Case Study

Quality of Life of Sickle Cell Disease Patients with Recurrent Acute Painful Episodes

Haider Hafiz Alhashim[1], Sadiq Mustafa Almubarak[2], Mohammad Ali Al Subaie[2], Duaa Abdulaziz Aljuhaymi[3], Somaiyah Saeed Alwadai[4], Atheer Jafar Almalki[5], Amer Musa Al-Qarni[6], Jafar Al-Ali[7], Shaker Hamad Azyabi[8], Reem Nasser Rayani[8], Abdulmalik Zaheralliyali[9], Khames Alzahran[10*]

[1]Consultant Internal Medicine and Hematology, Prince Saud Bin Jalawy Hospital, Al-Ahsa, Saudi Arabia. [2]Medical Student, King Faisal University, Al-Ahsa, Saudi Arabia. [3]Medical student, Princess Nourah University, Riyadh, Saudi Arabia.[4]Medical Student, Najran University, Najran, Saudi Arabia. [5]Medical Student, Taif University, Taif, Saudi Arabia.[6]Medical Student, Umm Al-Qura University, Al-Qunfudhah, Saudi Arabia. [7]General Practitioner, Prince Saud Bin Jalawy Hospital, Al-Ahsa, Saudi Arabia. [8]Medical Student, College of Medicine, Fakeeh College for Medical Sciences, Jeddah, Saudi Arabia. [9]College of Medicine, University of Jeddah, Jeddah, Saudi Arabia. [10]BDS, PGD in Endo, Saudi Board of Endodontic SR, King Faisal Specialist Hospital & Research Centre, Riyadh, Saudi Arabia.

Abstract

Sickle cell disease (SCD) is a hereditary condition that is characterized by a severe painful episode. Vaso-occlusion, persistent hemolysis, and enhanced erythrocyte adhesiveness to vascular endothelium are the disease's pathologic hallmarks. Similar to other persistent medical problems, SCD is frequently made more difficult by psychological problems linked to the disease's chronic nature and additional symptoms of illness. The main objective of this study was to assess the Quality of life of sickle cell disease patients with recurrent acute painful episodes in Saudi Arabia. This cross-sectional observational study uses a questionnaire to collect data from patients diagnosed with sickle cell disease in Saudi Arabia. Our study enrolled 405 participants. The majority of the population falls in the 18-25 age group, with 36% of the population falling in this category. 34.6% of the population is male and 65.4% is female. The score of quality of life among the participants was as follows, the majority of individuals, 51.9%, reported having a moderate quality of life, while 26.7% reported having a good quality of life, and 21.5% reported having a poor quality of life. Gender, educational level, and monthly income were the only parameters that showed significance with quality-of-life score, with p-values of 0.049, 0.040, and 0.009. The quality of life of SCD patients experiencing recurrent acute painful episodes in Saudi Arabia is a complex issue influenced by various medical, social, and cultural factors. Our study showed that the majority of participants exhibited a moderate quality of life level.

Keywords: Sickle cell, Recurrent acute painful episodes, Saudi Arabia, Quality of life.

INTRODUCTION

Sickle cell disease (SCD) is a hereditary condition that is characterized by a severe painful episode [1]. The mutant hemoglobin molecules, specifically hemoglobin S (HbS), undergo polymerization when deprived of oxygen, resulting in a sickle-shaped morphology of the red blood cells and a decrease in the cell membrane's mobility [2]. Vaso-occlusion, persistent hemolysis, and enhanced erythrocyte adhesiveness to vascular endothelium are the disease's pathologic hallmarks [3]. VOC's complicated mechanism is still being thoroughly analyzed [4]. The relationship between the pathologic processes of SCD that are in charge of the continuous inflammation and the hosts' adaptive systems is most likely to be altered in favor of the pathologic processes, which is when VOC happens [4]. SCD is common in Saudi Arabia. However, it is more prevalent in the Eastern and Southern parts of the country [5]. It was estimated that 2400 Saudi children and teenagers out of 1,000,000 have sickle cell disease [6]. Similar to other persistent medical problems, SCD is frequently made more difficult by psychological problems that are linked to the disease's chronic nature as well as additional symptoms of illness [6]. Between 21.6% and 44% of SCD patients are estimated to have depression, which is linked to more hospitalizations, pain crises, and a worse quality of life [7]. In 2021, a study showed that a substantial percentage of patients claimed that SCD had a significant detrimental influence on their emotions (60%) as well as their academic performance (51%) and their ability to work full-time (53%). In the 12 months preceding the survey, there were reported 5.3 VOCs on average (SD = 6.8); the median

