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# Caring for dementia caregivers: How well does social risk screening reflect unmet needs?

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#### Abstract

**Background:** Unmet social and caregiving needs can make caregiving for a person with dementia more difficult. Although national policy encourages adoption of systematic screening for health-related social risks (HRSRs) in clinical settings, the accuracy of these risk-based screening tools for detecting unmet social needs is unknown.

**Methods:** We used baseline data from dementia caregivers (N = 343) enrolled in a randomized controlled trial evaluating CommunityRx-Dementia, a social care intervention conducted on Chicago's South Side. We assessed caregivers' (1) unmet social and caregiving needs by querying need for 14 resource types and (2) HRSRs using the Center for Medicare & Medicaid Services (CMS) Accountable Health Communities (AHC) screening tool. Using unmet social needs as the reference, we examined the sensitivity of the AHC tool to detect food, housing, and transportation needs. Analyses were stratified by gender.

**Results:** Most caregivers were women (78%), non-Hispanic (96%), Black (81%), partnered (58%) and had an annual household income  $\geq$ \$50K (64%). Unmet social and caregiving needs were similarly prevalent among women and men caregivers (87% had  $\geq$ 1 need, 43% had  $\geq$ 5 needs). HRSRs were also prevalent. The most common HRSR was lack of social support (45%). Housing instability, difficulty with utilities and having any HRSRs were significantly more prevalent among women (all *p* < 0.05). The AHC screener had low sensitivity for detecting unmet food (39%, 95% confidence interval [CI]: 27%–53%), housing (42%, 95% CI: 31%–53%), and transportation (22%, 95% CI: 14%–31%)

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needs. Sensitivity did not differ by gender for food (41% for women and 30% for men, p = 0.72) or housing (44% for women and 29% for men, p = 0.37) needs. For transportation needs, sensitivity was 27% for women versus 0% for men (p = 0.01).

**Conclusions:** Men and women caregivers have high rates of unmet social needs that are often missed by the CMS-recommended risk-based screening method. Findings indicate a role for need-based screening in implementing social care.

K E Y W O R D S

caregiving, dementia, health-related social risks, social care

# INTRODUCTION

Unpaid caregivers provide care for more than 11 million family members and friends with Alzheimer's disease and related dementias (ADRD) in the United States.<sup>1</sup> Studies of dementia caregivers suggest high rates of selfidentified unmet social needs (e.g., desire for resources to address adverse social conditions such as a food pantry to relieve food insecurity),<sup>2</sup> and high rates of unmet caregiving needs (e.g., desire for resources such as respite care or support groups). For example, in a 2013 study (N = 246), 89% of dementia caregivers reported having at least 1 unmet "resource referral" need.<sup>3</sup> Of concern, a 2015 study (N = 227) found that fewer than 20% of dementia caregivers knew how to access community resources.<sup>4</sup> Recent advances in national dementia policy call for addressing the support needs of dementia caregivers,<sup>5,6</sup> yet there are no standard clinical practices that allow dementia caregivers to identify their unmet social or caregiving needs.

Caregiving, including, but not limited to dementia caregiving, is also known to be associated with higher rates of health-related social risks (HRSRs),<sup>7–9</sup> defined as "adverse social conditions that are associated with poor health, like social isolation or housing instability."<sup>2</sup> The U.S. Centers for Medicare & Medicaid Services (CMS) and others are calling for integration of social with medical care, including routine assessment and assistance for adverse health-related social conditions.<sup>10</sup> Social risk screening identifies an individual's propensity for social conditions that may negatively impact their health. In the aggregate, social risk data give insight to adverse conditions across a population that may benefit from preventive intervention. In contrast, need-based screening allows individuals' to identify the types of resources they need or want to address adverse social conditions.<sup>2,11,12</sup> Although the terms "social risk" and "social need" are often used interchangeably, they are not synonymous.<sup>2</sup>

## Key points

- Male and female dementia caregivers have high rates of social risks and higher rates of unmet needs.
- The Accountable Health Communities social risk screener had low sensitivity for unmet needs, particularly for transportation needs among men.

#### Why does this paper matter?

Risk-based screening tools may fail to capture dementia caregivers' unmet needs.

