychology where individuals are pursuing therapy to help them live a more complete, fulfilling, and satisfying life. Additionally, information from this study could be useful, as empirical

evidence, to the Ghana Association of Persons with Albinism (GAPA) in requesting funding from the State and international agencies to help improve quality of life for people with albinism.

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CHAPTER TWO

Literature Review

Theoretical Framework

The theories underlying this study are the biopsychosocial model, the transactional model of stress and the stress-buffer hypothesis. These theories are further explained in this chapter.

Biopsychosocial model. According to the biopsychosocial framework, health and illness are influenced by the interaction of biological, psychological, and social processes (Wachtel, 2005). Physical and psychological conditions may have a biological, psychological, and social element and these interactions should be understood in order to provide effective interventions (Engel, 1977; Wachtel, 2005). Unlike the prevailing one-dimensional causal approach to the understanding of health problems, the biopsychosocial perspective offers a multidimensional and interactive approach to understanding health problems (Wachtel, 2005). The biopsychosocial model has been described as lacking a philosophical framework which leads to eclecticism, rather than integration of the biological, psychological, and social processes (Benning, 2015; McLaren, 1998). Despite this criticism evidence for the success of the model in addressing physical and mental health problems have been found (Faree & Rapley, 2017). The theory is therefore a good basis for this study because it takes into account the effect of a biological condition (albinism) and how the social interactions (stigma and perceived social support) influence the psychological health (SWB) of an individual living with this health condition.

The transactional model of stress. According to the transactional model of stress proposed by Lazarus and Folkman (1984), stress is not an isolated phenomenon but rather a result of the interaction between a stressor, the environment and the thought process that occurs when the stressor is encountered. Lazarus and Folkman (1984) define stressor as a

situation where the internal adaptive resources of the individual do not match the demands of the environment. The most important process in this model is not the presence of the stressor per se, rather how an individual chooses to give meaning to the situation. This transactional process depends on an individual's values, goals, and beliefs, and environmental factors like demands and resources available. This is why two people may react to the same stressor in completely different ways (Biggs, Brough, & Drummond, 2017). Meaning given to a stressor is done in a process called cognitive appraisal and is defined by Folkman (2013) as "the individual's continuous evaluation of how things are going in relation to his or her personal goals, values and beliefs" (p. 1913). Two types of cognitive appraisal occur when a person encounters a stressor.

First, an individual must decide if a situation is of importance or irrelevant to him. This process is known as primary appraisal. If the stressor is not dismissed as irrelevant, the individual now has to give importance to the stressor by interpreting it as harmful, challenging or threatening (Biggs et al., 2017; Folkman, 2013). Second, after an individual has examined the importance of the stressor, he/she then goes further to do a secondary appraisal. In the secondary appraisal, the individual identifies and evaluates his or her coping resources, situational variables, and coping styles (Biggs et al., 2017). Coping is a strategy an individual employs, usually thoughts and actions, to alter the source of stress in order to reduce the stress being experienced (Krohne, 2002). Coping resources, situational and emotional variables and the nature of the stressor determine the coping actions selected to deal with the stressor (Biggs et al., 2017). The appraisal processes are not isolated and distinct but rather interrelated complex processes involving simultaneous interchange between primary and secondary appraisal. Therefore even after initial primary and secondary appraisal, coping efforts as well as new information from the

environment can result in cognitive reappraisal where the situation is reappraised to determine if the coping strategy utilized was successful (Biggs et al., 2017)

Lazarus' model of appraisal processes, however, has been criticized as being overly cognitive and overly conscious. Contemporary models of responses to stressful events observe that appraisals are not necessarily cognitive; nor are they necessarily conscious. A person may make nonconscious demands and resource appraisals in the event of a stressful situation (Blascovich & Mendes, 2000).

There is a lot of literature on the different types of stressors and the various coping mechanisms involved in dealing with stress. Much of the literature focus on problem-focused, emotion-focused and maladaptive coping (Biggs et al., 2017). Problem-focused coping style is used by an individual to alter the source of stress and involves strategies like information gathering, seeking advice and problem solving while emotion-focused coping has to do with relieving a person from the emotional distress caused by the stressor, using strategies like distancing and humour (Berjot & Gillet, 2011; Newness, 2011). Social support has been described in the literature as either a problem focused or an emotion focused coping mechanism depending on the stressor encountered or as a coping resource which influences the choice or efficacy of a coping strategy used in response to a stressor (Thoits, 1995).

Stress-buffer hypothesis. One of the most effective ways people cope with stressful events is with social support (Taylor et al., 2004). According to the stress-buffer hypothesis, social support influences physical and psychological health by providing an individual with psychological and material resources needed to cope with stressors (Cohen, 2004). The stress-buffering model operates on the interaction of stress and social support. When people perceive social support as available to them in times of distress, that

perception alone helps to alleviate or protect them against stress which may have resulted in psychological distress (Cohen, 2004; Cohen & Wills, 1985). Social support does this by interrupting the pathway of the harmful effects of the stressor by acting as a moderator thereby reducing the perceived importance of the stressor to the individual (Mossakowski & Zhang, 2014).

This process of buffering can occur via several ways. First, social support can redefine the effects of a stressor for an individual. The perception of the harm that is introduced by the stressor will be countered by the perception that that individual has the resources (that is, social support) needed to alleviate that stressor. In this case, an individual does not in fact recognize a situation as being stressful, thereby reducing the harmful effect of the stressor. Another way in which social support may act as a buffer is by reducing the affective reaction to the stressor after perceiving it as harmful or threatening (Cohen & Pressman, 2004). The way in which social support works in this process is by providing an avenue to reduce or eliminate the effects of the stressor. Talking to close family or friends may help to alleviate or reduce the impact of a problem for an individual. Social support may also act as a buffer by acting as an intervention therefore reducing the stress reaction to the stressor. Social support can further provide a solution to the problem or reduce the perception of importance of the problem or providing a distraction to the problem. Physiologically, social support can directly influence the reaction to stressors by tranquilizing the neuroendocrine system so that people react less to stressors and facilitate health promoting behaviors like healthy eating habits, rest and exercise in place of maladaptive coping mechanisms like anxiety and depression (Cohen & Pressman, 2004).

Sociologists have studied types of social support and its buffering effects (Mossakowski & Zhang, 2014). According to Cohen and Wills (1985) and Cohen (2004),

social support will work effectively in reducing the effects of stressful events when the form of assistance matches demands of the event. For example, a high school leaver having anxiety about what course to read in the university will benefit more from informational social support rather than instrumental social support. When stressors are perceived as harmful they often develop into feelings of helplessness and this may threaten the self-esteem of an individual (Cohen & Wills, 1985). In such situations, esteem support may be successful in alleviating that threat to self-esteem. Informational support helps a person to reappraise a stressor that was perceived as threatening or challenging to non-threatening. Informational support also suggests alternate or appropriate coping responses that counter a perceived lack of control. Esteem and informational support are therefore more likely to respond to a wide range of stressors. Instrumental support and social companionship in contrast are most effective when they provide resources that are closely linked to the specific need elicited by a stressful event. For example, stress from loneliness would be best alleviated by social companionship. If stress however is as a result of economic problems, then it would best be alleviated by instrumental support (Cohen, 2004; Cohen & Wills, 1985).

Practically, however, there have been confounding results on the evidence of the buffering effect of social support. A meta-analysis by Pascoe and Richman (2009) confirmed that only a few studies demonstrated the moderating role of social support in the relationship between stigma and stress on physical health outcomes. Most studies found no evidence of moderation, and a few of the studies reviewed found some forms of social support intensifying the relationship between enacted stigma and poor health outcomes

Review of Related Studies

Stigmatization of PWA. According to Link and Phelan (2001), “the very nature of labels conferred spells out the separation of ‘us’ from ‘them’ ” (p. 370). Labels suggest that a person is what they are labeled. They go on further to demonstrate this by using mental illness as an example. An individual who has cancer, for example, is simply a person with cancer. That person is not cancerous, he/she is still a part of the ‘normals’ but just happens to have an illness. A person is, however, seen as ‘schizophrenic’ or ‘bipolar’ rather than as a person with bipolar affective disorder or schizophrenia. They argue that this is an ongoing process of stigma, where a person is not just another individual with a condition but rather the individual is the condition. That is, a ‘them’ separate from ‘us’. PWA were previously responding to the label ‘albino’, however this was considered inappropriate and the term ‘person with albinism’ is now accepted because it puts the individual before the condition (Baker, 2011, p. 2). This label however has not been very successful in convincing the majority that PWA are just a part of them but happen to be living with a genetic condition. Albinism has had considerable effect on the social and personal lives of PWA in Africa most of which have been contributed to how others view PWA as being different from them.

