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Exploring Psychosocial Challenges Among Patients with Sickle Cell Disease: A Cross-Sectional Study

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Abstract

Introduction. Sickle cell disease (SCD) is a group of inherited hemoglobin disorders marked by alterations affecting the β-globin chain of hemoglobin. These could lead to persistent hemolytic anemia, severe acute and chronic pain.
Purpose. To comprehend the impact of SCD on various facets of patients' lives, including education, employment, relationships, and mental health.
Materials and methods. This descriptive cross-sectional study examines the psychosocial challenges of sickle cell disease (SCD) among patients in Basra city, Iraq. Conducted over three months at the Basra Hematology Center in Al Sayyab Teaching Hospital, the study enrolled 120 patients aged 15 and above diagnosed with SCD or sickle thalassemia. Utilizing structured interviews and standardized questionnaires.
Results. The prevalence of psychosocial challenges, with a significant proportion reporting difficulties in education, career choices, social relationships, and mental well-being. Pain intensity assessments using the Visual Analog Scale underscored the severity of pain experienced by participants. Additionally, socio-demographic factors such as age showed associations with pain scores.
Conclusion. This study highlights the significant psychosocial challenges faced by SCD patients, affecting various aspects of their lives including education, employment, relationships, and mental health. While certain socio-demographic factors showed associations with pain scores.
Keywords: sickle cell disease, psychosocial challenges, chronic pain, Vasoocclusive crises, β-globin chain

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Изучение психосоциальных проблем у пациентов с серповидноклеточной анемией: перекрестное исследование

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Резюме

Введение. Серповидноклеточная анемия представляет собой группу наследственных нарушений гемоглобина, характеризующихся изменениями, затрагивающими β-глобиновую цепь гемоглобина. Это может привести к стойкой гемолитической анемии, сильной острой и хронической боли.
Цель. Понять влияние серповидноклеточной анемии на различные аспекты жизни пациентов, включая образование, работу, отношения и психическое здоровье.
Материалы и методы. В данном описательном поперечном исследовании изучаются психосоциальные проблемы пациентов с серповидноклеточной анемией в городе Басра (Ирак). В исследовании, проводившемся в течение трех месяцев в гематологическом центре Басры клинической больницы Аль-Сайяб, приняли участие 120 пациентов в возрасте 15 лет и старше с диагнозами «серповидноклеточная анемия» или «серповидная талассемия». Использовали структурированные интервью и стандартизированные анкеты.
Результаты. Психосоциальные проблемы распространены среди пациентов с серповидноклеточной анемией, при этом значительная часть пациентов сообщает о трудностях в образовании, выборе карьеры, социальных отношениях и психическом благополучии. Оценка интенсивности боли с использованием визуально-аналоговой шкалы подчеркивает тяжесть боли, которую испытывали участники. Кроме того, социально-демографические факторы, такие как возраст, показали связь с оценкой боли.

Заключение. Исследование подчеркивает серьезные психосоциальные проблемы, с которыми сталкиваются пациенты с серповидноклеточной анемией, влияющие на различные аспекты их жизни, включая образование, трудоустройство, отношения и психическое здоровье. Некоторые социально-демографические факторы отражают связь с показателями боли.
Ключевые слова: серповидноклеточная анемия, психосоциальные проблемы, хроническая боль, вазоокклюзионные кризы, цепь β-глобина

