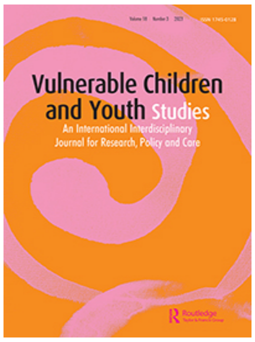

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Sickle cell disease in Sudanese children & psychosocial problems faced by children and parents – a two-scale study

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ABSTRACT

Sickle cell disease (SCD) is an inherited red blood cell (RBC) disorder transmitted to the child through the parental genes. SCD is a serious public health problem in Sudan, ranging from 18.2% to 30.4%, with the sickle cell anemia gene known to be prevalent in the Khartoum area. This study aimed to explore the psychosocial impact of SCD on affected children and parents and to identify the relationship between psychosocial problems experienced by children and parents with the use of two scales. To address the research aim, the Strengths and Difficulties Questionnaire (SDQ) was administered among $n = 170$ SCD children aged 6–12 years. In addition, the Depression, Anxiety, Stress Scale-21 (DASS-21) was used to measure levels of depression, anxiety, and stress in parents of children with SCD. Most of the children experienced substantially high emotional symptoms ($n = 113$), with conduct problems ($n = 113$), hyperactivity ($n = 100$), and peer problems ($n = 86$) being close to average. Most of the parents had the normal level of depression ($n = 78$), anxiety ($n = 92$), and stress ($n = 85$), with severe and extremely severe cases being the least recorded. Further analysis of the association between the SDQ scale and DASS-21 showed a significant association between parental stress and children's conduct problems ($p = 0.009$), hyperactivity ($p = 0.03$), and the prosocial behavior of the child ($p = 0.03$). No association was found between parental anxiety, depression, and emotional symptoms, conduct problems, hyperactivity, and peer problems. Future research is recommended to explore the incidence of SCD in children at birth and parental actions after diagnosis.

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Sickle cell disease; psychosocial impact; children; parents; Sudan

Introduction

Sickle cell disease (SCD) is an inherited red blood cell (RBC) disorder transmitted to the child through the parental genes, characterized by mutations affecting the β-globin chain

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of hemoglobin (Rees et al., 2010; Williams, 2016; Centers for Disease Control and Prevention (Centers for Disease Control and Prevention [CDC], 2017). SCD causes lifelong acute and chronic complications, including pain and swelling of the hands and feet, heart failure, and chronic leg ulcers. Children with SCD may also have strokes, which can negatively affect cognitive function, school performance and predict long-term cognitive limitations in adulthood (Brandow & Liem, 2022; Piel et al., 2013; Wastnedge et al., 2018).

The origin of the sickle gene comes from sub-Saharan Africa, where transatlantic trade and global migration contributed to the spread of the disease around the world (Naoum, 2011; Piel et al., 2013). Annually, with an average of 300 000 children born with sickle syndrome, SCD is recognized as a significant cause of infant mortality associated with noncommunicable diseases (Piel et al., 2013). However, the number of children born with SCD remains high in the African continent, where at least 240,000 children are born each year with sickle cell anemia (Williams, 2016).

The Republic of South Sudan is located in northeast Africa and is considered a lower middle-income country with persistently poor health outcomes and huge disparities between urban and rural areas (Ebrahim et al., 2017; United Nations International Children's Emergency Fund (United Nations International Children's Emergency Fund [UNICEF], 2019; World Health Organization [WHO], 2022). Poverty-related endemic infectious diseases, malnutrition, and poor perinatal outcomes are responsible for a huge burden on the healthcare system of the country (WHO, 2022). As a result of the growing burden of chronic non-communicable diseases (NCDs) and communicable diseases poses serious challenges to the health system. Thus, over 78,000 children under the age of 5 die annually from preventable causes such as malaria (UNICEF, 2019). The inconvenience of infrastructure, such as lack of adequate access to laboratories, and limited resources, including labor shortages contribute to poor health care delivery, which in turn undermines disease control efforts (Charani et al., 2019; Talha et al., 2022). Access to health care is a major concern for many Sudanese families. Thus, 70% of the population has access to a health facility within 30-minute drive from home, and 80% have access to a health facility within an hour's drive, and the quality of the health facility is often insufficient. As a result of a lack of medical resources, accompanied by insufficient training among health workers, and a lack of public awareness, rates of SCD worsened the poor health of the Sudanese population since 1926, when the first case was reported (Daak et al., 2016; Sabahelzain & Hamamy, 2014; UNICEF, 2019; WHO, 2022).

In 1926 Archibald reported the first case of sickle cell anemia in Sudan and Africa. In 1950 the first case of the HbS gene was reported in Sudan (Archibald, 1926; El-Hazmi et al., 2011). More recent studies have shown that sickle cell gene frequencies vary from region to region in Sudan. In the 1980s, when drought and famine hit western Sudan, there was a massive migration, and many tribes settled around Khartoum, Sudan's capital. This unique situation has made Khartoum a multi-ethnic area with almost all Sudanese tribes, which has 'positively' contributed to the increase in SCD cases. In Sudan, SCD is now a serious public health problem ranging from 18.2% to 30.4%, with the sickle cell anemia gene known to be prevalent in the Khartoum area (Charani et al., 2019; Elderdery et al., 2011; Sabahelzain & Hamamy, 2014).

The treatment and care of SCD and its complications require a durable guideline that includes supportive care, symptomatic treatment, and preventive measures, the ultimate goal of which is to relieve symptoms and maintain a good quality of life in the affected population (Brandow & Liem, 2022; Charani et al., 2019; Sabahelzain & Hamamy, 2014; Wastnedge et al., 2018). While the physiological consequences of this health condition are well known among adults, less is known about the psychosocial consequences of SCD, especially in the pediatric age group and their parents. Therefore, this study aimed to explore the psychosocial impact of SCD on affected children and parents and identify the relationship between psychosocial problems experienced by children and parents with two scales.

