Assessing and Addressing Social Determinants of Health Among Children and Youth With Special Health Care Needs

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Abstract

Over several decades, a field of research has emerged to examine social and environmental factors that contribute to health inequities among children and youth with special healthcare needs (CYSHCN), with the goal of reducing inequities through identifying and mitigating these social determinants of health (SDH). The Children and Youth with Special Healthcare Needs National Research Network (CYSHCNet) national research agenda development process, described in a companion article, recognized SDH, as experienced by CYSHCN, and the effects on health inequity and child and family outcomes as a high priority area. Important gaps named included which strategies best identify and mitigate the effects of negative SDH and which outcomes are most meaningful to families receiving SDH-focused interventions. In this area, the highest priority questions were the following: 1) How can SDH be routinely addressed in the course of care for CYSHCN? 2) Which interventions most effectively integrate SDH to improve child and family outcomes? Here, we discuss the impact of SDH on CYSHCN, efforts to screen for and intervene upon SDH in this population, and gaps in the current research on SDH specific to CYSHCN. We make several recommendations for research studies that will move the field forward. This work should achieve a greater understanding of patterns and impacts of SDH experienced by CYSHCN. It will also contribute to optimizing identification of SDH and improving interventions to achieve equity in health outcomes identified by patients and families as important to them.

Keywords: children with special healthcare needs; health equity; social determinants of health

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What's New

Despite evidence on screening and interventions for social determinants of health (SDH), little is specific to children and youth with special health care needs. We address research gaps in screening, interventions, family/children and youth with special health care needs prioritized outcomes for SDH screening and interventions to address SDH, and systems and policy approaches.

Social determinants of health (SDH), as defined by the World Health Organization, are "the conditions in which people are born, grow, work, live, and age. . .as shaped by the distribution of money, power, and resources at global, national and local levels."[1] SDH can have positive or negative impacts on health, and negative SDH are responsible for most health inequities.[2] Healthy People 2030 defines five domains of SDH: economic stability, education access and quality, social and community context, health care access and quality, and neighborhood, and built environment.[3] Specific examples include air quality, public transportation, proximity to health care facilities, access to safe housing and healthy foods, and social connectedness.

Multiple studies have examined associations of SDH with health outcomes. Early-life adverse experiences, such as racism, poverty, family or neighborhood violence, exposure to substance abuse/misuse and limited education, affect health-related behaviors and neurological and immune systems.[4,5] SDH, such as caregiver mental health challenges, lack of a medical home, and financial stress, have been associated with increased risk of mental, behavioral, and developmental disorders.[6]

For children and youth with special health care needs (CYSHCN), SDH are associated with the presence and severity of health conditions, and CYSHCN and their families can be significantly more affected by SDH due to their higher health and social needs. For example, children with asthma exposed to poorer air quality or family hardships are at additional risk of hospitalization,[7,8] and multiple SDH, such as food insecurity, are associated with

developmental risk.[9] CYSHCN are more likely to have adverse childhood experiences, be bullied, and experience racism.[10] Racial and ethnic disparities are seen in studies of prevalence, access to care and resources, care coordination and satisfaction with care among CYSHCN.[11] CYSHCN, particularly children with medical complexity and disabilities, require supports, services, and coordination across multiple systems within the domains of SDH,[12] such as in education, housing, employment and transportation systems. Social determinants that affect access to these services can be especially impactful.

Because of SDH's connections to health inequities, national guidelines[13,14] and experts[15,16] recommend screening for SDH in clinical settings and including SDH in policy agendas. Systematic and scoping reviews[17,18] found the majority of tools are not well validated, narrow in scope, and lacked involvement of youth or families in development. Caregiver views on screening are generally supportive[19]; however, only a minority of pediatricians report routinely and uniformly screening for SDH, primarily due to feasibility of screening and responding to SDH.[20] Specific factors that promote screening in health care settings include value-based payment models, institutional support for screening, clear screening protocols that accommodate clinic workflow, establishment of linkages to and communication with community support services, and implementation of screening in settings that provide continuous care, eg, primary care practices.[21,22]

Interventions in health care settings to systematically address SDH based on screening results primarily have involved referrals to community-based services and enrollment in safety net programs facilitated by patient navigators (health care team members who help families overcome barriers to accessing health and social services), care managers, or volunteers. Outcomes measured have included enrollment in services, health care utilization, health-related quality of life and caregiver well-being. Findings have generally been positive in terms of addressing SDH for children and adults.[21,23]

The Children and Youth with Special Healthcare Needs National Research Network (CYSHCNet) national research agenda development process identified priorities for health systems research.[24] Highest priority topics related to SDH were the following: 1) How SDH can be routinely addressed in the course of care for CYSHCN? 2) Which interventions most effectively integrate SDH to improve child and family outcomes?

