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Sickle Cell Disease and Social Determinants of Health – A Scoping Review

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Abstract

Social determinants of health (SDoH) may impact outcomes in sickle cell disease (SCD). We conducted a comprehensive literature review of five electronic databases to elucidate the relationship between SDoH and SCD, and identify gaps in the literature. Our search yielded 59 articles which we organized into five SDoH areas: Neighborhood and Built Environment, Health and Healthcare, Social and Community Context, Education, and Economic Stability. We found that social determinants, such as access to healthcare, were inconsistently evaluated. Improved recognition and understanding of SDoH should enhance the development of programs that directly address its detrimental effects on patients with SCD.

Keywords

social determinants; healthcare access; healthy literacy; environment; quality of life

INTRODUCTION

Sickle cell disease (SCD) is an inherited blood disorder that affects approximately 100,000 individuals in the United States (U.S.) and occurs in an estimated 300,000 newborns annually worldwide.[1–2] Patients with SCD suffer from numerous complications, including acute and chronic pain and end-organ dysfunction, that require rigorous clinical follow-up and intervention to prevent deterioration of health.[3]

Social determinants of health (SDoH) have been defined as "the conditions in the environment where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks."[4] The World

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CONFLICT OF INTEREST DISCLOSURES

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Health Organization[5] identifies SDoH as a key factor in determining the health status of individuals with chronic complications. Research indicates that SDoH, such as inadequate housing, food insecurity, and limited access to affordable healthcare, shape the health behavior of patients with SCD[6] similarly to their effects on other chronic conditions such as cancer[7] and cystic fibrosis[8].

In the US, SDoH affects overall health outcomes more than medical care.[6] This difference is more evident in patients with SCD compared to the general population. Because SCD primarily affects individuals of African descent[9] the burden of managing a chronic illness while experiencing racial disparities and other socioeconomic factors significantly influences health outcomes and quality of life.[10]

Given the nature of SCD and its serious health outcomes associated with a wide range of determining factors, there has been increased interest in the impact of SDoH on SCD. This scoping review aims to synthesize the current evidence from the literature and identify gaps in knowledge to guide further research that will improve understanding of the association between SCD and SDoH.

METHODS

This scoping review was conducted following the Arksey and O'Malley[11] scoping review method. We utilized a comprehensive search strategy following the checklist provided by Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews (PRISMA-ScR)[12] to identify the highest possible number of relevant articles and minimize publication bias.

Information Sources and Search Strategy

This literature review aimed to identify peer-reviewed journal articles that examined the association between SCD and SDoH. Sources of information included PubMed (pubmed.ncbi.nlm.nih.gov), SCOPUS (scopus.com), CINAHL (ebscohost.com), PsycINFO (ovid.com) and Web of Science (webofknowledge.com). Unpublished manuscripts, reports, and evaluations were not searched for this review. A biomedical librarian assisted with the primary search and provided expertise in developing Boolean search in PubMed. Search terms were selected by consensus and used in various combinations to develop robust search results and ensure that all relevant articles were included. The authors reviewed the primary results from PubMed before search terms were entered into other databases.

Search terms were selected based on five SDoH areas from Healthy People 2020[4]: (a) Neighborhood and Built Environment; (b) Health and Healthcare; (c) Social and Community Context (d) Education; (e) Economic Stability. Search terms included: cognitive functioning, health literacy, unemployment, disability, food desert, food insecurity, neighborhood economic distress, poverty, stigma, health inequity, discrimination, home environment, access to healthcare, temperature, air pollution, tobacco smoke, incarceration, quality of life, insurance, and transportation. These keywords were combined with the terms "sickle cell disease" and "hemoglobinopathies" to search for relevant articles.

Eligibility criteria

Eligible articles: 1) included individuals with SCD (any genotype) or patient-caregiver dyads, 2) were original research articles published in English between 1975 (based on the publication of the first article that addressed SDoH in SCD) and 2020, and 3) evaluated the association between SDoH and SCD health outcomes. Abstracts without a corresponding manuscript, review articles, book chapters, and case reports were excluded.

