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KNOWLEDGE, AWARENESS, AND WILLINGNESS CONCERNING HEMATOPOIETIC STEM CELL DONATION AND TRANSPLANTATION FOR SICKLE CELL DISEASE AMONG ADULTS OF KSA.

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Abstract

Background: sickle cell disease (SCD) is a genetic disorder caused by a single nucleotide mutation; this takes place on the beta-globin chain due to the presence of valine rather than glutamine on position 6. SCD is linked to a high rate of morbidity, a shorter life span, and a lower standard of living. A community survey shows SCD incidence in KSA having the highest rates in Eastern and Southwest regions. Stem cell transplantation is a promising treatment for life-threatening disorders, but its therapeutic applications remain limited because of lack understanding of stem cell therapy. Generally, the knowledge and acceptance of the HSCT are low worldwide, and overall, there is a long waiting list for HSCT. It is estimated that almost 60% and 30% of Saudi children and adult patients, respectively, who seek HSCT do not find well-matched donors. A major reason for the inadequacy in the number of available HSC donors has been attributed to the lack of community awareness and the availability of incorrect information about the importance of HSCT in SCD treatment.

Objectives: The study aims to assess knowledge, awareness, and willingness regarding BM donation and transplantation for SCD among adults of KSA.

Methodology: A cross-sectional study was conducted in Saudi Arabia targeting adults aged 18 and more years of age. The data was gathered via self-administered electronic survey and was entered using Microsoft Office Excel Software (2016) and analyzed using IBM SPSS Statistics for Windows version 20. Results: The total sample size of 1255 participants, 2.5% demonstrated a high degree of knowledge,

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while the majority, comprising 81.6%, exhibited a low level of understanding. Additionally, 15.9% of the participants fell within the medium level category. These findings suggest a notable disparity in the levels of knowledge and awareness among the adult population in KSA regarding HSCT for sickle cell disease, there is also about 63% have heard about HSCT and only 37% reported never hearing about it.

Conclusion: HSCT serves as a crucial remedy for severe medical conditions. In Saudi Arabia, there is a pressing demand for donors due to prevalent diseases such as sickle cell disease. Almost 63% of our study participants have heard about HSCT for SCD and 37% did not hear. Further, only 58.6% of our study participants are willing to donate, a percent must be increased to match the real need for HSCT. National education programs must be directed to medical schools as well as the general population to increase awareness about HSCT, which may lead to a better attitude and willingness for HSCT donation.

Keywords: sickle cell disease (SCD), Hematopoietic stem cell transplantation (HSCT), Kingdom of Saudi Arabia (KSA).

Introduction:

Sickle cell disease (SCD) is a genetic disorder caused by a single nucleotide mutation that takes place on the beta-globin chain due to the presence of valine rather than glutamine at position 6 [1]**.** It is inherited in both homozygous and double heterozygous genotypes via autosomal recessive inheritance [2]**.** It is distinguished by sickle hemoglobin polymerization, which causes red blood cells to have a sickle-shaped shape, causing vaso-occlusive phenomena, persistent hemolysis, and progressive anemia [3]**.** Acute pain episodes, acute chest syndrome, and stroke are common acute difficulties; however, chronic difficulties, such as chronic kidney disease, can harm all organs [4]**.** SCD is linked to a high rate of morbidity, a shorter life span, and a lower standard of living [5]. If sickle cell patients develop chronic acute chest syndrome, regular intense pain, or a stroke, as one fifth of them do in the KSA, they may need hematopoietic stem cell transplantation **(**HSCT) [6]. WHO estimates globally 3,000–4000 newborns diagnosed with hemoglobin defects annually [7]. A community survey shows SCD incidence in KSA ranges from 6-145 per 10,000 individuals, with Eastern and Southwest regions having the highest rates [8]. Till and McCulloch's 1961 discovery of HSCT led to the development of the hematopoietic stem cell niche concept [9]. Saudi Arabia pioneered hematopoietic stem cell transplantation in 1984; it was the first Arab country, with 500 allogeneic transplants performed annually [10]. Internationally, a 2016 Minnesota study found 247 medical students have positive attitudes towards joining bone marrow registry and stem cell donation, with 43% currently members and 68% learning about HSCT during medical school. However, misconceptions can hinder participation [11]. In 2016, a cross-sectional study in Nigeria found 64.5% of respondents aware of BMT as a treatment for SCA, with 67.8% believing it could cure SCD. However, acceptance was minimal. To encourage more adoption regarding BMT, education, psychological support, and awareness should be improved [12]**. On the** Saudi Arabian level, a 2023 cross-sectional nationwide study in KSA analyzed 474 Saudi female participants regarding their awareness of stem cell transplantation (SCT). Results showed 20.9% of participants identified stem cell sources, 27.6% knew centers, and 36.9% understood factors affecting SCT performance. Half of participants rely on the

