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A Qualitative Study of Chronic Pain and Self-Management in Adults with Sickle Cell Disease

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Abstract

Acute, intermittent vaso-occlusive pain is the hallmark of sickle cell disease (SCD) and is associated with substantial morbidity and impaired quality of life (QOL). The subgroup of adults with SCD who transition from recurrent, acute pain to chronic, persistent pain have even greater QOL impairment and higher rates of healthcare utilization. Self-management is central to SCD management; however, its role in chronic pain management is not established. This qualitative study was conducted to answer the following research questions: (1) What is the chronic pain experience of adults with SCD? (2) What self-management strategies do adults with SCD use for chronic pain? and (3) Do adults with SCD have any needs in the self-management of chronic pain? Eighteen Black adults with SCD completed a demographics questionnaire and an interview. The majority of the participants were 21–30 years of age (mean 33.5, SD 7.6), female (61.1%), employed at least part-time (61.1%), single/never married (72.2%), and had a SCD type of sickle cell anemia (55.5%). Interview analysis revealed three major themes: (1) the chronic pain experience; (2) strategies for managing chronic pain; and (3) challenges and needs in managing chronic pain. Study findings can be used to support chronic pain management among adults with SCD. Further research is needed to devise and implement effective strategies for the prevention and management of chronic SCD pain.

Keywords

Chronic pain; sickle cell; adult; self-management; needs assessment

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1. Introduction

Sickle cell disease (SCD), an inherited red blood cell disorder, is associated with numerous complications that result in increased morbidity and mortality, and estimated annual medical costs exceeding \$1.1 billion.^{1–4} Acute vaso-occlusive pain episodes are the main complication of SCD and the most common reason for healthcare encounters.⁵ However, some adults with SCD transition from acute pain to chronic pain.⁶ Acute exacerbation of chronic pain often results in emergency department visits or hospitalizations.^{7,8}

Chronic SCD pain has been recently defined as ongoing pain that is present on most days over six months.⁹ Contributing factors are variable and may include avascular necrosis of joints, bone infarction, leg ulcers, osteomyelitis, and central and peripheral sensitization.^{10–12} In a daily diary study, 54% of adolescents and adults with SCD reported having pain 51% of the time and 29% reported pain almost daily.¹³ In a review study of adults with SCD, chronic pain ranged from 29–100% across seven studies, with a weighted mean of 65%.¹⁴ In a study of complementary and alternative medicine use for pain, 92% of adults with SCD reported pain lasting from six months to greater than two years.¹⁵

Prevention and management of chronic SCD pain is an ongoing challenge. Opioids, which are commonly used, have often been suboptimal.^{16–18} Moreover, the long-term efficacy of chronic opioid therapy for chronic SCD pain has not been established.^{7,16} In fact, individuals with SCD on chronic opioid therapy experience greater pain, poorer functional outcomes, and higher healthcare utilization than individuals not on this therapy, despite disease severity.¹⁶ Use of opioids as a primary management strategy is further complicated by increasing restrictions on opioid access in response to the current opioid epidemic in the United States (U.S.).^{19,20} In 2016, over 40% of all U.S. opioid overdose deaths involved a prescription opioid.²¹ Of the deaths, rates were higher among non-Hispanic White and American Indian or Alaskan Native adults than non-Hispanic Black and Hispanic adults.^{21,22} The SCD community in the U.S., which consists primarily of Black individuals, is not largely affected by the opioid epidemic yet faces significant negative effects because of access restrictions, leading to the need for more self-management.^{23,24}

Self-management is a self-motivated and collaborative process, involving patients, their family members, and healthcare providers, to manage chronic disease symptoms.²⁵ This process is particularly relevant to individuals with SCD because they experience most of their pain at home, and disease management primarily focuses on preventing and managing pain.^{12,26} While self-management of acute SCD pain has been investigated,^{26–30} there are no published peer-reviewed studies to date which evaluate self-management of chronic SCD pain. There is also a paucity of research which directly captures, in the patient's own voice, the chronic pain experience and the impact of chronic pain on quality of life. Therefore, this qualitative study was conducted to answer the following research questions: 1. What is the chronic pain experience of adults with SCD? 2. What self-management strategies do adults with SCD use for chronic pain? and 3. Do adults with SCD have any needs in the self-management of chronic pain?

