Using a Community-Engaged Research Approach to Prioritize Self-Management Needs of Adults with Sickle Cell Disease

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ABSTRACT

Background: Sickle cell disease (SCD) is the most common blood disorder in the United States. Self-management is vital for mitigating sickle cell symptoms. However, limited research has reported self-identified priorities and needs for self-management among adults living with SCD, and few researchers have used a community-engaged research approach.

Objectives: We conducted community-engaged, qualitative research to learn about self-management needs among adults living with SCD.

Methods: Focus groups were conducted among adults with SCD and stakeholders in the SCD community (parents of adults with SCD and healthcare providers). A qualitative descriptive design and thematic analysis were employed.

Results: Four focus groups were conducted with 23 adults living with SCD and one was conducted with four community stakeholders. Of the adults with SCD (ages 20-34), 69.6% (n = 16) were ages 25-34 and 87% (n = 20) had sickle cell anemia. All (100%, n = 23) identified as Black and most (69.6%, n = 16) identified as female. All four community stakeholders identified as Black females and were ages 50-55. Thematic analysis generated three themes: (1) unsafe healthcare; (2) mental health needs and psychosocial support; and (3) successfully transitioning from pediatric care to adult care.

Conclusions: Healthcare gaps and healthcare provider bias are barriers to successful SCD self-management. Therefore, for individuals with SCD, interventions should be developed to anticipate the transition from pediatric care to adult care, improve healthcare, and support self-management strategies and skills.

KEYWORDS: Sickle cell disease, adults, self-management, community-based participatory research, health disparities

Sickle cell disease (SCD), the most common inherited blood disorder in the United States (U.S.), affects at least 100,000 Americans.[1] Hallmark symptoms of SCD, such as pain,[2] contribute to significant morbidity and frequent healthcare encounters annually.[3] To mitigate SCD symptoms, patients' self-management is vital.[4] Self-management involves engaging in daily, self-motivated planning and actions to manage symptoms and promote health, while enhancing well-being and quality of life (QoL).[4-6] Knowledge of SCD and a collaborative relationship with healthcare providers (HCPs) create the necessary foundation for developing effective self-management skills.

Challenges to self-management among adults living with SCD include low self-efficacy, insufficient support from family, friends, and HCPs, poor care coordination, and overall lack of information.[4,5,7] Research that identifies adults' priorities and needs for SCD self-management, given these challenges, is scarce. Moreover, few researchers have used a community-based participatory research (CBPR) approach.[8,9] CBPR denotes principles and practices that enable investigators to better integrate community partners and stakeholders into the research process and employ collaboration to address matters of importance to the community.[10,11] CBPR is effective in reducing inequities and sustaining positive outcomes,[11] thus a perfect fit for exploring knowledge gaps regarding adults' priorities and needs for SCD self-management.

The purpose of this community-engaged, qualitative research was to learn about self-management needs among adults with SCD. By applying CBPR principles,[12] this information was gathered in collaboration with people living with SCD and stakeholders in the SCD community. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to guide the development of this research report.[13]

Methods

Our research employed a qualitative descriptive design using focus groups. Ethics approvals were obtained from the University's Institutional Review Board before engaging with adults living with SCD and community stakeholders.

Community Partnership

Eighteen months prior to research initiation, the principal investigator (PI) began a community-engaged partnership with the local SCD community. The purpose of this partnership was to identify, prioritize, plan, and conduct research projects to benefit the SCD community. To develop this partnership, the PI engaged in discussions with four adults living with SCD to explore seeking grant support for community partnerships and research collaboration. Of the four adults with SCD, one joined the research team while others offered to provide insight as needed given limited availability. The PI continued meeting with the group monthly and as needed. A partnership was also established with SCD community members given shared interest in understanding the community's needs and strengths. Community partners included parents of adults with SCD, HCPs, a faith-based organization (FBO), and a Black-owned business that promotes social wellness in the community. Our community partners worked together to delineate priorities for self-management needs among adults, ages 18-35, with SCD. The priorities encompassed three primary domains: emergency department (ED) encounters, mental health needs, and psychosocial support. Subsequently, our community partners were actively involved in determining the logistics of conducting the focus groups, developing the focus group guide, and recruiting participants. Community partners were also invited to participate in dissemination activities, and one (E.O.) agreed to serve as a co-author.

