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KNOWLEDGE GAPS, ATTITUDE AND BELIEFS OF THE COMMUNITIES ABOUT SICKLE CELL DISEASE IN EASTERN AND WESTERN UGANDA

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ABSTRACT

Background: The management of sickle cell disease (SCD) has remained insurmountable in developing countries such as Uganda, because most communities are not aware of it.

Objective: To determine knowledge gaps, attitudes and beliefs of the communities about sickle cell disease in Eastern and Western Uganda.

Design: Cross sectional descriptive study.

Setting: The districts of Sironko and Mbale in Eastern Uganda and Mbarara and Ntungamo in Western Uganda.

Subjects: Households, students and health workers.

Results: Household respondents from Eastern Uganda were more aware of SCD than those from Western ($p < 0.001$), with the majority reporting that they had seen more people with SCD in their communities than those from the West ($p < 0.001$). Fewer ($< 1.9\%$) believed SCD was due to witch craft. Eight per cent of household respondents in Eastern believed it was a curse from God compared to 2% in the West. Less than 18% of the household respondents knew they could have children with SCD and ($< 52\%$) of health workers knew SCD screening methods. Fewer ($< 14\%$) of the health workers had participated in screening. Less than 20% of the respondents knew their sickle cell status.

Conclusion: Respondents from Eastern Uganda were more aware of SCD than those from Western. Minority of the respondents knew their SCD status and few health staff knew how to screen it. There is need to sensitise communities and policy makers about prevention, screening and treatment of SCD.

INTRODUCTION

Beliefs, attitude and knowledge of the communities have contributed to the reduction and management of SCD. One study from USA found that improved understanding of SCD and constant assessment of parental beliefs about the disease was necessary for its management at home (1). Other studies found that communities where parents were more enlightened about SCD were more positive towards sickle cell screening (2). However, lack of screening programmes especially in areas with low prevalence of SCD, was associated with

negative attitude of the communities towards screening (3).

According to the available literature on SCD in Uganda, no population based studies have been carried out to determine knowledge gaps, attitude and beliefs of communities and health workers about SCD and its detection.

This study was therefore done to determine the knowledge gaps, attitude and beliefs of the communities about SCD and its detection in Eastern and Western Uganda. The findings would be used by decision makers for policy formulation of sickle cell management programmes.

MATERIALS AND METHODS

Study design and site: This was a cross sectional descriptive study which was carried out in Sironko and Mbale in Eastern and Mbarara and Ntungamo in Western Uganda. These districts were conveniently selected because these were districts which were involved in collaboration with innovations at Makerere University Committee (I@Mak.com), the founder of this project.

Study populations: These were households and secondary school students from both rural and urban setting and health professionals from health centres IV with paramedical training. These health professionals were chosen to avoid bias.

Sample size: The sample size of 571 household respondents was calculated using Kish and Leshlie formula (4). An acceptable error of 0.05 and 95% confidence interval were used. The number of villages in each district was calculated using probability proportions based on population size of the districts. Secondary schools and health sub-districts (health centers IVs) were selected using simple random sampling procedure.

Study procedure: Adults from households with children, were selected for interviews using a procedure according to World Health Organisation protocols. The data were collected using a structured questionnaire from interviewees after obtaining informed consent.

Students: The same procedure used to select secondary schools was used to select student participants from these schools. Twelve male and female students were randomly selected from each school and data were collected from them using a questionnaire.

Health workers: The paramedical health staff to be interviewed were not randomly selected because some health centres had as few as six eligible staff. Instead, all eligible staff at the health centre were

personally interviewed after obtaining informed consent.

Data analysis: The data were entered and analysed using software package for social sciences 10.0 (SPSS 10.0) (6). The statistical difference of the knowledge gaps, attitude and beliefs in these study populations was compared using open source epidemiologic statistic programme for public health version 2.2.1 (OPENEPI) using 2x2 contingency tables (7). A p-value of ≤ 0.05 was considered statistically significant.

Ethical clearance: Permission to carry out this study was sought from Faculty Research and Ethical Committee and Uganda National Council of Science and Technology (UNCST).

RESULTS

Two hundred and eighty rural and urban household respondents were interviewed from the study population of Mbale and Sironko in Eastern Uganda and 309 from the study population of Mbarara and Ntungamo in the West giving a total of 589 household respondents, which was a little (1.03%) more than the minimum calculated sample size of 571. Eighty eight students were interviewed from eastern and 85 from western giving a total of 173 students. Thirty four health workers respondents were interviewed in Eastern Uganda and 42 in Western giving a total of 76 health workers. These gave an overall total of 838 respondents (Table 1). A total of 214 female and 188 male respondents were interviewed in Eastern Uganda, whilst two hundred and twenty nine female and 207 male respondents were interviewed from the West. This gave an overall total of 838 respondents interviewed from both study populations (Table 3).

