CAHIERS MAGELLANES-NS
Volume 07 Issue 1
2025

ISSN:1624-1940
http://magellanes.com/

HAEMOPOIETIC STEM CELL TRANSPLANTATION AS TREATMENT OPTION FOR SICKLE CELL ANEMIA PATIENTS IN SAUDI ARABIA: KNOWLEDGE AND ACCEPTANCE LEVEL.

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Abstract

Background: Sickle cell disease (SCD), also known as severe autosomal recessively inherited red blood cell sickness, has an incidence in Saudi Arabia ranging from 6 to 145 instances per 10,000 people. Hematopoietic stem cell transplantation (HSCT) is considered to be the definitive and curative therapy. Our study aims to evaluate the knowledge and acceptance of HSCT as a therapy in Saudi Arabia. **Objectives:** Our cross-sectional study to assess Knowledge and Acceptance level of Haematopietic Stem cell Transplantation (HSCT) as treatment option in sickle cell anemia. **Methodology:** A cross-sectional study was carried out from July to December 2024. The data for this study collected from Saudi Arabian regions using an Arabic-language questionnaire, and the study's population consist of Saudi adults over the age of 18, male or female, who suffer from sickle cell anemia, as well as people whose family members suffer from this disease. Participants were recruited after obtaining the questionnaire, which shared via several social media platforms (including Twitter, Snapchat, Instagram, WhatsApp, and Facebook). The minimal target sample size of 384 was determined using a procedure based on prevalence estimation, 95% confidence interval, and 5% margin of error. **Results:** In our study on the knowledge and acceptance of hematopoietic stem cell transplantation (HSCT) for sickle cell anemia in Saudi Arabia, we surveyed 386 young participants, predominantly female (68.7%), with a significant portion (31.3%) aged 21 to 23. Findings revealed that while nearly half (46.1%) support HSCT as a potential cure, a notable 43.3% remain hesitant due to fears of

ISSN:1624-1940
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procedure complications and outcomes. Alarmingly, 56.5% demonstrated low knowledge levels about HSCT, emphasizing the critical need for educational initiatives. Additionally, 74.4% advocated for government funding for stem cell donations, highlighting awareness gaps and the necessity for better information dissemination. **Conclusion**: This study illuminates significant gaps in knowledge and acceptance regarding HSCT as a treatment option for SCA in Saudi Arabia. The findings underscore the need for targeted educational initiatives to improve awareness and address concerns related to HSCT.

Keywords: Knowledge, Acceptance, HSCT, Sickle cell disease.

Background:

Sickle cell disease affects 8 million patients around the world [1]. A point mutation in the β- globin gene causes the sixth amino acid to be substituted from glutamic acid to valine, resulting in the production of hemoglobin S (Hb S), the blood disorder known as sickle cell disease (SCD) [2]. Characterized by erythrocyte deformation brought on by the polymerization of aberrant hemoglobin, which in turn causes erythrocyte deformation and subsequent clinical alterations [3]. Nowadays, a wide range of diseases are treated with hematopoietic stem cell transplantation (HSCT), such as acute, chronic, and myelodysplastic syndromes, thalassemia, aplastic anemia, Fanconi anemia, bone marrow failures, immunological deficits, and metabolic disorders [4]. This particular therapy uses the patient's own hematopoietic stem cells (autologous transplants) or cells from another person (allogeneic transplants) as the therapeutic material [5]. Sickle cell disease was initially documented in the Eastern Province of Saudi Arabia in the 1960s [6]. Community-based surveys in Saudi Arabia report a Sickle cell disease prevalence in adolescents of 24 per 10,000 people [7] Saudi Arabia is estimated to have approximately 61,000 individuals with Sickle cell disease, among whom approximately 10,536 could be considered for hematopoietic stem cell transplantation [8]. Allogeneic Hemopoietic Stem cell transplantation is the only approved curative option for sickle cell disease patients [9]. Donor typically is matched related donor; however alternative donor may be considered. Clinical indications that qualify patient to be enrolled in include recurrent 3 0r more vaso-occlusive crises in 2 years or 2 or more acute chest syndromes in 2 years despite optimal standard of care (eg, HU, L-glutamine, crizanlizumab, and chronic transfusion therapy) [10], history of non-debilitating stroke or silent brain infarct, moderately significant CNS event lasting more than 24 hours, MRI findings consistent with brain injury or damage even if asymptomatic, moderately sever increased velocity by transcranial doppler, sickle hepatopathy (including iron overload) and portal hypertension, red cell transfusion therapy 8 or more per year for year or more to prevent vaso-occlusive crises, avascular necrosis of one or more joints, red cell alloimmunization, recurrent priapism, mild to moderate pulmonary hypertension (but not sever or oxygen dependent with tricuspid regurgitant velocity more than 2.6 m/s on echocardiogram, sickle-related renal insufficiency biopsy proven or creatinine more than 1.5 upper level of normal. [11, 12, 13, 14] Eligibility criteria include age 14-40 years, liver function tests within 2 times upper limit of normal, absence of chronic active hepatitis due to any viral illness, absence of varices or congestive gastropathy, absence of splenomegaly, pulmonary function tests within 25% of normal predicted, absence of sever pulmonary hypertension, absence of sever disabling cerebrovascular stroke or moyamoya disease on MRI brain, absence of acute chest syndrome 2 months from conditioning or vaso-occlusive crises 2 weeks from conditioning [14]. De la fuente et all published recently at Blood journal An Analysis of the European Society for Blood and Bone Marrow Transplantation Hemoglobinopathy Working Party