Methods

Study design and population

A descriptive cross-sectional study was conducted at Gaafar Ibnauf (Khartoum), the largest children's hospital in Sudan. The study sample included children diagnosed with sickle cell anemia, in whom the diagnosis was established within one year or more before the start of the study.

Eligibility criteria

The study included children with SCD aged 6 to 12 years (children of school age) diagnosed a year or more before the start of the study. The study excluded children with SCD associated with disability, who did not go to a specialized clinic with their parents, adopted children, and children over 12 years of age.

Sample size

This cross-sectional study applied the purposive sampling technique, that is, to identify and select participants who are particularly knowledgeable or experienced and ready to convey experience and opinions related to the study aim. Thus, the sample size of this study was based on the number of SCD children and parents at the time of data collection who met the inclusion criteria for the study. As a result, $n = 170$ children and $n = 170$ parents were included in the study.

Instrumentation

A clinical design questionnaire for socio-demographic data was used. To address the research objective, the Strengths and Difficulties Questionnaire (SDQ) was used. With the internal reliability of the instrument ranging from 0.45–0.80 to 0.63–0.86, it is one of the most widely used screening tools, consisting of 25 items equally divided into five scales that measure emotional symptoms, conduct problems, hyperactivity-inattention, peer problems, and prosocial behavior (Mieloo et al., 2012). The Depression, Anxiety, Stress Scale-21 (DASS-21) was used to measure levels of depression, anxiety, and stress in parents of children with SCD. The scale reported high reliability of Cronbach's Alpha coefficients for depression, anxiety, and stress, which were 0.91, 0.84, and 0.90, respectively (Oei et al., 2013).

Procedures

The study administration was confirmed by the Al-Neelain University Institutional Review Board. Permission was obtained from the ethics committee of the hospital and the consultants responsible for the patient were informed. Informed consent was obtained from the parents of children.

Data analysis

Statistical Package for the Social Sciences (SPSS version 28.0, Armonk, NY: IBM Corp, U.S.A.) was used to compile and analyze the acquired data. Demographic data were presented as descriptive statistics, frequency (n), and percentage (%). Descriptive statistics were followed by an analysis of certain demographic data with included scales, as well as an association between some SDQ and DASS-21 variables with the use of Chi-square test. A p-value of less than 0.05 was considered statistically significant at 95%.

Results

This research aimed to explore the psychosocial impact of SCD on affected children and parents and to identify the relationship between psychosocial problems experienced by children and parents with the use of two scales. As can be seen from Table 1, most of the children belonged to the age group of 6–8 years. Most children had SCD for more than five years. In terms of family structure and caregivers, the majority of children had two parents ($n = 131$), with mothers mostly being the primary caregivers ($n = 146$). In fact, there were only two children in whom both mother and father shared the role of caregiver. In terms of family socioeconomic status, the majority of children were in low socioeconomic conditions, with financial hardship associated with child's health condition reported 'always' by $n = 106$ and 'somewhat' by $n = 53$ parents (Table 1). The level of education of caregivers ranged from illiterate ($n = 46$), secondary ($n = 50$) to primary ($n = 59$). Only $n = 14$ parents have higher education; with one missing data, and most parents had an average level of knowledge about the child's health status condition.

The analysis of the Strengths and Difficulties Questionnaire (SDQ) showed that most of the children experienced 'substantially high' emotional symptoms ($n = 113$), with conduct problems ($n = 113$), hyperactivity ($n = 100$), peer problems ($n = 86$) being 'close to average'. At the same time, the pro-social behavior of the most participants ($n = 135$) was also 'close to average', which is a positive indicator (Table 2).

Descriptive statistics of the Depression, Anxiety, Stress Scale –21 (DASS 21) for parents of SCD children showed that most of the parents had the normal level of depression ($n = 78$), anxiety ($n = 92$), and stress ($n = 85$) (Table 3), with severe and extremely severe cases being the least recorded.

Descriptive statistics were followed by an analysis of certain demographic data with included scales, as well as an association between some SDQ and DASS-21 variables with the use of Chi-square test. As can be seen from Table 4, family socioeconomic status was significantly associated with peer problems among SCD children, with low status leading to close to average peer problems ($p = 0.000$). However, there was no significant association between disease duration and conduct problem or hyperactivity in children.

Table 1. Socio-demographic data of $n = 170$ SCD children and parents

Variable	Frequency (n)	Percent (%)
Age		
6–8 years	74	43.5
9–10 years	28	16.5
11-12years	68	40
Sex		
male	89	52.4
female	81	47.6
Duration from time of diagnosis		
2 years	30	17.6
3–5 years	26	15.3
more than 5 years	114	67.1
Family status		
single parents	38	22.4
two parents	131	77.1
missing data	1	0.6
Caregiver		
mother	146	85.9
father	14	8.2
other	8	4.7
mother and father	2	1.2
Caregiver Education level		
primary	59	34.7
secondary	50	29.4
university	14	8.2
illiterate	46	27.1
missing data	1	0.6
Socioeconomic status of the family		
good	13	7.6
moderate	42	24.7
low	115	67.6
Parents awareness about their child condition		
sufficient	41	24.1
average	72	42.4
little	48	28.2
none	7	4.1
missing data	2	1.2
Financial difficulties resulting from child disease		
always	106	62.4
somewhat	53	31.2
none	8	4.7
missing data	3	1.8
Child academic achievement		
high	23	13.5
moderate	64	37.6
low	79	46.5
missing data	4	2.4

Similarly, children's emotional symptoms were not significantly associated with parental awareness of the child's health status. In terms of demographic data of parents and DASS-21 scale, it was found that financial difficulties resulting from child disease was significantly associated with mild to moderate levels of parental depression ($p = 0.009$). Furthermore, parents with primary and secondary level of education were more likely to experience anxiety ($p = 0.002$). In terms of stress and academic achievement of children, the stress level ranged from low to moderate ($p = 0.01$) (Table 4).