The recruited female and male participants, were aged between 18-60 years and were from urban and rural settings. The majority were peasants and students with primary and secondary education. The details of the socio-demographic characteristics of the respondents are as shown in Table 2.

Table 1
Number of respondents interviewed in Eastern and Western Uganda

	Mbale and Sironko (Eastern region)	Mbarara and Ntungamo (Western region)	Total
Household respondents	280	309	589
Student respondents	88	85	173
Health workers respondents	34	42	76
Total	403	436	838

Table 2
The socio-demographic characteristics of all the respondents

Variable		Eastern (n=402)		Western (n=436)	
Age: (18-60 years)		No.	(%)	No.	(%)
Sex	Male	188	46.8	207	47.5
	Female	214	53.2	229	52.5
Education	Informal	22	5.5	24	5.5
	Primary	129	51.9	155	35.6
	Secondary	192	47.8	157	36.0
	Tertiary	51	12.7	68	15.6
	University	8	2.0	32	7.4
Occupation	Employed	82	20.4	120	27.6
	Student	121	30.1	118	27.5
	Peasant	141	35.1	99	22.7
	Self employed	58	14.4	209	47.9
Religion	Catholic	85	21.1	174	39.9
	Protestant	142	35.3	188	43.1
	Muslim	111	27.6	18	4.1
	Orthodox	4	1.0	7	1.6
	Reedemed	10	2.5	16	3.7
Location	Rural	215	53.5	237	54.4
	Urban	187	46.5	199	45.6
Distance to health centre	<3 km	115	28.6	99	22.7
	3-10 km	138	34.3	103	23.6
	> 10 km	81	20.1	50	11.5
	Uncommitted	68	16.9	184	42.2

Knowledge gaps: Seventy three per cent of the household respondents from Eastern Uganda were aware of SCD compared to 59% from the West ($p < 0.001$) (OR 1.85: 95% CI: 1.31-2.62). Forty nine percent of household respondents from the East claimed that persons with SCD had been detected in their communities compared to only 20% from the West ($p < 0.001$) (OR 3.93: 95% CI: 2.49-6.20). Forty five per cent of the students from the East claimed that persons with SCD disease had been detected in their communities compared to 18% from the West ($p < 0.001$) (OR 3.94: 95% CI: 1.73-8.98). Fifty two percent of the health workers from the East knew sickle cell disease screening methods compared to

50 % from the West ($p > 0.05$) (OR 1.07: 95% CI: 0.39-2.93). Notably, 14% of the health staff from the East screened for SCD compared to 9% from the West. Less than 20% of the respondents knew their sickle cell status (Table 3).

Beliefs: Eight per cent of the household respondents in Sironko and Mbale believed that SCD was a punishment from God compared to 2% from Mbarara and Ntungamo. Seventy eight per cent of the household respondents from the East believed SCD could be prevented by premarital screening compared to 74% from the west ($p > 0.05$) (OR 1.2: 95% CI: 0.77- 1.94) (Table 4).

Table 3
Knowledge of respondents about SCD in Eastern and Western Uganda

	Eastern		Western		Odds	95% CI	P-value
	No.	(%)	No.	(%)	Ratio		
Households (non- students)	n=280 100		n=309 100				
Awareness about sickle cell disease (SCD)	204	72.9	183	59	1.85	1.31-2.62	<0.001
Only for those aware (n=204)							
Seen persons with SCD in community	100	49.0	36	19.7	3.93	2.46-6.20	<0.001
Knew they could possibly have children with SCD	30	14.7	32	17.4	1.04	1.61-1.76	0.887
Knows his/her SC status	5	2.5	2	1.1	2.78	0.55-20.9	0.234
Students	n =88 92		n =85 89				
Awareness about sickle cell disease (SCD)	62	70.5	50	58.8	1.67	0.89-3.13	0.114
Only those aware (n=62)							
Seen persons with SCD in his/her community	28	45.2	9	18	3.94	1.73-8.98	<0.001
Knows his/her SC status	1	1.6	0	0	-	-	0.052
Health workers	n=34 71		n=42 88				
Awareness about sickle cell disease (SCD)	29	85.3	32	76.2	1.81	0.55-5.93	0.342
Knows can be managed if diagnosed early	27	79.4	33	78.6	1.05	0.35-3.20	0.936
Only for those aware (n=29)							
Correctly know screening method (s)	15	51.7	16	50	1.07	0.39-2.93	0.896
Screen for sickle cell disease	4	13.8	3	9.4	1.55	0.32-7.58	0.617
Knows his/her SC status	4	13.8	2	6.3	2.4	0.41-14.21	0.366
Came across SCD patients	20	69.0	10	31.3	4.57	1.71-12.24	0.002