For example, not all people who screen positive for food insecurity will identify a current need for food support. Conversely, people indicating a need for food support may score as "marginally food secure" on a widely used food insecurity screening assessment,<sup>13</sup> a threshold below which assistance would be triggered. Although CMS calls its widely used Accountable Health Communities (AHC) assessment tool the "Health-Related Social Needs Screening Tool," it assesses risks (not needs). The degree to which this risk-based screening tool captures an individual's unmet social needs is unknown.

The CommunityRx-Dementia (CRx-D) trial was a single-blind, randomized controlled trial (RCT) (n = 170 cases, n = 173 controls, NCT04146545) of a social care intervention for dementia caregivers on Chicago's South Side, a predominantly African American/Black community.<sup>14,15</sup> The present study used baseline data to (a) describe dementia caregivers' unmet social and caregiving needs and (b) evaluate how well a widely used HRSR screening tool identifies unmet social needs. In addition, given the known differences in HRSRs among

women and men,<sup>16–18</sup> and the disproportionate burden of caregiving among women,<sup>19</sup> we also examined the patterns of unmet social and caregiving needs and the performance of the HRSR screening tool to detect unmet social needs by caregiver gender.

# METHODS

## Design, setting and study participants

CommunityRx-Dementia is an IT-based, point-of-care intervention that provides dementia caregivers with personalized referrals for basic, social, and caregiving-related resources. The study protocol has been described in detail previously.<sup>14</sup> Findings are reported following CONSORT 2010 guidelines.<sup>20</sup>

CommunityRx-Dementia was conducted at a large academic medical center that serves a densely populated urban area. The 42 ZIP code target region included contiguous ZIP codes surrounding the medical center that served local residents and had resource data that were needed to deliver the CommunityRx-Dementia intervention. The majority of the target population identify as non-Hispanic African American or Black. More than 49% of the population has an annual household income <200% of the federal poverty level.<sup>21</sup> Participants were English and Spanish-speaking family and friend caregivers of community-dwelling people living with dementia who lived in a 42 ZIP code target region and agreed to receive text messages from the research team. All participants provided written informed consent. This study was approved by the University of Chicago Institutional Review Board.

Potential subjects were identified via electronic health records and recruited via telephone. Potential subjects were individuals listed as the emergency contact for a medical center patient with at least one diagnosis code for Alzheimer disease or a related dementia. Following completion of the baseline survey, participants were randomized 1:1 to receive usual care or usual care plus CommunityRx-Dementia. Regardless of study arm, all participants were included in this analysis.

## Data collection and measures

Data used in this study were collected December 2020 to February 2023 using interviewer-administered surveys via phone or Zoom (depending on the participant's preference) REDCap surveys. To reduce potential social desirability bias, during consent, participants were told that their responses would remain confidential. Race,

Unmet social and caregiving needs were captured by asking participants about need for resources for them or their household. Participants were asked if their household used each of the following social and caregiving resources: education for dementia caregiving, respite care, home care, or end-of-life care; mental health care; free food, food delivery, or places to register for SNAP (Supplemental Nutrition Assistance Program); or fitness, financial, transportation, housing instability, safety, or legal services. Participants who indicated that their household did not use a resource were asked if their household needed that resource (yes or no). Participants who indicated that their household used a resource were asked if that resource met the needs of their household (yes, somewhat or no). An unmet social or caregiving need was defined as endorsing "yes" to their household needing a resource or endorsing "no" or "somewhat" to whether a resource they used met their needs. The 14 types of unmet needs queried were selected based on dementia care guidelines, unmet needs identified in prior studies of dementia caregivers,<sup>24</sup> expert opinion (i.e., geriatricians, gerontologists, caregivers), and alignment with HRSRs queried on the AHC screener (e.g., food insecurity).

