BMC Public Health

RESEARCH

Open Access

Determinants of knowledge, attitudes, and practice towards sickle cell disease in Alebtong district, Lango region, Northern Uganda

Agaba Peninah[1*], Nankinga Olivia[1], Candia Douglas Andabati[2], Musiimenta Euniky[3] and Nagawa Tracy[3]

Abstract

Background Sickle cell disease (SCD) is a debilitating hereditary medical condition associated with pain, stigma, morbidity, and early death. To reduce the prevalence and improve the quality of life of persons with SCD, improved knowledge, practices and reduced stigma are key for Uganda since improved medical breakthroughs in SCD diagnosis, care, and management are expensive in Uganda. However, there is limited research on knowledge, attitudes, and practice (KAP) towards SCD, therefore this study presents the levels and determinants of SCD KAP in Alebtong district, Lango region in Northern Uganda.

Methods Data was obtained from 500 respondents aged 18 years and above in three sub-counties in Alebtong district. Multinomial logistic regression was used to identify key determinants of one's knowledge and attitudes toward SCD. Binary logistic regression model was used to find the key determinants of SCD practices in Alebtong district.

Results More than half of the respondents had good knowledge of SCD (60.8%) and good attitudes (87.0%). However, a very small percentage had ever tested for SCD (4.4%). The highest proportion of the respondents had a fair knowledge of SCD (49.6%) and good attitudes (82%). However, a very small percentage had ever tested for SCD (4.4%). Factors significantly associated with knowledge of SCD were residence, the commonest health information channel, and listening to the radio. Urban residents and those who mostly received their health information from community announcers were less likely to have a fair knowledge of SCD. Still, urban residents, those who mostly received their health information from community announcers, and those who never listened to the radio at all were less likely to have good knowledge of SCD. Respondents who listened to the radio less than once a week and those who never listened to the radio at all were less likely to have good attitudes toward persons with SCD. Respondents who completed primary education were more likely to test for SCD (aOR = 8.2, $p = 0.05$, 95%CI = 1.01–66.4).

Conclusion Respondents had relatively high levels of good knowledge and attitudes towards SCD, but few had tested for SCD. This was significantly associated with access to information either through school, radio, or health

*Correspondence:
Agaba Peninah
agabapeninah@gmail.com; peninah.agaba@mak.ac.ug

Full list of author information is available at the end of the article

providers. Communities, researchers, healthcare programmers, and policymakers should prioritize health information availability through different media to increase knowledge, attitudes, and practice toward SCD.

Keywords Sickle cell disease, Knowledge, Attitudes, Practice, Testing, Uganda

Background

Sickle cell disease (SCD) is a pleiotropic inherited disorder of the blood, characterized by the appearance of sickle-shaped red blood cells and anemia. It results from homozygosity for the sickle beta-globin gene mutation at position 6 (glu > val), or compound heterozygosity for the sickle gene and either another mutation for a different hemoglobin variant or one of numerous beta-thalassemia mutations (SCD0-1000106). The chronic and debilitating medical condition is caused by a defect in red blood cells. It is one of the major genetic causes of mortality [1, 2]. Global statistics show that annually, over 300,000 babies are born with SCD and the number is estimated to increase over the years [3]. It is further reported that over 70% of individuals with SCD are in Africa [1, 4]. Sub-Saharan Africa is a region with the highest number of persons with SCD, and it contributes significantly to childhood mortality in this region [5, 6]. In Uganda, at least 20,000 babies are born with sickle cell trait annually [7], and this substantially increases the burden of the disease, especially among children.

Even though there have been medical and technological advances in the diagnosis and treatment of SCD which have led to improved survival and reduced mortality (improved life expectancy) among persons with SCD [7], these are still poor/lacking on the African continent [8–10]. SCA mortality has remained high with low life expectancy among SCD patients, estimated to be around 30 years in Africa [11, 12]. This is primarily due to the very low and wrong knowledge of SCD among practitioners and the general public [8], stigmatization from the general public, doctors, and family [10, 13], and poor management of SCD [9]. Currently, the only known cure for the blood disorder is a bone marrow transplant [14], however, this is costly for several Africans.

SCD is associated with morbidity and mortality and increases the socioeconomic burden and health burden at the micro and macro levels [15, 16]. Individuals with SCD have a higher risk of bacterial infections, which contribute to over half of deaths among SCD patients [2]. In children, SCD is linked to cerebrovascular disease and cognitive impairment [1], severe anemia, and multiple organ failure [17]. Key factors identified for the spread of SCD include: migration [12, 18], and poor knowledge [19]. The stigma towards SCD patients in Africa is partly due to; the negative attitudes towards individuals with SCD stemming from socio-cultural barriers [20, 21], delayed diagnosis [22], lack of access, and high cost of medical care [8, 22, 23] among other reasons. Socio-cultural barriers lead to poor knowledge about SCD which is associated with stigma and discrimination, worsened by the myths about the disease which have adverse effects on seeking care [13, 21].

The knowledge about SCD among patients and their caretakers is key in determining the level of care and the ability to prevent and manage painful episodes [24]. Knowledge determines the caregivers' understanding of the implications of having SCD. Knowledge further enables the caregivers to provide the appropriate physical and emotional support needed by persons with SCD [24]. Attitudes are important in determining the practices of the patients and their caretakers. Positive attitudes of health care providers, community members, and caregivers can enhance the ability of individuals to adhere to treatment and avoid the risk factors for transmission of SCD to future generations. On the other hand, negative attitudes may have negative implications for the patients, caretakers, and the community at large [25]. For example, care providers may not provide sufficient information to the caregivers, they may not respond appropriately to the changes in the health conditions of persons with SCD [13]. Additionally, the negative attitudes in the community may affect healthcare-seeking behavior [26].