Address for correspondence: Khames Alzahran, Saudi Board of Endodontic SR, King Faisal Specialist Hospital & Research Centre, Riyadh, Saudi Arabia.
Dr.khames.Alzahrani@gmail.com

How to cite this article: Alhashim HH, Almubarak SM, Al Subaie MA, Aljuhaymi DA, Alwadai SS, Almalki AJ, et al. Quality of Life of Sickle Cell Disease Patients with Recurrent Acute Painful Episodes. Arch Pharm Pract. 2023;14(S):A06231516.

was 3.0 (interquartile range: 2.0–6.0); 24% of these VOCs were treated at home, while 76% required medical attention. In the thirty days before the survey, exhaustion was the most often reported symptom (other than VOCs), categorized as "high severity" (65%) [8]. In addition, research was conducted on the relationship between frequency and severity of Vaso-occlusive crises and health-related quality of life and work productivity in adults with sickle cell disease that found Patients who experienced VOCs more frequently than patients who experienced VOCs less frequently reported larger effects on mood, social functioning, stiffness, sleep, and discomfort, as well as increased absenteeism, overall efficiency loss, and activity limitation. When categorized by VOC severity, significant effects on health-related quality of life and work and performance were also noted [9]. A recent study by Bindhani and Basanta Kumar demonstrates that All aspects, including the intellectual, psychological, and physical, were impacted. Their regular activities, such as working or attending school, how they perceived their professional success, how they passed the time and engaged in cultural activities, and socioeconomic characteristics were all impacted [10]. Reports on the health-related quality of life of sickle cell disease patients in Saudi Arabia are insignificant. These statistics are crucial for enhancing health-related quality of life early in life and give insight into patients' issues, most of which need immediate treatment. Therefore, the main objective of this study was to assess the Quality of life of sickle cell disease patients with recurrent acute painful episodes in Saudi Arabia.

Objectives

The main objective of this study was to assess the Quality of life of sickle cell disease patients with recurrent acute painful episodes in Saudi Arabia.

MATERIALS AND METHODS

Study Design and Study Setting

This cross-sectional observational study uses a questionnaire to collect data from patients diagnosed with sickle cell disease in Saudi Arabia. (Raosoft, Inc., Seattle, WA, USA) (22) measured the sample size with a 95% confidence level; the minimum sample size was 377. To do statistical analysis, data was subsequently transmitted to the SPSS application, version 20 (IBM SPSS Statistics for Windows, Version 20.0, Armonk, NY: IBM Corp).

Study Setting: Participants, Recruitment, and Sampling Procedure

The population of the research was consist of all Saudi patients who have SCD.

Inclusion and Exclusion Criteria

Individuals must be at least 14 years old and Saudi Arabian citizens to be included in this study. This research does not include anyone outside of Saudi Arabia or under the age of 14.

Sample Size

(Raosoft, Inc., Seattle, WA, USA) (22) measured the sample size with a 95% confidence level; the minimum sample size was 377.

Method for Data Collection and Instrument (Data Collection Technique and Tools)

A validated Structured questionnaire named Health-Related Quality of Life Scale was used. The questionnaire included 22 questions divided into four main sections. Section one included questions about socioeconomic background characteristics questions. The second section asks about core healthy days as well as physical and mental health in the last 30 days. The third section requested questions about activity limitations as physical, mental, or emotional challenges in everyday life, while the fourth section inquired about symptoms for healthy days.

