

RESEARCH ARTICLE

Empowering patients with sickle cell anemia and their families through innovative educational methods

Riley Plett^{1,3}  | Craig Eling² | Sarah Tehseen^{1,2}  | Kathleen Felton^{1,2} |
Gina Martin^{1,2} | Vivian Sheppard² | Megan Pegg² | Roona Sinha^{1,2,3}

¹Department of Pediatrics, University of Saskatchewan, Saskatoon, Canada

²Pediatric Hematology/Oncology Department of Pediatrics, Jim Pattison Children's Hospital, Saskatoon, Canada

³Department of Pediatrics, Undergraduate Medical Education, College of Medicine, University of Saskatchewan, Saskatoon, Canada

Correspondence

Roona Sinha, Pediatric Hematology/Oncology Department of Pediatrics, Jim Pattison Children's Hospital Room 3724 RUH - 103 Hospital Drive, Saskatoon, SK S7N 0W8, Canada.

Email: roona.sinha@usask.ca

Abstract

Sickle cell disease (SCD) is a group of inherited blood disorders caused by a mutation in the beta subunit of hemoglobin (HbS). SCD will hereafter be referred to as sickle cell anemia (SCA) as this is the term our patients and their families prefer. There are approximately 5000 Canadians living with SCA including children. Pediatric SCA patient education can: improve knowledge, decrease hospitalization, improve medication possession ratio, lead to better SCA-related functioning, and lower pain impact. Innovative educational materials were developed to improve knowledge and self-efficacy regarding the illness management of patients and parents/guardians. Patients ($n = 5$; aged 8–18) with SCA and parents ($n = 5$) of patients (aged 0–18) were recruited via flyers sent directly to patients and distributed through partner patient organization Sickle Cell Awareness Network of Saskatchewan. Patient and parent focus groups were held separately over Zoom to receive feedback for the video. An additional interview was held for a participant that required a translation of the video. Audio recordings were transcribed using Zoom and Otter.ai. The coding of transcripts was facilitated by NVivo (QSR International Pty Ltd, 2022, release 1.6.2). The thematic analysis centered around SCA management concepts relevant to the research aims. Important themes that emerged included 'Age Appropriateness', 'Empowerment', 'Knowledge Gaps', 'Linguistic Accessibility', 'Medication Adherence', 'Strength in Community', and 'Transition to Adult Care'. The video was well received, and "brought peace of mind". Patient feedback was incorporated into the final version of the educational materials.

KEYWORDS

hematology, pediatric hematology/oncology, sickle cell anemia, sickle cell disease

List of Abbreviations: ACS, acute chest syndrome; SCA, sickle cell anemia; SCAN SK, sickle cell awareness network of Saskatchewan; SCD, sickle cell disease.

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1 | INTRODUCTION

Sickle cell disease (SCD) is a group of inherited blood disorders caused by a mutation in the beta subunit of hemoglobin. SCD will hereafter be referred to as Sickle cell anemia (SCA) as this is the term our patients and their families prefer. There are approximately 5000 Canadians living with SCA [1]. The mutated B subunit causes polymerization of hemoglobin leading to sickling of red blood cells. Sick cells are prone to destruction and clog blood vessels resulting in ischemia [2, 3]. SCA is associated with anemia and vaso-occlusive pain crises that can lead to complications involving the bones, lungs, abdomen, brain, eyes, and reproductive system [4]. Life-threatening events are also common and include acute chest syndrome (ACS), ischemic stroke, and infection [4].

Pediatric SCA patient education can: improve knowledge, decrease hospitalization, improve medication possession ratio, lead to better SCA-related functioning, and lower pain impact [5–10]. Helpful resources currently available include self-care toolkits and apps that are easily accessible to academics but are not readily available to youth following internet searches [11–13]. Breakey et al. demonstrated by mimicking internet searches of adolescents that there is a lack of information with features desirable to adolescents on the internet written at an appropriate reading level [13]. In particular, there is a lack of information about the management and prevention of emergencies like ACS [13]. There is a need to develop age-appropriate educational materials for patients with SCA and their families utilizing media that can be easily accessed by patients through a layperson internet search.

Furthermore, educational materials are an important component of the transition to adult care and should be provided to patients starting from a young age. Acute care visits and rehospitalizations are frequent in those with SCA 18–30 years old [10]. Patients are vulnerable at this time and equipping youth with knowledge and self-efficacy of illness management is critical. A scoping review by Viola et al. suggests there is a growing abundance of effective programming available for transition to adult SCA care including electronic and in-person interventions [14]. Still, no research has been done to determine what specific educational materials are superior to others [14].

