

Exploring self-management in adult sickle cell disease patients' at a Teaching Hospital in Ghana

Ninon P. Amertil¹  | Elikem Keli Ayitey² | Doris Grace Kpongboe¹ | Priscilla Y. A. Attafuah^{1,3}

¹School of Nursing and Midwifery, Valley View University, Oyibi, Accra, Ghana

²DPL Data Consult, Accra, Ghana

³School of Nursing and Midwifery, University of Ghana, Accra, Ghana

Correspondence

Elikem Keli Ayitey, DPL Data Consult, Madina, Accra, Ghana
Email: keli.goldyn@gmail.com

Abstract

Aim: To evaluate the relationships among self-efficacy, uncertainty, self-management and emergency hospital visits yearly among adult sickle cell disease patients' and related demographics at a Teaching Hospital in Ghana.

Design: A quantitative cross-sectional design.

Method: A purposive and convenience sample of 85 adult clients from a sickle cell clinic in Ghana completed research instruments. Data collection occurred in March and April 2019. Instruments used were the self-efficacy scale, self-care agency scale, Mishel uncertainty scale and socio-demographic variables. Pearson correlation and regression techniques were used for analysis.

Findings: The correlation results showed a low positive and significant correlation between self-efficacy and self-management ($r = 0.357, p < .01$), a significant moderate negative relationship between self-efficacy and uncertainty ($r = -0.459, p < .01$) and a significant low negative relationship between self-management and uncertainty. For the regression, employment ($p = .003$) and marital status ($p = .002$) significantly predicted self-management among others.

Conclusion: Self-efficacy had positive and significant relationship with self-management. Similarly, patients with family support and employment experienced better self-management. Furthermore, patients with higher education and living with family had reduced illness uncertainty. Thus, the findings can improve self-care measures and mitigate illness uncertainty for better health outcomes.

KEYWORDS

Ghana, nursing, self-efficacy, self-management, sickle cell disease, uncertainty

1 | INTRODUCTION

Sickle cell disease (SCD) is a genetic disorder found mostly in people of African descent. The inherited blood disorder affects the shape of the red blood cells and marked commonly

by haemoglobin S (HbS) as opposed to the normal haemoglobin (HbA) (Matthie, 2013; Olowoyeye & Okwundu, 2010). It is estimated that SCD has an impact on approximately 20–25 million individuals globally with most residing in sub-Saharan Africa. In the United States also, around 100,000 individuals, most Black people

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2020 The Authors. *Nursing Open* published by John Wiley & Sons Ltd.

are known to carry the disease (Centers for Disease Control & Prevention, 2011).

Sickle cell disease is a chronic condition characterized by repeated painful episodes ranging in severity from mild to debilitating across the lifespan of persons. Ischaemic pain is a major feature manifesting with varying degrees of severe, episodic discomfort. It is the aggregation of the HbS in blood vessels which causes vascular occlusive crises, which in turn produces frequent and painful symptoms. This repetitive vaso-occlusive pain crises generates other complications including cerebrovascular accidents, necrosis of the hip, priapism, cardiovascular accidents and other ailments. It was found in a previous study that pain crises among persons with SCD is the most common reason cited for hospital emergency visits in the United States. As much as 67% of all hospital emergency visits out of an average annual total of more than 197,000 were attributed to pain (Yusuf et al., 2010). Generally, the frequency of pain episodes and development of complications are markers of risk of premature death among SCD population (Amertil, 1997). Apart from the physiological symptoms pointed to, persons suffering from SCD also experience severe psychosocial and psychological morbidities pervading every aspect of their life including depression, anxiety, feeling lack of self-worth and social isolation (Ahmadi et al., 2014; Amertil, 1997).

Sickle cell disease is life-long chronically disabling illness but with no reliable cure currently. Current medical interventions are largely aimed at alleviating suffering caused by pain. Individuals with SCD therefore must adopt behaviours that enhance self-management to help cope with the disease. Home self-management, in particular, has been found to mitigate pain and crises among SCD population and thus improving health and well-being. Self-management is a process where individuals affected with SCD participate actively in their health and well-being, using personal skills, abilities and attitudes for improved health outcomes and quality of life (Ahmadi et al., 2014; Jenerette & Murdaugh, 2008). Home self-management is generally considered critical in coping with SCD because of its advantages in lowering costs, enhancing health status and patients' quality of life (Jenerette et al., 2011). Self-efficacy pertains to the effectiveness of an individual to manage disease symptoms on daily basis caused by one's belief. In terms of illness uncertainty among individuals living with SCD, it is attributed to a lack of information needed to determine and predict the future of illness-related events (Amertil, 1997).