Previous studies have shown low levels while some observed high levels of knowledge and attitudes of sickle cell disease. Low levels of knowledge of SCD were found in studies in Nigeria (17.8%) [27], (20.6%) [28], South Sudan (26.9%) [19], and Middle-East in Saudi Arabia (28.8%) [29], while high levels of good knowledge of SCD were found among studies by El Hazmi [30], Tusubira [21] and Millan & their colleagues [31]. However, studies with low levels of knowledge were conducted among community members while those with high levels of good knowledge were among persons attending a sickle cell-related activity. Past studies in Uganda [21] and South Sudan [19] found most participants with poor attitudes towards SCD. A study in Uganda found that only 19.6% of the participants had ever tested for SCD [21].

Past research has shown education, age [28, 29, 32] and sex of the respondent as key predictors of knowledge, attitudes, and practices related to SCD [28]. Persons with higher education levels were found to have better knowledge of SCD [32, 33] and good attitudes towards SCD [32]. Young persons aged 5–19 years were found to have poor knowledge and poor attitudes towards SCD [32].

Improving peoples' knowledge, attitudes, and practices when engaging with persons with SCD can help in enabling SCD patients to cope with the disease. This

can facilitate them to live a relatively comfortable life as opposed to when they have to deal with disease challenges as well as stigmatization from the communities in which they live [13, 34, 35]. Assessing knowledge, attitudes, and practices is vital for identifying key areas and sub-groups of focus for interventions aimed at improving the lives of people with SCD and preventing its transmission. This study therefore aims at assessing the relationship between SCD knowledge, attitudes, practices, and background characteristics of individuals in Alebtong district of Uganda.

Methods

Data source

A cross-sectional household knowledge, attitudes, and practice (KAP) study was conducted in February 2022 by experienced research assistants with a good command of the local language in Alebtong district, Lango sub-region in Northern Uganda. We conducted a three-day training for research assistants to ensure that they competently collect the data. A structured questionnaire was developed for this study (supplementary file 1). Data was collected using computer-assisted personal interviewing (CAPI) designed using open data kit (ODK) software to cut out data entry costs and ensure high-quality data. Upon completion of the data collection exercise, data was downloaded to the computer for further data management and analysis. The questionnaires were translated into Langi and most interviews were conducted in Langi due to the illiteracy level (72%) in the district [18] and for comprehension purposes. Langi questions were back-translated to English to ensure that the meaning of the questions was not lost. In addition, we pre-tested the questionnaires in a predominantly Langi-speaking suburb/ community in Kampala city. Cronbach's alpha coefficient of internal consistency was 0.7422. Based on George and Mallery's rule of thumb [36], an alpha value above 0.7 is acceptable. Therefore, all items in our tool were internally consistent and reliable to assess knowledge, attitudes, and practices toward SCD.

Sampling strategy and sample size

The study was carried out in three sub-counties, one urban (Alebtong Town Council) and two rural (Abia & Adwir) to get a full picture of the KAP of SCD in the district. Alebtong district was chosen because it has a high prevalence of SCT among infants [7]. The sub-counties in Alebtong district were stratified according to whether they were rural or urban. Alebtong district has only one sub-county that is designated as urban, and thus Alebtong Town Council was automatically selected. Using simple random sampling, two sub-counties (Abia sub-county & Adwir sub-county) were selected from the rural strata using the goldfish bowl method [37].

A total of 500 participants were selected and interviewed, a participant was interviewed from each selected household. We selected more respondents from the rural areas since the district is predominantly rural. Within the respective sub-counties, systematic sampling was used to identify the households to be included in the study. Using a random starting point, every third household was then chosen along a zig-zag transect [38].

The sample was computed using Cochran (1964) [39]. We assumed a 95% confidence level, $\widehat{p}$ of 0.5 since we had no available information on population estimates of the prevalence for the study outcome variables for households in Alebtong or Lango sub-region, an 8% margin of error, a design effect of 1, and an expected response rate of 95%. A random sample of 158 households was to be selected from each selected sub-county. This would result in a sample size of 474 households. An additional 26 questionnaires were added in case of invalid questionnaires which translated to the total sample size of 500 participants. One hundred and sixty-one respondents were from Alebtong Town Council, 178 resided in Abia Sub-county while 161 lived in Adwir sub-county.

Population of the study

Female and male adults aged at least 18 years, the minimum age of consent in Uganda were selected from households. Mentally fit adults who consented to the interview were included. Mentally disturbed adults and children below 18 years were not included in the study. The household head was interviewed if present in the home. In instances where the household head wasn't available, the most knowledgeable adult in the home was interviewed.

Key variables

Information on socio-demographic characteristics like age, sex, marital status, education level, income, occupation and household characteristics, and access to media were collected. Data about the knowledge, attitude, and practices of the respondents regarding SCD were also collected.

Questions under the knowledge section focused on respondents' knowledge of the signs and symptoms of SCD, how a person gets SCD, how SCD is tested, the possibilities of having children with the sickle cell trait given the parent's SCD status, and medication for persons with SCD. In total, there were 15 knowledge questions with total responses converted to a scale out of 5, and respondents scored on a scale of 0–5 (Poor knowledge, 0–1 points; Fair knowledge, 2–3 points, Good knowledge, 4–5 points). For the practice section, the emphasis was on testing for SCD which was either tested or never tested for SCD. As for the attitude section, the focus was on how one felt about people with SCD, whether one

would be worried caring for a person with SCD, whether people with SCD should socialize or play, go to school, marry, have children, or work, whether one would be ashamed if someone in his/her family has SCD and if divorcing/separating with a partner with SCD is justified. In total, there were 10 attitude questions and respondents were scored on a scale of 0–10 (Poor attitude, 0–3 points; Fair attitude 4–6, Good attitude, 7–10 points). Respondents who reported that they had tested were considered to have good practices while those who had never tested were considered to have poor practices.