Awareness, knowledge and beliefs about albinism. Overall, the general awareness of albinism in Africa seems to be poor. Most of the research conducted in Africa on PWA have revealed that the most prevalent and persistent explanation for albinism is spiritual (Baker & Lund, 2017; Braathen & Ingstad, 2006; Machoko, 2013). Masanja, Mvena, and Kayunze (2015) in their investigation of the level of awareness of the condition among PWA found that half of PWA and their relatives in their study had little knowledge about their condition. Only 12% of PWA were fully aware of their condition. This echoes the findings of Hong, Zeeb, and Repacholi (2006), who conducted a survey among health

professionals in 12 African countries including Ghana and found that respondents were of the belief that a majority of PWA did not fully understand their own condition. In a study in Malawi, when parents of PWA were asked to explain what albinism was, only one was able to answer correctly (Braathen & Ingstad, 2006).

There are numerous myths and folklore in different African countries about how PWA came into existence. Braathen and Ingstad (2006) described a Malawian myth that tells a story about the origin of PWA. The conception of PWA was as a result of a couple who had sexual intercourse before marriage and was therefore cursed to produce many deformed offspring of which one is a PWA. “This myth still says today that people with albinism are a punishment from the gods for the sin that the first pair committed before they were married” (Braathen & Ingstad, 2006, p. 600). In Central African Republic as well as former Kongo, the belief is that PWA were water-children born of the water goddess, known as “*mami-wata*” which is always represented as a white skinned figure (Cimpric, 2010; Machoko, 2013). Albinism in Zimbabwe is linked to water spirits (which are revered and respected) by some Zimbabweans and also linked to evil spirits by others. The belief by the majority in Zimbabwe is that PWA are water spirits who manifest themselves on earth as people. There is a general belief that water spirits are a source of blessings and this is what targeted PWA for ritualistic killings. PWA are not seen as mortals, rather as spirits or reincarnations of spirits and since spirits cannot die, neither could PWA. In Ghana, evidence for a similar belief was demonstrated when a group of residents in Kadjebi in the Volta region flocked to see an obituary poster of a woman with albinism. According to the residents in the town it was their first time ever hearing of the death of a PWA as there was the popular belief that PWA do not die but rather disappear (Antwi, 2018). A similar belief exists in Malawi that suggests that PWA were not really people, not humans and hence do not die (Braathen & Ingstad, 2006). In Anlo-Ewe, a

language spoken in Ghana, “*Gesoshi*”, a name given to PWA, refers to a supernatural incomplete being suggesting that PWA are not fully human (Under the Same Sun [UTSS], 2015).

In Zimbabwe, there is the belief by some that PWA were born into the community gifted with many magical powers, blessings and gifts from the ancestors. As such, these individuals with such gifts must not live, rather be killed ritually soon after birth and offered back to the ancestors as a sacrifice. This would enable the rest of the population without the condition to be blessed in all aspects of their lives (Machoko, 2013). There has not been much academic research on the perceptions of the origins of albinism in Ghana. However, Wiafe-Akenteng (2017) found that in a sample of 146 university and non-university students in Ghana, less than half of the respondents ($N=64$) held traditional beliefs about the causes of albinism. A politician in Ghana announced on radio that his background research on albinism revealed that the condition was the result of sexual intercourse with a woman during her time of menstruation (Ayumu, 2017). There was the additional belief of contagion among people without the condition in other African countries. Braathen and Ingstad (2006) for example mentioned the practice of pregnant mothers in Malawi spitting when they saw a person with albinism so as to not give birth to a child with albinism. Baker et al. (2010) found that a majority of South Africans feared albinism to be contagious hence avoided contact with people with the condition. A respondent in their study recalled being told by her mother that her condition was as a result of her mother ‘catching the albinism’ when she touched a baby with albinism while pregnant with her. People in South Africa went to lengths to prevent ‘catching albinism’ from those with the condition. The mysteriousness around PWA cause people to fear them, admire them, or in some cases both.

Effect of albinism on social relationships. Unfortunately, fear has been reported as the dominant attitude towards PWA in Africa rather than admiration. PWA Zimbabwe are called names, ridiculed, beaten and avoided by peers who would not play with them. Others refuse to shake hands with them, which can be awkward and uncomfortable in certain social circumstances, like funerals where it is customary to shake hands to show bereavement. Some refuse to sit next to or share public transportation with PWA (Cruz-inigo et al., 2011). A New York Times Report in Ghana by Thompson-Hernández (2018) tell the story of a PWA who experienced cold stares and avoidance by people in public transport even when there was no other place to be seated. Even in instances where PWA migrated from their countries to countries they believed to be safer, they still experienced stigma from the community because superstitious beliefs prevented them from integrating with others in the community.

Similar beliefs regarding a particular phenomenon suggests similar cultural practices between African countries (Ikumola, 2015a). Ikumola interviewed PWA who had migrated from Tanzania to Kenya and South Africa to seek refuge and found that PWA suffered more discrimination than the average migrant because they were regarded firstly as strangers, and further as ‘strange beings’ because of their skin colour. Some respondents admitted to name calling such as ‘colonial masters,’ ‘white spy’, and ‘black Afrikaner’. Although they admitted that these names were often used playfully, they were hurtful to be described as colonial masters knowing the history of colonialism in Africa. Some respondents revealed systematic sidelining at school, religious, and business centers. For example, a respondent recalled how he had no friends at school and would have people talk to him only when there was a compulsory group assignment. Some shop owners in South Africa would not attend to PWA in the mornings because they believed it would bring them bad luck. There was also the popular belief not to engage PWA in

arguments as it could result in misfortunes. Another study conducted by Phatoli et al. (2015), in which the investigators interviewed five students with albinism and 10 without the condition found that some individuals without albinism had some stigmatizing perceptions about persons with albinism without enacting them, while others enacted the perceived stigma. One participant, for example, reported to have spat upon a person with albinism to prevent bad luck. As a way of dealing with the stigma surrounding albinism, participants excluded themselves from the rest of the population in order not to be judged or discriminated against.

Braathen and Ingstad (2006) in a study in Malawi indicated that PWA were stigmatized and treated differently depending on the social situation. In certain social situations, PWA were treated with respect and dignity just like anyone else. This ambiguity surrounding PWA was also evident in studies by Machoko (2013) and Selepe (2007). According to Machoko (2013), PWA were viewed as belonging to a magical world capable of doing good or evil. Some individuals believed PWA were a blessing to the community while others were of the belief that PWA were a bane to the community. Selepe (2007) found that some PWA in South Africa were treated with respect, acceptance and admiration by people in their community and stigmatized in other social situations.

According to UTSS (2015), PWA in Ghana experience name-calling. The name *Ofri* is alluded to mean 'borrowed skin' in the Akan language which iterates the perception that a PWA is a black man with a borrowed white skin (Akomolafe, 2010). A respondent interviewed by Akoyam (2015) recalls being called names like monkey, pig and small god in his village where he was the first to be born with albinism. There have been numerous reports of the hunting and killing of PWA in other African countries (Cruz-inigo et al., 2011; Ikumola, 2015). Parish (2003) as cited in Cimpric (2010) also makes mention of the trade of body parts of PWA in Ghana. Although a web search of

journal and online newspaper articles of killings of persons with albinism in Ghana revealed alleged incidences of the killing of PWA, there have not been any in-depth investigations into these claims. It would appear, per the literature currently available, that PWA in Ghana are not persecuted as rigorously as those in other African countries. However, myths surrounding their conditions can create the preconditions for attacks (UTSS, 2015). Abdul-Karim (2017) interviewed a member of GAPA who revealed that he was almost killed when he travelled to areas in the Eastern Region of Ghana in search of work, because of the belief that there would be a bumper harvest when a PWA was sacrificed to a particular god in that community. According to this respondent, a PWA was killed in that same area by a pastor for rituals.

