Research Article

Awareness about Sickle Cell Anaemia in young adults in Amravati.

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ABSTRACT

Background: Sickle cell disease continues to be a global health problem that presents major challenges to our health care systems. The reviewed Sickle Cell Disease (SCD) literature expresses a dire need for more public education and awareness on SCD Misconceptions of sickle cell disease have significantly contributed to the rise in the public's misunderstanding of sickle cell disease.

Aims:
1) To know awareness about sickle cell anaemia(SCA) among young adults attending 3 popular competitive coaching classes in Amravati district
2) To know sociodemographic factors associated with awareness about SCA.
3) To impart proper knowledge about SCA to them.

Methods: A descriptive study was conducted among young adults in the age group of 18-45 years for a period of 3 months from at various private coaching classes at Amravati District. Predesigned and pretested questionnaire was used as a data collection tool in students who consented for participation in study. After data collection all educated regarding sickle cell anemia.

Results: Out of 403 students 37.2% students had poor knowledge, 51.9% had average knowledge and only 10.9% had good knowledge .When their knowledge was assessed in three domains i.e. basic knowledge and clinical features of SCA, treatment and prevention category 57.1% students had basic knowledge about sickle cell disease and 24.3% and 28% students had knowledge about treatment and prevention category respectively. Most of participants i.e. 44.2% got information from doctor, while in 12.7% students source of information was television, radio, newspaper followed by friends and relatives in 5.2% only. No significant association was found between knowledge in each domain of SCA with age, sex, demographic location and occupation of the participants except education and basic knowledge which were significantly associated (p=0.01). Majority i.e.272 (67.5%) students were unaware of sickle cell status of themselves or their family members. Out of 403 only 77 (19.1%) participants were egger to know more about SCA while remaining 326 (80.9 %) were not interested at all.

Limitations: 1. No randomization is done 2. Can't generalised to whole public

Conclusion: Majority students had poor or average knowledge about sickle cell disease. This indicates the need for health workers and government system to focus more on preventive aspects of SCA among target age group. Television, radio and newspaper are important Medias to create awareness which are presently not used very effectively by government in creating awareness.

Key words: sickle cell anaemia, awareness, Young adults, coaching class students

INTRODUCTION:

Sickle cell anaemia (SCA) is an autosomal recessive disorder with phenotypic variation. It is one of the most common hereditary disease occurring worldwide, which may impact any organ or system of human body [1]. It is found in many parts of the world particularly in people whose ancestors from Sub-Saharan Africa, India, Saudi-Arabia and Mediterranean country [2].Sickle cell Disease(SCD) is also a public health problem in India with an estimated 5200 live birth each year. According to ICMR Survey sickle cell gene is found amongst various tribes of India, which varies from 5-34%[3].According to WHO, 10% of SCD patients die by the age of 1 year and in many sub –Saharan countries the mortality is much higher than that. Many states in India has higher burden of SCD. Gujarat is the 1st Indian state which had started sickle cell disease control program in 2005-06 followed by Maharashtra in 2008. Premarriage genetic screening and counselling should be the main focus of efforts at controlling SCD in developing countries because screening is relatively cheaper and far less invasive that prenatal diagnosis (PND). Besides, the psychological and socioeconomic issues at stake are far easier to manage than when a couple must decide on PND and selective abortion. Indeed, it has been argued that "no screening service should be established without adequate educational and counselling backup for the clients" [4]. Furthermore, it has been argued that higher levels of community knowledge reduce the need for face-to-face counselling and that community education is therefore cost effective as well as being an essential part of a screening programme [5]. But public awareness activity is less focused in this government programme and more emphasis is given on screening of population. The scarcity of SCA research in India exemplifies how our society fails to view sickle cell anaemia as a serious illness. Information and awareness-related activities are important component of effective public health strategies for reducing the morbidity and mortality among people with sickle cell anaemia. Without awareness and a public protest for a revolution, sickle cell anaemia will continue to be a silent killer to young people around the world. With this background present study was conducted to know about awareness of sickle cell anemia in competitive coaching class students of Amravati, which indirectly indicate success of sickle cell control programme running in Amravati since 2008.