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internet for their information. However, the Saudi Registry for Stem Cell Donors lists only 1.3% of donors [13]. A 2021 study at Jouf University revealed that 50.7% of medical and dental students were aware of the Saudi stem cell donor registry, while 72.4% had medium knowledge and 70% had high attitude scores [14]. Furthermore, in 2022, a cross-sectional study conducted in Jazan to assess 1167 community participants awareness and attitudes toward HSCT as a cure for SCD. 50% of participants believed SCD was curable, 78% were aware of HSCT, 57% correctly defined it, and 42% were willing to donate. National education programs are needed to reduce waiting lists and improve knowledge and attitude [15]. Stem cell transplantation is a promising treatment for life-threatening disorders, but its therapeutic applications remain limited. Consider a sample of Saudi adults who have inadequate knowledge about stem cell therapy. Increasing awareness and motivation is crucial. Educational efforts, counseling programs, and centers should be implemented to reduce waiting lists and improve some sickle cell disease cases. Community health education initiatives should emphasize donation and eradicate misconceptions about stem cell transplantation. Thus, in this study, we aim to assess the overall knowledge, awareness and willingness of HSCT for the treatment of sickle cell anemia among adults in KSA.

Materials and Methods:

Study design: This is an observational cross-sectional study. The study was conducted in the Kingdom of Saudi Arabia with randomly selected adults living in Saudi Arabia during December 2023 – May 2024.

Inclusion and Exclusion criteria:

In our study we included Residents of Saudi Arabia aged 18 and more, who agreed to participate in the survey. We have excluded Residents of Saudi Arabia aged less than 18 and who could not read Arabic.

Sample size :

Using the Raosoft sample size calculator (Raosoft Inc., Seattle, WA, USA, www.raosoft.com), the sample size for this study was determined. We found that 384 participants were sufficient to achieve a 95% confidence level and a 5% margin of errors.

Method for data collection and instrument (*Data collection Technique and tools)*: A self-administered questionnaire created on Google Forms was used to gather data. It has been made available online via social media tools. There was a total of 27 questions in the three sections of the questionnaire.

A) The first section includes a total of 12 questions about sociodemographic characteristics in terms of participant age, gender, nationality, city of residence, occupation, marital status, educational attainment, SSCDR registration status, awareness of the procedure, its difficulties, and sources of information about bone marrow transplantation.

b) The second section included 10 questions that tested participant's knowledge of the basic concepts of stem cells, including their definition, preparation of recipients for transplantation, ideal age for donation, factors influencing BMT success, complications, and cost.

c) The third section contained 5 questions designed to assess participant's attitudes and acceptance

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toward transplantation and donation of hematopoietic stem cells.

Scoring system:

We used a total of 15 survey questions to assess participants' attitudes and level of knowledge regarding hematopoietic stem cell donation and transplantation for sickle cell disease.

Knowledge score: The knowledge part consists of 10 questions. The correct response got one point, while "I don't know" or the incorrect response got zero. A score of 8 and above denoted a high degree of knowledge, Scores between 6 and less than 8 denoted a medium level of knowledge and score less than 6 denoted a low level of knowledge.

In Attitude score there are 5 questions that determine attitude and acceptance levels regarding transplantation and hematopoietic stem cell donation for sickle cell disease. The correct response got one point, while "I don't know" or the incorrect response got zero. Scores of 4 and above indicated a good attitude, 3 to less than 4 indicated a moderate attitude, and a score of less than 3 indicated a negative attitude**.**

Pilot test:

The survey was distributed to 20 persons, who were asked to complete it. This was done to assess the feasibility of the study and how simple the questionnaire was. The final analysis's findings did not include data from the pilot research.

Analyzes and entry method:

The computer's "Microsoft Office Excel Software" (2016) program was utilized to enter the data. In order to perform statistical analysis, then data was transmitted to the SPSS program, version 20 (IBM SPSS Statistics for Windows, Version 20.0, Armonk, NY: IBM Corp.)

Results:

Table (1) outlines the sociodemographic characteristics of the participants, with a total sample size of 1255 individuals. The distribution of participants based on age reveals that 42.4% were in the 18-25 age group, 29.8% in the 25-40 age group, and 27.8% were 40 years or older. In terms of gender, 34.3% were male and 65.7% were female. Most participants, 97.3%, were Saudi nationals, with only 2.7% being non-Saudi. The regional distribution showed that 13.2% were from the North of KSA, 29.8% from the South, 34.5% from the West, 10.8% from the East, and 11.7% from the Central region. When it comes to occupation, 5.1% were employed in the medical field, 5.3% were looking for work, 12.7% were housewives, 18.6% were students not in the medical field, 21.3% were students in the medical field, and 24.1% were employed but not in the medical field. Regarding marital status, 50.0% were single, 45.3% were married, 3.3% were divorced, and 1.4% were widowed. In terms of education level, the distribution was as follows: 0.2% uneducated, 1.0% primary education, 1.7% secondary education, 23.7% high school graduates, 8.9% diploma holders, 57.8% bachelor's degree holders, and 6.7%