Ghana has a long history of SCD predating the scientific discovery of the illness approximately a century ago (Konotey-Ahulu, 2014). The disease is well known in most communities and Ghanaians ascribe various local names that depict the nature of the pain and complications. Recent research through a new-born screening programme indicates that 1 in 50 births in Ghana (16,000–18,000 babies per year) are born with SCD. In comparison, the disease affects 1 in 365 African American births and is recognized as a public health concern (Centers for Disease Control & Prevention, 2011). It is vital noting that more children are born with SCD than HIV which is considered a major public health problem in Ghana. In addition, 20–25 per cent of new-born children carry the sickle cell trait (Druye, 2017). The population with SCD in Ghana is estimated to be around 400,000.

Simultaneously, SCD activities at the official level are relatively new and undeveloped. Current policy, programmes and services focus on new-born screening and clinical management. Treatment services do not routinely include psychosocial interventions nor interventions that focus on building the personal capacities of patients and families to effectively self-manage the day-to-day burden of the disease. There is also a general lack of scientific knowledge of self-management measures in Ghana causing patients with SCD to resort to use of traditional medicines which can possibly aggravate health conditions (Druye, 2017).

It is indisputable that SCD exerts tremendous stress on individuals physically, emotionally and mentally across the life span. People with the disease must therefore make adjustments to cope with this life-long disease burden. To date studies that have examined the relationships among the three constructs of self-management, self-efficacy and illness uncertainty are few. Moreover, the authors were unable to identify one study focusing on Ghanaian.

2 | BACKGROUND

Sickle cell disease self-efficacy is the belief in the ability of an individual to manage disease symptoms daily producing a desired outcome. Clay and Telfair (2007) found in a study evaluating chronic pain that higher levels of self-efficacy negatively affected severity of pain, meaning that it helped to reduce pain among patients. Another study also found that reduced self-efficacy produced greater disease symptoms, increased pain and hospital visits (Jenerette & Valrie, 2010). Thus, these studies demonstrated that self-efficacy of sickle cell patients is important in managing chronic disease.

In a study analysing the relationships among self-efficacy, self-care ability, demographic variables and other factors, Matthie (2013) using an exploratory correlation analysis and regression modelling found that SCD self-efficacy had a significant effect on self-care ability. The implication is that higher self-efficacy produced higher self-care ability. In another study which surveyed African American adults with sickle cell disease, the finding was that higher levels of self-efficacy not only reduced pain severity, but also lower levels of depression, stress and anxiety. It also translated into greater coping capacity and compliance with medical regimes (Edwards et al., 2001). Molter and Abrahamson (2015) analysed the relationship between self-efficacy and SCD health outcomes using academic literature. The study also focused on the transition between paediatric and adult care among sickle cell patients. Most studies covered for the survey pointed to positive associations between transition self-efficacy and health quality among SCD population. It was found that medical actions taken to promote self-efficacy generally helped to lessen SCD pain outcomes. A similar study by Baum (2013) focusing on self-efficacy in adolescents and young adults found that self-efficacy and disease management skills are required for a successful transition to adult medical care.

Self-management/care is an individual's ability to engage in daily activities to manage SCD symptoms in collaboration with

family, healthcare provider and other stakeholders (Schulman-Green et al., 2012). SCD self-care was found to improve health, life quality and lower healthcare costs (Jenerette et al., 2011). Tanabe et al. (2010) identified general self-care strategies to manage illness and for improving health outcomes. They include themes such as self-awareness, emotional support, career selection and success factors. Others are nutrition, advocacy, knowledge, physical activity, as well as complementary and alternative medicine.

Using a descriptive analytical study employing correlation and means (*t* tests), Al Nagshabandi and Abdulmutalib (2019) explored the relationships among SCD self-care, self-efficacy and demographic variables among adult clients. The authors used instruments including the sickle cell self-efficacy scale. The findings showed a statistically significant relationship between age, marital status, level of education, patient years with sickle cell disease and self-efficacy. The self-care construct also produced a significant association with level of education, living situation and patient years with sickle cell disease. Furthermore, there was a significant correlation found between self-efficacy and self-management. In a similar study using the *t* test for pre- and post-test analysis, Ahmadi et al. (2014) assessed self-management programmes on self-efficacy in patients with SCD. Results showed that 51% of participants had moderate self-efficacy before intervention, while after the intervention, about 81% of participants showed high self-efficacy.

Lenoci et al. (2002) undertook a study of 104 adults with SCD and made use of the Chronic Illness Assessment for SCD instrument. The study outcome was that self-care behaviours were positively influenced by Perceived control subscale, Feeling concerned and Worried subscale. This infers that patients who perceived greater satisfaction with health, higher perceived control and had greater concern about health were found to practise stronger self-care behaviours. Demographic indices are also good predictors of health quality of life among persons with SCD. Some examples are respondent's age, gender, yearly income, level of education and marital status (Jenerette & Murdaugh, 2008).

