Journal Pre-proof

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PII: S1499-2671(21)00061-7

DOI: https://doi.org/10.1016/j.jcjd.2021.02.005

Reference: JCJD 1424

To appear in: *Canadian Journal of Diabetes*

Received Date: 11 November 2020

Revised Date: 23 February 2021

Accepted Date: 24 February 2021

Please cite this article as: Hershey J, Morone J, Lipman T, Hawkes C, Social Determinants of Health, Goals and Outcomes in High-Risk Children with Type 1 Diabetes, *Canadian Journal of Diabetes* (2021), doi: https://doi.org/10.1016/j.jcjd.2021.02.005.

Social Determinants of Health, Goals and Outcomes in High-Risk Children with Type 1 Diabetes

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Key messages:

1) Despite advances in technology and type 1 diabetes care, children from low-income continue to have suboptimal outcomes and increased healthcare utilization.
2) Screening for adverse social determinants of health and addressing these barriers to glycemic control is not part of routine care of children and their families.
3) In children with poorly controlled diabetes, we have demonstrated a high prevalence of adverse social determinants of health, a potentially modifiable factor.

Keywords: social determinants, type 1 diabetes, socioeconomic status, goals, screening

Abstract Word Count: 251
Document Word Count: 3112; 4 tables

Author Disclosures**:**
Dr Hawkes, Dr Morone, Dr Lipman and Ms Hershey have nothing to disclose.

Funding Sources: This study was funded by a Chair's Initiative Grant by The Children's Hospital of Philadelphia and by School of Nursing Faculty Grant Award by The University of Pennsylvania School of Nursing.

Acknowledgements: N/A

Abstract

Introduction

Despite advances in technology and type 1 diabetes (T1D) care, children from low-income families continue to have suboptimal outcomes and increased healthcare utilization. This study aimed to describe social determinants of health (SDOH) in high-risk children with T1D, as well as their SDOH-related priority goals and to determine the correlation between SDOH, glycemic control, and healthcare utilization.

Methods

Caregivers of children aged 4 to 18 years with a diagnosis of T1D >1 year, poor glycemic control (hemoglobin A1c (A1C) ≥ 9.5%) or high healthcare utilization (≥2 diabetes-related hospitalizations, emergency department attendances, or missed outpatient appointments in the prior year) were included. Primary caregiver health-related quality of life (HRQOL), self-efficacy (MSED), and SDOH were assessed. Goals were identified following assessment by a community health worker.

Results

Fifty-three families were included; and most (n=48, 91%) had government insurance. Children had a median (IQR) age of 13.4 (12, 15.3) and median (IQR) A1C of 11.1 (10, 13) %. Almost half of the families (n=24, 45%) reported ≥1 adverse SDOH. One or more adverse SDOH was associated with significantly lower total HRQOL scores (56.6 [38.5, 70.7] vs. 77.8 [60.8, 92.4], p=0.004), but not associated with A1C (p=0.3), ED visits (p=0.9), or MSED (p=0.5).

Discussion

Screening for adverse SDOH and addressing these barriers to glycemic control is not part of routine T1D care. In children with poorly controlled T1D and high healthcare utilization, we have demonstrated a high

prevalence of adverse SDOH, which may represent a modifiable factor to improve outcomes in this patient population

Introduction

The majority of children with type 1 diabetes (T1D) have suboptimal glycemic control, especially during adolescence[1]. Low-income children, often from racial and ethnic minority communities, represent a particularly high-risk group[2, 3]. A recent study has demonstrated that North American children from low income have hemoglobin A1c (A1C) levels approximately 1.2% higher than those from higher income[4]. Despite advances in the role of technology in diabetes management, the gap in glycemic control in children of different income levels has been unchanged between 2010 and 2018, falling unduly on racial and ethnic minority youth[4]. Education-based interventions may disproportionately improve outcomes in those from higher income[5]. In addition, adoption of insulin pumps and continuous glucose monitors has been lower in those from lower income or ethnic minority groups[4, 6-8], possibly further widening the disparity in glycemic control.

Social determinants of health (SDOH) play a critical role in health outcomes. Material and social deprivation, as well as lower education levels, are associated with worse glycemic control in children[9] and increased risk of end-stage renal disease and coronary artery disease in adults with T1D[2]. Despite the association between social factors (including food insecurity, underinsurance, social supports, transportation and housing availability) and diabetes outcomes, screening for adverse SDOH[10] is not currently part of routine diabetes care[11, 12]. Furthermore, little is known regarding the specific goals that these families of children with T1D from lower income identify as their highest priorities[10]. Understanding these goals may help to identify supports that diabetes healthcare providers could focus on, in an effort to improve outcomes in this vulnerable population.

