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Unmet legal and social advocacy needs of children with sickle cell disease: Implications for health care payer costs

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ABSTRACT

Previous studies of advocacy needs faced by children and families have not differentiated needs that require attorney involvement ("legal advocacy needs") from needs best addressed by social workers or lay advocates ("social advocacy needs"). Studies have also not examined the relationship between either type of need and health care costs. We developed a novel, replicable process to differentiate between legal advocacy needs and social advocacy needs. We then collected cross-sectional data from a sample of 52 children with sickle cell disease who were at least 1 year of age, a population with high advocacy needs and high health care costs. Mean annual health care costs to payers for children whose families had a least one legal advocacy need were $16,314, compared to $5552 for children in families with no legal advocacy needs ($P = 0.007$). After adjusting for covariates, the presence of a legal advocacy need was associated with $12,040 more in health care costs to payers ($P = 0.02$). Whether interventions to prevent and resolve legal advocacy needs can reduce health care costs by addressing the social determinants of health warrants future study.

Social factors such as education, income, and safe housing play important roles in determining health outcomes (Blumenthal & McGinnis, 2015; Centers for Disease Control and Prevention, 2015; Woolf & Braveman, 2011). Many proposals to address these factors have focused on national policy reforms (Bradley & Taylor, 2015; Wilensky & Satcher, 2009). However, advocating for individual children and families to directly address specific social determinants of health is also critical. Medical-legal partnerships were developed to help low-income families by connecting medical providers with legal advocates providing free services to low-income clients (Murphy, Lawton, & Sandel, 2015). Medical-legal partnerships allow medical providers who detect health-impacting legal advocacy needs to make direct referrals to legal aid attorneys, who can in turn address problems such as heating shut-offs or the wrongful termination of food benefits that might cause or exacerbate chronic health conditions (Murphy et al., 2015; Rollins, 2015; Taylor, Bernstein, Carroll, et al., 2015). Existing studies of medical-legal models have reported increased provider knowledge of legal advocacy needs, improved health outcomes, and financial gains for hospitals after patients win health insurance appeals, though they have had extremely limited sample sizes (e.g., twelve participants) (Beeson, McAllister, Regenstein, et al., 2013; O'Sullivan, Brandfield, & Hoskote, 2012). Medical-legal partnerships are currently funded primarily through foundation grants, individual donors, and in-kind space donations from hospitals.

Existing research leaves two key gaps. First, no distinction has been made between advocacy needs that require attorney intervention ("legal advocacy needs") and advocacy needs that can be addressed by a social worker or lay advocate ("social advocacy needs"). For example, a family struggling to pay rent may need assistance from a social worker to search for more affordable housing or apply for a rental subsidy, but legal counsel would be required if the family was facing eviction proceedings. Despite the more severe health consequences of an eviction as compared to temporary difficulties with rent, existing studies have grouped both types of needs together (deJong, Wood, Morreale, et al., 2015; Geller, Vacek, Flynn, et al., 2014). Second, the effect of unmet social or legal advocacy needs on health care payer costs (via worsened health and increased health care utilization) has not been examined. As health systems explore new approaches to addressing the social determinants of health and to revise payment systems to allow reimbursement for services beyond traditional medical treatments

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(Mahadevan & Houston, 2015), and as recent studies have found links between public benefit programs that address determinants such as food security and healthcare cost savings (Berkowitz, Seligman, Rigdon, Meigs, & Basu, 2017; Sonik, 2016), examining connections between health-related advocacy needs and payer costs is timely.

Understanding these connections may be especially important for children with special health care needs, who tend to experience heightened material hardship and may be especially burdened by unmet legal and social advocacy needs that can worsen their health (deJong et al., 2015; Parish, Rose, Andrews, et al., 2008; Sonik, Parish, Ghosh, et al., 2016). Children with sickle cell disease, one of the most common inherited disorders in the US, represent a group with particularly elevated hardships due in part to the disease's complex sociopolitical history (Pettignano, Caley, & Bliss, 2011; Wailoo, 2001). Approximately 100,000 people with sickle cell disease are believed to live in the US (Hassell, 2010). These individuals are disproportionately African American, immigrants from Africa and the Caribbean, and Hispanic (Hassell, 2010). Complications can be severe and include pain episodes, stroke, and acute chest syndrome, all of which can yield high-cost healthcare utilization (Amendah, Mvundura, Kavanagh, et al., 2010; Mvundura, Amendah, Kavanagh, et al., 2009). Annual Medicaid expenditures in the US were estimated to be $11,075 per child with sickle cell disease, or $335 million in total, in a 2005 paper reviewing medical expenditures in pediatric sickle cell disease (Mvundura et al., 2009). This was $9369 higher than annual per child Medicaid expenditures for other children (Amendah et al., 2010; Mvundura et al., 2009). In considering the relationship between social vulnerability and health care costs, the potential for high exposure to both of these factors made children with sickle cell disease an ideal study population.