2. Theory

The Theory of Self-Care Management for Sickle Cell Disease, developed by Dr. Coretta Jenerette, states that self-care management resources positively mediate relationships among vulnerability factors and health outcomes.^{27–29} Vulnerability factors refer to additional challenges of SCD and include disease complications, lack of sickle cell crisis cue recognition/response, the number of crises per year, and overprotection by family. These factors negatively affect self-care management resources and health outcomes. Self-care management resources include assertive communication skills, coping behaviors, self-care ability, self-care actions, self-efficacy, and social support. Health outcomes relate to factors in SCD that influence quality of life and include depressive symptoms, self-esteem, pain management experience, and health-related stigma. In the context of this theory, we sought to understand how adults with SCD utilize self-management to address chronic pain and to assess their pain management experience as a health outcome. By examining the chronic pain experience, our goal was to identify potential challenges, needs, and vulnerability factors in the management of chronic SCD pain.

3. Materials and Methods

The University's Institutional Review Board approved this qualitative, descriptive study to obtain data from young adults enrolled in a larger study being conducted to evaluate the effectiveness of a decision aid for therapeutic options in SCD. Purposive sampling was used to recruit participants, between October 2016 and August 2017, from a geographically diverse population at national SCD conferences and local SCD clinics. The following were the inclusion criteria: Black adult, age >18, SCD diagnosis, pain on most days (three or more days each week) over the past six months, and the ability to read, write, and understand English. The first author contacted all participants via telephone using the telephone number they provided at recruitment. During the telephone call, they provided verbal informed consent then immediately responded to questions from a demographics questionnaire and completed an individual interview.

The first author used a semi-structured interview guide to conduct the interviews. She developed the interview guide using the chronic pain literature, the Theory of Self-Care Management for Sickle Cell Disease, and her previous work regarding self-management of acute pain in adults with SCD. Based on this information, she included three broad domains of questions relevant to the context of understanding chronic pain and self-management of chronic pain in adults with SCD. The domains included definition of chronic pain in SCD, experience with chronic pain, and self-management of chronic pain. Participants' responses to initial questions guided subsequent questions and probes were used to obtain details. Interview questions and sample probes from the guide are provided in Table 1. Interviews were approximately 23 to 53 minutes in length and each participant received a \$25 gift card after completing the interview. The first author wrote field notes during the interviews and the sessions were audio-recorded using an Olympus recorder that the first author previously used successfully to interview young adults with SCD via telephone. The audio-recorded sessions were transcribed verbatim by the first author and research support staff.

The first five interviews were transcribed and analyzed concurrently with data collection by the first author. She used emerging study findings to inform the revision of probes for use in subsequent interviews. After 13 additional interviews were completed, the first author de-identified the transcripts and assigned them a participant number. She then checked the transcripts for accuracy before subjecting them to qualitative content analysis. Qualitative content analysis is a research method used to interpret the content of text data by systematically identifying emerging themes or patterns in units of words, phrases, and sentences.^{31,32} Using this method, themes were summarized directly from the interviews, not a predetermined code book. The data were organized with Microsoft Word and Excel, and the following approach was used for analysis: 1. Reading the transcripts to become familiar with the data as a whole and making notes of initial analysis. 2. Identifying and quantifying words or content reflecting major thoughts, concepts, or patterns. 3. Organizing major thoughts, concepts, or patterns into categories and identifying associated exemplars. 4. Interpreting the content to understand its use in the context of the phenomenon. While conducting the interviews and analyzing the transcripts, the first author noted the repetition of concepts. This repetition was confirmed upon review of the transcripts by the second and third authors. Once no new concepts emerged, we believed that the identified themes addressed the questions.^{33,34} Therefore, it was determined that thematic saturation was reached after 18 interviews and participant recruitment concluded at that time. The first author consolidated the findings of the analysis and ordered them according to the research questions. All authors reviewed this information and provided feedback.

