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**Screening for Social Determinants of Health in a Comprehensive Pediatric Sickle
Cell Disease Clinic**

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Abstract

Problem: Social determinants of health (SDOH) affect health outcomes across the lifespan. The American Academy of Pediatrics recommends routine screening for SDOH. Poverty is a SDOH affecting health outcomes in children, especially in children with a chronic disease such as sickle cell disease (SCD). Children with sickle cell disease have a high burden of SDOH. This project sought to describe the SDOH barriers experienced by pediatric patients with SCD.

Methods: A descriptive survey/observational design, using a convenience sample of pediatric patients ages 0-19 years old in a comprehensive SCD clinic at a large, urban, Midwestern academic medical center was utilized for this project. The validated, self-reported, WE CARE screener, assessing eight domains of SDOH, was given to patients/families to fill out during a routine clinic visit. Any patient that endorsed one or more SDOH was given a community resource sheet with their After Visit Summaries (AVS). Data taken directly from these screeners was analyzed.

Results: During the pilot period (February – April 2022), 102 (75%) of 136 eligible unique patients/families were screened. A large majority of patients, 83% (68), endorsed at least one or more needs; 17% (34) patients/families did not endorse any needs. The most frequent needs endorsed were food at 21%, followed by the desire for more education at 17% and difficulty paying utilities at 16%.

Implications for Practice: Screening for SDOH should be universal/routine in comprehensive sub-specialty clinics that become medical homes for patients to allow for early referral and intervention to mitigate the effects of endorsed SDOH.

Social determinants of health (SDOH) are non-medical factors and conditions in which one is born, grows, works, lives, and ages that affect health outcomes across the lifespan (World Health Organization [WHO], 2021). Social determinants of health are grouped into 5 categories – economic stability, access to quality education, access to quality healthcare, neighborhood and built environment, and social and community context and examples include safe housing, racism/discrimination, violence, income, poverty, access to food and physical activity, and polluted air and water (U.S. Department of Health and Human Services., n.d.). SDOH account for 30-55% of health outcomes, contributing to health disparities and health inequities – the avoidable and unfair differences in health status (WHO, 2021; Centers for Disease Control [CDC] 2021). Poverty is one of the SDOH contributing to child health disparities (American Academy of Pediatrics [AAP], 2016).

Poverty is defined as having an income threshold of \$26,496 for a family of 4 (United States Census Bureau, 2021). According to the United States Census Bureau (2021), the most recently available data reveals a childhood poverty rate for American children under 18 years of age at 16.1% in 2020, compared to 14.4% in 2019. Childhood poverty increases the risk of poor health and developmental outcomes negatively effecting children's brain development, self-regulation, neuroendocrine dysregulation, executive function, and peer relationships (AAP, 2016). Poverty also exposes children to food insecurity, housing insecurity/homelessness, loss of healthcare, and school disruptions (AAP, 2016). Poverty has a profound effect in children with chronic disease, such as sickle cell disease (SCD), making them vulnerable to SDOH. SCD is a chronic genetic disease characterized by abnormal red blood cells that are hard, stick together,

and are shaped like a sickle instead of being round and flexible like a normal red blood cell (CDC, National Center on Birth Defects and Developmental Disorders [NCBDD], n.d.). Sickled cells die early and clump together in small blood vessels, blocking the flow of blood and oxygen to organs (CDC, NCBDD, n.d.). These blockages and lack of oxygen to tissues cause repeated episodes of severe pain, serious infections, stroke, and damage to many organs (CDC, NCBDD, n.d.). SCD affects millions of people worldwide but is more common in those with ancestry from sub-Saharan Africa, South and Central America, the Caribbean, Saudi Arabia, India, and several countries in the Mediterranean (CDC, 2020). The number of people in the United States (U.S.) living with SCD is estimated to be around 100,000 people, who are mostly Black, or another ethnic minority (CDC, 2020). The number of children in the U.S. living with SCD is unknown, but it is estimated that 1 of 365 Black children and 1 of 16,300 Hispanic children are born with SCD (CDC, 2020). Due to the U.S.'s history of systemic racism and injustice, including residential segregation and the lack of upward social mobility resulting from income and opportunity inequality, cycles of poverty among racial/ethnic minorities in the U.S. are common. This yields those with SCD disproportionately vulnerable to SDOH (AAP, 2016; Power-Hays, Li, et al., 2020). Children with SCD have a high burden of SDOH.