2 | METHODS

An innovative educational cartoon video targeted toward youth with SCA was developed to improve knowledge and self-efficacy regarding the illness management of patients and parents/guardians. Following a literature review, the medical student developed a script for the video. Due to the lack of information available on the internet regarding sickle cell emergencies, the video focused on these [13]. The script was then reviewed by the pediatric hematology team. Additionally, the script was reviewed by a patient and parent advisor team. The video was created using Powtoon video creator and in collaboration with the sickle cell awareness network of Saskatchewan (SCAN SK). Voice actors included a patient with SCA as representation was thought to be paramount. Ethics approval was attained through the University

of Saskatchewan Behavioural Research Ethics Board (ID: 2679). All proceedings involving patients were carried out according to the University research ethics board policies and procedures. Patients ($n = 5$; aged 8–18) with SCA and parents ($n = 5$) of patients (aged 0–18) were recruited via flyers emailed and mailed to patients and distributed through SCAN SK.

Information about age, gender, ethnicity, and race was gathered during the video interviews. All participants identified as Black, and/or of African descent. Specificities of ethnic identity will be kept confidential to protect participants' identities. Three of the patient participants were in the 16–18-year-old age range. The remaining two were between 8 and 10 years old. All identified as male. Most of the parent participants identified as female. One parent participant identified as male.

A patient focus group and parent focus group were held separately over Zoom to receive feedback on the video. An additional interview was held over Zoom for a participant that required video translation. Student researcher Riley Plett facilitated all Zoom meetings. Subtitles were provided on the video by YouTube auto-translate for the participant requiring translation. The parent of the participant requiring translation also aided in the translation of the focus group questions.

Audio recordings were transcribed using Zoom and Otter.ai. The coding of transcripts was facilitated by NVivo (QSR International Pty Ltd, 2022 release 1.6.2). The thematic analysis centered around knowledge and self-efficacy concepts relevant to the research question. Feedback from the focus groups was incorporated to refine the cartoon video and create a summary infographic requested by adolescent participants (S1, S2). The summary infographic was created using Canva and pulled information from the video.

3 | RESULTS

The video was well received by both parents and patients. It was thought to be “educational for all ages” and “brought peace of mind”. The themes that emerged are summarized in Table 1.

3.1 | Age appropriateness

The video's target audience was envisioned to be teens. The video was appropriate for adolescents according to parent participants. There were many requests that the video be made available to their teens. One parent (Parent Participant 5) stated “It uses terms that younger people can understand... and it also gave me ideas in terms of how to communicate with younger people.”

The young adult participants (16–18 years) thought the video would be better suited to younger audiences and that they would prefer a different media, such as an infographic.

“I believe that video is... really well done just for children. I think, grasps the children's attention. I also don't think it's too complex for the children to understand.

TABLE 1 Themes emerging from parental and patient focus groups. Material competency evaluates how the themes are reflected in the educational materials and future directions suggest areas for further study.

Themes	Material competency	Future directions
Age appropriate-ness	The media of communication (video, infographic, poster, etc.) needs to cater to the correct age group. The final materials (video and infographic) were age-appropriate.	Other media such as audio podcasts could be explored in different age groups. Collaboration with organizations with social media presence should be coordinated.
Empowerment	Patients and their families endorsed feeling supported in confidence in illness management by the materials.	Future RCT research could quantitatively evaluate improvement in illness management outcomes.
Knowledge gaps	The materials addressed knowledge gaps in patient/family knowledge including screening programming (ex. TCD ultrasound)	Additional knowledge gaps to be explored included managing SCA in pregnancy, eye complications, and navigating emergent healthcare settings.
Linguistic accessibility	The video was linguistically accessible due to Youtube™ translator function.	Infographics could be translated to be linguistically accessible.
Medication adherence	The materials provided an emphasis on strategies for medication adherence.	Further research could evaluate creative ways of approaching medication adherence.
Strength in community	The discussion with patients and parents demonstrated the importance of community support and this was reflected in the final educational materials.	Global communities to aid in SCA education and management would likely improve health outcomes.
Transition to adult care	The materials provide supplemental support for the transition to adult care beginning at a young age.	The materials could be added to and combined with other transitional materials to create a transitional program curriculum.

