Table S1. Summary of included articles.

Publication Author(s), Year, & Title	Study Design & Methods	Participant Demographics	Study Findings Specific to Medical Mistrust
Adegbola et al., 2012[69] *Voices of adults living with sickle cell disease pain*	**Design:** Qualitative, cross-sectional **Framework/Theory:** Heideggerian hermeneutic phenomenology methodology & van Manen's thematic analysis **Tools**: n/a **Time period of study:** n/a **Recruitment site:** National SCD support group **Country:** United States	**No of participants:** 13 adults **Gender:** Male (n=3); Female (n=10) **Type of SCD:** HbSS (n =11) , HbSC (n=1), HbSb-thal (n =1) **Age ranges**: 21-54 (average age 31 years old) **Ethnicities:** 100% African American **Income:** n/a **Education:** some college education (n=9) **Other demographics:** Single (n=9)	Narratives reflect concerns about inadequate care and provider bias Relationship with provider. One individual shared storing of a hearing HCP behind ED curtain: "Oh, it's the sick blood who wants her pain medicine again" "They act like they don't understand the [SCD] pain." Relationship with provider: fear of not receiving enough O2 when O2sat <95% or not receiving pain meds. Leads to patients thinking they need to educate themselves about SCD treatments so they can advocate necessary treatments and seek out HCPs that are informed and care.
Alleyne et al., 1994[36] *The management of sickle cell crisis pain as experienced by patients and their carers*	**Design:** Qualitative & descriptive, cross-sectional **Framework/Theory:** 'new paradigm' (Reason & Rowan, 1981) and feminist methodology (Webb, 1991) **Tools:** n/a **Time period of study:** n/a **Recruitment site:** SCD patients: local (London) sickle cell support group meetings; Nurses recruited from hematology unit who cared for patients **Country:** England	**No of participants:** 10 SCD patients; 10 nurses **Gender:** Female patients (n=8); Male patients (n=2). Female nurse participants (n=10) **Type of SCD:** n/a **Age ranges:** n/a **Ethnicities:** Afro-Caribbean (n=10) **Income:** n/a **Education**: n/a **Other demographics:** n/a	Patients reported feeling disbelieved and stigmatized by health professionals Delays in pain management #1: "I've got the feeling that some of them purposely prolong it." Delays in pain management #2: "They think we're like two-hour junkies you know, as soon as the time is up, we want a fix." All patients described not being treated as individuals and how they are perceived to have a 'bad name' Lack of individualized care #1: "We are sicklers and that's it." Lack of individualized care #2: "You are a sickler and we've got a bad name ... oh here's another one"
Bemrich-Stolz et al., 2015[74] *Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** semi-structured interviews **Time period of study:** Conducted over a six-month period **Recruitment site:** Adult hematology clinic in Alabama **Country:** United States	**No of participants:** 10 **Genders**: Female=7, Male=3 **Type of SCD:** n/a **Other demographics**: Insurance (Medicaid = 8; Private = 2); Disability (Yes = 9; No =1 [has applied]); Current therapy (hydroxyurea = 9; chronic transfusion = 1) **Income:** n/a **Education level:** 1 participant had completed some high school, 2 were high school graduates, 6 had completed some college, 1 was a college graduate **Age ranges**: Participants were aged 24 to 55 years **Ethnicities:** n/a	Mistrust with emergency room and new adult primary PCPs due to being treated like a "drug addict," as well as their lack of knowledge about SCD. Adult hematologists had good relationships with the patients. when compared to their pediatric doctors, who were described as "supportive, wonderful, respectful, helpful"
Brown et al., 2015[75] *Sickle cell disease patients with and without extremely high*	**Design:** Qualitative, cross-sectional **Framework/Theory:** Phenomenological & content analysis **Tools:** semi structured interviews **Time period of study:** 1/1/08 to 12/31/10	**No of participants**: 21 individuals; 16 SCD patients matched EHHU & LHU; 5 providers individually identified by EHHU as most important provider	"Doctors think, 'Oh, there's nothing wrong with her. She's just addicted to the pain meds" "Since I've developed trusting and understanding relationships between the doctors and nurses, they don't have a problem and they're not

hospital use: Pain, opioids, and coping	**Recruitment site:** Yale-New Haven Hospital Resource Information Management System **Country**: United States	**Gender:** Female = 10; Male = 6 **Type of SCD:** HbSS = 10; HbSC = 3; HbS-beta-thal = 3 **Age ranges**: 23-54 years **Ethnicities:** all self-identified African American **Income:** n/a **Education:** n/a **Other demographics**: n/a	labeling. Now, if I go somewhere else and they don't know me, the misconception is that I'm coming in asking for drugs"
Campbell et al., 2010[55] *Coming of age with sickle cell disease and the role of patient as teacher*	**Design**: Qualitative, cross-sectional **Framework/Theory**: Phenomenological method with thematic analysis **Tools**: semi structured interviews **Time period of study**: n/a **Recruitment site:** Comprehensive sickle cell clinic **Country**: United States	**No of participants:** 17 adolescents & young adults **Gender:** male (n=8); female (n=9) **Type of SCD:** HbSS (n=15), HbSC (n=2) **Age ranges:** 12-17 (n=6), 18-24 (n=8), 25-28 (n=3) years **Ethnicities**: 100% African American **Income:** n/a **Education:** n/a **Other demographics:** middle school student (n=1); high school student (n=6); student (n=1); college student part-time with employed part time (n=1); unemployed (n=6)	Participants cited being disbelieved by healthcare professionals and needing to teach them about their condition. Convincing the naysayers: "Quite frankly she was accusing me of wanting to stay to get drugs. It bothers me quite a bit because I'm not getting the treatment that I need because of fear of giving a sickle cell patient drugs that are addicting. But, what's worse-being in horrible pain or having to take medicine to control the pain? When people try to say, 'I'm not going to give you this because...' and they don't know if that's the actual cause or not.' " Unexpected role as teacher: "I remember one doctor said "So how long have you had sickle cell?" I'm like, "How long?" Are you serious? One doctor asked me, "What is that exactly?"... "I've gotten so many stupid questions people wouldn't even believe it."
