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### Cover Page Footnote

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## Patient perspectives of health-related social needs screening in an urban academic adult primary care practice

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### Abstract

Health-related social needs (HRSNs) affect health outcomes and healthcare utilization. Patients' perspectives on the incorporation of HRSN screening in primary care settings is limited. We sought to explore adult primary care patient perspectives of HRSN screening from optional patient-provided free-text comments as part of a pilot self-administered HRSN screening survey on seven domains of HRSNs from the Accountable Health Communities HRSNs Screening Tool. The survey was available in English, Chinese or Spanish with a section titled "Comments" that invited patient respondents to provide anonymous free-text responses. We performed a thematic analysis of the written patient comments. Of the 679 participants surveyed, 93 participants (13.7%) provided written comments. Participants expressed concern for others and gratitude for their health or socio-economic situation, commented on how HRSN screening could improve patient care, and shared stories of overcoming unmet HRSNs in the past. No written comments from participants conveyed dissatisfaction regarding HRSN screening. Identified themes of participant comments show participants' strong recognition of how health is impacted by unmet HRSNs. Our study adds to the literature of patient perspectives that support a role for HRSN screening in primary care that could help give voice to patient needs and facilitate the delivery of patient-centered care.

### Keywords

Patient perspectives, health-related social needs, health equity, patient-centered care, social care

### Introduction

Adverse social determinants of health, such as housing insecurity, food insecurity, and lack of transportation, can be unmet health-related social needs (HRSNs) that negatively impact health outcomes and increase healthcare utilization by patients.<sup>1-7</sup> Clinical care contributes to approximately 20% of health factors that influence health outcomes, while the remaining 80% can be attributed to social determinants of health, including social and economic factors.<sup>8</sup> For example, older adults with food insecurity have been found to have higher chronic disease burden and cost-related medication non-adherence compared to older adults without food insecurity.<sup>1</sup> Individuals with transportation barriers or experiencing homelessness with at least one chronic condition are more likely to have higher utilization of healthcare services.<sup>3-6</sup> Despite the known negative impacts of unmet HRSNs on health, emerging interest in addressing social needs,<sup>9</sup> and positive impact of screening and referral programs on patient experience and health,<sup>10</sup> social needs screening in the clinical setting has not been widely operationalized and integrated into primary care delivery.

Few studies have demonstrated that patients view incorporation of social needs screening and care in

primary care as something of growing importance in the clinical setting.<sup>11-16</sup> In one study, Medicare- and/or Medicaid-insured patients with complex social needs have previously expressed support for HRSN screening in clinical care and assistance to address unmet needs; many view that social needs impact their health.<sup>11</sup> In another study, adult primary care patients viewed social needs as being linked to their health and wellbeing and perceived health care systems as being in a position to identify social needs and facilitate linkages to resources to address needs.<sup>13</sup> While most studies have focused on quantitative measures to assess patient perspectives on social needs screening, less is known about patient beliefs and attitudes on social needs screening in adult primary care from a qualitative perspective. Qualitative data is essential to understanding human and lived experiences of patients in the context of unmet HRSNs to support the implementation of social needs screening and care in the primary care setting and promote patient-centered care. By screening for unmet HRSNs, health disparities research can be advanced within the clinical setting. Kilbourne and colleagues presented a health disparities research framework that describes an agenda for detecting, understanding, and reducing health disparities within the health care setting.<sup>17</sup> Motivated by the second phase of this framework, and as part of a pilot survey assessment of

unmet HRSNs in an urban academic adult primary care practice with a multiethnic and linguistically diverse patient population, we sought to explore patient perspectives of HRSN screening through optional written patient comments at the end of the survey to understand contextual factors at the patient-level that may be key determinants of health disparities within the clinical setting.

## Methods

A cross-sectional observational study was conducted to measure HRSNs among adult patients receiving care at an academic, urban primary care practice with three sites in San Francisco, California from February to October 2019.<sup>18</sup> HRSN screening was not systematically being collected in the practice at the time of this study. The practice serves over 25,000 multiethnic patients, in which 21% of the patient population identify as Asian American, 9% identify as Black/African American, and 8% identify as Latinx. The patient population is also linguistically diverse as the most common non-English spoken language among patients is Chinese (Cantonese and Mandarin) then followed by Spanish. Patients with a same-day appointment at one of the three sites of the primary care practice were eligible to complete a self-administered survey, which was available in English, Spanish, and Chinese and contained an open-ended section for free-text written patient comments. The study site institutional review board reviewed the study procedures and provided this study with exempt certification.

