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Psychosocial impact of leg ulcers on the quality of life of adults living with sickle cell disease in Ghana

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Abstract

Background Sickle cell disease-related persistent chronic manifestations, such as leg ulcers, continue to raise clinical and psychosocial concerns. The Quality of Life (QoL) issues have not been adequately defined in sickle cell disease (SCD) management. This study examined the psychosocial effects of leg ulcers in people living with SCD in Ghana.

Methods A total of 95 adult SCD patients aged 18–65 participated in the cross-sectional study, with 41 having chronic leg ulcers and 54 without leg ulcers. Participants were administered the Sickle Cell Illness Impact Measurement Scale (SIMS) to assess five main domains of QoL: general health perception, physical functioning, social functioning, emotional well-being, and quality of care. The Analysis of Covariance (ANCOVA) test was used to determine the differences in the quality of life between the groups while controlling for the effect of genotype, gender, and age. The multivariate logistic regression was conducted to identify the clinical and demographic predictors of QoL among adult SCD by examining the relationships between multiple independent variables and a binary QoL outcome.

Results Generally, SCD patients without leg ulcers had an overall good QoL ($p = 0.017$), functioned better socially ($p < 0.001$) and had good general health perception ($p = 0.012$) than their counterparts with leg ulcers. Patient's age at registration at clinic [aOR = 1.062 (95%CI 1.01, 1.12) $p = 0.022$], having a Sickle Cell Leg Ulcer (SCLU) [aOR = 3.716 (95%CI 1.44, 9.62) $p = 0.007$] predicted poorer QoL of the SCD population.

Conclusion These findings have significant clinical implications. Integrating early, enhanced and targeted interventions into the clinical management of SCD patients, especially those with sickle cell leg ulcers, is crucial to improving their quality of life.

Keywords Sickle cell disease · Sickle cell leg ulcers · Quality of life · Psychosocial effect · Ghana

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Abbreviations

ANCOVA	Analysis of covariance
CI	Confidence interval
GICG	Ghana Institute of Clinical Genetics
HbSC	Haemoglobin C
HbSS	Haemoglobin S
KBTH	Korle Bu Teaching Hospital
QoL	Quality of life
SCD	Sickle cell disease
SD	Standard deviation
SE	Standard error
SIMS	Sickle illness impact measurement scale
SCLUs	Sickle cell leg ulcers

1 Introduction

Sickle Cell Disease (SCD) is a genetic blood condition, particularly in Sub-Saharan Africa, India, and the Mediterranean regions [1, 2]. It is recognized as one of the most stigmatized haemoglobinopathies in the world [3, 4]. It is characterized by diverse clinical manifestations such as chronic haemolytic anaemia, pain crisis and multiple organ damage [5]. However, currently, due to improved care, sickle cell patients are living longer into adulthood but with a high risk of developing numerous disease complications. The prolonged impact of these clinical complications accelerates the ageing process and increases the risk of multi-organ damage [6, 7], including leg ulcers [8]. Sickle Cell Leg Ulcers (SCLUs) are the most predominant cutaneous complication in SCD [9].

The pathogenesis of SCLUs is multifactorial. Studies have implicated venous disease, blood viscosity, adhesion, infection, nitric oxide deficiency, blood hypercoagulability, haemolysis, trauma, and thrombosis in the pathogenesis of SCLU [9, 10]. Increasing age, genotype SS, being a male, low level of foetal haemoglobin, anaemia, and antithrombin deficiency have been identified as risk factors for the development of SCLU [7].

Globally, the prevalence of SCLU varies considerably due to geographical location. The prevalence was found to be between 2.5% in the USA, and 29.5% and 75% among general SCD patients and homozygous (SS) patients respectively in Jamaica [7, 11, 12]. In Africa, the reported prevalence rates were 7.5–29.4% in Nigeria, 24.6% in Cameroon and 10.3–18.6% in Ghana [7, 13]. The existing data suggests that SCLUs are chronic and associated with increased morbidity and poor quality of life [13, 14].

Several studies found that patients with SCLU experience psychological and emotional distress [13, 15]. These distresses are reported to include depression, anxiety, insomnia, low self-esteem and suicidal ideations [16]. SCLU population experience a significant level of stigmatization which manifests as non-disclosure of SCLU, discrimination and social isolation [3, 14]. Women with SCLUs are found to experience severe pain, odour, embarrassment, worthlessness, lifestyle changes and loneliness which potentially impact the psychosocial health of affected patients [17]. The social functioning of SCLU patients is compromised with many having poor relationships with significant others, poor work status and limited social activities [18]. Studies report a deficit in mobility which manifests in limitations in walking, running, and standing [17, 19].