■ INTRODUCTION

Sickle cell disease (SCD) is a group of inherited hemoglobin disorders marked by alterations affecting the β-globin chain of hemoglobin, leading to persistent hemolytic anemia, severe acute and chronic pain, and ongoing organ damage [1, 2]. Pain is a distinctive characteristic of SCD, significantly impacting patients' well-being and quality of life [3]. It manifests in various forms including acute intermittent pain, chronic daily pain, and acute-on-chronic pain, persisting from early infancy throughout patient's life [4]. As individuals age, chronic pain becomes increasingly prevalent, affecting 30% to 40% of SCD patients [5]. Vasoocclusive crises triggered by SCD often lead to intense acute pain, resulting from blood flow obstruction by sickled red blood cells in small vessels, reducing oxygen supply to affected organs. This pain can affect various anatomical regions, including bone structure, joints, and soft tissue, presenting symptoms such as dactylitis, acute joint necrosis, or acute abdomen [6]. Chronic pain in SCD refers to persistent pain experienced on most days for at least six months, and potentially originating from central sensitization or neuropathic mechanisms [7, 8]. The pain experienced in sickle cell disease often necessitates hospitalization, negatively impacts quality of life, potentially reduces survival rates, and leads to significant disability for many individuals [6]. Assessment of pain in SCD relies on patient self-reports, corroborated to identify underlying causes such as avascular necrosis or leg ulcers, with validated instruments crucial for clinical evaluation and decision-making [9].

In addition to the physical illness, sickle cell disease (SCD) patients also encounter a spectrum of psychosocial challenges, including social stigmatization, mental health disorders, sleep disruptions, interpersonal dynamics, substance dependency, and workplace biases [10]. Depression and anxiety frequently affect SCD patients, resulting in high pain levels and clinical complications, suboptimal therapy adherence, and disruptions in various life aspects [10, 11]. Another issue is social stigmatization that stems from diverse sources, including the use of opioids for pain management, racial identity (especially being of African descent), delayed growth or puberty, socioeconomic status, and the severity of the illness. Those with SCD who face stigma often contend with impaired sexual function, elevated stress levels, increased pain perception, inadequate coping mechanisms, medication non-adherence, and depression [12]. Moreover, sleep disturbances is also a common challenge. Notably, patients often experience a negative association between pain levels and sleep quality [13]. The most common sleep-disordered breathing is obstructive sleep apnea (OSA) which is attributed to upper airway obstruction resulting from compensatory adenotonsillar hyperplasia.

This condition follows splenic infarction and reactive lymph node enlargement due to recurrent infections [14].

SCD also poses a great risk for developing depression and anxiety, as demonstrated in a recent study by Al Marzouki et al. [15[involving 119 patients aged 18 and older that concluded that 45.4% of participants exhibited depressive symptoms, with slightly higher rates among male patients. Depression and anxiety can also exacerbate pain and hinder coping strategies, with reported incidences ranging from 26% to 33% for depression and 6.5% to 36% for anxiety [9]. This study aimed to explore the psychosocial experiences and pain intensity among individuals aged 15 and above with SCD.

■ MATERIALS AND METHODS

Study design

This descriptive cross-sectional study was conducted in Basra city at the Basra Hematology Center in Al Sayyab Teaching Hospital, spanning three months from September 1st to November 31st, 2023. The study was conducted three days a week, with each session lasting two hours from 10:30 a.m. to 12:30 p.m.

Sampling, methods and sample size

A convenient sample of 120 patients aged 15 and above, diagnosed with sickle cell disease (SCD) or sickle thalassemia, and attending the Hematology Center at Al-Sayyab Teaching Hospital in Basra city, were included in the study. The sample size was determined based on the available time period for the study. Patients included in the study either visited Basra Hematology Center independently or were referred from hematological clinics. The authors provided clear explanations regarding the purpose and nature of the study to all participants, emphasizing confidentiality, and obtained verbal consent from each subject before enrollment. Each selected patient underwent an interview in a private setting at the hospital using a specially designed structured questionnaire (see Appendix. 2) tailored for the study's objectives.

Interviews

The interviews lasted approximately 10–15 minutes and aimed to comprehensive understanding of the psychosocial encounters of SCD patients and how pain affects their daily activities.

Questionnaire

Patients who consented to participate completed standardized questionnaires in a private hospital setting. A medical student was present to assist with questionnaire administration and address any questions. A researcher-designed questionnaire was utilized. It comprised two sections: Section A focused on gathering respondents' demographic information, while Section B consisted of 20 items aimed at measuring the psychosocial challenges faced by SCD patients. The questionnaire's validity was ensured through expert validation in family medicine, while its reliability was established via the test-retest method, yielding a coefficient of 0.84.