Linguistically diverse research team members (English/Spanish and English/Cantonese/Mandarin) approached patients in clinic waiting rooms to complete the self-administered survey. Patients were provided an information sheet regarding the survey and given an opportunity to ask the research team questions. Upon receiving verbal consent, research team members offered patients the option of completing the survey in their preferred language via a study iPad, patients' own smartphone device, or paper copy of the survey. During completion of the survey, patients were given privacy by research team members to maintain anonymity. Patients then received a \$5 gift card and a paper copy of an in-language HRSN resource guide, which covered all HRSNs assessed, upon completion of the survey. Patients were encouraged to discuss any concerns that were prompted by the survey with their primary care clinician during their scheduled visit. Survey and written responses were inputted and stored in REDCap, a secure web-based application for building surveys and managing databases.<sup>19,20</sup> Free-text responses in Spanish or Chinese were translated into English by a bilingual research team member and verified by another bilingual team member.

The self-administered, anonymous survey included 13 questions that were adapted from the Accountable Health Communities HRSNs Screening Tool by the Centers for Medicare and Medicaid Services.<sup>21</sup> The survey assessed the following HRSN domains: housing instability and conditions (2 questions), food insecurity (2 questions), transportation problems (1 question), utility help needs (1 question), interpersonal violence (4 questions), financial strain (1 question), and family and community support (2 questions). Information regarding age, sex, and ZIP code of residence were also collected from patient respondents. At the end of the survey, a section entitled "Comments" invited patient respondents to provide optional, free-text comments. The survey was initially created in English and forward translated by bilingual research team members into Spanish and Chinese.

## Analysis

Respondents who did not provide qualitative comments at the end of the survey were excluded from this analysis. Descriptive statistics of sociodemographic characteristics and prevalence of each social need was ascertained using STATA 17 (StataCorp. 2021. *Stata Statistical Software: Release 17*. College Station, TX: StataCorp LLC).

Two coders conducted an inductive thematic analysis of patient comments verbatim. First, both coders independently reviewed all patient comments to familiarize themselves with the data. Both coders then conducted open coding by assigning free codes to each comment. The coders met to discuss the open coding process, and using the free codes, they developed a formal codebook with detailed definitions. Using the codebook, both coders applied codes to all comments and met weekly to discuss coding, disagreements, and individual interpretations and reflections of definitions as a means of reflexivity. During times of disagreement, a third reviewer was brought into discussions to review discrepancies. Revisions of code definitions were appropriately made based on each discussion, and codes were reapplied by the coders after each meeting. Through these discussions and reconciliation, coders continued to refine the codebook until consensus was reached. Themes were identified and mapped by the coders by reviewing and extracting codes and their respective coded data.

## Results

Among the 93 patients who provided comments, the mean age was 56.5 years old  $\pm$  18.1 (range 18–89) with 59.3% being under 65 years old and 64.8% were female; 92.5% completed the survey in English, 2.2% ( $n = 2$ ) completed in Spanish and 5.4% ( $n = 5$ ) completed in Chinese. In our study population, 68.8% reported at least one unmet HRSN with the most prevalent unmet HRSNs being financial strain (53.3%), at least one housing condition related issue (41.9%), and food insecurity (33.3%).

Furthermore, 20.4% of patients who provided comments also reported housing instability, 20.4% reported transportation problems, and 19.5% reported requiring support with daily activities. Also, 12.2% of patients felt socially isolated, 8.9% of patients screened positive for interpersonal violence, and 8.8% reported utility help needs. The remainder of the quantitative results for the entire population are available in the original publication for this study.<sup>18</sup>

Qualitative analysis of patient written comments revealed an overall positive response to HRSN screening, and no

narratives of HRSNs as a barrier to health, 2) comments on improving patient care via HRSN screening, 3) gratitude for their health status and socioeconomic situation, 4) patients expressing concern for others; and 5) patient narratives of overcoming HRSNs. These identified themes, their representative quotes, and associated codes are organized in Table 1 and further described below.

