



A Qualitative Review of Psychosocial Challenges Among Adults Living with Sickle Cell Disease

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Abstract

Sickle cell disease (SCD) is among the most common inherited blood disorders worldwide and is increasingly managed as a chronic condition in adulthood. Despite advances in survival, adults with SCD remain disproportionately affected by psychosocial challenges that are often underrecognized in clinical care. This qualitative review synthesizes evidence on the prevalence, drivers, and management of psychosocial difficulties in adults with SCD. A focused literature search of PubMed, Scopus, Google Scholar, and PsycINFO identified peer-reviewed studies published between 2000 and 2025. Eligible studies reported on depression, anxiety, psychosocial stressors, coping strategies, or interventions for adults (≥18 years) living with SCD. Findings indicate that adults with SCD experience high rates of depression (21–44%) and anxiety (7–36%), frequently associated with chronic pain, sleep disruption, and recurrent hospitalizations. Stigma and discrimination in healthcare settings, systemic racism, and socioeconomic instability further intensify psychological distress, undermining trust in providers and continuity of care. Social determinants, including food insecurity, housing instability, and transportation barriers, create a cycle in which poor psychosocial well-being worsens disease outcomes, which in turn exacerbate psychosocial burden. Nonetheless, resilience is evident, with adaptive coping, religious engagement, and strong social support linked to improved outcomes. Emerging interventions, including cognitive-behavioral therapy, mindfulness, and integrated multidisciplinary care delivered through in-person and telehealth models, demonstrate promise in reducing psychological morbidity and enhancing quality of life. Addressing the psychosocial burden of adults with SCD requires integrated

clinical strategies, policy reforms, and community-based approaches to reduce disparities and improve health-related quality of life.

Keywords: Sickle Cell Disease; Adults; Mental Health; Depression; Anxiety; Psychosocial; Resilience; Care

Introduction

Sickle Cell Disease (SCD) is one of the most common hereditary blood illnesses in the world, and it remains a serious public health problem [1]. The condition is caused by a hemoglobin gene mutation, which results in aberrant red blood cells that are stiff and sickle-shaped [1]. These cells restrict blood flow, causing pain episodes, anemia, and gradual organ damage [1].

In 2021, roughly 7.74 million people worldwide were living with SCD, a 41.4% increase from 2000 [1, 2]. Mortality has also been revised upward, with an estimated 376,000 fatalities per year, which is more than ten times greater than previous estimates [1, 2]. Children under the age of five account for roughly 81,100 of these deaths, ranking SCD as the world's 12th greatest cause of under-five mortality [1].

Each year, more than 500,000 infants are born with SCD, with nearly 80% occurring in Sub-Saharan Africa, a region where fragile healthcare systems exacerbate morbidity and mortality [2]. Limited access to neonatal screening, hydroxyurea medication, blood transfusion services, and curative options such as Hematopoietic Stem Cell Transplantation (HSCT) adds to poor survival rates in these areas [3]. Despite advancements in gene-editing technology and disease-modifying medications, disparities in access to care persist [3].

SCD also has a substantial health impact in high-income countries [4,5]. Approximately 100,000 people in the United States have SCD, with the vast majority identifying as non-Hispanic Black or African American [4]. Individuals with SCD continue to live more than 20 years less than the general population [4].

SCD has a lower level of healthcare infrastructure and research funding than other genetic illnesses [6]. For example, while affecting three times as many people in the United States as cystic fibrosis, SCD receives much less research funding [6]. These discrepancies lead to continuing gaps in care access, treatment development, and long-term health outcomes [6].

In stark contrast to the Psychosocial Challenges of Adults Living with SCD, the clinical manifestations of SCD are well documented, including Vaso-occlusive Crises (VOCs), stroke, pulmonary hypertension, renal impairment, and organ failure [7-11]. These consequences have a considerable influence on morbidity and mortality, requiring frequent hospitalizations and chronic illness treatment [7-11].

