

Increasing Sickle Cell Appointment Attendance: A Conversation Guide

for providers to use with patients and families

BACKGROUND

The majority of adults and caregivers of children with sickle cell disease (SCD) 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 regular, 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.

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 Disease Appointment Attendance: A Conversation and Facilitation Guide for Community-Based Organizations
- [Publication: Modifying Factors of the Health Belief Model Associated with Missed Clinic Appointments Among Individuals with Sickle Cell Disease](#)

USING THE CONVERSATION GUIDE

This conversation guide assumes that the provider and person or family living with sickle cell disease have watched the [video](#) about this issue of missed appointments. However, seeing the video is not necessary to

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.

having this important conversation with patients and their families to support them in finding solutions to the difficulty of SCD care.

The discussion can take place in a variety of ways, including one-on-one during a routine appointment, in a small group setting on an SCD “clinic day” when patients are in for tests and procedures, or while patients are waiting for a routine appointment to begin. **Because solving the problem of missed appointments takes a good, trusting relationship between the patient and provider, it’s useful for the provider to ask the family or individual about their own challenges and solutions and listen to understand the barriers or difficulties from the patient’s point-of view.** Therefore, if someone other than the provider has the conversation with the patient, the provider should be sure to follow up in routine appointments so the patient/family knows they are being heard. Because all relationships can be improved and because all families and individuals have some challenges with juggling sickle cell disease appointments, it is important for the conversation to take place with ALL patients and caregivers, rather than focusing on those the clinic sees as having problems.

Throughout the discussion, record responses in patient’s chart or other tool used by the clinic for appointment follow up and patient support. Note that while having a record is important for tracking and follow through, active listening is key to this relationship building question.

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

Introducing the Conversation:

You and I 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 their condition. And COVID-19 made that so much worse. Now that we’re all getting back to regular appointments, let’s look at what’s changed – and what still needs to change to make getting to appointments for easier for you/your family. First, I want to make sure I understand what can make getting to appointments hard for you/your family...and see if there is anything we here at the clinic/office/center can do to help. Plus, you might have ideas for working through problems that could help other people living with SCD. Does that sound OK?

Transportation:

Like you saw in the video, some people have trouble with transportation to appointments.

- How do you usually get here and to your/your child’s other sickle cell disease appointments?
- Do you run into problems with how to get to appointments?
- What makes this harder for you? (cost, distance, access to driver, availability of public transportation)

Response to transportation issues:

- ✓ If problem revealed, discuss potential solutions. Be prepared with local public transportation information, Medicaid vouchers for ride-sharing or taxis, and refer to local CBO for learning from other patients and caregivers.
- ✓ If no problem revealed, note current transportation option, so you can check that it is still viable at next visit. If solution is creative or new to you, suggest patient/caregiver share with others in the clinic or local CBO.

Scheduling:

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. I am really impressed with how you manage it all.

- 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?
- What do you use to keep track of your appointments and schedule? Do these strategies help?
- If we – here at the clinic – must change your appointment, how do you handle that?

Response to scheduling issues:

- ✓ If problem revealed, discuss potential solutions.
- ✓ Discuss appointment reminders and how your clinic provides them. Ask how clinic can be more alert to conflicts that come up.
- ✓ Talk about what calendar patient/family uses (wall, Google, Outlook) and how to keep track of clinic and family changes using their preferred method or support for them to learn/use a calendar that syncs with the clinic reminders.
- ✓ If no problem revealed, record answers, so you can refer to this response at next visit.

Questions Related to Health Literacy:

Having SCD means a lot of tests and treatments other people don't have. It can be confusing. Have you ever missed an appointment or test because you weren't sure what you needed to do? (i.e., patient didn't realize the preparation for a test and when they arrived, the test had to be rescheduled)

- Sometimes people move or change jobs their insurance changes or even ends – has that happened to you and made you miss an appointment or test?
- Have problems with insurance ever made you miss an appointment?

Response to health literacy issues:

- ✓ If problem revealed, discuss potential solutions.
- ✓ Discuss options available at your clinic: possible care coordinator, translator, or social worker
- ✓ Offer resources and information to connect to a local community-based organization that provides SCD information and support
- ✓ If no problem revealed, record answers, so you can refer to this response at next visit

Final Questions:

- Are there any other reasons you may have missed an appointment? Any other difficulties that make it hard for to get here sometimes?
- Is there anything else that I can do, as part of your team, to help you with any of the difficulties you might have with getting to appointments? (Take patient/family suggestions back to clinic staff rather than addressing in the moment. Commit to getting back to patient/family at next appointment)

Conclusion

Thank you so much for talking with me about this. Let's touch base at your future visits to be sure we've been able to help you with any appointment issues or ensure nothing comes up in the future that makes it hard for you to make your appointments.