**Current Experiences and Narratives of HRSNs as a Barrier to Health**

Many patients provided narratives and contextual considerations related to the HRSN domains assessed in

**Table 1. Themes, Representative Patient Quotes Elicited from Unmet HRSNs Screening, and Associated Codes**

Theme	Representative Patient Quotes	Associated Codes
<b>Current Experiences and Narratives of HRSNs as a Barrier to Health</b>	“I am couch surfing, as I am trying to recover from an on-the-job injury to my right shoulder, elbow, and wrist. I was also rear-ended at a stop light. I have lost my job due to injury, and I am fighting for treatment and compensation to heal and return to work, but it's really hard to do without stable income or place to live.”	<b>Housing Instability:</b> Participants are struggling with homelessness or feels insecure about their housing condition.  <b>Financial Strain:</b> Participants are struggling to get by due to financial strain (e.g., difficulty paying rent, buying food, etc.).
	“I'm a full-time graduate student with too many chronic health conditions and a program with cut-throat competition and pressure. Many of my hospitalizations in past 2 years have been due to stress making my health worse or because of flu or workshop toxins inhalation. My degree being affected due to this, and I wish I had someone to talk to as I'm having no family in [the] States. The pressure gets to you sometimes.”	<b>Isolation:</b> Participants feel isolated or lonely—they lack emotional support and/or desire more support.
<b>Comments on Improving Patient Care via HRSN Screening</b>	“I would like to see a computerized resource directory installed in public places across California.”	<b>Suggestions:</b> Participants provided suggestions (e.g., for the survey, resources, etc.).
	“I think this is a good survey, which will hopefully improve service to patients.”	<b>Humanitarian:</b> Participants expressed concern for other community members or acknowledge the utility of the survey.
<b>Gratitude for their Health Status and Socioeconomic Situation</b>	“I'm very fortunate to have HUD housing that costs 30% of my income, which is fixed. This low rent allows me to meet my basic needs pretty comfortably. I'm very very fortunate. And I live alone with my cat and hare.”	<b>Grateful:</b> Participants feel as though they are fortunate after taking the survey.
	“I am so grateful, thanks to God. So far, I am fine, health-wise, not bad for my age. Financially, socially, emotionally, mentally, physically—I am fine, thank you.”	<b>Grateful:</b> Participants feel as though they are fortunate after taking the survey.
<b>Patients Expressing Concern for Others</b>	“I always [see] missing support for people living with chronic disease because they're socially isolated. This situation leads to the worsening of disease, stress, anxiety, or depression.”	<b>Humanitarian:</b> Participants expressed concern for other community members or acknowledge the utility of the survey.
<b>Patient Narratives of Overcoming HRSNs</b>	“I'm in a much better situation now, but when I had young children, it was super stressful. For two years we were scared of eviction as well.”	<b>Resilience:</b> Participants revealed that they used to struggle with HRSNs, but with resilience, turned their life around.
	“When I was in my 20s [and] 30s, all of these questions would have been “often true,” “always,” “yes,” etc., but not anymore.”	<b>Resilience:</b> Participants revealed that they used to struggle with HRSNs, but with resilience, turned their life around.

comments directly conveyed concern or dissatisfaction with the pilot survey of HRSN screening questions. Five themes were identified: 1) current experiences and

the survey. In particular, patients discussed their experiences with housing instability, interpersonal violence, financial strain, lack of support with activities of

daily living and/or instrumental activities of daily living, and social isolation. Some patients' narratives were related to more than one unmet HRSNs and illustrated how unmet HRSNs can be interconnected, especially financial strain and housing instability. For example, one patient mentioned: "Living in San Francisco is very expensive for seniors on [a] fixed income even under rent control. I still have to work to make ends meet." Furthermore, one patient also described financial strain as being a barrier to healthcare access. In another example, one patient shared: "[My] biggest issue is [worrying] about losing disability or getting kicked off and not being able to keep health care, food, transportation, and work." Moreover, patients discussed how their past and current unmet HRSNs are affecting their health status. One patient stated: "I was assaulted this summer, but the situation was resolved through legal channels. I deal with anxiety as a result of the incident."

#### ***Comments on Improving Patient Care via HRSN Screening***

Patients also provided recommendations and ideas to improve patient access to social needs resources, such as free workshops on technology usage and public resource directories. For instance, one patient discussed, "I recommend workshops or classes in healthcare—free for disabled [individuals] to learn—[to] educate them on how to use MyChart [patient portal], cell phones, and how to deal with pain management." Furthermore, patients also commented on how HRSN screening could improve patient care by providing an avenue for patients to seek help in addressing unmet HRSNs. One patient commented: "I hope this survey helps others who are in dire need and are too scared to ask for help. Good luck with this program. It's a start."

#### ***Gratitude for their Health Status and Socioeconomic Situation***

Several patients expressed gratitude in general for their health status and/or socioeconomic situation, such as being able to afford rent. Some patients mentioned that taking the unmet HRSNs assessment elicited feelings of gratitude during and/or post-assessment. One patient stated, "Filling out this questionnaire shows me how fortunate I am." Moreover, many patients expressed gratitude for having their HRSNs met despite their health status and limitations due to medical conditions, such as being able to pay bills and having a good social support system. One particular patient mentions: "I [live] with my parents as a result of my medical conditions. If I had to live alone, I would have trouble paying all of my bills and getting around. My immediate family is wonderful, and I am very lucky to have their support. My extended family is not as understanding and make jokes about my health."

