Barriers to Patients' Acceptance of Social Care Interventions in Clinic Settings

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Introduction: Despite efforts to identify and address the social needs of patients in U.S. healthcare settings, researchers consistently find high rates of patients who decline social interventions after reporting that they have unmet social needs. It is an open question as to why people who screen positive for social risks decline assistance. This question was qualitatively explored in a community health center in Rhode Island.

Methods: From 2020 to 2021, a total of 26 patients with a positive screen for social risks were telephonically interviewed. Zoom focus groups with clinic staff and Community Advisory Board members were also conducted. Interviews were audio recorded and transcribed. Transcripts were read and analyzed by 4 investigators using an open-coding framework to identify themes emerging from the data and across interviews.

Results: A total of 6 dominant themes related to why patients decline social assistance emerged from the data and were identified across interviews and study populations. Participants explained that the wording of screening questions, along with voluminous paperwork and time constraints of the clinic sometimes resulted in inaccurate reporting. Patients' knowledge of limited resources from previous experiences of requesting social support but not receiving help was a theme. Shame/pride, stigma/discrimination, beliefs and lack of understanding, and fear/mistrust were also described.

Conclusions: Barriers to patients' acceptance of services to support social needs were influenced by multiple factors, both internal and external to the health center. These findings can inform best practices related to and the reliability of social risk screening processes in clinic settings to promote social justice and ensure health equity.
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INTRODUCTION

The influence of social contexts on the health of people is well documented.[1] The estimated number of deaths attributable to social factors in the U.S. is comparable with the number attributed to pathophysiologic and behavioral causes,[2] and scholars regularly report that social determinants are more influential in shaping health outcomes than access to quality medical care.[3] The shift toward value-based payment models and accountable-care communities is growing awareness and interest among healthcare providers in the U.S. to minimize patients' social risks as a strategy to reduce morbidity and mortality rates and healthcare expenditures. Data compiled by the AmeriHealth Caritas' clinical and healthcare analytics teams indicate a

30% reduction in hospital admissions and an 11% reduction in healthcare spending because of addressing social risks with Medicaid members.[4] Although there is no single, scientifically validated social risks screening tool (SRST) being used by healthcare providers, there are various standardized SRSTs and kits available.[5] Providence Community Health Centers (PCHC) implemented their SRST in May 2019, screening their patients once per year. The SRST consists of 7 modified questions from the PRAPARE (Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences) and Health Leads tools that ask about housing instability, food insecurity, exposure to violence, transportation, and access to utilities. Those indicating that they have unmet social need/s are asked whether they want assistance.

Despite evidence and recent efforts to identify and address social risks, health professionals and researchers consistently find significant rates of patients who screen positive for social risks but decline social care assistance to address those needs.[6−9] Consistent with these findings, PCHC completed 39,730 screenings in 2020 and found that 10% of patients screened positive for at least 1 need. Of the individuals who screened positive, about 36% wanted assistance. The rates of acceptance for assistance at PCHC are lower than expected. It is an open question as to why people who screen positive for social risks decline assistance. The primary objective of this qualitative study was to explore and describe—from the perspectives of patients, clinic staff, and members of the PCHC Community Advisory Board (consisting of patients and social service agency leaders)—why it is that people decline social assistance after they screen positive for risks. This article describes the dominant themes that emerged within and across the data collected.

METHODS

Population

PCHC serves a diverse, urban patient population and is the only Federally Qualified Health Center that serves the city of Providence, RI through 6 primary care centers, 1 health care for the homeless clinic, 1 school-based clinic, an integrated medical clinic imbedded in a behavioral health center, and a dental clinic. PCHC is the largest provider of services to those who are uninsured or with Medicaid (approximately 60% of patients) and reside in or near the city. In 2020, PCHC served 57,494 patients in Providence, a multicultural city that includes a large immigrant community, with 28.73% of residents born outside the U.S.; 43.3% of its population is Hispanic, 33.1% is White/not Hispanic, 16.8% is Black, 6% is Asian, and 4.7% identifies as >1 race/ethnicity.[10]