Scoring System

The Core Healthy Days Module subscale contains Q1. The answer format for this question is: 1 = excellent; 2 = very good; 3 = good; 4 = fair; 5 = poor.

The Core Healthy Days Module subscale also contains Q2, Q3, and Q4. The answer format for these questions is: 1 = number of days (fill in the blank); 2 = none.

The Activity Limitations Module subscale contains Q5. The answer format for this question is: 1 = yes; 2 = no.

The Activity Limitations Module subscale also contains Q6. The answer format for this question is: 1 = arthritis/rheumatism; 2 = back or neck problem; 3 = fractures, bone/joint injury; 4 = walking problem; 5 = lung/breathing problem; 6 = hearing problem; 7 = eye/vision problem; 8 = heart problem; 9 = stroke problem; 10 = hypertension/high blood pressure; 11 = diabetes; 12 = cancer; 13 = depression/anxiety/emotional problem; 14 = other impairment/problem.

The Activity Limitations Module subscale also contains Q7. The answer format for this question is fill-in-the-blank.
To calculate the unhealthy days score for each participant, sum up the number of physically unhealthy and mentally unhealthy days. The maximum score is 30 unhealthy days, even if the number of unhealthy days totals more than 30. To calculate a healthy days score, subtract the number of unhealthy days from 30 [11].

Analyzes and Entry Method

The computer's "Microsoft Office Excel Software" (2016) software was used to input data. To do statistical analysis, data was subsequently transmitted to the SPSS application, version 20 (IBM SPSS Statistics for Windows, Version 20.0, Armonk, NY: IBM Corp.).

Results and Discussion

The first parameter shown in **Table 1** is age, which is divided into five categories: less than 18, 18-25, 26-35, 36-45, and 46-55. The majority of the population falls in the 18-25 age group, with 36% of the population falling in this category. The second largest group is the 26-35 age group, which makes up 30.1% of the population. The smallest group is the 46-55 age group, which makes up only 3.5% of the population. The second parameter is gender, with 34.6% of the population being male and 65.4% being female. This indicates that the population is predominantly female. The third parameter is nationality, with 93.3% of the population being Saudi and 6.7% being non-Saudi. The fourth parameter is education level, which is divided into seven categories: no qualification, primary, middle, secondary, Bachelor's, diploma, and postgraduate. The largest group is the Bachelor's degree holders, which make up 39% of the population. The smallest group is those who have no qualifications, which make up only 0.7% of the population. The fifth parameter is occupation, which is divided into five categories: free business, part-time job, full-time job, retired, unemployed, and student. The largest group is students, which make up 36.5% of the population, followed by the unemployed, which make up 34.6% of the population. The smallest group is those with free businesses, which make up only 5.4% of the population. The final parameter is monthly income, which is divided into six categories: less than 5000 Saudi riyals, 5000-9.999 Saudi riyals, 10,000-14,999 Saudi riyals, 15,000-19,999 Saudi riyals, 20,000-29,999 Saudi riyals, and 30,000 Saudi riyals and more. The largest group is those with an income of less than 5000 Saudi riyals, which make up 76.5% of the population. The smallest group is those with an income of 20,000-29,999 Saudi riyals, which make up only 0.5% of the population.

Table 1. Sociodemographic characteristics of participants (n=405)