Studies have identified various biopsychosocial factors that predict Quality of Life (QoL) in sickle cell patients. Older age and being female were associated with poorer QoL in adolescents and young adults SCD patients [20, 21]. However, a more recent study found no association between age, gender and QoL in children with SCD [22]. Pain predicted poorer QoL in SCD patients [22–24]. Socioeconomic challenges and lack of disease awareness were also identified to be associated with poorer QoL [25]. Interestingly, illness severity markers such as genotype, Hemoglobin level, chronic organ damage etc. did not predict QoL in SCD [22, 24]. Being employed as a sickle cell patient predicts better QoL for people living with SCD [26].

Although, various, interventions have focused on the management of SCD cases, the burden still compounds as there are no clearly defined management protocols for leg ulcerations [27]. There is limited data on the psychosocial effects of SCLU in Sub-Saharan Africa [4, 28]. Specifically, the use of disease-specific QoL measures to investigate the psychosocial effects and predictors of QoL in the SCLUs population.

To the best of our knowledge, no study has compared the psychosocial effects of people with SCLU population and SCD patients without leg ulcers using disease-specific QoL measures. The objective of this study was to understand the psychosocial effects of leg ulcers among Ghanaians with sickle cell disease.

2 Materials and methods

2.1 Study design

The study was a clinic-based cross-sectional study conducted from December 2018 to May 2019 at the Ghana Institute of Clinical Genetics (GICG), which houses the Adult Sickle Cell Clinic of the Korle Bu Teaching Hospital (KBTH). Ethical approval was obtained from the Korle Bu Teaching Hospital (KBTH) Institutional Review Board (IRB) with protocol number KBTH-IRB/00075/2018. Administrative approval was obtained from the Ghana Institute of Clinical Genetics. The study was carried out in accordance with local and international rules and regulations of the Helsinki Declaration of 2013 [29]. Written informed consent was obtained from all participants before enrolling them in the study.

2.2 Study site

The study was conducted at the Adult Sickle Cell Clinic at KBTH. About 26,000 children, adolescents and adults were registered at the clinic at the time of the study (Adult Sickle Cell Clinic, Korle-Bu Records, 2018).

In the past, the clinic operated as a day-care and received patients referred from across the country, on an outpatient basis. However, in 2018, 5,451 adolescent and adult sickle cell patients utilize the clinic's services, accounting for a total of 20,788 annual visits [30]. Specialist physicians, nurses, clinical psychologists and other health professionals attended to patients at the facility. The clinic dedicated one day in the week to patients with SCLUs and other specific sickle cell-related complications.

2.3 Participants

Adult sickle cell patients with and without leg ulcers aged 18 years and above with genotype homozygous sickle cell anaemia (HbSS) or sickle haemoglobin C disease (HbSC) who receive care at the Adult Sickle Cell Clinic of the KBTH were recruited. The proportion of registered adult sickle cell patients with leg ulcers at the time of the study was 61. The majority of the participants were not on any evidence-based disease-modifying interventions such as hydroxyurea and exchange transfusions which may reduce the risk for leg ulcers and other sickle cell-related complications.

2.4 Materials

The sickle cell illness impact measurement scale (SIMS) was included in the questionnaire to measure the psychosocial effects of SCD. The SIMS is a 120-item questionnaire with items grouped under five main domains. The domains were (1) General health perception (pain, overall health, and health perception); (2) Physical functioning (mobility, walking and bending, arm function, and household tasks); (3) Social functioning (social activities, support from family and friends, work/vocation status, and relationship with significant others); (4) Emotional wellbeing (tension, mood, life satisfaction, life improvement, and general feelings) and (5) Quality of care (social services, access to care and perception of health personnel). Each of the 120 questions was scored on a 5-point Likert scale, with 5 as the worse outcome. This procedure is consistent with that described in Adams-Graves et al. [31]. SIMS's internal consistency was 0.86 [31]. Reliability for the Ghanaian sample was found to be 0.64, 0.62, 0.70 and 0.63 for general health perception, physical functioning, emotional functioning, and social functioning respectively [32].