Before the 2017 presidential elections of Ghana, an executive of GAPA appealed to the government to help protect its members since there was the belief by some politicians that the use of PWA could be beneficial to the presidential race (Antwi-Otoo, 2016). Communities like Atebubu and Abaase in the BrongAhafo Region, Burukuwa in the Kwahu North District and Akwamufie in the Eastern Region, do not allow persons with albinism to live there (Adogla-Bessa, 2017). The traditional chief of Burukuwa had announced that he could not guarantee the safety of PWA who chose to stay in Burukuwa because the god of the town had a grudge with PWA which spanned over 300 years (Akomolafe, 2010). A first year student of Atebubu Senior High School had been refused residency because, according to the traditional leaders, it was a taboo for a PWA to live in that village (Boateng, 2015).

Some stigma and discrimination against PWA involves preventing them from occupying certain traditional offices such as being a Chief. In Ghana, according to Akomolafe (2010), in the event that the eldest son in the line of traditional chieftainship happened to be a PWA, the throne would be passed over to his younger brother without

the condition as the community considers him to be polluted with albinism. Tweneboah (2012) examined the sacred nature of Akan chieftaincy, and found that in the Akan community, persons who were light-skinned could not ascend the throne. The author further explained light-skinned to mean lighter in dark skin complexion, a white person, or a PWA. The author went on to emphatically state that the latter was an impairment to the throne since a PWA was not only light skinned but also a person with a disability.

The narrative in Benin is strongly converse. PWA are reported to be treated with the utmost respect and admiration. It was an honor if a PWA entered a home and took food or other things from that home. “In Kongo, albinos are considered as special people. They are respected by everyone, so much so that they are allowed to visit the market and homes, and take whatever they need in terms of food or other things” (Cimpric, 2010, p. 28). PWA were at times forced to attend important political events like the election of the President of the Republic in Mali because of the belief that their presence would bring good luck to the candidates (Machoko, 2013). In South Africa, Selepe (2007) encountered a respondent who received admiration as she recalled some children who were fascinated by her skin color and hair and wished they had her skin and ‘golden hair’. This ambiguity surrounding the condition most often has no effect on the negative consequences of albinism. In Zimbabwe for example, if a PWA was perceived to possess a water spirit which was responsible for good fortune, he/she was killed to bring good fortune to others. If they believed that that PWA possessed evil spirits and would bring misfortune to the community, they were discriminated, stigmatized and eventually killed to safeguard the interests of the community (Machoko, 2013).

Effect of albinism on personal relationships and employment. PWA are also stigmatized in their attempt to form interpersonal relationships and gain employment. In some parts of Zimbabwe, there was the belief among others that PWA were not to marry.

This was fueled by the belief that mermaids (as PWA were believed to be) should not be married, and that they should rather be used for ritual sexual intercourse by chiefs and their relatives for the strengthening of chieftainship or for bringing prosperity (Machoko, 2013). In Ghana, many people do not consent to their relatives marrying a PWA (Akomolafe, 2010). Persons without the condition face stiff objections and opposition from family members when they want to be in relationships with PWA (Baker et al., 2010). According to Nzewla (2016), PWA were usually a last resort for men and women who could not attract any other person and women with albinism were more likely to find themselves in polygamous marriage. Ikumola (2015b), exploring the sexuality of PWA, found that men with albinism were more likely to get married compared to women with albinism. According to him, this is due to the patriarchal nature of African communities where male children were tasked with carrying the family name, thus, most male families took pains to ensure their male children got brides. Men who were more financially stable also had more chances of finding partners.

Work is an important factor for social acceptance and PWA often experience stigma in work settings. In the case of PWA, seeking employment offered many challenges since both their appearance and visual impairment played a role in the manner in which potential employees regarded them (Baker et al., 2010). Kuster (2000) as cited in (Cruz-inigo et al., 2011) discovered an educated PWA who had never held a job because her employers believed having her as a secretary would hurt the company's reputation and that albinism was contagious. Braathen and Ingstad (2006) interviewed a PWA in Malawi trained as a nurse who was denied employment because of the belief that the medicine used on patients would be too harsh on her skin.

Well-being and Quality of life of PWA

The majority of research on PWA has focused mainly on discrimination and the hunting of PWA for rituals. For the purpose of this study and the variables under investigation, literature that includes work on variables that seek to investigate well-being and quality of life are reviewed.

Studies on quality of life of PWA in Africa do not focus much on subjective reports of quality of life as they do on health-related quality of life. However, most studies report that PWA have poor quality of life. Kiprono, Joseph, Naafs and Chaula (2012) conducted a study with 149 participants with OCA in northern Tanzania, assessing the effect albinism had on quality of life. Participants reported very poor quality of life in relation to areas of education, relationships, and employment, and faced discrimination and challenges integrating into the community. The validated Nigerian version of the Dermatology Life Quality Index (DLQI) was used to assess quality of life. Majority of the respondents (60.4%) reported a high effect of albinism on their quality of life. When it came to the effect of albinism on relationships, a majority of those married reported marital problems due to their skin colour. Half of the respondents who were previously married reported albinism as the main reason for the breakdown of their marriage. A majority of the respondents (80.5%) reported having no problems with developing a relationship, whereas 17 (11.4%) had many difficulties in developing a relationship because of their condition. Consistent with most studies in Africa on PWA, a majority of the respondents (82.5%) had no problems with their family members, whereas the remaining 6% reported having severe problems with family members. Albinism also had an effect on employment. A majority of the respondents were unemployed (53.1%), whereas 39.8% were self-employed and 7% formally employed. Thirty-one (46.6%) of those respondents who were unemployed believed the reason for their unemployment was

because of their skin. Half (30) of those employed faced challenges in their work which was associated with sun exposure and poor vision. Another 6 (10%) experienced discrimination at work place. In the rural areas most of the respondents were farmers or worked in informal sectors.

In Braathen and Ingstad's (2006) in-depth interview with 25 people with albinism and their family members, they found that persons with albinism in Malawi had poor quality of life. However, the researchers emphatically stated that they could not attribute this to their condition since Malawians generally had poor quality of life. Selepe (2007) conducted a study in South Africa involving 40 teenagers with OCA and 60 teenagers without the condition between ages 13-19 years, to measure their level of self-esteem while investigating their experiences as PWA. The researcher found that regardless of the stigma PWA in the study faced, they 'ignored negative comments and did not take them to heart' (p. 48). PWA in the study reported higher self-esteem compared to those without the condition. The positive way these individuals saw, thought, and felt about themselves enabled them to be assertive and eventually strive towards self-actualization.

When compared with other skin conditions, results have generally favored the wellbeing of PWA compared to people living with other extensive visible skin conditions. Attama et al. (2016) compared the quality of life between people with leprosy and persons with albinism in south east Nigeria with 200 ($N= 100$, leprosy, $N= 100$, PWA). Participants with leprosy reported lower quality of life than PWA in all 4 domains of The World Health Organization Quality of Life-Brief (WHOQoL-Brief); physical, psychological, social relationship and environment domains. Ajose, Parker, Merrall, Adewuya, and Zachariah (2014) compared psychiatric distress between people with vitiligo and PWA in Nigeria using the Hospital Anxiety and Depression Scale (HADS) in a sample of 87 albinos and 102 vitiligo adult patients. Psychiatric distress was higher in

people with vitiligo (59%) compared to those with albinism (26%). Out of the respondents with psychiatric distress, people with vitiligo experienced more anxiety and depression compared to those with albinism. Attama et al. (2015) investigated the psychiatric morbidity among people with leprosy and albinism in southeast Nigeria. Hundred participants for each population were recruited. The General Health Questionnaire (GHQ-28) and Mini-International Neuropsychiatric Interview (MINI) were used. Results of the study revealed that at the cut off score of 5, people who had leprosy (55%) scored more compared to those with albinism (41%) for psychiatric distress. The risk of developing psychiatric morbidity was significantly higher among patients with leprosy than those with albinism. However, when specific psychiatric disorders were investigated on the MINI, persons with albinism scored more on the depression and generalized anxiety disorder scale. People with leprosy however scored more for drug/alcohol abuse.

Social support for PWA

In Braathen and Ingstad's (2006) study in Malawi, although PWA experienced discrimination from strangers, they received love and acceptance from their family members which they reported to be most important to them. Most of the parents expressed happiness when asked about their reaction to having a child with albinism. Every mother in the study spoke of a great love for their children. There were, however, situations where fathers rejected a child because of albinism. This rejection could be in mild forms where other family members avoid their relatives and refuse to share personal space or objects or in extreme cases where parents leave their babies with the condition to die (Baker et al., 2010; Cruz-inigo et al., 2011). Selepe (2007) found that the majority of participants in her study of PWA in South Africa felt comfortable in their families. They reported that their family members and their relatives accept their condition and love them unconditionally

even to the point of being overprotective compared to their siblings without the condition. Lund (2001) however reports instances where some family members would not share food or clothes with their relatives with albinism.