I do think an infographic would be like, more beneficial to teenagers.” - Patient Participant 1

With the teenagers, less was more. Patient Participant 3 stated that the infographic should have “all the important details summarized so there isn’t too much to read”.

Younger patient participants (aged 8–10) preferred the cartoon video format. References that adolescent participants found too juvenile were favorites for the younger ones. Patient Participant 4, our youngest participant stated “I like when they said Tik Tok is corny”.

3.2 | Empowerment

When asked if learning more about SCA made them feel better about managing their illness, patient participants agreed.

“You know, [the video] lets them understand that there’s something that they can do about the sickle cell to make it easier for them... I know that this information is going to help them. I can talk to them, but they need to have this information themselves. - Parent Participant 1.

Talking about managing SCA as a youth can be difficult. Parent participant 3 unpacks this:

“For young adults, a lot of times what I’ve noticed with my son, he’s very kind of reserved when it comes to talk-

ing about sickle cell. And that’s why I think one of the reasons participating in these things is a little bit tough on him. He does it but not too often.”

Encouragingly, the child of this participant was a leader in the patient focus group discussion. The meaningful engagement of this “reserved” patient embodied the empowerment created by connecting and learning about SCA with other youth.

Parent Participant 1 spoke about the use of magma as imagery and the comfort this metaphor provided:

“The usage of the magma. It gives you an understanding better of what can happen, and the thought that you have some control over it, that it doesn’t have to erupt, “it doesn’t have to get to that level. So that makes me feel good.”

3.3 | Knowledge gaps

The video was able to provide learning for patient and parent participants. Our youngest patient participant [4] said, “I learned that sickle cells can’t really bring oxygen; other blood cells can.” Another young participant [5] stated they “learned about the function of the sickle cells”.

Older teenage participants specifically commented on learning about why trans-cranial Doppler ultrasound and magnetic resonance imaging screening are important. “I did all these tests, but I never really knew why I was doing these tests. So, I felt like the video adequately

explained the reasoning behind the tests.” - Patient Participant 1.

For Parent Participant 2 it was helpful to hear familiar information in a new way: “You know, like today, just listening to that video... it was a different perspective, it was actually a revelation.”

Although participants were happy with the educational content of the video there were suggestions for future content. One parent suggested stressing the potential for sickle cell emergencies in other areas of the body such as in the eyes and the importance of screening eye appointments. Another suggestion was to include information on what to do to receive help when experiencing an SCA emergency. Another participant inquired about whether it is safe to take hydroxyurea in pregnancy.

3.4 | Linguistic accessibility

The importance of having educational materials available in many languages arose during the focus groups. A blatant example of this is that an additional separate interview was required for a participant that required translation for the video. Since many patients with SCA are newcomers to Canada, accessibility of educational materials in multiple languages is important. The participant that required translation found it adequate to have the audio in English with subtitles on the video. YouTube has an automatic translation function. The parent and patient stated this worked well for understanding. They also confirmed the speed was okay for listening in English and reading subtitles in their language and that this was good practice for their child to understand SCA in both English and in their first language.

3.5 | Medication adherence

Stressing the importance of medication adherence in the video, especially for hydroxyurea came up in both the patient and parent focus groups. Parent Participant 1 stated, “We’ve tried almost everything. When we go to the clinic, they spoke with him. But he’s still not getting it. So I don’t know what else to do.”

Parent Participant 4 suggested that maybe adding to the video the importance of routine in medication adherence could be useful. They shared: “I always make sure after supper, I’ll prepare a plate where I’ll put his tablets. “So, it’s a routine. And because of that, it’s easier to encourage him, because it’s not like I’m forcing it down on him.”

Patient participants also stressed the importance of encouraging youth to take their medication. This is especially important as youths take charge of their SCA management, as patient participant 3 puts it, “the older you get, the more freedom you have. But it doesn’t mean you shouldn’t take your medicine just because you’re older”. Patient Participant 2 suggested it “could be interesting to put on an infographic... how hydroxyurea, how that’s useful and what your life would look like if you

were taking your medicine every day versus like if you kind of just never took it.”