Methods:

A cross sectional study was carried out amongst young adults attending competitive coaching classes in Amravati from December 2014 to February 2015. Amravati is 2nd largest city in Vidharbha with actively running sickle cell control programme since 2008. In Amravati 35 coaching classes was running for competitive examination out of which 3 centres were selected randomly with criteria as most popular centre in Amravati. After permission from directors of coaching centres, all students in the age group of 18-30 years and residing in Amravati district were included in the study. Out of 450 students, 432(96%) agreed to participate in the study. From collected data 29 students which had age more than 30 years or residing outside Amravati were excluded.

Questionnaire was designed to elicit information on sociodemographic characteristics (Age, Sex, Education, Occupation, Address) and their knowledge regarding SCD. Questionnaire was translated in local language (i.e. Marathi/Hindi), It included twelve close ended questions and one open ended question. To avoid confusion, terminologies were explained to respondents during the data collection processes. Question number 1,4,7 tested knowledge regarding some basic facts and signs and symptoms of SCD, Question 3,5,6 tested knowledge about treatment modalities and Question 2,8,9,10 tested knowledge about preventive measures of the disease. Instructions about how to fill proforma, what is compulsory and what is not compulsory

(i.e. personal information like name, address and mobile number) were given to the participants. Also they were told if they don't know the answer, tick 'don't know' option rather than copying someone's answer or guessing the answer. The response option 'don't know' was included to avoid bias of giving probable answer. Out of 10 questions if student was able to answer less than 5 questions correctly was considered as having poor knowledge, if student could answer 5-7 questions correctly was considered as having Average knowledge and if he/she could answer 8-10 questions correctly he was considered as having good knowledge about SCA. Further the knowledge in each of the 3 domains mentioned above was tested separately and we categorized it into good or poor knowledge if student is able to answer two or more questions from each of the domain correctly. Question 12 and 13 collected the information about source from where they got information regarding SCA (multiple response type) and if they want to know more about disease respectively. Data generated with the questionnaire was checked manually for errors and entered into excel and analyzed using SPSS version 16, using the Chi square test of significance. p value <0.05 was considered statistically significant.

RESULTS:

Majority of the participants (47.6%) were in the age group of 18-22 years with a mean age of 23.42 yrs. There were more males 284 (70.5%) than females 119 (29.5%). Most of the participants 291 (72.2%) were the resident of urban area while 112 (27.8%) were from periphery (rural). Most of participants had completed their graduation 259 (64.3%) followed by higher secondary 112 (27.8%). Most of participants 307 (76.2%) were students**.** All this sociodemographic information is included in **Table- 1**. Majority of participants had basic knowledge about sickle cell anaemia(SCA) i.e, it is related to red blood corpuscles, 261 (64.8%), it is not due to eating cow's milk or curse of god, 290 (72%) and if proper treatment and precautions are taken Sickle cell disease (SCD)

Sr.No	Sociodemographic characteristics	Frequency	Percentage (%)
1	**Age in years**		
	18-22	192	47.6
	23-26	130	32.3
	27-30	81	20.1
2	**Sex**		
	Males	285	70.7
	Females	118	29.3
3	**Residence**		
	Urban	291	72.8
	Rural	112	27.2
4	**Education**		
	SSC	6	1.5
	Higher secondary	112	27.8
	Graduate	259	64.3
	Postgraduate	26	6.2
5	**Occupation**		
	Student	307	76.2
	Worker	20	5.0
	Farmer	17	4.2
	Businessman	8	2.0
	Housewife	18	4.5
	Service	29	7.2
	Private job	4	1.0

Table-1. *Sociodemographic characteristics of study participants*

patient can live long life, 297(73.7%).In treatment or preventive domain, only 53 (13.2%) respondents answered that SCD is completely curable with bone marrow transplantation , 37 (9.1%) answered that it is curable by homeopathic or Ayurvedic therapy, while 220 (54.6%) participants didn't know the answer. According to most of them 208 (51.6%) blood transfusion is the only treatment for SCD. Majority i.e. 220 (54.6%) were unaware about symptoms and signs of disease, only 100 (24.8%) respondents knew about all 3 complaints of SCD . Only 44.9% participants knew that it is hereditary disease and 166 (41.2%) knew that if child is affected then mother and father both required to have some form of disease (trait or disease). Most of respondents, 272 (67.5%) didn't know which cast is most affected with SCA while only 74 (18.4%) answered it correctly. Majority 272 (67.5%) were unaware about SCA status of themselves and their family members, only 11 (2.7%) students knew this. All the responses of participants to questions asked were shown in **Table-2.** When asked about the source of information about sickle cell anaemia, 178 (44.2%) students told that they got information about SCA from doctor,