Brocco (2016) examined the interrelationship between individual subjectivity of people with albinism and the stigma surrounding the condition. His study involved an indepth case study of a 28-year-old woman living with albinism in Tanzania and information from seven other respondents with the condition. His analysis based on this case study was that family ties, economic situations, friendship relations, intersubjective experiences and religious thoughts influence the social and psychological management of living with albinism in Tanzania. For example, respondents in his study were called names and avoided by some members of their communities however when stigma and discrimination were perceived by the respondents as impeding their social lives, they employed coping strategies like self empowerment through religion and family support to enhance social acceptance.

Research Rationale

Persons living with albinism in Ghana, just like their counterparts in other African countries such as Malawi (Braathen & Ingstad, 2006) and Tanzania (Brocco, 2016), experience social stigma and physical attacks that affect their psychological wellbeing. To my knowledge, there is no academic research on the experiences of PWA in Ghana. Currently, the expereinces of PWA in Ghana are predominantly reported by the media. Such media reports are not accessible to many people and do not capture the views of a sizeable number of PWA. Consequently, we know very little about their experiences in Ghana. This study, therefore, seeks to explore the experiences and subjective wellbeing of PWA in Ghana and also bridge the gap in literature on the experiences of PWA in Ghana. According to Ingstad (1995), there is a need to have empirical evidence to back statements

of stigmatisation and neglect of disabled people in third world countries without assuming that it occurs universally. Scientific research provides evidence-based information because it is based on gathering observable, empirical and measurable evidence. It is objective, in that it has built-in mechanisms to reduce biased interpretations of results. Scientific research is also subjected to careful scrutiny by other scientists which in turn allows for verification by attempting to reproduce results (Glazunov,2012). The present research would provide preliminary information on the experiences of PWA in Ghana. This information will enable health care providers and the general public to understand persons living with albinism, relative to their social relationships. The hypotheses of this study are stated and illustrated in Figure 1.

Hypotheses

1. There will be a statistically significant negative relationship between stigma and subjective well-being among people living with albinism.
2. There will be a statistically significant positive relationship between social support and subjective well-being among people living with albinism.
3. Social support will significantly moderate the relationship between stigma and subjective well-being among persons living with albinism.
4. There will be statistically significant differences in subjective well-being between men and women living with albinism.

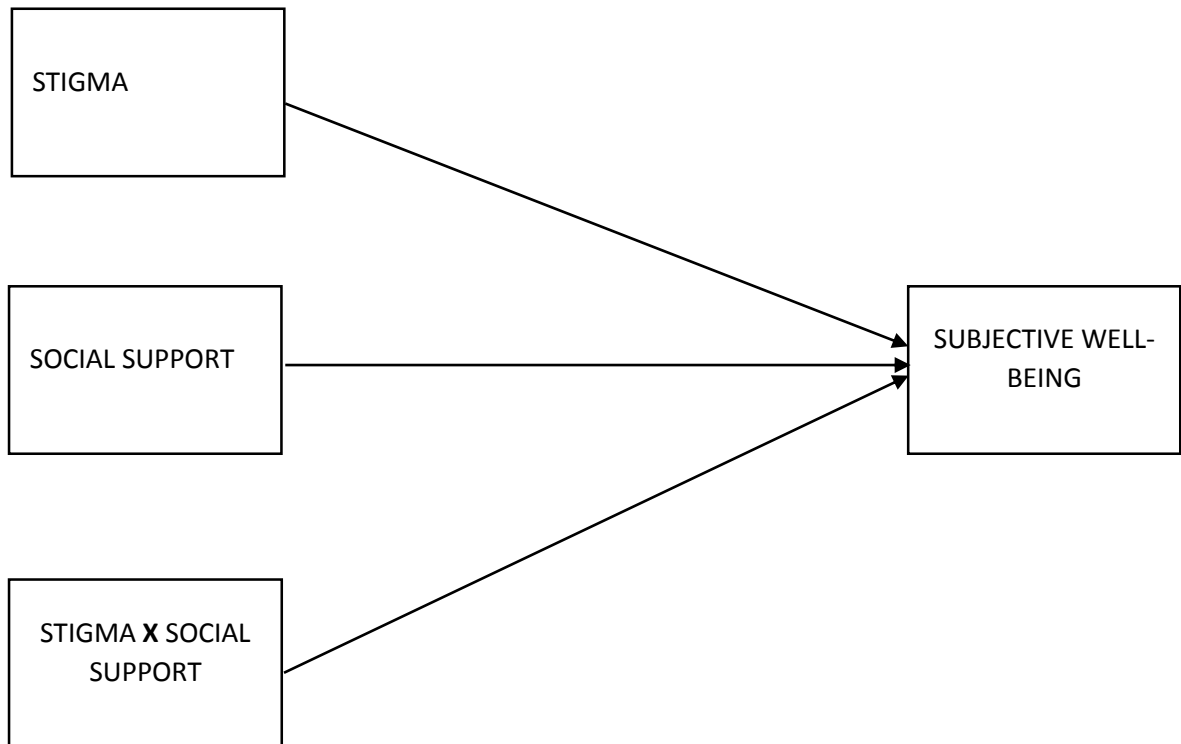


Figure 1: Hypothesised Model

CHAPTER THREE

Methodology

Participants

The participants for this study were PWA in Ghana who were members and non-members of the Ghana Association of Persons with Albinism (GAPA). Participants who were registered members of the association were recruited with the assistance of the GAPA. Only persons with OCA were selected for this study in accordance with the literature review which suggests that, OCA is the most visible form of albinism and that persons with OCA are more likely to be treated differently in a population that is predominantly dark skinned (Baker & Lund, 2017; Brocco, 2016). A total of 105 respondents ($n = 47$, male; $n = 58$, female) between the ages of 16 and 75 ($M = 31.52$, $SD = 12.06$) completed the survey. Thirty-one (31) of these respondents were living in the Greater Accra region, 10 in the Central region, 4 in the Eastern region, 32 in the Northern region, 27 in the Volta region and 1 respondent in the Brong-Ahafo region. Table 2 summarises the demographic characteristics of the respondents in this study.

Sampling Procedure

Probability method of sampling unfortunately is not always possible to undertake when there is not an easily accessible sampling frame (Browne, 2008). Because the population of interest did not have an accurate sampling frame, I used the purposive sampling technique as well as the snowballing technique to recruit participants for this study. Purposive sampling is used for special situations where the researcher uses his discretion, judgment and expertise in selecting participants with a specific purpose or characteristic in mind. Purposive sampling is also an appropriate sampling technique to use when a difficult-to-reach population needs to be studied (White & McBurney, 2013),

as it is the case in this research. The snowball sampling is also used in recruiting participants that are hard- to- reach because of feelings of social exclusion, vulnerability or disempowerment (Johnson, 2014; Sedgwick, 2013). The snowball approach used in this study involved two stages as described by Johnson (2014). The first stage involved the identification of a sample of respondents with the same or similar characteristics, which is PWA. The second stage involved the solicitation of referrals to other potentially eligible respondents believed to have the same characteristics (Johnson, 2014).

Measures

A survey questionnaire was created as an instrument for this research. The questionnaire included instructions on how respondents should complete the two parts of the questionnaire. The first part of the questionnaire instructed respondents to answer some personal questions about themselves. This section was meant to capture the demographic characteristics of the respondents. They included questions on age, sex and religious affiliation. The second part of the questionnaire instructed respondents to indicate their level of agreement or disagreement with statements found in each scale of measurement as detailed below.