Table 2. Descriptive statistics of the Strengths and difficulties Questionnaire (SDQ) for $n = 170$ SCD children

Scale and level	Frequency (n)	Percent (%)
Emotional Symptoms		
close to average	30	17.6
slightly raised	27	15.9
high substantial	113	66 .5
Conduct Problem		
close to average	113	66.5
slightly raised	26	15.3
high substantial	31	18.2
Hyperactivity		
close to average	100	58.8
slightly raised	37	21.8
high substantial	33	19.4
Peer Problems		
close to average	86	5.6
slightly raised	30	17.6
high substantial	54	31.8
Pro-social behavior		
close to average	135	79.4
slightly low	15	8.8
low substantial	20	11.8

Table 3. Descriptive statistics of the depression, anxiety, stress scale −21 (DASS 21) for parents of SCD children

Scale and level	Frequency (n)	Percent (%)
Depression		
Normal	78	45.9
Mild	33	19.4
Moderate	47	27.6
Severe	9	5.3
Extremely severe	3	1.8
Anxiety		
Normal	92	54.1
Mild	33	19.4
Moderate	15	8.8
Severe	11	6.5
Extremely severe	19	11.2
Stress		
Normal	85	50
Mild	30	17.6
Moderate	29	17.1
Severe	18	1.6
Extremely severe	8	4.7

Further analysis looked into association between SDQ scale and DASS-21 to explore how children's behavior impact parental level of depression, anxiety and stress. As can be seen from Table 5, while there is a significant association between children's conduct problems and parental stress ranging from mild, moderate to normal levels ($p = 0.009$), it is not significant for depression and anxiety. Similar patterns can be observed in the relationship between child's hyperactivity and parental stress, where close to average hyperactivity was associated with moderate to normal parental stress ($p = 0.03$), but had no effect on anxiety or depression. At the same time, children's pro-social behavior was significantly associated with parental

Table 4. The association between demographic data and SDQ and DASS-21 variables

Conduct Problem	Duration of disease from time of diagnosis in years n (%)					Chi-square *p*-value
	2 years	3–5 years	more than 5 years			
Close to average	20 (17.7)	15 (13.3)	78 (69.0)			χ^2 =6.93 $p = 0.14$
High substantial	2 (6.5)	7 (22.6)	22 (71.0)			
Slightly raised	8 (30.8)	4 (15.4)	14 (53.8)			
Hyperactivity	2 years	3–5 years	more than 5 years			
Close to average	14 (14.0)	16 (16.0)	70 (70.0)			
High substantial	5 (15.2)	6 (18.2)	22 (66.7)			
Slightly raised	11 (29.7)	4 (10.8)	22 (59.5)			
Parents awareness about their child condition	Emotional Symptoms					
	close to average	high substantial	slightly raised			
Missing data	1 (50.0)	1 (50.0)	0 (0.0)			χ^2 =11.50 $p = 0.18$
Average	10 (13.9)	49 (68.1)	13 (18.1)			
Little	8 (16.7)	28 (58.3)	12 (25.0)			
None	1 (14.3)	5 (71.4)	1 (14.3)			
Sufficient	10 (24.4)	30 (73.2)	1 (2.4)			
Socioeconomic status of the family	Peer Problems					
	close to average	high substantial	slightly raised			
Good	10 (76.9)	3 (23.1)	0 (0.0)			χ^2 =24.32 $p = 0.000$*
Low	51 (44.3)	48 (41.7)	16 (13.9)			
Moderate	25 (59.5)	3 (7.1)	14 (33.3)			
Financial difficulties resulting from child disease	Depression					
	Extremely severe	Mild	Moderate	Normal	Severe	
Missing data	0 (0.0)	1 (33.3)	0 (0.0)	2 (66.7)	0 (0.0)	χ^2 =26.47 $p = 0.009$*
Always	3 (2.8)	28 (26.4)	34 (32.1)	34 (32.1)	7 (6.6)	
None	0 (0.0)	0 (0.0)	3 (37.5)	5 (62.5)	0 (0.0)	

(*Continued*)

Table 4. (Continued).

Somewhat	0 (0.0)	4 (7.5)	10 (18.9)	37 (69.8)	2 (3.8)	
Anxiety	Caregiver education level					
	Missing data	Illiterate	Primary	Secondary	University	
Extremely severe	0 (0.0)	5 (26.3)	11 (57.9)	2 (10.5)	1 (5.3)	χ^2 =36.77 $p = 0.002$*
Mild	0 (0.0)	6 (18.2)	7 (21.2)	18 (54.5)	2 (6.1)	
Moderate	0 (0.0)	1 (6.7)	7 (46.7)	3 (20.0)	4 (26.7)	
Normal	1 (1.1)	31 (33.7)	33 (35.9)	23 (25.0)	4 (4.3)	
Severe	0 (0.0)	3 (27.3)	1 (9.1)	4 (36.4)	3 (27.3)	
Stress	Child academic achievement					
	Missing data	High	Low	Moderate		
Extremely severe	1 (12.5)	0 (0.0)	1 (12.5)	6 (75.0)		χ^2 =25.97 $p = 0.01$*
Mild	1 (3.3)	3 (10.0)	9 (30.0)	17 (56.7)		
Moderate	0 (0.0)	7 (24.1)	14 (48.3)	8 (27.6)		
Normal	1 (1.2)	11 (12.9)	42 (49.4)	31 (36.5)		
Severe	1 (5.6)	2 (11.1)	13 (72.2)	2 (11.1)		

*Significant at 95%.