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postgraduates. Furthermore, the participants included 2.9% sickle cell anemia patients, 1.1% parents of sickle cell anemia patients, 10.1% relatives of sickle cell anemia patients, 12.0% friends of sickle cell anemia patients, and 73.9% who did not know a sickle cell anemia patient at all. When asked if they had heard about bone marrow transplantation before, 63.3% answered yes, while 36.7% answered no. Among those who were aware of bone marrow transplantation, the sources of knowledge included patients with sickle cell anemia (6.8%), practitioners in the medical field (11.1%), social media and the internet (31.5%), TV shows (7.5%), and other sources (11.9%). Additionally, 31.3% did not provide an answer. Only 4.5% of participants had signed up in the Saudi Stem Cell Donor Registry (SSCDR), while 61.0% had not, and 34.5% were unaware of it. When asked about the most significant challenge facing bone marrow transplants, responses included no compatible or suitable donor (23.1%), decreased awareness levels (19.1%), operation costs (5.1%), fear of complications (15.3%), fear of death (7.4%), and 30.0% who were unsure.

Table (1): Sociodemographic characteristics of participants (n=1255)

Parameter		**No.**	**Percent (%)**
Age	18 - 25	532	42.4
	25 - 40	374	29.8
	40 or more	349	27.8
Gender	Male	430	34.3
	Female	825	65.7
Nationality	Saudi	1221	97.3
	Non-Saudi	34	2.7
Region	North of KSA	166	13.2
	South of KSA	374	29.8
	west of KSA	433	34.5
	East of KSA	135	10.8
	Central of KSA	147	11.7
Occupation	employed in the medical field.	64	5.1
	looking for work	66	5.3
	housewife	160	12.7
	others	161	12.8
	student but not in medical field	234	18.6
	student in medical field	267	21.3
	employed but not in medical field	303	24.1
Marital status	Single	627	50.0
	Married	569	45.3
	Divorced	42	3.3
	Widowed	17	1.4

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Education Level	uneducated	3	.2
	primary	13	1.0
	secondary	21	1.7
	high school	297	23.7
	diploma	112	8.9
	bachelor	725	57.8
	postgraduate	84	6.7
Participant	Sickle cell anemia patient.	36	2.9
	father or mother of a sickle cell anemia patient.	14	1.1
	relative of a sickle cell anemia patient.	127	10.1
	friend of sickle cell anemia patient.	150	12.0
	Don't know a sickle cell anemia patient at all.	928	73.9
Have you heard about bone marrow transplantation before?	Yes	795	63.3
	No	460	36.7
If yes, what is your source of knowledge about SCT?	from a patient with sickle cell anemia.	85	6.8
	from a practitioner in the medical field.	139	11.1
	From social media and internet	395	31.5
	From TV show	94	7.5
	others	149	11.9
	answerd by No	393	31.3
Did you ever sign up in Saudi Stem Cell Donor Registry (SSCDR)?	Yes	57	4.5
	No	765	61.0
	I don't know about it	433	34.5
In your opinion, what is the most important challenge facing bone marrow transplants?	No compatible or suitable donor	290	23.1
	Decreased level of awareness	240	19.1
	Operation cost	64	5.1
	Fear of complications	192	15.3
	Fear of the possibility of death	93	7.4
	I don't know	376	30.0

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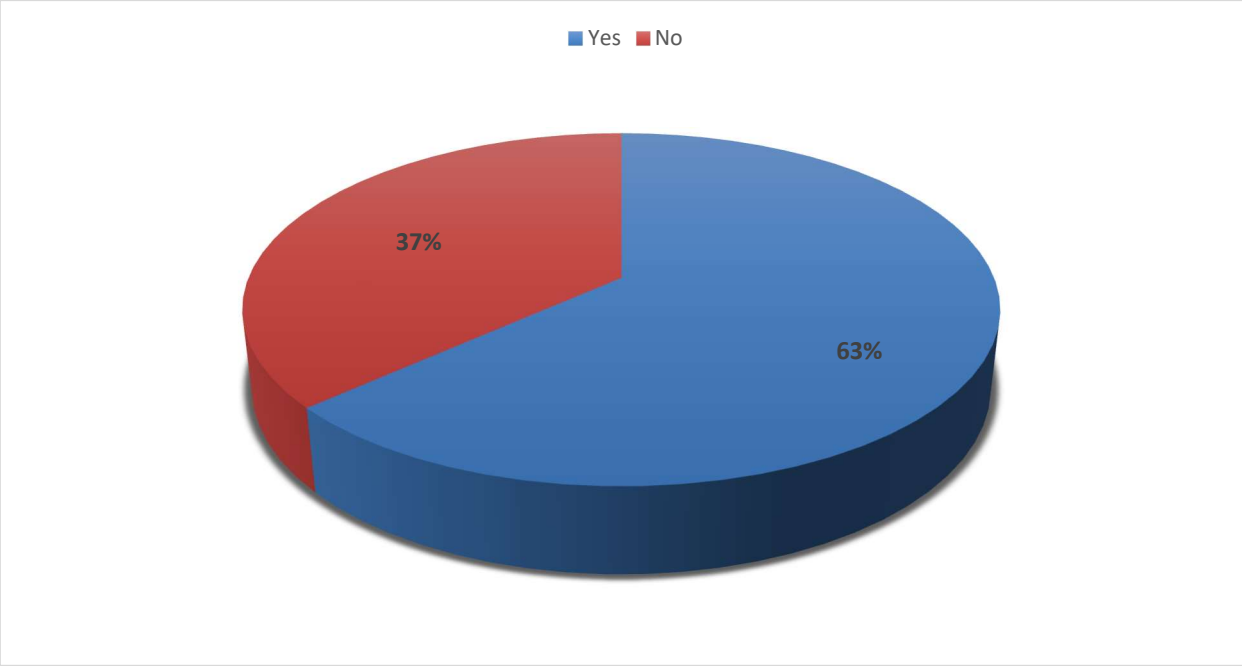
Figure (1): Illustrates having heard of bone marrow transplantation among participants (n=1255)