The American Academy of Pediatrics' policy statement on Poverty and Child Health in the United States recommends identification of families in need via the use of screening tools with a high sensitivity and specificity, such as the WE CARE survey (AAP, 2016). The purpose of this project was to identify SDOH in pediatric patients with SCD allowing for referral and intervention. The primary aim of this project was to screen

25 – 45% of pediatric patients with SCD in a comprehensive SCD clinic for SDOH within a 3-month period. The primary outcome measure was the number of patients screened in the first three months of implementation. Secondary outcome measures include the most prevalent SDOHs identified through screening and number of community resource sheets given vs. referral to social work for urgent needs following screening. Another outcome measure was the number of patients who declined screening. The study question is: Among pediatric patients with sickle cell disease, in a single center, ages 0-19 years, what SDOH barriers are experienced/reported by parents/caregivers?

Literature Review

This literature search was conducted using CINAHL, PubMed, and MEDLINE (EBSCO). Key search terms included *social determinants of health*, *sickle cell disease*, *social determinants of health screening*, and *pediatrics*. Use of the Boolean operators AND and OR were also used. Initially, 101 articles were generated using key search terms. Inclusion criteria included articles published from 2000-2021, age limiters were applied for children and adolescents 0-18 years with SCD, articles written in English, and studies occurring in the United States. Exclusion criteria included studies conducted outside of the United States, persons greater than 18 years of age, and studies screening for anything else other than SDOH. After applying inclusion and exclusion criteria, 40 results were generated. Also, a search using UMSL's Library Summon repository and Google and Google Scholar was conducted using the same keyword search terms as above. Ultimately, 10 articles were used for this literature review.

Several challenges exist in implementing universal screening for SDOH in the pediatric population. One area of concern is clinicians not knowing what screening tools exist, the accuracy of the tools, and how screening for SDOH informs care. A systematic review done by Sokol et al. (2019) provided insight into available screeners, settings where screeners are used and SDOH domains being screened. This review included 17 studies with 11 unique screeners revealing most screenings took place in a doctor's office with the parent or caregiver as the primary informant. Methods of screening included paper/pencil, computer or tablet, face-to-face interview, or phone interview. The domains assessed in most screeners were family context and economic stability. Only three of the 11 screeners had been tested for validity and/or reliability; consequently, it is unknown how accurately each tool measured SDOHs (Sokol et al., 2019). These findings highlight the hesitation of clinicians to routinely implement screening for SDOH. One of the strengths of this systematic review is the comprehensive search strategy that allowed for the identification of SDOH screening tools used in both research and in real-life practice (Sokol et al., 2019).

Another area of challenge in routinely screening for SDOH in the pediatric medical setting is the perspectives of clinicians and office staff and how universal screening fits into their daily workflow. Two qualitative studies involved interviewing clinicians and staff from several urban pediatric clinics who implemented universal SDOH screening to gain their perspectives on the experience. Both studies yielded similar results. Herrera et al. (2019) interviewed clinicians and staff members from three urban community health centers in Boston who were involved in a randomized-controlled trial implementing the WE CARE SDOH screening model. The four themes that were

identified representing clinician and staff perspectives are: benefits of the WE CARE model, prioritizing WE CARE, reliance on patient navigator, and resource limitations. Clinicians and staff found the WE CARE screening model assisted them in practicing holistic medicine and assisted parents to seek help for needs they may not have known support existed for. Clinicians found the screening and referral process easier to integrate into their practice than medical assistants (MAs) who felt untrained or improperly oriented to the new model, making initial integration into their workflow hard. Staff also felt that resources were largely insufficient to mitigate patients' needs and the time and difficulty in accessing resources were also frustrating for the staff (Herrera et al., 2019). Loo et al. (2021) investigated staff perspectives after implementing screening for SDOHs in four urban hematology/SCD clinics in the Northeastern U.S. Staff perspectives were consistent across all four clinics: families of children with SCD experience numerous unmet basic needs, the ability to address families' unmet basic needs depended on caregivers' capacity to act on staff's recommendations, and staff believed they had a role to play in addressing unmet basic needs of patients, but their ability to address those needs are limited by systemic and organizational factors beyond their control (Loo et al., 2021).