Sr. No.	Question asked	Total participants N=403		
		Correct answer	Wrong answer	Don't know
1	Sickle cell is related with.....	261 (64.8%)	30 (7.4%)	112 (27.8%)
2	Sickle cell is hereditary disease	181 (44.9%)	119 (29.5%)	103 (25.6%)
3	If proper treatment and precaution taken SCD patient can live long life	297 (73.7%)	16 (4%)	90 (22.3%)
4	It is due to eating cow's meat or curse of God	290 (72%)	20 (5%)	93 (23%)
5	SCD is completely curable with	53 (13.2%)	130 (32.3%)	220 (54.6%)
6	Only treatment in SCD is giving blood transfusion	72 (17.9%)	208 (51.6%)	123 (30.5%)
7	What are complaints of SCD patient	100 (24.8%)	155 (38.5%)	148 (36.7%)
8	If child is affected with SCD what it indicate	166 (41.2%)	40 (9.9%)	197 (48.9%)
9	It is possible to diagnose antenatal that foetus is affected or not	317 (78.7%)	13 (3.2%)	73 (18.1%)
10	SCD is more common in this community	74 (18.4%)	57 (14.1%)	272 (67.5%)

Table-2. *Distribution of participants according to answers given by them*

and television, radio, newspaper accounted to 51(12.7%) while friends and relative contributed to 21(5.2%) only as shown in **Table-5**. Out of 403 only 77 (19.1%) participants were egger to know more about SCA while remaining 326 (80.9 %) were not interested to know further about SCA.

Score Out of 10	Frequency	Percentage (%)
Poor knowledge <5	150	37.2
Average knowledge 5-7	209	51.9
Good score 8-10	44	10.9
Total	**403**	**100**

Table-3. *Knowledge score as per number of correct answers given by the participants*

When overall knowledge was tested, 37.2% students had poor knowledge,51.9% had average knowledge and only 10.9% had good knowledge (**Table-3**)**.** When these questions were divided in three domains i.e. basic knowledge and clinical features of sickle cell anaemia, treatment and prevention category 57.1% students had basic knowledge about SCA but only 24.3% and 28% students had knowledge about treatment and prevention category respectively (**Table-4**). When overall knowledge and knowledge in each domain (i.e. basic knowledge and clinical features of SCA, treatment and prevention category) were associated with sociodemographic variables like age, sex, education and demographic location of the participants and occupation, no significant association was found except

Knowledge domain	N=403	
	Poor knowledge	Good knowledge
Basic knowledge about SCD and about Signs/symptoms	173 (42.9%)	230 (57.1%)
Treatment	305 (75.7%)	98 (24.3%)
Prevention	290 (72.0%)	113 (28.0%)

Table-4. *Knowledge of participants as per different categories.*

education and basic knowledge about SCA(p=0.01) **(Table-6)**. Significant association was found between source of information and knowledge domain.

Source of information about SCD	Frequencies	Percentage (%)
Doctor	176	43.7
Television, Radio Newspaper, Books	144	35.7
Friends/relatives	81	20.1
From multiple sources	2	0.5

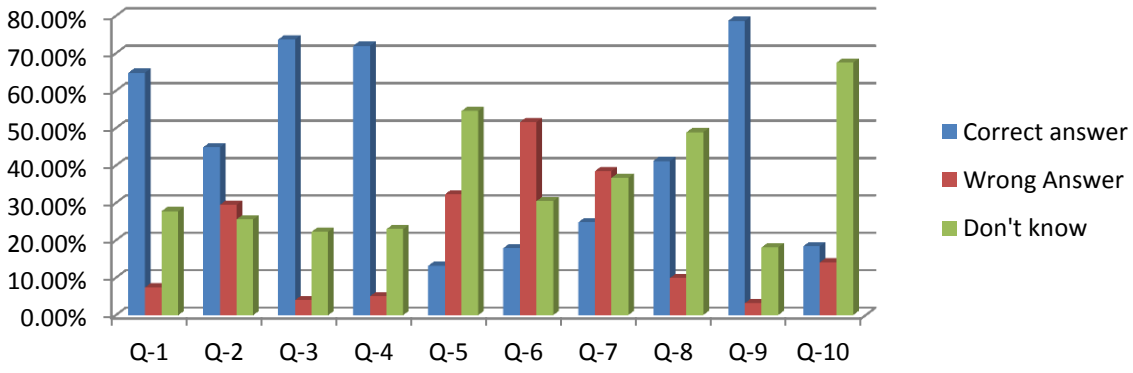
Table-5. *Knowledge of participants as per source of information to them*