Statistical data analysis

Data analysis was conducted using STATA statistical software version 15. A descriptive summary of the study participants' characteristics was done using frequencies and percentages. Pearson's chi-square test was used to examine the relationship between the three dependent variables i.e. respondent's knowledge, attitude, and practice, and the plausible independent variables. Independent variables found to be significantly associated ($p \leq 0.05$) with each of the dependent variables were considered for further analysis. Multinomial logistic regression was used to identify key determinants of one's knowledge and attitudes toward SCD. In contrast, the binary logistic regression model was used to identify the key determinants of SCD practices in Alebtong district. Knowledge and attitude outcomes had three categories (Poor, Fair, and Good) while practice had two outcomes (poor and Good).

The goodness of fit using likelihood chi-square for the overall models was significant at $p = 0.000$, $p = 0.0158$ & $p = 0.0022$ for knowledge, attitude, and practice of sickle cell disease respectively.

Results

Background characteristics of respondents

Three-quarters of the participants were female (65%), most were aged 25–34 years (27%), resided in rural areas (64%), had incomplete primary level of education (42%), were peasant farmers (88%), identified as Catholics (43%), and most were married (80%). Most participants listened to the radio at least once a week (77%) while most did not read the newspaper (91%) or watch television (85%) (Table 1- Appendix 1).

Levels of knowledge, attitudes, and practice towards SCD in Alebtong district, Northern Uganda

Table 2 shows that a total of 500 participants were interviewed. Regarding knowledge of SCD, the highest proportion of the respondents had fair knowledge (49.6%) followed by good (32.2%), and lastly poor (18.2%). As for attitudes towards persons with SCD, the majority of the respondents had good attitudes (82%), followed by fair attitudes (12.4%), and lastly poor attitudes (5.6%). With practice, only 4.4% (22) had good practices for SCD.

Knowledge of sickle cell disease

Based on the cross-tabulation results in Table 1 above, knowledge of SCD was significantly ($p \leq 0.05$) associated with sex, place of residence, the commonest health information channel, listening to the radio, and watching television. More females (35.1%) than males (26.9%) had a good knowledge of SCD. Rural respondents (34.4%) had a higher proportion with good knowledge of SCD compared to urban residents (28.3%). Good knowledge of SCD was also highest among respondents whose commonest health information channel was health providers (58.7%), who listened to the radio almost every day (42.7%) and watched television less than once a week (53.5%).

Based on the cross-tabulation results in the Table below, respondents' attitudes towards persons with SCD were significantly associated with the commonest health information channel ($p = 0.049$), and listening to the radio ($p = 0.022$). The majority of respondents whose commonest health information channel was the internet or telephone (87.5%), radio (84.1%), community announcers (84.1%), and health providers (84%) had good attitudes towards persons with SCD. Respondents who listened to the radio at least once a week (85.6%) and almost every day (85.3%) had the highest proportions with good attitudes towards persons with SCD.

Still from Table 1, differences in SCD practice/ testing were observed by education level ($p = 0.005$) and occupation ($p = 0.005$). SCD testing was high among respondents with complete primary education (9.2%) compared to those who had no education (1.0%). Respondents who were employed in sectors other than farming (11%) had tested for SCD more than those who were peasant farmers (3.4%).

Determinants of knowledge, attitudes, and practices of SCD in Alebtong district, Northern Uganda

Knowledge of sickle cell disease in Alebtong district, Northern Uganda

Table 3- The multinomial logistic regression results show that for respondents in urban areas relative to those in rural areas, the relative risk of having fair knowledge of SCD compared to poor knowledge decreased by a factor of 0.53 ($p = 0.02$, 95%CI = 0.31–0.90). Respondents who mostly received their health information from community announcers relative to the radio had a lower relative risk of having fair knowledge of SCD compared to poor knowledge (RRR = 0.51, $p = 0.04$, 95% CI = 0.26–0.98). Still, for respondents in urban areas relative to those in rural areas, the relative risk of having good knowledge of SCD compared to poor knowledge decreased by a factor

Table 1 Distribution of respondents by background factors and knowledge, attitudes, and practice of sickle cell disease