Pain intensity

Pain was assessed using the Visual Analog Scale (VAS), a method used to gauge pain severity by asking patients to rate their pain level on a scale from 0 to 10. Here, 0 denotes no pain, while 10 represents the most severe pain imaginable. Based on their scores, patients were categorized as follows:

- 0 = No pain.
- 1–2 = Mild, bothersome pain.
- 3–4 = Persistent, uncomfortable, bothersome pain.
- 5–6 = Distressing, distressing, distressing pain.
- 7–8 = Intense, dreadful, excruciating pain.
- 9–10 = Worst possible, unbearable, excruciating pain.

Data Collection Procedure

Identification and Recruitment: Potential participants were identified by the authors at Basra Hematology Center. They were approached and informed about the study's objectives and procedures.

Data Management

The research team securely stored and managed completed questionnaires and interview transcripts.

Informed Consent

Every participant received detailed information about the study, including their rights as participants, the questionnaire, and the confidentiality protocols for their data. Informed consent was obtained from each participant.

Confidentiality

Personal information and responses from participants were treated with utmost confidentiality and were securely stored and accessible only to authorized researchers.

Inclusion Criteria

Patients diagnosed with SCD/sickle thalassemia, aged 15 and above, of both sexes, attending Basra Hematology Center.

Exclusion Criteria

1. Patients diagnosed with SCD under the age of 15.
2. Patients with sickle cell trait, pregnant individuals, and those diagnosed with hematological malignancies.
3. Post-operative SCD patients.
4. Patients who declined participation in the study.

Statistical Analysis

SPSS program (Statistical Packages for Social Sciences – version 19) was used to carry out statistical analysis of the data. The results were tabulated. Chi-square test (χ^2) or Fisher exact test, coupled with logistic regression analysis, were employed to discern associations among variables. Statistical significance was established with a p-value below 0.05.

■ RESULTS

The socio-demographic features of the population are shown in Table 1. This study included 120 participants, with ages ranging from 15 to 65 years. The majority fell within the 15–24 age group, accounting for 55.8%. Those aged 25–34 constituted 29.2%, while those aged 35–64 represented 14.1%, and those aged 65 and above constituted only 8%.

Regarding gender distribution, slightly over half of the participants were male (53.3%), while females accounted for 46.7%. In terms of educational status, 41.7% had finished secondary school, 21.7% had attained a higher educational level, and only 3.3% were illiterate. The majority of participants (70.8%) were single, with only 29.2% being married. Additionally, the majority resided in urban areas (61.7%). Regarding disease management, a significant majority (94.2%) were under some form of management, while the remaining 5.8% were not. More than half of the participants (57.5%) had not undergone any surgical intervention, while 42.5% had undergone previous surgical interventions. In terms

Table 1
Socio-demographic features of the study population

Variable	No.	%
Age (years)		
15–24	67	55.8
25–34	35	29.2
35–44	10	8.3
45–54	3	2.5
55–64	4	3.3
65 and above	1	8
Sex		
Male	64	53.3
Female	56	46.7
Education		
No education	4	3.3
Primary school	40	33.3
Secondary school	50	41.7
Diploma	11	9.2
College	12	10
Master	3	2.5
Marital Status		
Single	85	70.8
Married	35	29.2
Residency		
Urban	74	61.7
Rural	46	38.3
Is the patient on medical treatment?		
No	7	5.8
Yes	113	94.2
Any previous surgical intervention (hip replacement or nerve block)?		
No	69	57.5
Yes	51	42.5