Uncertainty in illness is a major source of stress in the lives of chronically ill individuals. One characteristic of chronic illness is its frequent recurrence and the unpredictability of the exacerbations. Mishel (1990) stated that living with uncertainty fosters disorganization and reduces cognitive capacities. Patients come to accept uncertainty and unpredictability of their disease as a natural course of their lives. Therefore, a lack of information needed to determine and predict the future of illness-related events represents conceptual definition of uncertainty in illness in persons with SCD.

In a study examining the relationship between stigma, illness uncertainty and selected socio-demographics among SCD patients in Jamaica, Blake et al. (2018) found among others that illness uncertainty was higher in females than males and was lower among patients with higher education. The instruments used for the study were the Mishel uncertainty scale and Stigma in SCD Scale. Importantly also, the research found a positive correlation

between stigma and SCD uncertainty. The authors observed that not many researchers incorporate illness uncertainty in studying SCD patients.

One of the earliest studies examining the relationship among self-efficacy, uncertainty and self-management in adult clients with SCD was conducted in the United States in 1997 (Amertil, 1997). It was a descriptive, cross-sectional and regression analyses using a sample of 85 participants from 3 medical institutions. Data for the study were collected using self-care agency scale, self-efficacy scale and Mishel uncertainty in illness scale, in addition to the demographic variables. Results indicated a significant low negative correlation between self-care and uncertainty ($r = -0.24, p < .05$) and a significant low positive correlation between self-care and self-efficacy ($r = -0.25, p < .05$). For the regression analyses which used self-management, uncertainty, self-efficacy as outcome variables and demographics as predictors, level of education significantly and positively predicted uncertainty.

A substantial number of studies into SCD management tend to focus on self-care and variables such as self-efficacy, demographics and others. To cite examples, Matthie et al. (2015) considered self-care, self-efficacy, social support, demographics and other variables. Some studies considered self-care, self-efficacy and demographics (Ahmadi et al., 2014; Al Nagshabandi & Abdulmutalib, 2019). Jenerette and Murdaugh (2008) examined self-care, vulnerability factors and quality of life issues. Edwards et al. (2001) investigated self-efficacy, SCD symptomatology, pain severity and number of hospital visits. Adegbola (2011) examined self-efficacy, spirituality and SCD patients' quality of life. One other study integrated uncertainty, stigma and socio-demographics (Blake et al., 2018).

Research into self-management, self-efficacy and uncertainty specifically has received less attention in the literature as demonstrated. Besides the parent study, research on the three constructs is scarce in the literature. Indeed, no evidence was found in relation to studies in the context of Ghana. Illness uncertainty generates enormous stress in the lives of individuals living with chronic illness such as SCD. This is caused by frequent recurrence and the inability to predict exacerbations (Amertil, 1997; Blake et al., 2018). Consequently, the study would provide useful lessons on how uncertainty has an impact on patients' self-management, self-efficacy and the prospects of improving health care outcomes. The main question underpinning the investigation was this: what are the relationships among self-management, self-efficacy and uncertainty in adults with SCD at a Teaching Hospital in Ghana?

3 | THE STUDY

3.1 | Aims of study

The overall aim of the study was to evaluate the relationships among self-efficacy, uncertainty and self-management among adults (aged 18–60) with SCD. The following were the specific aims:

- First, to investigate the relationships among self-efficacy, uncertainty, self-management and socio-demographic indicators in individuals living with SCD.
- Second, to explain the extent to which demographic variables (age, gender, education, marital status, employment etc) influence self-efficacy, self-management and uncertainty.

3.2 | Design

A cross-sectional, descriptive design was used, to investigate study constructs and analyse variables.

3.3 | Participants

A purposive and convenience sample of 85 adult clients from the Sickle Cell Clinic at Korle-Bu Teaching Hospital, the leading teaching hospital in Ghana, completed questionnaires. They were adults diagnosed of SCD between the ages of 18–60 years and consented to participate in the study. To be eligible for the study, participants must have a history of attendance at the clinic and must be reporting for routine check-up (minor illnesses); inferring only out-patients were contacted. Patients who reported for crises events, having cognitive problems including depression, were excluded.

Sample size determination for this study was based on statistical power analysis used in the parent study. Power is the probability that analytical tests would produce significant results based on study sample. Power analysis is done in relation to effect size and alpha value. Generally, power index is normally set at 80% (0.8) or above (Abraham & Russell, 2008; Cohen, 1992). The effect size used was guided by Acock (2010) and Cohen (1988) medium effect estimate of 0.5, while alpha value was also put at 0.5. These values were analysed using G*Power tool and the required minimum sample size obtained is 85.

3.4 | Data collection

Primary data were used for the study involving the use of questionnaires. Three research instruments and a demographic questionnaire were used. Data collection took place in March and April 2019. A trained research assistant helped participants to complete instruments supervised by the second co-author. The research assistant approached potential respondents as they waited for consultation at the clinic and explained the study to them using the participant consent form. They were told participation was voluntary and confidential. Data were collected using the SCD self-efficacy scale, self-care agency scale, Mishel uncertainty in illness scale and the socio-demographic questionnaire.