2.5 Procedure

SCD patients with or without SCLUs attending the clinic on SCLU-dedicated days were approached and given information about the survey. Those who expressed interest in participating were made to complete the informed consent process and subsequently enrolled.

Two trained research assistants administered the study questionnaires. Information on the patients' socio-demographic background, date of registration at the clinic, use of hydroxyurea, membership of the patient peer support group, most recent haemoglobin levels and white cell count were retrieved from existing folders and records at the clinic. This was followed by the administration of the SIMS questionnaire to the participants.

2.6 Statistical analysis

The IBM SPSS Statistical software version 21 was used to analyze the data [33]. First, the data was assessed for missingness using the Little's MCAR approach and the test for normality and assumptions were conducted as part of the preliminary analyses [34, 35].

Next, descriptive and comparative analyses were conducted. Categorical variables were reported as frequencies and the continuous variables as means with standard deviations. Chi-square tests and independent sample t-tests were used to compare the demographic characteristics between the SCLU and non-SCLU groups. Additionally, a one-way ANCOVA test was performed to examine the mean differences in QoL scores between the groups, adjusting for genotype, gender, and age as covariates.

To determine the predictors of QoL, the QoL scores (ranging from 0 to 600, with lower scores indicating better outcomes) were divided into two groups based on the QoL mean value of 413.12. Patients with a mean QoL score less than or equal to 413.12 were assigned a value of '0', representing good QoL, while those with scores greater than 413.12 were assigned a value of '1', representing poor QoL. The mean-dichotomized QoL score was then used as the dependent variable in a series of logistic regression analyses. First, a univariate logistic regression was conducted to identify the clinical and demographic covariates associated with QoL outcomes. The significant covariates identified in this univariate analysis were included simultaneously as independent variables in a multivariate logistic regression model to assess their ability to predict the dichotomized QoL outcome. The goal of this approach was to determine the key clinical and demographic factors associated with good or poorer QoL in the study population.

3 Results

3.1 Sociodemographic and clinical characteristics of participants

Tables 1 and 2 summarize the socio-demographic and clinical data of 95 SCD patients (47 males, 48 females), including 41 with SCLU and 54 without. Most participants had the HbSC genotype. Among SCLU patients, 37 had HbSS and 4 HbSC, while non-SCLU patients comprised 1 HbSS and 53 HbSC. SCLU patients were predominantly male ($p = 0.005$), had lower hemoglobin levels ($p < 0.001$), and higher white blood count levels ($p < 0.001$). Non-SCLU patients were older (34.9 ± 13.9). Most participants were unmarried, employed, in peer support groups, and not on hydroxyurea.

3.2 Quality of life scores for SCLUs and non-SCLUs patients

Generally, the overall QoL of participants differs significantly ($p = 0.017$), patients without SCLUs had better QoL (399.11 ± 7.91) than the SCLUs group (435.21 ± 9.11). Patients without SCLUs had good general health perception ($p = 0.012$) and good social functioning ($p < 0.001$) than those with SCLUs. Similarly, patients without SCLUs had a good health perception ($p < 0.001$), good mood ($p = 0.022$), better work status ($p = 0.045$), and good relationship with significant others ($p < 0.001$) than those with SCLUs. However, no significant differences were found in physical functioning, emotional functioning and quality of care between the two groups (see Table 3).

3.3 Predictors of quality of life in SCD

Table 4 summarizes the univariate binary logistic regression analysis of the predictors of QoL among people living with SCD. Significant independent variables were age at registration at the clinic cOR = 1.06 (95%CI 1.01, 1.11) $p = 0.016$, Hydroxyurea medication use cOR = 0.19 (0.04, 0.91) $p = 0.038$, being married/cohabiting cOR = 2.67 (95%CI 1.04, 6.87) $p = 0.042$, and having SCLUs cOR = 2.88 (95%CI 1.24, 6.67) $p = 0.014$.