In 2017, our interdisciplinary team, housed within an urban pediatric academic medical center that provides care for approximately 2500 patients with diabetes, implemented a community health worker

(CHW) program. The goal of this program was to meet the needs of high-risk families and to address socioeconomic disparities across clinical outcomes in our T1D patient population[13]. These CHWs are members of the participants' community who have no specific training in T1D healthcare, but focus on partnering with families in addressing challenges related to SDOH. In this study we describe the baseline SDOH screening in this patient population and the specific goals identified by these families as priorities to address with the CHW. We also examine the correlation between baseline SDOH screening with glycemic control and healthcare utilization.

Methods

A prospective clinical study (NCT03475108) assessing the impact of CHWs in improving outcomes in children with T1D was performed at the Children's Hospital of Philadelphia. This study was approved by the Institutional Review Board at this hospital. Parent consent and, where relevant, child assent was provided for participation in this study. This study describes baseline data related to SDOH needs and goals of families at the initiation of receiving the CHW intervention.

Population

Caregivers of children and youth aged 4 to 18 years with a diagnosis of T1D for over one year were eligible for inclusion in this study if the child had poor glycemic control or high healthcare utilization. For the purposes of this study, we set the A1C threshold for inclusion $\geq 9.5\%$; high healthcare utilization was defined as ≥ 2 diabetes-related hospitalizations, diabetes-related emergency department attendances or missed outpatient diabetes appointments in the prior year. Participants were required to reside in Philadelphia County, or within a 30 minute drive of the hospital (to reduce travel time in the larger CHW intervention study). Participants were identified through the diabetes program's specific clinical registry that is paired with the medical records system. Within this registry, eligibility parameters were established based on criteria described previously. Patients who met criteria were then electronically "flagged" for recruitment. Eligible participants were confidentially recruited and consented in the diabetes clinic room

prior to their appointments. Those who consented to participate in the study, were enrolled and completed baseline measures. Participants were compensated for participation.

Questionnaires completed by primary caregivers

Social Determinants of Health

SDOH screening was completed by the primary caregiver on enrollment in this study. This questionnaire was developed by Health Leads USA[14] and includes ten questions. These questions screen for issues related to food insecurity, disconnected utilities, housing stability, child care, healthcare affordability, transportation, literacy, and safety. The final 2 questions of this tool ask the respondent if they would like assistance with any reported needs and if the need is urgent. The questions included in the measure are presented in Supplemental Table 1. A recent social needs screening analysis where this questionnaire was applied in an urban pediatric ambulatory care center in the Bronx, New York found 20% of 4949 unselected households reported one or more unmet social needs[15].

Health-Related Quality of Life

Primary caregiver health-related quality of life (HRQOL) was measured using the PedsQL Family Impact Module[16]. This consists of 36 items, in which caregivers self-report on their own functioning and family functioning as impacted by their child's health condition on a 5-point Likert scale. Scores range from 0-100, with higher scores indicative of better HRQOL. The Total Scale Score of the PedsQL Family Impact Module is the sum of all 36 items divided by the number of items answered. In addition, the measure also consists of two subscales: the Parent HRQOL Summary Score and the Family Functioning Summary Score. Parent HRQOL Summary Score consists of 20 items and is computed as the sum of the items divided by the number of items answered in the Physical, Emotional, Social, and Cognitive Functioning Scales. The Family Functioning Summary Score consists of 8 items and is computed as the sum of the items divided by the number of items answered in the Daily Activities and Family Relationships Scales. The Cronbach alpha for the PedsQL Family Impact Module Total Scale Score was

0.97, Parent HRQOL Summary Score was 0.96, and Family Functioning Summary Score was 0.90[16].

The PedsQL Family Impact Module is validated and has been used in studies of parental HRQOL in numerous pediatric chronic diseases including attention deficit and hyperactivity disorder[17] and sickle cell disease[18]. In a 2016 study using the 36-item PedsQL Family Impact Module, caregivers of adolescents with T1D in Saudi Arabia reported a mean Total Scale Score of 67.4, Parent HRQOL Summary Score of 66.7, and Family Functioning Summary Score of 73.1[19]. Similarly, in a recent study using a modified 25-item version of the PedsQL Family Impact Module conducted with 214 parents of children with T1D, mean total scores for non-intervention group parents ranged from 52-65.5[20].