Research Team

The research team consisted of academic and community members. Academic members included seven PhD-prepared female researchers (five with degrees in nursing and two with degrees in rehabilitation counseling) who have 60 years of combined experience in conducting research involving adults with SCD, implementing qualitative methodology, and facilitating focus groups. Community members were two women living with SCD, one with a master's degree and one undergraduate sociology student, who received focus group training from the PI.

Our ethnically diverse research team included three researchers of African descent, four White researchers, and one Asian American researcher who all had clinical, academic, or research experience interacting with adults with SCD, or Black or African American people. The two community research team members were individuals of African descent who were ages 20 and 24. The research team's identity and positionality contributed to the success of the research and an "insider" understanding of the needs of adults living with SCD. Academic team members' depth of experience in healthcare settings (spanning care, treatment, and policy) and research methodology was instrumental in shaping the CBPR approach. Our expertise in fostering nonjudgmental, unconditional positive regard allowed us to establish rapport and trust with research participants, which played a critical role in ensuring the generation of rigorous data. However, our identity and positionality with respect to our professional roles and experience with the SCD community may have influenced the conduct of the focus groups (e.g., how questions were worded and framed), participants' responses (e.g., how and in what ways they responded to questions), as well as evaluation and interpretation of the research data. To account for this and maintain reflexivity, member checking was implemented informally during the focus groups by asking participants to clarify their statements, explain their meaning, and validate our understanding of the data.[14-17]

Research Setting and Recruitment

The setting for this research was a Midwestern city in the U.S. where, as in many other U.S. cities, Black or African American residents disproportionately experience high unemployment, severe poverty, poor access to health resources, and limited opportunities for research participation.[18] Participants were recruited using purposive sampling by contacting individuals (in person, by telephone, and via email) who were identified through partnerships with community groups, SCD community-based organizations, FBOs, and an adult comprehensive SCD clinic. Information about the research project was disseminated through word-of-mouth referrals, flyers, announcements made by an FBO during weekly church services, and face-to-face discussions with potential participants.

Participants

Eligibility criteria for adults living with SCD were a diagnosis of SCD, ages 18-35, and the ability to speak and understand English. Eligibility criteria for community stakeholders were having an adult child (ages 18-35) with SCD or having a healthcare occupation that involved interacting with people with SCD and being able to speak and understand English. Participants were 23 adults with SCD and four community stakeholders (two parents of adults with SCD, a registered dietician, and a licensed counselor). All individuals provided written informed consent before participating in research activities.

Data Collection

Data were collected using a researcher-generated demographic survey and a focus group guide. The survey was administered to participants, in person prior to starting the focus groups,

to obtain information about their age, gender, and ethnicity, as well as hemoglobinopathy type for adults with SCD.

The research team developed the focus group guide (see Appendix 1) based on discussions with community partners, researchers with CBPR expertise, focus group co-facilitators' lived SCD experiences, and previous PI interactions with the SCD community. The guide, which was reviewed and approved by two adults who live with SCD, included questions reflecting priority areas for self-management needs identified by community partners: ED encounters and outcomes, mental health needs and interventions, and psychosocial support.

Five focus groups, each consisting of 4-6 participants and 1-2 researchers, were conducted during a 4-month period in a conference room at the FBO or Black-owned business. Each focus group session was facilitated by one or two research team members, at least one of whom was a researcher, a community member, an SCD advocate, or an adult with SCD. All participants had experiences of living with SCD through either personally having SCD or being in a close relationship with someone living with SCD.