All study procedures were conducted remotely owing to the coronavirus disease 2019 (COVID-19) pandemic. After approval from the IRB at Rhode Island College, a 3-step process to recruit patients for interviews was used. The SRST was administered randomly once per year, and all patients who had received a positive screen for at least 1 social risk received a text message from their clinics asking whether they could be contacted by a researcher. Research assistants (RAs) called every patient who had agreed, by text message, to be contacted (making not >3 call attempts per person) and invited them to participate. After obtaining informed consent, RAs conducted interviews telephonically. Clinic staff and board members were recruited for focus group interviews using e-mail. All study participants received $20 gift cards.

Measures

RAs conducted semistructured, telephonic interviews with 26 patients from 8 PCHC clinics. Interviews were completed in Spanish or English and lasted for approximately 45 minutes. Interview questions were designed to explore patient understandings of and experiences with the SRST and perceptions of the factors influencing patient decisions to reject or accept social assistance. Interviews were audio recorded and entered in NVivo for qualitative data storage and management as well as to make use of the software's transcription services. Interview transcripts were then edited for accuracy and deidentified by the study team and translated into English (as needed) by a translator. Information about whether the patient had declined or accepted assistance was collected as well as age, sex, and preferred language. The lead author conducted 4 focus group interviews that each lasted for about 75 minutes. Two focus groups were composed of 8 clinic staff members who worked with patients with social risks. Open-ended interview questions asked staff to discuss the SRST, experiences, and involvement in the social risks screening process. Two additional focus groups consisted of 8 members of the PCHC Community Advisory Board. One included board members who were patients (*n*=6), whereas the other consisted of leaders of social service agencies where patients were referred for social care services (*n*=2). Focus group interviews were conducted in English and recorded/transcribed through Zoom, and transcripts were edited for accuracy and deidentified. All participants were provided a copy of the SRST to look at during their interviews.

Analysis

The qualitative analysis involved 4 investigators who independently read transcripts and used open coding to identify themes emerging from the data. Investigators then discussed inductive codes, resolving differences to establish consensus for each theme before adding it to the code books (1 was developed for each population—patients, staff, and board members). This helped to ensure validity and reliability.[11] Once a theme was identified, additional examples were sought during subsequent reading and coding of transcripts. The lead author then engaged in axial coding of the data using the developed code books and existing literature to identify the factors influencing patients' acceptance or rejection of services to support social needs after social risks screenings.

RESULTS

A total of 6 dominant themes relating to why patients decline social assistance emerged from the data and were identified across semistructured and focus group interviews and study populations: perspectives/

Table 1. Dominant Themes From Patient Interviews With Additional Illustrative Quotes