Parameter		No.	%
Age	less than 18	55	13.6
	18_25	146	36.0
	26_35	122	30.1
	36_45	68	16.8
	46_55	14	3.5
Gender	Male	140	34.6
	Female	265	65.4
Nationality	Saudi	378	93.3
	Non-Saudi	27	6.7
Education Level	I don't have a qualification	3	.7
	primary	28	6.9
	middle	26	6.4
	secondary	121	29.9
	Bachelor's	158	39.0
	diploma	55	13.6
	Postgraduate	14	3.5
Occupation	free business	22	5.4
	part-time job	12	3.0
	Full-time job	80	19.8
	Retired	3	.7
	Unemployed	140	34.6
	student	148	36.5
Monthly Income (in Saudi Riyals)	Less than 5000 Saudi riyals	310	76.5
	From 5000-9.999 Saudi riyals	49	12.1
	From 10,000-14,999 Saudi riyals	28	6.9
	From 15,000-19,999 Saudi riyals	8	2.0
	From 20,000-29,999 Saudi riyals	2	.5
	30,000 Saudi riyals and more	8	2.0
Marital Status	Married	123	30.4
	Single	271	66.9
	Divorced	9	2.2
	Widowed	2	.5

In **Table 2**, when asked to describe their general health, a significant portion of respondents reported their health as either "good" (39.5%) or "very good" (29.1%), indicating a positive perception of their overall well-being. However, it's important to note that a considerable proportion described their health as "weak" (7.2%) or "acceptable" (17.0%). The survey also inquired about the number of days in the past 30 days during which individuals experienced poor physical health. The majority of respondents (58.8%) reported experiencing such issues for 1-10 days. Similarly, when it comes to mental health, a significant portion of respondents reported experiencing poor mental health for 1-10 days (40.2%) in the past 30 days. The impact of poor physical or mental health on daily activities was also assessed. A substantial portion of respondents (49.1%) reported that poor health affected their usual activities for 1-10 days in the past 30 days. Furthermore, the survey explored the limitations individuals faced in their activities due to weakness or health problems. A majority of respondents (70.1%) reported being limited in some activities, with back or neck problems, problems walking, and depression, anxiety, or emotional problems being among the most commonly cited health issues affecting activity levels. The need for assistance with personal care needs due to disability or health problems was also captured, with 21.0% of respondents. Pain, sadness, anxiety, and sleep-related issues were also assessed. For instance, a majority of respondents reported experiencing pain that made it difficult to carry out their usual activities for 1-10 days in the past 30 days.

Table 2. Knowledge of participants of online nutritional applications and tele-dietetics (n=405)

Parameter		No.	%
How would you describe your health in general?	Weak	29	7.2
	Acceptable	69	17.0

	Good	160	39.5
	very good	118	29.1
	Excellent	29	7.2
Currently thinking about your physical health, which includes physical illnesses and injuries, how many days in the past 30 days were your physical health not good?	0	69	17.0
	1_10	238	58.8
	11_20	69	17.0
	21_30	29	7.2
Thinking about your mental health, which includes stress, depression, and emotional problems, how many days in the past 30 days was your mental health not good?	0	133	32.8
	1_10	163	40.2
	11_20	77	19.0
	21_30	32	7.9
During the past 30 days, approximately how many days did poor physical or mental health prevent you from doing your usual activities, such as attention and self-care, work, or leisure?	0	95	23.5
	1_10	199	49.1
	11_20	76	18.8
	21_30	35	8.6
Are you limited in any way in any activities due to any weakness or health problem?	Yes	284	70.1
	No	121	29.9
What is the main obstacle or health issue that limits your activities?	Back or neck problem	133	32.8
	Lung/breathing problems	88	21.7
	Problems walking	94	23.2
	Other problems	139	34.3
	Hypertension	22	5.4
	Heart problems	17	4.2
	Depression, anxiety, or emotional problems	101	24.9
	Fractures and injuries to bones or joints	46	11.4
	Cancer	2	0.5
	Hearing problem	10	2.5
	Stroke problem	14	3.5
	Eye/vision problem	34	8.4
	Diabetes	20	4.9
	Arthritis/rheumatism	105	25.9
	Nothing	52	12.8
Because of any disability or health problem, do you need the help of other people to meet your personal care needs, such as eating, bathing, dressing, or getting around the house?	Yes	85	21.0
	No	320	79.0
During the past 30 days, how many days did pain make it difficult for you to do your usual activities, such as self-care, work, or recreation?	0	123	30.4
	1-10	217	53.6
	11-20	43	10.6
	21-30	22	5.4
During the past 30 days, how many days did you feel sad or depressed?	0	113	27.9
	1-10	180	44.4
	11-20	72	17.8
	21-30	40	9.9
During the past 30 days, how many days did you feel anxious, stressed, or tense?	0	80	19.8
	1-10	211	52.1
	11-20	76	18.8
	21-30	38	9.4
During the past 30 days, how many days did you feel like you didn't get enough rest or sleep?	0	67	16.5
	1-10	191	47.2
	11-20	87	21.5
	21-30	60	14.8
During the past 30 days, how many days did you feel healthy and full of energy?	0	45	11.1
	1-10	182	44.9
	11-20	116	28.6
	21-30	62	15.3

