



Roundtable on Resources for Sickle Cell Disease Caregivers: Meeting Summary

Overview

On May 25, 2021, [Sick Cells](#) and [Caregiver Action Network](#) (CAN) hosted a multi-stakeholder roundtable discussion with individuals who care for loved ones with sickle cell disease (SCD). The goal of the roundtable was to understand the specific challenges SCD caregivers face. Through hearing the caregivers' perspectives, Sick Cells in partnership with the CAN developed a "[Roadmap of Resources](#)" to support SCD caregivers, improve their quality of life, and reduce their stress. This document summarizes the roundtable discussion.

The objective of the discussion was to inform trainings for the [Caregiver Help Desk](#). The Caregiver Help Desk is a unique, free support center that provides support to caregivers via phone, email or live chat. Caregiver Action Network partners with [Caralle!](#)'s Care Advocates to serve a broad spectrum of family caregivers through the Help Desk. The output of this discussion will serve as a training guide to equip Care Advocates with educational tools and resources to better support SCD caregivers.

The discussion was designed to provide Care Advocates an opportunity to engage with SCD caregivers and better understand the day-to-day impact of caregiving and the challenges they face. It also provided an opportunity to discuss resources they have found helpful in order for these to be leveraged for others through the Caregiver Help Desk. Pediatric and adult SCD providers were invited to participate and discuss resources to improve provider:caregiver communications.

The roundtable was attended by 4 SCD caregivers, 4 Care Advocates, and 2 SCD clinical providers. Sick Cells and CAN Staff participated as moderators for the discussion. A list of all attendees is provided in **Appendix A**. This roundtable was conducted through the support of Novartis' 2021 Solutions to Empower Patients ([STEP](#)) program.

Summary of Themes

The roundtable participants shared personal anecdotes of lived experiences and challenges associated with caregiving. The participants' discussion covered six overarching topics:

- Impact of Caregiving on Caregiver Mental and Emotional Health
- Importance of Strong Support System
- Challenges with Providers and the Medical System
- Legal Challenges of Caregiving
- Financial Burden and Economic Impact
- Available Resources for SCD Caregivers