Variables	Frequency	Percent	Knowledge		Attitudes			Practice		
			Poor	Fair	Good	Poor	Fair	Good	Poor	Good
Age			*P* = 0.601			*P* = 0.487			*P* = 0.202	
18–24	106	21.2	24.5	48.1	27.4	9.4	10.4	80.2	93.4	6.6
25–34	135	27	17	49.6	33.3	3	13.3	83.7	94.1	5.9
35–49	131	26.2	14.5	51.2	34.4	5.3	11.5	83.2	98.5	1.5
50+	128	25.6	18	49.2	32.8	5.5	14.1	80.5	96.1	3.9
Sex			*P* = 0.010*			*P* = 0.447			*P* = 0.437	
Male	175	35	14.3	58.9	26.9	4	13.7	82.3	96.6	3.4
Female	325	65	20.3	44.6	35.1	6.5	11.7	81.9	95.1	4.9
Place of Residence			*P* = 0.003*			*P* = 0.264			*P* = 0.345	
Rural	320	64	13.8	51.9	34.4	5.9	10.6	83.4	96.3	3.8
Urban	180	36	26.1	45.6	28.3	5	15.6	79.4	94.4	5.6
Highest Education Level			*P* = 0.175			*P* = 0.081			*P* = 0.005*	
None	102	20.4	26.5	41.2	32.4	9.8	13.7	76.5	99	1
Incomplete primary	208	41.6	16.8	50	33.2	5.8	14.4	79.8	97.6	2.4
Complete primary	130	26	17.7	53.1	29.2	3.9	6.9	89.2	90.8	9.2
Secondary+	60	12	10	55	35	1.7	15	83.3	93.3	6.7
Religion			*P* = 0.082			*P* = 0.998			*P* = 0.302	
Catholic	216	43.2	22.7	50	27.3	5.6	12	82.4	97.2	2.8
Protestant/Anglican	210	42	13.8	48.6	37.6	5.7	12.4	81.9	94.3	5.7
Others	74	14.8	17.6	51.4	31.1	5.4	13.5	81.1	94.6	5.4
Occupation			*P* = 0.311			*P* = 0.053			*P* = 0.005*	
Peasant farmer	438	87.6	19	48.4	32.7	6.4	13	80.6	96.6	3.4
Others	62	12.4	12.9	58.1	29	0	8.1	91.9	88.7	11.3
Marital status			*P* = 0.335			*P* = 0.071			*P* = 0.909	
Single	34	6.82	17.7	50	32.4	8.8	14.7	76.5	97.1	2.9
Married	402	80.4	18.7	51	30.4	4.2	11.9	83.8	95.5	4.5
Formerly married	64	12.8	15.6	40.6	43.8	12.5	14.1	73.4	95.3	4.7
Commonest health information channel			***P = < 0.000****			*P* = 0.049*			*P* = 0.450	
Radio	201	40.2	17.4	56.7	25.9	4.5	11.4	84.1	96	4
Community announcer	88	17.6	31.8	54.6	13.6	4.6	11.4	84.1	95.5	4.6
Television	3	0.6	0	100	0	0	0	100	100	0
Internet/Telephone	8	1.6	12.5	87.5	0	0	12.5	87.5	100	0
Health providers	150	30	10.7	30.7	58.7	4.7	11.3	84	93.3	6.7
Other	50	10	22	60	18	16	22	62	100	0
Reading newspaper/magazines			*P* = 0.132			*P* = 0.423			*P* = 0.228	
Almost every day	4	0.8	0	75	25	0	25	75	100	0
At least once a week	26	5.2	7.7	61.5	30.8	0	23.1	76.9	92.3	7.7
Less than once a week	14	2.8	0	78.6	21.4	0	14.3	85.7	85.7	14.3
Not at all	456	91.2	19.5	47.8	32.7	6.1	11.6	82.2	96.1	4
Listening to radio			***P = < 0.000****			*P* = 0.022*			*P* = 0.933	
Almost every day	204	40.8	16.2	41.2	42.7	3.4	11.3	85.3	95.1	4.9
At least once a week	132	26.4	15.9	63.6	20.5	2.3	12.1	85.6	95.5	4.6
Less than once a week	45	9	13.3	44.4	42.2	11.1	13.3	75.6	95.6	4.4
Not at all	119	23.8	26.1	50.4	23.5	10.9	14.3	74.8	96.6	3.4
Watching television			***P* = 0.048***			*P* = 0.301			*P* = 0.793	
Almost every day	7	1.4	14.3	71.4	14.3	0	0	100	100	0
At least once a week	23	4.6	8.7	56.5	34.8	13	8.7	78.3	95.7	4.4
Less than once a week	43	8.6	11.6	34.9	53.5	4.7	4.7	90.7	93	7
Not at all	427	85.4	19.4	50.4	30.2	5.4	13.6	81	95.8	4.2

Table 2 Levels of knowledge, attitudes, and practice in Alebtong district, Northern Uganda

	Frequency	Percentage
Knowledge of SCD		
Poor	91	18.2
Fair	248	49.6
Good	161	32.2
Attitude towards SCD		
Poor	28	5.6
Fair	62	12.4
Good	410	82
Practice of SCD		
Poor	478	95.6
Good	22	4.4

of 0.37 ($p < 0.001$, 95%CI = 0.20–0.67). Also, respondents who mostly received their health information from community announcers relative to the radio had a lower relative risk of having good knowledge of SCD compared to poor knowledge (RRR = 0.35, $p = 0.02$, 95% CI = 0.15–0.85). Respondents who mostly received their health information from health providers relative to the radio had an increased relative risk of having good knowledge of SCD compared to poor knowledge (RRR = 4.35, $p < 0.001$, 95% CI = 2.09–9.03). Respondents who never listened to the radio at all relative to those who listened to it almost every day had a lower relative risk of having good knowledge of SCD compared to poor knowledge (RRR = 0.40, $p = 0.02$, 95% CI = 0.19–0.85).

Attitudes towards persons with SCD in Alebtong district, Northern Uganda

Based on the multinomial results in Table 4 below, only listening to the radio had a significant effect ($p \leq 0.05$) on attitude towards persons with SCD. Respondents who listened to the radio less than once a week compared to those who listened to the radio almost daily had a lower relative risk of having good attitudes towards SCD than poor attitudes (RRR = 0.24, $p = 0.03$, 95% CI = 0.07–0.88). Still, respondents who never listened to the radio at all relative to those who listened to it almost every day had a lower relative risk of having good attitudes towards SCD compared to poor attitudes (RRR = 0.32, $p = 0.03$, 95% CI = 0.12–0.90).

Practice/testing for sickle cell disease in Alebtong district, Northern Uganda

Only education level was significantly associated with testing for SCD at the multivariate level (Table 5). Respondents who had completed primary were eight times more likely to test for SCD compared to those with no education (aOR = 8.2, $p = 0.05$, 95%CI = 1.01–66.4) (Table 5 below).