Diabetes Self-Efficacy

The Maternal Self-Efficacy in Diabetes Scale (MSED) is the only tool designed specifically for parents of children with T1D[21]. It has been used in familial caregivers of children ranging from 4 to 21 years of age[22] and has been shown to correlate with glycemic control, with lower mean scores indicative of higher A1C levels[23].

The 17-item questionnaire asks the primary caregiver to rate their confidence in independently managing diabetes-related tasks on a 5-point scale ranging from 1 (*not at all confident*) to 5 (*very confident without help*)[21]. This study utilizes the scoring method proposed by Noser et al.'s exploratory factor analysis of the MSED[23]. Their analysis resulted in a three-factor model consisting of only 11 items from the original 17-item measure, total scores ranging from 11-55. The management subscale (MSED-M) evaluates parents' perceived ability to manage their child's T1D and consists of 2 items, scores ranging from 2-10. The problem-solving subscale (MSED-P) measures perceived ability to problem-solve issues surrounding glycemic control and consists of 6 items, scores ranging from 6-30. Lastly, the teaching subscale (MSED-T) measures perceived ability to teach their child about diabetes care and consists of 3 items, scores ranging from 3-15. The Cronbach alpha for the MSED total score was 0.83, MSED-M was

0.79, MSED-P was 0.79, and MSED-T was 0.76. The three-factor model has been previously tested among 135 caregivers and resulted in mean scores of 44.69 MSED total score, 7.77 MSED-M, 25.27 MSED-P, and 11.65 MSED-T[23].

Goal Setting

A multi-disciplinary study team including social work, medicine, nursing, and CHWs, was convened to determine the most effective and efficient process for capturing family goals. A focused assessment process for rapport-building and goal-setting with parents was developed and streamlined by the study team. This assessment was termed the '360 Goal-Setting Assessment' and comprised of the assigned CHW reviewing perceived SDOH-related challenges with the medical team, the family, and the school. Following these interactions, the CHW met with the family to prioritize and formally agree upon the goals to address. A matrix of family goals collected from all study participants was compiled. A process of content analysis of the goals matrix was conducted by the study group.

Statistical Analysis

Data were summarized as mean ± standard deviation (SD) or median (interquartile range [IQR]) if normal or non-normal distribution, respectively. Continuous variables were compared using t-tests if normally distributed, or the Mann-Whitney U tests if non-normal distribution. Chi squared tests were used to compare proportions between groups.

Results

There were 53 families included in this study, 16 (30%) of whom were single-caregiver households. The median (IQR) age of the children was 13.4 (12, 15.3) years and median (IQR) duration of T1D was 4.5 (3.2, 6.9) years. Only 18 (34%) children used continuous glucose monitors and 10 (19%) used insulin pumps. Most (n=48, 91%) had government insurance and were non-Hispanic Black (NHB) (n=40, 76%). Median (IQR) A1C was 11.1 (10, 13) % and, over the prior year, 28 (53%) missed ≥ 1 appointment, 27

(51%) had ≥ 1 diabetes-related emergency department visit, and 15 (28%) had been admitted to the hospital, for diabetes related complications that included diabetic ketosis, diabetic ketoacidosis, and severe hypoglycemia (Table 1).

Social Determinants of Health

Almost half of the caregivers (n=24, 45%) reported one or more adverse SDOH on the Health Lead USA questionnaire, and almost three quarters (n=17, 71%) of those who reported a social need requested assistance. Of those who reported a social need, 4 (17%) identified this need as urgent requiring immediate assistance. Food insecurity (n=11, 21%), disconnected utilities (n=10, 19%) and unstable housing (n=9, 17%) were the most common issues reported. These needs were also the most commonly reported among those who requested assistance (n=8, 47%; n=6, 35%; n=7, 41%). The presence of one or more adverse SDOH (p=0.03), or food insecurity (p=0.04), were independently associated with missing one or more appointment over the prior year (Table 2, Supplemental Table 1).

Health Related Quality of Life

When compared with those who reported no adverse SDOH, those with one or more adverse SDOH had significantly lower total HRQOL scores (56.6 [38.5, 70.7] vs. 77.8 [60.8, 92.4], p=0.004), parent HRQOL summary scores (60 [39.7, 68.2] vs. 75 [58.8, 95.6], p=0.004) and family functioning summary scores (58.9 [43.1, 66.3] vs. 58.9 [43.1, 66.3], p=0.005). They were also more likely to have missed one or more clinic appointments in the prior year (71% vs 38%, p=0.03) (Table 2). Of note, there was no significant difference in A1C between those with, and without, a reported adverse SDOH (11% [9.9, 12.4] vs 11.7 [10.4, 13.6], p=0.3).