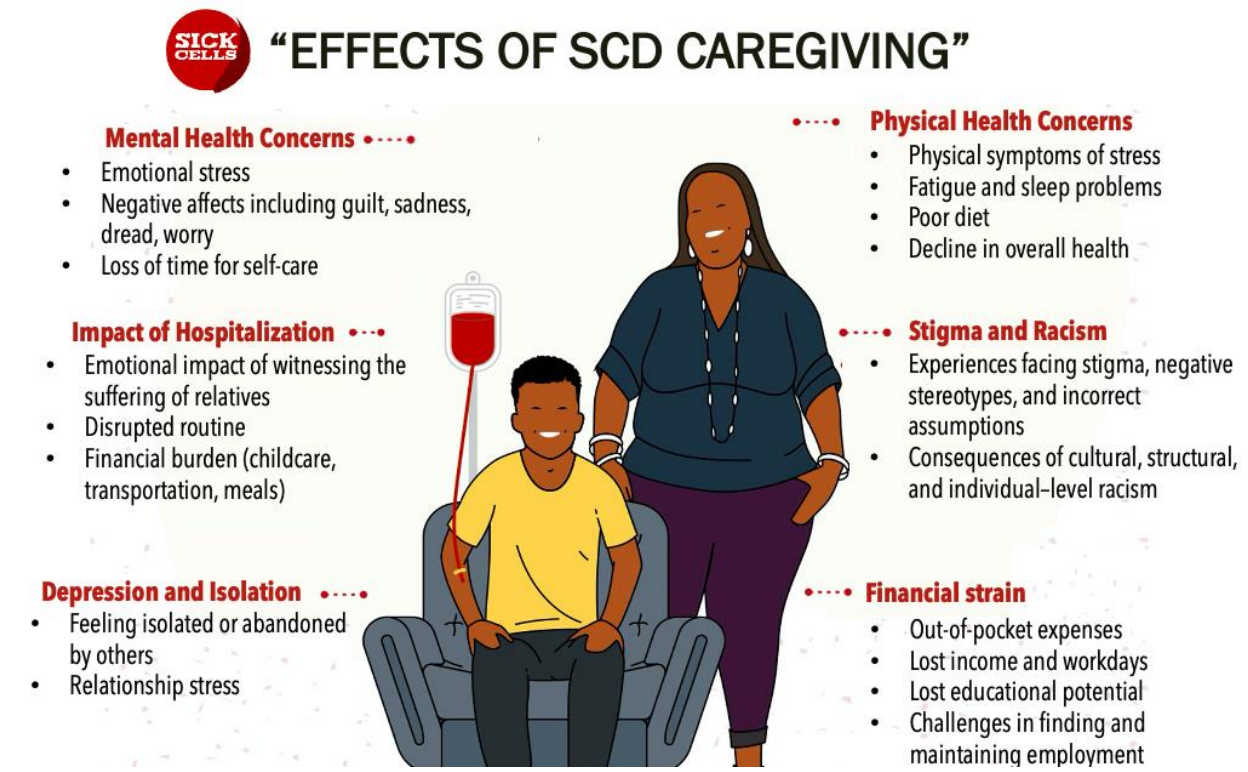
Agenda Overview

The agenda was developed by Sick Cells and CAN and included four sessions.

Session 1: Defining Needs from the SCD Caregiver Perspective

The roundtable discussion began with Sick Cells sharing findings from the “My Life with Sickle Cell Patient and Caregiver Survey.” The diagram summarized key concepts and issues raised by caregivers in the survey (Diagram 1). The caregiver participants were then asked to add their perspectives of the issues, sharing anecdotes of lived experiences and elaborating on challenges associated with caregiving that they have faced.

Diagram 1: Themes Identified from Sick Cells “My Life with Sickle Cell” Patient and Caregiver Survey, February 2020.



Participants explained that another major challenge they face is lack of education about SCD for healthcare providers. They described ER providers and other staff knowing little about the disease, and the constant battle and burden of caregivers to try to educate the clinical staff. This is an important area where resources are needed.

Several participants discussed the need for more supportive measures for mental health. One individual shared a story about challenges related to legal support and guardianship. Others talked about challenges related to the lack of social support. One participant shared how other family



members and friends do not understand the challenges they face as a caregiver, and therefore, do not provide adequate social support.

Racism was widely discussed as a major stressor. Because of stigma and discrimination, their loved ones do not receive adequate care. Caregivers are needed to step in and advocate, however oftentimes there is little guidance on what to do when your loved one is mistreated.

Caregivers expressed that it was critical for them to have a good pediatric hematologist, or someone that was willing to sit with them and teach them about SCD. Many knew little about the disease or the trait before receiving the diagnosis, so proper education is a critical piece for caregivers. There was also discussion about Latin Americans and Hispanics being an underappreciated population affected by SCD and the need to increase tailored education for these communities.

Session 2: Information and Resources to Address Clinical Barriers for SCD Care

The next session posed questions to the clinical providers. The goal was to discuss communication strategies and resources that could improve the provider-caregiver relationship and decrease burden for caregivers.

Several important resources were discussed, including clinical guidelines and educational materials from organizations like the National Institutes of Health (NIH), the American Society of Hematology (ASH), and Center of Disease Control and Prevention (CDC).

They also stressed the importance for caregivers to use available resources through the home clinics like provider portals, parent support groups, or nurse case managers. Additionally, there were recommendations for caregivers to join hospital committees or advisory boards.

Advice also included ensuring the caregiver was open and honest with their providers. It is important to discuss any social stressors or barriers that may be impacting the health of the patient. For example, are there factors that may be contributing to missed appointments, or is the family facing insurance issues? These are important conversations to have with the care team, and open communication will help build trust and improve care.