Table 3 Multinomial logistic regression determinants of knowledge of sickle cell disease in Alebtong district, Northern Uganda

Variables	Relative Risk Ratio	*P* > z	[95% CI]
Poor (base outcome)			
Fair			
Sex			
Male (ref.)	1.00		
Female	0.61	0.08	[0.35–1.06]
Residence			
Rural (ref.)	1.00		
Urban	0.53	**0.02**	[0.31–0.90]
Commonest health information channel			
Radio (ref.)	1.00		
Community announcer	0.51	**0.04**	[0.26–0.98]
Television	2034447.00	1.00	[0.00-]
Internet/Telephone	2.22	0.47	[0.25–19.46]
Health providers	0.99	0.98	[0.49–2.02]
Other	0.98	0.96	[0.42–2.29]
Listening to radio			
Almost every day (ref.)	1.00		
At least once a week	1.42	0.31	[0.72–2.78]
Less than once a week	1.56	0.43	[0.52–4.67]
Not at all	0.94	0.86	[0.49–1.82]
Watching television			
Almost every day (ref.)	1.00		
At least once a week	1.52	0.77	[0.09–24.43]
Less than once a week	0.62	0.72	[0.05–8.17]
Not at all	0.58	0.65	[0.05–6.12]
Good			
Sex			
Male (ref.)	1.00		
Female	1.08	0.81	[0.57–2.04]
Residence			
Rural (ref.)	1.00		
Urban	0.37	**0.00**	[0.20–0.67]
Commonest health information channel			
Radio (ref.)	1.00		
Community announcer	0.35	**0.02**	[0.15–0.85]
Television	2.05	1.00	[0.00-.]
Internet/Telephone	0.00	0.99	[0.00-.]
Health providers	4.35	**0.00**	[2.09–9.03]
Other	0.78	0.63	[0.27–2.20]
Listening to radio			
Almost every day (ref.)	1.00		
At least once a week	0.49	0.07	[0.23–1.06]
Less than once a week	1.10	0.87	[0.34–3.53]
Not at all	0.40	**0.02**	[0.19–0.85]
Watching television			
Almost every day (ref.)	1.00		
At least once a week	3.00	0.52	[0.10-87.24]
Less than once a week	3.30	0.46	[0.14–76.72]
Not at all	1.38	0.83	[0.07–26.90]

Table 4 Multinomial logistic regression of attitudes towards sickle cell disease in Alebtong disrict, Northern Uganda

Variables	Relative Risk Ratio	*P*>z	[95% CI]
Poor (base outcome)			
Fair			
Commonest health information channel			
Radio (ref.)	1.00		
Community announcer	1.46	0.62	[0.33–6.37]
Television	0.82	1.00	[0.00-.]
Internet/Telephone	309770.00	0.99	[0.00-.]
Health providers	1.28	0.69	[0.38–4.27]
Other	0.81	0.75	[0.23–2.92]
Listening to radio			
Almost every day (ref.)	1.00		
At least once a week	1.58	0.55	[0.35–7.18]
Less than once a week	0.33	0.16	[0.07–1.55]
Not at all	0.41	0.14	[0.12–1.34]
Good			
Commonest health information channel			
Radio (ref.)	1		
Community announcer	1.62	0.47	[0.44–5.87]
Television	504725.90	0.99	[0.00-.]
Internet/Telephone	295349.60	0.99	[0.00-.]
Health providers	1.35	0.57	[0.47–3.89]
Other	0.34	0.06	[0.11–1.03]
Listening to radio			
Almost every day (ref.)	1.00		
At least once a week	1.49	0.57	[0.37-6.00]
Less than once a week	0.24	**0.03**	[0.07–0.88]
Not at all	0.32	**0.03**	[0.12–0.90]

Table 5 Binary logistic regression of practice/testing for sickle cell disease in Alebtong district, Northern Uganda

Variables	Odds Ratio	*P*>z	[95% CI]
Education level			
None	1.00		
Incomplete primary	2.35	0.44	[0.27–20.42]
Complete primary	8.20	**0.05**	[1.01–66.41]
Secondary+	5.61	0.13	[0.59–53.54]
Occupation			
Peasant farmer	1.00		
Others	2.05	0.16	[0.76–5.54]

Discussion

The objective of this study was to assess the relationship between SCD knowledge, attitudes and practices, and background characteristics of individuals in Alebtong district of Uganda. This study observed variations in levels of good knowledge, good attitudes, and practices of sickle cell disease. A high percentage (82%) of the respondents had good attitudes toward persons with SCD, 32% had good knowledge of SCD, however, only 4% had ever tested for SCD. This study points to the existence of a significant gap in knowledge, attitudes, and practice regarding SCD. This study found that place of residence and access to media community announcers and health providers were key predictors of knowledge of SCD in Uganda. Only the frequency of listening to the radio was a significant determinant of attitudes towards SCD. Education level was the only variable significantly associated with testing for SCD.

Knowledge 32% of the respondents had good knowledge of SCD. This was higher than what has been observed in other sub-Saharan countries like Nigeria (17.8%) [27]20.6% [28], South Sudan (26.9%) [19], and Middle-East in Saudi Arabia (28.8%) [40]. Previous studies that found participants with good knowledge of SCD were those whose respondents were attending symposia and awareness lectures [30], community outreach [21], members of a sickle cell society [31], or persons with higher education levels [33, 41]. The high levels of knowledge of SCD among community members in Alebtong could be due to the high prevalence rate of SCD and exposure to several persons with visible symptoms in the region as has been found in a study by Amerli & colleagues [42]. Additionally, government efforts including establishing a sickle cell clinic in the district health facility with a designated focal person and sample collection hubs could have led to improved knowledge about SCD.