Data Selection and Extraction

Two reviewers independently conducted the literature search (HK, MK) and screened all titles and abstracts of studies to determine eligibility. Citation management and duplicate results were removed using EndNote (Clarivate Analytics). Reviewers (HK, MK) retrieved the full text of relevant articles. Disagreements regarding study eligibility were resolved through discussion among all reviewers (HK, MK, JP, WW) during biweekly meetings until a consensus was reached. Covidence (Covidence.org), a web-based platform that streamlines the production of systematic and scoping reviews, was used to supplement the review process. The reasons for excluding full-text articles are indicated in the PRISMA flowchart (Fig. 1).

Data Charting and Synthesis

Reviewers (HK, MK) independently performed data charting of articles included in the final full-text review. The following study characteristics were identified: author and year, research design, population, geographic region, SDoH variable, and study results. Studies were categorized by the SDoH areas in Healthy People 2020.[4] Narrative overviews of full-text review findings were organized in tabular summaries of extracted data (Tables 1–5).

RESULTS

Study selection

The PRISMA flow diagram is shown in Fig 1. A total of 1202 references identified through the literature review underwent abstract screening. Following the screening, 66 articles were included in the full-text review. References that did not meet the eligibility criteria were removed, including seven studies that described medical determinants of social outcomes instead of SDoH, leaving 59 articles for narrative synthesis.

Characteristics of Reviewed Articles

Tables 1–5 summarize the articles included. Studies were published recently, 73% since 2010 (Supplemental Fig S1). Most of the studies were primarily based in the United States (n = 43; 68%) and the remaining were conducted in the United Kingdom (n = 6), Nigeria (n = 4), Brazil (n = 3), Canada (n = 2), France (n = 2), Italy (n = 1), Saudi Arabia (n = 1), and Jamaica (n = 1) (Supplemental Fig S2). Study designs were primarily retrospective or cross-sectional. Approximately half of the studies were pediatric (n = 30, 51%) and the rest included adults only (n = 16), patient-caregiver dyads (n = 11) or both children and adults (using demographic data from national hospital databases) (n = 2).

Social Determinants of Health and Sickle Cell Disease

Neighborhood and Built Environment (Table 1)—Eleven studies assessed the effects of environmental factors on disease-related complications in patients with SCD. The population samples included both children and adults. The studies investigated outcomes associated with climate change, temperature fluctuation, air pollution, and tobacco exposure.

Patients' environments were often detrimental to health outcomes by increasing respiratory symptoms and VOC, contributing to increased acute care utilization. High wind speed and low humidity were associated with changes in skin temperature and increased frequency of painful episodes.[13–15] Large temperature changes and seasonal viral infections such as influenza, contributed to VOC.[13,16,17] A study conducted in Brazil[16] found that polluted air in the environment posed a significant threat to children with SCD. Air pollution caused by dust or pollen particles, and poisonous gases from car and truck exhaust (carbon monoxide, nitric acid, and ozone) was associated with frequent pain episodes.[19–21] Tobacco smoke exposure increased respiratory problems leading to recurrent hospitalizations.[22,23]

Health and Healthcare (Table 2)—Fifteen studies investigated the impact of poor access to healthcare and low health literacy. All these studies were conducted in the US, and included children and adults.

Access to Healthcare

SCD patients were more likely to experience delays in getting healthcare because of their race and/or because they lived in rural areas without a sound transportation system. [24,25] Both factors contributed to worsening health outcomes. Greater distance from sickle cell centers and absence of primary care increased the risk of hospitalization and 30-day readmission for patients with SCD, particularly children, compared to patients with other chronic conditions.[26–28] A few studies reported that the rate of visits to non-sickle cell clinics decreased in the regions with the availability of a comprehensive sickle cell center close to patients' homes.[29,30] Socioeconomic status played a significant role in determining access to healthcare. Lower-income patients paid higher healthcare costs and utilized emergency services more often due to a lack of stable insurance and/or primary care.[31–34]

Health Literacy

Health literacy, defined as "the degree to which individuals can obtain, process, and understand basic health information needed to make appropriate health decisions,"[35] was critical in determining disease-related outcomes for patients with SCD. Disease-specific knowledge plays a significant role in improving pain management, medication dosing, and healthcare services.[36,37] Increased SCD-specific literacy was associated with greater outpatient visits among adults with SCD.[38] Children of caregivers who did not have disease-specific knowledge or were financially insecure frequently missed scheduled clinical evaluations, which contributed to increased ED visits and hospitalizations for pain.[36–39]

Social and Community Context (Table 3)—Eighteen articles focused on understanding the impact of disease-related stigma, social support, and health-related quality of life (HRQoL) of patients with SCD, including both adults and children.