The Impact of Skin Disease on Daily Life (ISDL). The ISDL was designed by Evers et al. (2008). This instrument is a comprehensive self-report questionnaire that assesses a range of health implications of chronic skin diseases. This scale includes both generic and skin-specific aspects of disease-related quality of life (Evers et al., 2008). The ISDL has been previously used in studies on chronic skin diseases. It was selected and adapted for this study because of its frequent use in the study of the quality of life of people with skin conditions that affect their well-being. The ISDL is made up of five main categories; physical functioning, psychological functioning, stressors, illness cognitions and social support. For the purpose of this study, only the subscale measuring

stigmatization was used. This six-item subscale measures how respondents are treated by others because of their skin condition. Sample items include “other people find me unattractive because of my skin disease”, “I have the feeling that other people stare at my skin disease” and “Other people avoid contact with me because of my skin disease.” The items were slightly modified to suit the population in question. For example, the wording “skin disease” was replaced with “skin colour” and so item one for example reads “Other people find me unattractive because of my skin colour”. The items on this scale are measured on a four-point Likert scale ranging from 1 (*not at all agree*) to 4 (*completely agree*). Subscale scores were calculated by summing up the subscale’s item scores. The Cronbach’s alpha for the ISDL range from 0.64 and 0.70 (Evers et al., 2008). In this study, the Cronbach alpha coefficient for the stigmatisation subscale was .89 (95% CI = .80,.89).

The Multidimensional Scale of Perceived Social Support (MSPSS). The MSPSS developed by Zimet et al. (1988) was used in measuring social support. The MSPSS addresses specifically the subjective assessment of social support adequacy from three sources: family, friends and significant others. Each source of social support consists of four items. Some items include “My family really tries to help me”, “I have a special person who is a real source of comfort to me” and “I can count on my friends when things go wrong.” Each item is rated on a 7-point Likert scale ranging from 1 (very strongly disagree) to 7 (*very strongly agree*). A total score was calculated by summing up the results for all test items and dividing the results by 12. The alpha coefficient for the total scale is reported to be 0.85 (Zimet et al., 1988). In this study, the Cronbach’s alpha coefficient for the total scale was .86 (95% CI = .81,.90).

Personal Well-being Index (PWI). Subjective Well-being was assessed with the PWI developed by the International Well Being Group (2013). The PWI scale has seven core

domains with items on satisfaction, each corresponding to a quality of life domain such as standard of living, health, achievement in life, personal relationships, safety, community-connectedness and future security. There are two optional domains measuring satisfaction with religion and general life satisfaction and were added for this study. In this study, the original 11-point scale (0-11) was replaced with a 7-point Likert scale ranging from 1 (*very dissatisfied*) to 7 (*very satisfied*). Sample items are “How satisfied are you with feeling part of your community?”, “How satisfied are you with your personal relationships?”, “How satisfied are you with how safe you feel?”, and “How satisfied are you with your future security?”

The Cronbach’s alpha lies between .70 and .85 in Australia and abroad (International Well Being Group, 2013). The Cronbach’s alpha coefficient reported for this scale in this study is .83 (CI = .78,.88).

Data Collection Procedure

Data collection began after ethical approval was given by the Ethics Committee for Humanities (ECH), University of Ghana. This study adhered to the ethical standards provided by the American Psychological Association Ethics Code, the Ghana Psychological Council and the ECH. Information about the participants was confidential and the rights of participants were respected as much as possible. There was an explanation of the research and participants were informed of their right to end their participation if they did not feel comfortable at any point and time of the study, although they were encouraged to participate. All participants agreed to take part in the study except one who declined to take part. There were no participants who were unable to give consent to take part in the study due to cognitive deficits and all participants understood the nature of the study. For those persons below the age of 18, consent was first sought from their parents or guardians, whereas they provided assent. Care was taken by the researcher to

protect participants in this research from physical and mental discomfort, harm, and danger. For example, because this population is sensitive to sunlight, data collection was not conducted in areas where there was direct skin exposure to sunlight. Also, the questionnaires were printed out in font size 22 to accommodate those persons with low vision.

Data was first collected from a total of 31 respondents in Accra. All participants in Accra were members of GAPA and so they were recruited with the assistance of a member of the association who happened to be the immediate past secretary of the association. Participants were phoned first and then meetings arranged at their convenience. The questionnaires were completed either personally by the participants or had items and responses read out to them after which the participants were requested to select an appropriate response to each item, with assistance from the researcher and research assistants. The items on the questionnaire were read out to some participants because they had poor vision and found it difficult to see the items on the questionnaire although the items were printed in large font size. Participants who were not literate enough in the English language, the language of the questionnaire, were assisted to complete the questionnaire by the researcher together with the research assistants.

The second phase of data collection was done in Cape Coast, at a regional meeting of GAPA. A total of 10 PWA were present at the meeting and they all consented to complete the questionnaire. The third phase of data collection was done at Ho in the Volta Region. PWA in the Volta Region from whom data was collected were both members of the association and persons who were not members. Twenty-three (23) respondents were members of the association and 4 were not.

The fourth phase of data collection was carried out at Tamale in the Northern Region of Ghana. Some respondents in this region were members of the association but a majority of them were not members. A total of 32 people therefore completed the survey in this region. Some respondents completed the questionnaires personally while others were assisted to do so.

The final phase of data collection was done at Nsuobetor in the Eastern Region, where a sensitization programme was organised by “Engage Now”, a Non-Governmental Agency whose agenda include improving the quality of life of PWA. Data was obtained from a total of 5 persons from the Eastern Region. Throughout the data collection, research assistants with proficiency in the local languages where data were collected, assisted with the data collection process. In addition, the former GAPA Secretary who also has enormous experience in research provided timely assistance when needed. All research assistants received training prior to the conduct of the study.

Design

The research design for this study was a cross-sectional survey and standardized questionnaires were administered.

Analytic Strategy

All analyses for this study were conducted using the IBM Statistical Package for Social Science (SPSS) version 23.0. Normality checks were done on the data. Furthermore, descriptive analyses of the demographic variables were examined. Skewness and kurtosis were well within recommended ranges ± 2 advocated by proponents (e.g., Field, 2009; Trochim & Donnelly, 2006). To investigate the dimensionality of the constructs, exploratory factor analyses (EFA) were performed (Suhr, 2003). The principal component analysis (PCA) was used as the factor extraction method

in this study. This method uses the original correlation matrix and extracts factors that account for less and less variance of the underlying latent variable (Pallant, 2011). To assess factorability of the data, the Kaiser-Meyer-Olkin (KMO; Kaiser, 1974) measure of sampling adequacy and Barlett's Test of Sphericity (Bartlett, 1954) were used. The minimum factor loading was determined using ($r \geq .40$; Field, 2009) for the retention of items. Items that did not meet this cut-off criterion were deleted and not used in further analyses. Cattell's scree test and Kaiser's criterion were used to determine the number of factors to retain. The oblique rotation solution was used (direct oblimin). A one-factor solution for each scale was maintained after each analysis because a unidimensional construct was expected for further analyses.

Following the exploratory factor analyses, the internal consistency reliability (Cronbach's alpha) for each measurement scale was calculated as reported in the measures section.

To determine the suitability of the data for a hierarchical multiple regression a bivariate correlation was performed. To test the moderation hypothesis, the procedure recommended by Aiken and West (1991) was performed. The predictor variables under investigation were standardized before computing the interactions terms. The moderator variable was created by calculating the products of both standardized scores. Standardization of the scores was done to reduce multi collinearity and to enhance the interpretability of the interaction terms. At step 1, stigma and social support were entered into the regression equation as independent variables and subjective well-being as the dependent variable. At step 2, the dependent variable was maintained while the moderator (stigma x social support) was entered into the model.

CHAPTER FOUR

Results

Preliminary Results

The means, standard deviations, Cronbach's alphas, skewness and kurtosis of the study variables are reported in Table 1.

Table 1

Descriptive statistics and inter-correlations of variables.

Variables	M (SD)	Skew	Kurt	α	1	2	3
1 SWB	24.99(9.48)	-.18	-.75	.83	-		
2 Stigma	17.09(5.19)	-.41	-1.36	.85	-.46***	-	
3 Social Support	22.84(10.39)	1.51	-.87	.86	.39***	-.28*	-

Note. *** $p < .001$; * $p < .05$; Skew = skewness; Kurt = kurtosis; M = mean; SD = standard deviation

Demographic Characteristics of the Sample. A total of 105 respondents ($n = 47$, males; $n = 58$, females) between the ages of 16 and 75 ($M = 31.52$, $SD = 12.06$) completed the survey. Thirty-one (31) of these respondents were living in the Greater Accra region, 10 in the Central region, 4 in the Eastern region, 32 in the Northern region, 27 in the Volta region and 1 respondent in the Brong-Ahafo region. Out of this sample, 48 of the participants were married while 56 respondents were unmarried. Table 2 presents a summary of the demographics characteristics.