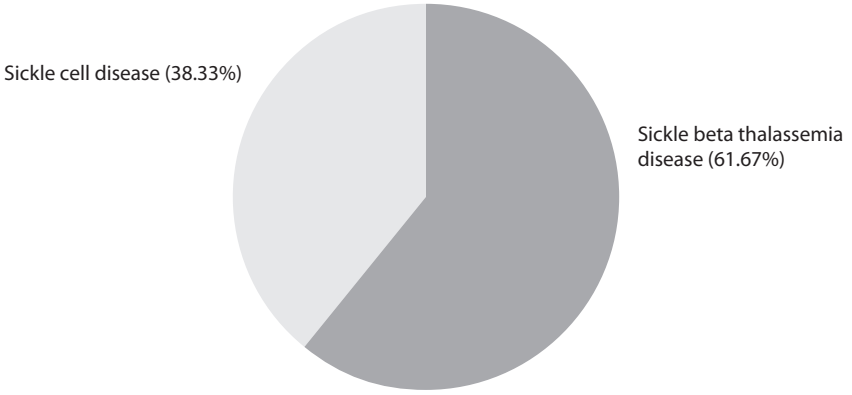

Fig. 1. Types of Haemoglobinopathies of study population

of disease distribution, the majority (61.67%) had sickle beta thalassemia, while the remainder (38.33%) had sickle cell disease. This is demonstrated in Fig. 1.

Table 2 shows the psycho-social impact of SCD among the study population. Specifically, 81.7% reported feeling happy when interacting with others, while 77.5% expressed concern about experiencing painful episodes during physical activities. Additionally, 74.2% reported feeling irritated or anxious, and 69.2% faced difficulties in their studies

Table 2
Psycho-Social impact of SCD among the study population

Variable	No.	%
SCD adversely impacts my overall social relationships (family, friends)		
No	62	51.7
Yes	58	48.3
My career options are restricted		
No	51	42.5
Yes	69	57.5
I have difficulty in study / get in school		
No Yes	37 83	30.8 69.2
I struggle to find a compatible partner for marriage / I face challenges within my marriage		
No	57	47.5
Yes	63	52.5
People avoid being around me		
No	94	78.3
Yes	26	21.7
I feel irritated/anxious		
No	31	25.8
Yes	89	74.2
I feel scared and vulnerable whenever I'm surrounded by friends		
No	85	70.8
Yes	35	29.2
I feel disconnected and lack a sense of belonging		
No	79	65.8
Yes	41	34.2

Table 2 end

I feel anxious about my life expectancy		
No	53	44.2
Yes	67	55.8
I feel happy with people		
No	22	18.3
Yes	98	81.7
My family shows no concern for my well-being		
No	98	81.7
Yes	22	18.3
I'm worry about painful episodes during exercises		
No	27	22.5
Yes	93	77.5
Do you have any previous history of suicide or thoughts of suicide?		
No	92	76.7
Yes	28	23.3
I feel unsettled when in public		
No	76	63.3
Yes	44	36.7
I struggle to consume any type of food		
No	46	38.3
Yes	74	61.7

or attending school. Eating limitations were reported by 61.7% of participants, and 57.5% felt restricted in their career choices. Furthermore, 52.5% found it challenging to find a suitable partner for marriage, and 48.3% perceived that SCD negatively impacted their social relationships. About 36.7% did not feel at ease in public settings, and 34.2% lacked a sense of belonging. Fear regarding life expectancy was reported by 55.8% of participants, while 29.2% felt scared and unprotected among friends. Additionally, 23.3% had a history of suicidal thoughts or attempts, and 21.7% felt that people avoided associating with them. Lastly, 18.3% perceived their families as being unconcerned about their well-being.

Table 3
Rank distribution of participants' psychosocial problems facing sickle-cell patient

Item No.	Psycho-social problems facing adults with sickle cell disease	Rank
14	I'm worry about painful episodes during exercises	1st
8	I feel irritated / anxious	2nd
4	I have difficulty in study / get in school	3rd
7	I struggle to consume any type of food	4th
2	My career options are restricted	5th
11	I feel anxious about my life expectancy	6th
3	I struggle to find a compatible partner for marriage/ I face challenges within my marriage	7th
1	SCD adversely impacts my overall social relationships (family, friends)	8th
6	I feel unsettled when in public	9th
10	I feel disconnected and lack a sense of belonging	10th
9	I feel scared and vulnerable whenever I'm surrounded by friends	11th
15	Do you have any previous history of suicide or thoughts of suicide?	12th
5	People avoid being around me	13th
13	My family shows no concern for my well-being	14th
12	I feel happy with people	15th