3.5 | Instruments

3.5.1 | Sickle Cell Self-Efficacy Scale

The 9-item SCD self-efficacy scale was used to measure self-efficacy. A 5-point likert scale was used to score items ranging from (“not all sure” “to very sure”) with higher scores equalling stronger illness self-efficacy (Edwards et al., 2001). The SCD self-efficacy scale when used by Edwards et al. (2001), the Cronbach's alpha value was reported to be 0.89. In the parent study, the alpha value was 0.77 (Amertil, 1997), while the present study recorded 0.72.

3.5.2 | Mishel Uncertainty in Illness Scale

This is a 5-point likert scale to measure uncertainty in illness. It ranges from 1 corresponding to strongly disagree to 5 which is strongly agree (Mishel, 1981, 1990). Altogether it has 32 items. In the parent study, the MUIS alpha value was 0.77 (Amertil, 1997). The present study had cronbach alpha value of 0.78.

3.5.3 | Self-Care Agency Scale

The 24-item Appraisal of self-care agency scale is used to measure perceived self-care ability. A scale of 1–5 is used to score items (“1 = totally disagree” and “5 = totally agree”) and the higher the score the greater is self-care ability (Evers et al., 1986). The alpha score was more than 0.70 in the original study (Jenerette & Murdaugh, 2008). In the parent study, the self-care agency scale alpha value was 0.67 (Amertil, 1997), while the current study had 0.65.

3.5.4 | Socio-demographic variables

The demographic variables used for the study included gender, respondent's age, marital status, level of education, living situation, age of first diagnosis for SCD and number of yearly hospital emergency visits (Jenerette & Murdaugh, 2008). The computed Cronbach's alpha value for the demographic instrument was 0.72.

3.6 | Ethical approval

The study was approved by Ethical and Protocol Review Committee, College of Health Sciences, University of Ghana: CHS-Et/M.6-5.17/2018/2019 in February 2019. Prior to collecting data, the respondents were required to sign participant consent form with the assurance that data collected would remain anonymous.

3.7 | Data analysis

Descriptive statistics, bivariate correlations and multiple regression techniques were used to analyse data using SPSS version 22 (Fieldandy, 2017). The demographic indicators were analysed using frequencies and percentages. The Pearson correlation technique was employed to analyse strength and direction of association among variables. Furthermore, the multiple regression model was used to examine the interrelationships among socio-demographic variables, self-efficacy, self-management and uncertainty. Three distinct models were used with self-efficacy, self-management and uncertainty as outcome variables while socio-demographic indicators served as predictors. A statistical significance level (p -value) of 0.05 was used for all interpretations, except another level was specified. SPSS version 22 was mostly used for all analyses (IBM SPSS). The questionnaires were piloted among 5 potential respondents to ensure clarity. Missing data were treated using the principle of substitution by participant's mean if the total missing items for a case fell below 10%. No values would be imputed if this threshold was exceeded. However, care was taken to ensure that all items were completed by respondents.

Before regression analyses, data were scrutinized to check regression assumptions of absence of multicollinearity and normality of data. Correlation coefficients among independent variables were all below 0.8. Also, the variance inflation factor (VIF) was less than 5 and tolerance statistics more than 0.2. These results showed absence of multicollinearity. The normal P-P plot was used to check if the values of residuals were normally distributed. Based on the plot, the values of the residuals did not show large deviation from the diagonal.

3.8 | Validity, reliability and rigour

The study used known questionnaires; self-care agency scale, self-efficacy scale, Mishel illness uncertainty scale used in previous studies involving SCD clients with good content validity (Blake et al., 2018; Edwards et al., 2001; Evers et al., 1986; Jenerette & Murdaugh, 2008). Instruments reliability (internal consistency) were measured using cronbach alpha already stated under the section instruments with alpha values more than 0.70 in most studies. The socio-demographic questionnaire has similarly been used internationally (Jenerette & Murdaugh, 2008).

4 | RESULTS

4.1 | Demographic variables

Table 1 shows the detailed results on the socio-demographic variables. The findings demonstrated a trend consistent with the broad academic literature (Al Nagshabandi & Abdulmutalib, 2019; Blake

TABLE 1 Socio-demographic variables of SCD patients (N = 85)