Carvalho et al., 2021[47] *Why does your pain never get better? Stigma and coping mechanism in people with sickle cell disease*	**Design:** Qualitative, cross-sectional **Framework/Theory:** The Sociological Theory of Stigma by Erving Goffman **Tools:** semi structured interviews **Time period of study:** January to July 2018 **Recruitment site:** Outpatient SCD center **Country:** Brazil	**No of participants:** 25 adults with SCD **Gender:** Male = 13, Female = 12 **Type of SCD: "**majority" of participants had Hb SS **Other demographics:** **Income:** Most participants were low-income, with many unemployed and some receiving retirement benefits due to SCD complications. **Education level**: Eighteen participants did not complete high school, while only two had some higher education, which was incomplete. **Age ranges:** 20 to 53 years old **Ethnicities:** Predominantly Black and Brown; only two participants identified as non-Black	Stigma from healthcare workers: Healthcare workers (nurses, doctors, even staff like a security guard at the hospital) doubted their pain severity and treated them like "drug addicts." Also, they specifically voiced that they were being treated differently because they were black patients. "A white patient wouldn't act like this"
Ciribassi & Patil, 2016[70] *"We don't wear it on our sleeve": Sickle cell disease and the (in)visible body in parts*	**Design:** Qualitative, cross-sectional **Framework/Theory:** Ethnographic approach **Tools:** Semi-structured interview guide and focus group discussions **Time period of study:** 2005 to 2008 **Recruitment site:** University Sickle Cell Clinic in Chicago Illinois **Country**: United States	**No of participants:** 25 adults with SCD **Gender**: Female = 13, Male = 12 **Type of SCD:** n/a **Other demographics:** n/a **Income:** n/a **Education level:** n/a **Age ranges:** n/a **Ethnicities:** n/a	Patients described their frustration when healthcare professionals doubt not only their pain, but their treatment regimen. They felt that their own experiences were disregarded in favor of scientific knowledge. "They think because they went to school, they're better...that they know more than you. They know more than you because they went to school." "I hope SCD is more recognized and more paid attention to because right now where I live, I had to explain to my doctor what SCD is. They had never asked, and I had never explained it to them, but they were treating me. That really upset me that I had never explained to them before or they never asked me before what it felt like."
Cole et al., 2007[76] *Black Women and Sickle Cell Disease:*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** Semi-structured interviews, with open-	**No of participants:** 10 adults with SCD **Gender:** Female = 10 **Type of SCD**: n/a	Women reported negative experiences with medical staff in EDs, but positive relationship with PCP. Pain levels were not taken seriously, doctors thought they were drug seeking, and doctors thought the women

Implications for Mental Health Disparities Research	ended questions focused on participants' experiences of stigma, stressful life events, and the perceived impact of Sickle Cell Disease (SCD) on mental health **Time period of study:** April 16, 2002, and October 17, 2002 **Recruitment site:** Multiple sites (sickle cell clinic waiting room, church support group for SCD, online recruitment from sickle cell association website, snowball method of friends and family referral, fliers mailed to SCD patients from an organization **Country:** United States	**Other demographics:** **Income:** Annual incomes ranged from $9,000 to $70,000 **Education level**: Six participants had either undergraduate or graduate degrees. The remaining four participants had completed some high school or had a high school diploma. **Age ranges:** Participants' ages ranged from 27 to 66 years, with a mean age of 41.2 years. **Ethnicities**: All participants identified as Black, African American, or of African descent.	were exaggerating their pain levels. Women are bothered that healthcare providers perceive them as "addicts." They also think their ethnicity/race is what makes doctors think they're "drug addicts." Doctors and nurses making them wait for pain control causes more stress and trauma to them.
Coleman et al., 2016[61] *How sickle cell disease patients experience, understand and explain their pain: An Interpretative Phenomenological Analysis study*	**Design:** Qualitative, cross-sectional **Framework/Theory:** Interpretative Phenomenological Analysis (IPA) **Tools:** Semi-structured interviews with thematic analysis **Time period of study:** n/a **Recruitment site:** a single SCD support group **Country**: England	**No of participants:** 7 adults with SCD **Gender:** Male = 3, Female = 4 **Other demographics:** 5 with Hb SS, 2 with Hb SC **Income:** n/a **Education level:** n/a **Age ranges:** 24–57 years **Ethnicities:** Black British African (n=4) British Caribbean (n=1) Black East African (n=1); Black British (n=1)	"Participants often felt their level of pain was misunderstood or not believed. At times this occurrence caused mistrust and misunderstanding with HCPs, particularly when additional analgesia was required. One participant has a saying, "pain is what the patient says it is, unless you have sickle cell, then it's what the doctor says it is."
Collins et al., 2022[34] *Communicating and understanding pain: Limitations of pain scales for patients with sickle cell disorder and other painful conditions*	**Design:** Qualitative, longitudinal approach **Framework/Theory:** Grounded theory, social transaction model of pain communication **Tools:** Semi-structured interviews **Time period of study:** Conducted over an 18-month period **Recruitment site:** "across England" **Country:** England	**No of participants:** 48 young people with SCD (included adolescents) **Gender**: n/a **Type of SCD:** n/a **Other demographics:** n/a **Income:** n/a **Education level:** n/a **Age ranges:** 13 to 21 years old **Ethnicities**: n/a	Being treated differently by hospital staff who are not specialized in training to SCD and lack of knowledge on the part of the hospital staff. Nurses, if they saw them laughing or not seeming to be in extreme pain, would downrate their pain score. Another theme was about distrust; they distrust nonspecialist providers who treat them like "drug addicts" for asking for pain medicine, and also makes it hard for them to communicate with the HCP. One patient reported being ignored by HCPs and nurses when in a pain crisis, so it makes her avoid the hospital altogether to avoid experiencing that again. They think HCPs are judging them negatively.
Crego et al., 2021[48] *Patient Perspectives of Sickle Cell Management in the Emergency Department*	**Design:** Mixed methods study, cross-sectional **Framework/Theory:** n/a **Tools:** ASCQ-ME, semi-structured interview guide administered individually and during focus groups **Time period of study:** May to August 2017 **Recruitment site:** Large comprehensive sickle cell clinic **Country:** United States	**No of participants:** 51 (included adolescents) **Gender:** Male=26, Female=24, 1 = missing **Type of SCD:** Hb SS (n=39), 11 other genotypes (not specified) **Other demographics:** n/a **Income:** 10 participants earned below $10,000, 14 earned between $10,000 and $29,999, 8 earned between $30,000 and $59,999, and 6 earned over $60,000 **Education level:** Some High School 4 individuals High School Grad/General Education Diploma 10 individuals Some College or Associates Degree 21 individuals Bachelor's Degree 9 individuals	Participants report that ED providers do not believe their pain and also report that suspected racism is the reason why the "white" HCPs treat them differently during a pain crisis, including nurses. Also reports that ED doctors should consult the SCD team, but they do not because they believe "I am a doctor and I know how to treat you."

		Graduate or Professional Degree 2 individuals Missing/Preferred not to respond, (n) 5 individuals **Ethnicities:** Non-Hispanic Black = 46 individuals Hispanic Black = 3 individuals Don't know = 1 individual Missing = 1 individual	
Durgum et al., 2023[42] *Patient and Caregiver Perspectives on Care-Seeking During a Vaso-Occlusive Crisis in Sickle Cell Disease: Results from Qualitative Interviews in Canada*	**Design:** Qualitative analysis, cross-sectional **Framework/Theory:** n/a **Tools:** One-hour telephone interviews following a semi-structured interview guide **Time period of study:** December 2020 and March 2021 **Recruitment site:** Recruited from a market research company and Sickle Cell Disease Association of Canada **Country**: Canada	**No of participants:** 23 (11 adult patients and 6 adolescent-caregiver dyads) **Gender:** Adolescent SCD pts (Male=4, Female=2), Adult SCD pts (10=Female, 1 =Male), caregivers (Female=5, Male=1) **Type of SCD:** n/a **Other demographics:** 74% female, 26% male, Canadian, almost all AA (91.3%) **Income:** n/a **Education level:** Education level varied, with most adult patients (9/11) holding a bachelor's or advanced degree, while caregiver education ranged from some college to bachelor's degree. **Age ranges:** 12-18 years **Ethnicities:** Almost all (91.3%) participants were Black/African American	ED staff do not take their pain level seriously, treat them like "drug addicts," and making them wait a long time. "racial bias impacts treatment."