As illustrated in table (2), The data presented sheds light on various important parameters related to the participants' knowledge of HSCT for the treatment of sickle cell disease. The responses from a sample size of 1255 individuals provide valuable insights into the perceptions and understanding surrounding this critical medical procedure. It is noteworthy that a significant portion of the participants, 32.7%, believe that sickle cell anemia patients can be cured or treated permanently, while 48.9% admitted to not knowing. When asked about bone marrow transplantation, 43.5% correctly identified it as a process involving the collection of stem cells from a suitable donor and their injection into the recipient's body. However, a concerning 36.5% indicated knowing nothing about bone marrow transplantation. Regarding the best person to donate bone marrow, 34.3% considered siblings, while 42.7% admitted to not knowing. The data also revealed varying perceptions on potential complications post-donation, with 47.4% unsure about the outcomes. Additionally, only 11.2% were aware of the expensive nature of bone marrow transplants in Saudi Arabia, while 68.7% had no idea about the costs involved. When asked about the best age for stem cell donation, 55.6% suggested 18-49 years, and 41% admitted to not knowing. The responses also highlighted a lack of consensus on the best way to prepare a patient for receiving stem cells, with 54.2% indicating they did not know. Furthermore, factors affecting the success of stem cell transplantation were perceived differently, with 66.9% acknowledging that all factors mentioned play a role. The data underscores the importance of enhancing knowledge and awareness among adults in KSA regarding hematopoietic stem cell donation and transplantation for sickle cell disease to improve understanding and decision-making in healthcare.

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Table (2): Parameters related to knowledge of HSCT for the treatment of sickle cell disease (n=1255).

Parameter		**No.**	**Percent (%)**
Do you think that sickle cell anemia patients can be cured or treated permanently?	Yes	411	32.7
	No	230	18.3
	I don't know	614	48.9
What do you know about the bone marrow transplantation?	nothing	458	36.5
	It is the process of transfusion of blood after it is taken from a suitable donor.	64	5.1
	A surgery in which bone from a suitable donor is cut and transplanted into the recipient's body.	187	14.9
	A process in which stem cells are collected from a suitable donor and injected into the recipient's body.	546	43.5
Who do you think would be the best person to donate bone marrow?	The mother to the daughter	136	10.8
	father to son	108	8.6
	Father to mother	45	3.6
	siblings	430	34.3
	I don't know	536	42.7
What are the problems that you expect to happen to the donor after the donation?	The probability of death	100	8.0
	Hemoglobin deficiency	198	15.8
	Severe illness	75	6.0
	He stays healthy	287	22.9
	I don't know	595	47.4
Choose the complications associated with a bone marrow transplant that you know.	body rejection	309	24.6
	infertility	29	2.3
	Attacking the donor's cells to the recipient's dying cells	205	16.3
	All of the above	212	16.9
	none of the above	69	5.5
	I don't know.	431	34.3
	Yes	191	15.2
	No	560	44.6

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Do you think that everyone who has a stem cell transplant will suffer from complications?	I don't know.	504	40.2
Do you have an idea about the cost of a bone marrow transplant in Saudi Arabia?	Yes, the process is expensive and costs a lot of money.	141	11.2
	Yes, the process is cheap, and anyone can pay for it	16	1.3
	Completely free	236	18.8
	I have no idea how much it costs.	862	68.7
What is the best age for stem cells donation?	18–49 years	698	55.6
	50 years or older	42	3.3
	I don't know	515	41.0
What is the best way to prepare a patient for receiving stem cells?	the patient receives high doses of chemotherapy and immunosuppressive medication	277	22.1
	direct injection with stem cell	298	23.7
	I don't know	680	54.2
What factors affect the success of stem cell transplantation?	the patient's age	72	5.7
	the patient's health	151	12.0
	the type of disease	56	4.5
	the donor's age	22	1.8
	the general health	114	9.1
	all of the above	840	66.9