GAPS

The differential impacts of screening and interventions for SDH on the health care and health of CYSHCN, compared to children without SHCN, are not well known. Factors unique to CYSHCN may influence effectiveness of screening and interventions. For example, SDH may have direct, observable effects on adherence to treatment, receipt of recommended care, family/caregiver stress, and condition-specific health outcomes. Also, CYSHCN, particularly children with medical complexity, have more frequent contacts with health care providers in different settings, which may present more opportunities for screening and identification of SDH, but also more need for flexibility and coordination of intervention components across settings.

SCREENING

Screening tools have not been adapted for CYSHCN, and evaluations of tools within subgroups of CYSHCN, such as by condition or medical complexity, have not been done. Whether existing screening tools over- or under-identify SDH in families of CYSHCN is not known. For example, questions about housing instability may not detect children with motor impairments in nonaccessible and therefore unsafe housing. Questions about food insecurity may not identify children with specific health-related nutritional needs, such as diabetes or cystic fibrosis. Given CYSHCN's multiple health system contacts, optimal logistics for screening (eg, which setting, how frequently) are not well understood. For example, screening too frequently could be redundant and burdensome for caregivers, yet targeted screening in certain settings (eg, emergency department for children with asthma) may be particularly high yield. Finally, because CYSHCN, especially children with medical complexity, have more detail in their electronic medical records, there may be opportunities to improve SDH screening by supplementing with information gleaned through natural language processing or from other electronic medical records fields.[25]

MEASUREMENT OUTCOMES

Health care systems and policymakers may be driven to focus on SDH in part to achieve health care savings,[26] and this motivation may be particularly relevant for CYSHCN. The move toward value-based payments and models that incentivize cost savings, efficiency and population health are key factors in increased interest in identifying SDH and reducing inequities.[22] However, the impact of value-based payment models has not been well studied for CYSHCN,[27] and families of CYSHCN may be concerned that interventions that prioritize cost-savings will compromise family and professional partnerships and quality of care. Patients and families may prioritize other outcomes, such as quality of life, school attendance and community participation, and caregiver stress. The World Health Organization's International Classification of Functioning, Disability and Health provides a framework for measuring outcomes related to a person's ability to function in society, taking into consideration the environmental context of that society[28]; this may have particular relevance for examining SDH in CYSHCN.

INTERVENTIONS

Many state programs and health systems are implementing national guidelines[29] for screening, referral and linkage to community-based services, yet more research is needed to assess the direct impact on SDH and health inequities.[30] Interventions to address SDH have generally tested one-time, single-setting screening and referral to

services, using printed resources and patient navigators.[31,32] Given that CYSHCN have more frequent health system contacts, research to examine reporting of social impacts on health over time in multiple settings will help inform screening efficiency and intervention planning. Whether particular models of or training for navigators and coordinators addressing SDH for CYSHCN is particularly effective is not well studied. In addition, the implementation of SDH-focused interventions for CYSHCN will likely need attention to integrating with large teams and developing relationships with agencies frequented by CYSHCN. Systems-level interventions are challenging given the required coordination across multiple systems that serve families of CYSHCN. Siloed data systems make it difficult to evaluate the impact of SDH interventions on health or quality of life outcomes. Screening tools do not elicit families' desire for interventions, and priorities or desire for intervention among caregivers of CYSHCN, who balance their child's care needs with employment and other family responsibilities, may differ from those without SHCN. Finally, there is evidence that SDH interventions in health care settings can positively influence other systems delivering services to children,[33] and this work should be expanded.