Table 5. The association between DASS-21 scale and SDQ variable

			SDQ Variables - Emotional Symptoms		
DASS-21 scale		Close to average	High substantial	Slightly raised	*p*-value
Depression	Extremely severe	1 (33.3)	1 (33.3)	1 (33.3)	$p = 0.73$
	Mild	4 (2.1)	23 (69.7)	6 (18.2)	
	Moderate	6 (12.8)	34 (72.3)	7 (14.9)	
	Normal	18 (23.1)	48 (61.5)	12 (15.4)	
	Severe	1 (11.1)	7 (77.8)	1 (11.1)	
Anxiety	Extremely Severe	3 (15.8)	14 (73.7)	2 (10.5)	$p = 0.55$
	Mild	8 (24.2)	22 (66.7)	3 (9.1)	
	Moderate	4 (26.7)	7 (46.7)	4 (26.7)	
	Normal	14 (15.2)	61 (66.3)	17 (18.5)	
	Severe	1 (9.1)	9 (81.8)	1 (9.1)	
Stress	Extremely Severe	1 (12.5)	5 (62.5)	2 (15)	$p = 0.54$
	Mild	8 (26.7)	20 (66.7)	2 (6.7)	
	Moderate	6 (20.7)	19 (65.5)	4 (13.8)	
	Normal	14 (16.5)	57 (67.1)	14 (16.5)	
	Severe	1 (5.6)	12 (66.7)	5 (27.8)	
			Conduct Problem		$p = 0.35$
Depression	Extremely severe	1 (33.3)	2 (66.7)	0	
	Mild	22 (66.7)	5 (15.2)	6 (18.2)	
	Moderate	34 (72.3)	5 (10.6)	8 (17)	
	Normal	50 (64.1)	18 (23.1)	10 (12.8)	
	Severe	6 (66.7)	1 (11.1)	2 (22.2)	
Anxiety	Extremely Severe	12 (63.2)	4 (21.1)	3 (15.8)	$p = 0.45$
	Mild	26 (78.8)	5 (15.2)	2 (6.1)	
	Moderate	11 (73.3)	3 (20)	1 (6.7)	
	Normal	59 (64.1)	15 (16.3)	18 (19.6)	
	Severe	5 (45.5)	4 (36.4)	2 (18.2)	
Stress	Extremely Severe	1 (12.5)	5 (62.5)	2 (25)	$p = 0.009$*
	Mild	20 (66.7)	8 (26.7)	2 (6.7)	
	Moderate	23 (79.3)	4 (13.8)	2 (6.9)	
	Normal	56 (65.9)	12 (14.1)	17 (20)	
	Severe	13 (72.2)	2 (11.1)	3 (16.7)	
			Hyperactive		$p = 0.10$
Depression	Extremely severe	1 (33.3)	2 (66.7)	0	
	Mild	23 (69.7)	6 (18.2)	4 (12.1)	
	Moderate	29 (61.7)	9 (19.1)	9 (19.1)	
	Normal	43 (55.1)	12 (15.4)	23 (29.5)	
	Severe	4 (44.4)	4 (44.4)	1 (11.1)	
Anxiety	Extremely Severe	10 (52.6)	6 (31.6)	3 (15.8)	$p = 0.10$
	Mild	13 (39.4)	10 (30.3)	10 (30.3)	
	Moderate	8 (53.3)	3 (20)	4 (26.7)	
	Normal	64 (69.6)	12 (13)	16 (17.4)	
	Severe	5 (45.5)	2 (18.2)	4 (36.4)	
Stress	Extremely Severe	2 (25)	4 (50)	2 (25)	$p = 0.03$*
	Mild	16 (53.3)	4 (13.3)	10 (33.3)	
	Moderate	16 (55.2)	7 (24.1)	6 (20.7)	
	Normal	59 (69.4)	11 (12.9)	15 (17.6)	
	Severe	7 (38.9)	7 (38.9)	4 (22.2)	
			Peer Problems		$p = 0.41$
Depression	Extremely severe	2 (66.7)	0	1 (33.3)	
	Mild	17 (51.5)	9 (27.3)	7 (21.2)	
	Moderate	19 (40.4)	18 (38.3)	10 (21.3)	
	Normal	44 (56.4)	22 (28.2)	12 (15.4)	
	Severe	4 (44.4)	5 (55.6)	0	
Anxiety	Extremely Severe	10 (52.6)	7 (36.8)	2 (10.5)	$p = 0.18$
	Mild	20 (60.6)	10 (30.3)	3 (9.1)	
	Moderate	6 (40)	7 (46.7)	2 (13.3)	
	Normal	41 (44.6)	29 (31.5)	22 (23.9_	
	Severe	9 (81.8)	1 (9.1)	1 (9.1)	

(*Continued*)

Table 5. (Continued).