Variable	Freq. (N)	%
Gender		
Female	55	64.7
Male	30	35.5
Education		
Primary/JHS	16	18.8
Secondary/SHS	39	45.9
Diploma non-degree	10	11.8
Bachelor degree	15	17.6
Master's degree	5	5.9
Employment		
Full-time	50	58.8
Part-time	11	12.9
Unemployed	24	28.2
Marital status		
Single	47	55
Married	29	34.5
Divorced/separated	9	10.5
Living situation		
Living alone	23	27
Shared housing with family	59	69.4
Shared housing with friends	2	2.6
Variable (Scale)	Mean	Stand. Dev.
Respondent's age	30 (Max = 53; Min = 18)	7.81
Emergency hospital visits yearly	3 (Max = 12; Min = 1)	1.64
Age at first SCD diagnosis	8.24 (Max = 34; Min = 1)	4.97

et al., 2018; Matthie et al., 2015). There were more women participants (65%), most respondents lived with family/friends (72%), per cent single (55%), most had secondary level education and the mean hospital emergency visits yearly was 3 (the same as found by Matthie et al., 2015). A notable finding from this study was that most SCD patients held full-time jobs (58.8%), while 13% had part-time jobs.

4.2 | Correlation analysis

4.2.1 | Self-efficacy

The correlation results showed a low positive and significant correlation between self-efficacy and self-management ($r = 0.357, p < .01$), a significant moderate negative relationship between self-efficacy and uncertainty ($r = -0.459, p < .01$), also, a significant low and positive correlation between self-efficacy and living situation ($r = 0.327, p < .01$).

4.2.2 | Self-management

The results showed a significant low negative relationship between self-management and uncertainty ($r = -0.260, p < .05$). The correlations between self-management, number of emergency hospital visits in a year and living situations were insignificant.

Furthermore, the correlation between uncertainty and living situation was significant low and negative ($r = -0.312, p < .01$). But there was an insignificant correlation between uncertainty and number of emergency hospital visits in a year. The significant results from correlation analysis are presented in Table 2.

4.3 | Multiple regression analyses

The second objective of study was analysed using the multiple regression equation. Overall three regression models were employed with self-management, uncertainty and self-efficacy as dependent variables, while the socio-demographics served as explanatory variables. The findings are shown in Tables 3–5.

4.3.1 | Model 1: Self-management as dependent variable

The predictors were employment, marital status, living situation and gender. The model accounted for 33% of variance in self-management and was statistically significant (R -square = 0.331; $F(4, 70) = 8.64, p < .01$). Both the techniques of stepwise regression and forced entry were used to examine relationships. Employment, marital status and gender significantly predicted self-management.

4.3.2 | Model 2: Uncertainty as dependent variable

The predictors included employment, marital status, education, gender and living situation. The independent variables collectively accounted for 28.4% of variance in uncertainty and was statistically significant (R -square = 0.284; $F(4, 71) = 7.036, p < .01$). Living situation and education significantly predicted uncertainty in illness.

4.3.3 | Model 3: Self-efficacy as dependent variable

The explanatory variables were living situation, education and gender. The predictors collectively explained 19% of variance in self-efficacy and the model was statistically significant (R -square = 0.190; $F(3, 72) = 5.63, p < .01$). Education ($p = .069$) and living situation ($p = .062$) did not predict self-efficacy.

5 | DISCUSSION

In our scrutiny of the academic literature, we found no studies on the three constructs used for this research in Ghana. The study was aimed at analysing the interrelationships among self-management, self-efficacy and uncertainty of SCD patients in Ghana, employing strictly a quantitative method. In addition to the paucity of studies on the topic in the Ghanaian context, there is generally not a plethora of research into SCD uncertainty particularly among adult patients globally (Blake et al., 2018). The findings from the correlation analysis indicated a low positive and significant association between self-efficacy and self-management. This implies that as self-efficacy increases, ability to self-manage illness also improves. This result is supported by several previous studies which found the same outcome (Al Naghabandi & Abdulmutalib, 2019; Matthie et al., 2015; Molter & Abrahamson, 2015). The finding suggests that individuals having the conviction to successfully execute specific activities and control illness daily has better self-management. A previous study underlined that when SCD clients perceived a lack of control over illness, the result is low self-management and accompanying morbidities such as anxiety, depression and low self-esteem (Amertil, 1997).

There was also a significant moderate negative relationship between self-efficacy and uncertainty, implying that as illness uncertainty increases self-efficacy measures decrease. This result is supported by the earlier one conducted in the United States (Amertil, 1997). Precedent studies denoted that illness uncertainty is characterized by stress, ambiguity and unpredictability in the case of a chronic disease. These make it difficult to predict daily acute conditions and complications undermining psychological health (Amertil, 1997; Blake et al., 2018). SCD patients are known to experience psychosocial morbidities which can effectuate low self-efficacy (Blake et al., 2018). The correlation between self-efficacy and living

TABLE 2 Correlations among variables

	Efficacy	Self-care	Uncertainty	Emergency visits	Living situation
Self-efficacy	1	0.357 ^a	-0.459 ^a	–	0.327 ^a
Self-care	–	1	-0.260 ^b	–	–
Uncertainty	–	–	1	–	-0.312 ^a

^aCorrelation is significant at the .01 level.