Discrimination

Self-reported stigma and perceived discrimination correlated with more interference from pain in the lives of individuals with SCD, and resulted in more hospital admissions and ED visits. [40,41] Patients who suffered from disease-related stigma were more likely to have an increased length of hospital stay due to the severity of their pain which lowered their HRQoL. [42,43]

Social Cohesion

Social support and good family functioning were associated with increased self-management and HRQoL. Positive coping strategies, family support, and reduced parenting stress were correlated with decreased healthcare utilization.[44] In contrast, patients' family dynamics, such as lack of communication and mutual respect, diminished problem-solving ability and passive parental coping, resulted in poor SCD self-management and increased pain events.[45]

Quality of Life

Patients with SCD with poor physical strength, more bodily pain and deteriorating emotional well-being often faced worse HRQoL, irrespective of gender, increasing age or family income.[10,46] Socioeconomic status and neighborhood economic distress predicted patients' functional outcomes and rate of hospital readmissions related to SCD pain. This pain contributed to impaired HRQoL for patients with SCD compared to patients without SCD but with similar financial status.[39,47–49] The studies conducted in Brazil and Saudi Arabia found that HRQoL of patients with SCD varied according to the health center where they received care.[50,51] At centers where health professionals received additional training in managing SCD, patients experienced reduced disease anxiety, fewer hospitalizations, and improved quality of life due to better disease management as compared to the health centers where patients were not cared for by providers with SCD expertise.[50–52] Additionally, their insurance type determined at which center they would receive care and thus impacted disease outcomes.[32,33,53]

Education (Table 4)—Five articles in this category highlighted the associations between low educational attainment, socioenvironmental risk, cognitive impairment, and parental education. The study populations included both children and adults.

A few studies conducted in the US and Nigeria examined the effects of sociodemographic factors, parental education, and family functioning in children with SCD.[52–55] In Nigeria, socioeconomic factors, number of individuals living per room in a house, social support, and educational level of the head of the household determined the severity of anemia in children with SCD who lived in a low-resource setting.[54,55] A few other studies conducted in the US found that the home environment and family functioning were significantly associated with cognitive development and HRQoL in children with SCD.[56,57] In the US, adult patients with SCD who did not achieve higher education experienced a greater rate of ED utilization and were often unemployed compared to their peers who completed post-high school education.[58]

Economic Stability (Table 5)—Eleven studies documented the effects of unemployment, food insecurity, low income, poverty, and housing instability that altered disease-related outcomes. These studies were conducted in regions of the US and Nigeria, and included adults and children.

Unemployment

Patients with SCD who lacked general cognitive ability, memory, and executive functioning were more likely to be unemployed when compared to their peers who attained higher education.[59] Employed patients had less severe pain episodes, did not utilize the ED as much, and had more disease-management knowledge and social support.[59] Unemployed patients suffered from significantly greater pain-related disruption in their lives along with other health-related problems that increased the use of opioids and created more difficulty in obtaining employment. Alternatively, employment status may not only be related to poor health.[60] Behavioral and social factors such as poor interpersonal relationships with management and other employees, low self-esteem, or lack of job skills due to cognitive deficits and irregular school attendance may also result in unemployment.[60]

Food Insecurity

Inadequate nutritional intake, access to fresh produce, and impaired growth were other factors that contributed to poor health outcomes. The households of individuals with SCD suffered from greater food insecurity compared to the national US average.[61] A study conducted in Brazil and Nigeria found that patients with SCD often lived in poor neighborhoods that lacked access to full-scale grocery stores and could not afford higher healthcare costs due to financial insecurity.[62] Some studies speculated that lack of enough nutrients was associated with frequent episodes of VOC and increased acute care utilization.[62,63]

Low Income and Poverty

The most readmissions and highest inpatient mortality occurred in patients living in the most socioeconomically deprived areas.[64] Recurrent acute health care utilization contributed to a significant burden on healthcare resources and diminished HRQoL of patients with SCD.[65] A study conducted in Nigeria reported that the number of residents in a household determined the likelihood of severe disease.[54] Regardless of distance to the nearest hospital or access to healthcare, living below the federal poverty threshold increased ED utilization.[66] Low-income children with SCD and neurobehavioral co-morbidities were more likely to have higher healthcare utilization due to frequent pain when compared to children with similar sociodemographic characteristics.[33,48]

Housing Instability

No eligible articles were found in this category.