The data provided in **Figure 1** showed the score of quality of life among the participants. The majority of individuals, 51.9%, reported having a moderate quality of life, while 26.7% reported having a good quality of life, and 21.5% reported having a poor quality of life.

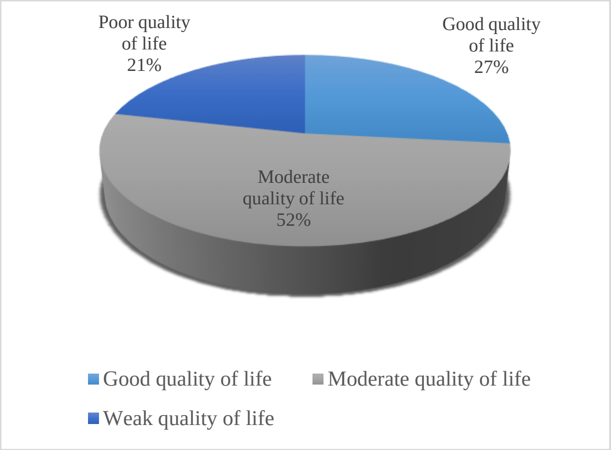

Figure 1. Quality of life score of sickle cell disease patients with recurrent acute painful episodes

Starting with age, the data provided in **Table 3** indicated that individuals aged 18-25 and 26-35 form the largest groups within the sample, comprising 36.0% and 30.1% of the total population, respectively. Interestingly, the "poor quality of life" category shows an increasing trend with age, peaking at 16.8% for the 36-45 age group. However, the differences in quality-of-life scores across age groups are not statistically significant, as indicated by the P values. Moving on to marital status, the data reveals that the majority of the sample population is single (66.9%), followed by married individuals (30.4%). However, there are no significant differences in quality-of-life scores based on marital status, as evidenced by the non-significant P value of 0.765. Gender-wise analysis demonstrates that females constitute a larger proportion of the sample population (65.4%) compared to males (34.6%). The quality-of-life scores for females also show a higher percentage (17.5%) in the "good quality of life" category compared to males (9.1%). This difference is statistically significant, as indicated by the P value of 0.049. When considering nationality, the data shows that Saudi nationals make up the majority of the sample (93.3%). However, the differences in quality-of-life scores between Saudi and non-Saudi nationals are not statistically significant, with a P value of 0.265. Education level presents a diverse distribution within the sample, with the majority having completed secondary education (29.9%) and bachelor's degrees (39.0%). The data suggests that those with lower educational qualifications or postgraduate degrees had higher quality of life scores. However, the differences in quality-of-life scores based on education level are statistically significant, as indicated by the P value of 0.040. Occupation-wise, the sample comprises a mix of students (36.5%), unemployed individuals (34.6%), and those in full-time employment (19.8%). The data indicates no significant differences in quality-of-life scores based on occupation, as all P values exceed the threshold for statistical significance. Finally, the analysis of monthly income in Saudi Riyals reveals that the majority of the sample population falls within the "Less than 5000 Saudi Riyals" category (76.5%) and they exhibit a higher score of quality of life (18.3%). The differences in quality-of-life scores across are statistically significant, as indicated by the P value of 0.009.