While the medical problems of SCD are widely understood, the psychosocial needs of adults are understudied [12]. According to studies, 18-44% of individuals with SCD report depression, and anxiety levels are higher than in the general population [13]. These psychosocial problems are associated with chronic pain, frequent hospitalizations, opioid-related stigma, and a cumulative burden of medical and psychosocial stressors [13-15].

Depression, in particular, is linked to lower health-related quality of life (HRQoL), more ER visits, higher healthcare expenses, and more functional impairment [13,14,15]. Although Löwe et al. [16] studied general care patients rather than those with SCD, their findings on the overlap between depression, anxiety, and somatization emphasize the possibility of functional impairment in populations with chronic illnesses. Given the recurrent pain and healthcare issues in SCD, these findings highlight the importance of thorough psychosocial assessment and integrated psychosocial therapies [16].

This review summarizes the current evidence on psychosocial challenges among people with SCD, focusing on prevalence, psychosocial stressors, healthcare gaps, societal determinants, coping techniques, and emerging interventions. By incorporating these findings, the review aims to inform comprehensive, equitable approaches to improving psychosocial well-being and related health outcomes for individuals with SCD. To anchor the narrative synthesis, this review applies a biopsychosocial framework, conceptualizing psychosocial outcomes in SCD as the product of interacting biological disease burden, psychological processes, and social-contextual factors, including stigma, structural racism, and access to care. Consistent with the available literature, the conclusions of this review primarily reflect evidence from high-income countries, particularly the United States, where most adult psychosocial SCD research has been conducted.

Literature Review

Prevalence and Patterns of Psychosocial Disorders in Adults with Sickle Cell Disease

Adults with SCD experience disproportionately high rates of psychosocial disorders compared to the general population [13]. Depression is the most commonly reported condition, with prevalence estimates ranging from 21% to 45%, while anxiety disorders affect approximately 7% to 36% of adults with SCD [13, 24]. Existing studies reveal wide-ranging estimates of depression among adults with SCD [25, 26]. While average prevalence across multiple studies is approximately 24%, some investigations have reported rates approaching 86% [25, 26]. Broader mood disorders have been identified in up to 35.7% of individuals screened [27, 28].

Gender disparities are also evident. Approximately 28% of women and 21% of men with SCD are affected by psychosocial disorders,

compared to 6% and 4%, respectively, in the general African American population [27, 28]. These statistics emphasize the urgent need for early detection and targeted psychosocial and mental health interventions in this high-risk population [27].

Depression and Anxiety: Clinical Burden

Depressive and anxiety symptoms in adults with SCD are closely tied to disease-related factors, including recurrent vaso-occlusive crises, chronic pain, and physical disability [30]. These psychiatric symptoms are associated with higher healthcare utilization, longer hospital stays, and an increased risk of opioid misuse [30, 31]. For instance, patients with depressive symptoms have a median hospital stay of four days, compared to three days among those without depression [31].

These findings highlight the clinical significance of integrating mental health screening and psychosocial assessment into SCD care [30, 31]. Early identification and treatment of depression and anxiety may improve not only psychiatric well-being but also pain management, treatment adherence, and healthcare outcomes [30, 31].

Substance Use, Psychosocial Disorders, and Pain in SCD

Comorbid psychosocial disorders, including clinically defined mental health conditions, in adults with SCD are frequently accompanied by substance use disorders, further complicating disease management [27, 35]. In a community-based sample of Black American adults with SCD, 38.8% reported at least one mental health disorder, including mood disorders (17.6%) and anxiety disorders (24.7%), compared to Black Americans with other non-heritable medical conditions [28].

Similarly, psychosocial disorders in SCD are strongly correlated with pain severity and opioid use [30]. Adults with depression or anxiety often report more frequent and severe pain episodes and are at greater risk for opioid misuse [30]. This interplay underscores the need for integrated care models that address pain management, psychosocial and mental health needs, and substance use simultaneously, rather than treating these issues in isolation [27, 28, 30, 35].