Figure (2): Illustrates the best way to prepare a patient for stem cells transplantation among participants (n=1255)

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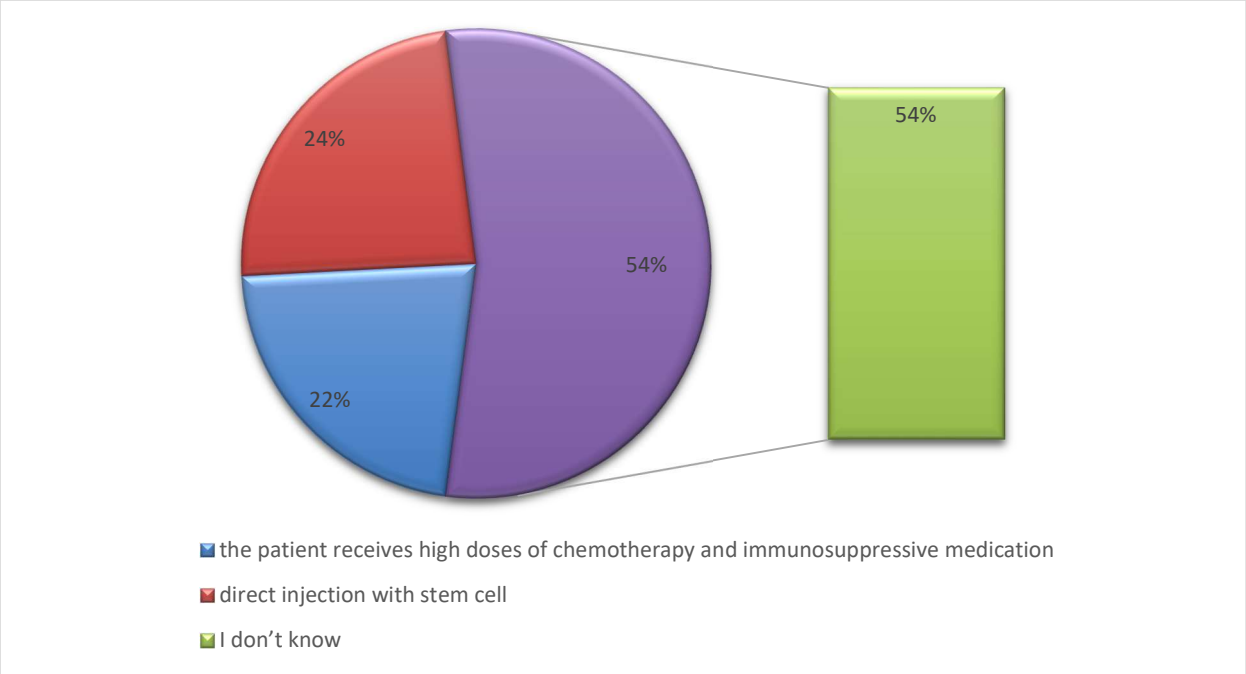

Table (3) presents the score results pertaining to knowledge and awareness about HSCT for sickle cell disease treatment. The table indicates that out of the total sample size of 1255 participants, 2.5% demonstrated a high degree of knowledge, while the majority, comprising 81.6%, exhibited a low level of understanding. Additionally, 15.9% of the participants fell within the medium level category. These findings suggest a notable disparity in the levels of knowledge and awareness among the adult population in KSA regarding HSCT for sickle cell disease, highlighting potential areas for targeted educational interventions and awareness campaigns to enhance understanding and promote informed decision-making in this critical healthcare domain.

Table (3): Shows knowledge and awareness about HSCT for the treatment of sickle cell disease score results.

	Frequency	Percent
High level	32	2.5
Low level	1024	81.6
Moderate level	199	15.9
Total	1255	100.0

Table (4) reveals that out of the 1255 participants surveyed, a notable 58.6% expressed acceptance towards donating bone marrow or undergoing a transplant, while 41.4% rejected the idea. Moreover, a significant majority (68.1%) acknowledged stem cell transplantation as a lifesaving therapy, with only a small percentage (3.7%) expressing uncertainty about its efficacy. The data also revealed a high level

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of willingness among participants to undergo SCT if needed for treatment (82.5%) and to donate stem cells to save a family member's life (86.4%). When asked about the reasons for their acceptance of stem cell donation, the majority cited helping patients and understanding the importance of the procedure (68.4%), while a smaller percentage mentioned other reasons (19.4%) or expressed outright rejection of donation (12.3%).

Table (4): participants Attitude and acceptance of HSCT for the treatment of sickle cell disease (n=1255).