Participants also completed the 10 items from the CMS AHC Health-Related Social Needs Screening Tool that assess risk for five core HRSRs (food and housing insecurity, transportation, and utilities difficulties and safety) and three questions from two additional domains assessing social support and financial strain. Each item was scored using the AHC scoring guidelines (Supplementary Tables S1 and S2).<sup>25</sup>

# Statistical analysis

Baseline sociodemographic characteristics were described overall and stratified by gender. Bivariate associations were calculated for baseline variables by gender, using chi-square tests. Rates of each unmet social and caregiving need and each HRSR (yes/no) were tabulated overall and by gender. Differences by gender were tested using chi-square tests. In three domains where the two tools overlapped (food insecurity, housing instability, and transportation), sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV), and 95% confidence intervals (CIs) were calculated by comparing ₄\_\_\_JAGS

the AHC screener results to rates of unmet social needs overall and by gender. Self-identified unmet social needs were considered the gold standard (diagnostic). Because of the small proportion of those who screened positive for interpersonal violence (n = 8, 2%), we were unable to test the sensitivity of the AHC screener for this domain. Rates of unmet utilities needs were not queried. Differences by gender in sensitivity, specificity, positive predictive value, and negative predictive value were assessed using chi-square tests. All analyses were completed using STATA 18 (StataCorp. LLC, College Station, TX).<sup>26</sup>

# RESULTS

Caregivers (N = 343) predominantly identified as African American / Black (81%), 58% were employed, 64% had an annual income of \$50,000 or more, and 65% were caring for a parent or parent-in-law. Nearly two-thirds (60%) of care recipients had moderate or severe dementia. There were no statistically significant differences in sociodemographic characteristics between men (22%) and women (78%), though a smaller proportion of women reported annual income of at least \$50,000 (62% vs. 71%), were partnered (56% vs. 66%), or were completely confident that they could find resources in their community (43% vs. 55%) (Table 1).

Unmet social and caregiving needs were prevalent among men and women—85% and 88% had at least one unmet need, respectively. Sixty-six percent of women and 59% of men endorsed three or more unmet needs. Fortythree percent of women and forty percent of men endorsed five or more unmet needs. Caregiver education was the most common unmet need for both men and women, followed by need for mental health support (Figure 1). Rates of unmet needs overall and by type did not significantly differ by gender (*p*-values >0.05).

Prevalence of HRSRs based on the AHC screener were also high overall, with nearly two-thirds of participants screening positive for at least one of seven HRSRs. Lack of social support, financial strain, and housing insecurity were the most prevalent HRSRs (Figure 2). Women were significantly more likely than men caregivers to have one or more HRSR (69% vs. 51% in men, p = 0.01). Women caregivers also had significantly higher rates of housing instability (26% vs. 11% among men, p < 0.01) and problems with utilities (11% vs. 3% among men, p = 0.03). Thirty-five percent of participants screened positive for two or more HRSRs (35% of women and 32% of men, p > 0.05).

Overall, the AHC screener exhibited low sensitivity for detecting each of the three unmet social needs

examined. Sensitivity was lowest for transportation needs (22%, 95% CI: 14%, 31%), followed by food (39%, 95% CI: 27%, 53%) and housing (42%, 95% CI: 31%, 53%). Sensitivity was not significantly different by gender for food (41% for women and 30% for men, p = 0.72) and housing (44% for women and 29% for men, p = 0.37) needs. In contrast, for transportation needs, sensitivity was 0% for men versus 27% for women (p = 0.01) (Figure 3). Specificity overall ranged from 84% to 92%. Specificity was similar by gender for food and transportation, but significantly lower for women for housing (81% for women vs. 95% for men, p = 0.01). PPV of the AHC screening items was low for both men and women (range: 0%-61%), but particularly poor for food and transportation for men (30% and 0%, respectively). Negative predictive value (NPV) of the AHC items ranged from 71% to 89% and was highest for food for both men and women (Figure 4).

## DISCUSSION

Supporting caregivers for the growing population of people living at home with dementia requires attention to the basic material or social needs of caregivers in addition to caregiving-specific needs like dementia education and respite care. Although African American/Black people with dementia are more likely than others to live at home with dementia,<sup>27</sup> and their caregivers deliver more hours of care,<sup>28</sup> extant studies of dementia caregivers' needs under-represent this population. This study of predominantly African-American and Black women and men caregivers, corroborates a prior report from a largely white sample,<sup>3</sup> that nearly nine in 10 had at least one unmet need and more than 40% had 5 or more. For each of 9 of the 14 social and caregiving need types we queried, more than a quarter of caregivers identified an unmet need. Patterns of needs were similar among women and men caregivers, filling a gap in knowledge about gender differences, especially among African-American/Black caregivers. The most prevalent unmet needs among women and men were for caregiver education, home care, mental health support and respite care, services provided by several organizations in the study region.<sup>29</sup> The high rate of unmet needs despite available resources suggests that caregivers may lack knowledge of resource availability or encounter other barriers to access and use that may be modifiable.

