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## Sickle Cell Disease Stories on YouTube: A Comparison of Nigeria, Ghana, Uganda, and Kenya

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Sickle cell disease (SCD) is a group of blood disorders common across Sub-Saharan Africa. Countries such as Nigeria and Ghana have a high prevalence of the inherited condition, which causes, for most patients, severe pain during a crisis and can lead to serious complications, such as anaemia and stroke. This study examines messaging about SCD in Kenya, Nigeria, Ghana, and Uganda posted on YouTube. It used DISCERN and Global Quality Score instruments to analyse a total of 58 videos from the four countries. Most were from news organizations. The most common DISCERN and Global Quality Score was a 3, which means the basic background information provided was not extensive but still useful. There was an association between the type of message and video uploader (Fisher's exact,  $p = 0.0001$ ). However, no significant associations were found between the type of message and country (Fisher's exact,  $p = 0.219$ ), using overall DISCERN and video uploader (Fisher's exact,  $p = 0.485$ ), or using global quality score and video uploader (Fisher's exact,  $p = 0.818$ ). The videos analysed not only gave the public some medical information but also addressed some of the social issues associated with SCD and helped to increase public awareness of the disease.

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## INTRODUCTION

Sickle cell disease (SCD) is characterized by an inherited abnormality in the oxygen-carrying protein in red blood cells that makes them rigid and sickle-shaped and can prevent oxygen reaching parts of the body. Several types of crises can entail 5 to 7 days of intense pain; various complications can cause life-threatening health problems (CDC, 2022). A bone marrow transplant can cure patients but is costly and requires a match.

Sickle cell disease is one of the most common blood disorders (NIH, 2022). According to the World Health Organization (2022), approximately 120 million people suffer it, and more than 60% of them live in Africa, where an estimated 1,000 babies are born with it each day, and over half of them will not live to five-years-old. Strategies to decrease the mortality rate in Sub-Saharan Africa include increasing awareness, "neonate screening", and comprehensive care (Esoh et al., 2021). To raise awareness, the Africa Health Organization (AHO, 2020) holds sickle cell week during the month of June. It tries to combat misinformation about the disease and recommends screening for the trait before marriage. Newborn screening raises questions about access and expense, and comprehensive care relies on access to medications, such as hydroxyurea and penicillin, which many families in the region cannot afford (Dexter & McGann, 2023).

Thus, increasing awareness about sickle cell disease is one of the most viable interventions, and research examining message content, form, and platform is urgently needed. This study examines messages about SCD posted on YouTube, a US website where videos can be shared free of charge, in countries with high disease burden: worldwide, incidence is highest in Nigeria, and Ghana and Uganda are among the top ten (World Atlas,

2017); SCD is the most common genetic disease in Kenya.

An estimated 30 million people use YouTube each day, and approximately 80% are not from the United States (Donchev, 2023). YouTube reaches slightly more than 35% of the world's population and slightly more than 25% of Kenya, Ghana, and Nigeria's populations (Ceci, 2023). Americans post videos to provide information about a range of illnesses (Madathil et al., 2015). Om, Mathew, and Nawaz (2021) examined sickle cell videos on YouTube using three different scales and found their quality relatively low. A recent study by Slick et al. (2023) found that more than half of the sickle cell medical information on the analysed social media sites was inaccurate. Based on the previous literature, it is important to continue to examine messages posted on social media platforms such as YouTube about the genetic disorder such as SCD that has a great impact on Sub-Saharan African countries.

## METHODS

To examine narratives about sickle cell disease in four African countries (Kenya, Nigeria, Ghana, and Uganda), the researchers analysed YouTube videos during spring 2023. The countries used in the analysis have high rates of sickle cell disease and high rates of YouTube use for Africa (Ceci, 2023; World Atlas, 2017). The goal was to analyse 15 videos for each country, and in addition to having audio, the videos had to meet the following inclusion criteria: the country's name in the title or the heading/transcript; 10 minutes or less; posted six years ago or less; and mainly in English. Repeat videos were not used. The researchers used the search terms "sickle cell disease and [the name of the country]" or "[name of the country] and sickle cell disease". Fifteen videos from Kenya, Nigeria, and Uganda met the criteria but only 13 from Ghana, for a total of 58.

The data analysis relied on two instruments commonly used to assess YouTube videos and health information: DISCERN and the Global Quality Score (Andan & Aydin, 2022; Batur et al., 2022; Calisir & Ece, 2022). DISCERN was used to analyse the “quality of written consumer health information”, or the reliability of information pertaining to treatment of different illnesses. It is 15 questions plus an overall question inform the overall score (Charnock et al., 1999). It can be used by someone who is not an expert in the medical area (discern online, n.d.). The researchers used the first nine questions to score the final 16th question to assess an overall rating. Scores range from 1 to 5, from “serious shortcomings to minimal shortcomings” (Charnock et al., 1999, p. 111). Questions were modified to address sickle cell disease.