ISSN:1624-1940
http://magellanes.com/

for over 1400 patients transplanted between 2010 and 2021, the 2 years OS and EFS were 95.7% and 92.9% for children and 93.7% and 80.8% 90.5) for adults, respectively. De la Fuente data was presented at American society of hematology 2024 and it showed excellent outcomes for stem cells transplantation as a curative therapy for SCD across all ages with high rate of cure irrespective of age [15]. In 2024, at the King Abdullah International Medical Research Center, a total of 300,384 participants answered an online survey. The majority (90.71%) stated they would like to learn more about stem cell therapy, but more than half (56.94%) claimed they were unfamiliar with the idea. A comparable proportion (50.41%) expressed concerns about its safety [16]. In contrast to the 2024 survey, a 2022 study conducted in Jazan province found that a much larger proportion, 78% of participants, were already aware of Hematopoietic Stem Cell Transplantation (HSCT) before the study. Moreover, a comparable 57% of individuals were able to accurately define HSCT, and an even greater 42% said they would be willing to donate stem cells. This indicates significantly more familiarity and acceptance of HSCT in the Jazan province compared to the KAIMRC survey results reported in 2024 [17]. Moreover, In comparison to participants who had never completed high school, those with a bachelor or graduate degree were more likely to have aware about HCT as a potential SCD treatment [18].

In Saudi Arabia, we see a rise in hematological disorders, particularly sickle cell anemia, and we need HSCT, but the attitude and acceptability of HSCT as a treatment are limited. A key cause for the inadequate number of accessible HSC donors has been linked to a lack of community awareness and the availability of inaccurate information regarding the relevance of HSCT in SCD therapy. There is minimal data on community awareness and opinions concerning HSCT in Saudi Arabia. Thus, the purpose of this study is to analyze the general awareness and acceptance of HSCT for the treatment of sickle cell anemia among the Saudi community.

Objective:

Our cross-sectional study to assess knowledge and acceptance level of Haemopoietic Stem cell Transplantation (HSCT) as a treatment option for sickle cell anemia in Saudi Arabia.

Methodology:

Study design and Setting:

A cross-sectional study conducted from July 2024 -December 2024, in Saudi Arabia, based on a self-structured questionnaire.

Subject: Participants, recruitment and sampling procedure:

The study's population consisted of Saudi adults over the age of 18, participants were recruited in November 2024 from people receiving the questionnaire that distributed via social media platforms (including Twitter, Snapchat, Instagram, WhatsApp, and Facebook).

Sample size:

A sample size calculation was conducted to determine the minimum number of respondents needed for a representative sample of the population. Using Raosoft sample size calculator with an indicator percentage of 0.50, a margin of error of 5%, and a 95% confidence interval, the calculated sample size

ISSN:1624-1940
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was 384.

Inclusion and Exclusion criteria:

This study includes all Saudi patients who suffer from sickle cell anemia, whether male or female, in addition to people whose family suffers from this disease. On the other hand, non-Saudi patients were excluded from this study.

Method for data collection, instrument and score system:

Structured questionnaire was used as a study tool. This instrument was developed after consulting relevant study conducted at Jazan University, Jazan, in Saudi Arabia [9]. The final version of the questionnaire comprised of 24 categorized into three main sections. The first section contained questions about socioeconomic background characteristics. The second section assessed the knowledge about sickle cell anemia and hematopoietic stem cell transplantation as treatment. The third section focused on the acceptance level of stem cell transplantation and its associated complications. The survey instrument was a self-administered anonymous questionnaire in Arabic, consisting of questions regarding sickle cell anemia and hematopoietic stem cell transplantation knowledge, and the level of acceptance of hematopoietic Stem cell Transplantation as treatment option for sickle cell anemia patients, and assessed the interest in funding stem cell donor or their employers by government.

Data collection involved obtaining participants' responses to the questionnaire. The questionnaire included demographic information such as age, gender, and residential area (Southern region or other areas, such as Western, Central, Eastern, and Northern region). Participants were asked about their knowledge of sickle cell anemia, hematopoietic Stem cell Transplantation and its cost in Saudi Arabia, whether anyone in their family suffers from sickle cell anemia,
and its associated complications. Additionally, they were asked about their acceptance of hematopoietic stem cell transplantation as a treatment option for sickle cell anemia patients.

Scoring system:

The study utilized a total of 24 statements to assess the participants' acceptance and knowledge. This included 8 statements related to demographics, 6 for measuring knowledge, and 10 for assessing acceptance. Each correct answer was awarded 1 point, while incorrect answers or "I don't know" responses received 0 points. The maximum possible knowledge score was 6 points.

These knowledge scores were then divided into three levels based on Bloom's original cut-off points those scoring 6were classified as having a high level of knowledge, corresponding to the 80.0%-100.0% range, participants scoring between 4 and 5 points were considered to have a moderate level of knowledge, within the 60.0%-79.0% range, and those scoring 3 or below were categorized as having a low level of knowledge, falling below 59.0% on Bloom's scale. The participants were ultimately divided into three groups based on their final knowledge scores.

Pilot test:

Twenty individuals involved in a pilot study to see if the questionnaire's phrasing is comprehensible and straightforward. Before any data collection begins, each participant asked to read and sign a consent

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form. The pilot study's data examined, but they won't be included in the major study.

Analyzes and entry method:

Data was entered on a computer with Microsoft Excel (2016) for Windows. Data analyzed using the SPSS (Statistical Package for Social Sciences) software program version 20.