CMS is advocating for integration of social with medical care for older adults. Many health systems are adopting its AHC tool to systematically assess for health-related adverse social conditions.<sup>30</sup> Although the name of the tool indicates it assesses social needs, the items do not specifically ask respondents to endorse a desire for

**TABLE 1** Sociodemographic, economic, and household characteristics of caregivers by gender (N = 343).

	Men ( <i>n</i> = 75)	Women ( <i>n</i> = 268)	<b>Overall (</b> <i>n</i> = 343)	<i>p</i> -value				
Demographics								
Age								
Less than 50 years old	20 (26.7%)	53 (19.8%)	73 (21.3%)	0.290				
50 to <65 years old	37 (49.3%)	130 (48.5%)	167 (48.7%)					
65 years old or greater	18 (24.0%)	85 (31.7%)	103 (30.0%)					
Relationship with care recipient								
Parent or parent-in-law	49 (65.3%)	173 (64.6%)	222 (64.7%)	0.551				
Spouse/partner	16 (21.3%)	47 (17.5%)	63 (18.4%)					
Other	10 (13.3%)	48 (17.9%)	58 (16.9%)					
Caregiver race								
Black/African American	61 (81.3%)	217 (81.3%)	278 (81.3%)	0.944				
White	6 (8.0%)	24 (9.0%)	30 (8.8%)					
Other	8 (10.7%)	26 (9.7%)	34 (9.9%)					
Caregiver ethnicity								
Latinx	5 (6.8%)	9 (3.4%)	14 (4.1%)	0.196				
Partnership status								
Single	25 (34.3%)	116 (43.9%)	141 (41.8%)	0.137				
Partnered	48 (65.8%)	148 (56.1%)	196 (58.2%)					
Employment								
Employed	47 (62.7%)	150 (56.4%)	197 (57.8%)	0.331				
Unemployed	28 (37.3%)	116 (43.6%)	144 (42.2%)					
Household income								
<\$50,000	21 (28.8%)	98 (38.0%)	119 (36.0%)	0.147				
≥\$50,000	52 (71.2%)	160 (62.0%)	212 (64.1%)					
Education								
Less than college graduate	38 (50.7%)	117 (43.7%)	155 (45.2%)	0.281				
College graduate	37 (49.3%)	151 (56.3%)	188 (54.8%)					
Insurance status								
Medicaid or medicare	31 (41.3%)	116 (43.8%)	147 (43.2%)	0.648				
Private	39 (52.0%)	138 (52.1%)	177 (52.1%)					
Other/none	5 (6.7%)	11 (4.2%)	16 (4.7%)					
Number of people in household								
Self	7 (9.3%)	41 (15.3%)	48 (14.0%)	0.220				
Self +1	40 (53.3%)	116 (43.3%)	156 (45.5%)					
Self +2 or more	28 (37.3%)	111 (41.4%)	139 (40.5%)					
Number of children in household								
No children	61 (81.3%)	211 (78.7%)	272 (79.3%)	0.875				
1 child	9 (12.0%)	38 (14.2%)	47 (13.7%)					
2 or more children	5 (6.7%)	19 (7.1%)	24 (7.0%)					
Health and behavioral								
Severity of dementia, PWD								
Mild	31 (44.3%)	98 (38.6%)	129 (39.8%)	0.388				
Moderate/severe	39 (55.7%)	156 (61.4%)	195 (60.2%)					
				(Continues)				

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#### TABLE 1 (Continued)

	Men ( <i>n</i> = 75)	Women ( <i>n</i> = 268)	Overall $(n = 343)$	<i>p</i> -value
Caregiver health				
Fair or poor	15 (23.1%)	47 (18.6%)	62 (19.5%)	0.414
Good, very good or excellent	50 (76.9%)	206 (81.4%)	256 (80.5%)	
Caregiver depression				
None to mild	51 (78.5%)	182 (76.8%)	233 (77.2%)	0.777
Moderate to severe	14 (21.5%)	55 (23.2%)	69 (22.8%)	
Self-efficacy for finding resources				
Less than completely confident	34 (45.3%)	154 (57.5%)	188 (54.8%)	0.062
Completely confident	41 (54.7%)	114 (42.5%)	155 (45.2%)	