Session 3: Understanding Existing Resources from Help Desk Staff

In the third session, the Care Advocates shared their experience and expertise supporting caregivers through the Caregiver Help Desk. Through the discussion, several resources were identified that can address several of the challenges described in earlier sessions. Specifically, the CAN website provides resources for caregivers struggling with mental health, stress, and physical health concerns. Financial strain is also a familiar challenge caregivers face, and Care Advocates shared stories of helping guide other caregivers to locate services for medication funding or copays.



Care Advocates shared personal stories of the impact of the COVID-19 pandemic and the increased need for resources related to depression and isolation. They also explained that they have resources for therapists and counselors who are experienced in dealing with stigma and racism, which could be an important support for SCD caregivers.

Session 4: The Journey Map of a SCD Caregiver

The final session focused on the creation of “**The Journey Map of a SCD Caregiver**”. This graphic serves as a way to visualize the experience an individual goes through as a caregiver to a loved one with SCD. By mapping the individual’s experience, others can understand the pain points, and work to develop specific solutions. Roundtable participants reviewed the journey map and identified resources to bridge the gaps. The final journey map can be viewed in Appendix B.

“The Journey Map of a SCD Caregiver” was adapted from the U.S. Department of Health and Human Services (HHS) [Health+ SCD Initiative](#) and supported by data from Sick Cells’ “My Life With Sickle Cell” Patient and Caregiver Survey.

Roadmap of Resources

The roundtable discussion identified a number of helpful tools and resources to address the specific needs and challenges of SCD caregivers. Following the roundtable, the Sick Cells and CAN teams also gathered materials from other organizations and sources to address any gaps. These resources are summarized in the [Roadmap of Resources](#) document and can be found on the [Caregiver Resources](#) page on the Sick Cells’ website.

Next Steps

As of July 2021, the Caregiver Help Desk will utilize the Roadmap of Resources to assist SCD caregivers navigating the healthcare system and to aid their selfcare, family care, and care of their loved ones with SCD. Additionally, Sick Cells in partnership with the CAN will continue to promote educational materials, resources and services designated to meet the specific needs of SCD caregivers. For more information about these efforts and available resources for SCD caregivers, please check out the [Caregiver Resource](#) page on the Sick Cells website.

Acknowledgements

We are extremely thankful to each participant for their contribution in this roundtable discussion and for their commitment to the advocate for caregivers in the SCD community. Additionally, we thank Novartis for their generous support of our work.



Appendix A: Roundtable Attendees

Name	Stakeholder Group
Jean-Marc Dejoie	SCD Caregiver
Nairobi Casildo Portillo	SCD Caregiver
Rebecca Seavers	SCD Caregiver
Carla Lewis	SCD Caregiver
Jennifer Piscitello	Care Advocate (Carallel)
Stephanie Banta	Care Advocate (Carallel)
Meghan Cashman	Care Advocate (Carallel)
Hillary Ebach	Care Advocate (Carallel)
Barbara Speller-Brown	SCD Provider
Mandy David	SCD Provider
Emma Andelson	Sick Cells Staff
Ashley Valentine	Sick Cells Staff
Maggie Jalowsky	Sick Cells Staff
Abby Tainter	Sick Cells Staff
TaLana Hughes	Sick Cells Advisor
Chance Browning	CAN Staff
Nichole Goble	CAN Staff
Lisa Winstel	CAN Staff
Jodi Koehn-Pike	CAN Staff



Appendix B:

[see next page]



The Journey Map of a SCD Caregiver

The **Journey Map of a SCD Caregiver** is a blueprint of the encounters an individual can go through as a caregiver to a loved one with sickle cell disease (SCD). This diagram was created by [Sick Cells](#) and used during the May 2021 **Roundtable on Resources for SCD Caregivers** in effort to visualize an individual's experience and align resources and support. This caregiver journey map is adapted from [the HHS Health+ SCD Initiative](#) and supported by data from Sick Cells' "My Life With Sickle Cell" Patient and Caregiver Survey and roundtable discussion.