Elander et al., 2004[62] *Understanding the Causes of Problematic Pain Management in Sickle Cell Disease: Evidence That Pseudoaddiction Plays a More Important Role Than Genuine Analgesic Dependence*	**Design**: Qualitative, cross-sectional study **Framework/Theory:** n/a **Tools:** Semi-structured interviews **Time period of study:** n/a **Recruitment site:** Two outpatient clinics **Country:** England	**No of participants:** 51 **Gender:** Male = 17, Female = 34 **Type of SCD:** Hb SS (n=38), Hb SC/beta thal (n= 13) **Other demographics:** currently working/studying (n=26) **Income:** n/a **Education level:** Varying educational levels with 5 participants having no qualifications, 25 with high school exams, 11 with further education, and 10 with higher education degrees **Age ranges:** 18 to 54 years, average age 34 years old **Ethnicities:** Family origin Africa 37 Family origin Caribbean 14	A patient described suspicion of a nurse cutting the patient's pain dose in half: "The nurse decided to cut down the dose, without the doctor's permission. When I saw the drug chart, I saw she was giving half the dose." Patients described disputes with staff about analgesia: "When I had to come to the hospital screaming with pain, a nurse told me I was pretending. I went without analgesia." "There is always an argument. I am allergic to morphine and sometimes there is an argument because the hospital wants to use morphine more." "The nurses used to say, 'You are hooked on the drugs. You are not really in that much pain.'" "I was convinced the nurse was trying to kill me. I was in a great deal of pain but discharged myself, called my friend to come get me." Maladaptive behaviors: taking other analgesics in the hospital, using analgesics prescribed to others outside of the hospital, as well as self-discharge from the hospital. Using illicit drugs and injecting analgesics "With the old pethidine pumps, I would give myself a boost by pushing the syringe along"
Evensen et al., 2016[64] *Quality of Care in Sickle Cell Disease: Cross-sectional Study and Development of a Measure for Adults*	**Design:** Quantitative, cross-sectional study **Framework/Theory:** n/a **Tools:** ASCQ-Me QOC **Time period of study:** October 2008 to May 2009 **Recruitment site:** Seven different clinical sites	**No of participants:** 561 completed the ASCQ-QOC survey **Gender:** Female = 359, Male = 202 **Type of SCD:** 64% Hb SS, 21% Hb SC, 10% HbS-beta thal, remaining participants as "other"	36.5% of participants reported waiting greater than two hours in an ER to receive pain medication. 25.2% of the sample reported waiting between one to two hours for pain medication in the ER. 44% of the sample reported that bad experiences in the ER significantly impacted their decision to avoid going to ER for care during a crisis.

Reporting on Ambulatory and Emergency Department Care	(rural health center, community-based organization, academic medical center clinic) **Country:** United States	**Other demographics:** n/a **Income:** n/a **Education level:** n/a **Age ranges:** 63% were aged 18 to 34 years, 20% were aged 35 to 44, and 18% were aged 45 years and older. **Ethnicities:** n/a	46% of the sample reported four or more episodes of pain crisis, where they tried managing the pain on their own at home instead of going to a hospital/clinic. 65% of participants reported that ER doctors and nurses did not believe them about the severity of their pain.
Ezenwa et al., 2016[57] *Healthcare injustice in patients with sickle cell disease*	**Design:** Mixed methods, cross-sectional **Framework/Theory:** n/a **Tools**: Healthcare Injustice Questionnaire; qualitative portion as 2 open-ended questions at end of questionnaire asking patients "If there is something more you need to add about your being treated unfairly, please use the space below to tell us about it." **Time period of study:** May to July 2011 **Recruitment site:** Large metro SCD clinic **Country:** United States	**No of participants:** 52 **Gender**: Male = 1; Female = 41 **Type of SCD:** Hb SS (n = 42), 6 with Hb SC (n=6), “other” (n=4) **Other demographics:** n/a **Income: n/a** **Education level:** high school (n=48) **Age ranges:** age 18 to 25 years (n=13), 26 to 45 years (n=31) **Ethnicities:** 48 = AA, 1 = Hispanic, 3 = Other	Participant 24N's example of a negative experience of one specific nurse at adult care center: " [...] very insensitive; she has insulted me on several occasions and made me cry. This has caused unnecessary stress during my crisis [...] (this has made me feel) [...] uncomfortable [...] no longer use the center [...] this is unacceptable [...] because I could avoid hospitalizations." "The doctor did not listen to me and gave me more than I usually take and he overdosed me"
Harris et al., 1998[37] *Adults with sickle cell disease: Psychological impact and experience of hospital services*	**Design:** Mixed methods, cross-sectional **Framework/Theory**: n/a **Tools:** Symptom Checklist-90-Revised; Global Severity Index (GSI), semi-structured interview **Time period of study:** n/a **Recruitment site:** Inpatient hospital site **Country**: England	**No of participants:** 27 adult inpatients **Gender:** Female =12, Male = 15 **Type of SCD:** n/a **Age ranges:** Male (range 21-35 years; mean age 28); Female (range 18-60; mean age 30 years) **Ethnicities**: All African or African-Caribbean origin **Income**: n/a **Education**: n/a **Other demographics:** n/a	Patients expressed frustration with the care received and feelings of not being taken seriously. 44% (12) had complaints about the staff's negative attitude toward SCD patients. Experience of hospital services #1: "They don't believe you, they're biased against sickle cell people." Experience of hospital services #2: "I am just afraid to come to the hospital because of the attitudes of the nurses."
Hauser et al., 1999[51] *Transitioning Adolescents with Sickle Cell Disease to Adult-Centered Care*	**Design:** Qualitative, cross-sectional **Tools:** Focus group interviews with semi-structured, open-ended questions. **Framework/theory**: n/a **Time period of study:** n/a **Recruitment site:** 4 different sickle cell clinics in a Midwest city **Country:** United States	**No of participants:** 22 adolescents with SCD and their caregivers (n=17) and clinicians **Other demographics:** 3 groups (22 adolescents ages 13 to 21, with mean age 16 years old), adolescent’s caregivers (17 parents, 4 grandparents, 1 aunt), and clinicians **Gender:** Adolescent (Male = 12, Female = 10), caregivers majority female **Type of SCD:** Hb SS (n=20), Hb SC (n=1), HbS-beta thal (n=1) **Education level:** Average grade completed - 9th grade **Age ranges:** 13 to 45 years **Ethnicities:** African American, Belizean or Nigerian, Other	"I worry that I will have a doctor that doesn't know SCD. Some doctors don't know how to treat SCD and they act like they do"
Jabour et al., 2019[77] *The Role of Patient-Physician Communication on the Use of Hydroxyurea in*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** Semi-structured qualitative interviews **Time period of study:** October 2015 – July 2016	**No of participants:** 21 adults with SCD **Gender:** Female = 13, Male = 7 **Type of SCD:** n/a **Other demographics:** average age 44 years, **Income**: n/a	Among interviewed participants who had stopped taking hydroxyurea, they described not feeling listened to or heard by their physicians such as feeling dismissed about concerns about side effects. "I felt like I told him and he wasn't hearing me" "I'm pretty much like, why is she still talking about this [medication]? I

Adult Patients with Sickle Cell Disease	**Recruitment site:** Urban adult sickle cell center **Country:** United States	**Education level:** n/a **Ethnicities:** 100% African American/Black	tell her no every time, will she give up? But she doesn't. She asks me every time."