Table 3. Association between sociodemographic characteristics and quality of life score of sickle cell disease patients with recurrent acute painful episodes (n=405)

Parameter		Quality of life score			Total (N=405)	P value
		Good quality of life	Moderate quality of life	Poor quality of life		
Age	less than 18	11	34	10	55	0.601
		2.7%	8.4%	2.5%	13.6%	
	18_25	38	72	36	146	
		9.4%	17.8%	8.9%	36.0%	
	26_35	37	60	25	122	
		9.1%	14.8%	6.2%	30.1%	
	36_45	20	34	14	68	
		4.9%	8.4%	3.5%	16.8%	
	46_55	2	10	2	14	
		0.5%	2.5%	0.5%	3.5%	
marital status	Single	74	137	60	271	0.765
		18.3%	33.8%	14.8%	66.9%	
	Married	33	65	25	123	
		8.1%	16.0%	6.2%	30.4%	
	Divorced	1	6	2	9	
		0.2%	1.5%	0.5%	2.2%	
	widow	0	2	0	2	
		0.0%	0.5%	0.0%	0.5%	
Gender	Male	37	82	21	140	0.049
		9.1%	20.2%	5.2%	34.6%	
	Female	71	128	66	265	
		17.5%	31.6%	16.3%	65.4%	
Nationality	Saudi	98	200	80	378	0.265
		24.2%	49.4%	19.8%	93.3%	
	Non-Saudi	10	10	7	27	
		2.5%	2.5%	1.7%	6.7%	
Education Level	I don’t have a qualification	1	0	2	3	0.040
		0.2%	0.0%	0.5%	0.7%	
	Primary	6	17	5	28	
		1.5%	4.2%	1.2%	6.9%	
	Middle	4	16	6	26	
		1.0%	4.0%	1.5%	6.4%	
	Secondary	30	74	17	121	
		7.4%	18.3%	4.2%	29.9%	
	Bachelor's	41	77	40	158	
		10.1%	19.0%	9.9%	39.0%	
	Diploma	19	21	15	55	

		4.7%	5.2%	3.7%	13.6%	
	Postgraduate	7 1.7%	5 1.2%	2 0.5%	14 3.5%	
Occupation	Free Business	4 1.0%	11 2.7%	7 1.7%	22 5.4%	0.516
	Pat time job	1 0.2%	7 1.7%	4 1.0%	12 3.0%	
	Full-time job	25 6.2%	44 10.9%	11 2.7%	80 19.8%	
	Retired	0 0.0%	2 0.5%	1 0.2%	3 0.7%	
	Unemployed	38 9.4%	68 16.8%	34 8.4%	140 34.6%	
	Student	40 9.9%	78 19.3%	30 7.4%	148 36.5%	
Monthly Income (in Saudi Riyals)	Less than 5000 Saudi riyals	74 18.3%	165 40.7%	71 17.5%	310 76.5%	0.009
	From 5000-9.999 Saudi riyals	16 4.0%	24 5.9%	9 2.2%	49 12.1%	
	From 10,000-14,999 Saudi riyals	7 1.7%	18 4.4%	3 0.7%	28 6.9%	
	From 15,000-19,999 Saudi riyals	3 0.7%	2 0.5%	3 0.7%	8 2.0%	
	From 20,000-29,999 Saudi riyals	1 0.2%	1 0.2%	0 0.0%	2 0.5%	
	30,000 Saudi riyals and more	7 1.7%	0 0.0%	1 0.2%	8 2.0%	

Sickle cell disease is a genetic blood disorder characterized by the presence of abnormal hemoglobin, leading to the formation of sickle-shaped red blood cells. Recurrent acute painful episodes, known as vaso-occlusive crises, are a hallmark feature of SCD and significantly impact the quality of life of affected individuals. In Saudi Arabia, SCD is a prevalent condition, and understanding the quality of life of patients experiencing recurrent acute painful episodes is crucial for improving their care and well-being [6].