Diabetes Self-Efficacy

As presented in Table 2, there were no significant differences across MDES total and subscale scores between those who had no adverse SDOH and those who has at least one (Table 2). The MDES total,

MSED-Management, MSED-Problem-Solving, and MSED-Teaching scores were all substantially higher than prior normed samples[22], suggesting higher diabetes-related self-efficacy in mastering overall diabetes-related management, problem-solving and teaching skills. Reasons for this difference in our sample may be attributable to the intensive level of clinical support and education provided by the diabetes clinic in this study. In this population where SDOH are the primary barriers to optimal diabetes control, diabetes education/knowledge, as captured by the MSED measures, is not likely to be the primary issue driving poorer outcomes.

Goals

There were 133 goals identified by families working with CHWs, with a mean of 2.5 and range of 1-4 goals per family. Twelve common themes emerged by group consensus. The twelve theme categories and examples of goals are presented in Table 3. The majority of goals reported were related to the first three categories, health and diabetes management, behavior and mental health, and living situation.

Discussion

We have demonstrated a high prevalence of adverse SDOH in the families of children with T1D who have elevated A1C or healthcare utilization. Within this population, those with one or more adverse SDOH, significantly lower HRQOL (both family functioning and parent HRQOL scores) was reported and higher rates of missed appointments were seen. This was despite similar glycemic control and diabetes self-efficacy, highlighting the impact of SDOH on healthcare utilization and HRQOL. High-priority goals identified by these families are in the remit of a CHW, suggesting a role for adding this member to the diabetes multidisciplinary team.

The prevalence of adverse SDOH in this population of children with poorly controlled T1D or high healthcare utilization was approximately twice as high as has been described in large unselected populations attending urban ambulatory pediatric clinics[15]. Adverse SDOH including housing

instability, poverty, food insecurity, lack of transportation and violence have negative implications on health[24, 25]. The most frequently cited SDOH challenges noted within this study were related to food insecurity, needing assistance with utilities, concerns for stable housing, and childcare. Screening for, and addressing, these needs can have positive effects on parental employment, connection with social resources, reducing homelessness[26] and improved food security[27]. CHWs may be uniquely placed to address SDOH, and prior studies have demonstrated their efficacy in improving, education, income, housing, neighborhood safety, food security, and social inclusion leading to improvements in overall pediatric and adult patient health[28-30].

Traditionally, diabetes outcomes have focused almost entirely on glycemic control and risk of developing complications. This disease places a significant burden on the family. Patient-reported outcomes, including quality of life and self-efficacy, can be a higher priority for some families than reducing A1C concentration[31]. Diabetes self-efficacy did not differ between parents who experienced no adverse SDOH and those who did. This disconnect between self-efficacy and glycemic control highlights the multifactorial drivers of glycemic control beyond self-efficacy, of which SDOH may be one. In fact, education-based interventions will improve glycemic control for some children, but those from lower income, predominantly NHB families (i.e. the majority of those included in this study), continue to have worse outcomes despite similar or better attendance at education or nutrition appointments[7], or exposure to intensive education programs[5]. The multitude of non-SDOH factors that may influence glycemic control in this population of children with poorly controlled diabetes may also explain the why there were similar A1C levels between those with and those without adverse SDOH in this study.

Families in this study proposed a wide range of prioritized SDOH-related goals. Among the eleven major categories of family goals captured in this study, the most common themes related to a broader need for social support, assistance with health system navigation and health literacy, and help accessing concrete material resources. The need for increased social support was demonstrated by goals that focused on

desires to improve family relationships and to develop, or enhance, social resource connections. Having low levels of social support have been associated with worse outcomes in T1D[32, 33]. Relative to the SDOH, family and friend relationships are considered a form of "social capital" and defined as, "those features of social relationships—such as levels of interpersonal trust and norms of reciprocity and mutual aid—that facilitate collective action for mutual benefit"[34]. Deficits in social capital contribute to a perpetuation of racial health disparities[25]. Health literacy impacts access to resources and chronic disease management and can pose significant barriers especially to low-income families, contributing to health inequities[35]. Similarly, basic necessities, such as food, housing, and transportation are integral to a family's health and well-being and constitute concrete material needs[36]. Addressing these basic resource needs can have a positive impact on child health[37]. In this study, the most frequently identified goals related to addressing food insecurity, housing, transportation and utility supports. These are also common material resources requested by other pediatric families who live in poverty or low socioeconomic status within the U.S.[38].