Parameter		No.	Percent (%)
Do you want to donate bone marrow or undergo a bone marrow transplant, or allow your child to have the operation?	Accept	736	58.6
	Reject	519	41.4
Is stem cells transplantation a lifesaving therapy?	Yes	855	68.1
	No	47	3.7
	I don't know	353	28.1
Would you accept SCT if you needed treatment?	Accept	1036	82.5
	Reject	219	17.5
If there is a need to donate stem cells to save the life of a family member, would you accept the donation?	Accept	1084	86.4
	Reject	171	13.6
What is the reason for your acceptance of stem cell donation?	Helping patients and Knowing about its importance	858	68.4
	others	243	19.4
	I reject donation	154	12.3

Table (5) presents insightful data on the attitudes and acceptance levels regarding HSCT for the treatment of sickle cell disease. The table illustrates that a significant portion of the participants exhibited a positive attitude towards HSCT, with 64.9% displaying a good attitude, while 14.1% had a moderate attitude, and 21.0% held a negative attitude. These findings shed light on the varying perspectives and sentiments within the adult population of KSA regarding HSCT as a treatment option for sickle cell disease.

Table (5): Shows Attitude and acceptance about HSCT for the treatment of sickle cell disease score results.

	Frequency	Percent
Good attitude	815	64.9
Moderate attitude	177	14.1
Negative attitude	263	21.0

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Total	1255	100.0

Table (6) shows that the level of knowledge and awareness of HSCT for the treatment of sickle cell disease among Saudi population is statistically significant related to the region of residence (p value= 0.023), occupation, participant's relation to SCD patient and if the patient signed up to SSCDR. It also shows statistically insignificant relation to gender, age, nationality, education level and marital status.

Table (6): Relation between knowledge and awareness of HSCT for the treatment of sickle cell disease and sociodemographic data of participants (n=1255).

Parameters		**Knowledge level**		**Total (N=)**	**P value***
		Low	**Moderate and High**		
Gender	Female	662	163	825	0.087
		64.6%	70.6%	65.7%	
	Male	362	68	430	
		35.4%	29.4%	34.3%	
Age	18 - 25	424	108	532	0.320
		41.4%	46.8%	42.4%	
	25 - 40	309	65	374	
		30.2%	28.1%	29.8%	
	40 or more	291	58	349	
		28.4%	25.1%	27.8%	
Nationality	Saudi	1000	221	1221	0.093
		97.7%	95.7%	97.3%	
	Non-Saudi	24	10	34	
		2.3%	4.3%	2.7%	
Region	South of KSA	306	68	374	0.023
		29.9%	29.4%	29.8%	
	East of KSA	98	37	135	
		9.6%	16.0%	10.8%	
	North of KSA	143	23	166	
		14.0%	10.0%	13.2%	
	West of KSA	351	82	433	
		34.3%	35.5%	34.5%	
	Central of KSA	126	21	147	
		12.3%	9.1%	11.7%	
Occupation	employed in the medical field.	40	24	64	0.0001
		3.9%	10.4%	5.1%	

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	looking for work	60	6	66	
		5.9%	2.6%	5.3%	
	housewife	137	23	160	
		13.4%	10.0%	12.7%	
	others	136	25	161	
		13.3%	10.8%	12.8%	
	student but not in medical field	207	27	234	
		20.2%	11.7%	18.6%	
	student in medical field	189	78	267	
		18.5%	33.8%	21.3%	
	employed but not in medical field	255	48	303	
		24.9%	20.8%	24.1%	
Education Level	uneducated	3	0	3	0.052
		0.3%	0.0%	0.2%	
	Primary	12	1	13	
		1.2%	0.4%	1.0%	
	Secondary	20	1	21	
		2.0%	0.4%	1.7%	
	high school	252	45	297	
		24.6%	19.5%	23.7%	
	diploma	96	16	112	
		9.4%	6.9%	8.9%	
	bachelor	579	146	725	
		56.5%	63.2%	57.8%	
	postgraduate	62	22	84	
		6.1%	9.5%	6.7%	
Marital status	Widowed	16	1	17	0.053
		1.6%	0.4%	1.4%	
	Single	494	133	627	
		48.2%	57.6%	50.0%	
	Married	479	90	569	
		46.8%	39.0%	45.3%	
	Divorced	35	7	42	
		3.4%	3.0%	3.3%	
Participant	Sickle cell anemia patient.	23	13	36	0.0001
		2.2%	5.6%	2.9%	
		8	6	14	

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	father or mother of a sickle cell anemia patient.	0.8%	2.6%	1.1%	
	relative of a sickle cell anemia patient.	99	28	127	
		9.7%	12.1%	10.1%	
	friend of sickle cell anemia patient.	115	35	150	
		11.2%	15.2%	12.0%	
	Doesn't know a sickle cell anemia patient at all.	779	149	928	
		76.1%	64.5%	73.9%	
Did you ever sign up in Saudi Stem Cell Donor Registry (SSCDR)?	Yes	44	13	57	0.006
		4.3%	5.6%	4.5%	
	No	606	159	765	
		59.2%	68.8%	61.0%	
	I don't know about it	374	59	433	
		36.5%	25.5%	34.5%	

P value was considered significant if ≤ 0.05.