Results:

Table (1) displays various demographic parameters of the participants with a total number of (386). A striking feature is the preponderance of young people, encompassing 21 to 23 years old, constituting 31.3 % of the sample, suggestive that this may be concerning attention to higher education and the initial stages of career. It is heavy biased in favor of the gender, Ladies 68.7 per cent, which means potentially looking for a disparity in the views offered by participant males. The sample appears to have a relatively high educational attainment based on majority who hold a bachelor's degree (60.4%), and employment status shows approximately 56% are students thereby making it relevant to study youth. Almost half of the participants make below 1000 SAR per month, which might show that these people are under social pressure. Finally, marital status simply denotes that the vast majority (71.8%) are immunologically solitary (and lack personal affiliations to sickle cell anemia); this may undermine the study's usefulness in prompting educational and awareness as to its prerequisites.

Table (1): Sociodemographic characteristics of participants (n=386)

Parameter		***No.***	***Percent (%)***
Age (Mean:28.0, STD:11.8)	20 or less	104	26.9
	21 to 23	121	31.3
	25 to 35	77	19.9
	36 or more	84	21.8
Gender	Female	265	68.7
	Male	121	31.3
Residential region	Northern region	10	2.6
	Southern region	163	42.2
	Central region	40	10.4
	Eastern region	18	4.7
	Western region	155	40.2
Educational level	Primary school	3	.8
	Middle school	7	1.8
	High school	102	26.4
	Diploma	21	5.4
	Bachelor's degree	233	60.4
	Postgraduate degree	17	4.4
	Uneducated	3	.8
Occupation	Student	216	56.0
	Healthcare sector employee	31	8.0
	Non-healthcare sector employee	49	12.7
	Freelancer work	19	4.9
	Unemployed	54	14.0
	Retired	17	4.4

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Monthly income	Less than 1000 SAR	191	49.5
	1000 to 5000 SAR	94	24.4
	5000 to 10000 SAR	38	9.8
	10000 to 15000 SAR	19	4.9
	More than 15000 SAR	44	11.4
Marital status	Single	277	71.8
	Married	97	25.1
	Divorced	7	1.8
	Widowed	5	1.3
You are	A patient with sickle cell anemia	3	.8
	Parent of a patient with sickle cell anemia	3	.8
	Relative of a patient with sickle cell anemia	16	4.1
	Friend of a patient with sickle cell anemia	40	10.4
	I do not know any patient with sickle cell anemia at all.	324	83.9

As shown in figure 1, The presented data is from a survey of a total sample of 386 people about how they understand the bone marrow transplantation procedure. A large majority — 231 or about 59.9 per cent — of the respondents were able to correctly identify this procedure within the group as one whereby stem-cells are harvested from a suitable donor and they are injected into the recipient. On the other hand, 57 respondents, i.e. about 14.8 % of them had the mistaken impression that it was a surgical procedure in which some of the bone is taken out from a donor and some is sutured in. Furthermore, of the 29 participants who obtained the process from a suitable donor, 7.5% claimed association between the process and a blood transfusion. In fact, some 69 people, or 17.9 percent, said they had zero clue of how it works.

Figure (1): Illustrates knowledge of bone marrow transplant definition among participants.

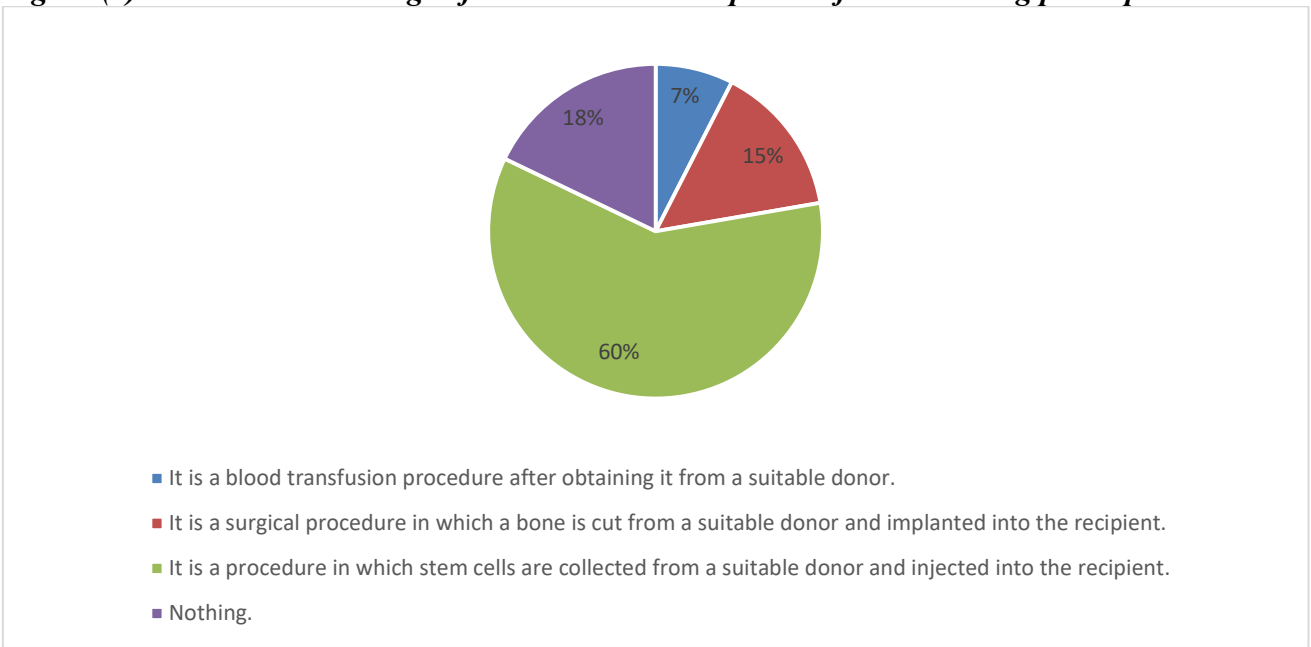

Table 2 presents the data offering a revealing information as to awareness and understanding about