Cognitive Impairment and Screening Practices

Cognitive impairment is a secondary focus of this review, included because neurocognitive changes can meaningfully influence psychosocial functioning, coping capacity, and treatment adherence among adults with sickle cell disease (SCD).

Recent research highlights the importance of routine cognitive screening and the use of advanced neuroimaging modalities, including positron emission tomography (PET), near-infrared spectroscopy (NIRS), transcranial Doppler (TCD), magnetic resonance imaging (MRI), and electroencephalography (EEG), to identify early cognitive abnormalities [36]. These assessments are increasingly used to inform timely clinical intervention and may contribute to improved long-term neurological and psychosocial outcomes [33, 36].

Early identification of cognitive and mood disturbances supports timely psychosocial or pharmacological intervention, with potential benefits for treatment adherence, daily functioning, and overall quality of life among adults with SCD [36].

Psychosocial Stressors

Adults with SCD face persistent psychosocial stressors that significantly influence psychosocial well-being and adjustment trajectories. Frequent hospitalizations, the unpredictability of symptoms, and the lifelong nature of the disease generate chronic stress and contribute to ongoing adjustment difficulties [38, 41]. This continuous need to adapt to fluctuating health demands places individuals at heightened risk for psychological strain.

Stigma and discrimination within healthcare settings and in broader society further intensify emotional distress among adults with SCD [39]. Wu et al. [40] reported that patients frequently encountered

discriminatory treatment in clinical environments where their self-knowledge about their condition was often dismissed. Requests for pain relief were at times met with the stigmatizing label of “drug-seeking,” which contributed to mistrust, delays in care, and emotional distress [40, 48].

Pain is a central mediator of psychological morbidity in SCD. Chronic and unpredictable VOCs disrupt daily functioning, impair sleep, and contribute to fatigue and feelings of hopelessness [41]. Sleep disturbances caused by pain, sleep-disordered breathing, and nocturnal hypoxemia further contribute to emotional dysregulation, cognitive challenges, and reduced quality of life [41].

Social isolation is also a common experience for individuals with SCD. Limited understanding and support from peers, frequent hospitalizations, and experiences of bullying, abuse, or being unfairly labeled as lazy contribute to feelings of alienation, frustration, and hopelessness [41]. These challenges increase vulnerability to depressive symptoms and negatively affect overall well-being [41, 43, 44].

Role of Social Support Networks

Despite substantial psychosocial challenges, many adults with SCD depend on social support networks, including parents, friends, spouses, and siblings, for emotional support, assistance during crises, and help with health-related needs [42]. These networks play a crucial role in coping and highlight the importance of identifying relationships that may benefit from additional support [42].

Health System Gaps

Challenges in Transitioning to Adult Care

Transitioning from pediatric to adult care represents a particularly vulnerable period for individuals with SCD [17,18]. Pediatric care models typically provide integrated, multidisciplinary support, including hematology, psychology, and social work services [17-19].

In contrast, adult care is often fragmented, with fewer specialized providers, leading to suboptimal continuity of care [19]. Only about 60% of patients successfully establish care with adult hematologists, leaving many reliant on emergency departments for acute pain management and ongoing health needs [10,11,17-21,23]. This discontinuity is associated with increased complication rates, more frequent crises, psychological distress, and unnecessary hospitalizations, highlighting the critical need for structured transitional care programs to support individuals as they move into adulthood [21].

Treatment Access Barriers

Significant barriers also exist in accessing effective treatments. Hydroxyurea, a widely studied disease-modifying therapy, remains underutilized among adults with SCD due to limited provider familiarity, inconsistent insurance coverage, and patient mistrust [45]. Newer interventions, including hematopoietic stem cell transplantation and emerging gene therapies, remain inaccessible to most individuals because of high costs, limited treatment infrastructure, and systemic inequities that restrict availability [3, 46].