Access to health information through the radio and health professionals was observed to influence knowledge of SCD in this study. Studies have shown that media access through radio [43, 44] and health professionals [43, 45, 46] are a key source of information on health in different communities and subgroups. It was observed in this study that individuals who listened to the radio almost daily and those who received health information from health providers had good knowledge of SCD. In Uganda, the government and other stakeholders use health providers, the radio, and community health workers known as village health teams (VHTs) as the main channels for passing on health information to the population.

Surprisingly, whereas studies elsewhere found that urban residents have better knowledge of diseases like HIV [47], this study observed that urban residence was associated with reduced odds of fair and good knowledge of SCD. This could be because most health interventions target rural populations due to the presumption that they have limited access to knowledge and services compared to urban residents. Though not scientifically proven, urban and rural residents of Alebtong district seem to be similar though the district is administratively classified as urban and rural.

Attitudes A high proportion (82%) of respondents reported good attitudes towards persons with SCD. This is contrary to previous studies in Uganda and South Sudan where most participants expressed negative attitudes towards persons with SCD [19, 21]. Some other studies have found lower proportions of persons with good attitudes towards pre-marital genetic counseling in Saudi Arabia [43] and South Sudan [19]. Among the three indicators studied, participants demonstrated good attitudes towards persons with SCD and this points to communities in Alebtong district being accommodative of persons affected by SCD.

Listening to the radio was the only significant determinant of attitudes towards SCD in this study. Respondents who did not listen to the radio at all and those who listened to the radio less than once a week had a lower relative risk of having good attitudes towards SCD than poor attitudes compared to those who listened to the radio almost daily. Access to the radio increases people's knowledge about a health phenomenon and this shapes people's attitudes about health conditions and persons affected by them. Since radio, is the most used and accessible channel for passing on health-related information [48], constant exposure to it is bound to enhance people's knowledge of SCD and subsequently attitudes. This in turn results in reduced stigma and discrimination towards persons with SCD.

Testing The levels of SCD testing were very low at 4.4%. A previous study in Uganda found that only 19.6% of the respondents had ever tested for SCD [21]. The low testing among persons in Alebtong district could be due to the limited access to SCD testing services in the district. This is partly due to the high cost of testing equipment and low funding for SCD-related services by the government.
Education was the only factor significantly associated with testing for SCD. According to previous studies on practice, education exposes individuals to health-related information [49]. Such knowledge increases the demand for screening for diseases [50, 51] which could explain the increased likelihood of testing for SCD among persons who attained some level of formal education in Alebtong district.

Strengths and limitations of the study

This study is based on cross-sectional data which is limited in that one cannot assess causality of relationships in the study variables. Another limitation of this paper is that it is based on findings from a small region of Uganda, the results could be specific to this region. However, this study provides data on SCD KAP that could be used to inform policy in the district and the Northern region as a whole.

Conclusion

Respondents have relatively high levels of good knowledge and attitudes towards SCD, but few have been tested for SCD. This study found that education level, age, place of residence, and religion, as well as access to media through radio and health providers were key predictors of knowledge of SCD in Alebtong district, Uganda. Attitudes towards persons with SCD were significantly associated with listening to the radio. Only education level was significantly associated with having tested for SCD.

Government and other key stakeholders should prioritize health information availability through different media to improve knowledge, attitudes, and practice, especially testing towards SCD which will, in turn, improve the lives of people with SCD and prevent its transmission to enable Uganda to achieve SDG3.

Abbreviations

KAP	Knowledge, Attitude, and Practice
SCD	Sickle Cell Disease
SDGs	Sustainable Development Goals
TASO	The Aids Support Organisation
UNCST	Uganda National Council of Science and Technology

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12889-025-22042-6.

Supplementary Material 1

Acknowledgements

The authors are grateful to Makerere University, Department of Population Studies, and Uganda Sickle Cell Rescue Foundation for creating an enabling environment that made it possible to carry out this research study. We acknowledge the study participants for their participation in the study. We also appreciate the research assistants' contribution to the data collection. Special thanks go to the Alebtong local government and Alebtong Health centre staff for their support throughout this study.

Author contributions

Conception and design of study: A.P, O.N, C.A.D, E.M, T.N; Data Analysis Plan: A.P, O.N, C.A.D; Data Analysis: C.A.D, interpretation of data: A.P, O.N, and C.A.D; drafting the manuscript: A.P & O.N; revising the manuscript; A.P, O.N, C.A.D, E.M, T.N. All authors have read and approved the final manuscript for publication.

Funding

The funding for this study was obtained from the government of Uganda through the Makerere Research and Innovations Fund.

Data availability

Data will be made available by the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the Aids Support Organisation (TASO) Institutional Review Board (registration number TASO 2021-75) and registered with the Uganda National Council of Science and Technology (UNCST). This research was performed following the relevant guidelines and regulations per the Declaration of Helsinki. All participants gave verbal informed consent before each interview. Detailed information about the purpose of the study, why they were chosen, potential risks and benefits, and that participation was

voluntary and participants could withdraw at any point were provided/given to participants before the interview. Participants' information was anonymous as no personal data was collected.

Consent for publication
All authors have read and agreed to the published version of the manuscript.

Competing interests
The authors declare no competing interests.