The significant predictors of QoL from the multivariate logistic regression are shown in Table 5. Participants with late age at registration were 1.06 times more likely to have a poorer QoL aOR = 1.06 (95% CI 1.01–1.12) $p = 0.022$. Also,

Table 1 Mean differences of the Sociodemographic and clinical characteristics of SCD patients with leg ulcers (N = 41) and SCD patients without leg ulcers (N = 54)

Variables	SCD with Leg Ulcer (n = 41)	SCD without Leg Ulcer (n = 54)	*t*	df	*p*
Average age (years) *M (SD)* (Total)	29.6 (7.9)	34.9 (13.9)	− 2.19	93	**0.031**
HbSS (n = 38)	30.3 (8.0)	34.0 (0.0)			
HbSC (n = 57)	23.5 (2.4)	34.9 (14.1)			
Average age at SCD diagnosis (years) *M (SD)* (Total)	7.7 (6.5)	11.0 (8.4)	− 2.06	80.80	**0.043**
HbSS (n = 38)	7.2 (6.1)	6.0 (0.0)			
HbSC (n = 57)	12.0 (9.0)	11.2 (8.5)			
Average age at registration (years*) M (SD)* (Total)	11.8 (8.3)	12.7 (10.3)	− 0.42	88.53	0.677
HbSS (n = 38)	12.1 (8.4)	6.0 (0.0)			
HbSC (n = 57)	9.8 (8.2)	12.8 (10.3)			
Average of last two haemoglobin levels (g/l) *M (SD)* (Total)	7.5 (1.7)	11.2 (1.4)	− 10.78	60.83	**< 0.001**
HbSS (n = 38)	7.3 (1.3)	11.4 (0.0)			
HbSC (n = 57)	10.5 (2.6)	11.2 (1.5)			
Average of last two white blood count (10^9 /L*) M (SD)* (Total)	12.2 (3.9)	8.4 (3.5)	4.64	65.09	**< 0.001**
HbSS (n = 38)	12.2 (3.9)	6.1 (0.0)			
HbSC (n = 57)	12.3 (4.1)	8.4 (3.5)			

Bold values indicate the significant *p*-values

participants with SCLUs were 3.72 times more likely to have a poor QoL as compared to those without SCLUs aOR = 3.72 (95% CI 1.44–9.62) $p = 0.007$.

4 Discussion

In this study, we investigated the psychosocial impact of leg ulcers in individuals with SCD in Ghana. Our findings revealed several significant associations between sociodemographic and clinical factors and the psychosocial functioning of participants with leg ulcers compared to those without.

Our results indicated that participants with leg ulcers were predominantly younger (29.6 ± 7.9) mostly male, had the HbSS genotype, were more anaemic, had higher white blood cell counts, which could indicate higher rates of infection, and were diagnosed earlier compared to those without leg ulcers.

The psychosocial impact of leg ulcers in SCD was evident across various domains, including general health perception and social interactions. Participants with leg ulcers reported significantly poorer QoL outcomes in these domains compared to those without, reflecting the multifaceted challenges posed by leg ulcers in individuals' daily lives.

Notably, certain factors emerged as predictive of psychosocial functioning. For instance, participant's age at registration at the clinic, and having a SCLUs predicted poor overall psychosocial functioning.

4.1 Sociodemographic and clinical characteristics of SCLUs patients and non-SCLUs

The average age of participants with SCLUs was younger (29.6 ± 7.9) than those without SCLUs (34.9 ± 13.9). This finding is consistent with findings from studies in Brazil, Nigeria, and Ghana which found that the average age of patients with SCLUs was younger than 30 years [7, 36]. About 76.3% of the SCLUs onset occur before age 30 years [7, 8, 37]. The early onset in majority of patients may have accounted for the similarities in findings. Furthermore, the age differences between the SCLU and non-SCLU groups could have contributed to the observed variations in this study. Special provisions should be made early for young people to improve care.

Gender differences in SCLUs development were also found. SCLUs were more common in males than females. These findings are consistent with prior studies that found SCLUs to be more common in males than females [38, 39]. Generally, women have an increased tendency to visit their primary care provider more often than men with non-communicable diseases [40]. Although access to SCD care is poor in Africa [41], females have been found to access health care, have

Table 2 Frequencies of Sociodemographic characteristics of SCD patients with leg ulcers (N = 41) and SCD patients without leg ulcers (N = 54)