Social Determinants of Health

This section focuses on the conceptual relationships between social conditions and psychosocial outcomes in adults with sickle cell disease.

Social stressors often exacerbate disease-specific challenges, including chronic pain, functional limitations, and recurrent hospitalizations, leading to higher rates of depression, anxiety, and broader psychosocial distress among adults with SCD [23,28,32]. These impacts are particularly pronounced for African American and Black individuals, who not only have a substantially higher prevalence of SCD but also face compounded disadvantages from poverty, under-resourced communities, and structural racism. Evidence

from clinical and community-based studies consistently indicates that unmet or inadequately addressed social needs intensify disease burden and are closely linked to adverse mental health outcomes in this vulnerable population [23, 28, 32]. Addressing these disparities requires culturally responsive, equity-focused interventions that enhance access to essential resources, reduce systemic barriers to care, and expand affordable mental health and psychosocial services, alongside comprehensive bias and anti-racism training for healthcare providers [28, 32].

Coping Mechanisms and Resilience

Despite these challenges, adults with SCD demonstrate resilience through adaptive coping strategies. Problem-solving, religious engagement, and strong social support networks are consistently associated with reduced depressive symptoms and improved quality of life [42]. Faith-based coping, in particular, provides meaning and emotional regulation in contexts of chronic adversity [47].

Conversely, maladaptive strategies such as avoidance, denial, or substance misuse are linked to increased psychological morbidity [48]. Targeted interventions that strengthen resilience, coping skills, and self-efficacy have shown promise in mitigating mental health burden [49].

Interventions and Models of Care

Evidence-based psychosocial and mental health interventions remain limited but growing [48]. Cognitive-behavioral therapy (CBT) and mindfulness-based interventions reduce depressive symptoms and pain-related distress in adults with SCD [50, 51]. Collaborative care models integrating mental health professionals into hematology clinics have been associated with improved treatment adherence, reduced emergency utilization, and higher patient satisfaction [52, 53].

Telehealth has emerged as a promising approach, particularly for rural or underserved patients who face mobility or transportation barriers. Early studies indicate feasibility, acceptability, and positive effects on psychological outcomes [54, 55].

Methods

Literature Search Strategy

This qualitative review synthesizes evidence on mental health and psychosocial challenges among adults with SCD. An informative and exploratory search was conducted in PubMed, Scopus, and PsycINFO for articles published between 2000 and 2025. Keywords included “sickle cell disease,” “adult,” “mental health,” “depression,” “anxiety,” “psychosocial stress,” “coping,” and “intervention,” with Boolean operators and MeSH terms used to capture relevant studies. The purpose of the search was to identify key studies for thematic narrative synthesis, rather than to perform an exhaustive systematic review.

Eligibility Criteria

Studies examining mental health or psychosocial challenges among adults (≥ 18 years) with SCD were considered. Studies focusing solely on children, case reports without a mental health focus, or non-English publications were not considered. Key findings were summarized narratively to identify relevant themes.

Synthesis of Findings

Findings were synthesized qualitatively using thematic analysis. Themes were drawn across studies regardless of design (quantitative, qualitative, or mixed-methods) to identify mental health challenges, coping strategies, psychosocial stressors, and interventions. This approach provides a narrative overview of the psychosocial and mental health experiences of adults with SCD.

Results

The included studies consistently identified depression and anxiety as the most frequently reported psychosocial conditions among adults

living with sickle cell disease (SCD) [13, 16, 24–28, 32]. Across studies, psychological distress was commonly reported in the context of chronic pain, fatigue, sleep disruption, and recurrent hospitalizations [14, 79–81]. Several investigations documented co-occurring depression and anxiety, with findings indicating associations between psychological symptoms and increased pain perception, functional limitations, and reduced quality of life [14, 35]. Gender differences were noted in some studies, with psychosocial burden influenced by caregiving responsibilities, social expectations, and healthcare experiences [34, 82]. Co-occurring substance use disorders, including opioid misuse, were also reported and were associated with more complex clinical management needs [35, 57, 58, 83].