DASS-21 scale		SDQ Variables - Emotional Symptoms Close to average	 High substantial	 Slightly raised	*p*-value
Stress	Extremely Severe	5 (62.5)	1 (12.5)	2 (25)	p = 0.39
	Mild	16 (53.3)	9 (30)	5 (16.7)	
	Moderate	12 (41.4)	14 (48.3)	3 (10.3)	
	Normal	45 (52.9)	22 (25.9)	18 (21.2)	
	Severe	8 (44.4)	8 (44.4)	2 (11.1)	
			Pro-social behaviour		p = 0.07
Depression	Extremely severe	0 (0)	2 (66.7)	1 (33.3)	
	Mild	28 (84.8)	3 (9.1)	2 (6.1)	
	Moderate	37 (78.7)	6 (9.1)	2 (6.1)	
	Normal	64 (82.1)	7 (9)	7 (9)	
	Severe	6 (66.7)	2 (22.2)	1 (11.1)	
Anxiety	Extremely Severe	13 (68.4)	3 (15.8)	3 (15.8)	p = 0.67
	Mild	27 (81.8)	5 (15.2)	1 (3)	
	Moderate	14 (93.3)	1 (6.7)	0	
	Normal	72 (78.3)	10 (10.9)	10 (10.9)	
	Severe	9 (81.8)	1 (9.1)	1 (9.1)	
Stress	Extremely Severe	3 (37.5)	3 (37.5)	2 (25)	p = 0.03*
	Mild	21 (70)	7 (23.3)	2 (6.7)	
	Moderate	24 (82.8)	1 (3.4)	4 (13.8)	
	Normal	72 (84.7)	8 (9.4)	5 (5.9)	
	Severe	15 (83.3)	1 (5.6)	2 (11.1)	

*Significant at 95%.

stress. Thus, the more pro-social the child was, the more normal was the parent's stress level ($p = 0.03$) (Table 5).

Discussion

Predominant among people of Sub-Saharan Africa (SSA), Mediterranean, Middle Eastern, and Indian origin, SCD was recognized by the World Health Organization (WHO, 2010) and the United Nations (UN, 2009) as a public health priority. This study has become one of the few contributions that examined the psychosocial impact of SCD on affected children and parents and determined the relationship between psychosocial problems experienced by children and parents using the SDQ and DASS-21 scales in Sudan, where the rates of SCD are among the highest.

Demographic data of the current study showed that the most affected age group were children between the ages of six and eight, with most SCD children suffering from the disease for more than five years. This pattern is consistent with an earlier study of Brazilian children that showed that the age range of SCD predominates between the ages of three and six years (da Silva Filho et al., 2012) and is reflected in the global data on SCD prevalence at birth (CDC, 2017; Kanter & Kruse-Jarres, 2013; Modell & Darlison, 2008).

In 2020, to combat and manage this public health crisis, the American Society of Hematology (American Society of Hematology [ASH], 2021), SSA hematologists and public health professionals, and the Consortium for Newborn Screening in Africa (CONSA) launched an initiative to demonstrate the benefits of newborn screening (NBS) and early access to clinical interventions in seven countries including Kenya, Ghana, Liberia, Nigeria, Uganda, Tanzania, and Zambia. However, Sudan was not included in this study, where the lack of a screening program may be a major factor in missed diagnosis in neonates with SCD or other conditions that may be clinically occult early in life but have negative consequences for neurodevelopmental and physical development (Egesa et al., 2022; Meier & Miller, 2012; Ajinkpang et al., 2022). Taking into consideration the lack of an NBS program in Sudan, future research is recommended to explore the incidence of SCD in children at birth and parental actions after diagnosis. At the same time, the role of medical workers as the main source of information should not be underestimated, which requires studying their knowledge and attitude to SCD children and communication with their parents (Babiker et al., 2012). The latter is particularly important, since, as shown in this study, most parents do not have higher education and have average knowledge about the health status of their child, which can dramatically affect the care and quality of life of the family as a whole, and not just the SCD children (Amour & Jumanne, 2021; Ajinkpang et al., 2022).

Further findings of the Strengths and Difficulty Questionnaire (SDQ) among $n = 170$ children with SCD in this research showed that while emotional symptoms were substantially high, behavior problems, conduct problems, hyperactivity, and peer problems where close to average. At the same time, prosocial behavior was also close to average, which can be seen as a positive result despite the disease. Compared with international data, the results of this study can be considered positive. Thus, an earlier study by Dias et al. (2013) and Lorencini and Paula (2015) found a clear impact of the disease on the behavior and development of these children, i.e., they were increased risk of behavioral and emotional problems (Hysing et al., 2007). A more recent study in Brazilian SCD children with the administration of SCD also confirmed previous data, indicating a large effect of SCD on the behavior and development of patients with this disease. The authors found that 88.9% of the children had an impact in some of the parameters evaluated by the questionnaire in some parameters (Pereira et al., 2021). Similarly, a study among Norwegian children with various chronic diseases (CD) with the administration of SDQ found an increased risk of emotional and behavioral problems in children with CD compared with non-CD peers in both boys and girls (Hysing et al., 2007).

Given these conflicting data and the fact that most of the variables in the SDQ were close to the average, further exercise with the administration of statistical test was undertaken to explore the relationship between socioeconomic data and SDQ variables. The only significant findings related to the family socioeconomic status and peer problems among SCD children ($p = 0.000$). However, there was no significant association between disease duration, and conduct problem or hyperactivity in children, or emotional symptoms. Previous research assessed psychosocial and social problems in children with SCD in diverse populations, including children from Saudi Arabia and the Netherlands, and the results were inconclusive (Madani et al., 2018; van den Tweel et al., 2008). Thus, to conclude that Sudanese children's peer problem was significantly higher due to their health status would be an ambiguous statement. Future research is recommended to examine the exact peer problems in children with SCD, which may shed light on whether the problem is caused by a health condition (e.g., SCD) or by society and family income in society, which is found to be a major factor influencing peer problems all over the world (Hijmans et al., 2010; Wang et al. 2022; Kuerten et al., 2020).