Jean-Baptiste et al., 2022[40] *Individuals with sickle cell disease using SBAR as a communication tool: A pilot study*	**Design:** Mixed methods, (part of quasi-experimental larger parent study), cross-sectional **Framework/Theory:** Revised Theory of Self-Care Management for Sickle Cell Disease (SCMSCD) from 2014 **Tools:** SBAR exemplars/"trainer videos" **Time period of study:** August-December 2017 **Recruitment site:** Emergency department **Country**: United States	**No of participants:** 18 adults with SCD **Gender:** 68% female, 32% male **Type of SCD**: n/a **Age ranges:** n/a **Ethnicities:** n/a **Income:** n/a **Education:** 8th to 11th grade: 3%; completed high school or GED: 29%; after high school training: 3%; some college: 39%; college graduate: 23%; postgraduate: 3% **Other demographics:** n/a	Patients described healthcare providers making dismissive assumptions about the patients' reason for seeking care, specifically that HCPs assume a person of color is a "drug addict," which delayed care because the patients had to convince the HCP they needed pain management. Patients described that HCPs based their evaluation of the patient on the appearance of the patient and not looking like they were in pain. Patients described not being believed by HCPs; they described how doctors and nurses spoke to them as if they were lying about their pain. "The way the nurse and doctor talked to her [in the trainer video] is exactly how they talked to you as they think that you are lying about how you are feeling."
Mathur et al., 2016[60] *Multiple levels of suffering: Discrimination in health-care settings is associated with enhanced laboratory pain sensitivity in sickle cell disease*	**Design:** Mixed methods, cross-sectional **Framework/Theory:** n/a **Tools**: Interpersonal Processes of Care Survey (IPC-18) discrimination subscale; Pain Scale; Center for Epidemiological Studies Depression Scale; Pain Catastrophizing Scale; Pain Anxiety Symptoms Scale; Pittsburgh Sleep Quality Index; Multigroup Ethic Identity Measure **Time period of study:** n/a **Recruitment site:** Comprehensive sickle cell center **Country**: United States	**No of participants:** 71 adults with SCD **Gender:** Female = 51, Male = 20 **Type of SCD:** HbSS, HbSC, HbS beta-thal reported (no breakdown provided) **Age ranges:** 19-64 years. **Ethnicities**: 68 = African American/Black, 3 = multiracial **Income:** n/a **Education:** high school or less (n=12); some college (n=32); bachelor's or more (n=27) **Other demographics**: n/a	38% (n=27) of participants reported some experience with discrimination in health settings; of these 27 individuals, 21 reported doctors paid less attention to them due to race. 30% (n=22) of participants reported they felt discriminated against by doctors because of race or ethnicity. 51% of female participants reported discrimination by doctors on the basis of race or ethnicity.
Matthie et al., 2016[78] *Perceptions of young adults with sickle cell disease concerning their disease experience*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** Modified Successful Aging with SCD Life Review Interview Guide **Time period of study:** August 2010 to September 2012 **Recruitment site:** Outpatient sickle cell clinic **Country**: United States	**No of participants:** 29 young adults **Gender:** Female = 23, Male = 6 **Type of SCD:** Hb SS (57.8% of sample) **Age ranges:** mean age 25.8 years old **Ethnicities:** 100% African American **Income:** n/a **Education:** mean 13.2 years of education **Other demographics:** 35.6% employed full-time or part time; 71.6% single/never married	Reported difficulties accessing care and feeling dismissed by providers "So I don't like going to the emergency room unless I come here [Sickle Cell Clinic] because they know what they doing over here, but … where I live at, they act like they don't know. They act like I am a junkie or something because I ask for pain medication, which I don't feel that is right, because if I go into a pain crisis, you should give me the medication." "I feel like since I do cause the pain myself, I need to try and fix it myself and I feel like the doctors are... I don't know. It's just I feel like some doctors are judgmental."
Masese et al., 2021[49] *A Needs Assessment of Persons with Sickle Cell Disease in a Major Medical Center in North Carolina*	**Design:** Mixed methods, descriptive, cross-sectional **Framework/Theory:** n/a **Tools:** PROMIS (scale that measures degree of pain interference), semi-structured interview guide administered individually and in focus groups **Time period of study:** 2017 **Recruitment site:** Sickle cell clinic **Country:** United States	**No of participants:** 58 **Gender** Male = 26, Female = 24, 1 missing **Type of SCD:** 38 Hb SS (n=38), Hb SC (n=8), Other (n=4), missing (n=1) **Other demographics:** n/a **Income**: n/a **Education level:** n/a **Age ranges:** 16-66 years old **Ethnicities:** 45 = non-Hispanic Black, 3 = Hispanic, remaining participants = other. Predominantly non-Hispanic Black	Patient describes worry about finding a PCP who is knowledgeable in the management of SCD; with one reporting that their former PCP did not communicate well and collaborate well with their hematologist, leading them to become distrusting of new providers. Other focus group interview results revealed fear of being stigmatized as "drug seeking" by healthcare workers. Also reported feeling like a guinea pig with hydroxyurea "My nurse had on gloves and I asked why she has on gloves and she said that HU is chemotherapy, to which I thought, 'I'm on chemo?"
Maxwell et al., 1999[63] *Experiences of hospital care and treatment*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools**: semi-structured interviews administered	**No of participants:** 57 **Gender:** Female (n=32); Male (n=25) **Type of SCD:** Hb SS or HBS/b-thal (n=44);	Patients reported being mistrusted by health professionals, suspected of exaggerating or minimizing pain, contributing to anxiety, avoidance of care, and altered treatment-seeking behavior

seeking for pain from sickle cell disease: qualitative study	individually and during focus group discussions **Time period of study**: n/a **Recruitment site:** Hospital inpatient; online recruitment; outpatient hematology clinic **Country**: England	Hb SC (n=9); unknown (n=4) **Age Ranges:** 20-40 years (n=49); 41-60 years (n=6) **Ethnicities:** West African (n=29; 51%); Afro-Caribbean (n=26; 46%); Other African (n=2; 4%) **Income:** n/a **Education:** n/a **Other demographics:** n/a	Mistrust #1: "The doctor will look at you, and he goes, 'I don't think that you're in a lot of pain" Mistrust #2: "They get suspicious because they can't believe you can be better in two days, but if I can look after myself, I don't see why I should be there... I feel better, I can stop taking [the painkillers] ... Once I didn't have no more pain but they [were] giving me tablet which I didn't know [were] painkillers" Stigma: "The nurse turned around to me and said "It's not because we don't wanna give you the painkillers, it's cos we're scared that you're gonna get hooked on it and we don't wanna see you down on the street husting drugs." "They kept saying, 'I think we're going to send you home,' and yet I knew it was the sort of chest pain that I should be in... So there was this debate ... in the end I was right-it was sickle lung." "You need to talk about what's bothering you, but that is not an issue when you go in hospital-they see that you've got sickle cell and that's it... I went into a state where I was practically suicidal and nobody recognized nothing except that I had sickle crisis." "I think you have to educate yourself because you'll be in wards where nurses have never seen a sickler .. it didn't come up in their training... so I think it really comes down to you at the end of the day." "I've been in many hospitals [names five; laughter from group]... If I go to the hospital and my pain's not controlled, I don't care if I die, I'll get out of that hospital and go somewhere else to get pain free or to control my pain..."