Themes (% of participants)	Sample quotes from patient interviews
Perspectives/experiences with questions/clinic paperwork (73%)	"They are routine questions to see if a person is good or in danger or if they need benefits." (253) "I believe that [they ask these questions] for them to take statistic reports—just having reports." (002) "The individual who ask[ed] me is the individual who starts the visit—who [is] checking your vitals and stuff with the normal questions. And then these were added . . . [so] the interview was longer. The way they were asked to me was in line with the other questions." (656) "They're collecting data more than anything else—on a population scale. I know that a lot of these things are something that a doctor's office can't help me with. So it's just kind of like research." (68)
Patient knowledge and previous experiences (34%)	"Because this [question] is about housing . . ., they [clinic staff] haven't done much for me [with that]." (211) "I've gone there [the Homeless Center] fifteen times and they never help me because they were so overloaded by so many homeless people . . . they couldn't help everybody." (040) "(They always just) send you to a food bank . . . . A lot of times, especially now [during the pandemic], they don't really have a lot there. I don't expect it to be a grocery store, but if you're sending me there and my child and I [are] at the health center because we have some type of [disease] . . . and we go there—we can't even eat any of that food [that is available]!" (patient focus group participant)
Shame/pride (65%)	"Some [people] might feel shame in answering with the truth. For example, the first time they asked me if I needed food or [things] like that, I [said] no when I really did need [help]. . . . [I have] a memory—I felt kind of embarrassed . . . letting another human being [know] that I was doing really bad [because] . . . I am not used to [being in] this type of situation so I [felt] kind of embarrassed." (6) "There [were] times when I lost sight of everything. When I needed something, I couldn't get anything 'cause I didn't want to ask anybody [for help]. I was embarrassed." (644)
Stigma/discrimination (27%)	"The way that they treat people also . . . it really, really, hurts people's feelings. I mean, when you [are an] immigrant you feel down when someone discriminate[s] your race and your language. . . . You know, what happens is when people go to ask for even an application, they—the person who's at the front desk—they also talk to you with body language. This is what I [felt] when I went to places like that. They [staff] are acting up with body language [that says], 'What are you doing here?'" (patient focus group participant) "They might be judged . . . [so] they're cautious to answer some of the questions because they don't want to get in trouble. . . . And [because of] their pride. . . . Because, for me, I was homeless for twelve years. And asking for stuff like that made me feel less than [other people and that] people were laughing at me." (14)
Beliefs and lack of understanding (54%)	"God gave us doctors to save lives and not to save the financial situation. Imagine you were a doctor and you have twenty patients. Besides helping them with their health, will you also help them financially? Tell me yes, or no? You won't be able to." (211). "I don't think they can do much [because] of the way the system is set up. I don't think they can do much . . . it's a dream that would never come true." (6). "I don't think that the doctors have that kind of power . . . [to] help with those kinds of questions. I don't think the doctor should go into why your lights shut off." (229)
Fear/mistrust (42%)	"Maybe because of immigration status. If they are afraid of being sought out, then they are not going to give that information. And they are afraid to get help from the government. So I think it really boils down to immigrants afraid of being called out." (605) "There's definitely fear [because] you don't always know how an institution is going to respond if you answer in the affirmative to a question like that." (68) "Because they [are] scared if they have children and do not want [child protective services] to get involved if they do not have enough food. Like how can you take care of your kids if you do not have food? What if the person has a warrant? They do not want the police to get involved if they have a domestic violence situation." (245)

experiences with screening questions/clinic paperwork, patient knowledge and previous experiences, shame/pride, stigma/discrimination, beliefs and lack of understanding, and fear/mistrust. The perspectives and experiences of patients are emphasized (Table 1), whereas additional, relevant insights from focus groups with staff and social-service providers are offered to triangulate and further contextualize data.

From 2020 to 2021, 42 people enrolled in the study. The mean age of the 32 patient participants was 45 years. Patient participants included 26 individuals who completed a semistructured interview and 6 who participated in a focus group interview because they were also board members. Most (24 of 32) were female, and 8 requested interviews in Spanish. All 26 semistructured interview participants screened positive for at least 1 social risk, and 22 declined assistance. Of the 8 staff members

participating in the focus groups, 7 were female; the mean age was 34 years; and they identified as White/Hispanic (5 of 8), Black/Hispanic (2 of 8), and Black/African (1 of 8). The advisory board members working at social service agencies were both White females with a mean age of 49 years.

All patient participants reported being comfortable answering the SRST questions—felt respected by staff, who were described as professional—and showed a general understanding of what the questions were asking and how they related to health. Most perceived the SRST as a routine or standard part of—and undifferentiated from all—the clinic's data collection, with little practical meaning. This sentiment was echoed across focus groups, including with clinic advisory board members who were patients (while looking at the SRST during the interview), as illustrated by the comment "I have a story

with those questions. [It is] a long questionnaire. ... More than 26 questions! ... Why [do] they ask a lot of questions that make the person frustrated? That is [a] problem with [the SRST]."