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hematopoietic stem cell transplantation (HSCT) as a therapeutic approach for patients with SCA. According to the 386 respondents, nearly half (46.1%), support the idea of a permanent cure in transplantation and a worrying one in third (26.2%) are sceptical or unaware. While nearly three-quarters (75.9%) have heard of bone marrow transplant, a large 4.1% have not known that the relevant cells to treat is hematopoietic stem cells, suggesting that much basic knowledge remain to be introduced. Variability of understanding transplant procedure itself also is present with only 59.8% responding correctly to the method of stem cell collection and administration. In addition, there is a critical need for information on the procedure's cost given the fact that more than half (58.5%) of the respondents do not know what it costs.

Table (2): Parameters related to knowledge about haemopoietic stem cell transplantation as treatment option for sickle cell anemia patients (n=386).

Parameter		***No.***	***Percent (%)***
Do you believe that a patient with sickle cell anemia can be cured or treated permanently?	No	101	26.2
	Yes	178	46.1
	I don't know	107	27.7
Have you heard about bone marrow transplantation before?	No	93	24.1
	Yes	293	75.9
Can hematopoietic stem cells used as a treatment?	No	16	4.1
	Yes	257	66.6
	I don't know	113	29.3
What do you know about the bone marrow transplantation procedure?	It is a blood transfusion procedure after obtaining it from a suitable donor.	29	7.5
	It is a surgical procedure in which a bone is cut from a suitable donor and implanted into the recipient.	57	14.8
	It is a procedure in which stem cells are collected from a suitable donor and injected into the recipient.	231	59.8
	Nothing.	69	17.9
Who do you expect to be the best person to donate bone marrow?	Mother to daughter	55	14.2
	Father to son	37	9.6
	Mother to father	13	3.4
	Sibling to any person	107	27.7
	I don't know	174	45.1
Do you have an idea of the cost of bone marrow transplantation in Saudi Arabia?	Yes, the procedure is expensive and costs a lot of money.	99	25.6
	Yes, the procedure is affordable and within the reach of most people.	13	3.4
	It is entirely free.	48	12.4
	I have no idea about the cost	226	58.5

As shown in figure (2), The public perception with regard to the potential donors of bone marrow is

ISSN:1624-1940
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provided by data derived from a total sample size of 386 respondents. In a very big majority, 55 people, or around 14.2%, said that donating to one's daughter by a mother would be the best thing. Possibly as a result of the inherent maternal bond and of mothers being seen to naturally put their children's health and wellbeing before their own there are views like this. However, 37 respondents, i.e., about 9.6 respondents, consider fathers as the best candidates for giving to their sons, which reflects paternal responsibility and patrimony. A mother donating to a father was less of an anticipated prospect — just 13 respondents, just 3.4%. Despite this, the highest response, recorded in "Sibling to any person," was 107 people (27.7%) who indicated this as their response indicating the perceived importance of sibling relationships in terms of health. Fourth, 174 respondents, about 45.1%, chose 'I don't know' and were manifesting uncertainty.

Figure (2): Illustrates best person to donate bone marrow among participants.