Table (7) shows that participants Attitude and acceptance of HSCT for the treatment of sickle cell disease among Saudi population is statistically significant related to gender (p value= 0.0001), age, region of residence, occupation, education level and marital status. It also shows statistically insignificant relation to nationality, participant's relation to SCD patient and if the patient signed up to SSCDR.

Table (7): Relation between participants Attitude and acceptance of HSCT for the treatment of sickle cell disease and sociodemographic data of participants (n=1255).

Parameters		**Attitude**			**Total (N=)**	**P value***
		Good	**Moderate**	**Negative**		
Gender	Female	569	121	135	825	0.0001
		69.8%	68.4%	51.3%	65.7%	
	Male	246	56	128	430	
		30.2%	31.6%	48.7%	34.3%	
Age	18 - 25	373	77	82	532	0.001
		45.8%	43.5%	31.2%	42.4%	
	25 - 40	223	50	101	374	
		27.4%	28.2%	38.4%	29.8%	
	40 or more	219	50	80	349	

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		26.9%	28.2%	30.4%	27.8%	
Nationality	Saudi	790	174	257	1221	0.530
		96.9%	98.3%	97.7%	97.3%	
	Non-Saudi	25	3	6	34	
		3.1%	1.7%	2.3%	2.7%	
Region	South of KSA	250	56	68	374	0.0001
		30.7%	31.6%	25.9%	29.8%	
	East of KSA	93	12	30	135	
		11.4%	6.8%	11.4%	10.8%	
	North of KSA	110	23	33	166	
		13.5%	13.0%	12.5%	13.2%	
	West of KSA	297	64	72	433	
		36.4%	36.2%	27.4%	34.5%	
	Central of KSA	65	22	60	147	
		8.0%	12.4%	22.8%	11.7%	
Occupation	employed in the medical field.	50	7	7	64	0.0001
		6.1%	4.0%	2.7%	5.1%	
	looking for work	27	7	32	66	
		3.3%	4.0%	12.2%	5.3%	
	housewife	103	21	36	160	
		12.6%	11.9%	13.7%	12.7%	
	others	97	21	43	161	
		11.9%	11.9%	16.3%	12.8%	
	student but not in medical field	140	38	56	234	
		17.2%	21.5%	21.3%	18.6%	
	student in medical field	202	35	30	267	
		24.8%	19.8%	11.4%	21.3%	
	employed but not in medical field	196	48	59	303	
		24.0%	27.1%	22.4%	24.1%	
Education Level	uneducated	1	0	2	3	0.0001
		0.1%	0.0%	0.8%	0.2%	
	Primary	6	2	5	13	
		0.7%	1.1%	1.9%	1.0%	
	Secondary	7	1	13	21	
		0.9%	0.6%	4.9%	1.7%	
	high school	203	36	58	297	
		24.9%	20.3%	22.1%	23.7%	
	diploma	76	16	20	112	

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		9.3%	9.0%	7.6%	8.9%	
	bachelor	472	117	136	725	
		57.9%	66.1%	51.7%	57.8%	
	postgraduate	50	5	29	84	
		6.1%	2.8%	11.0%	6.7%	
Marital status	Widowed	3	1	13	17	0.0001
		0.4%	0.6%	4.9%	1.4%	
	Single	434	95	98	627	
		53.3%	53.7%	37.3%	50.0%	
	Married	357	78	134	569	
		43.8%	44.1%	51.0%	45.3%	
	Divorced	21	3	18	42	
		2.6%	1.7%	6.8%	3.3%	
Participant	Sickle cell anemia patient.	25	4	7	36	0.123
		3.1%	2.3%	2.7%	2.9%	
	father or mother of a sickle cell anemia patient.	9	0	5	14	
		1.1%	0.0%	1.9%	1.1%	
	relative of a sickle cell anemia patient.	96	12	19	127	
		11.8%	6.8%	7.2%	10.1%	
	friend of sickle cell anemia patient.	101	18	31	150	
		12.4%	10.2%	11.8%	12.0%	
	Doesn't know a sickle cell anemia patient at all.	584	143	201	928	
		71.7%	80.8%	76.4%	73.9%	
Did you ever sign up in Saudi Stem Cell Donor Registry (SSCDR)?	Yes	38	5	14	57	0.675
		4.7%	2.8%	5.3%	4.5%	
	No	501	105	159	765	
		61.5%	59.3%	60.5%	61.0%	
	I don't know about it	276	67	90	433	
		33.9%	37.9%	34.2%	34.5%	

P value was considered significant if ≤ 0.05.