McGill et al., 2023[33] *Depressive and Insomnia Symptoms Sequentially Mediate the Association Between Racism-Based Discrimination in Healthcare Settings and Clinical Pain Among Adults With Sickle Cell Disease*	**Design:** Quantitative secondary data analysis conducted within a longitudinal parent study **Tools:** IPC-18, CES-D, ISI, BPI **Time period of study:** December 2010 to November 2014 **Recruitment site:** Part of a larger NIH-funded parent study that recruited participants by phone **Country**: United States	**No of participants:** 68 **Gender:** Female =48, Male = 20 **Type of SCD**: n/a **Other demographics:** n/a **Income:** n/a **Education level:** 78% (N=53) had some college education or higher **Age range**s: 19 to 64 years **Ethnicities**: n/a	The study had significant findings from the Discrimination Subscale of the Interpersonal Process of Care Survey, with racism-based discrimination in healthcare settings impacting pain interference scores, as well as daily pain severity, and was also positively associated with depressive symptoms and insomnia symptoms.
Nelson & Hackman, 2013[52] *Race matters: Perceptions of race and racism in a sickle cell center*	**Design:** Quantitative, cross-sectional **Framework/Theory:** n/a **Tools:** 11-item survey adapted from CDC 2008 Behavior Risk Factor Surveillance System (BRFSS) and Sickle Cell Transfer Questionnaire w/selected questions; Influence of Patient Race of Provision of Health Care Services Index **Time period of study:** n/a **Recruitment site:** Hematology clinic **Country**: United States	**No of participants:** 112 SCD patients/families and 135 staff **Gender:** Female patients (n=78), male patients (n = 34) **Type of SCD**: n/a **Age ranges:** Patient/Family ages 12 to >50 with 58.2% >30; staff 20->50 with 73.5% >30 years old **Ethnicities:** Patient/Family - African (40; 36.4%); African-American (60; 54.6%); Race Black or African-American (n=100; 92.6%) Staff - European-American (n=107; 85.6%) Race White (n=127; 94.1%)	1. More patients/families felt race affects quality of care for SCD patients (50% vs 31.6%) 2. Patients/families perceived being treated differently because of race in outpatient and inpatient settings (11% vs 10.9) 3. Compared to staff, patients/families perceived race affecting interpersonal relationships with caregivers (47.5% vs 29.2%)

		Income: n/a **Education:** n/a **Other demographics:** 92.6% patients/families identified as Black or African-American; 94.1% of staff identified as white	
Oyedeji et al., 2025[50] *"Death is as much part of life as living": Attitudes and experiences preparing for death from older adults with sickle cell disease*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** Semi-structured interviews **Time period of study:** June to November 2019 **Recruitment site:** Comprehensive sickle cell center **Country**: United States	**No of participants:** 19 adults with SCD **Gender**: Male = 10; Female = 9 **Type of SCD:** HbSS n=10; HbSC n=7; HbSbeta n=2 **Age ranges:** >50 (mean of 58 years; range 50-71) **Ethnicities:** African American (n-18); non-Hispanic Black (n=19) **Income:** median household <=$50k **Education:** high school grad or less = 5; some college/associates/technical school = 7; bachelor's = 5; advanced degree = 3 **Other demographics:** excluded if wheelchair bound (mobility was required to perform functional assessments in parent study); employment status: working (9); unemployed (1); disabled (6); retired (2); other (1)	"He perceived that his doctors were giving up on him. He described being upset because he felt more could be done to save his life, so he transferred to another health system" Described that the effect of being told to sign an advanced directive in the middle of a crisis or acute hospitalization felt as though the doctors were giving up on them. Participants described wanting to sign an advanced directive only when they are in good health and not during a crisis.
Phillips et al., 2022[53] *Perspectives of individuals with sickle cell disease on barriers to care*	**Design:** Mixed methods, cross-sectional **Framework/Theory:** n/a **Tools:** semi-structured interview guide and Access Barriers Checklist: Advocates (checklist developed at Oregon Health & Sciences University & adapted for study) **Time period of study:** March to June 2018 **Recruitment site:** Comprehensive sickle cell centers **Country**: United States	**No of participants:** 208 participants completed quantitative survey; 44 participants completed interviews **Gender:** Survey (58.2% female); Interview (54.5% female) **Type of SCD**: Survey only: HbSS or HbS-beta-thal (72.1%); SC (20.2%); Other (3.4%) **Age ranges:** Survey (<=18 years [8.2%]; 19-30 years [44.2%]; 31-50 years [39.4%]; >50 years [1%])Interview (mean age 31.1 years; age ranges 15-46 years) **Ethnicities:** Survey only: (95% Black; 90.4% Non-Hispanic or Latino); Interview (Non-Hispanic/Black (97.8%) **Income**: Survey only: <=20k (55.8%); 20,001-50k (19.7%); >=50,001 (10.6%) **Education:** Survey only: less than high school (15.4%); high school graduate/GED (21.6%); some college (29.8%); college graduate or professional (28.4%) **Other demographics:** Interview (Insurance - Medicare only [9.1%]; Medicaid only [20.5%]; private only [9.1%]; State sponsored plan [11.4%]; Private +Medicare [2.2%]; Medicare + Medicaid [40.1%]); Survey (Employment - Working (24.5%); Disabled	Quantitative findings (sample size 193): 56% (108/193) identified at least one barrier related to provider knowledge and attitudes. Qualitative themes on lack of trust, treated differently Lack of trust "My issue is more of a trust factor ... I know I have sickle cells; I'm aware I have sickle cell, but we're all different and we all, you know. respond differently" Treated differently: "The stigmatism that haunts sickle cell patients about the opioids and morphine. ... You see, our society accepts and treats cancer patients differently. They can't see that sickle cell disease is something you're born with. I'd say their pain is less than ours. However, they get better treatment, pain management than sickle cell patients"

		(34.6%); Student (14.4%); Unemployed-Looking for work (12%))	
Renedo et al., 2019[35] *Not being heard: Barriers to high quality unplanned hospital care during young people's transition to adult services - evidence from 'this sickle cell life' research*	**Design**: Qualitative, longitudinal approach **Framework/Theory**: Grounded Theory + inductive thematic analysis **Tools:** semi-structured interview guide **Time period of study:** ~18 months 2016-2017 **Recruitment site:** Hospital with comprehensive sickle cell services; patient advocate network **Country**: England	**No of participants:** 48 **Gender:** Female =30; Male = 18 **Type of SCD**: n/a **Age ranges:**13-21 years (mean 16.6) **Ethnicities:** n/a **Income**: n/a **Education:** n/a **Other demographics**: n/a	"I always felt like it was kind of condescending and it was kind of like, yeah, you don't really have this. You don't fit the textbook definition, so you shouldn't be here. As opposed to why are you feeling like this? How are you feeling? What could possibly be wrong? Let's try and solve it."