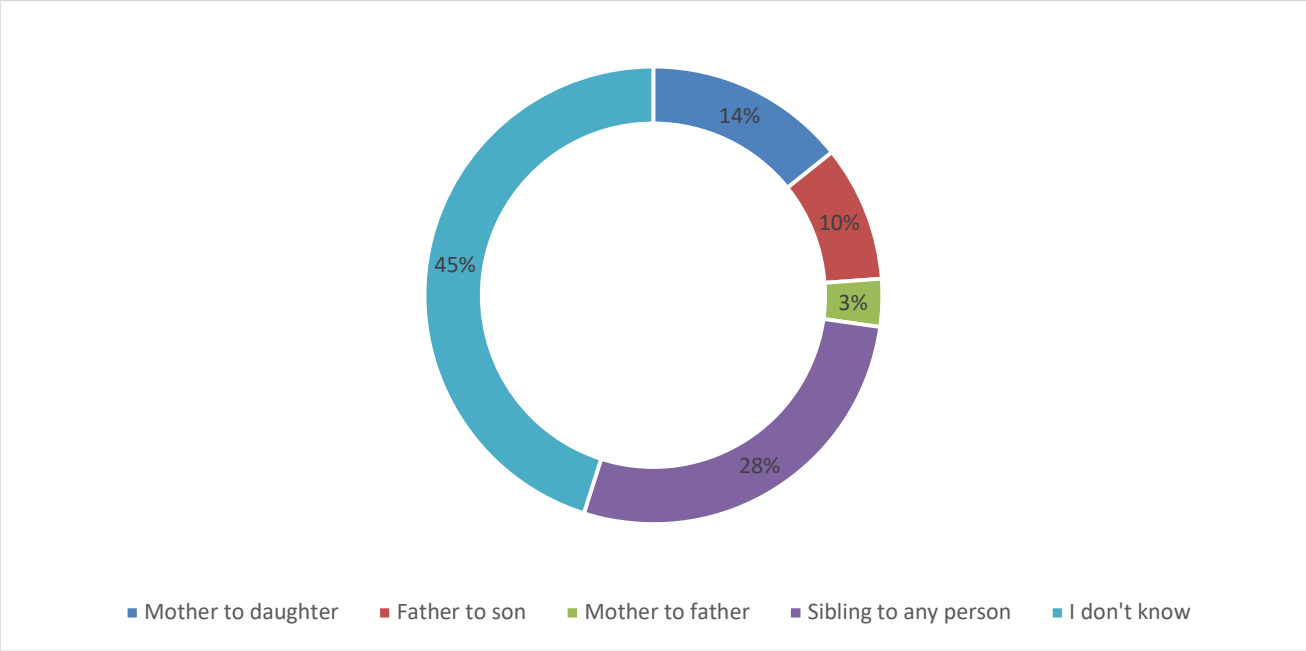

Table 3 presents data pertaining to the participants' readiness to take haemopoietic stem cell transplantation (HSCT) as a treatment of choice for sickle cell anemia, with a very great percentage of 56.7% ready to accept such a treatment. Nevertheless, a great deal of 43.3% are reluctant mainly due to worries linked to pitfalls, procedural failure, and probable demise. The apprehensions revealed fear of complications (51.5%) and fear of failure of the procedure (35.3%) clearly indicate that suitable educational measures addressing misconceptions regarding HSCT were urgently needed. Additionally, the data shows a yawning informational gap—more than 40 percent (41.1 percent) of participants were unsure about the effect of the donation on the donor's health, underscoring a need for understanding disease and risk, on the one hand, and resources about the realities and dangers of stem cell donation on the other. Strong consensus (74.4%) that governmental funding of stem cell donors is needed; predominant belief (60.6%) in difficulty of donor compatibility.

Table (3): participants' acceptance of haemopoietic Stem cell transplantation as treatment option for

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sickle cell anemia patients (n=386).

Parameter		***No.***	***Percent (%)***
Would you accept a bone marrow transplant as treatment for sickle cell disease?	No	167	43.3
	Yes	219	56.7
If the answer is no, what are the reasons for your reluctance? (n=167)	Fear of complications	86	51.5
	Failure of the procedure	59	35.3
	Death	22	13.2
Do you know someone who has undergone a bone marrow transplantation?	No	192	49.7
	Yes	194	50.3
If yes, what were the results? (n=192)	Good	24	12.5
	Bad	60	31.3
	I don't know	110	57.3
If the answer is bad, what were the problems happened? * (n=60)	Graft rejection	33	55.0
	Heart diseases	24	40.0
	Infertility	10	16.7
	Obesity	9	15.0
	Diabetes	13	21.7
	Donor cells attacking recipient cells	31	51.7
	Death	21	35.0
	I don't know	4	6.7
What problems do you expect might occur for the donor after donation? *	Possibility of death	74	19.2
	Low hemoglobin levels	121	31.3
	Severe illness	66	17.1
	Remain in good health	81	20.9
	I don't know	177	45.9
Do you think that everyone who undergoes a stem cell transplantation will experience complications?	No	149	38.6
	Yes	74	19.2
	I don’t know	163	42.2
Choose the complications associated with bone marrow transplantation that you are aware of *	Graft rejection	200	51.8
	Heart diseases	43	11.1
	Infertility	21	5.4
	Obesity	9	2.3
	Diabetes	21	5.4
	Donor cells attacking recipient cells	174	45.1
	Death	76	19.7
	None of the above	12	3.1
	I don't know	152	39.4
In your opinion, what is the main challenge facing bone marrow transplantation procedures? *	Lack of a compatible or suitable donor	234	60.6
	Low level of awareness	130	33.7
	Cost of the procedure	135	34.9

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	Fear of complications	168	43.5
	Fear of the possibility of death	128	33.2
	I don't know	92	23.8
Do you agree that the stem cell donors or their employers should be funded by the government?	No	13	3.4
	Yes	287	74.4
	I don't know	86	22.3

Results may overlap

Table 4 shows interesting reflections on knowledge levels about hemopoietic stem cell transplantation as a treatment for patients suffering from sickle cell anemia in a cohort of 386. Only 1.6% of respondents had a high level of knowledge, whereas 42.0% had a moderate understanding of the subject. On the other hand, the most of them, i.e., a higher 56.5%, showed low knowledge levels, which imply that there is an urgent requirement to raise the education and awareness in this significant field of hematology.

Table (4): Shows knowledge about haemopoietic stem cell transplantation as treatment option for sickle cell anemia patients score results.

	Frequency	**Percent**
High knowledge level	6	1.6
Moderate knowledge	162	42.0
Low knowledge level	218	56.5
Total	386	100.0

Table (5) shows that knowledge about haemopoietic stem cell transplantation as treatment option for sickle cell anemia patients has statistically insignificant relation to gender, age, residential region, educational level, occupation, monthly income, marital status and relation to sickle cell anemia patient

Table (5): Relation between knowledge about haemopoietic stem cell transplantation as treatment option for sickle cell anemia patients and sociodemographic characteristics.