Author details
[1]Department of Population Studies, Makerere University, Kampala, Uganda
[2]Department of Planning and Applied Statistics, Makerere University, Kampala, Uganda
[3]Uganda Sickle Cell Rescue Foundation, Kampala, Uganda

Received: 13 May 2024 / Accepted: 20 February 2025
Published online: 07 March 2025

References

1. Rees DC, Williams TN, Gladwin MT. Sickle-cell disease. Lancet. 2010;376(9757):2018–31.
2. Tluway F, Makani J. Sickle cell disease in Africa: an overview of the integrated approach to health, research, education and advocacy in Tanzania, 2004–2016. Br J Haematol. 2017;177(6):919–29.
3. Piel FB, Hay SI, Gupta S, Weatherall DJ, Williams TN. Global burden of sickle cell anaemia in children under five, 2010–2050: modelling based on demographics, excess mortality, and interventions. PLoS Med. 2013;10(7):e1001484.
4. Makani J, Ofori-Acquah S, Nnodu O, Wonkam A, Ohene-Frempong K. Sickle cell disease: new opportunities and challenges in Africa. Sci World J. 2013;2013(1):193252.
5. Grosse SD, Odame I, Atrash HK, Amendah DD, Piel FB, Williams TN. Sickle cell disease in Africa: a neglected cause of early childhood mortality. Am J Prev Med. 2011;41(6):S398–405.
6. Ware RE. Is sickle cell anemia a neglected tropical disease? PLoS Negl Trop Dis. 2013;7(5):e2120.
7. Ndeezi G, Kiyaga C, Hernandez AG, Munube D, Howard TA, Ssewanyana I, et al. Burden of sickle cell trait and disease in the Uganda sickle surveillance study (US3): a cross-sectional study. Lancet Global Health. 2016;4(3):e195–200.
8. Adigwe OP, Onoja SO, Onavbavba G. A critical review of sickle cell disease burden and challenges in sub-Saharan Africa. J Blood Med. 2023:367–76.
9. Galadanci N, Wudil B, Balogun T, Ogunrinde G, Akinsulie A, Hasan-Hanga F, et al. Current sickle cell disease management practices in Nigeria. Int Health. 2014;6(1):23–8.
10. Mukinayi Mbiya B, Tumba Disashi G, Gulbis B. Sickle cell disease in the Democratic Republic of congo: assessing physicians' knowledge and practices. Trop Med Infect Disease. 2020;5(3):127.
11. Paulukonis ST, Eckman JR, Snyder AB, Hagar W, Feuchtbaum LB, Zhou M, et al. Defining sickle cell disease mortality using a population-based surveillance system, 2004 through 2008. Public Health Rep. 2016;131(2):367–75.
12. Piel FB, Steinberg MH, Rees DC. Sickle cell disease. N Engl J Med. 2017;376(16):1561–73.
13. Bulgin D, Tanabe P, Jenerette C. Stigma of sickle cell disease: a systematic review. Issues Ment Health Nurs. 2018;39(8):675–86.
14. Makani J, Williams T, Marsh K. Sickle cell disease in Africa: burden and research priorities. Annals Trop Med Parasitol. 2007;101(1):3–14.
15. Baldwin Z, Jiao B, Basu A, Roth J, Bender M, Elsisi Z, et al. Medical and non-medical costs of sickle cell disease and treatments from a US perspective: a systematic review and landscape analysis. PharmacoEconomics-Open. 2022;6(4):469–81.
16. Lobo C, Moura P, Fidlarczyk D, Duran J, Barbosa R, Oliveira T, et al. Cost analysis of acute care resource utilization among individuals with sickle cell disease in a middle-income country. BMC Health Serv Res. 2022;22(1):42.
17. Chakravorty S, Williams TN. Sickle cell disease: a neglected chronic disease of increasing global health importance. Arch Dis Child. 2015;100(1):48–53.
18. Lindenau JD, Wagner SC, Castro SMd, Hutz MH. The effects of old and recent migration waves in the distribution of HBB* S globin gene haplotypes. Genet Mol Biology. 2016;39(4):515–23.
19. Daak AA, Elsamani E, Ali EH, Mohamed FA, Abdel-Rahman ME, Elderdery AY, et al. Sickle cell disease in Western Sudan: genetic epidemiology and predictors of knowledge attitude and practices. Tropical Med Int Health. 2016;21(5):642–53.
20. Diallo D, Tchernia G. Sickle cell disease in Africa. Curr Opin Hematol. 2002;9(2):111–6.
21. Tusuubira SK, Nakayinga R, Mwambi B, Odda J, Kiconco S, Komuhangi A. Knowledge, perception and practices towards sickle cell disease: a community survey among adults in Lubaga division, Kampala Uganda. BMC Public Health. 2018;18:1–5.
22. Egesa WI, Nakalema G, Waibi WM, Turyasiima M, Amuje E, Kiconco G, et al. Sickle cell disease in children and adolescents: A review of the historical, clinical, and public health perspective of Sub-Saharan Africa and beyond. Int J Pediatr. 2022;2022(1):3885979.
23. Esoh K, Wonkam-Tingang E, Wonkam A. Sickle cell disease in sub-Saharan Africa: transferable strategies for prevention and care. Lancet Haematol. 2021;8(10):e744–55.
24. Fetuga AA, Balogun MR, Akinsete AM. Knowledge of SCD and psychosocial burden experienced by caregivers of children with SCD at a secondary level hospital in Lagos, Nigeria-A cross sectional study. J Clin Sci. 2020;17(4):113–9.
25. Mulumba LL, Wilson L. Sickle cell disease among children in Africa: an integrative literature review and global recommendations. Int J Afr Nurs Sci. 2015;3:56–64.
26. Wesley KM, Zhao M, Carroll Y, Porter JS. Caregiver perspectives of stigma associated with sickle cell disease in adolescents. J Pediatr Nurs. 2016;31(1):55–63.
27. Adewoyin A, Alagbe A, Adedokun B, Idubor N. Knowledge, attitude and control practices of sickle cell disease among youth corps members in Benin City. Nigeria Annals Ib Postgrad Med. 2015;13(2):100–7.
28. Ngwengi NY, Fon PN, Mbanya D. Distribution of haemoglobin genotypes, knowledge, attitude and practices towards sickle cell disease among unmarried youths in the Buea health district, Cameroon. Pan Afr Med J. 2020;37(1).
29. Al-Qattan HM, Amlih DF, Sirajuddin FS, Alhuzaimi DI, Alageel MS, Bin Tuwaim RM et al. Quantifying the levels of knowledge, attitude, and practice associated with sickle cell disease and premarital genetic counseling in 350 Saudi adults. Advances in Hematology. 2019;2019.
30. El-Hazmi M. Pre-marital examination as a method of prevention from blood genetic disorders. Community views. Saudi Med J. 2006;27(9):1291–5.
31. Millan J, van Teijlingen E, Eboh W. Knowledge and attitudes towards sickle cell disease screening: A study of members of the UK sickle cell society. 2006.
32. Oludare GO, Ogili MC. Knowledge, attitude, and practice of premarital counseling for sickle cell disease among youth in Yaba, Nigeria. Afr J Reprod Health. 2013;17(4).
33. Kehinde ME, Sowunmi C. Sickle cell disease knowledge, premarital genotype screening, and marital decision among unmarried students of Lagos state Polytechnic Ikorodu, Lagos, Nigeria. EASIJ. 2021;3(5):53–65.
34. Blake A, Asnani V, Leger RR, Harris J, Odesina V, Hemmings DL, et al. Stigma and illness uncertainty: adding to the burden of sickle cell disease. Hematology. 2018;23(2):122–30.
35. Leger RR, Wagner LD, Odesina V. Stigma in adults with sickle cell disease and family members: scale development and pilot study in the USA and Nigeria. Int J Afr Nurs Sci. 2018;9:23–9.
36. Gliem JA, Gliem RR. Calculating, interpreting, and reporting Cronbach's alpha reliability coefficient for Likert-type scales. InMidwest research-to-practice conference in adult, continuing, and community education 2003 Oct 8 (Vol. 1, pp. 82–87).
37. Ghafoor F, Tabassum R, Rehman S, Naz I, Munawar A, Waseem SA. Comparison of effectiveness of muscle energy technique versus PNF in individuals with hamstring shortness. Biomedical J Sci Tech Res. 2023;50(1):41234–41.
38. Okoko JM, Prempeh N. Transect walk research method. InVarieties of qualitative research method.: selected contextual perspectives 2023 Jan 2 (pp. 469–75). Cham: Springer International Publishing.
39. Cochran RS, editor. Multiple frame sample surveys. Proceedings of the Social Statistics Section, American Statistical Association; 1964.
40. Al-Qattan HM, Amlih DF, Sirajuddin FS, Alhuzaimi DI, Alageel MS, Bin Tuwaim RM, et al. Quantifying the levels of knowledge, attitude, and practice associated with sickle cell disease and premarital genetic counseling in 350 Saudi adults. Adv Hematol. 2019;2019(1):3961201.
41. Chukwurah E, Oduma F, Madubuattah C, Chukwurah F. Assessment of knowledge and attitude of sickle cell genetic screening among fresh undergraduate students of Ebonyi state university. Nigeria: Abakaliki; 2019.