Variables	SCD with leg ulcer (n = 41)	SCD without leg ulcer (n = 54)	χ^2	df	N	*p*
Gender *n* (%)			7.742	1	**95**	**0.005**
HbSS (n = 38)						
Male	24 (64.9)	0 (0.0)				
Female	13 (35.1)	1 (100.0)				
HbSC (n = 57)						
Male	3 (75.0)	20 (37.7)				
Female	1 (25.0)	33 (62.3)				
Education *n* (%)			2.805	3	91	0.423
HbSS (n = 38)						
Basic	0 (0.0)	0 (0.0)				
JHS	11 (31.4)	1 (100.0)				
SHS	18 (51.4)	0 (0.0)				
Tertiary	6 (17.2)	0 (0.0)				
HbSC (n = 57)						
Basic	0 (0.0)	1 (2.0)				
JHS	1 (25.0)	18 (35.3)				
SHS	3 (75.0)	20 (39.2)				
Tertiary	0 (0.0)	12 (23.5)				
Hydroxyurea medication use *n (%)*			0.953	2	95	0.621
HbSS (n = 38)						
Yes	5 (15.6)	0 (0.0)				
No	27 (84.4)	0 (0.0)				
HbSC (n = 57)						
Yes	0 (0.0)	5 (11.4)				
No	4 (100.0)	39 (88.6)				
Employment *n (%)*			1.465	2	95	0.451
HbSS (*n* = 38)						
Yes	21 (56.8)	1 (100.0)				
No	16 (43.2)	0 (0.0)				
HbSC (*n* = 57)						
Yes	2 (50.0)	28 (52.8)				
No	2 (50.0)	25 (47.2)				
Marital status *n (%)*			0.138	1	95	0.710
HbSS (*n* = 38)						
Single/Separated	26 (72.2)	1 (100.0)				
Married/Cohabiting	10 (27.8)	0 (0.0)				
HbSC (*n* = 57)						
Single/Separated	4 (100.0)	38 (71.7)				
Married/Cohabiting	0 (0.0)	15 (28.3)				
Belonging to SCD support group *n* (%)			0.953	2	95	0.621
HbSS (n = 35)						
Yes	24 (70.6)	1 (100.0)				
No	10 (29.4)	0 (0.0)				
HbSC (n = 54)						
Yes	2 (66.7)	32 (62.8)				
No	1 (33.3)	19 (37.2)				

Bold values indicate the significant *p*-values

JHS = Junior High School| SHS = Senior High School| Primary: Grades 1–6, foundational education for ages 6–11. JHS: Grades 7–9, Junior High School for ages 12–14, leading to BECE. SHS: Grades 10–12, Senior High School for ages 15–18, culminating in WASSCE. Tertiary: Post-secondary education, including diploma, degree, and professional programs

Table 3 Quality of life of SCD patients with leg ulcer (N = 41) and SCD patients without leg ulcer (N = 54) (mean comparison)