The second instrument, the Global Quality Score, also uses a scale of 1-5, with 1 representing the lowest quality and 5, excellent quality (Bernard et al., 2007).

Two researchers focused on scoring for both DISCERN and the Global Quality Scale. One has extensive knowledge about sickle cell disease; the other, less. This approach gathered two perspectives on the videos. Each researcher answered the DISCERN and Global Quality Scale questions. After independently scoring the questions, they compared scores for reliability. Disagreement about the overall score using either instrument was resolved by reviewing their scores for the earlier DISCERN questions and discussing their interpretations of the videos to arrive at the final score for overall quality.

The researchers coded video content analysis in Excel. One researcher was responsible for coding background information about the videos: duration, when they were uploaded, the number of likes and dislikes, and the number of subscribers. Who uploaded the video - individual, news organization, health organization, government organization, or other – was also coded. Last, the purpose of the videos was also coded for informative, personal experience, event, or other. STATA version 17.0 (StataCorp, 2021) was used for the data analysis.

## RESULTS

The researchers analysed a total of 58 videos based on the keywords sickle cell disease and the four specific countries. Kenya, Nigeria, and Uganda produced 15 eligible videos, while only 13 from Ghana met the requirements for analysis (see *Table 1*). Each was unique, not a duplicate. The videos were analysed by the type of sickle cell disease messages they contained. Over 74% (n = 43) were assessed as informative. They explained that SCD is a genetic disorder, for example, and/or discussed some of the physical effects of the disease. Personal stories accounted for the second-most frequent type (20.69%, n = 12).

The study also coded for who uploaded the video based on information provided on the YouTube page. As *Table 1* shows, more than 60% (n = 36) were news organizations. Healthcare organizations accounted for 15.52% (n = 9), and other organizations for 22.41% (n = 13).

**Table 1: Descriptives**

		n	%
Type of Message	Informative	43	74.14
	Personal Stories	12	20.69
	Events	1	1.72
	Others	2	3.45
Number of videos per country	Kenya	15	25.86
	Nigeria	15	25.86
	Ghana	13	22.41
	Uganda	15	25.86
Video Uploader	News Organization	36	62.07
	Individual	0	0

	n	%
Health Organization	9	15.52
Government	0	0
Other	13	22.41

The number of likes and views per country was also analysed. The country with the most likes was Nigeria, with a mean of 30.53 (SD = 70.41), followed by Ghana at 21.31 (SD = 42.81). The

country with the most views of total videos was also Nigeria, with a mean of 1913 (SD = 4310.5), again followed by Ghana 1461 (SD = 2701; see *Table 2*).

**Table 2: Likes and views per video**

	Country	n	Mean	STD	Min.	Max.
Number of Likes per Video	Kenya	15	6.6	8.72	0	33
	Nigeria	15	30.53	70.41	1	275
	Ghana	13	21.31	42.81	0	159
	Uganda	15	4.00	4.38	0	16
Views of Videos	Kenya	15	718.13	1181.63	66	4400
	Nigeria	15	1913	4310.5	37	17000
	Ghana	13	1461.39	2701	32	10000
	Uganda	15	818.47	1830.93	5	7300

Two researchers coded the DISCERN score for each video. The most common score was 4 for some/moderate shortcomings (74.14%, n = 43). The same percentage of items scored 2 or 4 (12.07%, n = 7). Only one (1.72%) video had an extensive shortcoming, with a DISCERN score of 1, and none of the videos were given a score of 5 once both coders discussed them. The overall mean DISCERN score was 2.96 (see *Table 3*).

The Global Quality Score for video quality was also coded. Most of the videos were scored 3 for moderate quality (53.45%, n = 31). The next highest percentage scored 4 for moderate quality (31.03%, n = 18), and 10.34% (n = 6) scored 2: lower quality but useful. A score of 5 (excellent quality) was awarded to 3.45% (n = 2) of the videos, and one (1.72%) was assessed as 1 for low quality. The overall score for the mean Global Quality Score was 3.24 (see *Table 3*).

**Table 3: DISCERN and global quality scores**

	Score	n	%
DISCERN	1 Extensive issue	1	1.72
	2	7	12.07
	3 Some/moderate issues but not extensive	43	74.14
	4	7	12.07
	5 Minimal issues	0	0
Global Quality Score	1 Low Quality	1	1.72
	2 Low Quality but Useful	6	10.34
	3 Moderate Quality	31	53.45
	4 Good Quality	18	31.03
	5 Excellent Quality	2	3.45

A chi-square test revealed an association between the uploader of the video and the type of message (Fisher's exact,  $p = 0.0001$ ). However, no association was found between country and type of message (Fisher's exact,  $p = 0.219$ ; see *Table*

4). No association was identified between uploader and DISCERN score (Fisher's exact,  $p = 0.485$ ) and uploader and Global Quality Score (Fisher's exact,  $p = 0.818$ ; see *Table 5*).