Throughout the study, the following measures were used to ensure qualitative rigor.^{35,36} The first author, a trained researcher who has expertise in interviewing adults with SCD, conducted the interviews. To ensure credibility during the interviews, she asked participants to clarify their statements and validate her understanding of the data.^{35,37,38} In addition, she assessed the field notes and transcripts for similarities among participants' responses. The authors, combined, have several years of research expertise in SCD, self-management, pain, qualitative methodology, and qualitative data analysis. The analytic approach was consistently utilized by the first, second, and third authors, and there were frequent discussions of independent analyses amongst all authors to understand team member perspectives and achieve agreement regarding the themes and interpretations. The breadth of expertise of the team allowed for the exploration of varied perspectives and interpretations to achieve understanding of the participants' experiences, and served to strengthen confirmability.³⁶

4. Results & Discussion

Study participants included 18 Black adults with SCD. Of the participants, the majority (n=10; 55.5%) were 21–30 years of age (mean 33.5, SD 7.6), female (n=11; 61.1%), employed at least part-time (n=11; 61.1%), single/never married (n=13; 72.2%), and had a SCD type of HbSS or sickle cell anemia (n=10; 55.5%). Further details regarding participants' characteristics are reported in Table 2.

4.1 Interviews

Interview analysis revealed three major themes for the participants in this study: (1) the chronic pain experience; (2) strategies for managing chronic pain; and (3) challenges and needs in managing chronic pain.

4.1.1 Chronic Pain Experience—All study participants attempted to describe their chronic pain experience. In their discussions, they addressed the frequency of pain, pain locations on the body, pain quality, pain patterns, definition of chronic SCD pain, and how this pain influences their life.

In this study, chronic pain was both highly prevalent and highly variable. In their descriptions of the type of pain experienced, study participants used words and numerical ratings to report mild to severe chronic pain. During a typical week, 55.5% (n=10) of the participants reported experiencing pain daily. Chronic pain was reported in 14 body sites with 61.1% (n=11) of the participants reporting at least two pain sites. Pain sites included the back, leg, thigh, arm, hip, knee, shoulder, ankle, wrist, neck, elbow, head, muscles, and bones. The back was the most common pain site (61.1%; n=11).

Participants used a number of terms to describe the quality of pain that mostly referred to the sensory aspect of pain. Participants offered these terms without any prompting from the interviewer. Terms used included: aching/deep ache, spasm, pressure, unbearable, overbearing, stabbing, stiffness, discomfort/uncomfortable, irritation, sharp, burning, tight, aggravating, deep, hammering, radiating, excruciating, arthritic, grinding, inflamed, throbbing, electric probe/nerve pain, dull, constant, and soreness. The pain experience and resulting use of descriptive terms varied not only within the sample but also for individual participants:

“It alters. Sometimes it can be sharp, sometimes it can be stabbing, sometimes it just can be like hammering. Umm sometimes it can just be like a radiate type pain.”
(21 year old female with Hemoglobin SS)

It was challenging for participants to identify pain patterns as the pain varied from day to day. In general, they reported that their pain was typically worse in the morning, upon waking, or in the evening/at night. In addition, the pain was often intensified by participants' levels of activity and stress. It often started at a low level and then increased:

“My pain it can start like, my daily pain, just kind of aggravating pain, on a pain scale I guess it would be about 3 or 4... And then you know that can go up to an 8 you know on a bad day or even a 9 where I do have to take my pain meds and it gets to the point where I can't walk, where I am limping, I'm in tears, so that's just my thing. It varies from day to day.” (23 year old female with Hemoglobin SS)