Staff participants also discussed experiences with voluminous clinic paperwork—in terms of time—to suggest a relationship with inaccurate reporting, including false positives on the SRST: "[It] is the timeframe [at the clinic]. ... the doctors have to see 25 people and they have 15 minutes.... The [staff member] go[es] into the room and [has] five minutes to get through all the pre work [questions]!" Another staff member added, "The questions get asked very quickly. ... The patient agrees with whatever you present to them. ... I think people are thinking, 'Why am I answering all these questions? I'm just going to say yes because this has to be over!'" Staff further spoke of challenges—and false positives—produced by asking patients to reflect on their social needs over a period of 12 months: "Some of the patients [think], 'Oh, six months ago I had this problem.'... Immediately, they click *Yes*, and that generates the report and we call them and they [say], 'Oh, no. I just mentioned that because it happened six months ago.'"

Approximately 34% of patients attributed the dismissal of assistance to the knowledge of and previous experiences related to the limitations of social services and resources, especially food and housing. One person said bluntly, "They are terrible. ... That stuff [resources] just isn't really there. So the problem [for] a lot of people ... [is that] the help that claims to be available is subpar, doesn't work, or is not there. And that's a big factor [in patients' declining assistance]."

Patients' previous experiences requesting social support but not receiving adequate help were discussed across the data:

> It doesn't bother me [to ask for help]. It's a matter of if someone is actually going to help me. If I answer the question, is it going to provide any kind of assistance? I don't really think I actually received help when I answer[ed] the questions honestly. ... If they're not going to help you, there's no point in asking the question. ... You get to a point where you just give up and say, 'Forget it [I don't want help]!'

Some participants explained that they reported social risks but did not request assistance because they knew that they were ineligible for services: "I make too much money, $80 too much ... [so] I had to stop taking one medication because I couldn't afford it [or get help]." During focus group interviews, staff confirmed challenges related to strict eligibility criteria for federal

services that excluded people who were undocumented, had criminal records, fell within gaps, or were barely above the required low-income level. Leaders of social service agencies also spoke of their inability to fully assist people: "The real issues our clients are facing are so systemic and structural that ... all we do is harm reduction.... If we prevent you from being evicted this month, [soon] you'll have another eviction because people are structurally underwater. We don't have the tools to change that."

Two additional explanations offered by patient participants were shame/pride and stigma/discrimination. The most cited reason that patients declined social care interventions was shame/pride:

> [A barrier] is shame or pride. I have children. I should be able to provide for them. ... I just don't want to feel like I'm not able to provide for my own. ... And [for] a lot of people, all they have left is their pride. They have some dignity and don't want to be begging everywhere. ... [They think], 'I don't have anything else. I want to be able to feel like I got some dignity.'

Linked to this idea were reports of stigma and discrimination enacted by health and service providers—a theme that emerged across the interviews of more than one quarter of patient interviews and all focus groups. One patient participant offered that social service agencies strategically shamed patients to discourage use: "There is an implication in society that it's a bad thing [to get assistance]. It makes people bad, lazy, and a freeloader. [At the] doctor's office and social service [agencies], they play up that shame and use it to keep people from utilizing their services. It's why people don't proactively engage in social services." During a focus group with patients, participants discussed these linked themes: "When you ask [for help], people talk down to you. They're shaming people. They don't have to say [anything]. [It's] their body language and facial expressions .... [The problem] is the way the help is being offered." Leaders of social service−providing entities substantiated processes of stigma and discrimination at work when discussing a major barrier as "a pervasive environment of racial, social, and economic injustice. We're literally pushing a boulder uphill on behalf of people who are disenfranchised from most of society's protections and benefits and who face tremendous discrimination just showing up in spaces."

The theme of patients' beliefs and lack of understanding about what would happen/what resources would be provided if they requested assistance was described as a reason help was declined. This theme was observed in over half of the patients' transcripts and across all focus

groups. These participants showed a belief that healthcare workers could not adequately address their social needs, and several directly stated that it was not the doctors' or the health centers' place/role to do so: "The questions are important, even though I do not think they will be able to help. . . . At least they know we [have] economic needs. [But] it does not matter how much we want it [help]." Others articulated that they did not know what would happen if they requested help. A patient participant offered a suggestion to remedy the problem: "Maybe [staff] can explain who their partners are. . . . If you're asking me about housing, explain [your partners] to me. . . . If . . . you are not a housing entity, I don't understand why you're asking. I really don't." Staff and social-service leaders underscored these sentiments while emphasizing the need for better communication and coordination of information sharing between patients, clinic staff, and social service agencies.