*Note*: (1) "Other" race included 2 American Indian or Alaska Native caregivers, 13 multiracial caregivers, and 19 caregivers who identified as another race than listed. (2) Scoring less than or equal to 18 was defined as mild dementia on the 12-item Dementia Severity Rating Scale; scoring greater than 18 was defined as moderate/severe dementia. (3) Caregiver health was assessed using the PROMIS global physical health item (1 = fair to 5 = excellent on a 5-point Likert scale). (4) Caregiver depression was assessed using the Patient Health Questionnaire-9; a score of less than 10 was defined as none to mild and a score of 10 or greater was defined as moderate/severe depression. (5) Self-efficacy for finding resources was assessed using the question, "How confident are you in your ability to find resources in your community that help you manage your health?" "Not at all confident," "not very confident," "uncertain," and "somewhat confident" were coded as ""less than completely confident," versus "completely confident." (6) Cell totals may not be equal to 343 because of refusals and don't know responses.



FIGURE 1 Rates of (A) unmet needs and (B) health-related social risks (HRSRs) among dementia caregivers, overall.

any kind of assistance. This study asks whether risk-based screening can effectively estimate dementia caregivers' needs or desires for assistance. We compared caregivers' stated resource needs in three domains to responses to the risk-focused AHC tool in those same domains. We find that risk-based assessment fails to identify most dementia caregivers' food, housing, and transportation needs (39%, 42%, and 22% sensitivity



FIGURE 2 Rates of (A) unmet needs and (B) health-related social risks (HRSRs) among dementia caregivers, by gender. Asterisk (\*) indicates *p*-value significant at p < 0.05; (\*\*) indicates *p*-value significant at p < 0.01.



FIGURE 3 Sensitivity, specificity, and predictive value of the Accountable Health Communities screener for unmet needs (A-food, B-housing, and C-transportation), overall. NPV, negative predictive value; PPV, positive predictive value.



**FIGURE 4** Sensitivity, specificity, and predictive value of the Accountable Health Communities screener for unmet needs (A—food, B—housing, and C—transportation) by gender. NPV, negative predictive value; PPV, positive predictive value. Asterisk (\*) indicates *p*-value significant at p < 0.05.

overall, respectively). These findings are consistent with a similar study in the pediatric caregiving context where fewer than 60% of caregivers screened positive for both a social risk and need.<sup>31</sup> Findings also corroborate the prior observation that, although the concepts are often used interchangeably, social risks and social needs are not synonymous.<sup>2,11</sup> Concerningly, screening for HRSRs may increase feelings of stigma, especially if identified risks are discordant with self-identified needs.<sup>32</sup> However, we found high specificity in our study for unmet needs, and studies have found HRSR screening to be acceptable and appropriate to a majority of patients, regardless of their social risk status.<sup>33,34</sup> Additionally, in one study, most patients agreed that health systems should help address HRSRs.<sup>35</sup>

Although the number and kinds of unmet social and caregiving needs were similar for women and men caregivers, we found some significant gender differences in the distribution of HRSR factors. This finding is consistent with a prior report.<sup>36</sup> Specifically, rates of risk for housing instability and difficulty paying utilities among women caregivers were more than double and triple, respectively, those seen among men caregivers. We also found gender differences in the performance of the AHC risk screener for detecting unmet caregiver needs. Most concerningly, although more than a quarter of men endorsed unmet transportation needs, not one screened positive for transportation risk on the AHC screener. This

finding, that the AHC screener is less sensitive for detecting unmet needs among men, may partly explain why we find significant gender differences in rates of some HRSRs but not in unmet needs. We also note that the mechanisms driving resource needs for women and men caregivers may be different. Women, who take on disproportionate responsibility for caregiving,<sup>23</sup> tend to suffer higher economic burden than men caregivers because of gender gaps in lifetime earnings.<sup>19</sup> Unmet needs of women caregivers may be more heavily attributable to costs associated with accessing resources, like time, transportation, and need for respite care. In contrast, a systematic review suggests that men caregivers' unmet needs may be driven more by factors such as under-utilization of supportive resources, social networks, ability to rely on women family members for respite care, a greater need to embody self-reliance because of traditional views of masculinity, and feelings of guilt in asking for assistance.37