For study participants, there was a clear distinction between acute pain and chronic pain. Acute pain was described as sickle cell pain or pain crisis while chronic pain was described as 'regular pain' or 'normal pain' that they primarily attributed to the effects of sickle cell over time:

“Chronic pain is a pain that I have every day and sickle cell crisis is an extremely different pain... Yeah it is completely different... A crisis is a crisis and chronic pain is every day.” (39 year old female with Hemoglobin S Beta Thalassemia; participant unsure if she’s Beta Thalassemia + or 0)

Although participants were able to differentiate between types of pain, they experienced difficulty in assigning a specific definition to chronic pain:

“Chronic sickle cell pain can be a lot of things actually. Pain can vary from simple headaches to major pain such as legs, arms, even chest. Umm so there’s really no exact definition of chronic sickle cell pain. You just have to kinda know your sickle cell...” (21 year old male with Hemoglobin SS)

“Umm chronic pain is like...I don’t know...chronic pain is like you just have the pain all the time no matter what you do. You have pain all the time.” (25 year old male with Hemoglobin SS)

Participants alluded to the impact of chronic pain on their quality of life. Notably, chronic pain hindered them from participating in activities or completing the plans for the day:

“...pain standing in my way of doing something I want to do... maybe I won’t move at all.” (25 year old male with Hemoglobin S Beta Thalassemia +)

“A daily thing, you never know how to quite explain it, it is a constant pain, it’s constant battle every day, in not knowing what you can and cannot do, never have a definitive plan, having to cancel, cause you never know when the chronic pain is going to pop up. If the meds are going to work, if they are not going to work. You have to like change, everything.” (29 year old female with Hemoglobin S Beta Thalassemia 0)

“The pain is just there. I can’t even do an activity to notice an activity would hurt me. I can’t do it anyway.” (39 year old female with Hemoglobin S Beta Thalassemia; participant unsure if she’s Beta Thalassemia + or 0)

“I could be shopping, like grocery shopping and I can’t make it around the whole store or by the time I’m done grocery shopping, my legs are hurting... Umm I don’t cook as much because even cooking, standing up on my legs to cook causes problems. So I don’t cook much, not as much as I would like to.” (34 year old female with Hemoglobin SC)

Chronic pain also interfered with the attainment of life goals and contributed to psychological distress:

“I’m still fighting depression all the time because I don’t like the situation where my life is at. I would love to be working, I would love to be you know, driving a car or having things that other people, regular folks have you know, have a family or get married, all these type a things you know, relationships and all that type a stuff so. Living this way is just like you’re missing a lotta things that normal, regular life, you would feel that is part of life, having a normal life you know. There a lotta things I missing in my life that I feel like should be different you know so.” (43 year old male with Hemoglobin SS)

4.1.2 Strategies for Managing Chronic Pain—All study participants discussed their use of self-management activities and behaviors to manage chronic pain. They used these strategies to help reduce the pain, cope with the pain, and maintain or improve their physical functioning.

The majority of the study participants (n=11; 61.1%) reported that they were not currently receiving treatment specifically targeting chronic pain. Participants determined their own definition of “treatment for chronic pain”, which included getting physical therapy or working with a bone specialist, and stated that they were not receiving these services. Those who reported that they were currently receiving treatment, described treatment as pain medications. Individuals in this study managed their chronic pain at home. They noted therefore that development of self-management strategies was a priority. One participant described spending time in making preparations and planning things out as a *“full-time job, a full-time child, a full-time life.”* (25 year old female with Hemoglobin SS).

To manage chronic pain, all study participants used a variety of non-pharmacological and pharmacological strategies described in Table 3. The most frequently used strategies were warmth/heat (n=16; 88.9%) pain medications (n=16; 88.9%), distraction (n=13; 72.2%), dealing with emotional or physical stress (n=13; 72.2%), intake (n=12; 66.7%), and cognitive reframing/relaxation (n=12; 66.7%). Participants learned these ways to manage chronic pain from other individuals with sickle cell and family members, by researching information online or using books, through life experience/trial and error, and from formal, adult education such as mental health coursework.