The journey map is discussed in 3 phases:

1. Caregiver of a child with SCD
2. Caregiver of an Adolescent with SCD
3. Caregiver of an Adult with SCD

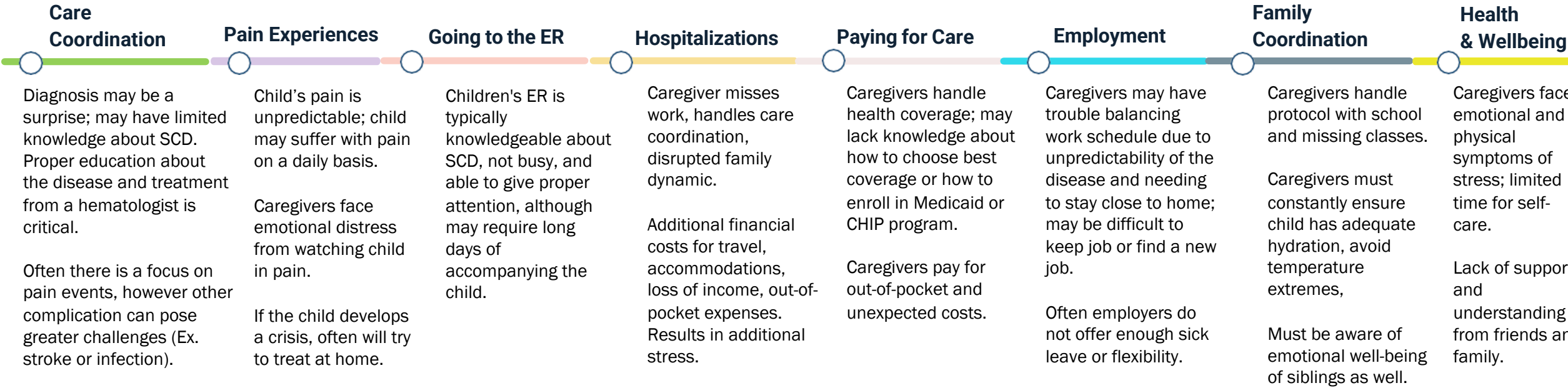
Each phase highlights **eight "pain points"** or common areas where caregivers experience challenges or barriers that may require support:





Caregiving for a Child with SCD

Caregivers bear the responsibility of all care coordination, decisions, life interruptions, and more



“Waking up to your child screaming in agony at 4 o’clock in the morning is a feeling that I wish on no one.”

“She is 4 so we are constantly telling her to stay hydrated, not be too hot or cold and wash her hands. Tough to have a normal childhood with limitations.”

“Our daughter doesn’t get recess during the winter while all her classmates go outside.”

“Caring for a person with SCD makes it difficult to obtain new employment since the need for FMLA is almost inevitable. It will take 12 months before one becomes eligible and one will probably lose job for absenteeism before they hit the 12 month eligibility.”

“You have no control of your life as a caregiver. Your child with sickle cell also has no control. You can try your best to provide for the basic health and nutrition for your child, but you can’t predict and control when a crisis occurs.”



Caregiving for an Adolescent with SCD

With the young adult reaching transition age, there are many new and unfamiliar barriers.

Care Coordination

Caregiver must help prepare adolescent for transition.

Knowledgeable adult providers are hard to find; may also require coordination of multiple specialists they didn't need before.

Pain Experiences

Unpredictable and disabling pain crises can last 4+ days; SCD adults often develop chronic daily pain.

Caregivers responsible for the care when loved one is unable to care for themselves.

Going to the ER

Adolescent faces new challenges of negative experiences and stigma in ER; need caregiver as advocate.

Adult ER often is busy, lacks SCD expertise, and is discriminatory.

Often suspicious of young, potentially "drug seeking" SCD patients.