Perhaps because patients were not clear about what would happen if they requested assistance, the theme of fear/mistrust came up in approximately 42% of patient interview transcripts and during all focus groups. Some emphasized that patients fear that their children would be taken away: "They feel that if they [request assistance] their children may be taken . . ., that [a] social worker would come in, get involved, and then they could end up losing their children." Others rooted mistrust in legal statuses, including a fear of being deported: "Some people [are] afraid to communicate . . . because they are afraid as immigrants . . . [of being] deported or reported to immigration." Staff corroborated these concerns during their focus groups: "[Many of our patients are] undocumented or the legal status is unofficial. When you ask these probing questions, it turn[s] them off from [wanting help with] a need."

DISCUSSION

The purpose of this study was to explore and describe why patients decline social assistance after screening positive for a social risk. Data presented suggest that barriers to patients' acceptance of social care interventions in a clinic setting are influenced by both internal and external contexts. These data support and extend the limited amount of research on the topic in the U.S.

Consistent with previous research,[12,13] these data suggest that patients understood and felt comfortable answering the SRST questions in their clinics. Still, most patients perceived the SRST as one of many questionnaires they filled out during appointments and thus had little practical value beyond clinic data collection. External funding mandates require Federally Qualified Health Centers to screen patients annually; thus, the SRST asks about risks in the last 12 months.

Participants reported that this framing can lead to false positives, or that the SRST was picking up risks not active at the time of reporting, which has been suggested elsewhere: the wording on the screening tool may result in inaccurate reporting.[3] This study takes the understanding of the potential fallibility of the SRST further by contextualizing it in a busy health center and by incorporating the perspectives of staff.[9] Although researchers/healthcare professionals might think of the SRST as a discreet questionnaire, these data suggest that this is not necessarily the way patients perceive and experience it. Instead—given time constraints—patients and staff move quickly through multiple screenings, which can influence the patient understanding of the questions and the help that is available to further lower the validity of screening tools.

As documented in previous qualitative studies of social risk screenings in patients,[9,13] the data presented in this article point to previous experiences—patients' knowledge about the limitations of resources, their ineligibility for them, and the limited ability of their healthcare team to adequately address social risks—as reasons patients declined social care interventions. Related to previous research on SRST acceptability that reports lower appropriateness of screening among patients who have experienced healthcare discrimination,[12] interviews from this study revealed that previous experiences of being stigmatized/discriminated against—described as associated with shame/pride—were reasons that people did not want assistance. The findings that patients' beliefs or their lack of both expectations that providers resolve social risks and understanding of what would happen if they requested assistance are also consistent with the findings of previous research on social aid acceptability.[13] Consequently, in this study, those who were portrayed as particularly vulnerable—parents and immigrants who were undocumented—were described as being wary of social services and fearful of being reported to authorities and thus declining assistance.

Limitations

Although the remote study procedures ensured that the research respected patient privacy, was conducted safely, and did not burden health center staff during a global pandemic, it may have introduced biases. Although reflective of the views of patients from across PCHC clinics, findings are based on interviews with a small sample of clinic patients who were mostly female and English or Spanish speakers. The remote nature of this study required significant effort, language/literacy capabilities, and a level of trust by the participants to be interviewed on the phone by an investigator who they did not know. Given patients' concerns about safety related to their social risk screenings, it is possible that

the experiences and perspectives of those most at-risk and likely to decline social interventions were not captured. However, the value added through qualitative research is less about offering a demographically representative sample than about providing transparency of methods and analysis.[11] This qualitative research offers a depth of understanding to larger, quantitative findings —such as consistently revealing significant rates of patients' declining social assistance—to show how and why this is so.