Tests	SCD with leg ulcer (n = 41)		SCD without leg ulcer (n = 54)		F-test	Cohen's d	p-value
	Mean (SE)	95% CI	Mean (SE)	95% CI			
General health perception	49.02 (2.08)	44.88, 53.16	40.52 (1.69)	37.17, 43.88	6.62	0.069	**0.012**
Pain	31.02 (1.76)	27.53, 34.51	29.67(1.42)	26.84, 32.49	0.236	0.003	0.628
Overall health	2.35 (0.24)	1.86, 2.83	1.63 (0.20)	1.23, 2.02	3.49	0.037	0.065
Health perception	15.78 (1.03)	13.60, 17.71	9.23 (0.84)	7.56, 10.89	15.36	0.15	**< 0.001**
Physical functioning	36.22(2.74)	30.78, 41.65	34.76 (2.22)	30.36, 39.17	0.11	0.001	0.738
Mobility	11.56 (4.86)	7.98, 12.37	9.61 (4.54)	8.89, 12.44	0.08	0.001	0.779
Walking and bending	10.41 (1.22)	7.97,12.84	10.82 (0.99)	8.85, 12.79	0.05	0.001	0.831
Arm function	8.91 (1.32)	6.29,11.52	7.89 (1.07)	5. 77, 10.01	0.24	0.003	0.627
Household task	6.73 (0.71)	5.33, 8.13	5.39 (0.57)	4.25. 6.53	1.44	0.016	0.233
Emotional wellbeing	236.62 (8.54)	219.64, 253.61	230.95 (7.41)	216.20, 245.70	0.17	0.02	0.684
Tension	13.17 (0.72)	11.73, 14.61	11.40 (0.63)	10.14, 12.64	2.28	0.027	0.135
Mood	13.57 (0.80)	11.98, 15.16	10.62 (0.65)	9.34, 11.91	5.39	0.057	**0.022**
Life satisfaction	62.10 (5.26)	51.65, 72.55	75.09 (4.26)	66.63, 83.56	2.42	0.026	0.123
Life improvement	89.21 (5.96)	77.37, 101.04	83.05 (4.83)	73.46, 92.63	0.43	0.005	0.516
General feelings	59.45 (3.93)	51.65, 67.25	50.69 (3.18)	44.38, 57.01	1.98	0.020	0.163
Social functioning	64.02 (2.90)	58.26, 69.78	43.26 (2.35)	38.60, 47.93	20.42	0.190	**< 0.001**
Social activities	13.83 (1.05)	11.76, 15.91	10.70 (0.85)	9.02, 12.38	3.57	0.038	0.062
Support from family and friends	9.93 (8.89)	8.17, 11.69	6.42 (0.72)	5.00, 7.85	6.23	0.070	0.014
Work status	22.45 (1.38)	19.72, 25.18	18.01 (1.11)	15.80, 20.22	4.15	0.050	**0.045**
Relationship with significant others	17.80 (1.37)	15.09, 20.52	8.13 (1.11)	5.93, 10.33	19.99	0.180	**< 0.001**
Quality of care	50.36(2.78)	44.85, 55.87	46.23 (2.25)	41.76, 50.69	0.88	0.010	0.350
Social services	21.29 (2.06)	17.20, 25.38	20.39 (1.67)	17.08, 23.71	0.08	0.001	0.784
Access to care	8.12 (1.09)	5.96, 10.29	6.70 (0.88)	4.95, 8.46	0.68	0.007	0.413
Perception of health personnel at the clinic	20.95 (1.10)	18.76, 23.13	19.13 (0.89)	17.36, 20.90	1.09	0.010	0.300
SIMS TOTAL	435.21 (9.11)	417.08, 453.33	399.11 (7.91)	383.37, 414.84	5.94	0.068	**0.017**

Bold values indicate the significant *p*-values

SIMS: Sickle Cells Illness Impact Measurement Scale

better health-seeking behaviour and live longer than men which may have led to improved quality of care and reduced complications for female patients [30, 42]. Comprehensive SCD care for patients should target the male population to improve care and reduce the risk of complications. Future studies should explore interventions to reduce the risk factors associated with SCLUs in SCD males. It is worth noting that gender imbalance between the SCLU and non-SCLU groups was a limitation of this study.

The majority of the participants with SCLUs have a severe form of SCD with HbSS genotype (Table 1). These findings are consistent with prior studies that reported SCLUs to be more common among SCD patients with genotype SS than the less severe genotypes [8]. These findings may be attributed to the high risk of chronic haemolysis leading to vascular damage in patients with the HbSS genotype, compared to those with HbSC genotype [43]. A mean haemoglobin level of 7.5 ± 1.7 g/dL was recorded and is consistent with findings from other studies [39, 44]. Although hydroxyurea has been approved in the comprehensive management of SCD, the majority of participants were not on it, which could be due to financial constraints, medication supplies and many systemic factors. In addition to hydroxyurea, many more disease-modifying drugs have been recently approved for the prevention of SCD-related complications and attempts should be made to include these drugs in SCD care. More longitudinal studies started early in life, are needed to understand the mechanism and benefits of disease-modifying drugs, blood transfusion and gene therapies in the prevention of SCLUs. Furthermore, genotype imbalance between the SCLU and non-SCLU groups was a limitation of this study.

Table 4 Univariate binary logistic regression of predictors of quality of life of sickle cell patients (N = 95)

Variables	B	Mean (SE)	95% CI	p-value	cOR
Age (years)	0.01	0.02	0.98, 1.05	0.499	1.01
Education (years)	− 0.09	0.09	0.77, 1.08	0.278	0.91
Age at SCD diagnosis	0.06	0.03	1.00, 1.12	0.067	1.06
Age at registration at the clinic	0.06	0.02	1.01, 1.11	**0.016**	1.06
last two haemoglobin levels (g/l)	− 0.12	0.09	0.74, 1.06	0.191	0.89
Last two white blood counts (10^9 /L)	0.03	0.05	0.93, 1.14	0.571	1.03
Gender	− 0.38	0.41	0.30, 1.54	0.359	0.69
Hydroxyurea medication use	− 1.68	0.81	0.04, 0.91	**0.038**	0.19
Employment status	− 0.74	0.45	0.20. 1.15	0.099	0.48
Marital status	0.98	0.48	1.04, 6.87	**0.042**	2.67
Support group	− 1.01	0.42	0.75, 3.95	0.202	1.72
Genotype	− 0.39	0.41	0.31, 1.52	0.35	0.68
Group (SCLU/ Non-SCLU)	1.06	0.43	1.24,6.67	**0.014**	2.88