Each person reported using a combination of strategies. The majority (n=13; 72.2%) reported using three or more strategies. In addition, 50% of the participants (n=9) reported using two or more types of warmth/heat, two or more strategies for dealing with emotional or physical stress, and two or more methods of cognitive reframing/relaxation. Generally, choice of strategies depended on several factors including the pain location, type, and severity, and access to the strategy. Participants reported using similar strategies, in the same manner, to try to alleviate both acute and chronic pain. The difference was that for chronic pain, they employed fewer strategies, used them less often, and found them to be more effective in relieving the pain.

Despite using pain medications as a self-management strategy, almost half of the participants (n=8; 44.4%) expressed reservations about the use of these types of medications, especially opioids. They reported a strong preference for employing non-pharmacological strategies before utilizing medications, and they used non-pharmacological strategies more frequently. The overarching message was that pain medications limited their ability to perform their daily activities and that they were not always effective:

“I rather do as many things that’s natural that I can at first...before the medicine...I hate that stuff because I’m zombified.” (25 year old female with Hemoglobin SS)

“So, I changed doctors...it was with the hopes of finding someone who would listen to my symptoms and be willing to do more than just throw pain medicine at me...I just feel like the medication and treatment that I’m getting now is, I don’t

know, I guess it's not very consistent, so sometimes I'll take the medicine and it won't help, and then other times I take it and I feel like it helps some...I don't know, it's tough...I just hurt so much and it's frustrating because, it's like I take all this medication and I'm still weak and have a hard time getting out, and when I do get out of the house, I'm pushing through pain.” (23 year old female with Hemoglobin SS)

4.1.3 Challenges and Needs in Managing Chronic Pain—Study participants discussed encountering challenges in managing their chronic pain that included barriers to implementing strategies and the ineffectiveness of strategies. In addition, they addressed the need for additional support to better manage chronic SCD pain at home.

Adults in this study were adept at using self-management strategies in an attempt to address their chronic pain as they were accustomed to managing their acute pain in similar ways. Of the participants, 66.7% (n=12) reported being confident that they can manage pain from day to day. However, a major challenge in managing their pain was that self-management strategies were not always effective. Amongst and even for individual participants, there was wide variability in the effectiveness of the strategies. Some participants experienced pain relief or pain reduction because of using a particular strategy; however, other participants found the same strategy to be ineffective. In addition, a strategy was beneficial for participants given a specific circumstance but was ineffective at other times. There was no consensus regarding which strategies work and which do not, and there was no discernable clear benefit of one approach over another. Participants also reported encountering barriers to managing their chronic pain at home. These included: being in pain, doubts, mental state/depression, the home environment, other responsibilities, inconvenient strategies, doctors' reluctance to prescribe necessary pain medications, stress, weather, limited finances, and needing to depend on others for assistance.

Participants expressed the need for additional support to manage their chronic pain at home. In response to the question, “Is there anything that you would you like to know, learn, or need to better manage your pain at home?” participants requested: new information/additional strategies, more convenient care such as nursing care in the home, confirmation and reassurance that self-management strategies are appropriate and beneficial, psychological therapy/counseling, and support at home to take care of household tasks. Overall, participants felt as though something was needed to better manage their pain and expressed interest in learning additional information that might be helpful:

“I like to look at myself as an expert of sickle cell. But, there's still some things that I didn't even know.” (29 year old female with Hemoglobin S Beta Thalassemia 0)

“I'm open to learning anything to manage it at home to stay away from the hospital.” (34 year old female with Hemoglobin SC)

4.2 Discussion

We report results of the first qualitative study that directly captures the individual's perspective on the chronic pain experience of adults with SCD, their use of self-management

for chronic pain, and their unmet needs in the management of chronic pain. Thus, this investigation fills a knowledge gap in the literature and highlights information needed to support adults with SCD as they continue to manage their pain at home. Findings will also be helpful in positively influencing research and practice to improve pain outcomes among individuals with SCD.