CONCLUSIONS

This study suggests that barriers to patients' acceptance of services to support social needs were influenced by multiple factors both internal and external to the health center. These data point to a need for clinic leaders to ensure that workflow allows adequate time for staff to implement the SRST to improve the validity and desired outcomes of the screening process. Sufficient time is necessary for staff to communicate and contextualize the screening questions as well as make clear to patients how they will be helped if they request assistance. Time is also essential so the most vulnerable patients feel safe and can be reassured that their requests for assistance will not be used against them. These data further underscore the importance of clinic and social service staff trainings on body language and tone so that patients do not feel and/or experience shame and discrimination while seeking social assistance. These findings can inform best practices related to social risk screenings in clinical settings to promote social justice and ensure health equity in the U.S.

CREDIT AUTHOR STATEMENT

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REFERENCES

1. Wilkinson R, Marmot M. *Social determinants of health.* 2nd ed. Geneva, Switzerland: WHO; 2003. http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf.
2. Galea SM, Tracy M, Hoggatt KJ, DiMaggio C, Karpati A. Estimated deaths attributable to social factors in the United States. *Am J Public Health.* 2011;101(8):1456–1465. https://doi.org/10.2105/AJPH.2010.300086.
3. De Marchis EH, Alderwick H, Gottlieb LM. Do patients want help addressing social risks? *J Am Board Fam Med.* 2020;33(2):170–175. https://doi.org/10.3122/jabfm.2020.02.190309.
4. AmeriHealth Caritas. Community health navigators address social determinants of health to impact high hospital utilization. Philadelphia, PA: AmeriHealth Caritas; 2019. https://www.amerihealth-caritas.com/assets/pdf/infographics/ahc-infographic-social-determinants.pdf.
5. James CV. Actively addressing social determinants of health will help us achieve health equity. *HealthIT Answers.* May 9, 2019. https://www.healthitanswers.net/actively-addressing-social-determinants-of-health-will-help-us-achieve-health-equity-2/. Accessed December 13, 2021.
6. De Marchis EH, Pantell M, Fichtenberg C, Gottlieb LM. Prevalence of patient-reported social risk factors and receipt of assistance in federally funded health centers. *J Gen Intern Med.* 2020;35(1):360–364. https://doi.org/10.1007/s11606-019-05393-w.
7. Gruß I, Varga A, Brooks N, Gold R, Banegas MP. Patient interest in receiving assistance with self-reported social risks. *J Am Board Fam Med.* 2021;34(5):914–924. https://doi.org/10.3122/jabfm.2021.05.210069.
8. Garg A, Boynton-Jarrett R, Dworkin PH. Avoiding the unintended consequences of screening for social determinants of health. *J Am Med Assoc.* 2016;316(8):813–814. https://doi.org/10.1001/jama.2016.9282.
9. Byhoff E, Garg A, Pellicer M, et al. Provider and staff feedback on screening for social and behavioral determinants of health for pediatric patients. *J Am Board Fam Med.* 2019;32(3):297–306. https://doi.org/10.3122/jabfm.2019.03.180276.
10. QuickFacts: Providence City, Rhode Island. U.S. Census Bureau. https://www.census.gov/quickfacts/providencecityrhodeisland. Updated July 1, 2021. Accessed February 23, 2022.
11. Lambert H, McKevitt C. Anthropology in health research: from qualitative methods to multidisciplinary. *BMJ.* 2002;325(7357):210–213. https://doi.org/10.1136/bmj.325.7357.210.
12. De Marchis EH, Hessler D, Fichtenberg C, et al. Part I: a quantitative study of social risk screening acceptability in patients and caregivers. *Am J Prev Med.* 2019;57(6):S25–S37 suppl 1. https://doi.org/10.1016/j.amepre.2019.07.010.
13. Byhoff E, De Marchis EH, Hessler D, et al. Part II: a qualitative study of social risk screening acceptability in patients and caregivers. *Am J Prev Med.* 2019;57(6):S38–S46 suppl 1. https://doi.org/10.1016/j.amepre.2019.07.016.