Table 2

Demographics of sample.

Variables	<i>N</i>	%	<i>M</i>	<i>SD</i>
Gender				
Male	47	44.8		
Female	58	55.2		
Age			31.52	12.06
Marital Status				
Married	48	45.7		
Unmarried	56	53.3		
Missing data	1	1		
Level of Education				
JHS	39	37.1		
SHS	34	32.4		
Diploma	11	10.5		
Degree	11	10.5		
Masters degree	4	3.8		
No formal education	6	5.7		
Religion				
Christian	62	59.0		
Muslim	41	39.0		
Other	2	1.9		
Region				
Greater Accra	31	29.5		
Central Region	10	9.5		
Eastern Region	4	3.8		
Northern Region	32	30.5		
Volta Region	27	25.7		
Brong-Ahafo Region	1	1.0		

Main Results

Hypothesis one. Hypothesis 1 states that there will be a statistically significant negative relationship between stigma and subjective well-being among PWA. The results from a hierarchical multiple regression reveals that social stigma had a negative relationship with subjective well-being ($B = -.38, p < .001$). The model was significant, $R^2 = .27, F(2, 102) = 19.19, p < .001$ with the model explaining 27% of the variance in subjective well-being. Thus, the hypothesis that stigma will have a negative relationship with subjective well-being was supported (see Table 3).

Hypothesis Two. Hypothesis 2 states that there will be a statistically significant positive relationship between social support and subjective well-being among PWA. The result reveals that a significant positive relationship exists between social support and SWB significantly contributing to the variance in SWB at ($B = .28, p < .01$). Thus, the hypothesis that social support will have a positive relationship with subjective well-being was supported.

Hypothesis Three. Hypothesis 3 states that social support will moderate the relationship between social stigma and subjective well-being among people with albinism. It was found that social support did not moderate the relationship between stigma and subjective well-being as indicated by the non-significant interaction effect ($\beta = -.12, p = .144$). This means that Hypothesis 3 was rejected.

Table 3

Hierarchical Multiple Regression Analyses for Stigma, Social Support and SWB.

Variable	B	SEB	β	T	R^2	ΔR^2	Model F	ΔF
Step 1					.27		19.19***	
Constant	20.99	.70		29.6				
Stigma	-3.11	.75	-.38***	-4.7				
Social Support	2.27	.74	.28*	2.9				
Step 2					.29	.02	13.67***	2.17 ^{ns}
Constant	20.78	.72		28.2				
Stigma	-3.02	.75	-.37***	-4.5				
Social Support	2.36	.74	.29**	3.0				
Stigma x Support	-.77	.73	-.12 ^{ns}	-1.33				

Note. Dependent variable = Subjective Well-being. * $p < .05$, *** $p < .001$, *ns* = not significant

Hypothesis Four. Hypothesis 4 states that there would be a significant difference in subjective well-being between men and women living with albinism. Using an independent samples t-test the results show that men ($M = 21.52$, $SD = 8.50$) reported slightly higher levels of subjective well-being than women ($M = 18.90$, $SD = 7.55$). However, this result was not statistically significant ($t [102] = 1.67$, $p = .25$). This means that the hypothesis was rejected (see Table 4).

Table 4

Independent T-Test comparing males and females on Subjective well-being (N = 104)

Gender	<i>n</i>	<i>M (SD)</i>	<i>t</i>	<i>df</i>	<i>P</i>
Male	46	21.52 (8.50)	1.67	102	.25
Female	58	18.90 (7.55)			

Note. M = Mean. SD = Standard deviation.

Summary of results

The study found that stigma is negatively related to subjective well-being (see Figure 2, for the observed model). This implies that increasing levels of stigma is related to poorer subjective well-being. The study also found that social support is positively related to subjective well-being meaning higher levels of social support leads to higher levels of subjective well-being. Social support however did not moderate the relationship between stigma and subjective well-being. No significant gender differences were found in subjective well-being.

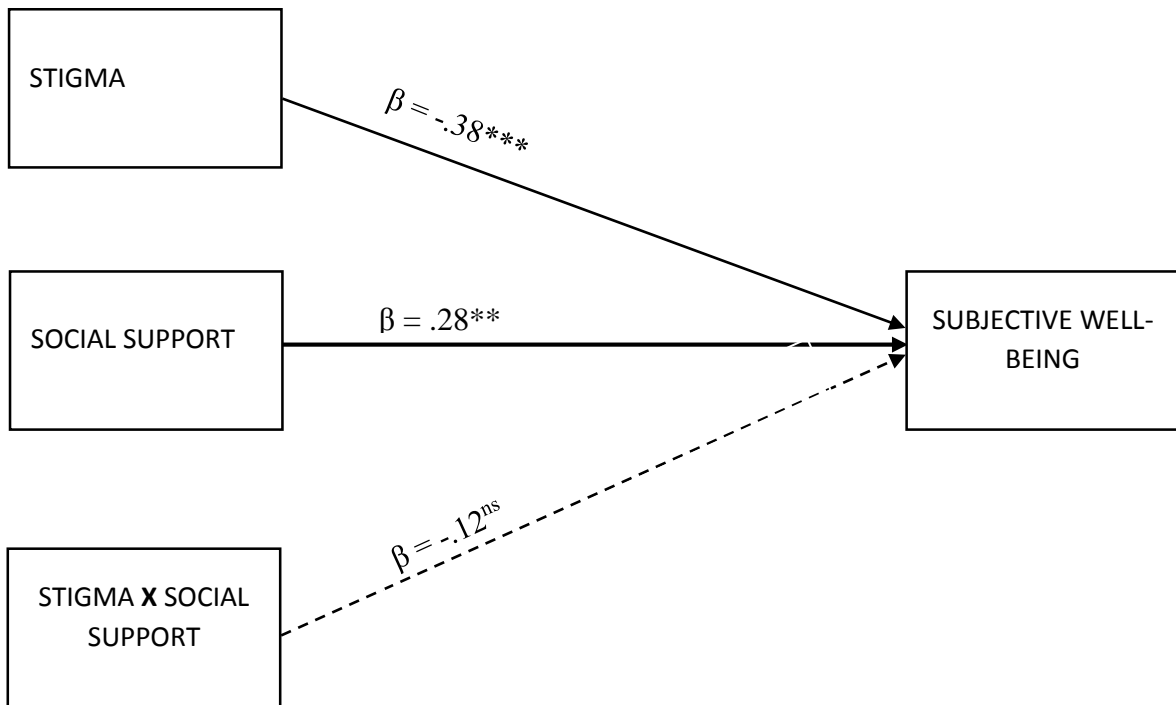


Figure 2: Observed Model

Figure 2 represents the observed model of the study. Social support and stigma have a direct effect on SWB. The interaction of social support and stigma however have no moderating effect on SWB

CHAPTER FIVE

Discussion

Stigma and SWB

The aim of this study was to investigate the experiences of PWA in Ghana by assessing stigma, social support, and SWB. This study also examined the moderating role of social support on the relationship between stigma and SWB. As predicted, stigma was significantly negatively related to SWB. In addition, social support significantly positively predicted SWB. Social support did not moderate the relationship between stigma and SWB and there were no gender differences in SWB.

PWA in this study experienced forms of stigma like those reported in other African countries (Baker et al. 2010; Cruz-ingio et al. 2011; Ikumola, 2015). These experiences included unpleasant remarks about their skin, stares, avoidance and perceived unattractiveness by others. The level of stigma varied according to the type of stigma experienced. The most persistent stigmatizing attitude experienced by respondents was being subjected to stares by others. When it came to feelings of attractiveness, a majority of the respondents ($N= 81$) believed they were perceived as unattractive by others. A reason for this may be that in a country that has a population with predominantly dark-skinned complexion, the preconception of beauty may be more biased to include characteristics salient in a 'normal skinned' person. In addition to this problem of skin colour not fitting in with the 'normals', the lack of melanin production exposes their skin to harsh climatic conditions resulting in blemishes and sun spots. PWA in Ghana do not have the advantage of having white flawless skin like those with the condition in less temperate regions. A majority of the participants had bad skin because of lack of protection from the sun. This may be the basis on which many people find PWA to be unattractive.