Hospitalizations

Caregiver is responsible for teaching child to make medical decisions and coordinating work and school disruptions during traumatic life periods.

Caregiver misses work and other life disruptions.

Paying for Care

Caregiver worries over child's health coverage and impact on continuity of care; child may lose Medicaid coverage.

Caregiver must teach child how to choose insurance, when to enroll, etc.; may struggle to continue financing their care.

Employment

Caregivers continue to face negative impacts on work with lost time at work, decreased productivity, lost career opportunities, and unpaid absences.

Family Coordination

Child may desire to be more independent and fit in with peers; Caregivers face challenges with teen defiance or rebellion.

May require legal support re: health care proxies, living wills, and HIPAA.

Health & Wellbeing

Caregivers experience caregiver burnout, neglects their own needs, and suffer from physical and emotional exhaustion; Often lack social support.

“Regular ER doctors sometimes dismiss their pain. They don't give them enough pain medicine to help the pain [...] Sometimes doctors/nurses treat sickle cell patients bad.”

“Caring for a child with SCD is a constant mental burden whether the child is in crisis or not. There are also many comorbidities with SCD that we have faced: AVN, asthma, loss of hearing, retinal bleed. SCD is way more than pain.”

“I worry alot about my child.”

“SCD is very unpredictable. Everything you do is in the context of SCD. Where do you go for college? What's the weather?”

“You have no control of your life as a caregiver. Your child with sickle cell also has no control. You can try your best to provide for the basic health and nutrition for your child, but you can't predict and control when a crisis occurs.”

“I have missed so many job opportunities, class withdrawals, and work hours. I have stop counting.”



Caregiving for an Adult with SCD

Caregivers continue to experience many challenges when providing “informal care” or support for their spouse, adult child, or loved one with SCD.

Care Coordination

Pain Experiences

Going to the ER

Hospitalizations

Paying for Care

Employment

Family Coordination

Health & Wellbeing

With disease progression, patients may have complications in multiple organ systems; may affect functions and lead to impairments that require more involvement from a caregiver.

Lack of specialized care, advance care planning, and longstanding racism in health care create challenges.

Pain exacerbations may become more frequent, requiring greater caregiver involvement.

Stigma can be compounded by racism and can pose significant barriers to pain management.

Patients face bias, excessive wait times, insufficient pain medication, and emotional distress of not being believed. Caregivers are needed to advocate for patient while in ER or file complaints after ER visit.

Often patients may be discharged while possible still sick and in pain; Caregivers are needed to assist with recovery.

Emotional trauma of the hospitalization can linger for caregivers.

Financial burden worsens with age; caregivers often are needed to help mitigate health care costs for patients.

Caregivers may need assistance to reentering the work force after many years of unemployment.

Unpredictability of onset of unforeseen complications may continue to limit employment opportunities.

New challenges may arise if patients have children and require childcare; may rely on the help and support of friends and other family members to step in.

Effects of prolonged stress and post-traumatic stress disorder impact caregivers; struggle to find the time and the energy to take care of their own health.

“It pains me to see the mistreatments that they endure while being in the hospital, the judgments that are passed. The lack of understanding and urgency to their needs bothers me. It’s so much trouble [for] my wife to receive her pain medications.”

“Daily health maintenance without a paid caregiver for serious complications such as seizures, memory impairments, heart failure, renal failure, acute chest and bone death make it nearly impossible to hold down a full time job even with a FMLA in place.”

“As a caregiver I am unable to work and make my place in the world due to negligent hospital care. Instead I spend my life fighting against a racist system.”

“I find that, as a caregiver, I downplay my own health issues so as not to worry my daughter as they seem insignificant in comparison. I also feel that I am judged unfairly by others if I don’t rush to her side when both she and I know this is a “minor” crisis. Yet folks also judge if I am gone too long once she’s released from the hospital. And I don’t get time to recuperate from the time spent caring for her either (and feel guilty for wanting it). Mental health care is very important for all involved.”