Discussion:

Hematopoietic stem cell transplantation (HSCT) represents a crucial medical intervention that holds the potential to save lives while mitigating a range of medical conditions, including leukemia, myelodysplastic syndromes, sickle cell anemia, thalassemia, severe combined immunodeficiency, and

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specific malignancies. [16] The two primary methods employed for HSCT are bone marrow transplantation (BMT) and peripheral blood stem cell transplantation (PBSCT) [17]. In approximately 75% of cases, PBSCT has become the preferred source of stem cells, supplanting BMT in recent years [18]. Due to the favorable outcomes achieved in treating particular severe medical conditions, stem cell research, therapy, and donation have captured the attention of the scientific community, healthcare organizations, and patients [19]. Saudi Arabia has the highest incidence of sickle cell disease SCD among all Middle Eastern countries, with the majority of cases being reported in the eastern part of the country, followed by the southwestern region [20]. SCD is a genetic condition that is characterized by a short lifespan, crescent-shaped RBCs which is mediated by the existence of abnormal Hb. This abnormality is pathogenic to different organs and may cause multiple complications. This disease is characterized by the presence of at least one copy of Hb "S". The disease can be homogeneous as SS phenotype or heterogeneous as SC. This pathogenic Hb can result in abnormality in Hb polymerization which may result in abnormality in the morphology of red blood cells (RBCs) [21]. Individuals carrying this abnormal form of Hb usually experience painful episodes which are known as vaso-occlusive crises (VOC). These crises are mediated by the occlusion of small blood vessels with abnormally shaped RBCs [22]. The current treatment protocol for SCD is limited to the management of the clinical manifestations which includes the use of hydroxyurea, blood transfusions, and other supportive care such as analgesic, prophylactic antibiotic prescription, and psychological support, which have improved the life expectancy of patients with SCD. The aim of this study is to assess knowledge, awareness, and willingness regarding BM donation and transplantation for SCD among adults of KSA. Regarding knowledge about HSCT for SCD, we have found that about 63% have heard about HSCT and only 37% reported never hearing about it, there is also a statistically significant relation between the level of knowledge and awareness of HSCT for the treatment of sickle cell disease and the education level of the participants. Another study conducted in Jazan Province, Saudi Arabia, revealed that almost 78% of the study participants already had heard about HSCT in the past, and 57% defined HSCT correctly. Moreover, a better level of knowledge and attitude was associated with people with higher education or individuals with medical professionals (57%) compared to the previously reported studies which targeted medical students [23, 24, 25]. On the other hand, a study carried out in 2016 in Riyadh, Saudi Arabia found that the level of knowledge among nursing students was poor, and the knowledge was enhanced by educational programs [26]. Moreover, Hazzazi et al. conducted a study in 2019 to measure the awareness of medical students in Jazan University about HSCT and they found that the majority of the medical students lacked the proper knowledge on HSCT and only about 9% of the participants were willing to donate [27]. Moreover, in Taif, Saudi Arabia, another study was published in 2020 which aimed to measure the knowledge and attitude of medical students of Taif university toward HSCT. The study showed a low level of basic knowledge about HSC and only 2% of the participants donated bone marrow in the past [28]. Another study that targeted the public population in Saudi Arabia concluded that the overall knowledge of the study subjects about HSCT was low, and a positive correlation was found between the level of education and the knowledge about HSCT which is consistent with our results [29]. Regarding attitude and acceptance about HSCT for the treatment of sickle cell disease, a significant portion of the participants exhibited a positive attitude towards HSCT, with 64.9% displaying a good attitude, while 14.1% had a moderate attitude, and 21.0% held a negative attitude.

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There is a statistically significant relation between positive attitude and gender, age, region of residence, occupation, education level and marital status (p value < 0.05). On the other hand, a study conducted in Saudi Arabia found that the female gender is significantly associated with better knowledge; however, a difference in positive attitude toward HSCT was not affected by gender differences. In Africa, Adediran et al. conducted a study in a tertiary hospital in Nigeria in 2016 and found that about 65% of the participants were aware of HSCT and the level of knowledge was significantly associated with better attitude [30]. It seems explainable that the difference between the percent of knowledge in our study (63%) and what Adediran et al. reported in Nigeria (65%) could be related to the type of individuals recruited in both studies. Another report from Malaysia conducted among nursing students found a poor correlation between knowledge and attitude toward HSCT. [31]

Conclusion:

HSCT serves as a crucial remedy for severe medical conditions. In Saudi Arabia, there is a pressing demand for donors due to prevalent diseases such as sickle cell disease. This study was conducted to fill the gap in knowledge about public awareness and attitude toward HSCT for SCD. Almost 63% of our study participants have heard about HSCT for SCD and 37% did not hear. Further, only 58.6% of our study participants are willing to donate, a percent must be increased to match the real need for HSCT. National education programs must be directed to medical schools as well as the general population to increase awareness about HSCT, which may lead to a better attitude and willingness for HSCT donation.

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Ethical approval

Ethical approval was obtained from the research ethics committee at University of Hail with Application number: [H-2023-441]. 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.

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Conflict of interests

The authors declare that there are no conflicts of interest.

Informed consent:

Written informed consent was obtained from all individual participants included in the study.

Data and materials availability

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

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