While the literature establishes universal screening for SDOH in pediatric primary care settings is necessary and feasible, the literature also has few findings for establishing the same screening in pediatric subspecialties. Two such studies describe the feasibility and acceptability of implementing routine SDOH screening in pediatric subspecialties of oncology and hematology that often become medical homes for patients. In the quantitative descriptive study by Zheng et al. (2018), 448 newly diagnosed children with

cancer who planned to proceed with chemotherapy at the Dana Farber/Boston Children's Cancer and Blood Disorders Institute were offered the Psychosocial Assessment Tool 2.0 (PAT) as part of routine oncology care. The screener contained questions about general financial hardship and household material hardship (HMH). Of those families who completed the screener, an overwhelming 95% were willing to answer questions specifically assessing for HMH on a self-reported tool, demonstrating that screening for poverty as part of routine oncology care is acceptable to parents (Zheng et al., 2018). The quality improvement (QI) study by Power-Hays, Li, et al. (2020) sought to implement the SDOH screening system developed in pediatric primary care and oncology clinics in a comprehensive SCD clinic to improve the support provided to patients. The findings revealed 58% of visits (out of 267 eligible patient visits) had a completed screener in the electronic medical record (EMR) and 80% of those with endorsed needs on the screener were given a resource sheet with their after-visit summary (AVS) (Power-Hays, Li, et al., 2020). Thirty-four percent of patient visits reported no unmet needs, while 66% reported at least one unmet socioeconomic need (Power-Hays, Li, et al., 2020). These findings suggest universal screening in a comprehensive SCD clinic is practical using current resources and staff and it was viewed favorably by patients/parents (Power-Hays, Li, et al., 2020). In addition to screening in pediatric subspecialty care, a prospective randomized controlled trial done on screening for food insecurity in the emergency department (ED) revealed a high comfort level of screening among patients regardless of the medical setting (Cullen et al., 2019). Of the 20% of patients reporting food insecurity, 83.2% of them preferred tablet-based screening over verbal interview; further, 86.1% vs. 80.2% reported more comfort in completing the screen in the ED compared to their

child's doctor's office, however, comfort in both settings were highly rated (Cullen et al., 2019). Although these studies occurred at single medical centers, which limits the generalizability of findings, the results demonstrate screening for SDOH in pediatrics is possible and acceptable and should become part of routine pediatric care regardless of the medical setting.

It is unknown which SDOH are associated with worse disease outcomes in SCD, but some studies demonstrate an association between unmet basic needs and increased healthcare utilization. A retrospective study done at Boston Medical Center showed ED reliance, or ED_r (number of ED visits divided by the number of ED and outpatient encounters), was increased for those patients with at least one HMH versus those with none (15.9 vs. 5.9, $p = 0.0001$). Housing and utility hardship were independently associated with increased ED_r (Power-Hays, Patterson & Sobota, 2020). Another retrospective study of children with HbSS disease, active in the Cincinnati Children's Hospital Medical Center's SCD registry, showed that children with higher deprivation index trended toward higher numbers of ED visits and hospitalizations than those in the low deprivation group, regardless of disease modification therapy with Hydroxyurea (Thomas et al., 2019). Average hospitalizations were statistically significant in the low vs. high deprivation group (4.2 vs 5.2, $p = 0.01$) (Thomas et al., 2019).