In this study, the majority of the participants reported experiencing chronic pain daily; yet, they were not receiving specific treatment for this pain. These findings are consistent with previous reports of a high incidence of chronic pain in individuals with SCD,^{13–15} and that SCD pain is primarily managed outside of the healthcare setting.^{12–14,26} In the absence of effective management modalities for chronic SCD pain, these findings reinforce the importance of self-management for adults with SCD, and the need for more targeted and effective pain management strategies to supplement self-management. A thorough understanding of the individual pain experience is necessary for developing these strategies; thus, a more comprehensive, individualized pain assessment may be required for adults with SCD who report chronic pain.^{39,40} This assessment may include evaluating the location and duration of the pain, characteristics or quality, aggravating and relieving factors, pain threshold and expectations, current treatment, use of self-care behaviors to deal with the pain, facilitators of and barriers to self-management, the presence of psychological distress, and using magnetic resonance imaging or x-rays to further evaluate the pain and its origin. This is a critical first step for good pain management because a thorough understanding of the individual pain experience will be helpful in determining more targeted and effective management methods.

Adults in this study felt that it was important to employ self-management strategies. Some of the strategies they used are similar to strategies reported in other chronic pain studies.¹⁴ However, there was wide variability in the effectiveness of the strategies. This may possibly be attributed to the presence of different underlying causes of pain, types of pain, and types of strategies available to the participant. Strategies used by participants in this study to manage chronic pain are also similar to those used by adults with SCD to manage both acute pain and chronic pain.^{14,26,39,41,42} This may present an area of risk because individuals with SCD may not be addressing their chronic pain with the most appropriate strategy or combination of strategies for the specific type(s) of pain. By completing an individual assessment of patients' use of self-management and self-management needs, healthcare providers can identify any gaps in patient knowledge and offer necessary support. Support may include providing information regarding helpful non-pharmacological strategies and the availability of community pain resources such as clinics or support groups. In addition, future research is needed to determine the influence of non-pharmacological strategies on chronic pain among individuals with SCD.

In this study, some of the participants reported trying to avoid medication, especially opioids, and used them only as a last resort after using non-pharmacological strategies. This practice was also reported by individuals with SCD who experience acute pain.³⁰ Members of the SCD population are often incorrectly perceived by healthcare providers as drug-seekers or addicts.^{27,43–45} Adults with SCD are at risk for significant health-related stigma because of disease challenges that include having a chronic condition characterized by

severe pain, activity limitations, absenteeism from school and work resulting in limited education and financial resources, and increased use of the healthcare system.^{27–29,46} Negative interactions with healthcare providers and the perception of being a drug seeker or addict further contributes to this stigma. This stigma, in turn, contributes to psychological distress and poor coping, which leads to poorly managed pain. The observations in this study and others support the fact that the SCD community is not largely affected by the opioid epidemic.^{23,24} Nonetheless, it is possible that this vulnerable population may suffer negative consequences as a result of efforts aimed at addressing the current opioid epidemic in the U.S. When providing care to individuals with SCD, clinicians should first consider the differences among tolerance, physical dependence, pseudo-addiction, and addiction.⁴⁷ They should also take into consideration that the appropriate use of opioids is applicable and should be individualized to the patient.⁴⁸

Challenges to managing chronic pain included being in pain, other responsibilities, and stress. This supports previous reports of barriers to performing self-care behaviors among adults with SCD who experience acute pain.^{27,30} In addition to these challenges, study participants mentioned experiencing levels of depression because of pain and expressed the need for therapy/counseling. Other individuals with SCD have also requested that pain assessment involve consideration of psychosocial factors.³⁹ Access to psychological care and/or psychosocial resources may not be available to individuals with SCD who often have financial limitations.⁴⁰ Therefore, when developing care plans for these individuals, healthcare providers should also evaluate and address psychological issues because they could exacerbate pain and decrease the overall effectiveness of therapy. Inconvenient strategies were also reported as a challenge to managing pain and participants expressed a desire to learn more about pain management modalities that have helped others. Given the current dearth of evidence-based information which may be used to address these needs, future research is required to identify modalities for chronic pain management in adults with SCD and to develop objective measures of self-management effectiveness.