3.6 | Strength in the community

The importance of community was demonstrated through connections made at the focus groups themselves. Early in the parent focus group, participants began asking about connecting with other families. At this time some participants were connected to SCAN SK. Parent Participant 2 illustrated the importance of SCA families coming together:

“And especially, most of us when we come to Canada, and, you know, we come from places where family support system is very huge. And when we can hear the support system is not as huge as it was back home with our extended families, you know... So that interaction of different parents coming together different kids, you know... we need to be able to create that environment.”

In the patient focus group, the importance of knowing you aren’t alone was emphasized in Patient Participant 2’s comment,

“Yeah, oh, maybe, um, one thing that like maybe on an infographic because they kind of always have like stats, maybe if there’s like a stat of like, how many other kids also deal with sickle cell because when I was younger, I always thought that it was like, only me until I met [another patient with SCA]. And then after I met [them], like, sometimes I’d go to the doctor, and they would say that there are more people now... And I really never thought that many people had it. So maybe like, that’s like that would be kind of encouraging to older teenagers too.”

Talking about SCA was found to be important, not only within SCA communities but with classmates and teachers at school. It was suggested that the cartoon video might even be useful to be shared in schools. Importantly this would also be “an opportunity to be able to put material out there that will ease our kids.” Patient Participant 2 elaborates on the importance of this.

“When I was in elementary school, they gave me this book... to help me tell my classmates that I had sickle cell and there’s like, certain things that they can do to help me if I’m in pain and stuff. And I found at the time I really didn’t want to tell anybody but I found that it helped me a lot. So if there is like kids in elementary school who are scared to tell them, like, tell their classmates... maybe that video can help them explain what’s wrong with them and stuff.”

Our youngest participant stated he would like to share the video with his friends at school.

3.7 | Transition to adult care

A common thread woven throughout the conversation was the transition to adult care. The dynamics of family relationships were explored in this transition. The parent participants all stated that they were quite involved in their child's SCA management, providing constant support at all ages. Parent Participant 3 reflected on providing support for hydroxyurea adherence, "I know, eventually he'll get it and just do it on his own. But until then I still want to be that little voice in his ear. Encouragement." Patient Participant 1 reflects on their perspective as a youth,

"I found as I was transitioning throughout my teenage years I kind of just started getting to know my body more I started to know like, what the limits were, like how hard I could push myself. And as I knew my body, people, like friends and family around me, just trusted me. So I feel like it is one of those things that does just come with experience as well."

It also became apparent that the issue of seeking emergent care was also an important one in the community. As in any emergency, quick assessment and treatment are crucial. Awareness is increasing in sickle cell emergent care, especially in pediatric departments. Participant 2 continues,

"Some doctors... know what's happening. 'We're getting your medication like all loaded up', but before it was like they had to call an on-call doctor. And that would take a while just for me to get medication. So kind of slowed down the process and you're sitting in pain for a little longer, but it's gotten better now."

However, parent participants expressed that work still needs to be done in addressing sickle cell care in an adult setting, especially as youth transition to adult care. Parent Participant 3 recalls,

"We had a crisis and we ended up with the adults. There was no information. They treated it like you had a cold or you know, he was in minor pain. And then I had to, you know, step out, got up and voiced my opinion, and eventually a doctor came and, you know, offered us the care that he deserved. They are not ready yet to deal with [them] coming in as young adults. And information needs to be there, ASAP."

For pediatric sickle cell patients, emergency cards have proved useful in the past. Patient Participant 2 recalls,

"They gave us a little card that said that, like we have sickle cell and like, like the stuff that we can do in like the first like 20 min that they get there to help relieve the pain. And I think that was pretty helpful. But now that I'm older, it really doesn't help. It's... [for] the pediatrics."

Also, the young adults in the group highlighted the importance of recognizing their role as their own illness experts. They communicated that the rate-limiting step to receiving treatment is provider awareness of emergent management for sickle cell crises, especially regarding medications.

"I also feel like I can pretty much tell a doctor, what I'm feeling like how I'm feeling, and probably what medications I would need. Like, because when I go in there, I pretty much know what's happening... and like, see if they could get it approved faster because I know not like every nurse can distribute medication like that. But stuff like that would help." - Patient Participant 2

4 | DISCUSSION

There is a need for age-appropriate educational resources to be available for patients with SCA and their families. Our cartoon video and teen infographic have the potential to assist in transition care and are meant to be shared with patients starting at a young age.