Bold values indicate the significant *p*-values
cOR: Crude Odds Ratio

Table 5 Multivariate binary logistic regression of predictors of quality of life of sickle cell patients (N = 95)

Variables	B	Mean (SE)	95% CI	p-value	aOR
Age at registration at the clinic	0.06	0.03	1.01, 1.12	**0.022**	1.062
Hydroxyurea medication use					
No			Reference		**1**
Yes	− 1.42	0.92	0.04, 1.48	0.124	0.242
Marital status					
Single			Reference		**1**
Married/Cohabiting	0.85	0.54	0.81, 6.69	0.116	2.329
Group					
Non- SCLU			Reference		**1**
SCLU	1.313	0.49	1.44, 9.62	**0.007**	3.716

Bold values indicate the significant *p*-values
aOR: Adjusted Odds Ratio

Further, the study found that SCLUs participants were diagnosed and registered early at the clinic for management and care of SCD as compared to the non-SCLUs group. These may be attributed to the disease severity and the type of SCD which are found to trigger early onset of complications leading to the initiation of screening and subsequently SCD diagnosis and care [45, 46]. In Ghana, the absence of a national newborn screening program contributes to the delay in SCD diagnosis, management and increased prevalence of SCLUs [47, 48].

Another evidence of the association of SCLUs with disease severity is the elevated white blood count found in the SCLUs group compared to the SCD without the SCLUs group in this current study, in keeping the literature [48]. Elevated WBC increases the adhesion of leukocytes to blood cells and the endothelium leading to Vaso-occlusion [49]. Vaso-occlusion may lead to tissue ischaemia which has the propensity to break down the skin or delay the healing process, resulting in chronicity of the leg ulcer [50].

4.2 Psychosocial effects of leg ulcers in SCD

4.2.1 Psychosocial effect

Just like in most chronic conditions, SCD generally affects the QoL of patients [22, 51]. The QoL of the participants were worse with SCLUs [52] due to poorer psychological, physical, emotional, and social perceptions of leg ulcers by patients. SCLUs sufferers were largely stigmatised by their close relatives, and medical professionals due to factors such as discomfort, effusions, and the stench associated with the ulcers [53, 54]. Research reports that leg ulcers affect all areas of patients' lives leading to lifestyle changes [52]. More often, SCLUs patients avoided social activities because of stigma [11]. The emotional wellness of SCLUs patients was often compromised due to loneliness and social defunctness [14]. These factors may have contributed to the overall poor QoL of SCLUs participants. Interventions should include the psychosocial implications of living with SCLUs.

4.2.2 General health perception

The study showed that SCD patients with leg ulcers had significantly poor general health perception compared to their counterparts without leg ulcers as reported in ref. [55]. The aetiology for this finding is varied. Firstly, the majority of studies report that pain associated with leg ulcers in SCD is more excruciating, debilitating, difficult to manage and long-lasting compared to vaso-occlusive crises [55], causing sleep disturbances [56]. Secondly, the findings showed that poor overall health contributed to the poor general health perception among the SCLUs group compared to sickle cell patients without SCLUs [57, 58]. This was compounded by the poor management of SCLUs in clinics and hospitals due to the lack of specialized care, prolonged healing duration and the cost of treatment [30].

4.2.3 Physical functioning

Physical functioning among the SCLUs patients although it was not significant, it was compromised compared to the SCD patients without leg ulcers. Most of the deficits were demonstrated in mobility, walking and bending, and household tasks, consistent with the literature [17, 19]. This is probably due to the intensity of pain, the heaviness associated with SCLUs, and emotional distress related to fear and embarrassment [59].

4.2.4 Emotional functioning

The emotional functioning was not significant however the SCLUs compared to the non-SCLUs patients performed poorly in this study. These were significantly reflected in their mood. Similar studies have corroborated these findings. Studies indicate significant emotional distress among sickle cell patients with active leg ulcers [14, 15].