While all participants were members of the SCD community, two types of focus groups were conducted to maintain homogeneity within the groups regarding SCD status. Four focus group sessions involved adults living with SCD, and one session involved parents of adults living with SCD and HCPs. The small size of the focus groups allowed ample time for active interaction among participants and discussion of individual experiences and opinions.[19] The rich, in-depth data obtained from participants during these five focus group sessions was adequate for analysis and generation of meaningful results to answer our research questions;[20] therefore, we concluded recruitment and data collection.

All focus groups were audio-recorded using a digital recorder and transcribed verbatim by professional transcriptionists. Facilitators also documented observation notes during and after each session. Participants received a $50 gift card and a meal during each session, which was approximately 90 minutes in duration.

Data Analysis

Demographic data were summarized using descriptive statistics while analysis of focus group transcripts and observation notes employed thematic analysis.[21] A deductive approach to coding relies on frameworks or theories that provide predefined codes to guide the coding.[22] In contrast, we conducted coding using an inductive approach that permitted us to develop codes from the raw data without imposition of existing theoretical structures.[22] The PI conducted an initial review of all transcripts and observation notes to formulate a code book. One member of the research team, who is living with SCD, reviewed and affirmed the initial code book. Afterward, the PI applied the codes from the code book to 40% of the transcripts, a second team member critically reviewed the initial coding, and then two additional team members independently analyzed the transcripts using the code book. The code book was refined throughout the analysis to integrate new codes and evolving ideas. Consensus discussions were utilized to address any differences and achieve agreement regarding applied codes. Recurring patterns and categories identified across focus groups were then further evaluated and summarized as themes.

Results

Of the 23 adults with SCD (ages 20-34), 69.6% (n = 16) were ages 25-34 and 87% (n = 20) had sickle cell anemia. All (100%, n = 23) identified as Black and most (69.6%, n = 16)

identified as female. All four community stakeholders identified as Black females and were ages 50-55. The three themes generated by thematic analysis of the focus groups (FG) characterize challenges, needs, and assets for self-management among adults with SCD: (1) Unsafe healthcare; (2) Mental health needs and psychosocial support; and (3) Successfully transitioning from pediatric care to adult care.

Unsafe Healthcare

Participants with SCD identified experiences in the ED that presented obstacles to managing their health. In the ED, participants reported waiting for hours before receiving treatment. Hours elapsed (one participant stated 12 hours elapsed) before pain was managed, if they were not discharged home prior to achieving pain management. One participant (P) described her experience:

> *"...I went to [hospital name] and they didn't give me an IV, they didn't give me any fluids. Yeah, they got me back there faster but all he gave me was a Percocet 5 and then it was oral. And so, by the time that he came back, he had already had my discharge papers and I'm like, 'I don't feel any better. They didn't do anything. What do you mean you have my discharge papers?' And he's like, 'Oh, well we can try to give you another one. You think that'll work?' I'm like, 'Well, give me something. You're trying to discharge me without me even feeling better.' I'm like, 'What do you mean?'"* (FG1, P3)

Participants reported receiving poor quality of care in the ED. They reported issues with receiving necessary medication or appropriate amounts of medication, such as medications for nausea or pain. One participant stated: "*I have been to an emergency room here that told me, they don't give sickle cell patients any...any IV medication for sickle cell pain. They don't*

prescribe narcotics there" (FG4, P2). Others reported being told they would have to wait until the sickle cell clinic opens to receive care. Additionally, the care they did receive was not appropriate for SCD patients and did not adhere to SCD care/treatment plans patients established with their HCPs. One participant stated:

> *"I'm allergic to morphine so I'll get Dilaudid, but that will still make me itch really, really bad. In the clinic, for me, I have to get Benadryl. In the emergency room they told me that they stopped giving sickle cell patients Benadryl because it makes them high and that's what a lot of sickle cell patients come into the hospital for."* (FG4, P3)

Overall, participants experienced an incongruence between expected and actual care, emphasizing that members of the healthcare team in the ED failed to provide standardized, immediate care consistent with national guidelines. One participant remarked:

> *"If there are treatment guidelines for sickle cell pain, why aren't they being followed? They've been released by the National Heart, Lung, and Blood Institute, and they recommend how quickly somebody with sickle cell pain should be given a pain medication when they come into the emergency room, but they're not being followed, and why are they not being followed? We have to ask those questions."* (FG5, P2)

A contributing factor noted by participants was that HCPs need education regarding SCD and training to improve care because SCD is unlike other chronic conditions involving pain.