Lastly, interventions paired with screening for SDOHs in the pediatric context have been similar in most of the studies found in the literature, including several studies mentioned in this review. These interventions usually involve giving a printed resource sheet to families and/or using a patient navigator or social worker to help with referral and accessing community resources. A randomized controlled trial done in two safety-net

hospitals in California by Gottlieb et al. (2016) demonstrated the superiority of having an in-person navigator to help with resource referral. This trial randomly assigned patients and parent/caregiver to the control arm – written community resource information only – or to the intervention arm - meeting with an in-person navigator after the child’s clinic visit or by telephone. As hypothesized, caregivers in the intervention arm reported a decrease in their number of social needs by a mean (SE) of -0.39 (0.13) needs compared to caregivers’ report of a small increase in needs in the control arm by a mean (SE) of 0.22 (0.13), from intake to the four month follow up (Gottlieb et al., 2016). Caregivers also reported statistically significant improvement in global child health in the navigation arm compared to the control arm at the 4-month follow-up (Gottlieb et al., 2016). The qualitative study referenced earlier by Herrera et al. (2019) also demonstrated that staff relied heavily on the patient navigator to help with resources and patient needs. A gap that remains in the literature in determining effective interventions when a social need is identified was highlighted in a recent data analysis study that attempted to understand how often parents and youth request assistance for reported social needs (Sokol et al., 2021). Eighty percent of pediatric patients seen within the study period completed a SDOH screener at least once (n=39,251 encounters; 30, 486 unique children). While 8% of patients indicated a need in 3,056 encounters (2,739 used in the final analysis), only 2% requested a referral for the identified need (Sokol et al., 2021). The social needs that were significantly associated with a request for intervention were housing insecurity, food insecurity, and employment and transportation needs (Sokol et al., 2021). Certainly, limitations exist for both studies. Limitations of the study by Gottlieb et al. included patient navigation depended on trained volunteers, which makes it less reproducible in

real-world clinical scenarios, low rate of enrollment and study attrition, and the lack of masking of navigators and research assistants may have resulted in enrollment bias and survey results (2016). The strength of the study by Sokol et al. was the real-world medical setting in which SDOH screening took place. The real world setting posed a limitation because of the inability to control how the screening system was implemented (Sokol et al.,2021).

Screening for SDOH has been recommended in routine pediatric primary care by the American Academy of Pediatrics and is emerging in subspecialty care, such as hematology and oncology clinics, which become medical homes. Although there are many limitations in the literature regarding SDOH screening, from the lack of available and valid screeners, to implementing screening efficiently, the current body of evidence demonstrates screening for SDOH in pediatric healthcare settings is feasible, reasonable, and generally accepted by patients. Interventions such as printed resource sheets provided to parents who indicate a need or a patient navigator connecting families to resources, have proven to mitigate the effects of poverty and other SDOH on pediatric patients (Gottlieb et al., 2016; Sokol et al., 2021). There remain many gaps in the literature about screening for SDOHs in pediatric patients with SCD and the impact SDOHs has on this population. Further research on SDOH screening in pediatric patients with SCD can aid in data generation and knowledge acquisition, ultimately promoting the development of more precise interventions.

The evidence-based practice (EBP) framework chosen to implement this project was the Plan-Do-Study-Act (PDSA) cycle. The PDSA cycle is a historically proven, basic scientific method of continuous quality improvement (Sollecito & Johnson, 2020).

This framework supports small scale, iterative changes to test an intervention. It allows for rapid assessment and flexibility in adapting changes per feedback to ensure purposeful solutions are developed (Sollecito & Johnson, 2020). The four steps of the PDSA cycle are: (1) Plan - determining the test or observation, including a data collection plan; (2) Do is trying out the test on a small scale; (3) Study involves taking time to analyze the data and results; (4) Act is refining the changes based on learned feedback from the test (Institute For Healthcare Improvement, 2021). The use of PDSA cycles in healthcare quality improvement initiatives have proven successful.

Methods

Design

This QI project used a descriptive survey/observational design. Quantitative data collection included number of screenings administered, frequency of endorsed SDOH and prevalence of specific SDOHs, number of community resource sheets given to patients who endorsed any SDOH, and number of patients referred to SW for endorsed urgent needs.