Our aims were (i) to measure distinct legal and social advocacy needs among families that included at least one child with sickle cell disease, and (ii) to determine the association between legal advocacy needs in this population and health care payer costs.

1. Methods

1.1. Sample

The study was conducted at two academic medical centers in one city. Institutional Review Board approval for the study was obtained from both hospitals involved. Children 17 years of age or younger with sickle cell disease of any genotype and their parents/guardians were eligible to participate; the study hospitals cared for approximately 250 such children in total. We used convenience sampling and collected cross-sectional data. Eligible families were approached during clinic appointments, blood transfusions, or inpatient stays between August 2013 through February 2014 by trained research assistants. Written informed consent from parents (along with written assent from children ages 12–17 and verbal assent from children ages 7–11) was sought at the onset of interactions and individuals could choose to not participate (2 parents/guardians), to receive social-legal needs screening and services (described below) without participating in the study (3 parents/guardians), or full participation in the study (48 parents/guardians with 53 children with sickle cell disease). No remuneration was provided. Data on demographics and advocacy needs were collected from the parents/guardians, and data on sickle cell disease genotype and comorbidities were collected from electronic health records. Billing and reimbursement data were collected from the medical center financial offices.

1.2. Measures

1.2.1. Dependent variable

The dependent variable was the total payer-reimbursed medical center costs for each child's outpatient, inpatient, urgent, emergency, and specialty care for one year prior to the day of screening. Hospitals bill insurers at widely varying rates, so actual reimbursements were used to provide an accurate picture of true costs to payers (Centers for Medicare and Medicaid Services, 2015). Children with sickle cell disease seen at the study hospitals were known to rarely seek care at other facilities, an observation consistent with prior findings about hospital-focused utilization patterns in this population (Raphael, Dietrich, Whitmire, et al., 2009; Raphael, Rattler, Kowalkowski, et al., 2013), and (per parent report) none of the study children received care at outside facilities during the study period. Additionally, virtually all children in the state where the study occurred have health insurance, and all study children were in fact insured, so bias introduced by uninsured patients was not a concern. We therefore felt that our payer-costs measure was reliable. We did not collect medical or cost data for one child who was less than a year old as our dependent variable was full annual costs.

1.2.2. Independent variable

The independent variables of interest were the presence of one or more legal advocacy needs and the presence of one or more social advocacy needs. These advocacy needs were identified through a screening tool that built off an existing questionnaire developed to detect legal advocacy needs with greater sensitivity than medical providers alone were able to identify (Keller, Jones, Savageau, et al., 2008). The original instrument was modified in several ways for study purposes. First, it was expanded based on iterative consultations with medical, legal, and social service providers familiar with the study population. Next, the instrument was narrowed based on the areas of need that the providers felt were most relevant to the health of children with sickle cell disease in the region of study. The three domains of advocacy needs chosen—consistent with needs previously identified by Pettignano et al.—were public benefits, housing, and education (Pettignano et al., 2011).

Finally, the tool was adjusted to distinguish between legal advocacy needs and social advocacy needs. A methodology for making these distinctions has not previously been proposed. We therefore developed a novel approach to identify and distinguish between the two types of needs using the following principles (Woolf & Braveman, 2011): non-attorneys are barred from providing certain services, such as representation in court or the provision of legal advice and counsel (legal advocacy needs) (Blumenthal & McGinnis, 2015); non-attorneys routinely provide certain services—for example, helping with applications for programs like the Supplemental Nutrition Assistance Program (SNAP) (social advocacy needs); and (Centers for Disease Control and Prevention, 2015) there are advocacy needs that may be routinely handled by attorneys in one context but by non-attorney advocates in other contexts. For example, social workers with special training at one hospital may appeal denied SNAP applications, whereas social workers at another hospital might not and instead have to refer such cases to a local legal aid organization (expectations/restrictions from state licensing bodies for social workers will also be relevant). This need for appeal assistance would be classified as a legal advocacy need in the latter hospital but a social advocacy need in the former. There were both practical and outcome-based considerations behind this context-based framework for deeming certain advocacy needs as “legal” even when they did not technically require an attorney. The practical consideration was that an attorney may be the only actual option in a context where no non-attorneys knew how to handle the case. The outcome-based consideration was that waiting to label such an advocacy need as “legal” until it worsened into something serious enough to technically require an attorney would also allow the health consequences of the need to worsen in the meantime.

We used the principles described above to determine whether a given advocacy need should be labeled legal or social in the context of the study hospitals. The screening and referral instruments showing our decisions for each need are in *Appendices 1 and 2*. We placed each specific type of advocacy need (e.g., a particular housing need) on a