Educational materials need to be age appropriate. Breakey et al. found that there is a lack of information available on the internet for youth with SCA that is age-appropriate [13]. This was echoed by our teenage participants who requested concise infographics. In the age of social media, it is important to consider the most age-appropriate media for educational material delivery. In the clinic, it would be easy to show the cartoon video to younger participants as there is a growing abundance of tech available such as iPads in this setting. Teens are looking to the internet, doing independent searches for their information [13]. To ensure the video is easily accessible to SCA youth doing their own internet searches, the video is now publicly available at <https://www.youtube.com/watch?v=54n6mIpN-q0> and the description includes appropriate keywords (The publisher is not responsible for content hosted on third party websites.) [13]. Notably, the teens acknowledged some important information to include would be statistics about the prevalence of SCA and information on how medication adherence can change their quality of life.

The materials need to be linguistically accessible. Given that many families of kids with SCA are newcomers to Canada, it is imperative that educational materials are available in a patient's own language. YouTube auto-translator was found to be acceptable to our participant but this might not accommodate every patient's needs. Involving a translator frequently in the delivery of educational materials would most appropriately address accessibility.

Education requires family and community support. Medication adherence arose as a whole family concern. The developed educational materials could be used as a starting point for patient/family/provider brainstorming about how to take medication consistently. Strategies for medication adherence were incorporated into the final version of the video to prompt discussion.

Support does not stop within the family, as demonstrated in a teen's comment about needing to know that they are not the only kid with SCA. Statistics were included in the infographic about the prevalence of SCA. This underlines the importance of educational materials addressing not only knowledge and management pieces but also questions youth have about the SCA community and their place in it. The video and infographic could be delivered with additional components, such as those suggested by Viola et al. (ie. facility tours, peer support, etc.) [14].

A major theme that arose that will require ongoing collaboration is SCA emergency department care during the transition to adult care. Better SCA health outcomes are not only an issue of patient/family education but rely on health care provider education as well. Access to timely and quality emergency care and differences between pediatric and adult populations are becoming recognized as a concern in other provinces as well. In Ontario, one study found that adults are waiting much longer than their pediatric counterparts, despite visiting the ED 2.5 times more frequently [15]. This highlights the importance of collaboration for SCA emergency management. For patients and their families, future educational materials could implement components of how to navigate the health care system as an adult, especially when seeking emergent care. For providers, there are many resources available for emergent SCA management including a point-of-care emergency department online tool developed by the American College of Emergency Physicians and American Society of Hematology pocket guides for SCD [16, 17].

There are limitations to this study. It should be noted that all patient participants were male and the majority of parent participants were female. There may be gender differences in how the educational materials are received and what participants value as important in educational materials. This study was also performed within Saskatchewan and was composed entirely of Saskatchewan participants and it is not guaranteed that our findings are generalizable to other centres.

Our novel educational materials add to a growing collection of those available for pediatric SCA illness management and transition. Few studies evaluate specific materials and instead evaluate the overall effectiveness of programs [14]. Our study evaluates specific educational materials, assessing patient and parent concerns, so that our materials reflect the needs of these target populations. Ultimately, our novel education materials were found to be age-appropriate and empowering, addressing knowledge gaps across all ages. Efforts are being made to collaborate with the Canadian Hemoglobinopathy Association and SCAN SK to help distribute the materials. Further randomized control trial research is needed to evaluate the impact of specific educational materials on improving SCA patient knowledge and confidence in illness management.

AUTHOR CONTRIBUTIONS

Riley Plett contributed to study design, educational materials creation, recruitment, data collection, data analysis, and manuscript editing. Roona Sinha, Craig Eling, Sarah Tehseen, Kathleen Felton, Gina Martin, Vivian Sheppard, and Megan Pegg contributed to study design, educational materials creation, recruitment, data collection, and manuscript editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author, roona.sinha@usask.ca. The data are not publicly available due to their containing information that could compromise the privacy of research participants.

ETHICS STATEMENT

Ethics approval was attained through the University of Saskatchewan Behavioural Research Ethics Board (ID: 2679). All proceedings involving patients were carried out according to the University research ethics board policies and procedures.

PATIENT CONSENT STATEMENT

Verbal informed consent for publication of their contributions without identifying information was obtained from the study participant when the capacity to consent was appropriate. For some younger participants, verbal informed parent consent and verbal informed participant assent were obtained.

ORCID

Riley Plett  <https://orcid.org/0000-0003-1317-6729>

Sarah Tehseen  <https://orcid.org/0000-0002-1794-9672>

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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