Parameters		***Knowledge level***		***Total (N=386)***	***P value****
		High or moderate knowledge	**Low knowledge level**		
Gender	Female	118	147	265	0.556
		70.2%	67.4%	68.7%	
	Male	50	71	121	
		29.8%	32.6%	31.3%	
Age	20 or less	40	64	104	0.348
		23.8%	29.4%	26.9%	
	21 to 23	58	63	121	
		34.5%	28.9%	31.3%	
	25 to 35	37	40	77	
		22.0%	18.3%	19.9%	

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	36 or more	33	51	84	
		19.6%	23.4%	21.8%	
Residential region	Northern region	5	5	10	0.370
		3.0%	2.3%	2.6%	
	Southern region	62	101	163	
		36.9%	46.3%	42.2%	
	Central region	18	22	40	
		10.7%	10.1%	10.4%	
	Eastern region	7	11	18	
		4.2%	5.0%	4.7%	
	Western region	76	79	155	
		45.2%	36.2%	40.2%	
Educational level	Primary school	1	2	3	0.758
		0.6%	0.9%	0.8%	
	Middle school	3	4	7	
		1.8%	1.8%	1.8%	
	High school	38	64	102	
		22.6%	29.4%	26.4%	
	Diploma	9	12	21	
		5.4%	5.5%	5.4%	
	Bachelor's degree	106	127	233	
		63.1%	58.3%	60.4%	
	Postgraduate degree	9	8	17	
		5.4%	3.7%	4.4%	
	Uneducated	2	1	3	
		1.2%	0.5%	0.8%	
Occupation	Student	98	118	216	0.141
		58.3%	54.1%	56.0%	
	Healthcare sector employee	19	12	31	
		11.3%	5.5%	8.0%	
	Non-healthcare sector employee	21	28	49	
		12.5%	12.8%	12.7%	
	Freelancer work	7	12	19	
		4.2%	5.5%	4.9%	
	Unemployed	18	36	54	
		10.7%	16.5%	14.0%	
	Retired	5	12	17	
		3.0%	5.5%	4.4%	
Monthly income	Less than 1000 SAR	83	108	191	0.642
		49.4%	49.5%	49.5%	
	1000 to 5000 SAR	42	52	94	
		25.0%	23.9%	24.4%	
	5000 to 10000 SAR	18	20	38	
		10.7%	9.2%	9.8%	

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	10000 to 15000 SAR	10	9	19	
		6.0%	4.1%	4.9%	
	More than 15000 SAR	15	29	44	
		8.9%	13.3%	11.4%	
Marital status	Single	121	156	277	0.594
		72.0%	71.6%	71.8%	
	Married	44	53	97	
		26.2%	24.3%	25.1%	
	Divorced	2	5	7	
		1.2%	2.3%	1.8%	
	Widowed	1	4	5	
		0.6%	1.8%	1.3%	
You are	A patient with sickle cell anemia	1	2	3	0.290
		0.6%	0.9%	0.8%	
	Parent of a patient with sickle cell anemia	1	2	3	
		0.6%	0.9%	0.8%	
	Relative of a patient with sickle cell anemia	11	5	16	
		6.5%	2.3%	4.1%	
	Friend of a patient with sickle cell anemia	19	21	40	
		11.3%	9.6%	10.4%	
	I do not know any patient with sickle cell anemia at all.	136	188	324	
		81.0%	86.2%	83.9%	

P value was considered significant if ≤ 0.05.

Discussion:

This study aimed to assess the levels of knowledge and acceptance of HSCT among those affected by SCA and their families living in Saudi Arab (a country where SCA is a common genetic disorder for this region). This study finds that the participants have an unfortunate lack of knowledge about HSCT. Nearly half of the respondents realized that HSCT could be a cure for SCA, yet about half were skeptical and some had no clue regarding the procedure. Both this and previous research on similar knowledge deficits in other populations confirms this. For example, in Nigeria study found that just 30 percent of people were aware of HSCT as a treatment option for SCA, implying that most people will not be aware and may be less likely to accept them or access the treatment [19]. In addition, a global burden of sickle cell disease systematic review pointed to the importance of educational initiatives to improve awareness and understanding of treatment options, including HSCT [20]. The present study's findings emphasize the requirement for targeted educational programs to increase knowledge about HSCT, particularly in regions of high SCA prevalence.

Notably, in this study, however, the percentage of participants who were willing to accept HSCT as a treatment option was 56.7%. This is a great find, as other studies have shown lower accepting rates. Importantly, fears of complications and procedural risks mean that only 40 per cent of patients with SCA in Sudan were willing to consider HSCT in this study [21]. In this present study, we believe that the greater acceptance rate of this may have to do with an increasing awareness of HSCT benefits and an increased availability of information on social media, which was used for recruitment of the participants in this study. This study aimed to assess the levels of knowledge and acceptance of HSCT

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among those affected by SCA and their families living in Saudi Arabia (a country where SCA is a common genetic disorder for this region).

This study finds that the participants have an unfortunate lack of knowledge about HSCT. Nearly half of the respondents realized that HSCT could be a cure for SCA, yet about half were skeptical and some had no clue regarding the procedure. Both this and previous research on similar knowledge deficits in other populations confirms this. For example, in Nigeria study found that just 30 percent of people were aware of HSCT as a treatment option for SCA, implying that most people will not be aware and may be less likely to accept them or access the treatment [19]. In addition, a global burden of sickle cell disease systematic review pointed to the importance of educational initiatives to improve awareness and understanding of treatment options, including HSCT [20]. The present study's findings emphasize the requirement for targeted educational programs to increase knowledge about HSCT, particularly in regions of high SCA prevalence.