DISCUSSION

Given the magnitude of social and clinical barriers faced by patients with SCD, a comprehensive understanding of the impact of social determinants of health outcomes

is essential to develop specific interventions to maximize the health of this vulnerable population.[67] The current scoping review focuses on evaluating and synthesizing the published literature on SCD and SDoH. We found a lack of specificity and in-depth reporting of barriers associated with SCD and SDoH in the literature that warrant further research.

Most studies addressing SDoH in SCD have been published in the US in the last decade, highlighting recent interest and increased attention to the impact of SDoH in SCD.[67] Our review found that SDoH categories such as neighborhood and built environment, access to healthcare, economic stability, and quality of life, have been explored more than other social determinants, such as education, unemployment, food insecurity, discrimination, and social cohesion. Other factors, such as housing instability, have not been discussed, indicating that significant gaps exist within SDoH literature, and further exploration is necessary.

Most studies highlight sociodemographic, economic, and environmental factors as the fundamental social risk factors leading to most health problems. In particular, the effects of SCD complications on quality of life [47,48,50,51] have been addressed in depth. However, factors such as the impact of health literacy,[36–39] race,[40–43] area of residence,[64] and level and location of care received[26–30] have hardly been explored, if at all. Furthermore, understanding psychosocial needs such as family functioning is equally important to maximize health benefits of patients with SCD.

Many studies identified during the literature review were limited to children and caregivers and lacked longitudinal analyses to study the impact of SDoH over time. Studies with children often compared patients with SCD to their healthy peers or children with other chronic complications to highlight the increased odds of experiencing worse HRQoL in patients with SCD.[44–51] Research with caregivers focused on improving their health literacy through continuous education on disease-specific knowledge (such as medication dosing or navigating the healthcare system) to increase the caregivers' ability to make appropriately informed decisions for their child's health. [36–39] A few studies explored the impact of SDoH outcomes in adults with SCD highlighting the educational gaps and low socioeconomic status that can lead to unemployment.[58–60] As patients become older, managing a lifelong chronic illness while keeping a stable and continuous source of income, and balancing the need to take care of sick family members is challenging. Therefore, researchers should emphasize studying the long-term effects of SDoH to promote the development of comprehensive care plans that are applied longitudinally to the patients' treatment course.

African American/Black patients with SCD, and patients who belong to ethnic minority groups experience more delays in care than non-African American/Black patients.[40–43] Despite being recognized as one of the most important social determinants in SCD, the association between discrimination, disease-related stigma, and healthcare utilization in SCD has been understudied. A few studies have reported that perceived discrimination in healthcare systems may be a significant risk factor in chronic diseases, and lead to racial and ethnic disparities.[41,43] Negative experiences at a healthcare facility, and lack of trust between a patient and a provider reduce the likelihood of patients adhering to physicians' recommendations, increase the frequency of pain episodes among patients with SCD, and

affect the overall health and quality of life.[40–43] There is a need to develop programs that address the type and frequency of discrimination in the healthcare system and examine the prevalence of stigma associated with SCD.[69] Increased understanding and support of emotional health may build trust among patients and medical professionals, reduce disease severity and hospitalizations, and lead to a better quality of life.[40–43]

The current healthcare system emphasizes lifestyle changes and counseling as essential strategies for preventing disease-related complications in patients with SCD. However, these interventions may not fully address the social and clinical barriers associated with the disease, such as health disparities. [68] In addition, despite receiving standardized care in the hospital setting, patients will return to their homes and pre-existing multifactorial environmental stressors such as poverty and food insecurity that contributed to the initial hospitalization; therefore, standard medical treatment benefits will remain not fully realized.[65,66] Because each impacts the other, it is essential to consider patients as the sum of their environment and medical condition.