Descriptive statistics of the Depression, Anxiety, Stress Scale −21 (DASS-21) for parents of children with SCD showed that most parents had normal levels of depression, anxiety, and stress. Hence, further analysis was performed to explore the relationship between DASS-21 variables and parental sociodemographic data. Financial hardship related to a child's health has been found to be significantly related to mild to moderate levels of parental depression. In contrast, a study of caregivers of children with SCD in Nigeria and Kenya found that caregivers experience significantly high levels of depression due to their child's health status and financial burden (Adegoke & Kuteyi, 2012; Kuerten et al., 2020). Similarly, female caregivers in the Netherlands exhibited poor health-related quality of life (HRQOL), characterized by depressed mood, disturbances in activities of daily living, vitality, sleep, happiness, and cognition (van den Tweel et al., 2008).

This study also showed that Sudanese parents with primary and secondary level of education were more likely to experience anxiety and stress ranging from mild, moderate to normal, which was associated with the academic achievement of children. This pattern was reflected in a study by Conger and Donnellan (2007), who found that lower parental education and income was associated with higher parental stress. One of the explanations for the higher levels of stress and anxiety in Sudanese parents can be explained by the fact that although they have not achieved their educational goals, they are anxious for that their child to study better and get a higher education (van den Tweel et al., 2008; Adegoke & Kuteyi, 2012; Madani et al., 2018; Kuerten et al., 2020; Johnson et al., 2022). However, this hypothesis, based on the results of this study and the summary of evidence, needs to be further explored, preferably through qualitative methods, to allow parents to share their observations within this framework.

Taking into consideration the unique contribution of this study, in order to provide a complete picture of the collected data from this setting, further analysis was carried out to find an association between DASS-21 and SDQ. The most affected variable from DASS-21 scale was found to be parental stress, which was significantly associated with children's conduct problems, hyperactivity and prosocial behavior. Prosocial behavior refers to all behaviors that meet social expectations and benefit society. Prosocial behavior can be beneficial in the adjustment of children and the successful development of youth, the survival, development and well-being of individuals and people with certain health conditions (Pastorelli et al., 2016; Trumello et al., 2022; Zhang et al., 2022). Moreover, since no relationship was found between the other DASS-21 variables and SDQ, qualitative studies are needed to explain these trends and allow comparison or new hypotheses.

In sum, while clinical research continues to focus on the prevention and definitive cure of SCD before adulthood, this health condition continues to be a complex disorder with significant variability among individuals and an accumulation of age-related diseases that make it difficult to treat. Therefore, early detection of infants with SCD using NBS can be a great contribution to improving the quality of life not only for children, but also for their parents. This is especially important in developing countries such as Sudan, where there is a lack of literacy in general and specifically in dealing with complex childhood illnesses (Egesa et al., 2022; Meier & Miller, 2012; Pereira et al., 2021; UNICEF, 2019; WHO, 2022). Although the findings of this study can be considered somewhat positive, the education of the parents could have had a better impact on the lives of their children. As mentioned earlier, the role and contribution of health workers cannot be underestimated and should be encouraged in this. They are expected to provide parents with sufficient knowledge and information through seminars or workshops (Egesa et al., 2022; UNICEF, 2019; WHO, 2022). This approach can be the main approach to improve the quality of life of children and families and will allow parents to communicate, leading to better outcomes by learning from experience of others and sharing the 'pain'. Finally, this article can serve as a basis for future mixed-methods research, in which quantitative data can be explained through qualitative data collection, providing rigor to findings and a panoramic view of what is known and where the gap is in the SCD-related studies in Sudan.

Limitations

In addition to the added value of this study, there are certain limitations that future researchers are expected to address. This study was a single center study that provides limited information for only one setting. Future studies should consider including several health facilities that can provide more detailed data from different regions of Sudan. The age group of the study sample was limited to 12 years. Future studies should consider involving different age groups, including young adults and adults, to allow comparison of psychosocial behaviors in different age groups.

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Data availability statement

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

Ethics approval and consent to participate

The study administration was confirmed by the Al-Neelain University Institutional Review Board. Permission was obtained from the ethics committee of the hospital and the consultants responsible for the patient were informed. Informed consent was obtained from the parents of children.

References

Adegoke, S. A., & Kuteyi, E. A. (2012). Psychosocial burden of sickle cell disease on the family, Nigeria. *African Journal of Primary Health Care and Family Medicine*, *4*(1), 1–6. https://doi.org/10.4102/phcfm.v4i1.380

Ajinkpang, S., Anim-Boamah, O., Bimpong, K. A., Kanton, F. J., Pwavra, J. B. P., & Abdul-Mumin, A. (2022). Sickle cell disease in children: Knowledge and home-based management strategies among caregivers at a Tertiary facility in Northern Ghana. *BioMed Research International*, *2022*, 3384813. https://doi.org/10.1155/2022/3384813

American Society of Hematology. (2021). *Consortium on newborn screening in Africa (CONSA) highlights the need for newborn screening of sickle cell disease in Africa*. https://www.hematology.org/newsroom/press-releases/2021/consa-highlights-the-need-for-newborn-screening-of-sickle-cell-disease-in-africa

Amour, M. A., & Jumanne, S. (2021). Caregivers' level of knowledge and home-based practices for prevention of sickle cell disease related complications among children attending Mnazi mmoja hospital in Zanzibar. *International Journal of Africa Nursing Sciences*, *14*, 100303. https://doi.org/10.1016/j.ijans.2021.100303

Archibald, R. G. (1926). A case of sickle cell anaemia in the Sudan. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, *19*(7), 389–39. https://doi.org/10.1016/S0035-9203(26)90485-9

Babiker, A. M., Jurayyan, N. A., Mohamed, S. H., & Abdullah, M. A. (2012). Overview of diagnosis, management and outcome of congenital hypothyroidism: A call for a national screening programme in Sudan. *Sudanese Journal of Paediatrics*, *12*(2), 7–16.

