

Increasing Sickle Cell Disease Appointment Attendance: A Conversation & Facilitation Guide

for community-based organization use with members

BACKGROUND

The majority of adults and caregivers of children with sickle cell disease reported having had to miss a clinic appointment in the previous 12 months, according to a 2018 multi-year national study conducted by the Mid-South Clinical Data Research Network.¹ This means that a majority of children and adults living with sickle cell disease (SCD) may miss out on therapies that have the potential to improve their health and lives. The mid-South collaborative's important research affirms what patients and families have been feeling: there are significant barriers that make it difficult for patients to always attend appointments and addressing those barriers could greatly improve health outcomes. Further, the COVID-19 pandemic of 2020 and 2021 made it all the harder for those living with SCD to get routine, urgent, or emergency care for symptoms and treatment of the disease.

In late 2019, the National Institute for Children's Health Quality (NICHQ) conducted in-depth interviews of providers, patients, and caregivers to better understand this issue of missed appointments and to begin to generate solutions. A key takeaway from those interviews was that, while the reasons for missed appointments vary, addressing the barriers depends heavily on one thing: the relationship between the patient and provider – the clinic and caregiving family members. These interviews also underscored the importance of community-based organizations in the lives of those living with SCD, and a CBO's positive influence on the patient/provider relationship.

RESOURCES

- [Video: Improving Appointment Attendance for Sickle Cell Disease Patients](#)
- [Webinar Recording: Increasing Appointment Attendance: A Vital Opportunity to Improve Health Outcomes for Those Living with Sickle Cell Disease](#)
- [Webinar Recording: Conversations to Improve Patient/Provider Relationships and Increase Appointment Attendance](#)
- Infographic: Understanding Sickle Cell Disease Missed Appointments (available soon)
- Increasing Sickle Cell Appointment Attendance: A Conversation Guide for Providers
- [Publication: Modifying Factors of the Health Belief Model Associated with Missed Clinic Appointments Among Individuals with Sickle Cell Disease](#)

¹ Robert M. Cronin, Jane S. Hankins, Jeannie Byrd, Brandi M. Pernell, Adetola Kassim, Patricia Adams-Graves, Alexis A. Thompson, Karen Kalinyak, Michael R. DeBaun & Marsha Treadwell (2018) Modifying factors of the health belief model associated with missed clinic appointments among individuals with sickle cell disease, *Hematology*, 23:9, 683-691.

USING THE CONVERSATION GUIDE

This guide is written for CBOs and other family and patient advocacy organizations to use in group or individual settings, sharing the [video](#) in advance or at the beginning of the session. The video is helpful in providing background and generating conversation by introducing barriers to appointment attendance that might be harder for some participants to talk about. During a session, the video can be shown in two parts, as the first half of the video shares barriers and the second half focuses on solutions.

Format Suggestions

Consider sitting in a circle or around a table to create a more open conversation among all. When discussing solutions, consider breaking a larger group into groups of 3-4 by barrier and having groups share out discussion results. This can prevent putting participants “on the spot” about their personal challenges.

SAMPLE SCRIPT (in black) & FACILITATOR SUGGESTIONS (in blue)

Introducing the Conversation (after viewing the video together)

We all know that even before COVID-19 pandemic, it was hard for a lot of people [children, adults, parents, caregivers] living with sickle cell disease get to all the appointments to treat and their condition. And COVID-19 made that so much worse. Now that we’re mostly getting back to regular appointments, let’s look at what’s changed – and what still needs to change to make getting to appointments easier for you and your family. I know everyone here has come up with ways to get to appointments and it would be great to share those with the group. So, in our session today, we’ll talk together about solutions – and also give some approaches to talk to clinic staff and providers about appointments when we need to.

Opening Discussion:

Before we start talking about specific challenges, let’s talk about what you thought of the video.

- What do you think about what people in the video said about barriers to getting to appointments?
- Have you had issues getting to appointments, whether regular visits or more involved visits?
- Anyone want to share an example and what happened? (i.e., arrived too late because of XXX, visit was rescheduled, had to return the following week, missed two work/school days instead of one)
- What about the health consequences of missing a visit for you/your child? (Probe what concerns them, what they do when it happens; gently address any misconceptions if others do not comment)

Transportation:

Like you saw in the video, some people have trouble with transportation to appointments, whether they live in an urban or rural area, use their own car, or use public transportation.