With regards to unpleasant remarks made about their skin only 11 participants did not identify at all with this phenomenon. Although this study did not investigate what type of unpleasant remarks were passed, it may be inferred from literature that these unpleasant remarks would involve name-calling. The literature in Ghana shows that PWA experience name-calling which were deemed by them as derogatory and unacceptable. Name-calling is part of the ongoing process of stigma where the stigmatized are constantly reminded of their difference. Name-calling of PWA in Ghana usually involves labels that describe the mysteriousness of albinism which has the tendency to perpetuate their alienation and isolation. The stigmatizing attitude which was found to be inconsistent with other studies was the issue of contagion. Most participants in this study revealed that people were not of the belief that albinism was contagious.

Regarding the relationship between stigma and SWB, the results revealed that the more stigma respondents felt, the less SWB they reported. These results are consistent with those of other studies that have linked stigma to negative consequences (Major, 2008; Miller, 2008). PWA experience chronic stigma which is a constant reminder of their difference. Feelings of not belonging in a society that thrives on community living will have a negative impact on how an individual positively evaluates his/her life. Constant rejection results in negative feelings like low self-esteem, depression, hurt, anger and in extreme cases suicidal feelings (DeWall & Bushman, 2011). Due to the chronic stigma experienced, PWA in Ghana find themselves in environments that constantly expose them to negative and distressing situations. As such, they have to constantly find ways to deal with the stressors from the society. According to Major (2008), people with a stigmatized identity experience what is termed social identity threat. This leads them to become alert to situational cues that signify a possible devaluation on the basis of their social identity. Being on high-alert for such cues and trying to challenge them if necessary, is an extra

burden that can impair well-being. High alert for such cues can further lead to more physiological arousal and in particular, cardiovascular responses among stigmatized persons which can result in negative health outcomes and further influence a preexisting health condition negatively (Berjot & Gillet, 2011; Garrido-hernansaiz, Heylen, Bharat, Ramakrishna, & Ekstrand, 2016).

Additionally, stigma does not only lead to isolation but also results in prejudice, mistreatment and discrimination. There is the tendency for PWA to be mistreated because a rationale has been created for this mistreatment. Due to the fact that they are not seen as part of the society, others may not feel obligated to protect their well-being as they would have done for others. Constantly protecting oneself against potential mistreatment adds to the burden of daily living and will result in negative psychological states. PWA compared to the rest of the population may have limited access to certain resources such as employment, housing, occupational advancement and educational opportunities (Baker et al., 2010). These limitations can have a negative effect on how PWA live fulfilling and satisfying lives as they may be more concerned about surviving in a society that rejects them rather than enjoying life to the fullest.

Social Support and SWB

Studies that investigated social support of PWA in Africa found an important source of social support for PWA to come from families (e.g. Braathen & Ingstad, 2006; Brocco, 2016). This study's findings are consistent with this literature that reveal that although PWA are shunned by others, they are loved and respected by other people, especially those around them. Most of the stigma experienced is from outsiders who have no relationships with PWA. Those around them treat them with love and respect. In this study, participants reported receiving more social support from significant others compared to family and friends. A probable reason for high social support from significant

others may be because persons without the condition face stiff objection and opposition from family members when they want to be in relationships with PWA. It would appear that participants in this study who had partners had found people who accepted them wholeheartedly and supported them regardless of their condition and opposition from others. According to Mickelson (2001),

Individuals who perceive a stigma may feel that those who live with them and their stressor on a day-to-day basis are more accepting and understanding, whereas those outside the household are more judgmental. Furthermore, their fear of rejection or insult may lead to impaired perceptions of support availability and social interactions as well as to increased withdrawal from their network of family and friends (p.1047).

A majority of participants in the Northern Region were married. This may be partly influenced by the culture and religion in the Northern Region. According to de Groot, Kuunyem, and Palermo (2018) the incidence of child marriages is highest in the three Northern regions in Ghana than that of the whole country. This study did not investigate if those female participants who were married were in a monogamous or polygamous marriage. However, the culture, religion, and traditions in the Northern region allow for a man to marry more than one wife (van Bodegom, 2011) and according to Nzelwa (2016), women with albinism often found themselves as second wives.

The positive relationship between social support and SWB suggest that feelings of belonging even from a small group of people result in positive feelings. This in turn enhances positive evaluations of life. Social support from a select few was instrumental in making PWA feel better about their condition because it creates the impression that even though others rejected them, there were those who were willing to embrace and accept them regardless. Social support can also reduce the uncertainty about a threatening situation and offer options on how to solve problems that was faced by respondents.

Talking to friends and family may be enough to reduce negative feelings resulting from stigma experienced. For respondents, the presence of family, friends and significant others may have created and/or enhanced positive feelings like love, acceptance, and increased self-esteem with their constant encouragement and motivation. This may have been enough to make them look at life from a different (positive) perspective in a society that is rejecting. Social support also means social acceptance from a group of people. When individuals belong to a group they are motivated to maintain healthy behaviours and lifestyle because of feelings of obligation to other members of the group. This is so they can protect each other and be available for one another in times of need. A majority of the respondents in this study reported being satisfied with their life on a whole which is consistent with Addai et al. (2013) whose study on SWB in the Ghanaian population revealed 61% respondents reported being satisfied and somewhat satisfied in life with only 25% of Ghanaians indicating that they were not satisfied in life. According to Major (2008), members of many chronically stigmatized groups report positive levels of subjective well-being. Results from this study indicate that when PWA have close social ties, they report positive mental health supporting the assertion by Kapteyn et al. (2009) that although there are no significant determinants of subjective well-being, positive social relationships may influence subjective well-being.

Moderating role of social support

Although social support had a positive influence on SWB of participants, it was not in itself sufficient to moderate the effects of stigma on SWB. There have been mixed results when it comes to the moderating role of social support on outcomes of psychological distress and well-being (Pascoe & Richman, 2009). These mixed results suggest a complex relationship between stress and social support. A possible explanation for this may be that the effects of stigma are so strong that although social support was

available, it was ineffective as a coping mechanism for the stresses of stigma. Link et al. (1997) found negative effects of stigma to be so enduring that even when processes were put in place to moderate stigma, they failed because of the deeply held stereotypes and beliefs by others. Chronic stigma has resulted in automatic differential treatment of those who were perceived as bearing a mark of deviance. Regarding participants in this study, although they were satisfied with the social support they received, this support was not enough to mitigate the effect of stigma on their SWB. In other words, it may be argued that the effects of stigma may have been so persistent and prevalent that the social support provided and received by the participants in this study was not enough to buffer the negative effects on SWB.

When levels of stress are disproportionately higher than the levels of social support available, the buffering effect of social support is undermined (Cohen & Wills, 1985). This is especially evident in chronically stigmatized populations where chronic stigma can influence the availability of social support. Various researchers (Cohen & Wills, 1985), Mickelson, 2001;) Takada, Weiser, Kumbakumba, Muzoora, & Martin, 2014) found that when the stigma surrounding an individual is so strong, it affected that person's access to and mobilization of social support. Goffman (1963) described this as "courtesy stigma" which is the process where people who are "related through the social structure to a stigmatized individual...are all obliged to share some of the discredit of the stigmatized person" (p. 30). Other work suggest that people do not offer support for the fear that they may be linked to such undesirable characteristics too. Another effect stigma can have on the access and mobilization of social support is when stigmatized individuals start to believe and internalize the negative stereotypes held against them (self-stigma). When this happens, it leads to the development of negative feelings like shame, low self-esteem, and isolation (Corrigan & Watson, 2002; Link et al., 1997) and prevents them

from seeking help from others. Isolation from others serves as a way to protect oneself from the threat of rejection and therefore, even when social support is available, PWA would rather not seek it for the fear of being turned away.

Another explanation for this finding may be that the support that was provided was different from what was needed by the recipient. According to Thoits (1982), not all sources and types of social support are adequately effective in reducing distress and also not all social ties possessed by individuals are necessarily supportive. For example, Atefoe (2013) in a study on the mental health of women in Ghana found that the influence of perceived social support depends on whether the support available is helpful or not. She hypothesised that the respondents in her study may not have considered the social support available as helpful or perhaps they perceive or experience unpleasant interactions from these sources of support. According to Cohen and Wills (1985), social support also acts as a buffer to specific needs and not a wide range of needs. The stigma experienced by participants in this study may require them to benefit more from a different type of coping mechanism rather than the one investigated. Although perceived social support has been found to be a better indicator of mental health, this relationship is so because perceived social support prevents psychological distress while received social support is engaged when distress has occurred. Participants experience stigma which may be chronic and hence may utilize received social support more effectively than perceived social support. For example, most of the respondents in this study reported being dissatisfied with their standard of living. In this case they may not benefit much from the perception that help is readily available but would rather benefit from help that is given out. Therefore, perceived social support may not have as much buffering effects as received social support would have. Nzelwa (2016), for example, found that in a sample of PWA in Tanzania, respondents rejected coping strategies like social support as permanent solutions to

discrimination and believed they were not adequate enough to address and solve the psychosocial problems they faced.