Brandow, A. M., & Liem, R. I. (2022). Advances in the diagnosis and treatment of sickle cell disease. *Journal of Hematology & Oncology*, *15*(1), 20. https://doi.org/10.1186/s13045-022-01237-z

Centers for Disease Control and Prevention. (2017). *What is sickle cell disease?* https://www.cdc.gov/ncbddd/sicklecell/facts.html.

Charani, E., Cunnington, A. J., Yousif, A. H. A., Seed Ahmed, M., Ahmed, A. E. M., Babiker, S., Badri, S., Buytaert, W., Crawford, M. A., Elbashir, M. I., Elhag, K., Elsiddig, K. E., Hakim, N., Johnson, M. R., Miras, A. D., Swar, M. O., Templeton, M. R., & Taylor-Robinson, S. D. (2019). In transition: Current health challenges and priorities in Sudan. *BMJ Global Health*, *4*(4), e001723. https://doi.org/10.1136/bmjgh-2019-001723

Conger, R. D., & Donnellan, M. B. (2007). An interactionist perspective on the socioeconomic context of human development. *Annual Review of Psychology*, *58*(1), 175–199. https://doi.org/10.1146/annurev.psych.58.110405.085551

Daak, A. A., Elsamani, E., Ali, E. H., Mohamed, F. A., Abdel-Rahman, M. E., Elderdery, A. Y., & Fawzi, W. (2016). Sickle cell disease in western Sudan: Genetic epidemiology and predictors of knowledge attitude and practices. *Tropical Medicine & International Health*, *21*(5), 642–653. https://doi.org/10.1111/tmi.12689

da Silva Filho, I. L., Ribeiro, G. S., Moura, P. G., Vechi, M. L., Cavalcante, A. C., & de Andrada-Serpa, M. J. (2012). Sickle cell disease: Acute clinical manifestations in early childhood and molecular characteristics in a group of children in Rio de Janeiro. *Revista brasileira de hematologia e hemoterapia*, *34*(3), 196–201. https://doi.org/10.5581/1516-8484.20120049

Dias, T. L., Enumo, S. R. F., França, J. A. D., & Nascimento, R. C. D. L. (2013). Health of children with sickle cell disease: School performance and cognitive. *Revista de Educação Pública*, *22*(49), 575–594.

Ebrahim, E. M., Ghebrehiwot, L., Abdalgfar, T., & Juni, M. H. (2017). Health care system in Sudan: Review and analysis of strength, weakness, opportunity, and threats (SWOT analysis). *Sudan Journal of Medical Sciences*, *12*(3), 133–150. https://doi.org/10.18502/sjms.v12i3.924

Egesa, W. I., Nakalema, G., Waibi, W. M., Turyasiima, M., Amuje, E., Kiconco, G., Odoch, S., Kumbakulu, P. K., Abdirashid, S., & Asiimwe, D. (2022). Sickle cell disease in children and adolescents: A Review of the historical, clinical, and public health perspective of Sub-Saharan Africa and beyond. *International Journal of Pediatrics*, *2022*, 3885979. https://doi.org/10.1155/2022/3885979

Elderdery, A. Y., Mohamed, B. A., Cooper, A. J., Knight, G., & Mills, J. (2011). Tribal distribution of haemoglobinopathies in a Sudanese patient population. *Journal of Medical Laboratory and Diagnosis*, *2*(4), 31–37.

El-Hazmi, M. A., Al-Hazmi, A. M., & Warsy, A. S. (2011). Sickle cell disease in middle East Arab countries. *The Indian Journal of Medical Research*, *134*(5), 597–610. https://doi.org/10.4103/0971-5916.90984

Hijmans, C. T., Fijnvandraat, K., Oosterlaan, J., Heijboer, H., Peters, M., & Grootenhuis, M. A. (2010). Double disadvantage: A case control study on health-related quality of life in children with sickle cell disease. *Health and Quality of Life Outcomes*, *8*(1), 1–8. https://doi.org/10.1186/1477-7525-8-121

Hysing, M., Elgen, I., Gillberg, C., Lie, S. A., & Lundervold, A. J. (2007). Chronic physical illness and mental health in children. Results from a large-scale population study. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *48*(8), 785–792. https://doi.org/10.1111/j.1469-7610.2007.01755.x

Johnson, Y. L., Woodward, K., Dampier, C., Cohen, L., & Sil, S. (2022). Biopsychosocial factors associated with parenting stress in Pediatric sickle cell disease. *Journal of Clinical Psychology in Medical Settings*, *29*(2), 365–374. https://doi.org/10.1007/s10880-021-09837-6

Kanter, J., & Kruse-Jarres, R. (2013). Management of sickle cell disease from childhood through adulthood. *Blood Reviews*, *27*(6), 279–287. https://doi.org/10.1016/j.blre.2013.09.001

Kuerten, B. G., Brotkin, S., Bonner, M. J., Ayuku, D. O., Njuguna, F., Taylor, S. M., & Puffer, E. S. (2020). Psychosocial burden of childhood sickle cell disease on caregivers in Kenya. *Journal of Pediatric Psychology*, *45*(5), 561–572. https://doi.org/10.1093/jpepsy/jsaa021

Lorencini, G. R. F., & Paula, K. M. P. D. (2015). Behavioral profile of children with sickle cell anemia. *Temas em Psicologia*, *23*(2), 269–280. https://doi.org/10.9788/TP2015.2-03

Madani, B. M., Al Raddadi, R., Al Jaouni, S., Omer, M., & Al Awa, M. I. (2018). Quality of life among caregivers of sickle cell disease patients: A cross sectional study. *Health and Quality of Life Outcomes*, *16*(1), 176. https://doi.org/10.1186/s12955-018-1009-5