Saudi Arabia has a relatively high prevalence of SCD, with a significant impact on the healthcare system and affected individuals. The recurrent acute painful episodes associated with SCD often lead to frequent hospitalizations and substantial healthcare utilization. Moreover, the chronic nature of the disease and its associated complications can have a profound effect on the physical, emotional, and social well-being of patients [7].

Several factors contribute to the impaired quality of life experienced by SCD patients with recurrent acute painful episodes in Saudi Arabia. These include the severity and frequency of pain crises, limitations in physical activity, social stigma, emotional distress, financial burden, and inadequate access to comprehensive care and support services. Additionally, the lack of awareness and understanding of SCD among the general population and healthcare providers may further exacerbate the challenges faced by affected individuals [3].

According to our findings, the majority of participants (39.5%) rated their general health as good, and 40.2% chose 1-10 days in the past 30 days where their mental health was not good. Also, 44.3% of our population said that in the past 30 days, they felt depressed or sad for 1-10 days. According to the statistics of another study, around 33% of patients with SCD had symptoms of clinical depression [12]. Out of these, 72% were women, a proportion that closely matches the 65% observed in the overall population [13].

In our study, other problems were the most reported health issue (34.3%) that limited participants' activity, followed by back or neck problems (32.8%), arthritis/rheumatism (25.9%), and depression, anxiety, or emotional problems (24.9%).

According to our research, we are the first study to assess quality of life score related to sickle cell disease patients with recurrent acute painful episodes. However, our results indicated that the majority of individuals, 51.9%, reported having a moderate quality of life, while 26.7% reported having a good quality of life, and 21.5% reported having a poor quality of life. Highlighting the need for concerted efforts from healthcare providers, policymakers, and the community at large to provide more efforts in sustaining and increasing facilities to increase quality of life.

The management of SCD in Saudi Arabia faces various challenges, including limited access to specialized healthcare facilities, shortages of essential medications, and a lack of standardized care protocols. Furthermore, the stigma associated with chronic illnesses, including misconceptions about SCD, can lead to social isolation and hinder the overall well-being of patients. Addressing these challenges is essential for improving the quality of life of SCD patients and ensuring equitable access to comprehensive care and support services [6].

To enhance the quality of life for SCD patients with recurrent acute painful episodes in Saudi Arabia, a multi-faceted approach is needed. This includes increasing public awareness about SCD, implementing comprehensive and culturally sensitive care programs, providing access to specialized healthcare services, and offering psychosocial support for patients and their families. Additionally, research efforts aimed at understanding the unique aspects of SCD in the Saudi Arabian population can inform targeted interventions and improve patient outcomes [2-4].

One of the limitations of this study is its small sample size. The study was conducted on a limited number of sickle cell disease patients in Alhasa, which may not be representative of the general population. This could potentially skew the results and limit the generalizability of the findings. Another limitation of this study is the use of self-reported measures. The study relied on patient-reported outcomes, which may be subject to bias or inaccuracies. Patients may over or underreport their pain levels or quality of life, which could affect the validity of the results. Furthermore, the study did not account for other factors that may affect the quality of life of sickle cell disease patients, such as socioeconomic status, access to healthcare, and comorbidities. These factors could potentially confound the results and limit the conclusions drawn from the study.

Understanding the impact of recurrent acute painful episodes on the quality of life of Sickle Cell Disease (SCD) patients is crucial for developing targeted interventions and improving overall patient care. By identifying the specific challenges and needs of these patients, healthcare providers can tailor treatment plans and support systems to enhance their quality of life. Furthermore, the findings of this study may also contribute to the development of new therapeutic approaches and guidelines for managing SCD-related pain, potentially leading to improved patient outcomes and reduced healthcare costs. As such, this research has the potential to inform future clinical practices and policies, ultimately benefiting SCD patients not only in Alhasa but also globally.