4.2.5 Social functioning

The significantly poor social functioning seen in the SCLUs group was manifested in their limited social activities, work status and relationship with significant others [17, 37]. The discomfort with social situations and frequent hospitalization may explain the decrease in social activities [17]. The intense pain, compromised health and the restrictions of leg ulcers lead to poor work status while the over-dependency on partners leads to poor relationships with significant others in patients with SCLUs [14].

4.3 Predictors of QoL in SCD patients

Previous studies have reported increasing age, gender and genotype as predictors of health-related quality of life in SCD patients [60, 61]. However, this current study did not find any association between these variables and QoL. This can be attributed to specific participant characteristics such as the balance of genders, the predominantly older age and the lack of disease-modifying drug (i.e. Hydroxyurea) in most patients.

In this study, participant's ages at registration at the clinic and having SCLUs were found to predict poor overall QoL among SCD patients. The initiation of comprehensive care for patients starts with being registered at the clinic. Access

to SCD care and management includes novel therapies, nutritional supplements and SCD peer support groups, which have been found to improve QoL [62]. Late registration at the clinic limits access to SCD care and increases the risk of complications which leads to poor QoL [63]. Future interventions should focus on early diagnosis through national newborn screening to enable prompt initiation of comprehensive care, including psychosocial care, to enhance QoL for individuals living with SCD. Likewise, having a SCLUs is predictive of poor overall QoL, due to both clinical and psychosocial complications of living with SCLUs. Having SCLUs is indicative of a severe form of SCD characterized by increased risk for the development of clinical complications such as pain, low hemoglobin level and poor physical functioning [43]. In addition, the psychosocial impact of living with SCLUs such as stigma, unemployment, emotional and social difficulties, also contribute to worsen patient QoL [64]. Early comprehensive care including psychosocial care should be part of the interventions to improve QoL in people living with SCLUs.

Although the study presents interesting findings, they may not be representative of the SCD population at the Adult Sickle Cell Clinic at KBTH due to potential selection bias. Another limitation was the disproportionately smaller number of patients with HbSC in the SCLUs group, coupled with a control group composed solely of sickle cell patients with HbSC, which is considered a less severe SCD genotype.

5 Conclusion

The study investigated the psychosocial effect of leg ulcers among Ghanaians with sickle cell disease. Consistent with prior studies, the study found that SCD patients especially those with SCLUs experienced a poor quality of life. Among the SCD population, older age at registration at the clinic, and having a leg ulcer were predictive of poor quality of life. These findings underscore the need for comprehensive care, targeted and psychosocial care interventions addressing disease severity and its implications on leg ulcer development and management of SCD.

Additionally, multidisciplinary care models that include not only medical professionals but also psychologists, social workers, and patient advocates could be explored. These teams could provide comprehensive support addressing both the physical and emotional challenges of living with SCD and leg ulcers. Intervention strategies should also focus on early screening and education to help patients understand the psychosocial aspects of their condition and the importance of adhering to treatment plans. Incorporating community-based programs that reduce stigma and raise awareness about the psychosocial impact of SCD could also improve the patient experience and encourage better healthcare-seeking behaviours.

Finally, further research should investigate structured training for healthcare providers to better address the psychosocial needs of patients with SCLUs. This could include workshops or programs that focus on empathetic communication, mental health support, and the integration of psychosocial care into routine medical practice.

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Author contributions M.A.A, A.A, A.M.H, F.J.K, and M.K.K conceptualised, collected and analysed the data for the study. S.K.A, C.T.N, E.M and K.H.A conducted the literature research, screened, and extracted articles. M.A.A, A.M.H, F.J.K, A.A, M.K.K, and K.H.A drafted the manuscript. All the authors read and approved the final manuscript.

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Data availability Raw data were generated at the GICG, KBTH. Derived data supporting the findings of this study are available but restrictions apply to the availability. However, the data is available on request to the corresponding author- Dr. Mary Akua Ampomah of the Fred Newton Binka School of Public Health (mampomah@uhas.edu.gh).

Declarations

Ethics approval and consent to participate The study (KBTH-IRB/00075/2018) adhered to international standards and local laws and regulations, of the Helsinki Declaration, 2013. Administrative approval was obtained from the GICG, and written informed consent was obtained from all participants involved in the study.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

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