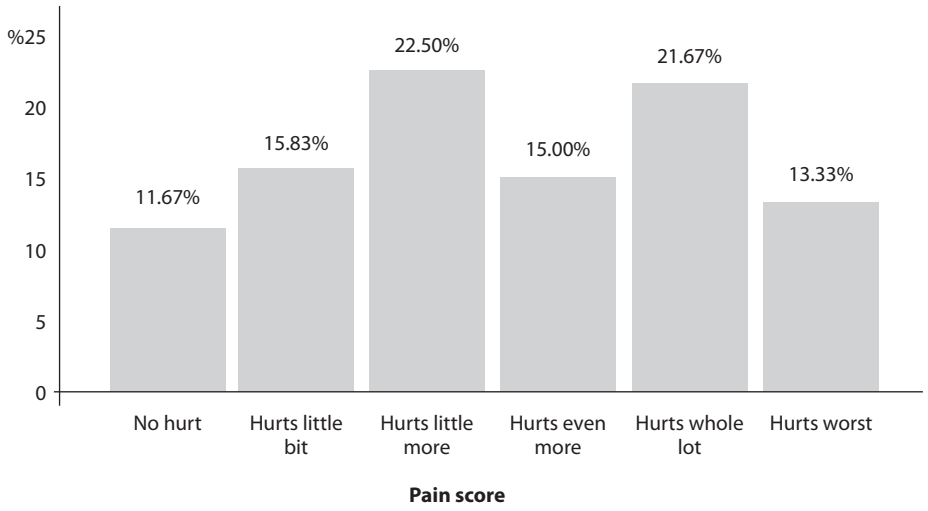

Fig. 2. Pain perception score among SCD patient

Table 4
The adversely impaction of SCD on social relationships and socio- demographic factors association

Variables	**No**		**Yes**	
Age of Respondent (years)	**No.**	**%**	**No.**	**%**
15–24	39	62.9	28	55.8
25–34	13	21	22	37.9
35–44	6	9.7	4	6.9
45–54	2	3.2	1	1.7
55–64	2	3.2	2	3.2
65 and above	0	0	1	1.7
Fisher Exact test = 5.836, P=0.048				
Education level	**No.**	**%**	**No.**	**%**
Illiterate	2	3.2	2	3.2
Primary education	19	30.6	21	36.2
Secondary education	30	48.4	20	34.5
Diploma	5	8.1	6	10.3
Collage	3	4.8	9	15.5
Master	3	4.8	0	0
Fisher Exact test =7.735, P=0.065				
Sex	**No.**	**%**	**No.**	**%**
Male	31	50.0	33	53.3
Female	31	50.0	25	46.7
X^2=1.503, P=0.110				
Marital Status	**No.**	**%**	**No.**	**%**
Single	45	72.6	40	69.0
Married	17	27.4	18	29.2
X^2=0.190, P=0.145				

Table 4 end

Pain Score	No.	%	No.	%
No Hurt	8	12.9	6	11.7
Hurts little bit	10	16.1	9	15.8
Hurts little more	11	17.7	16	27.6
Hurts even more	14	22.6	4	6.9
Hurts whole lot	13	21.0	13	22.4
Hurts worst	6	9.7	10	13.3
X^2=7.695, P=0.04				

Table 3 presents the average and ranking of respondents' descriptions regarding the psycho-social challenges encountered by sickle cell patients.

Regarding the pain score, the distribution was as follows: 22.50% experienced a little more pain, 21.67% experienced a whole lot of pain, 15.83% experienced a bit of pain, 15.00% experienced even more pain, 13.33% experienced the worst pain, and the lowest percentage, 11.67%, reported no pain (Fig. 2).

In terms of the adverse impact of SCD on social relationships and socio-demographic factors, significant associations were observed with age and pain scores (p-value <0.05). However, no significant associations were found with other socio-demographic factors such as educational level, sex, and marital status (Table 4).