Overall, chronic pain had a negative impact on the quality of life of adults in this study. Others have reported similar data regarding the negative effects of chronic pain on physical and social functioning, mental health, and energy.¹⁴ According to the Theory of Self-Care Management for SCD, vulnerability factors negatively influence self-management resources and health outcomes.^{27–29} Vulnerability factors highlighted in this study include inadequate clinical pain management and barriers to implementing self-management strategies. These factors interfered with the use of self-management resources and negatively influenced health outcomes which primarily included the pain management experience, depressive symptoms, and health related stigma. If adults with SCD are not able to employ important self-management resources to control and cope with chronic SCD pain, then they may experience worse pain, depression, and quality of life.

The strengths of this study should be considered in the context of the following limitations. Characteristics of study participants do not reflect those of the general adult SCD population. In this study, there was a high proportion of females, an SCD type of HbSS or sickle cell anemia, and current employment. In addition, participants were recruited from national SCD conferences and local SCD clinics. Although analyses did not reveal

differences in these two groups, individuals who attend conferences may be more motivated than others and may seek out information to better manage their condition. The majority of the participants had the type of SCD considered the most severe and thus may have experienced more pain than those with other SCD phenotypes. Individuals in this study were not specifically asked to rate the severity of their chronic pain but many included or alluded to this information in their descriptions of the type of pain experienced. We did not inquire as to whether participants could distinguish between acute crisis pain and acute exacerbations of chronic pain. In our previous work, we noted that study participants experienced difficulty in describing their pain types and thus more work is needed in this area.³⁰ In addition, we did not specifically ask participants whether they had received any formal instruction in non-pharmacologic techniques such as cognitive-behavioral therapy, relaxation, or mindfulness to assist with managing pain. Follow-up questions may have also included an exploration of previous clinical care and mental health care. Overall, other adults with SCD may have a different chronic pain experience and may not share the same self-management ability. Those without access to a local SCD clinic may also experience greater challenges in the management of their chronic pain. Lastly, this study relied on participants' self-report and thus the data may be subject to social desirability bias.

5. Implications

Chronic pain in SCD, much like in other conditions, is a challenge to manage but a more strategic approach can be applied to better address this public health problem. After completing a thorough pain, psychological, and self-management needs assessment for adults with chronic SCD pain, an individual pain management plan can be developed. Various strategies should be included in the plan based on the individual assessments. Pain should be addressed with the medications proven to be most effective and support should be offered to optimize self-management. Further research is critically needed to develop interventions for the management of chronic pain in this population which target specific factors influencing the pain.

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Table 1.

Interview questions/prompts and sample probes

Domains	Questions/Prompts	Sample Probes
Definition of chronic pain in SCD	1. How would you define chronic pain?	a. How would you define chronic pain as it relates to sickle cell? b. During an average week, on how many days do you experience that kind of pain?
Experience with chronic pain	2. Tell me about your experience with chronic pain	a. Describe the type of chronic pain you experience. b. Where on your body do you feel this chronic pain? c. What patterns do you notice with your chronic pain? d. Are you currently undergoing treatment for chronic pain?
Self-management of chronic pain	3. Tell me about the things that you do to manage your chronic pain	a. Do you feel confident that you can manage your chronic pain from day to day? b. How controlled is your chronic pain with your current management? c. What strategies do you use? d. How do you decide which strategy to use for the chronic pain? e. Which strategies are most helpful in managing your chronic pain? f. Which strategies are least helpful in managing your chronic pain? g. How did you learn ways to manage your chronic pain? h. What are some things that get in the way of your managing your chronic pain? i. What are some things that help you or make it easier to manage your chronic pain? j. Do you need someone to help you manage your chronic pain at home? k. Is there anything that you would like to know, learn, or need to better manage your pain at home? l. If you were to teach someone about managing sickle cell, what are the most important things you would include regarding management of chronic pain?