Conversation Starters

- How do you usually get to your/your child’s sickle cell disease appointments?
- How much is transportation a problem for you?
- What about transportation makes it hard? (e.g., cost, distance, access to driver, availability of public transportation)? [consider listing on flip chart or white board]

Discussion:

Full group or small discussion breakouts by transportation challenge (i.e., no car/no one to drive; poor public transportation; cost of transportation no matter the manner)

- What do others do about [this challenge]?
- What does the clinic offer?
- What ideas/solutions could help?

Be prepared with local public transportation information; information about Medicaid vouchers for ride-sharing, public transit, taxis, own car mileage; CBO supports.

Scheduling and Keeping Track of Appointments:

Because people living with sickle cell disease have so many appointments and not all of them in the same place, keeping track can be really challenging.

Conversation starters:

- Do you feel you have enough time in your schedule to make and attend your appointments?
- What other obligations can take over? (e.g., school, work, other appointments, finding childcare)?
- How do you cope when a last-minute conflict comes up?
- Has anyone ever forgotten an appointment or gone on the wrong day?

Discussion:

Full group or small discussion breakouts by scheduling challenges that come up in the group discussion such as work conflicts/school conflicts or priorities; SCD illness (pain crisis prevented regular appointment attendance); issue with other children/family members; childcare for other children; forgetting/wrong day.

- How do you decide what to do when a work emergency or a school conflict comes up?
- What do you use to keep track of your appointments and schedule?
- How does the clinic help you keep track?
- If your clinic changes your appointment, how do you handle that?

Be prepared with examples of schedule tracking tools your participants might use, such as google calendar, clinic/center calendar and reminders.

Concerns Related to Being Prepared for Appointments (Health Literacy):

Living with SCD means a lot of tests and treatments others don't have to deal with, which can be confusing.

Conversation starters:

- Have you ever missed an appointment or test because you weren't sure what you needed to do? (Example if needed: you didn't realize the preparation for a test and when you got there, they had to cancel the test)
- Have problems with insurance ever made you miss an appointment?

Discussion:

Full group or small discussion breakouts by challenges, such as not understanding complicated instructions or requirements; confusing insurance coverage; not understanding value/purpose of routine appointments or tests, such as stroke screening (transcranial doppler).

- How much does it matter to understand all the complex information?

- How do you get information about tests and procedures?
- Do you have problems keeping track of insurance information?
- How does your clinic help when it comes to keeping you informed? Where else do you get information?
- How do you think [this CBO] could help?

Be prepared to suggest access to information about SCD tests and procedures from your organization, the Sickle Cell Disease Association of America, or other patient- and family-centered organizations.

Partnership with Your Provider

Although it didn't come up in the study, when they were getting ready for the video, family and patients who were interviewed talked a lot about missing appointments and their relationship with their provider. Some families felt that their provider or clinic staff just did not understand how hard getting to appointments could be, and sometimes made them feel embarrassed or bad about things they couldn't control.

Sometimes it's hard to share with our providers about challenges because they might be about money, where we live, or our job, and we don't think our doctor will understand us. An important purpose of this session is to help you feel comfortable bringing up your appointment challenges with your provider or the clinic staff.

- How comfortable do you feel with talking to the staff about your or your family's challenges with getting to appointments?
- What challenges are you not comfortable sharing with your provider? (Possible answers: don't have a car, don't understand the medical information, cannot read well in English, don't have a phone that has a calendar like everyone else, can't afford to bring all my kids with me or to get childcare for them; no matter what, it costs money and I sometimes I don't have it)
- What would help that conversation go well for you?

Conversation Role Play:

Have participants pair up and role play (or simply discuss if more comfortable) how a conversation with their/their child's provider or clinic staff would go. Allow each pair to choose their attendance "barrier" to discuss. Repeat with new pairs so each participant gets to be "patient" and "provider." Allowing your participants to put themselves in the provider's place can help their understanding – and thus benefit the relationship.

Debrief with full group: How did that go? What worked? How did you get the conversation started? What would you do differently? What would make you more comfortable if you did this in "real life?" Which role did you like better? Why?

Conclusion

Thank participants for engagement in discussion and solutions. Identify/offer any additional resources based on the issues and solutions that emerged.