Setting

This project took place in a single-center, urban, midwestern, pediatric comprehensive Sickle Cell clinic serving approximately 450 patients with Sickle Cell Disease. This pediatric sub-specialty clinic is part of a large, regional, academic medical center.

Sample

A convenience sample of pediatric patients ages 0-19 years with sickle cell disease (any genotype) was used. Patients presenting for routine sickle cell care, English

speaking, or non-English speaking but with an interpreter were included. Exclusion criteria consisted of patients older than 19 years of age, non-English speaking without an interpreter, and patients seeking care for urgent needs.

Approval Processes

This project was approved by the leadership team of the Division of Pediatric Hematology/Oncology. Approval from the IRB at University of Missouri - St. Louis and the St. Louis Children's Hospital QI/Research Department were granted prior to data collection.

Procedures

Permission to use the validated WECARE (Well Child Care, Evaluation, Community Resources, Advocacy, Referral, Education System) SDOH screening tool used in a similar QI project at Boston Medical Center's comprehensive Sickle Cell clinic was obtained prior to the start of this project. This self-reported paper screener was distributed by clinic staff, with a prescribed script describing the reason for screening, to every parent/caregiver of a patient younger than 18 years old at the beginning of a routine visit and was collected by the provider or coordinator at the end. For patients 18-19 years old, the screener was given to them directly to fill out unless they designated their parent/caregiver to fill out instead. Parents/patients were given the opportunity to decline screening. All patients endorsing one or greater needs received a resource sheet with appropriate community resources at discharge with their After Visit Summaries (AVS). For immediate or urgent needs identified, such as no food in the house or nowhere to stay the night, patients were referred to the dedicated SCD program social worker for urgent intervention in addition to the resource sheet. Patient names and birth dates were obtained

on the paper screener, but no identifying information was used in the data analysis.

Completed screeners were kept in a binder and locked in a cabinet when not in use during the 3-month implementation/pilot period. After the initial pilot was completed, screeners were scanned into the patient's EMR in Epic.

Data Collection/Analysis

Data was collected from the validated WECARE screening tool assessing eight domains of SDOH including housing, food, utilities, etc. This tool is a one-page, self-reported questionnaire. Data from the screener was manually entered into a Microsoft Excel file and analyzed to display SDOH prevalence. Patients were de-identified using an alpha-numeric system including their first initial and day of birth. Patient data collection was capped at 12 weeks. The process measures tracked and analyzed over 12 weeks includes the number of screenings completed, number of screenings declined, number of resource sheets given and number of referrals to social work. Process data is displayed as a run chart. All data was analyzed by the student private investigator (PI) and physician partner/mentor.

Results

This project was implemented and piloted for 12 weeks between February – April 2022. The implementation period yielded a total of 102 completed screeners (75%) out of an eligible 136 unique patients/families who presented for a routine, non-sick/non-urgent clinic visit. Only 1 patient/family declined screening. The screening assessed eight domains of SDOH – housing, food, medication, transportation, utilities, daycare, employment and education. While 17% (34) of patients/families did not endorse any needs, 83% (68) endorsed one or more needs. The most frequent needs endorsed were

food at 21%, followed by the desire for more education at 17% and difficulty paying utilities at 16%. Emergency food insecurity, meaning having no food at home for tonight was endorsed by 2% of patients; housing insecurity, including emergency housing was endorsed by only 1% of patients (see Figure 1).

The dedicated social worker for the SCD comprehensive program was available on clinic days when SCD patients are usually seen, for urgent food or housing needs. Her workflow was not significantly impacted by implementation of this screening as it was her usual practice to follow up with patients during clinic visits, whether in person or via phone afterward for patients who asked for assistance during a clinic visit. Instituting this screening process, however, helped to reveal previously unknown needs and it streamlined patient discussion and resource referral by the SW.

In terms of process measures, implementing SDOH screening did not impede the existing clinic flow or impose significant delays. Seventy-five percent of eligible patients were screened during the implementation period, and 100% of patients who endorsed one or more needs were given a resource sheet with their AVS. Qualitatively, clinic staff, providers, clinical coordinators and SW viewed this screening process positively and reported the families also viewed this process positively and seemed enthusiastic about the screening.