Beyond psychiatric symptomatology, stigma and discrimination within healthcare settings emerged as recurrent themes. Participants frequently reported experiences of being labeled as drug-seeking, dismissed, or delayed in receiving pain treatment [40, 59, 83]. Social isolation was also widely described, often related to repeated hospitalizations, employment disruption, educational interruptions, and limited public understanding of SCD [42, 61, 86]. Conversely, family support and strong interpersonal relationships were associated with improved emotional adjustment and adaptive coping [42].

Health system factors were consistently linked to psychosocial outcomes. Discontinuities in care, particularly during transition from pediatric to adult services, were associated with reduced access to specialized providers, increased emergency department utilization, and inconsistent treatment engagement [10, 11, 17–21, 23, 87]. Underutilization of disease-modifying therapies such as hydroxyurea was attributed to provider knowledge gaps, insurance limitations, and patient mistrust [45, 89]. Access to advanced therapies, including hematopoietic stem cell transplantation and emerging gene-based treatments, was reported to be constrained by cost and infrastructure limitations [3, 46].

Structural inequities disproportionately affecting individuals of African descent were frequently identified as contributing to psychosocial burden [23, 28, 32, 39, 60]. These inequities were associated with increased psychological distress and barriers to continuity of care. Neurocognitive impairments related to cerebrovascular complications and chronic hypoxia were also reported and were linked to challenges in treatment adherence and self-management when unrecognized [33, 36, 37]. Studies examining coping identified both adaptive strategies, including problem-solving, religious engagement, social support, and maladaptive responses such as avoidance and substance misuse [42, 47, 48]. Emerging intervention studies reported positive outcomes associated with cognitive behavioral therapy, culturally tailored programs, collaborative care models, digital platforms, and telehealth-based services [60, 63–76].

Discussion

This review highlights the substantial psychosocial complexity associated with adult sickle cell disease and reinforces the importance of understanding SCD within a biopsychosocial framework. The frequent co-occurrence of psychological distress and physical symptom burden observed across studies [14, 35, 56] suggests a dynamic interplay in which pain, functional limitation, and emotional distress influence one another over time. These findings support the integration of routine psychosocial screening and intervention within comprehensive SCD management rather than limiting care to biomedical symptom control.

Stigma within healthcare settings represents a critical contextual factor shaping patient experience. Recurrent perceptions of dismissal, suspicion of drug-seeking behavior, and delayed pain treatment [40, 59, 83] may undermine therapeutic alliances, contribute to anticipatory stress, and discourage timely care-seeking.

When situated within broader structural inequities affecting individuals of African descent [23, 28, 32, 39, 60], these experiences reflect intersecting clinical and societal influences that compound vulnerability and reinforce disparities in health outcomes.

The transition from pediatric to adult care emerges as a period of heightened psychosocial and clinical risk. Evidence linking care discontinuity with reduced access to specialized providers and increased emergency department utilization [10, 11, 17–21, 23, 87] suggests that fragmented systems may intensify stress and compromise treatment engagement. Strengthening transitional care models and ensuring coordinated adult services may mitigate these risks and promote sustained continuity.

System-level barriers to disease-modifying and advanced therapies further illustrate the influence of structural determinants on psychosocial well-being. Underutilization of hydroxyurea despite strong evidence of efficacy [45, 89], along with restricted access to hematopoietic stem cell transplantation and emerging gene-based therapies [3, 46], may shape perceptions of prognosis, control, and therapeutic possibility. These barriers highlight the interdependence of medical access and psychological outlook.

Neurocognitive vulnerabilities introduce additional complexity to disease management. Cognitive impairments associated with cerebrovascular complications and chronic hypoxia [33, 36, 37] may affect coping capacity, adherence, and self-management when not routinely identified. Incorporating cognitive screening into standard care may therefore support functional outcomes and enhance individualized treatment planning.