Considering our findings as well as the current guidelines provided by professional societies, such as The National Academies of Sciences, Engineering, and Medicine (NASEM)[70] and The American Society of Hematology (ASH),[71] SDoH should be integrated into healthcare delivery and treatment decisions of patients with SCD. Three interventions are especially relevant to achieve this: (1) providing ongoing cultural competency training for healthcare professionals to improve health outcomes and increase mutual understanding among patients and providers; (2) ensuring that the design of clinical trials reflects cultural diversity, allowing the medical community to assess the effectiveness of similar therapies among different populations; and (3) supporting programs that allow individuals from minority backgrounds to become a part of the healthcare workforce to improve the quality of healthcare for minority populations.[70,71] Finally, a broader understanding of the disease from a global health perspective, and interventions such as a universal screening and referral program for SDoH are needed to improve clinical outcomes and HRQoL for patients with SCD.[10] Collaboration among medical institutions from resource-rich and low-resource countries will help to improve the research infrastructure, transference of knowledge among providers will lead to a better understanding of the disease, and sharing resources such as disease-modifying therapies for SCD will maximize health benefits and improve the quality of life of patients with SCD.

LIMITATIONS

Some potential methodological limitations of our scoping review are worth mentioning. Although the current scoping review reported findings following PRISMA guidelines and included a diverse set of inclusion criteria to assess the association of social determinants with SCD comprehensively, we may have missed some relevant articles and unpublished studies in the “gray” literature. We only included the studies published in peer-reviewed journals to focus on the most robust available evidence in the literature, so potential publication bias could not be excluded. Additionally, studies had small sample sizes, were primarily cross-sectional, and lacked a global perspective, which limited our interpretation of the findings. Furthermore, some SDoH areas, such as housing instability, were not

represented at all, highlighting the need for further elucidation of the impact of SDoH on outcomes for SCD.

CONCLUSIONS

External pressures such as pandemics, economic instability, and societal unrest have highlighted the relationship between SDoH, healthcare utilization, and health outcomes in historically marginalized communities. The traditional healthcare system emphasizes biomedical problems as the primary cause of poor health outcomes and often overlooks social risk factors that increase the frequency of hospitalizations, morbidity, and mortality.[67] The evidence from our literature review shows that SDoH may play a prominent role in access to care and success of treatment of patients with SCD. SDoH should be considered when designing randomized clinical trials, perhaps by including the impact of selected social factors when stratifying patients at randomization and/or considering them as endpoints of the study. A more comprehensive understanding of the association between SCD and SDoH will help better position researchers to design new patient-centered interventions that could improve health equity and health literacy, open doors for better healthcare, and reduce negative impacts of SDoH in SCD.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

ASH	American Society of Hematology
E.D.	Emergency Department
HRQoL	Health Related Quality of Life
NASEM	National Academies of Sciences, Engineering, and Medicine
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews
SCD	Sickle Cell Disease
SDoH	Social Determinants of Health
U.S.	United States of America
VOC	Vaso-Occlusive Crisis