Notably, in this study, however, the percentage of participants who were willing to accept HSCT as a treatment option was 56.7%. This is a great find, as other studies have shown lower accepting rates. Importantly, fears of complications and procedural risks mean that only 40 percent of patients with SCA in Sudan were willing to consider HSCT in this study [21]. In this present study, we believe that the greater acceptance rate of this may have to do with an increasing awareness of HSCT benefits and an increased availability of information on social media, which was used for recruitment of the participants in this study. Nevertheless, one must respond to the worries expressed by the 43.3 percent of participants who chose to remain undecided, especially in relation with the risks and risks of HSCT. Previous research has found that fear of complications represents a major barrier for acceptance of HSCT in different populations [22]. Thus, HSCT should thus be supported by comprehensive educational initiatives which would address these fears and clear information about risks and benefits of HSCT.

This study also reports another noteworthy finding; that many HSCT patients are nearly unaware of the financial implications of the procedure. More than half of all participants cited a lack of awareness of the associated costs of HSCT. This gap in knowledge is important because financial barriers can play a major role in treatment acceptance and access. In a US study, financial concerns were a major barrier to HSCT consideration resulting in delayed treatment and poorer health outcomes [23]. In Saudi Arabia where practically the costs of healthcare are covered by the government it is important to provide guarantee that patients are cognizant of the costs and accessible money related help programs with respect to HSCT. Such an arrangement would ease the cash concern as well as enhance acceptance rates.

This study also needs to discuss the demographic trends observed. Most were young adults, mostly female, many were students. This demographic profile suggests the need to establish educational initiatives that can operate successfully with younger people. Previous research has shown that younger individuals are more likely to respond to such educational interventions as are interactive and easy of access [24]. Moreover, the large proportion of participants with a bachelor's degree makes it likely that educational efforts could achieve better results if they draw on such a reservoir of prior knowledge. Increasing awareness and acceptance of SCA and HSCT could be done by engaging students with SCA and HSCT in discussions using university programs and social media campaigns.

However, caveats exist about the valuable insights gained from this study. Firstly, it may be that self-reported data is biased since participants may overestimate their knowledge or acceptance levels. A study on self-reported health knowledge has demonstrated that individuals often overestimate their own knowledge, giving rise to false high self [25]. Secondly, recruiting of participants through social media may have restricted diversity of the sample since individuals deprived of social media access may have been excluded. Future studies could utilize a more complete recruitment strategy in order to generate a

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more representative sample. Also, this cross-sectional design does not allow the establishment of causal relationship between knowledge and acceptance levels. Studies tracking how knowledge and acceptance change with time after educational interventions would be interesting to see.

Conclusion:
Gaps in known and accepted knowledge about HSCT as a treatment option for SCA in Saudi Arabia are highlighted in this study. The findings serve as a call to action for targeted educational efforts to increase awareness and address concerns surrounding HSCT. Improving treatment outcomes for those affected by SCA in Saudi Arabia is possible by improving knowledge and acceptance. Future research should assess the effectiveness of educational interventions and on long term effects of an increased knowledge on treatment acceptance and health outcomes.

Acknowledgement:

We thank the participants who all contributed samples to this study.

Ethical approval:

An informed consent was obtained from each participant after explaining the study in full and clarifying that participation is voluntary. Data collected were securely saved and used for research purposes only.

Funding:

There was no external funding for this study.

Conflict of interests:

The authors declare no conflict of interest.

Informed consent:

Written informed consent was acquired from each individual study participant.

Data and materials availability:

All data associated with this study are present in the paper.

References:

1. Thomson, A. M., McHugh, T. A., Oron, A. P., Teply, C., Lonberg, N., Tella, V. V., ... & Hay, S. I. (2023). Global, regional, and national prevalence and mortality burden of sickle cell disease, 2000–2021: a systematic analysis from the Global Burden of Disease Study 2021. The Lancet Haematology, 10(8), e585-e599.
2. Cimpeanu E, Poplawska M, Jimenez BC, Dutta D, Lim SH. Allogeneic hematopoietic stem cell transplant for sickle cell disease: The why, who, and what. Vol. 50, Blood Reviews. Churchill Livingstone; 2021.