■ DISCUSSION

Apart from the physical health issues associated with sickle cell disease, patients also face complex psychosocial obstacles, including pain crises, sleep disorders, interpersonal relationships and social stigma. These challenges also impact their families and social networks, and can significantly affect the overall effectiveness of treatment [10]. This cross-sectional study involving 120 SCD patient, revealed that the majority of cases fell within the age group of 15 to 24 years old. More than half of the participants were male (53.3%), while the remaining (46.7%) were female. Additionally, the majority of participants (70.8%) were single, with only 29.2% being married. Similar to a previous study conducted in Nigeria by Theresa et al. [16], the majority of respondents (61.7%) hailed from urban areas. This also align with the Sickle Cell Data Collection Program (SCDC) in Tennessee by Allison et al. [17]. In terms of educational level, a similar distribution was observed by Harris et al. [18], with the vast majority of patients had a secondary school degree or a higher educational degree.

Regarding management, the majority of patients (94.2%) were undergoing treatment, while the remaining 5.8% were not. These results are in line with those obtained from the international Sickle Cell World Assessment Survey (SWAY) by Osunkwo et al. [19]. Furthermore, more than half of the participants (57.5%) had not undergone any procedures like hip replacements or nerve blocks, while 42.5% had undergone previous surgical interventions. A similar trend was seen in a cross-sectional study by Alshurafa et al. [20].

Moreover, 57.5% reported limitations in their choice of career, which has severe psycho-social implications, similar to findings from a previous study by Thomas et al. [21]. Additionally, a notably high proportion of patients (74.2%) felt irritated or anxious,

consistent with findings suggesting increased depression and anxiety among individuals with SCA by Molock et al. [22]. Additionally, concerns about painful episodes during exercise were reported by 77.5% of participants by Gouraud et al. [23] concluded that, in addition to the effect of anemia in SCD on diminishing oxygen delivery to the skeletal muscle, patients also exhibit significant skeletal muscle dysfunction, resulting in reduction in functional capacity and overall quality of life. Furthermore, 48.3% perceived that SCA adversely affected their overall social relationships. This is consistent with the findings of Adzika et al. [24].

Difficulties in studying or attending school were reported by 69.2% of participants. A previous cross-sectional survey of SCA patients by Osunkwo et al. showed significant impact of SCD on achievement in school and career progress a finding which is consistent with the present study (19) Additionally, 52.5% found it challenging to find a suitable partner in marriage. Oladiran et al. [25] studied the influence of SCD on the choice of romantic partners. They reported concerns about passing on the disease, caregiving responsibilities, lifestyle limitations, fear of complications, and stigma surrounding SCD. Moreover, 23.3% reported a history of suicide or suicidal thoughts, consistent with a previous study by Oliveira et al. who reported a percentage of 20% [26]. This could be attributed to the strong religious beliefs among the population, as religion has been linked to lower rates of suicidal thoughts in some studies [27].

Regarding the association between the adverse impacts of SCA on social relationships and socio-demographic factors, there was a significant association with age and pain scores, with a p-value less than 0.05, similar to findings from previous studies by Edwards et al. [28] and McClish et al. [29]. However, no significant associations were found with other socio-demographic factors such as educational level, sex, and marital status. This aligns with findings from studies by Harris et al. [18] and Adzika et al. [24].

While the study provided valuable insights into the targeted population, several limitations need consideration. These include the potential response bias in self-reported data, the cross-sectional nature limiting causal inferences, subjective pain assessment methods, and limited sample size. Despite these limitations, the study contributes to understanding the psychosocial challenges faced by SCD patients, highlighting the need for further research addressing these complexities in diverse settings and populations.

■ CONCLUSION

This study highlights the significant psychosocial challenges faced by SCD patients, affecting various aspects of their lives including education, employment, relationships, and mental health. While certain socio-demographic factors showed associations with pain scores, further research is needed to better understand the complex interplay between these factors and the impact of SCD.

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