Methodological Challenges

There are several challenges to conducting research on SDH interventions for CYSHCN. First, the population is heterogeneous when studied without regard to specific conditions, and intervention effects may be difficult to ascertain if condition-specific or complexity-based subpopulations are not identified. For this reason, it may be difficult to scale and replicate interventions for different communities and settings and assess the impact of systems changes and policies. Second, interventions around SDH that involve integrating with health care teams are likely to have contamination issues if randomization is at the patient level. Third, resources available to CYSHCN may differ based on geographic location. States have different levels of funding for programs for CYSHCN, although such differences may allow for quasi-experimental comparisons among states. Rural areas may have fewer resources. Having fewer resources may dampen the effects of SDH-focused interventions, regardless of model or clinical factors. Lastly, the potential for bias in data collection and research methods can lead to underrepresentation or misrepresentation of communities made vulnerable due to systemic and social inequities. With the comparatively small population size, data sets are often unable to be analyzed by both CYSHCN status and race/ethnicity, in addition to SDH. Efforts to engage CYSHCN, families and communities in research at all levels is a crucial investment of time and resources to ground research and programs in the strengths and needs of those most impacted by inequities.

Recommendations for Future Research

We propose the following studies, based on the identified gaps in the field and the initial agenda-setting process.

Identifying Optimal SDH Screening Strategies

Methods for screening for SDH could include patient/family-reported questionnaire, standard interview questions, and extraction of elements of the medical record. Because CYSHCN are seen in several different settings (eg, emergency department, primary care, home health care settings), there are potentially multiple opportunities for screening. Identifying optimal approaches for screening across the system is a priority to make it more efficient, effective, and acceptable to patients and families. Examples of useful studies may include the following:

1. A study that evaluates optimal screening strategies for identifying SDH in a way that allows for comprehensive and coordinated intervention. For health systems and communities implementing SDH screening, a mixed methods approach that analyzes screening data collected as part of routine care, data on the response to positive screens, and patient/family interviews of the screening/intervention experience could identify ways to make screening and referral better for families and more efficient for health systems. This study should focus on identifying gaps and redundancies in the screening process, performance of screening tools in identifying SDH specifically for CYSHCN compared to children without SHCN and within CYSHCN subpopulations, and burden/acceptability for families completing screening tools.

Identifying Families' Priorities for Outcomes Measurement in Studies of Interventions Regarding SDH

Patient and family priorities for outcome measurement are also important to this field. Bringing family-prioritized outcomes to the forefront will ensure evaluation and return-on-investment considerations are reflective of the indirect (eg, morbidity, disability, parental time/stress) and intangible (quality of life, societal well-being, health equity) costs and benefits. These will balance other outcomes (eg, health care quality) that are traditionally included in health services research. Useful studies may include the following:

1. Partnership with patients and families to identify outcomes important to them that can be used in future studies evaluating interventions to mitigate negative SDH. We recommend using effective community engagement techniques, such as those outlined in Family Voices' *Framework for Assessing Family Engagement in Systems Change*,[34] that bring together researchers and patients and families of CYSHCN as equal partners to produce recommendations for outcome measurement for studies on SDH. This would involve a systematic review of known outcomes, identification of gaps in current outcome measurement methods, and a ranking process to prioritize the most critical and relevant outcomes.

LONGITUDINAL EXAMINATION OF REPORTED SDH IN CYSHCN AND ASSOCIATION WITH CLINICAL CHARACTERISTICS

SDH screening has been implemented in some settings, and there are—or will be—longitudinal data on SDH. Understanding the trajectory of SDH and associations with outcomes could clarify which SDH have a particularly deleterious effect on health and other outcomes, and thus may clarify the social determinants for which screening and intervention would be high-yield. Useful studies might include the following:

- Within one or more health systems with SDH screening, conduct a study combining electronic clinical and demographic data and SDH screening results to examine change in SDH reported over time and clinical (eg, type of condition, severity, medication use, technology dependence), demographic (race/ethnicity, neighborhood characteristics, insurance type), and utilization (eg, hospitalizations, emergency department visits, and outpatient visits) associated with SDH patterns (eg, persistence, resolution, domains of SDH).
- Within existing, population-based longitudinal surveys that collect data on children, embed or enhance questions on SDH, along with special health care needs, health and development outcomes, and health care utilization. Many such surveys are household-based, which can provide information on family-level SDH.