Table 2.

Characteristics of participants

Variable	Category	N	Percentage
Age	21–30	10	55.5%
	31–40	3	16.7%
	41–46	5	27.8%
Gender	Female	11	61.1%
	Male	7	38.9%
Employment Status	Employed, Part-time	6	33.3%
	Employed, Full-time	5	27.8%
	Not employed, disabled	4	22.2%
	Full-time student	2	11.1%
	Self-employed, disabled	1	5.6%
Relationship Status	Single/never married	13	72.2%
	Divorced	2	11.1%
	Domestic Partner	2	11.1%
	Married	1	5.6%
Annual Household Income	Less than \$15,000	4	22.2%
	\$15,000 – \$35,000	3	16.7%
	\$35,000 – \$55,000	7	38.8%
	\$55,000 – \$75,000	1	5.6%
	Greater than \$75,000	2	11.1%
	Not sure	1	5.6%
Sickle Cell Disease Type	Hemoglobin SS (HbSS)	10	55.5%
	Hemoglobin SC (HbSC)	2	11.1%
	Hemoglobin S Beta	2	11.1%
	Thalassemia 0 (HbSβ ⁰)		
	Unsure	4	22.2%
Participant's Age When Parent(s) Informed of Disease Diagnosis	Birth-1 year	10	55.5%
	1–3 years	4	22.2%
	3–5 years	2	11.1%
	>10 years	2	11.1%
Number of Individuals Living in Household (Participant included)	1 resident	6	33.3%
	2 residents	3	16.7%
	3 residents	5	27.7%
	4 residents	2	11.1%
	5 residents	1	5.6%
	6 residents	1	5.6%

Table 3.

Self-management strategies

Category	Strategy	Description	Percentage
Nonpharmacological therapy	Warmth/heat	Hot/warm bath, hot shower, heating pad, hot packs, and ingesting something hot	88.9%
	Distraction	Listening to music, playing video games, watching television, writing, reading a book, art therapy, talking on the telephone or texting, checking emails or doing some type of work, and spending time with family or friends	72.2%
	Dealing with emotional or physical stress	Laughing, avoiding triggers, avoiding overdoing things/pacing self, and getting lots of rest/sleep	72.2%
	Intake	Drinking water, healthy diet, and natural foods or drinks (such as green shake, aloe juice, green juice, garlic, wheat grass, and spirulina)	66.7%
	Cognitive reframing/relaxation	Meditation, self-affirmations, deep breathing, massage, and healing touch	66.7%
	Physical activity	Staying active, walking the dog, exercising, playing basketball, yoga, Zumba, physical therapy, aqua therapy, and bowling	55.5%
	Spirituality	Prayer, reading the Bible, reading the Koran, and speaking healing over body and spirit	44.4%
	Medical equipment	Braces and compression socks	5.6%
	Bath products	Epsom salt and essential oils (such as lavender earth oil, eucalyptus, frankincense, and marjoram)	5.6%
Pharmacological therapy	Pain medications	Prescription pain medications (such as Dilaudid, Tylenol with codeine, Oxycodone, Oxycontin, MS Contin, Morphine, and Flexeril) and over-the-counter pain medications (such as Ibuprofen, Tylenol, Advil, Motrin, and Excedrin)	88.9%
	Sickle cell medications	Hydroxyurea	44.4%
	Over the counter topical creams or analgesics	Capsaicin, Icy Hot, Real Time Pain Relief, Pain Away, and Salonpas patch	27.8%
	Vitamins	Folic acid, vitamin D, calcium, multivitamin without iron, and One-a-day	27.8%