Rizio et al., 2022[43] *The relationship between frequency and severity of vaso-occlusive crises and health-related quality of life and work productivity in adults with sickle cell disease*	**Design:** Quantitative cross-sectional observational study **Framework/Theory**: n/a **Tools:** ASCQ-Me, WPAI-SHP **Time period of study**: 2 months in 2019 **Recruitment site:** Online recruitment through market research company and patient advocacy groups **Country:** United States	**No of participants:** 303 **Gender:** Female = 221, Male = 82 **Type of SCD:** Hgb SS (n=156), HbSC (n=60), Other (n=42), Did Not Know (n=44) **Age ranges:** mean age was 34.37 years **Income:** n/a **Education level:** n/a **Ethnicities:** 270 = African American, 15 identified as white, 1 as Asian **Other demographics:** 120 employed	101 participants (33.3% of the sample) reported difficulty trusting healthcare professionals.
Royal et al., 2011[58] *Living With Sickle Cell Disease: Traversing 'Race' And Identity*	**Design:** Mixed methods, cross-sectional **Framework/Theory:** n/a **Tools:** MIBI-S **Time period of study:** 2010 and early 2011 **Recruitment site:** Utilizing the Duke Adult Comprehensive Sickle Cell Center demographic database, patients were phone called, emailed, and approached during clinic visits **Country:** United States	**No of participants:** 46 **Gender:** Female = 26, Male =20 **Type of SCD:** Hb SS (n= 31) **Age ranges:** 18 - 59 years **Income:** n/a **Education level:** Some high school 3 High school graduate 9 Some college 17 College graduate 13 Graduate/Professional 4 **Ethnicities:** 42 participants identified themselves as Black or African American, two as Hispanic/Latino, and two as Other **Other demographics:** n/a	1/5 of participants reported that healthcare workers treated them like “drug addicts.” "My race does influence my experience with SCD because blacks were viewed in a negative light." " Many nurses and doctors have treated me horribly and stigmatized me as a patient, without even knowing my health history, without even knowing me as a person. SCD patients (particularly Black SCD patients) have to deal with the stereotype (one that's widely perpetuated throughout the health care field) of being "drug addicts", "drug seeking only", or "drug addicted exaggerators".
Sinha et al., 2019[45] *Management of Chronic Pain in Adults Living With Sickle Cell Disease in the Era of the Opioid Epidemic*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** semi-structured interview guide **Time period of study:** May 2017 to June 2018 **Recruitment site:** National conferences, 2 SCD clinics, and SCD symposia **Country:** United States	**No of participants:** 15 adults with SCD **Gender:** Female = 13, Male = 2 **Type of SCD:** HbSS, HbSC, and/or HbS-b-thal reported, breakdown not provided **Age ranges:** 21-52 years old **Income:** n/a **Education level:** n/a **Ethnicities:** 100% African American **Other demographics:** social security benefits (n=10); employed full-time or part-time (n=5)	ED providers stigmatize patients as drug seeking and ED providers lack knowledge of SCD and pain management while ignoring the hematologist's specialized protocol for pain management. Participants reported that marijuana decreased their depression and anxiety, and that it provides relief without the grogginess of opioids and may allow them to reduce or eliminate opioids altogether. Participants also expressed concern about smoking marijuana due to risk of acute chest syndrome.
Sinha et al., 2018[46] *From Trust to Skepticism: An In-*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** Semi-structured, open-ended interviews,	**No of participants:** 95 adults with SCD **Gender:** Female = 71, Male = 24	SCD patients under age 31 years old seemed to express more trust toward HU, and over age 31 were more mistrusting of treatment. Ages 18 to 30 also reported more positive relationships with their doctor. The

depth Analysis Across Age Groups of Adults with Sickle Cell Disease on Their Perspectives Regarding Hydroxyurea	transcribed verbatim and analyzed using NVivo 11 software for qualitative content analysis **Time period of study:** Data was collected over a period concluding in 2018, though the specific starting date is not **Recruitment site:** Recruited from national conferences and two SCD clinics **Country:** United States	**Type of SCD:** n/a **Age ranges:** 18 to 67 years old **Income**: n/a **Education level:** High school or GED (n=17); Some college (n =34); Bachelor's degree (n = 18); Master's or PhD (n= 18); Other (n = 8) **Ethnicities:** Predominantly African American, with 93 identifying as African American, 1 as "other," and 1 as multiracial **Other demographics:** 50% unemployed	older group, Group 2, was full of distrust and reported more behaviors consistent with alternative therapies to treat SCD. Some participants reported their belief that HCPs are not up to date on the latest treatments, or expressed the belief that not all treatment options were being discussed with them (information being withheld).
Smith et al., 2017[41] *Identifying social-behavioral health needs of adults with sickle cell disease in the emergency department*	**Design:** Mixed methods, cross-sectional **Framework/Theory:** n/a **Tools:** semi structured interview guide; Emergency Department Sickle Cell Assessment of Needs and Strengths (ED-SCANS) **Time period of study:** August 1, 2013, for 14 months **Recruitment site:** Large urban emergency department **Country**: United States	**No of participants:** 147 interviews but some patients interviewed >1 **Gender:** n/a **Type of SCD**: n/a **Age ranges:** >18 years old **Ethnicities:** n/a **Income:** n/a **Education:** n/a **Other demographics:** n/a	Healthcare access barriers suggest systemic neglect; emotional distress is linked to fragmented care Other Barriers to Care: "When I come to the emergency department, they look at me funny. They think I'm a junkie. If I have chest pain, I have to go to the emergency department. Sometimes the wait is very long. I hate how the emergency department treats SCD patients. We are made to feel like drug seekers. I don't come to the emergency room because of the stereotyping. There is no SCD clinic in my hometown, and limited Medicaid options for us."
Strickland et al., 2001[73] *Use of focus groups for pain and quality of life assessment in adults with sickle cell disease*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** semi structured interview guide administered during focus groups **Time period of study:** n/a **Recruitment site:** SCD clinic **Country:** United States	**No of participants:** 10 adults with SCD; 11 family members (siblings, grandparents, parents) **Gender:** female patients (n=7); male patients (n=3) **Type of SCD:** n/a **Age ranges:** 25-46 years old **Ethnicities:** 100% African American **Income**: n/a **Education:** n/a **Other demographics:** n/a	Participants reported feeling labeled as "addicts," judged, and disrespected by healthcare providers, which led to anger and emotional distress. Anger & Hostility: "They (health care providers) think there's nothing wrong with you. Or, retarded blood, retarded mind. You are just here for drugs... What do they do? (When it's) time for your medication they drag their behinds." Disenfranchisement: "My experience is being categorized...by family members and friends, staff of hospitals and doctors...It frustrates me." Belief of Others of Drug Dependency #1: "If you are going in (to the hospital) at the same time with another sickle cell patient...they figure well, this person is coming for drugs. You are just coming for drugs and that's wrong." Belief of Others of Drug Dependency #2: "When you (health care providers) look at me and say that I am an addict for getting a medicine that is going to make me feel better in a disease I have no control over whatsoever, then I know right then and there you are categorizing me. You are looking down on me. You have nothing good to think about me. So, it makes me very angry. It really does.