Findings should be interpreted in light of limitations. Caregivers were identified using electronic medical record data from their own or their care recipient's visits. This method of recruitment may under-estimate social needs and risks because it could exclude caregivers with limited or no access to medical care. Although the sample included a relatively large proportion of male caregivers, statistical comparisons could only detect large gender differences. All caregivers identified as male or female, which may limit generalizability to other gender groups. This study helps address a knowledge gap because of under-representation of African-American/Black caregivers in prior studies and reflects the population in the study geography. Although we could not stratify findings by race or ethnicity, findings corroborate evidence from studies of predominantly white caregivers. Willingness and ability to participate in text messaging were required for study participation, although fewer than 1% of caregivers screened declined for this reason. Self-reported risks may be subject to recall or misclassification bias. However, potentially stigmatizing conditions, such as food insecurity or interpersonal violence, are more likely to be under- than over-reported.<sup>38,39</sup> Bias in estimates of risks and needs would therefore tend toward underestimation.

With CMS leading the way, health care is moving quickly to integrate social care into practice. The National Academies of Medicine's 5As framework for social care calls for awareness of and assistance with social risks and needs, adjustment of care to social conditions, and alignment and advocacy at the systems and community levels.<sup>40</sup> Our study suggests that social care for people with dementia and their caregivers should account for the likelihood that risk-based screening may not effectively identify caregivers' social needs and misses a range of caregiving needs entirely. Effective assistance for caregivers requires attention to knowledge of, access to, and willingness to use supportive resources. Lastly, to effectively deliver social care that addresses the unmet needs of all caregivers, clinical strategies are needed to systematically identify dementia caregivers at their own and their care recipient's health care visits.<sup>41</sup>

## **AUTHOR CONTRIBUTIONS**

V.A.W. led the writing of the manuscript and design of this study, led the data analysis, and contributed to the interpretation of data, and created the visualizations. S.T.L. contributed to the conceptualization and design, methodology, analysis, funding acquisition, investigation, supervision, and writing (original writing and critical review). E.S.H. contributed to the conceptualization and design, methodology, analysis, funding acquisition, investigation, supervision, and writing (critical review). S.A. contributed to the analysis, validation, and interpretation of data and the preparation of the manuscript, including critical review and editing. A.E.J. contributed to preparation of the manuscript, specifically critical review, commentary or revision-including pre- or postpublication stages. S.B. contributed to the conceptualization, interpretation, critical review of the manuscript, and editing. K.T. contributed to the conceptualization, methodology, supervision, visualization, writing review and editing. J.A.M. contributed to the conceptualization,

data curation, formal analysis and interpretation of findings, funding acquisition, investigation, and writing (original writing and critical review) for this study.

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## CONFLICT OF INTEREST STATEMENT

Stacy Tessler Lindau was the founder and owner of a social impact company, NowPow, LLC, which was acquired by Unite USA, Inc. (dba Unite Us) in 2021. Neither the University of Chicago nor UChicago Medicine is endorsing or promoting Unite Us or its business, products, or services. Stacy Tessler Lindau is an unpaid advisor to and holds stock in Unite Us, LLC. Stacy Tessler Lindau is co-founder and Chief Innovation Officer of STEAMe, LLC. Stacy Tessler Lindau is an editor on Female Sexual Dysfunction for UpToDate and received royalties <\$100/year in 2019, 2020 for this work. Subsequent royalties have been paid to the University of Chicago. Stacy Tessler Lindau and her spouse own equity in Glenbervie Health, LLC, an entity unrelated to the topic of this study. Preliminary data from this manuscript were presented at the Gerontological Society of America on November 8, 2023 (https://gsa2023.eventscribe.net/), the Interdisciplinary Association for Population Health Sciences on October 3, 2023 (https://iaphs.org/conference/ conference-program/), and submitted to the University of Chicago College Center for Research and Fellowships Undergraduate Research Symposium on February 12, 2024.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

**Supplementary Table S1.** Accountable health communities tool for querying health-related social risks.

**Supplementary Table S2.** Survey instrument for screening for 14 unmet social needs at baseline.

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