Importantly, resilience factors remain evident across studies. Social support, religious engagement, and adaptive coping strategies were associated with improved emotional adjustment and quality of life [42, 47], whereas maladaptive responses such as avoidance and substance misuse were linked to poorer psychological outcomes [48]. Emerging intervention models, including culturally responsive cognitive behavioral therapy, collaborative care approaches, and telehealth-based services, demonstrate promising effects on psychological and functional outcomes [60, 63–76]. Sustained implementation of integrated, culturally responsive, and equity-informed care models may therefore strengthen long-term psychosocial well-being among adults living with SCD.

Implications for Practice and Policy

The findings of this review highlight the need for integrated, equity-centered strategies that address the complex interplay of biological, psychological, and social factors shaping the lived experiences of adults with sickle cell disease (SCD). Strengthening care delivery requires coordinated clinical and policy reforms that move beyond symptom management to encompass comprehensive, person-centered support.

A central priority is the integration of psychosocial and behavioral health services into routine SCD care. Embedding mental health professionals within hematology and primary care settings can facilitate early identification of psychological distress, timely intervention, and continuity of support. Collaborative care models that promote interdisciplinary communication may reduce fragmentation and position psychosocial care as a standard component of chronic disease management rather than an ancillary service.

Routine psychological and psychosocial screening should also be incorporated into adult SCD management. The use of validated assessment tools for depression, anxiety, trauma-related symptoms, and cognitive changes enables systematic monitoring and early detection of comorbid conditions. Given the fluctuating clinical course of SCD, ongoing assessment is essential to ensure responsive and adaptive care planning.

Addressing structural inequities within healthcare delivery is equally critical. SCD disproportionately affects African American and Black populations in the United States, underscoring the importance of cultural humility, anti-bias training, and stigma-reduction initiatives among healthcare providers. Institutional investment in equity-focused education may enhance patient-provider trust, improve communication, and ultimately strengthen treatment adherence and outcomes.

Beyond the clinical setting, policies must confront the social determinants of health that compound psychosocial burden. Housing instability, food insecurity, transportation barriers, and employment challenges can significantly impede disease management and quality of life. Integrating social work services, case management, and resource navigation within SCD programs may mitigate these barriers and support sustained engagement in care. Partnerships with community and faith-based organizations offer an additional avenue for strengthening psychosocial support. Trusted community networks can facilitate culturally resonant health education, reduce stigma, and reinforce coping resources outside formal medical environments. Such collaborations extend the continuum of care and foster community-level resilience.

Finally, expanding telehealth services is a crucial way to improve access to psychological therapies and follow-up care, especially for people living in rural or underserved areas. Digital platforms can improve flexibility and continuity; however, implementation initiatives must address differences in technology access and literacy to avoid exacerbating existing imbalances. Collectively, these findings support a biopsychosocial and structurally informed approach for SCD care that connects clinical practice and policy with the complex realities of people living with this disorder.

Limitations

This review is qualitative in nature rather than systematic, and as such, some relevant studies may not have been captured. The included literature varied widely in study design, ranging from cross-sectional surveys to qualitative investigations, which limited direct comparison and precluded meta-analytic synthesis. In addition, heterogeneity in diagnostic instruments, sample sizes, and measurement of psychosocial constructs may affect the precision of prevalence estimates reported across studies.

Although substantial global research on sickle cell disease exists, this review intentionally focused on evidence from high-income settings, particularly the United States, to enable a focused synthesis of adult psychosocial outcomes within a relatively consistent healthcare and policy context. As a result, the findings may have limited generalizability to low- and middle-income settings, where healthcare infrastructure, resource availability, and sociocultural contexts differ substantially and where the burden of SCD is greatest, especially in sub-Saharan Africa. The exclusion of non-English publications may have further limited the representation of some global perspectives.