Meier, E. R., & Miller, J. L. (2012). Sickle cell disease in children. *Drugs: Education, Prevention and Policy*, *72*(7), 895–906. https://doi.org/10.2165/11632890-000000000-00000

Mieloo, C., Raat, H., van Oort, F., Bevaart, F., Vogel, I., Donker, M., & Jansen, W. (2012). Validity and reliability of the strengths and difficulties questionnaire in 5-6 year olds: Differences by gender or by parental education? *PloS One*, *7*(5), e36805. https://doi.org/10.1371/journal.pone.0036805

Modell, B., & Darlison, M. (2008). Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization*, *86*(6), 480–487. https://doi.org/10.2471/BLT.06.036673

Naoum, P. C. (2011). Sickle cell disease: From the beginning until it was recognized as a public health disease. *Revista brasileira de hematologia e hemoterapia*, *33*(1), 7–9. https://doi.org/10.5581/1516-8484.20110006

Oei, T. P., Sawang, S., Goh, Y. W., & Mukhtar, F. (2013). Using the depression anxiety stress scale 21 (DASS-21) across cultures. *International Journal of Psychology: Journal International de Psychologie*, *48*(6), 1018–1029. https://doi.org/10.1080/00207594.2012.755535

Pastorelli, C., Lansford, J. E., Luengo Kanacri, B. P., Malone, P. S., DiGiunta, L., Bacchini, D. & Sorbring, E. (2016). Positive parenting and children's prosocial behavior in eight countries. *Journal of Child Psychology and Psychiatry*, *57*(7), 824–834. https://doi.org/10.1111/jcpp.12477

Pereira, F. B., Pedroso, G. C., Resegue, R. M., Ribeiro, M. V. V., Hokazono, M., & Braga, J. A. P. (2021). Behavioral characteristics of children with sickle cell disease. *Revista paulista de pediatria : orgao oficial da Sociedade de Pediatria de Sao Paulo*, *39*, e2019341. https://doi.org/10.1590/1984-0462/2021/39/2019341

Piel, F. B., Patil, A. P., Howes, R. E., Nyangiri, O. A., Gething, P. W., Dewi, M., Temperley, W. H., Williams, T. N., Weatherall, D. J., & Hay, S. I. (2013). Global epidemiology of sickle haemoglobin in neonates: A contemporary geostatistical model-based map and population estimates. *Lancet*, *381*(9861), 142–151. https://doi.org/10.1016/S0140-6736(12)61229-X

Rees, D. C., Williams, T. N., & Gladwin, M. T. (2010). Sickle-cell disease. *Lancet*, *376*(9757), 2018–2031. https://doi.org/10.1016/S0140-6736(10)61029-X

Sabahelzain, M. M., & Hamamy, H. (2014). The ethnic distribution of sickle cell disease in Sudan. *Pan African Medical Journal*, *18*(1). https://doi.org/10.11604/pamj.2014.18.13.3280

Talha, M., Osman, B., Abdalla, S., Mirghani, H., & Abdoon, I. (2022). Pediatric sickle cell disease in Sudan: Complications and management. *Anemia*, *2022*, 3058012. https://doi.org/10.1155/2022/3058012

Trumello, C., Ballarotto, G., Ricciardi, P., Paciello, M., Marino, V., Morelli, M. & Babore, A. (2022). Mothers and fathers of pre-school children: A study on parenting stress and child's emotional-behavioral difficulties. *Current Psychology*, 1–12. https://doi.org/10.1007/s12144-022-03599-6

United Nations. (2009). *Secretary-General's message on sickle-cell disease*. https://www.un.org/sg/en/content/sg/statement/2009-06-19/secretary-generals-message-sickle-cell-anaemia .

United Nations International Children's Emergency Fund. (2019). *Sudan health: Supporting high impact interventions to save lives of mother and babies*. https://www.unicef.org/sudan/health

van den Tweel, X. W., Hatzmann, J., Ensink, E., van der Lee, J. H., Peters, M., Fijnvandraat, K., & Grootenhuis, M. (2008). Quality of life of female caregivers of children with sickle cell disease: A survey. *Haematologica*, *93*(4), 588–593. https://doi.org/10.3324/haematol.11610

Wang, Y., Xie, T., & Xu, J. (2022). Family socioeconomic status and Internalizing problem behavior among Chinese Adolescents: The Chain mediation effect of academic performance and peer conflict. *Frontiers in Psychology*, *13*, 902545. https://doi.org/10.3389/fpsyg.2022.902545

Wastnedge, E., Waters, D., Patel, S., Morrison, K., Goh, M. Y., Adeloye, D., & Rudan, I. (2018). The global burden of sickle cell disease in children under five years of age: A systematic review and meta-analysis. *Journal of Global Health*, *8*(2), 021103. https://doi.org/10.7189/jogh.08.021103

Williams, T. N. (2016). Sickle cell disease in Sub-Saharan Africa. *Hematology/Oncology Clinics of North America*, *30*(2), 343–358. https://doi.org/10.1016/j.hoc.2015.11.005

World Health Organization. (2010). *Sickle Cell Disease: A Strategy for the WHO African Region*. https://www.afro.who.int/sites/default/files/2017-06/afr_rc60_8.pdf.

World Health Organization. (2022). *Stakeholders recommit to enhance efforts to eliminate neglected tropical diseases in South Sudan*. https://www.afro.who.int/countries/south-sudan/news/stakeholders-recommit-enhance-efforts-eliminate-neglected-tropical-diseases-south-sudan

Zhang, W., Yu, G., Fu, W., & Li, R. (2022). Parental psychological control and children's prosocial behavior: The mediating role of social anxiety and the moderating role of socioeconomic status. *International Journal of Environmental Research and Public Health*, *19*(18), 11691. https://doi.org/10.3390/ijerph191811691