DISCUSSION:

Our study basically aimed to know awareness about SCD amongst young adults between the age group of 18-30 years attending coaching classes in Amravati district. The idea behind this was by checking their knowledge about the disease and planning appropriately plan awareness activities we will help in reducing prevalence of the disease. Like other studies age group included in our study was 18-30 of age which is a reproductive age group and act as target group for preventive strategy of sickle cell anaemia in next generation [6,7]. Various western studies on assessing knowledge attitude and behaviour of youth on sickle cell anaemia (SCA) are available but in India very few studies are carried out but that too not in general population [8].While most of studies are concerned with students of higher secondary school, high school or college student enrolled in community health courses [1,9,10,11,12]. Like our study, most of studies showed poor knowledge about SCA, mainly on treatment and preventive part of disease. Our study included more males than females like study done by Vasava et al in tribal adolescents while in other studies females outnumbered males [11,13,14,15]. Similar to our study, study by Arrayed et al in Bahrain had majority of the participants educated up to graduate and higher secondary but none were from health profession or medical student like in studies done at Lagos by Animasahun [14,16]. Majority of participants knew that sickle cell is the disease related to red blood corpuscles and it is not due to curse of god or eating cows meat but less than 30% aware about clinical features of sickle cell disease (SCD) which was much less than other studies at Bahrain and African-American women where SCA control programme and education campaigns were already running [13,14] but approximately similar to Dyson et al study in screened population from African- Caribbean Descent[7]. Majority of participants in our study knew that if proper treatment and precautions are taken Sickle cell disease patient can live longer life but most of them also believed that giving blood transfusion is only treatment modality for SCD and only very few of them knew that it could be completely curable with bone marrow transplantation. While study in Bahrain by Arrayed et al showed that 10.1% participants consider it as completely curable disease while 53.2% thought blood transfusion as main treatment modality[14] .–Study by Boyd et al 86% of women also thought that there is no cure for sickle cell disease [6]. In our study, only 44.9% knew that sickle cell anaemia is inherited genetic disease which is comparable with study among high school students in Jamaica and another study among adolescents in India where 49% and 46.2% respectively knew this, while study from Bahrain among 200 general public where educational campaigns about awareness of Sickle cell

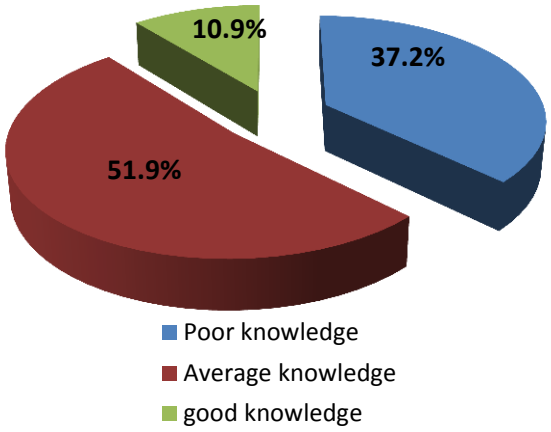
Sociodemographic characteristics	Basic knowledge		Treatment knowledge		Preventive knowledge	
Age in years						
18-22	83	109	153	39	138	54
23-26	52	78	92	38	91	39
27-30	38	43	60	21	61	20
	$\chi2=0.987,p=0.06$		$\chi2=3.492,p=0.17$		$\chi2=0.698,p=0.705$	
Sex						
Males	123	162	213	72	211	74
Females	50	68	92	26	79	39
	$\chi2=0.784,p=0.67$		$\chi2=0.821,p=0.66$		$\chi2=2.41,p=0.299$	
Residence						
Urban	122	169	220	71	209	82
Rural	51	61	85	27	81	31
	$\chi2=0.43,p=0.51$		$\chi2=0.004,p=0.95$		$\chi2=0.01,p=0.920$	
Education						
SSC	5	1	5	1	5	1
Higher secondary	53	59	86	26	83	29
Graduate	111	148	197	62	183	76
Postgraduate	4	22	17	9	19	7
	$\chi2=13.03,p=0.01$		$\chi2=4.19,p=0.38$		$\chi2=1.248,p=0.870$	
Occupation						
Student	130	177	239	68	218	89
Worker	9	11	17	3	15	5
Farmer	9	8	12	5	13	4
Businessman	5	3	5	3	6	2
Housewife	6	12	14	4	13	5
Service	11	18	15	14	21	8
Private job	3	1	3	1	4	0
	$\chi2=4.67,p=0.58$		$\chi2=11.81,p=0.06$		$\chi2=1.99,p=0.920$	