COMPARE THE EFFECTIVENESS OF SDH INTERVENTION MODELS FOR CYSHCN

Most studies of interventions to mitigate negative SDH involve connecting families to resources using staff in navigator or coordinator roles. Adaptations needed specific to CYSHCN have not been studied. We propose the following:

- Studies to determine the level of intensity needed for family navigator-focused interventions for CYSHCN. We propose a mixed-methods study of existing SDH screening/intervention programs in health care settings that use navigators integrated into medical homes. Prospective data on tasks performed when addressing SDH and semistructured interviews of navigators and families of CYSHCN can shed light upon the skillset, training, and supervision of navigators; level of integration with the medical team; and intensity of services needed. This hypothesis-generating study would be used to design a comparative effectiveness trial of a low intensity model using family navigators with standard training, which includes training on resources, network building, and motivational interviewing versus a high intensity model, whereby navigators would receive additional training on topics relevant to CYSCHN, for example, disability rights and special education systems. This study may also identify which social determinants are most amenable to family navigator interventions in health care settings.

UNDERSTANDING THE IMPACTS OF SYSTEM-LEVEL POLICIES THAT TARGET SDH ON HEALTH INEQUITY AND OTHER FAMILY-CENTERED OUTCOMES FOR CYSHCN

Most policies (eg, housing, transportation, and economic) are created for the general population, and it is not known whether policies unintentionally amplify disparities for CYSHCN. For example, do policies that expand health coverage or affordable housing with income-level eligibility requirements miss families of CYSHCN that experience financial hardships? Does telehealth expansion exacerbate disparities for CYSHCN who lack resources to participate? Policies to organize, finance, and deliver health and community-based services may be more effective if surveillance of SDH and referral information are used to tailor interventions. Examples include tiering systems for CYSHCN based on reported SDH,[35] standardized accountability across systems, and facilitated referral processes that link families to programs. Furthermore, do equity-centered policies improve outcomes for CYSHCN and their families? Therefore, we propose:

- Comparative analyses of 1) policies across states, communities or health systems using large datasets, such as all-payer or Medicaid claims databases, state CYSHCN program data, and national health surveys (eg, Medical Expenditure Panel Survey, National Survey of Children's Health). Such studies could compare a state, community or health system that implemented an SDH-targeting policy with a matched population that did not implement the approach. Difference-in-differences analyses could identify changes in outcomes for CYSCHN and their families (eg, better coordinated care, reduced caregiver stress, reduced ED visits, etc.); and 2) intended impacts of a policy or systems change initiative to the actual experiences and outcomes for CYSHCN and their families. A retrospective study using family surveys and/or interviews could ascertain whether a SDH-focused policy was associated with positive or negative outcomes for CYSHCN and their families and could also compare differences in impacts related to racial and ethnic disparities among CYSHCN.
- A systems dynamics modeling study to examine the diverse consequences of social determinants related policies and systems initiatives on outcomes for CYSHCN. System dynamics uses interacting feedback loops to model nonlinear and cumulative effects of multiple inputs to complex systems over time. Differential and algebraic equations are developed from a broad spectrum of measured and experiential data. Modeling is an iterative process of scope selection, hypothesis generation, causal diagramming, quantification, reliability testing, and policy analysis.[36] Model development would involve key stakeholders such as

families, YSCHN, providers, payors, community representatives, health systems administrators, and state health agencies. A robust model would simulate the impact of different polices and interventions singly and in combination. Similar methodology has been used in assessing potential impact of interventions to reduce chronic illness.[37] A model for SDH of CYSHCN could offer insights into how SDH strategies compare with one another on uptake and outcomes, and increase understanding of which strategies may have greatest leverage in the short and long term.

CONCLUSIONS

SDH are especially influential for CYSHCN. This paper identifies opportunities to address gaps in screening tools, interventions, family-prioritized outcomes, and systems-level approaches to address SDH for CYSHCN. The proposed studies will inform screening and interventions in health care settings by understanding the adaptations needed to better identify and mitigate negative SDH for CYSHCN. Policy-level studies will inform systems approaches to SDH to address the root causes of health inequities for CYSHCN, identify where efforts intended to mitigate negative impacts fall short or disproportionately affect CYSHCN, and identify how efforts could eliminate inequities for CYSHCN and their families by better addressing SDH.

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