Participants who had acquired a high level of pain self-management encountered challenges when seeking clinical assistance. They revealed that the quality of care they received was dependent on HCPs' biases regarding how a patient should respond to pain. One participant

stated: "*When you're living with pain your whole life, you know how to manage it. And so, even though you're in a lot of pain, you are holding on tight and trying to be strong, and so people might assume that you are not really suffering*" (FG5, P2). However, obvious signs of distress did not result in improved care. One participant stated: *"There's been a couple of times where I've been in the hospital crying, like literally showing my tears of distress, and I still had to wait there for hours. And the only thing that they do is give you a blanket. I've had to wait five hours just to get to triage, let alone get a room"* (FG3, P4). Another stated: *"…even sometimes I've shown up by ambulance and they still have me sit in the lobby"* (FG1, P3). Additionally, participants described several experiences and interactions with HCPs that they felt were prejudicial regarding people with SCD, such as being considered as drug-seeking when requesting necessary and appropriate care. One participant stated:

> *"I avoid the ER because they treat you like you're a drug addict, popping drugs. It's true, they do. They just assume you're there just to get your hit or whatever. They don't need to say it upfront to your face to get the vibe that you're thinking that. I can tell. But I know personally…even [at] a children's hospital, it's always been a battle, as far as having people question the legitimacy of what you're going through and the severity of it."* (FG1 P5)

Because of perceived, past negative experiences in the ED, participants often used self-management instead of seeking care and delayed seeking care until there was no other option.

Mental Health Needs and Psychosocial Support

Participants felt that SCD was misunderstood by HCPs, family, and friends. Although their pain was severe, it was not always visible or understandable to others, so their reports of

pain were not always believed. Lack of belief in the patient contributed to participants experiencing stress and compromised mental health, which were also overlooked. Sometimes participants minimized their experience of SCD to appear "normal" because they did not want others to feel sorry for them or to be treated differently. However, when they displayed resilience and perseverance by "*holding on tight and trying to be strong*," it was assumed that they were doing well with their mental health.

A mental health challenge identified by participants was feeling responsible for their own sadness about SCD and blaming themselves for their symptoms. One participant shared:

> "*I found myself blaming me for everything like, 'Oh, well it's my fault that this is happening ...Oh, it's my fault that this went that way instead of going this way.'... It's like, 'Oh, well maybe if I would've did this or maybe if I would've put on an extra pair of pants, or maybe if I would've stayed home. It's a struggle on top of a struggle.*" (FG1, P3)

Additionally, the chronic, severe, and persistent nature of SCD caused them to feel hopeless. A parent participant shared: "*My daughter does transfusions every five weeks. One time she came up to me and she was like, 'I just feel like I'm living my life in five-week chunks.' And then she said, 'If it doesn't work, I'm just going to die*'" (FG5, P2). In response to her daughter's distress, this parent also had feelings of hopelessness "*because you keep thinking about the disease, the treatment, and the life one's child must lead because of SCD*" (FG5, P2).

Participants with SCD valued having a support person, whether family, friend, or community member, when presenting to the hospital during a pain episode. As one participant said, "*because any time you have a high level of pain, different things are going on with your body like that. Who wants to go through that alone?*" (FG5, P1). Participants reported that support persons also needed support, both physically and emotionally. A parent participant

suggested that part of the hospital admission process for people with SCD should be to also ask about needs of the support person. They said, "*she's [person with SCD] not the only one that's going through crisis, you're [support person] going through crisis. And I think they [healthcare team at the hospital] forget that*" (FG5, P1). Participants also indicated that having a mental HCP visit them in the ED or hospital would provide needed holistic care. Further, they identified the need for access to an outpatient mental HCP who had training and experience working with people with SCD. One participant said:

> *"If you're going to be working with sickle cell patients, or any type of patient, if there are issues of depression, issues of anxiety, you have to really know how to approach that, and talk about it. Because there's a lot of denial, because of the stigma…*" (FG5, P2)

Other ways participants indicated that the healthcare team could be useful included offering support groups, facilitating a trusted relationship with consistent providers, and having HCPs who are knowledgeable about SCD and who treat patients as individuals. One participant explained, "*I would say first and foremost what I've learned is that not every sickle cell patient is the same. We have different experiences because my sister has it too, and she has had a completely different life experience than me*" (FG1, P1). One participant also mentioned a need for assistance from HCPs with educating individuals outside the healthcare system who impact patients' lives, and assistance with obtaining accommodations that might be needed at work or school.

Successfully Transitioning from Pediatric Care to Adult Care

Participants with SCD highlighted an abrupt shift in support systems and available resources as they transitioned from pediatric care to adult care. In the pediatric setting, multidisciplinary teams consisting of nurse practitioners, hematologists, social workers, and

other specialists collaborated to address their medical, emotional, and social needs. In the adult care setting, there was a striking difference:

> *"Everything changed when you hit adulthood…When you were a child, you had all those privileges... Everything in the world. But now as you're an adult, everything is limited to you."* (FG3, P2)

The transition to adult care was largely characterized by less help as well as a lack of comprehensive and clear communication from the medical team. One participant noted that *"It wasn't really a transition at all. It was just like jumping"* (FG1, P2). When considering their experiences, participants with SCD overwhelmingly desired the same style of care, support, communication, and access to resources in adult care as they received in pediatric care.

Participants with SCD also expressed frustration when confidentiality was prioritized over parental involvement during the transition period. They felt this focus hindered the support that young adults could receive from a parent. One participant shared:

> *"Allow their parents to like, be there for their [child's] care. They [HCPs] kind of like, push that part away because of patient confidentiality."* (FG3, P1)

During the transition process, participants with SCD expected their healthcare teams to be mindful of their individual needs and collaborate with their support system (e.g., family and friends)—both expectations of person-centered care. Participants also emphasized the importance of having a peer who can provide support, guidance, and understanding based on their first-hand experiences.

Discussion

Using a CBPR approach enabled contextualized learning about the challenges, needs, and assets for self-management among adults living with SCD. We found that healthcare gaps and HCPs' biases are major challenges to self-management, and that adults with SCD need support to address mental health concerns and the transition from pediatric care to adult care. Assets for self-management included having experience and knowledge regarding pain self-management, an awareness of clinical care standards for people with SCD, and family members as dependable allies and advocates. Research findings highlight the need to recognize adults with SCD as experts regarding their own bodies and consider them as members of their own healthcare team.

Perceived discrimination, or bias, is a strong predictor of severe clinical pain among individuals with SCD.[23] Discrimination also contributes to undertreatment of pain and poor interpersonal interactions among adults with SCD and HCPs. Although the SCD community is not largely affected by the opioid epidemic,[24,25] significant negative assumptions unjustly persist with respect to HCPs' perceptions of adults with SCD and stigma regarding their pain medication and management needs. The unique mental health needs and psychosocial support challenges experienced by adults with SCD are further exacerbated by the detrimental effects of bias, and can lead to feelings of isolation, loneliness, and hopelessness,[26] which in turn negatively influence the pain experience. Additionally, feeling misunderstood and judged by HCPs precludes the capacity for trust and prevents patients' engagement with treatment plans, contributing to ongoing health inequities.[27,28] A macro level of advocacy is essential for educating HCPs about SCD and training them to use established guidelines[29] to provide standardized, ethical, and empathetic healthcare to people with SCD that also addresses psychosocial needs. It may also be beneficial to consider how systemic racism in healthcare

influences healthcare quality for adults with SCD and whether those issues intersect with perceived bias by healthcare team members.