Table 4
Beliefs of respondents about SCD in Eastern and Western Uganda

	Eastern		Western		Odds	95% CI	P-value
	No.	(%)	No.	(%)	Ratio		
Households (only for those aware of SCD)	n=204		n=183				
Causes of SCD							
Natural	59	28.9	72	39.3	0.88	0.60-1.30	0.518
Punishment from God	17	8.3	4	2.1	4.92	1.73-17.22	0.002
Witchcraft	4	1.9	3	1.6	1.48	0.30-8.0	0.63
Acquired from parents	117	57.3	94	51.3	1.64	1.17-2.30	0.004
Can be prevented by screening before marriage	158	77.5	135	73.8	1.2	0.77-1.94	0.403

Continuation of Table 4

Students (only for those aware of SCD)	n=62		n=50				
Natural	22	35.5	15	30	1.56	0.74-3.25	0.246
Punishment from God	0	0	0		0	0	
Witchcraft	0	0	0		0	0	
Acquired from parents	36	58.1	30	60	1.27	0.69- 2.35	0.452
Can be prevented by screening before marriage	47	75.8	41	82.0	0.63	0.30-1.34	0.324
Health workers (only for those aware of SCD)	n=29		n=32				
Natural							
Punishment from God	5	17.2	3	9.3	2.21	0.47-12.07	0.318
Witchcraft	0	0	0	0	0	-	-
Acquired from parents	0	0	0	0	0	-	-
Can be prevented by screening before marriage	26	89.7	30	93.8	1.30	0.46-3.67	0.634
	25	86.2	26	81.3	1.40	0.22-9.01	0.298

Attitudes: Fifty eight per cent of the respondents from the East felt sympathetic about patients' illness compared to 67% from the West. Eleven per cent and 3% of the respondents from the East and the West felt embarrassed respectively ($p < 0.001$) (OR 4.5; 95% CI: 1.65-12.27). Thirty eight per cent felt depressed about

patients' illness from the East compared to 22% from the West ($p < 0.001$) (OR 2.25; 95% CI: 1.42-3.57). Over 85% of the respondents were willing to be screened for SCD, although 8% of the respondents from the East were not willing to be screened compared to 12% from the West (Table 5).

Table 5
Attitude of respondents about SCD in Eastern and Western Uganda

	East		West		Odds Ratio	95% CI	P-value
	No.	(%)	No.	(%)			
Attitude of household respondents to patients	n=180*		n=185*				
Sympathetic	105	58.3	124	67.0	0.69	0.45-1.05	0.088
Depressed	69	38.3	40	21.6	2.25	1.42-3.57	<0.001
Angry	20	11.1	7	3.8	3.18	1.31-7.72	0.008
Embarrassed	20	11.1	5	2.7	4.50	1.65-2.27	0.001
Not affected	2	1.1	4	2.1	0.51	0.09-2.81	0.469
Attitude towards SC screening	n=280		n=309				
Willing to be screened	257	91.8	270	87.4	1.61	0.94-2.78	0.083
Not willing	23	8.2	36	11.7	0.68	0.39-1.18	0.169
Attitude of the students to patients	n =59*		n=51*				
Sympathetic	29	49.2	26	51.0	0.93	0.44-1.97	0.851
Depressed	13	22.0	18	35.3	0.52	0.22-1.20	0.132
Angry	8	13.6	1	2.0	7.73	1.18-176.6	0.030
Embarrassed	9	15.3	1	2.0	8.86	1.38-202.6	0.016
Not affected	1	1.7	3	5.9	0.28	0.01-2.70	0.299
Attitude towards SC screening	n=88		n=85				
Willing to be screened	75	83.2	73	85.9	0.95	0.41-2.22	0.906
Not willing	13	14.8	18	21.1	0.65	0.29-1.42	0.282

* Only respondents who reported to have had an ill person

Sources of information about health: The main sources of information of the household respondents about health, in descending order, were radio, health visitors, community, newspapers and lastly television, whilst for the student respondents they were health visitors, radio, television and community (Table 6).

Table 6

The main sources of information of the household and student respondents about health in Eastern and Western Uganda

Variable	East		West		Odds Ratio	95% CI	P-value
	No.	(%)	No.	(%)			
Households	n=280		n=309				
Health visitors	125	44.6	188	60.8	0.52	0.37-0.72	0.001
Radio	174	62.1	202	65.4	0.87	0.62-1.22	0.313
TV	41	14.6	45	14.6	0.61	0.40-0.93	0.016
Newspapers	47	16.8	68	22.0	1.25	0.82-1.92	0.305
Community	96	34.3	101	32.7	1.07	0.76-1.51	0.511
Students	n=88		n=85				
Health visitors	53	60.2	39	45.9	1.77	0.98-3.27	0.046
Radio	38	43.2	35	41.2	1.09	0.54-1.99	0.594
TV	17	19.3	27	31.8	0.51	0.26-1.97	0.048
Newspapers	20	22.7	16	18.8	1.27	0.61-2.65	0.401
Community	17	19.3	4	4.7	4.81	1.56-15.08	0.001

The main sources of information of the rural household respondents about health were mostly health visitors and radio whilst the urban respondents were more privileged to watch television and read news papers besides getting information from health visitors and community (Table 7).