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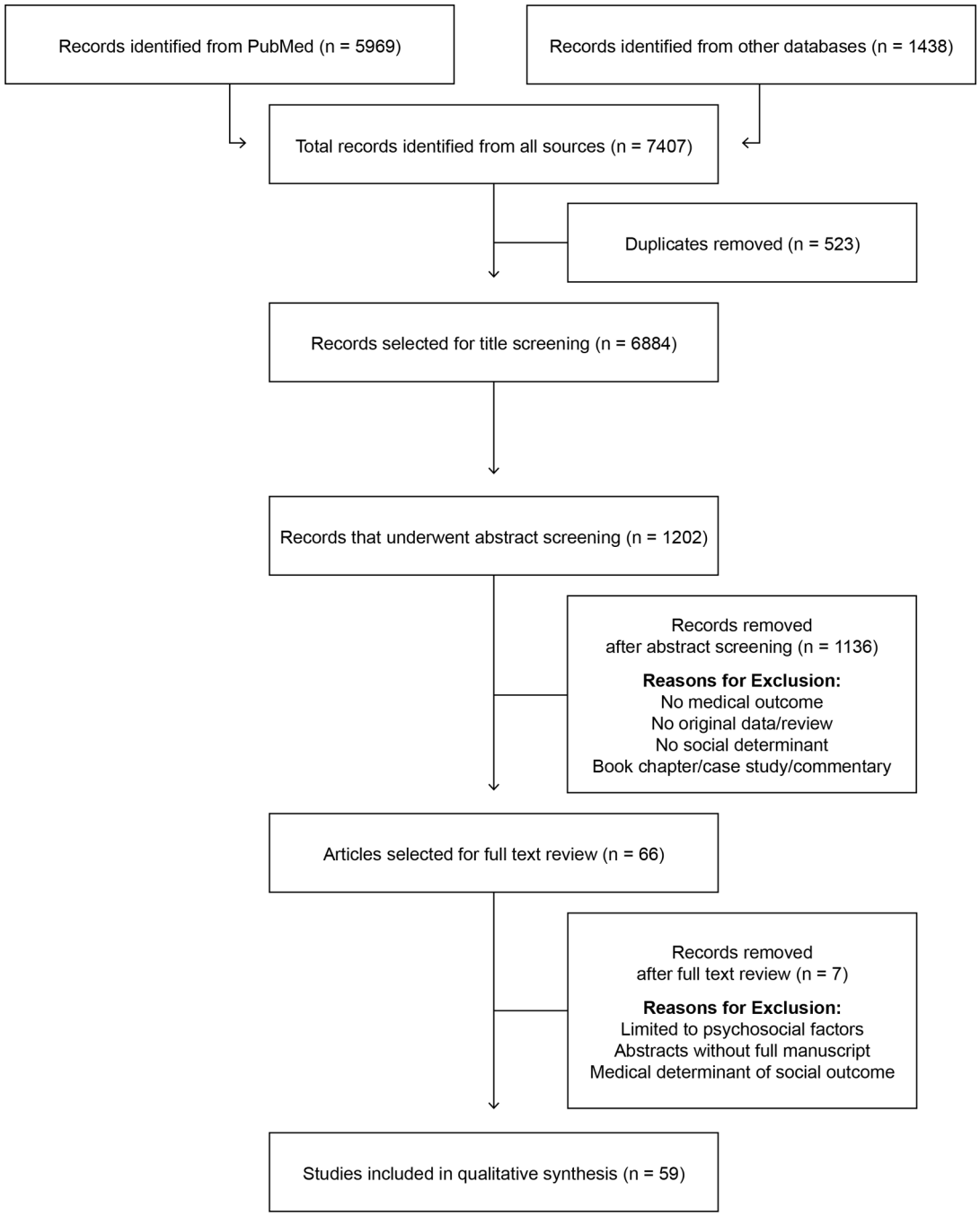

Figure 1:
PRISMA Flow Diagram for the Search of SCD and SDoH Literature

TABLE 1.

Neighborhood and Built Environment Articles Included in Review

Author (Year)	Research Design	Study Population	SDoH Variables	Results
Blumberg (2020)	Observational	77310 ED visits (US)	Air pollution (CO, NO2, SO2, O3)	Urban air pollution (traffic pollutant) triggered ACU
Wachnian (2020)	Retrospective	118 children (Canada)	Temperature fluctuation	Large temperature changes triggered VOC
Parriault (2019)	Retrospective	384 children/adults (French Guiana)	Meteorological data (weather, influenza)	Temperature/humidity decreased VOC. Flu affected pain severity
Barbosa (2015)	Case-Crossover	3180 adolescents (Brazil)	Air pollution (CO, NO2, SO2, O3)	Ambient air pollution triggered VOC
Cohen (2013)	Cross-sectional	252 children (US/UK)	Tobacco Exposure	Tobacco exposure increased respiratory problems
Mittal (2009)	Prospective	93 children (UK)	Air pollution (PM, NO NO2)	Air pollution predicted more stroke related complications in SCD
Nolan (2008)	Case-Crossover	813 children/adults (US)	Meteorological data (climate, wind speed)	Males with SCD had more VOC events due to wind speed in warm climate
Yallop (2007)	Retrospective	1413 children/adults (UK)	Air pollution (NO, CO, O3, SO2)	Air quality affected VOC and increased hospitalizations
Jones (2005)	Observational	1413 children/adults (UK)	Meteorological data (temperature)	Climate changes affected skin temperature that increased VOC
West (2003)	Retrospective	52 children (US)	Tobacco exposure	Tobacco smoke increased SCD crises
Redwood (1976)	Retrospective	161 children/adults (Jamaica)	Meteorological data (temperature, rainfall)	Low temperature increased hospitalizations for VOC in patients with SCD

SCD = Sickle Cell Disease, VOC = Vaso-occlusive crisis, ACU = Acute care Utilization, US = United States, UK = United Kingdom

TABLE 2.