^bCorrelation is significant at the .05 level.

TABLE 3 Regression analysis of self-management

Variables	B	SE	SB	T	p
Constant	86.291	2.150	—	40.131	.001
Employment	1.603	0.513	0.363	3.123	.003
Marital status	1.907	0.585	0.353	3.261	.002
Gender	-1.853	0.885	-0.231	-2.094	.040
Living situation	-0.840	806	-0.107	-1.042	.301

Note: $R = 0.575$; R -square = 0.331; $F(4, 70) = 8.64$; $p < .001$.

TABLE 4 Regression analysis of uncertainty

Variables	B	SE	SB	T	p
Constant	84.754	6.332	—	13.385	.001
Years of sch.	2.733	1.369	0.266	1.997	.050
Gender	6.104	2.748	0.263	2.221	.030
Living sitn.	-6.139	2.545	-0.269	-2.412	.018
Employment	-0.211	1.667	-0.017	-0.127	.900

Note: $R = 0.533$; R -square = 0.284; $F(4, 71) = 7.036$; $p < .001$.

TABLE 5 Regression analysis of self-efficacy

Variables	B	SE	SB	T	p
Constant	31.688	1.720	—	18.428	.001
Gender	-1.993	0.764	-0.323	-2.610	.011
Living sitn.	1.308	0.691	0.215	1.893	.062
Years of sch.	0.603	0.326	0.221	1.849	.069

Note: $R = 0.436$; R -square = 0.190; $F(3, 73) = 5.627$; $p < .005$.

situation showed a significant low and positive association. The inference is that patients living with family have better self-efficacy. Some past studies have uncovered that family support positively affects SCD outcomes (Jenerette et al., 2011). The finding suggests family support has the potential to increase personal beliefs to adequately perform daily activities relating to SCD management.

In respect of the correlation between self-management and uncertainty, the study found a significant low negative relationship between the two constructs. The implication is that as illness uncertainty increases, the individual's ability to self-manage decreases. This result is very much consistent with the parent study. SCD uncertainty diminishes perceived ability of individuals to control their care (Amertil, 1997). The correlations between self-management, living situation and number of hospital emergency visits in a year were insignificant. On the whole, we found there was no association between self-management, self-efficacy and number of hospital emergency visits. This finding is in total agreement with Matthie et al. (2015). Furthermore, we found a significant low and negative relationship between uncertainty and living situation. The plausible explanation is that patients living with family have reduced illness uncertainty. The suggestion is that social support networks including

family can help individuals make a better sense of illness events and mitigate adverse outcomes (Blake et al., 2018).

The second aim of study stated: "to explain the extent to which demographic variables (age, gender, education, marital status, employment etc) influence self-efficacy, self-management and uncertainty." We examined the interrelationships using the multiple regression equation. Three separate models were employed to correspond with the three constructs serving as dependent variables. For the first model, where self-management was outcome variable, among the explanatory variables used, employment, marital status and gender significantly predicted self-management. Concerning employment, the suggestion is that SCD respondents who are currently working can manage illness better than the unemployed. One can argue that employed individuals have more disposable income to spend on their health needs for better self-care. Similarly, respondents who are married handle illness better, perhaps due to support from spouse and family. With respect to gender, female was coded 1 and male 2 and the result suggests reduced self-care in males relative to females.

For the second model, the results demonstrated that living situation and education significantly predicted uncertainty in illness. Living situation connotes SCD respondents living with family. Education suggests individuals with knowledge can manage illness better, hence mitigating uncertainty. The association between education and uncertainty is consistent with the parent study (Amertil, 1997) and Blake et al. (2018). The educational profile of respondents showed that most had higher education. This can help to access and use disease information which may lower uncertainty. The results for third model showed education ($p = .069$) and living situation ($p = .062$) did not significantly predict self-efficacy. But the two variables have important implications for SCD clients care given their closeness to the significant threshold. In the study undertaken by Al Naghabandi and Abdulmutalib (2019), level of education significantly predicted self-efficacy, implying the level of education enhances self-efficacy.

This study reinforces the parent study in highlighting the need for understanding illness uncertainty in self-management among SCD patients. As emphasized in this study, illness uncertainty has not been extensively researched among SCD patients. The results from the study denoted an inverse significant relationship between illness uncertainty relative to self-efficacy and self-management. The correlation between illness uncertainty and self-management concurs with the parent study. Similarly, the significant positive correlation between self-efficacy and self-management is in agreement with the parent study. The significant correlations between living situation in relation to self-efficacy and uncertainty give credence to the critical role of family support in managing SCD. The modelling results further enhanced the parent study as level of education and living situation predicted illness uncertainty (like the parent study). Neither education nor living situation predicted self-efficacy in this study consistent with the parent study. In contrast to the parent study (Amertil, 1997), employment and marital status predicted

self-management. The difference in findings could be attributed to socio-spatial disparities between United States and Ghana.