Taylor et al. (2004) found that even when social support was available to individuals in collectivistic cultures, its mere presence did not mean that these individuals will utilize the social support. The authors investigated the patterns of social relationships practiced in a given sociocultural context and how this can affect the use and effectiveness of social support. According to them, decisions to seek social support are likely to be affected by norms and expectations of the society an individual finds himself in. A cross-cultural study using a sample of Asians and Europeans found that contrary to the notion that collectivistic communities will seek social support more, less Asians reported using social support for coping with stress compared to Europeans. The reason for this was that in collectivistic societies, individuals strive to promote group harmony. Respondents may have preferred not to burden the social network and to solve their problems individually instead. Thus, cultural differences in how individuals weigh the weight of self-goals and group goals may produce cultural differences in whether individuals cope with stressors by enlisting the help of the social support network. In this study, perceived social support was not the mechanism used by participants to counter the effects of stress. Since the transactional model of stress is an ongoing process which involves reappraisal, in the event that perceived social support did not alleviate the stressor, participants may have considered other resources like resilience, self-esteem, and religion, which have been demonstrated to moderate the effects of stigma on psychological well-being, to cope with the stresses of stigma.

Gender differences in subjective well-being.

There has been disagreement in the literature over whether there are gender differences in SWB (Giusta, Jewell, & Kambhampati, 2011). In this study, although men reported slightly higher levels of subjective well-being, the difference was not statistically significant. This is consistent with other findings in Ghana as well as other parts of the world that did not find any gender differences in well-being (e.g. Addai et al., 2013; Sahu, 2013). According to Batz and Tay (2017), gender differences may not be observed in SWB because of adaptation and habituation. Men and women both adapt to the environments and situations they find themselves in; hence, since both genders are experiencing the same surroundings, there will most likely be little gender differences in well-being overall. Also, individuals who go through certain experiences that are chronic (e.g. stigma and discrimination) become used to those experiences; hence there will be little or no gender difference in subjective wellbeing since they are all in it together. Giusta et al. echoes this notion by stating that gender effects often disappear when measuring SWB of specific subgroups of the population. The non-significant difference in SWB between the genders may be because they are a very specific subgroup who go through chronic stigmatization; hence regardless of being male or female, all genders are likely to have similar life experiences. The everyday gender disparities that may account for differences in subjective well-being within the 'normal' population may not be evident in this population, as people view them as PWA first rather than males or females.

Limitations and Recommendations of the Study

There are a few limitations to note in this study. A limitation that affected this study immensely is the number of respondents who were able to complete the survey. There is no data to show the prevalence rate of albinism in Ghana and although the association has reported over 2000 members (Thompson-Hernández, 2018), these numbers

are based on NOAH estimation of the prevalence of albinism in countries outside the U.S. The current database of GAPA shows that they do not have up to 2000 members. Attempts were made to involve more people in the study by expanding the research setting to other regions in Ghana. Regarding the sample size used, there were plans by the association to organize sensitization programs in other regions but these were called off due to various reasons and therefore data collection had to be called off in those regions. For example, data was collected from only one respondent from Brong-Ahafo in Accra because there was supposed to be a sensitization program in BrongAhafo (specifically Atebubu) which unfortunately could not happen.

Although quantitative data has its advantages, it also has its disadvantages in that it is restrictive and does not allow participants to provide information that is not captured by the questionnaire. The purely quantitative nature of the research limited responses relating to daily experiences especially about stigma and also sources of stress and social support that may be peculiar to this population. Stigma, social support, and subjective well-being are all complex phenomena separately. Stigma however may have its own unique influence on how social support is received and utilized. This research therefore opens up avenues for more work to be done on the experiences of this population. Further research on this population should consider the use of qualitative research design to explore their experiences. Another limitation of this study lies in the use of translated versions of the scale as well as the use of translators. Efforts were made to ensure the validity and reliability of the translated questionnaires through the EFA. A comparative analysis however could not be conducted for the translated and original versions of the scale because the translated scales were not marked for identification for data analysis therefore there may be some information may have been lost in translation which could not be controlled.

Similar to Braathen and Ingstad (2006), this study sought to measure SWB of PWA without inferring that they are better or worse off than the rest of the population without the condition. Further studies should investigate this with comparative studies on both persons with and without the condition using the same variables to ascertain if differences noticed are as a result of the genetic condition.

Conclusion and Implications

At the time of this study, the only existing information on PWA in Ghana was from newspaper articles, both print and online. Other African countries had considerable literature on the experiences of PWA however much of that literature concentrated on the killings and persecution of PWA and stigma faced. A few studies investigated social support and quality of life, with a further minority investigating the subjective aspect of quality of life; Subjective well-being. Additionally, the studies on persons with albinism in Africa did not investigate the direct effect of stigma on variables like social support and SWB. In this study, not only was this done, but the role of social support on the relationship between stigma and personal well-being was investigated. Gender differences in subjective well-being were also investigated.

PWA in Ghana do experience stigma just like those in other African countries, and the level of stigma experienced varied on the type of stigma experienced. Consistent with other studies in Africa, PWA do receive social support from those around them and this goes a long way to positively influence their SWB. A majority of the participants reported being satisfied with their lives, however, the social support they received was low and was not in itself sufficient to moderate the effects of stigma on their SWB. There were no gender differences in SWB. This study has implications for further academic research on this population in Ghana because it provides a backdrop for which other studies can be modelled. It also has implications for studies in other African countries where variables

apart from stigma of PWA can be investigated. The results from this study have implications for the albinism community in Ghana in their efforts to raise awareness about their experiences of living with this genetic condition as this study provides preliminary information of those experiences.

For PWA in this study, the buffering effect of social support was non-existent. According to Folkman (2013), individuals go through a process known as cognitive reappraisals, where different meanings and coping strategies are employed when the previous appraisals and strategies fail. It would appear that when social support did not act as a buffer, respondents employed either different appraisals or coping strategies to deal with the stressors of stigma because only a small number of respondents reported being dissatisfied with their lives ($N= 25$). These results have implications for positive psychology interventions where therapies are developed to harness the strengths of individuals to help promote psychological well-being. Clinical and counselling psychologists who wish to provide their services to this population should consider interventions that focus on strengths as opposed to reducing distress as participants had enacted some coping strategy that did not involve the help of others to feel satisfied with their lives.

A majority of studies on albinism in Africa have revealed that a lack of awareness about the condition is what creates the stigma for PWA (Cruz-inigo et al., 2011; Masanja et al., 2015). This lack of awareness was on the part of persons with the condition, the general public, and even health care professionals (Braathen & Ingstad, 2006; Hong et al., 2006; Machoko, 2013). The differential treatment of PWA in this study suggests that efforts must be made to educate the general public on the plight of this vulnerable population and on their condition. Information about the negative consequences of stigma on the psychological health of PWA should be disseminated by individuals, NGO's and

government agencies in order to help reduce the amount of stigma experienced. Education about the condition may put others at ease in order to interact with them socially. Masanja et al. found that there was a positive relationship between education and attitudes toward PWA. The more people knew about the condition, the more compassion they showed persons with albinism.

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APPENDIX

Ethical Approval



UNIVERSITY OF GHANA
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

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

My Ref. No.....

1st November, 2017

Ms. Adjeiwa Akosua Afram
Department of Psychology
University of Ghana
Legon

Dear Ms. Afram,

ECH 026/17-18: STIGMA, PERCEIVED SOCIAL SUPPORT AND SUBJECTIVE WELL-BEING OF PERSONS WITH ALBINISM IN ACCRA, GHANA

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

Expiry Date: 31/05/18
On Agenda for: Initial Submission
Date of Submission: 18/09/17
ECH Action: Approved
Reporting: Quarterly



Please accept my congratulations.

Yours Sincerely,

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

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