#### ***Patients Expressing Concern for Others***

Patients included expressions of concern for other patients and members of their community in the context of

HRSNs, and their reason for concern. For example, one patient stated, "I am more concerned about these issues for other senior citizens, who are less resourceful than me." For some patients, the survey prompted them to consider and give to others. In one example, one patient requested the research staff to "give my gift card [\$5 incentive] to a person who needs it."

#### ***Patient Narratives of Overcoming HRSNs***

Some patients shared stories of overcoming unmet HRSNs in the past, especially housing instability and exposure to interpersonal violence. For example, one patient described being homeless with their daughter for nearly two years before moving into stable housing. They stated: "For 23 months, my daughter and I were challenged by homelessness and unsuitability for approximately 15 months before we were accepted to SHARE housing subsidy grant based on my health issues." In another example, one patient discusses finding financial independence and stability after leaving an abusive relationship sharing, "These situations on this survey are not something I feel with that often now a days because I have found more stability after leaving an abusive spouse and gaining access to more financial security, but they marked several years in my life (5+ years). Thanks for collecting this data."

#### **Discussion**

In an urban academic primary care practice, anonymous comments from patient respondents of a pilot HRSN survey conveyed a positive-leaning response to HRSN screening. There were no written comments expressing dissatisfaction or concern about the HRSN survey they completed in the primary care clinic. The identified themes of the written comments show how patients recognize how health and wellbeing are affected by unmet HRSNs, illustrate personal experiences of facing and overcoming social needs, and display the potential for community within the assessment of social needs. These patient perspectives of HRSN screening also underscore the perceived role of adult primary care clinics to screen and address social needs that impact health.

Our findings contribute to the growing literature of patient perceptions of social needs screening and care (e.g., identifying and addressing social needs through referrals to resources or programs) in the primary care setting, in line with current literature reporting on quantitative patient ratings of social needs screening and care.<sup>11–16</sup> Comments provided by patients from our study conveyed an understanding of the relationship between social needs and healthcare and patient-centered outcomes. Respondents that chose to make anonymous written comments at the end of the HRSN survey provided intimate and personal narratives on their past or current experiences with unmet social needs, introspection on their current health status,



and expressions of gratitude to or compassion for others. The content of the comments suggest that patients may be seeking a way to share these lived experiences that impact their health within how they receive primary care; HRSN screening could give an opening to discuss some of these challenges and barriers with their primary care team.

In our study, we sought to include patient perspectives reflecting the linguistic diversity of the patient population served at the primary care practice. Incorporation of patients, as key stakeholders in design and implementation of quality improvement initiatives and healthcare delivery innovations, is imperative to mitigate health disparities and to promote health equity in primary care,<sup>11,13</sup> especially as patients and their perspectives are central to the care experience. In the case of integration of social needs screening and care in primary care, consideration of personal narratives from patients that have or are currently experiencing unmet social needs aligns with the core principles of patient-centered care and could be a compelling approach to support efforts towards institutional and structural changes for the integration of social needs care.

A limitation to our study includes a modest sample size given that only a subset of respondents from the initial study sample provided written comments, which also limits generalizability to the patient population of our academic primary care practice in San Francisco, CA. Another limitation was that there was a lack of a specified question for the comments section and possibility of bias introduced in the form of sampling or social desirability. The perspectives of other stakeholders, such as clinicians, who are also important participants in the patient care experience and operationalization of social needs screening and care in primary care, were also not assessed. A strength of this study includes inclusion of patient comments in Chinese and Spanish in the analysis from a multiethnic and linguistically diverse primary care patient population.

Our findings add to the growing literature that patients are in support of social needs screening in clinical care and that the relationship between unmet social needs, such as housing instability and financial strain, to health and wellbeing are apparent. In particular, this work unveils patient views and perspectives on social needs screening in the health care setting and potential acceptance of screening. These qualitative data is important in the next steps of implementation as they detail important factors and the potential role that both patients as stakeholders and their stories may play in the implementation process of strategies aimed to address unmet social needs. Patient voices can be a source of motivation and driver of the adoption of both screening and intervention on unmet social needs in health care settings. More work is needed to better understand the perspectives of patients from

underserved racial/ethnic communities as well as patients who are limited English proficient—in order to design and implement primary care social care infrastructure, including screening and referrals to resources that are responsive to and centered around the needs of all patients.

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