The transition from pediatric care to adult care is a critical and challenging period for individuals living with SCD. During adolescence, for example, families of adolescents with SCD may encourage more independence, but the adolescents' lack of skills in medication management and navigation of healthcare is a barrier to care.[30] Sudden shifts in care without adequate resources intensify challenges inherent in developing self-management skills while establishing independence as an adult.[30] A successful transition is dependent on fostering a collaborative, patient-centered approach to disease management and promotion of well-being that accounts for and addresses actual and potential gaps in care. Additionally, fostering self-efficacy skills can improve self-management, complimented by family support and employment.[5] Achieving a balance between maintaining patient confidentiality and involving support systems in care planning and decision-making is a critical aspect of improving the transition process and improving the self-management ability of young adults with SCD during the transition period and beyond.

The Theory of Self-care Management for Sickle Cell Disease[31] posits that factors contributing to vulnerability, such as unsafe healthcare and discrimination in healthcare settings, challenges to mental health, and lack of transition support, negatively influence self-management and health outcomes, including health-related quality of life. Care seeking is an important element of self-management. Delayed care seeking or avoidance of the ED increases the risk of SCD complications, having pain that is difficult to treat or requires higher levels of treatment, the need for hospitalization, and increased length of hospital stay, thus higher healthcare costs.[31] In

the ED, adults with SCD frequently contend with dual biases of disease and race, which perpetuate the stereotype of drug-seeking behavior.[32] Negative care experiences in the ED contribute to challenges in obtaining medications and any resources necessary for self-management outside of the healthcare setting. Additionally, challenges to mental health (e.g., depression, anxiety, and elevated stress)[33-35] and inadequate transition support can increase the pain burden,[33,36] which in turn negatively affect self-management. Interventions are necessary for addressing these vulnerability factors and improving self-management to achieve better outcomes among adults with SCD.

Strengths and Limitations

Strengths of this research include utilizing qualitative methodology and a CBPR approach. Introduction of the research project to the SCD community began approximately 4 months before recruitment. Personal contacts between the PI and members of the SCD community occurred weekly to establish trust and consideration of participation. Recruitment was conducted in collaboration with community representatives and included countless telephone calls, flyers, in-person meetings, and word-of-mouth communication.

This research should be considered in the context of a few limitations. People living with SCD may be considered as a hidden and hard-to-reach population, making them difficult to recruit for research. In fact, our participants constituted approximately 18% of the 18–35-year-olds living with SCD in a Midwestern city. Thus, we had an important, albeit relatively small number of participants. Generalizability is limited by our inclusion of participants from one community and the high proportion of female participants with sickle cell anemia. Other adults

with SCD may have different types of SCD, healthcare experiences, and self-management knowledge.

Implications

Prior to entering healthcare settings, individuals living with SCD can benefit from being prepared to advocate for themselves when in healthcare settings. Self-efficacy preparation may involve developing a comprehensive care notebook that includes their medical information, pain management strategies, and emergency contacts. Moreover, preparing patients to communicate effectively with HCPs, by teaching them communication methods like Situation, Background, Assessment, Recommendation (SBAR),[37] can help make interactions more efficient and less stressful.

A "community of advocates" is an important source of support for individuals with SCD. Engaging with SCD community groups facilitates connections with others who have shared experiences and creates opportunities for mutual emotional support.[38] Learning from others with lived SCD experience about effective self-management strategies, available resources, mental health support, and navigating challenges during the transition period[39] supports better self-management and health outcomes. Educating healthcare providers, family members, and the public about SCD can combat the health-related stigma that persons with SCD often experience,[40] which can also help to expand their "community of advocates". Lastly, to reduce discrimination experienced by people with SCD in healthcare settings, HCPs and SCD allies can provide leadership by implementing implicit bias training.[41]

Conclusions

The experiences of adults with SCD in this qualitative research were primarily characterized by negative encounters with healthcare team members and an ongoing struggle to obtain adequate care. The healthcare gaps and discrimination they reported are barriers to successful SCD self-management. Therefore, interventions should be developed to address these gaps, improve healthcare quality, and support adults with SCD in enhancing self-management strategies and skills.

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