ISSN:1624-1940
http://magellanes.com/

3. Krishnamurti L. Hematopoietic Cell Transplantation for Sickle Cell Disease. Vol. 8, Frontiers in Pediatrics. Frontiers Media S.A.; 2021.
4. Alhomrani M, Alamri AS, Alsanie WF, Alrobiey AE, Asiri RM, Alaseri SM, et al. Knowledge and attitude of Taif university students on stem cell banking. Indian J Pharm Educ Res. 2021;55(4):1207–12.
5. Hreńczuk M, Gruszkiewicz P, Małkowski P. Knowledge, Opinions, and Attitudes of Students of Warsaw Universities Toward Hematopoietic Stem Cell Transplantation. Transplant Proc. 2021 Jul 1;53(6):1784–91.
6. Jastaniah W. aEpidemiology of sickle cell disease in Saudi Arabi. Vol. 31, Annals of Saudi Medicine. 2011. p. 289–93.
7. Al-Qurashi MM, El-Mouzan MI, Al-Herbish AS, Al-Salloum AA, Al-Omar AA. The prevalence of sickle cell disease in Saudi children and adolescents A community-based survey. Available from: www.smj.org.sa
8. Alsultan A, Jastaniah W, Al Afghani S, Al Bagshi MH, Nasserullah Z, Al-Suliman AM, et al. Demands and challenges for patients with sickle-cell disease requiring hematopoietic stem cell transplantation in Saudi Arabia. Pediatr Transplant. 2016 Sep 1;20(6):831–5.
9. Angelucci, E., Matthes-Martin, S., Baronciani, D., Bernaudin, F., Bonanomi, S., Cappellini, M. D., ... & Peters, C. (2014). Hematopoietic stem cell transplantation in thalassemia major and sickle cell disease: indications and management recommendations from an international expert panel. haematologica, 99(5), 811.
10. Kanter, J., Liem, R. I., Bernaudin, F., Bolaños-Meade, J., Fitzhugh, C. D., Hankins, J. S., ... & Tisdale, J. (2021). American Society of Hematology 2021 guidelines for sickle cell disease: stem cell transplantation. Blood advances, 5(18), 3668-3689.
11. Gluckman, E. (2013). Allogeneic transplantation strategies including haploidentical transplantation in sickle cell disease. Hematology 2013, the American Society of Hematology Education Program Book, 2013(1), 370-376.
12. Krishnamurti, L., Neuberg, D. S., Sullivan, K. M., Kamani, N. R., Abraham, A., Campigotto, F., ... & Walters, M. C. (2019). Bone marrow transplantation for adolescents and young adults with sickle cell disease: Results of a prospective multicenter pilot study. *American journal of hematology*, *94*(4), 446-454.
13. Guilcher, G. M., Truong, T. H., Saraf, S. L., Joseph, J. J., Rondelli, D., & Hsieh, M. M. (2018, April). Curative therapies: Allogeneic hematopoietic cell transplantation from matched related donors using myeloablative, reduced intensity, and nonmyeloablative conditioning in sickle cell disease. In Seminars in hematology (Vol. 55, No. 2, pp. 87-93). WB Saunders.
14. Walters, M. C., Patience, M., Leisenring, W., Eckman, J. R., Scott, J. P., Mentzer, W. C., ... & Sullivan, K. M. (1996). Bone marrow transplantation for sickle cell disease. *New England Journal of Medicine*, *335*(6), 369-376.
15. de la Fuente, J., Galimard, J. E., Dalissier, A., Al Zahrani, M., Alahmari, A., Almohareb, F., ... & Angelucci, E. (2024). Allogeneic Transplantation for Sickle Cell Disease Offers High Rates of Cure with Low Incidence of Severe Chronic GVHD in Both Children and Adults: Real World Data from 2010-2021. An Analysis of the European Society for Blood and Bone Marrow Transplantation Hemoglobinopathy Working Party. Blood, 144, 176.
16. Aboalola D, Ramadan M, Baadhaim M, Alsiary R, Badraiq H, Alghamdi T, et al. Public awareness and understanding of stem cell treatments available in Saudi Arabia and their trust in hospitals and research centers involved in stem cell research—a cross sectional study. Front Public Heal. 2024;12(April):1–9.

ISSN:1624-1940
http://magellanes.com/

17. Hurissi E, Hakami A, Homadi J, Kariri F, Abu-Jabir E, Alamer R, et al. Awareness and Acceptance of Hematopoietic Stem Cell Transplantation for Sickle Cell Disease in Jazan Province, Saudi Arabia. Cureus. 2022 Jan 7;
18. Stallings AM, Majhail NS, Nowacki AS, Onimoe GI, Hanna R, Wen J, et al. Parent and Guardian Knowledge of Hematopoietic Cell Transplantation as a Treatment Option for Sickle Cell Disease [Internet]. Vol. 41, J Pediatr Hematol Oncol. 2019. Available from: www.jpho-online.com
19. Thai, D. (2023). A paper-embedded thermoplastic microdevice integrating additive-enhanced allele-specific amplification and silver nanoparticle-based colorimetric detection for point-of-care testing. *Lab on a Chip*, 23(24), 5081-5091. https://doi.org/10.1039/d3lc00739a
20. Johnkennedy, N., Joseph, N., Oly–Alawuba, N., Chidozie, N., Joy, A., & C, O. (2020). Evaluation and pathobiological significance of zinc, selenium, and platelet levels in sickle cell anemia. *Innovare Journal of Medical Sciences*. https://doi.org/10.22159/ijms.2020.v8i2.37003
21. Nacif, L., Mello, E., Pinheiro, R., Lima, F., Martino, R., Andraus, W., … & D'Albuquerque, L. (2018). Successful liver transplantation case report from a deceased donor with sickle cell anemia. *Case Reports in Transplantation*, 2018, 1-4. https://doi.org/10.1155/2018/5154136
22. Sabahelzain, M. and Hamamy, H. (2014). The ethnic distribution of sickle cell disease in Sudan. *Pan African Medical Journal*, 18. https://doi.org/10.11604/pamj.2014.18.13.3280
23. Reeves, S., Jary, H., Gondhi, J., Kleyn, M., Wagner, A., & Dombkowski, K. (2018). Pneumococcal vaccination coverage among children with sickle cell anemia, sickle cell trait, and normal hemoglobin. *Pediatric Blood & Cancer*, 65(10). https://doi.org/10.1002/pbc.27282
24. Silva, R., Amarim, M., Figueiredo, T., Gestinari, R., & Tomazi, L. (2016). Sickle cell anemia in the Boqueirão Kilombo community, Bahia, Brazil. *Scientia Plena*, 12(9). https://doi.org/10.14808/sci.plena.2016.091002
25. Sissoko, M., Coulibaly, M., Koumaré, S., Sacko, O., Keita, S., Keita, S., … & Sanogo, Z. (2021). Surgical management of a case of splenic necrosis at Point G CHU in Bamako. *Surgical Science*, 12(04), 103-106. https://doi.org/10.4236/ss.2021.124012