Health and Healthcare Articles Included in Review

Author (Year)	Research Design	Study Population	SDoH Variables	Results
Access to Healthcare				
Kayle (2020)	Retrospective	3635 adults (US)	Insurance type	Medicaid expansion did not improve enrollment or ACU
Carroll (2018)	Prospective	73 adults (US)	SES, ACU	SES and pain-related anxiety increased ACU in patients with SCD
Brodsky (2017)	Retrospective	88 adults (US)	PCP, insurance type, ACU	Absence of PCP and ACU frequency increased 30-day readmission
Jacob (2016)	Cross-sectional	38 adults (US)	Barriers to care	Parents of patients with SCD reported more barriers to care due to the gap in primary care
Smeltzer (2016)	Prospective observational	545 children (US)	Distance to CSCC	Greater distance to CSCC decreased hospital admissions
Liem (2014)	Cross-sectional	200 adults (US)	Primary care access, barriers to ACU, PCP	More access to PCP associated with less ED visits
Boulet (2010)	Probability sample survey	19427 children (US)	Barriers to healthcare access	Patients with SCD reported delay in accessing care and worse health outcomes
Raphael (2009)	Cross-sectional	296949 children (US)	Medicaid coverage, gaps in insurance	Low-income children with SCD had more ACU and higher expenses
Shankar (2008)	Cross-sectional	1214 children (US)	Distance to CSCC	Neighborhoods with CSCC facilities observed less outpatient visits & more hospitalizations
Haque (2000)	Cross-sectional	1189 adults/children (US)	Socioeconomic disparity, rural/urban access	Rural patients had low SES/more barriers to SCD clinic; urban patients had more medical issues
Hand (1995)	Retrospective	172 Adolescents/ Adults (US)	Insurance type, Primary / Specialty care use	Stable insurance (Medicare) and primary care did not affect ACU for patients with SCD
Health Literacy				
Carden (2016)	Cross-sectional	142 adults (US)	Health literacy, disease knowledge	Lack of disease specific knowledge increased ED visits
Cronin (2019)	Cross-sectional	530 adults (US)	Financial insecurity, social support, health literacy	Missed clinic visits due to financial problems increased hospitalizations/readmissions
Morrison (2018)	Cross-sectional	100 adults (US)	Health literacy, pain treatment skills	Children of parents who underdosed pain medicine had more ED visits for pain

*SES = Socioeconomic status, SCD = Sickle Cell Disease, ED = Emergency Department, ACU = Acute Care Utilization, PCP = Primary Care Provider, CSCC = Comprehensive Sickle Cell Center, US = United States

TABLE 3.

Social and Community Context Articles Included in Review

Author (Year)	Research Design	Study Population	SDoH Variables	Results
Discrimination				
Bediako (2016)	Prospective	262 Adolescents/ Adults (US)	Self-reported Stigma	Stigma affected disease severity/acute care utilization
Haywood (2014)	Cross-sectional	291 Adolescents/ Adults (US)	Demographic, health status, pain burden	Perceived discrimination associated with higher pain severity
Martin (2018)	Cross-sectional	92 Adolescents (US)	SCD-related stigma, social support, QOL	More stigma increased SCD pain/hospital admissions and decreased quality of life
Stanton (2010)	Retrospective	49 Adults (US)	Discrimination, trait optimism	Patients with SCD with more discrimination/trait optimism had greater acute care encounters
Social Cohesion				
Mitchel (2007)	Mixed methods	53 Adults (US)	Coping strategies, family functioning	Positive coping & better family functioning was related to low health care utilization.
Psihogios (2018)	Cross-sectional	83 Adults (US)	HRQL, family efficacy	Family efficacy/less parental stress improved SCD self-management and HRQL
Quality of Life				
Power-Hays (2020)	Prospective	200 Children (US)	SDoH, HRQL	Patients with SCD face more SE hardships. Universal screening for SDoH needed
Mougianis (2020)	Cross-sectional	71 Adolescent (US)	Racism, HRQL	Racism predicted more depressive symptoms
Kayle (2020)	Retrospective	3635 Adults (US)	Insurance	Medicaid expansion did not improve acute care utilization
Cortright (2020)	Retrospective	126 Children (US)	SDoH, QOL	Patients with SCD with high social disadvantages had more acute care encounters
Oliveira (2019)	Cross-sectional	4956 Children (Brazil)	QOL	QOL varied with health centers when adjusted for sociodemographic
Cronin (2019)	Cross-sectional	531 Adults (US)	Ambulatory care cost, QOL	Sociodemographic predicted rate of hospital admissions/readmissions
Robinson (2014)	Prospective	55 Children (US)	Insurance, QOL	Insurance type affected disease-related complications and QOL
Bundy (2012)	Retrospective	851 Children (US)	Financial status, QOL	Medicaid-insured children with SCD connected better with generalists than hematologists
Amr (2011)	Retrospective	285 Adolescents (Saudi Arabia)	Sociodemographic, HRQL	SCD complications and sociodemographic correlates had poor impact on HRQL
Panepinto (2009)	Cross-sectional	104 Children (US)	HRQL	Family income poorly affected HRQL
Palermo (2008)	Retrospective	56 Children (US)	Family Income, HRQOL	SES and neighborhood economic distress predicted pain outcomes
Hand (1995)	Retrospective	172 Adolescents/ Adults (US)	Socio-economic distress, QOL	Stable insurance (Medicare) and primary care did not affect ACU