Thomas et al., 2002[56] *The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups*	**Design:** Qualitative, cross-sectional **Framework/Theory:** Phenomenology **Tools**: semi structured interview guide administered during focus groups **Time period of study:** 8 weeks **Recruitment site:** Sickle cell clinics **Country:** England	**No of participants:** 17 **Gender**: Male=7, Female = 10 **Type of SCD:** HgbSS (numerical value not given) **Age ranges:** 15 to 35 years old **Ethnicities:** 49% West African and 51% African-Caribbean **Income**: n/a	Patients expressed high psychological distress and a lack of confidence in receiving appropriate care. All participants reported only seeking medical help and hospitalization as a last resort because of the unhelpful attitudes of hospital staff and the hurt it causes. "The simple fact is, I don't want to be branded as a drug addict. I don't want to be blatantly told I am not in pain when I am." "I've just come across a lot of negative attitudes and I think a lot of them don't understand what sickle cell is about so they can't understand what

		Education: n/a **Other demographics:** n/a	we are going through. It's a case of when you ask for pain killers they spend an hour checking it." Many participants identified feelings of anger and frustration from hospital treatment: "I think, I am going to get angry, because I am sitting in pain and they don't do nothing. They just sit there..."oh the doctor will be with you in a minute" and an hour goes by" "They don't believe the pain could be that bad" "...everybody's in pain and nobody's doing anything about it, nobody's listening to anyone... it makes me feel like, you know, my life is worth nothing to them. You could drop down dead, they wouldn't care you know, another bed for somebody else."
Treadwell et al., 2020[54] *Health care disparities among adolescents and adults with sickle cell disease: A community-based needs assessment to inform intervention strategies*	**Design:** Mixed methods, cross-sectional **Framework/Theory:** n/a **Tools:** PROMIS (Patient-Reported Outcomes Measurement Information System); ASCQ-ME QoC (Adult Sickle Cell Quality of Life Measurement Information System Quality of Care; SCSES (Sickle Cell Self-Efficacy Scale) SCD Barriers Checklist, semi structured interview guide **Time period of study:** Oct 2017 to March 2018 **Recruitment site:** Recruitment flyer; outpatient clinic **Country**: United States	**No of participants:** 58 adolescents & adults with SCD; 51 healthcare providers; 5 community stakeholders **Gender:** Male=25; Female = 33 **Type of SCD:** Hb SS = 71% of sample **Age ranges:** Age 15-25 years (n=18; 51.0%); 26-35 (n=21; 36.2%); 36-50 (n=18; 31.0%), Mean age 31 years old **Ethnicities:** African American (n=54); White (n=1); Other, don't know (n=7); Non-Hispanic Origin or Ancestry (n=51) **Income:** <30k (n=23; 39.7%); 30k to <60k (n=14; 24.1%); >=60k (n=19; 32.8%) **Education:** Elementary, high school, no diploma (n=2; 3.4%); high school (graduate, GED) (n=14; 24.1%); some college no degree (n=13; 22.4%); associates degree (n=16; 27.6%); bachelors (n=6; 10.e3%); masters (n=3; 5.2%) **Other demographics:** Occupation (working now n-23; 39.7%); (disabled, permanently or temporarily n=19; 32.8%); Insurance - Medicaid/MediCal (n=40; 69.0%); Medicare (n=16; 27.6%); Private (n=13; 22.4%); state-sponsored health plan (n=8; 13.8%); marital status never married (n=41; 70.7%)	Mistrust of health system among participants cited as a barrier to care and research engagement Transition from pediatric to adult: adults noted satisfaction plummeted as they aged due to few providers experienced in adult SCD care and compounded by negative experiences such as stigma, racism, and being labeled as drug-seeking. Care coordination and provider communication: perceived ED physicians and nurses didn't care about them
Wakefield et al., 2017[39] *Perceived Racial Bias and Health-Related Stigma Among Youth with Sickle Cell Disease*	**Design:** Quantitative, cross-sectional observational **Framework/Theory:** n/a **Tools:** PRaCY, CSS, CES-D, PedsQL, DSC **Time period of study:** May 2012 to June 2014 **Recruitment site:** Both inpatient and outpatient sites **Country:** United States	**No of participants:** 28 **Gender:** Female participants (71% of sample) **Type of SCD:** Hb SS (n=19), Hb SC (n=5), Hb beta-thal+ (n=3), Hb beta-thal (n=1) **Age ranges:** 13 to 21 years old **Ethnicities:** Black or African-American (23) More than one race (5) Hispanic (3) **Income**: n/a **Education**: n/a **Other demographics**: n/a	Four youth with SCD reported incidences of racial bias in medical settings.

Wakefield et al., 2018[38] *Describing Perceived Racial Bias Among Youth with Sickle Cell Disease*	**Design:** Mixed methods, cross-sectional **Framework/Theory:** n/a **Tools:** PRaCY, semi-structured interview guide **Time period of study:** May 2012 and June 2014 **Recruitment site:** Both inpatient and outpatient recruitment **Country:** United States	**No of participants:** 20 **Gender**: Female = 14, Male = 6 **Type of SCD:** HbSS (n=14), HbSC (n=5), HbSBeta0-thal (n=1) **Age ranges:** 13 to 21 years old **Income:** n/a **Education level**: n/a **Ethnicities**: Predominantly Black or African American **Other demographics:** n/a	Four participants reported medical racial bias in medical settings a staff member who was repeatedly rude (n=2) Feeling that the needed to wait longer than others for clinic appointments (n=1) Pain with discounted at a different hospital setting (n=1). "I had gotten sick and I had been taken to the ER in the [outside hospital location] ...it seemed like we were in the twilight zone. I'm so used to coming to [home institution] and getting good care...I actually had to wait like two hours while I was in pain, like really bad pain, to get treated."