42. Armeli C, Robbins SJ, Eunpu D. Comparing knowledge of β-thalassemia in samples of Italians, Italian-Americans, and non-Italian-Americans. J Genet Couns. 2005;14:365–76.
43. Chen X, Orom H, Hay JL, Waters EA, Schofield E, Li Y, et al. Differences in rural and urban health information access and use. J Rural Health. 2019;35(3):405–17.
44. Mukama T, Ndejjo R, Musabyimana A, Halage AA, Musoke D. Women's knowledge and attitudes towards cervical cancer prevention: a cross sectional study in Eastern Uganda. BMC Womens Health. 2017;17:1–8.
45. Ghiasi A. Health information needs, sources of information, and barriers to accessing health information among pregnant women: a systematic review of research. J maternal-fetal Neonatal Med. 2021;34(8):1320–30.
46. Kabagenyi A, Ndugga P, Wandera SO, Kwagala B. Modern contraceptive use among sexually active men in Uganda: does discussion with a health worker matter? BMC Public Health. 2014;14:1–8.
47. Oginni AB, Adebajo SB, Ahonsi BA. Trends and determinants of comprehensive knowledge of HIV among adolescents and young adults in Nigeria: 2003–2013. Afr J Reprod Health. 2017;21(1):26–34.
48. UBOS. National Population and Housing Census. 2014, Main Report, Kampala, Uganda. Uganda Bureau of Statistics Uganda Bureau of Statistics; 2016.
49. Onukwugha F, Magadi M, Hayter M, editors. Trends and Determinants of comprehensive knowledge of HIV/AIDS among unmarried adolescents in Nigeria. 2017 International Population Conference; 2017: IUSSP.
50. Lépine A, Terris-Prestholt F, Vickerman P. Determinants of HIV testing among Nigerian couples: a multilevel modelling approach. Health Policy Plann. 2015;30(5):579–92.
51. Nnko S, Kuringe E, Nyato D, Drake M, Casalini C, Shao A, et al. Determinants of access to HIV testing and counselling services among female sex workers in sub-Saharan Africa: a systematic review. BMC Public Health. 2019;19:1–12.

Publisher's note