**Table 4: The Association between type of message, video uploader, and country**

		Type of Message			
		Informative n	Personal Stories n	Events n	Other n
Video Uploader	News Organization	35	1	0	0
	Individual	0	0	0	0
	Health Organization	3	6	0	0
	Government	0	0	0	0
	Other	5	5	1	2
<i>Fisher's exact, p = 0.0001</i>					
Country	Kenya	13	1	0	1
	Nigeria	9	6	0	0
	Ghana	9	3	0	1
	Uganda	12	2	1	0
<i>Fisher's exact, p = 0.219</i>					

**Table 5: Association Between DISCERN, Global Quality Score, and Video Uploader**

		Overall DISCERN					Global Quality Score				
		1 n	2 n	3 n	4 n	5 n	1 n	2 n	3 n	4 n	5 n
Video Uploader	News Organization	0	4	26	6	0	0	4	19	11	2
	Individual	0	0	0	0	0	0	0	0	0	0
	Health Organization	0	2	7	0	0	0	1	6	2	0
	Government	0	0	0	0	0	0	0	0	0	0
	Other	1	1	10	1	0	1	1	6	5	0
<i>Fisher's exact, p = 0.485</i>						<i>Fisher's exact, p = 0.818</i>					

**DISCUSSION**

YouTube has become a popular online source for health information (Madathil et al., 2015). Studies have analysed the information posted on YouTube about several types of health conditions, such as heart problems and diabetes (Birch et al., 2022; Chen et al., 2013; Leong et al., 2018). This study was designed to examine YouTube messages about sickle cell disease in four African countries, Kenya, Nigeria, Ghana, and Uganda, where incidence is high (WHO, 2022; Zho & Travassos, 2022). How the disease is discussed on popular media platforms, such as YouTube, could have an effect on screening and accessing treatment.

Results show that news organizations are the main providers of SCD content on YouTube. More than half of the 58 videos were developed and posted by different news organizations across the four countries. This finding demonstrates public interest in providing the local audience with information about the disease. Most of the stories used images in explaining its genetic origin and

that both parents must have the trait. Some stories tried to debunk myths about SCD, and some encouraged genetic counselling, so couples could find out if they both have the trait, and testing newborns for the disease (Ohene-Frempong et al., 2005; Tegha et al., 2021), since in Sub-Saharan Africa, SCD may not be diagnosed until children are older than toddlers (Sims et al., 2021). Some stories provided information about centres where people could go for SCD treatment and counselling. As one recent study in Ghana found, young people willing to accept genetic counselling were not sure where such services were offered (Appiah et al., 2020). A study in Nigeria discussed the importance of campaigns to help people learn their genotypes (Ajilore et al., 2019).

More than 70% of the videos were given a 3 rating for overall quality using the DISCERN instrument, which means the researchers took some issue with the content but still found the videos meaningful and somewhat informative. For the Global Quality Score, slightly more than

50% received a 3, and slightly more than 30% received a 4, which means the videos provided some information about the disease that could be useful for patients, caregivers, and the overall community. The scores in this study are slightly higher than those in another study examining SCD information in 66 videos posted on YouTube (Om et al., 2021): where the DISCERN score was 1.79; the GQS score was 2.67; and the Journal of the American Medical Association (JAMA) benchmark score was 1.26.

The current study also showed a correlation between the type of uploader and the video's content. The main uploaders were news organizations. Health educators could work with news organizations to increase awareness about SCD; for example, new scientific information, treatments, and health events taking place in local communities. They could ensure that news organizations interview experts who will accurately inform the public about SCD in the four countries.

Both DISCERN and GQS scores are similar to other scores of health information on YouTube (Cakmak & Mantoglu, 2021; Melchionn et al., 2023). However, some studies have assessed lower scores (Mert & Bozgeyik, 2021; Ozsoy-Unubol & Alanbay-Yagci, 2021). While the videos analysed on the platform do add information about a disease that many people, including those most affected, know little about, some of it is questionable. Those seeking or stumbling on information about SCD on YouTube should check its accuracy with their medical providers.

Some limitations to the study were that the videos studied only included those from the past six years and 10 minutes or less. Some met the six-year requirement but were over 10 minutes. They were also limited to 15 videos for each country. Each of these limitations may have excluded relevant content, and overall, the study might have had more power if it had included more videos from more Sub-Saharan countries.

## CONCLUSION

Based on a search of the literature, little is known about how SCD in Sub-Saharan Africa is discussed on YouTube. While imperfect, the videos analysed help to increase awareness of the disease among those most susceptible and most affected. As previously stated, more than half of the videos come from news organizations, which show their importance in disseminating information about the genetic disorder. Since most of the video uploaders and content producers for the videos of this study come from news outlets, it also shows these media outlets could help to educate a larger audience than their local television viewers.

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