Additionally, a chi-square test of independence was performed to examine the relationship between insurance (public vs. private) and whether unmet needs were endorsed on screening. The relationship between these variables was statistically significant, $\chi^2 (df=1, N=102) = 12.01, p = .05$. Patients with public insurance were more likely to report unmet needs on screening for SDOH.

Discussion

This QI project demonstrated the feasibility of screening for SDOH in the SCD population with existing clinic staff and program resources. The initial aim of this project was to screen 25-45% of 450 patients with SCD for SDOH in the first 3 months of implementation, however this goal was not reached; we achieved screening 22.9% of our total patient population with SCD. In hindsight, the aim of screening 25-45% of patients with SCD at this single site within a 3-month period may have been an overreach. The first week of implementation commenced in February and no patients were screened due to a snowstorm that resulted in all of the patients with SCD rescheduling their appointments or no-showing. Clinic factors that contributed to the fluctuation in the rate of screening was the variation in clinic staff and flow on any given day based on reassignment of duties to accommodate a busy clinic and other staffing shortages. This made the flow of extending screening to eligible patients unclear on some days. This variation in the screening process could have been improved by developing a clinic flow diagram visible to all clinic staff, regardless of their job duties. Patient factors that contributed were patients who no-showed their appointments and 1 family declined screening.

The descriptive results of this single center project confirm that patients with SCD followed in this clinic have a high burden of SDOH. Results of 83% of patients endorsing at least one need is likely underscored by the long reaching effects of the global COVID19 pandemic where the childhood poverty rate in the U.S. increased from 12.1% in December 2021 to 17% in January 2022 due to the expiration of the monthly Child Tax Credit payments (Center on Poverty and Social Policy, 2022). Black and Latino

children had the highest increase in poverty rates from December 2021 to January 2022 at 25.4% and 23.9%, respectively (Center on Poverty and Social Policy, 2022). The previous point is important to consider as children with SCD are predominantly black or another ethnic minority. The three most prevalent needs endorsed by this QI project were food insecurity, followed by education, then utilities, mirroring the three most prevalent needs endorsed by Power-Hays et al. (2019). Also, the statistically significant value of the chi-square test of independence demonstrates having public insurance can be viewed as a proxy for poverty in childhood.

The screening of 102 unique patients/families out of 136 eligible patients and only one declination establishes parental positive regard and comfort of self-reported screening for SDOH/unmet needs. The studies in the literature review by Zheng et al. (2018) and Cullen et al. (2019) both demonstrated high percentages of parental comfort with self-reported screening for household material hardships. The Cullen et al (2019) study showed a significantly higher percentage of parents being more comfortable reporting FI via tablet vs. verbal interview; although this project didn't utilize tablets for screening, but a paper/pencil method, the lack of verbal interview in screening for needs likely contributed to the comfort and positive outlook parents had toward the screening process.

Lastly, the implications for continued improvement are to determine the kind of education parents are interested in – adult educational opportunities, improved SCD education, or both; to transition screening to an electronic modality to alleviate the administrative burden of program coordinators having to keep track of paper screeners, and to determine whether families who endorsed needs made contact with community

resources and which of those resources proved beneficial in mitigating needs. The strength of this project was the sample size of 102 unique patients/families and the project was constructed from existing evidence in the literature. A limitation is the single center setting which restricts the generalizability of results.

Conclusion

This project was initiated to improve care of patients with SCD and to identify targeted interventions leading to improved outcomes for these patients. The project found pediatric patients with SCD have a high burden of SDOH, suggesting routine screening is necessary. It is feasible to implement SDOH screening with adequate core staffing, including a social worker; and the low touch intervention of providing a resource sheet upon discharge from clinic to patients who endorse needs is also achievable.

Comprehensive clinics for chronic diseases such as SCD, which often become medical homes, should follow the recommendations of the AAP to universally screen for SDOH to allow for early intervention and referral.

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Figure 1

Prevalence of SDOH Needs Identified