*SCD = Sickle Cell Disease, QOL = Quality of Life, HRQL = Health related quality of life, ED = Emergency Department, SDoH = Social determinants of health, ACU = Acute Care Utilization, US = United States, SE = Socioeconomic status

TABLE 4.

Education Articles Included in Review

Author (Year)	Research Design	Study Population	SDoH Variables	Results
Bello-Manga (2020)	Cross-sectional	941 children (Nigeria)	Education level of a household	Severe anemia associated with low education of a household
Bills (2020)	Comparative	70 children (US)	SES, cognitive/behavioral function	Parent/family functioning was independent of SES
Fields (2016)	Single prospective cohort	43 children (US)	Home environment, SES, parental education	Home environment predicted cognitive development
Jonassaint (2016)	Retrospective	258 adults (US)	Education attainment	Low education completion associated with ED care
Oluwole (2016)	Cross-sectional	56 Children (Nigeria)	Sociodemographic, cognitive functioning	Sociodemographic factors correlated with cognitive impairment

*SES = Socioeconomic Status, ED = Emergency Department, US = United States

TABLE 5.

Economic Stability Articles Included in Review

Author (Year)	Research Design	Study Population	SDoH Variables	Results
Employment				
Williams (2018)	Prospective descriptive	95 adults (US)	Employment, SBF	Employment/stable home related to low acute care encounters
Sanger (2016)	Retrospective	50 adults (US)	Unemployment	Low education related to more frequent VOC and unemployment
Food Insecurity				
Ghafuri (2020)	Cross-sectional	Children (US)	Food insecurity	Patients with pain/ACS were more food insecure
Adegoke (2017)	Comparative	Children (Brazil, Nigeria)	Nutrition status, access to care	Under-nutrition was prevalent in patients with SCD
Mandese (2016)	Observational	Children (Italy)	Nutrition Intake, impaired growth	Inadequate nutrition affected SCD severity
Low-Income/Poverty				
Bello-Manga (2020)	Cross-sectional	941 Children (Nigeria)	SES, poverty, hospital cost	Severe anemia associated with more children in each room per house
Kumar (2020)	Retrospective	National record of readmission (US)	Education level, Poverty	Low SES/admission at high volume centers predicted more readmissions
Aljuburi (2013)	Retrospective	National hospital record (England)	Healthcare expenditure	Living in socio-economically deprived areas increased risk of readmission
Glassberg (2012)	Retrospective	985 children (US, Canada, UK, France)	Family Income	Low-income increased ED use for SCD pain
Panepinto (2009)	Cross-sectional	178 children (US)	SES	Low family income related to more ED readmissions and worse HRQL
Raphael (2009)	Retrospective	Children (US)	Low income	Patients with SCD with low income have more acute care encounters

*SBF = Socio-behavioral factors, SCD = Sickle Cell Disease, ACS = Acute Chest Syndrome, SES = Socio-economic Status, HRQL = Health related quality of life, US = United States, UK = United Kingdom, ED = Emergency Department