Conclusion

The quality of life of SCD patients experiencing recurrent acute painful episodes in Saudi Arabia is a complex issue influenced by various medical, social, and cultural factors. Our study showed that the majority of participants exhibited a moderate quality of life level. Addressing the challenges faced by these individuals requires a concerted effort from healthcare providers, policymakers, and the community at large. By implementing targeted interventions and support services, it is possible to improve the well-being and overall quality of life for SCD patients in Saudi Arabia.

ACKNOWLEDGMENTS: None
CONFLICT OF INTEREST: None
FINANCIAL SUPPORT: None
ETHICS STATEMENT: Ethical approval was obtained from the Research Ethical Committee at King Fahad Hospital-Hofuf (Ethical approval number: 109-EP-2023). Participants were informed that their participation is voluntary and filling the questionnaire indicates their consent to participate.
Written consent was obtained from all individual participants included in the study.

References

1. Al Jabri WH. Family Quality of Life in the Context of Pediatric Sickle Cell Disease in Oman (Doctoral dissertation, Case Western Reserve University). 2023.
2. Access O. We are IntechOpen, the world’s leading publisher of Open Access books Built by scientists, for scientists TOP 1 % Role of Sociodemographic and Economic Variables in Crisis and Mortality in Patients with SCD: Case Study of Sub-Saharan Africa.
3. Uwaezuoke SN, Ayuk AC, Ndu IK, Eneh CI, Mbanefo NR, Ezenwosu OU. Vaso-occlusive crisis in sickle cell disease: current paradigm on pain management. J Pain Res. 2018;11:3141-50.
4. Jang T, Poplawska M, Cimpeanu E, Mo G, Dutta D, Lim SH. Vaso-occlusive crisis in sickle cell disease: a vicious cycle of secondary events. J Transl Med. 2021;19(1):397.
5. Ahmed AE, Alaskar AS, Al-Suliman AM, Jazieh AR, McClish DK, Al Salamah M, et al. Health-related quality of life in patients with sickle cell disease in Saudi Arabia. Health Qual Life Outcomes. 2015;13(1):1-9. doi:10.1186/s12955-015-0380-8
6. Bin Zuair A, Aldossari S, Alhumaidi R, Alrabiah M, Alshabanat A. The Burden of Sickle Cell Disease in Saudi Arabia: A Single-Institution Large Retrospective Study. Int J Gen Med. 2023;16:161-71.
7. Dairi M, Almatrfi SS, Alsharif MM, Fatani BA, Almatrafi OA, Mandurah AS, et al. Prevalence of Psychological Symptoms and Its Impact on the Quality of Life of Sickle Cell Disease Patients in Makkah, Saudi Arabia. Cureus. 2022;14(12):1–12.
8. Osunkwo I, Andemariam B, Minniti CP, Inusa BPD, El Rassi F, Francis-Gibson B, et al. Impact of sickle cell disease on patients' daily lives, symptoms reported, and disease management strategies: Results from the international Sickle Cell World Assessment Survey (SWAY). Am J Hematol. 2021;96(4):404-17.
9. Rizio AA, Bhor M, Lin X, McCausland KL, White MK, Paulose J, et al. The relationship between frequency and severity of vaso-occlusive crises and health-related quality of life and work productivity in adults with sickle cell disease. Qual Life Res. 2020;29(6):1533-47.

10. Bindhani BK, Nayak JK. Quality of life among individuals with sickle cell disease: A study from Koraput district, Odisha. Int J Acad Res Dev. 2018;3(2):726-30.
11. Duration A, Level R, Format A, Core T, Days H, Core T, et al. Health-Related Quality of Life Scale. 2016.
12. Adam SS, Flahiff CM, Kamble S, Telen MJ, Reed SD, De Castro LM. Depression, quality of life, and medical resource utilization in sickle cell disease. Blood Adv. 2017;1(23):1983-92.
13. Jenerette C, Funk M, Murdaugh C. Sickle cell disease: a stigmatizing condition that may lead to depression. Issues Ment Health Nurs. 2005;26(10):1081-101.