These limitations highlight the need for future context-specific psychosocial research in low- and middle-income settings to support the development of equitable and globally relevant care strategies for adults living with SCD.

Recommendations for Future Research and Practice

Despite growing recognition of the psychosocial burden associated with sickle cell disease (SCD), substantial gaps remain in the evidence base. Advancing scholarship and clinical practice requires methodologically rigorous, globally inclusive, and implementation-oriented research that aligns with the complex realities of adults living with SCD.

Longitudinal investigations are particularly needed to elucidate psychosocial trajectories over time. The predominance of cross-sectional designs limits understanding of the dynamic progression of depression, anxiety, cognitive changes, and social stressors across the life course. Prospective cohort studies that follow individuals through key developmental and structural transitions, including transfer from pediatric to adult care, employment entry, family formation, and aging, would provide more robust insight into patterns of vulnerability, adaptation, and resilience.

Expansion of research within African, Caribbean, and Middle Eastern contexts is also essential. Although the global burden of SCD is concentrated in these regions, much of the published literature originates from high-income countries. Cross-cultural studies are needed to examine sociocultural influences on stigma, coping strategies, help-seeking behaviors, and care delivery models. Generating geographically diverse evidence will enhance contextual relevance and improve the generalizability of findings.

There is a parallel need to develop and psychometrically validate screening instruments that are responsive to the lived experiences of adults with SCD. While general mental health measures are commonly employed, they may inadequately capture condition-specific stressors such as chronic pain burden, disease-related stigma, and cumulative healthcare encounters. Tailored and culturally validated assessment tools would strengthen diagnostic precision and inform targeted intervention planning.

Future research should also incorporate implementation science frameworks to evaluate the integration of psychosocial and behavioral health services within hematology and primary care settings. Beyond establishing efficacy, studies must examine feasibility, acceptability, cost, scalability, and long-term sustainability. Such approaches are critical for translating evidence-based interventions into routine clinical practice and ensuring system-level adoption.

Rigorous intervention trials remain a priority. Randomized controlled trials assessing cognitive behavioral therapy, mindfulness-based interventions, peer support programs, and telehealth-delivered modalities should evaluate not only symptom reduction but also functional outcomes, quality of life, treatment adherence, and cost-effectiveness. A comprehensive outcome assessment will clarify the comparative value and practical applicability of these interventions.

Sustained policy engagement is essential to advance equitable progress in the care of adults living with SCD. Advocacy efforts should prioritize increased and sustained funding for SCD research, expansion of integrated and interdisciplinary care models, and strengthened investment in community-based psychosocial and behavioral health infrastructure. Aligning empirical evidence with health policy development is critical to addressing longstanding structural disparities and improving access to comprehensive, person-centered care. Collectively, these priorities support the advancement of a rigorous, equity-focused, and globally responsive research agenda capable of strengthening both scientific understanding and clinical practice in SCD care.

Conclusion

Adults with SCD face disproportionately high psychosocial challenges, including depression, anxiety, and diminished quality of life. These outcomes are closely tied to chronic pain, stigma, systemic racism, fragmented care, and social determinants of health. The transition to adult care remains particularly precarious, exacerbating disparities.

Addressing these challenges requires comprehensive, integrated approaches: embedding psychosocial and mental health services into haematology clinics, leveraging telehealth, expanding adult specialist training, and addressing systemic inequities through policy and community interventions. Future research should prioritize

longitudinal studies, scalable interventions, and evaluations of multidisciplinary models, with particular focus on underserved populations. However, it is important to note that most evidence informing these approaches is derived from high-income healthcare systems, and applicability to low- and middle-income countries may be limited by differences in healthcare infrastructure, resource availability, and sociocultural contexts.

SCD is both a medical and psychosocial condition. Without addressing the psychosocial and mental health dimensions, efforts to improve survival and quality of life will remain incomplete.

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