Weisberg et al., 2013[71] *"I'm talking about pain": sickle cell disease patients with extremely high hospital use*	**Design:** Qualitative, cross-sectional **Framework/Theory:** Grounded theory **Tools:** Semi-structured interview guide **Time period of study:** Jan 1, 2008 to December 31, 2010 **Recruitment site:** Found patients from hospital utilization records at single urban academic medical center **Country:** United States	**No of participants:** 8 **Gender:** Female = 5, Male = 3 **Type of SCD:** Hgb SS (n=5); Hgb SC (n=1), other (n= 2) **Age ranges:** 24 to 37 years old **Ethnicities**: n/a **Income:** n/a **Education:** n/a **Other demographics:** Inpatient hospital stays over 2 years ranged from 94 days to 263 days total for the group	Patients described deep mistrust of healthcare providers, feeling judged and misunderstood. "That's all our bodies know, is meds, meds, meds. Some doctors think we are taking too much. How can we be taking too much if our bodies need it?" Many participants expressed reluctance to try new therapies, specifically hydroxyurea: "These new chemicals, you come across doctors who say 'there's this new medicine out, it's been out for such and such a long time, can we try with you?' NO. I am not a guinea." Participants reporting attachment to the children's hospital and institution: "I loved pediatrics. They treat you better. It's the adult side I can't stand." and "Some people in the [pediatric] ER, they know us and I call them my family...they already know what I need." In contrast, the hospital experience in adulthood was characterized by bitter relationships with staff, distrust, and racism. Also reported issues with length of stay in adult hospitals and doctors not listening to them at time of discharge: "I say to the doctor, I'm not ready yet. And they say, 'Well you can't live here in the hospital. Why do you think you're not ready for discharge yet? You're never going to be pain free' to which I say 'I know that. I've been dealing with this all my life. I know I'm never gonna be pain free!"
Wickersham et al., 2022[72] *Experiences of African Americans Living With Sickle Cell Disease*	**Design:** Qualitative, cross-sectional **Framework/Theory:** Ecological Framework for Palliative Care of People with SCD, and also Leninger Culture Care Theory **Tools:** Semi-structured focus groups guided by an interview guide based on the Ecological Framework for Palliative Care of People with SCD and Leininger's Culture Care Theory **Time period of study:** Data were collected in February 2020 **Recruitment site:** Community center, done by SCD foundation representatives **Country:** United States	**No of participants:** 16 **Gender:** Female = 12, Male = 4 **Type of SCD:** Hb SS (n=13), Hb S-beta thal (n=3) **Income**: n/a **Education level:** n/a **Age ranges:** 22 to 71 years old **Ethnicities:** 100% African American **Other demographics**: n/a	"There was a nurse that told me that sickle cell was not a disease." "He (Doctor) was, like, "You just want drugs don't you? And then they'll say, 'Well, you don't look like you have sickle cell." Well, how am I supposed to look?" "And then when you're trying to go through all this with your doctors and your nurses about how you're treated and all this, and they just don't want to be bothered with it, so we just try not to go." "You go in there and you tell them what the problem is, and they look at you like you're stupid, like you don't even know what you're talking about." "This doctor saw everybody else, all the White people, before he saw me. But he was treating me for the wrong thing. He was treating me for rheumatic fever." "Because so many people to the ER, they do your labs, and if there's hemoglobin "like [mine] used to be an eight or so. And that's like, 'Oh, yeah. Hemoglobin is at eight. You can't possibly be in a crisis." I go to (place) every six weeks to get the transfusions, so of course, my hemoglobin's gonna be high: That doesn't mean I'm not in a crisis..."

			"Everybody knows their body. And I can remember a time when I went to the ED, and I was telling them that I was having severe pain in my leg. Well, they did every test that they could possibly do. So, I asked them to do a Doppler study. They wouldn't do the Doppler study. So, I ended up going to my hematologist... and they have their own machines there... And I was right. I had a blood clot..."
Williams-Gray & Seinrich, 2015[59] *Challenges and Resilience in the Lives of Adults with Sickle Cell Disease*	**Design:** Qualitative, cross-sectional **Framework/Theory:** Critical Race Theory & Phenomenology (Hycner) **Tools:** semi-structured interview guide with questions on SCD experiences, quality of care, and resilience factors administered during focus group sessions **Time period of study:** 2012 **Recruitment site:** Bronx Chapter of Sickle Cell Thalassemia Patients Network **Country:** United States	**No of participants:** 23 adults with SCD **Gender:** Female = 21, Male = 2 **Type of SCD**: n/a **Age ranges:** 18 to 70 years **Income**: n/a **Education level:** n/a **Ethnicities**: 19 = non-Hispanic Black, 2 = White, 1 = Hispanic, and 1 = mixed race. **Other demographics:** n/a	"When you're there at night, it was terrible. I was taken up to my room, when they were doing all these tests and one nurse said to the orderly: "Hurry up and put her away." You don't have a name. You have nothing." "My experience with sickle cell has been that I don't want to go to a hospital. I think they're insulting. I think that because of my skin color, they think I'm an idiot. I think it's racism; pure simple racism." "I truly believe that racism exists with sickle cell disease. You can see by the funding. Cystic fibrosis gets more money generated to that organization than sickle cell disease because I think the majority are whites... You see commercials [for] every disease in the world. Why isn't there a commercial for sickle cell?" "In sickle cell, we get poor treatment, centers close, no doctors. I read something once where it said that no doctors are really interested in hemoglobinopathy beause it, it's primarily in African Americans." ""It's always like, oh, another sickler... First of all, I'm not a sickler. I have a name!" "It's the forgotten disease" "I feel like they look at all sicklers as drug seekers because you come in asking for a dose that a normal person who does not have sickle cell would not need. But this is a different type of pain, and I don't think that they really understand that. I've had to create scenes where I've had to call out for them to understand this is not just a bellyache, this is not a regular-let me pop a Tylenol and I'll be fine. This is serious pain where you can't function. And so for them to be looking at you like: "Let's wait and see before we medicate you because that's a really high dose." "They look at you with disdain. They don't believe that this pain is genuine. They think that you're there because you want meds." "Being hospitalized for a sickle cell crisis shouldn't take more than seven to eight days, maybe ten days for me with a blood transfusion. And the same hospital that I go to yearly, every time I have a crisis, they will wait three or four days before they transfuse. They'll wait two or three days before they give me the appropriate amount of opiates... And one I start receiving that proper care it's like the fourth or fifth day." "There's funding for children with sickle cell disease and then once you become an adult, all the adult clinics have closed... Pediatrics ER just treated you differently becuase you are children. They can't blame the babies and the little people. "treated like a dog" "Like the last time I was in the hospital, [I was told] 'Oh shupt up! You're not that sick!' Nurses and doctors would say that. 'You were just here... and now you're back. You're not that sick. Shut up.'"

Young et al., 2020[44] *Let Their Voices Be Seen*	**Design:** Qualitative, cross-sectional **Framework/Theory:** n/a **Tools:** Photovoice technology of photography and journaling followed by a focus group discussion to analyze themes **Time period of study:** Over 4 weeks **Recruitment site:** Recruited 8 SCD adults who had participated in previous research studies from Memphis using Qsource (healthcare consultant company) **Country:** United States	**No of participants:** 8 adults with SCD **Gender:** Male = 5, Female = 3 **Type of SCD:** n/a **Age ranges:** 26 to 56 years old **Income:** n/a **Education level:** n/a **Ethnicities:** 100% Black/African American **Other demographics:** n/a	"I try to avoid the ED as much as possible." "Every time I enter the ED, I wonder if it will be the last time. Are they going to take my life seriously?" "When you have sickle cell disease, you have to look a certain way. If you look shabby then you're a drug user." All patients report they have been accused of drug seeking, and all report delays in care