The current hospital-based model of multidisciplinary diabetes care is not empowered to address these community-based challenges. However, the goals identified by these families are within the scope of a community-based health advocate, such as a CHW. CHWs routinely advocate for program eligibility and assist families with navigating healthcare and social safety net programs and offer help with completing application and enrollment forms[28, 39], facilitate connections with behavioral health professionals and social work teams qualified to improve family dynamics, and connect families with peer support resources[40] and networks[41]. However, SDOH screening needs to be implemented to routine diabetes care in order to identify and address the significant challenges faced by these families. As a comparison, depression screening is becoming a critical component of routine diabetes care and addressing depression, when identified, can improve outcomes[42-44]. A similar approach to SDOH is required if we are to address the well-described socioeconomic disparities in diabetes outcomes that exist.

A strength of this study is the detailed patient-reported outcome data in a high-risk population that is often under-represented in clinical research. Similarly, understanding the specific goals of these families are helpful in designing future patient-centered interventions. It should be noted, however, that this is a single-center study and includes a relatively small sample size of families based in Philadelphia. This may affect the generalizability of these data, as SDOH and goals are likely to be determined by the needs of the communities, as well as the availability of local services. Nevertheless, adverse SDOH are highly prevalent amongst children in the United States[15, 45], and this study highlights the utility of screening for these in pediatric diabetes.

Conclusion

Managing an intensive, complex and potentially life threatening pediatric chronic illness such as T1D places an enormous physical, mental and emotional burden on families. This chronic disease management burden disproportionately impacts families already experiencing increased social determinants barriers, such as housing, food, employment and utility insecurities. It has been increasingly established that social determinants and structural barriers create and perpetuate social and economic inequities and contribute significantly to health disparities seen in low-income families[24]. Additionally, health outcomes are more heavily influenced by social factors than by genetics or health behaviors. Particular to diabetes, measures of overall "social complexity," indicative of increasing social determinant barriers such as low income, single parent families and housing insecurity, are correlated with higher rates of poor glycemic control[46]. We hypothesize that it will be extremely difficult to achieve optimal glycemic control in children without first addressing adverse SDOH. Growing evidence on the role of CHWs in addressing SDOH continues to show a positive impact on chronic disease outcomes in adult[47-49] and pediatric populations[50], particularly in patients with diabetes[51].

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Table 1: Baseline demographics and clinical characteristics of children included in this study. Unless otherwise stated, data are presented as median (interquartile range).

Characteristic	**n = 53**
Age, years	13.4 (12, 15.3)
Male sex, n (%)	25 (47%)
Duration of T1D, years	4.5 (3.2, 6.9)
Continuous glucose monitor use	18 (34%)
Insulin pump use	10 (19%)
Hemoglobin A1c	11.1 (10, 13)
Government insurance, n (%)	48 (91%)
Healthcare utilization in prior year. n (%)	
Missed appointments	
0	25 (47%)
1-2	24 (45%)
> 2	4 (8%)
Hospital admissions	
0	38 (72%)
1-2	14 (26%)
> 2	1 (2%)
Emergency department visits	
0	26 (49%)
1-2	23 (43%)
> 2	4 (8%)
Race / ethnicity	
Non-Hispanic black	40 (76%)

Non-Hispanic white	8 (15%)
Hispanic	3 (6%)
Other	2 (3%)
Questionnaires	
PedsQL Family Impact Module Total Scale Score	67.4 (52.8, 87.8)
Parent HRQOL Summary Score	66.3 (51.9, 86.9)
Family Functioning Summary Score	71.9 (50, 96.9)
MSED Total Score	48 (41, 53)
MSED-M	9 (7.5, 10)
MSED-P	27 (23.5, 30)
MSED-T	13 (9.5, 15)
Social determinant of health screen, n (%)	
Food insecurity	11 (21%)
Disconnected utilities	10 (19%)
Concern for stable housing	9 (17%)
Childcare issues	7 (13%)
Healthcare cost	4 (8%)
Transport to healthcare	2 (4%)
Difficulty reading	2 (4%)
Safety at home	1 (2%)
Help Requested	*17 (32%)*
Urgent Help Requested	*5 (9%)*

Table 2: Comparison of clinical and psychosocial outcomes in those with, and without, one or more adverse social determinant of health (SDOH). Continuous variables compared using Mann Whitney U test, categorical variables using chi squared test.