5.1 | Limitations

Several limitations were identified in the study. This study adopted purely a quantitative method; meaning important qualitative information to complement findings could not be added. An important item such as home remedies or self-care measures used by patients in the home setting in support of hospital treatment was not included. It is recommended this is considered in a future qualitative study. Participants were recruited from one large hospital with a sickle cell clinic. Other hospitals with sickle cell centre should be considered in future studies.

6 | CONCLUSION

This study has shed additional light on the interrelationships among self-management, self-efficacy and uncertainty among adults with sickle cell disease. In particular, the study makes several interesting findings on Mishel illness uncertainty scale and complements previous of illness-related events. This study found a significant inverse relationship among uncertainty, self-efficacy and self-management, suggesting uncertainty of illness worsens SCD outcomes consistent with the parent study. Thus, improving SCD outcomes requires mitigating uncertainty which is rather an under-researched area in the literature. Evidently, many more studies are warranted to comprehend fully the interactions among self-care, self-efficacy and uncertainty in coping with sickle cell disease and mitigating pain episodes. Similarly, additional studies on SCD self-management, psychosocial and physiological complications are necessary to increase nursing knowledge, patient education, policy and development of nursing care interventions. Furthermore, in this study employment had a significant association with self-management. Since SCD patients tend to be unemployed in other countries as demonstrated in the literature, it would be relevant to investigate in-depth the labour market activities of patients in the Ghanaian context. Lastly, we found self-efficacy and living with family improved self-management, so these can be useful guides in intervention development by clinicians.

ACKNOWLEDGEMENTS

We acknowledge the cooperation received from Dr. Yvonne Dei-Adomakoh, nurses and staff at the Sickle Cell Clinic, Korle-Bu Teaching Hospital, Accra. Thanks also to the patients who took time to complete the questionnaires.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

N.P.A., E.K.A., D.G.K.: Substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data.

N.P.A., E.K.A., P.Y.A.A. and D.G.K.: Drafting the manuscript or revising it critically for important intellectual content, final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content, agreeing to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

DATA AVAILABILITY STATEMENT

Data used for the study are available from the corresponding author upon request.

ORCID

Ninon P. Amertil  <https://orcid.org/0000-0002-2424-120X>

REFERENCES

- Abraham, W. T., & Russell, D. W. (2008). Statistical power analysis in psychological research. *Social and Personality Psychology Compass*, 2(1), 283–301. <https://doi.org/10.1111/j.1751-9004.2007.00052.x>
- Acock, A. (2010). *A gentle introduction to Stata* (3rd ed.). Stata Press.
- Adegbola, M. (2011). Spirituality, self-efficacy and quality of life among adults with sickle cell disease. *Southern Online Journal of Nursing Research*, 11(1), 5.
- Ahmadi, M., Shariati, A., Jahani, S., Tabesh, H., & Keikhaei, B. (2014). The effectiveness of self-management programs on self-efficacy in patients with sickle cell disease. *Jundishapur Journal of Chronic Disease Care*, 3(3), e21702. <https://doi.org/10.17795/jjcdc-21702>
- Al Nagshabandi, E. A., & Abdulmutalib, I. A. M. (2019). Self-care management and self-efficacy among adult patients with sickle cell disease. *American Journal of Nursing Research*, 7(1), 51–57. <https://doi.org/10.12691/ajnr-7-1-7>
- Amertil, N. (1997). *Self-management in adult clients with sickle cell disease (SCD)*. Phd in nursing dissertation submitted to University of Massachusetts Amherst and University of Massachusetts Worcester.
- Baum, D. (2013). *Adolescents with sickle cell disease: Self-efficacy as a factor in readiness to transition from pediatric to adult medical care*. Ed.D. dissertation. The George Washington University.
- Blake, A., Asnani, V., Leger, R. R., Harris, J., Odesina, V., Hemmings, D. L., Morris, D. A., Knight-Madden, J., Wagner, L., & Asnani, M. R. (2018). Stigma and illness uncertainty: Adding to the burden of sickle cell disease. *Hematology*, 23(2), 122–130. <https://doi.org/10.1080/10245332.2017.1359898>
- Centers for Disease Control and Prevention (2011). *Facts about sickle cell disease*. Retrieved from <http://www.cdc.gov/ncbddd/sicklecell/facts.html>
- Clay, O., & Telfair, J. (2007). Evaluation of a disease-specific self-efficacy instrument in adolescents with sickle cell disease and its relationship to adjustment. *Child Neuropsychology*, 13, 188–203. <https://doi.org/10.1080/09297040600770746>
- Cohen, J. (1992). A primer power. *Psychological Bulletin*, 112(1), 155–159.
- Cohen, J. (1988). *Statistical power analysis for behavioural sciences*, 2nd ed. United States: Lawrence Erlbaum Associates.
- Druye, A. (2017). *Self management strategies for people with sickle cell disease in Ghana*. A thesis submitted to the Victoria University of Wellington in fulfilment of the requirements for the degree of Doctor of Philosophy in Nursing. Victoria University of Wellington. Retrieved from <https://researcharchive.vuw.ac.nz/xmlui/handle/10063/6265>
- Edwards, R., Telfair, J., Cecil, H., & Lenoci, J. (2001). Self-efficacy as a predictor of adult adjustment to sickle cell disease:

- One-year outcomes. *Psychosomatic Medicine*, 63, 850–858. <https://doi.org/10.1097/00006842-200109000-00020>
- Evers, G., Isenberg, M., Phillipsen, G., Brouns, G., Halfens, R., & Smeets, H. (1986). The 'appraisal of self-care agency' ASA-scale: Research program to test reliability and validity. *Proceedings of the International Nursing Research Conference New Frontiers in Nursing Research* (p. 130). University of Alberta, Canada.
- Field, A. (2017). *Discovering statistics using IBM SPSS* (5th ed.). Sage Publications
- Jenerette, C., Brewer, C., & Leak, A. (2011). Self-care recommendations of middle-aged and older adults with sickle cell disease. *Nursing Research and Practice*, 22, 58–63. <https://doi.org/10.1155/2011/270594>
- Jenerette, C., & Murdaugh, C. (2008). Testing the theory of self-care management for sickle cell disease. *Research in Nursing & Health*, 31(4), 355–369. <https://doi.org/10.1002/nur.20261>
- Jenerette, C., & Valrie, C. (2010). The influence of maternal behaviors during childhood on self-efficacy in individuals with sickle cell disease. *Journal of Family Nursing*, 16, 422–434. <https://doi.org/10.1177/1074840710385000>
- Konotey-Ahulu, F. (2014). Sickle cell and other haemoglobinopathies: The genetics that touches you and me. Retrieved from <https://blog.sicklecell.md/sicklecell/sickle-cell-and-allied-haemoglobinopathy>
- Lenoci, J. M., Telfair, J., Cecil, H., & Edwards, R. F. (2002). Self-care in adults with sickle cell disease. *Western Journal of Nursing Research*, 24(3), 228–245. <https://doi.org/10.1177/01939450222045879>
- Matthie, N. (2013). *Sickle cell disease: The role of self-care management*. Graduate theses and dissertations. Retrieved from <http://scholarcommons.usf.edu/etd/4538>
- Matthie, N., Jenerette, C., & McMillan, S. (2015). Role of self-care in sickle cell disease. *Pain Management Nursing*, 16(3), 257–266. <https://doi.org/10.1016/j.pmn.2014.07.003>
- Mishel, M. H. (1981). The measurement of uncertainty in illness. *Nursing Research*, 30(5), 258–263.
- Mishel, M. (1990). Reconceptualizing of the uncertainty in illness theory. *Journal of Nursing Scholarship*, 22(4), 256–262. <https://doi.org/10.1111/j.1547-5069.1990.tb00225.x>
- Molter, B., & Abrahamson, K. (2015). Self-efficacy, transition and patient outcomes in the sickle cell disease population. *Pain Management Nursing*, 16(3), 418–424. <https://doi.org/10.1016/j.pmn.2014.06.001>
- Olowoyeye, A., & Okwundu, C. I. (2010). Gene therapy for sickle cell disease (review). *Cochrane Database of Systematic Reviews*, 8, 1–8. Art. no: CD007652. <https://doi.org/10.1002/14651858.CD007652.pub5>
- Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., Redeker, N. S., Reynolds, N., & Whittlemore, R. (2012). Processes of self-management in chronic illness. *Journal of Nursing Scholarship*, 44, 136–144. <https://doi.org/10.1111/j.1547-5069.2012.01444.x>
- Tanabe, P., Porter, J., Creary, M., Kirkwood, E., Miller, S., Ahmed-Williams, E., & Hassell, K. (2010). A qualitative analysis of best self-management practices: Sickle cell disease. *Journal of the National Medical Association*, 102(11), 1033–1041. [https://doi.org/10.1016/S0027-9684\(15\)30730-6](https://doi.org/10.1016/S0027-9684(15)30730-6)
- Yusuf, H., Atrash, H., Grosse, S., Parker, C., & Grant, A. (2010). Emergency department visits made by patients with sickle cell disease. *American Journal of Preventive Medicine*, 38(4), S536–S541. <https://doi.org/10.1016/j.amepre.2010.01.001>

How to cite this article: Amertil NP, Ayitey EK, Kpongboe DG, Attafua PYA. Exploring self-management in adult sickle cell disease patients' at a Teaching Hospital in Ghana. *Nurs Open*. 2021;8:1336–1344. <https://doi.org/10.1002/nop2.750>