Table-6. *Association of knowledge about SCD with sociodemographic factors*

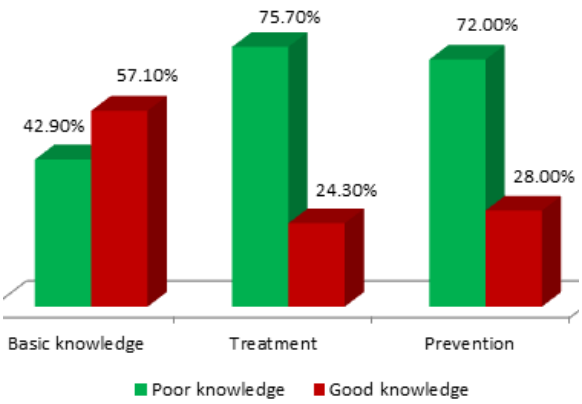


Graph-1. *Distribution of participants according to answers given by them*

disease are going on,84% knew this[10,13,15]. In our study very few (41.2%) participants had knowledge about how the SCD is transmitted in the family which is similar to the study by Dyson while other studies by Arrayed and Durotoye showed 56% and 58.5% participants knew this respectively [7,14,17]. Similar to our study, low level of awareness about the communities affected by SCA and about sickle cell status of the family member was found in other study [14]. Indianstudy by Desai et al showed that only 26%



Graph-2. *Knowledge score as per number of correct answers given by the participants*



Graph-3. *Knowledge of participants as per different categories.*

people were aware about the Sickle cell anaemia and it is autosomal and 25% knew how it is transmitted and were aware about its contingency and basic treatment[15]. While similar study in tribal student by Desai et al showed 40% of students were aware about the Sickle cell anaemia and know it is autosomal disease and 32.5% know how it is occurs and its symptoms and complications[9].When asked about the source of information about sickle cell anaemia, 44.2% participants got information from doctor, and 12.7% from television, radio & newspaper while friends and relative accounted for 5.2% participants only. Similar to our study, in Nigerian study by Olankunle showed Common source of information included health professionals 36.5% [1]. In study at Bahrain by Arrayed et al 51% participants thought that television is best way to increase awareness which has the potential to be the most effective media to educate the public about SCD rather than relying solely on community seminars and information pamphlets. [14]. In study by Dyson et al when asked about the media they would prefer for getting information on sickle cell disease, 65.5% chosen Leaflet, 38.2% chosen counselling, 32.7% chosen videos and posters while 27.3% chosen poster and talk from health worker as mode of information[7]. In study by Boyd et al 36% of participants identified pamphlets and educational meeting followed by television (31%) and radio(28%) as the most effective ways of education [6]. Our study shows majority i.e.89.1% students had poor or average knowledge about sickle cell disease. Though good basic knowledge i.e. clinical features of SCD observed in 57.1% it is only 24.3% for preventive and 28% for treatment category. This indicates the need for health workers and government system to create more education among target age group. Television, radio and news paper are important Medias to create awareness which are presently not used very effectively by government in creating awareness.

Conclusion:

Majority students had poor or average knowledge about sickle cell disease. This indicates the need for health workers and government system to focus more on preventive aspects of SCA among target age group. Television, radio and news paper are important Medias to create awareness which are presently not used very effectively by government in creating awareness.

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