Variable	**No Adverse SDOH (n=29)**	**≥ 1 Adverse SDOH (n=24)**	**p**
Age, years	14 (12, 16)	13.3 (11.5, 15.1)	0.5
Duration of diabetes, years	4.2 (2.9, 7)	5.1 (3.6, 7)	0.4
Hemoglobin A1c, %	11.7 (10.4, 13.6)	11 (9.9, 12.4)	0.3
≥ 1 missed appointment, n (%)	11 (38%)	17 (71%)	0.03
≥ 1 ED visit, n (%)	15 (52%)	12 (50%)	0.9
≥ 1 hospital admission, n (%)	9 (31%)	6 (25%)	0.8
PedsQL Family Impact Module Total Scale Score	77.8 (60.8, 92.4)	56.6 (38.5, 70.7)	0.004
Parent HRQOL Summary Score	75 (56.8, 95.6)	60 (39.7, 68.2)	0.004
Family Functioning Summary Score	81.3 (65.6, 100)	58.9 (43.1, 66.3)	0.005
MSED Total Score	47 (41, 51)	40 (41.3, 53)	0.5
MSED-Management	9 (7.5, 10)	8.5 (7.3, 10)	0.9
MSED-Problem-Solving	27 (22.5, 30)	28 (24, 30)	0.5
MSED-Teaching	13 (9.5, 14)	13 (9.3, 15)	0.6

Table 3: Goal categories selected by family working with a community health worker.

Goal Category	**n**	**Example goals within this category**
Health & Diabetes management	27 (20%)	Implement 504 plan Assist patient in applying for membership at local gym Obtain technology to manage diabetes Help to read medical documentation
Behavior & mental health	24 (18%)	Find therapist for parent, child or sibling Link with specialist to address child's depression Parent to practice self-care
Living situation	21 (16%)	Access affordable housing or affordable home renovations Help parent enroll in first time home owners program Assist in negotiating rental arrears
Support for caregiver or child	11 (8%)	Help to repair relationship with family Family to access peer support resources Connect with other children with diabetes
Food / nutrition	8 (6%)	Connect with resources to provide low cost fruit and vegetables
Benefits / government programs	7 (5%)	Link family with resources to assist with utility bills
Education	7 (5%)	Find and enroll patient in school
Relationship with medical team	7 (5%)	Develop open communication with the medical team Find new primary care physician for patient Support transition to adult diabetes care
Transportation	5	Develop plan for transportation to & from school

	(4%)	Support disabled parent attending child's appointments
Work or education	4 (3%)	Mother to attend CareerLink resource fair Help parent attain General Education Diploma
Legal issues	3 (2%)	Apply for social security card Navigate bankruptcy process Adoption of child by caregiver
Other	9 (7%)	Access resources for warm clothing Improve credit score

Supplemental Table 1: The association between each SDOH in the Health Leads Questionnaire with ≥ 1 missed appointment, ED visit or hospital admission in the prior year. *chi-squared test

Health Leads Social Determinants of Health Screening Question	≥ 1 missed appointment			≥ 1 ED visit			≥ 1 hospital admission		
	Yes (n=28)	No (n=25)	*p	Yes (n=27)	No (n=26)	*p	Yes (n=15)	No (n=38)	*p
In the last 12 months, did you ever eat less than you felt you should because there wasn't enough money for food?	9	2	0.043	6	5	0.9	3	8	0.9
In the last 12 months, has your utility company shut off your service for not paying your bills?	7	3	0.3	4	6	0.5	2	8	0.7
Are you worried that in the next 2 months, you may not have stable housing?	7	2	0.15	3	6	0.29	2	7	0.9
Do problems getting child care make it difficult for you to work or study?	5	2	0.4	3	4	0.7	1	6	0.7
In the last 12 months, have you needed to see a doctor, but could not because of cost?	4	0	0.11	2	2	0.9	1	3	0.9
In the last 12 months, have you ever had to go without health care because you didn't have a way to get there?	2	0	0.5	1	1	0.9	1	1	0.5
Do you ever need help reading	1	1	0.9	1	1	0.9	1	1	0.5

hospital materials?									
Are you afraid you might be hurt in your apartment building or house?	1	0	0.9	1	0	0.9	0	1	0.9