Table 7

The main sources of information of the rural and urban household respondents about health in Eastern and Western Uganda

Variable	Rural		Urban		Odds Ratio	95% CI	P-value
	No.	(%)	No.	(%)			
Eastern	n=140		n=140				
Health visitors	75	53.6	50	35.7	2.08	1.29-3.37	0.001
Radio	75	53.6	99	70.7	0.48	0.29-0.78	0.001
TV	12	8.6	29	20.7	0.40	0.17-0.73	0.002
Newspapers	17	12.1	30	21.4	0.51	0.27-0.97	0.002
Community	18	12.9	58	41.4	0.21	0.11-0.39	0.001
Western	n=150		n=159				
Health visitors	97	64.7	91	57.2	1.37	0.86-2.16	0.09
Radio	120	80.0	82	51.6	3.75	2.26-6.24	0.001
TV	10	6.7	42	31.8	0.06	0.02-0.19	0.001
News papers	17	11.3	51	26.4	0.27	0.15-0.50	0.401
Community	41	27.3	60	37.7	0.62	0.38-1.0	0.03

DISCUSSION

The study sought to determine the knowledge gaps, attitude and beliefs about SCD from the communities in Mbale and Sironko in Eastern and Mbarara and Ntungamo in Western Uganda. Whereas there was increased awareness about SCD among household communities in the Eastern region compared to those in the West, as expected, these findings could have been influenced by differences in the prevalence of SCD in these study populations (8, 9). These results were similar to those by Armeli *et al* (10) who noted that people from areas of high prevalence of SCD were more likely to be more aware about it than those from areas of low prevalence.

However, there was no statistical difference between the student respondents from Eastern and Western Uganda as far as awareness of SCD was concerned. This finding probably indicated that the awareness of SCD between the students respondents in these regions were more sensitive to education background than the prevalence of SCD.

Similarly, the awareness about SCD in Western region appeared to have been influenced by both the location and education background of the household respondents other than prevalence. This was particularly noted among the urban household respondents whose awareness about SCD was high probably because they had secondary, tertiary and university education, watched televisions and read news papers unlike their rural counter parts who mostly had primary education and whose main sources of information about health were health visitors and radio.

While the majority of the respondents new sickle cell as '*siko cello*', which we believe was coined from English word sickle cell, few respondents had varying understanding of what sickle cell was with those from Eastern Uganda calling it '*Enkaka*' meaning yellow fever and Western Uganda communities calling it '*Okupumpura* (plague like), *Binyoro* (yaws) and *Kisipi* (herpes zoster). This observation probably explains why sickle cell still remains enigmatic among members in the communities.

The beliefs about SCD remain diverse in many communities as was seen in this study. While the majority believed SCD was acquired from parents, a few believed that it was "a curse from God", and was due to witchcraft. These observations are in agreement with the study by Ohaeri and Shokundi (11) which found that while the majority of the respondents believed that SCD was natural/genetic, a few believed it was "curse from God" and witchcraft. These findings are also similar to the study by Treadwell and Mc Clough (12) which noted that most of the respondents correctly believed that SCD was inherited from parents, although a few believed that it was acquired through blood transfusion and was contagious.

Whilst a few studies found positive attitude towards sickle cell screening to be linked to improved management of SCD, the findings of the current study indicated that although the majority of the respondents had high attitude towards sickle cell screening many did not know their sickle cell status. Besides, most of the health staff lacked skills on sickle cell screening methods, which probably explains why most of the district health centres were not screening for SCD and why most of these respondents had not been screened for SCD (3) and therefore did not know their sickle cell status.

Limitation of the study: Since the selection of the study districts was done using convenient sampling, the rest of the districts in Eastern and Western Uganda were not given an equal chance to be represented. So the current results cannot be generalised as representative of the whole Eastern or Western Uganda.

Conclusion and recommendations: Respondents from Eastern were more aware about SCD than those from Western Uganda. Some believed it was a 'curse from God' or that it was due to witchcraft. Most of the health centres were not screening for SCD and the majority of the respondents were not aware of their sickle cell status. There is therefore need to sensitise communities and policy makers about prevention, screening and management of SCD.

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