

Patient Perspectives on Addressing Social Needs in Primary Care Using a Screening and Resource Referral Intervention



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ABSTRACT:

BACKGROUND: Interest is growing in interventions to address social needs in clinical settings. However, little is known about patients' perceptions and experiences with these interventions.

OBJECTIVE: To evaluate patients' experiences and patient-reported outcomes of a primary care-based intervention to help patients connect with community resources using trained volunteer advocates.

DESIGN: Qualitative telephone interviews with patients who had worked with the volunteer advocates. Sample and recruitment targets were equally distributed between patients who had at least one reported success in meeting an identified need and those who had no reported needs met, based on the database used to document patient encounters.

PARTICIPANTS: One hundred two patients.

INTERVENTIONS: Patients at the study clinic were periodically screened for social needs. If needs were identified, they were referred to a trained volunteer advocate who further assessed their needs, provided them with resource referrals, and followed up with them on whether their need was met.

APPROACH: Thematic analysis was used to code the data.

KEY RESULTS: Interviewed patients appreciated the services offered, especially the follow-up. Patients' ability to access the resource to which they were referred was enhanced by assistance with filling out forms, calling community resources, and other types of navigation. Patients also reported that interacting with the advocates made them feel listened to and cared for, which they perceived as noteworthy in their lives.

CONCLUSIONS: This patient-reported information provides key insights into a human-centered intervention in a clinical environment. Our findings highlight what works in clinical interventions addressing social needs and provide outcomes that are difficult to measure using existing

quantitative metrics. Patients experienced the intervention as a therapeutic relationship/working alliance, a type of care that correlates with positive outcomes such as treatment adherence and quality of life. These insights will help design more patient-centered approaches to providing holistic patient care.

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INTRODUCTION

Recognition is growing that behavioral and social factors influence illness, recuperation, and wellness. Addressing behavioral and social needs is especially critical for low-income patients with challenges such as housing and food insecurities, lack of services in their language, limited transportation resources, and unstable employment and health insurance status.¹ However, patients may have protective factors such as social connections that could be strengthened to support health and resilience.^{1, 2}

Primary care clinics and delivery systems are experimenting with ways to support patients' needs. One approach is embedding trained patient advocates in clinics to connect patients to resources³⁻⁵ and provide coaching,⁶⁻⁸ health education,⁹⁻¹¹ follow-up, and assistance navigating healthcare and community systems.¹²⁻¹⁵ Embedded patient advocates may help patients and families achieve better health outcomes¹⁶ and save health systems money.¹⁷⁻²¹

Information is limited regarding patient experiences with interventions that connect them to resources to address unmet needs. We lack documentation of and reactions to services

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provided and how referrals to community resources impact unmet needs. Studies focused on patients receiving targeted care from a community health worker (CHW) for illnesses such as cancer¹⁴ or chronic conditions such as diabetes.^{15, 20, 22, 23} We found no in-depth studies of patient experiences with broadly scoped interventions of embedded patient advocates in primary care teams to screen and provide resource referrals for needs. Interventions using these advocates raise questions about the impact of serving populations with a range of demographics including income, immigration status, language, and culture. Measuring program impact is difficult due to variation in types and quality of referred services and participants' health concerns, preventing comparisons between programs, limiting power within evaluations, and hindering identification of controls.^{24, 25}

We do not know which components of primary care-embedded patient-advocate interventions most influence health and well-being. Evaluating intervention components is complicated because meeting all patient needs is not always possible; when needs are met, they may not directly, immediately influence health outcomes.

The mental health literature documents positive effects of establishing a "therapeutic relationship/alliance" based on "genuineness, empathy and positive regard."^{26–28} Therapeutic relationships are associated with increased treatment/medication adherence and better mental health outcomes.^{29–32} Despite the importance of these relationships, we found no work exploring processes, quality and impact of patient advocates through the lens of therapeutic relationships.

We analyzed qualitative interviews with 102 patients from an intervention that screened patients for social needs and referred them to resources. This intervention was piloted at West County Health Center (WCHC), a community health center operated by Contra Costa Health Services (CCHS). We focused on patients' experiences with the intervention and perspectives on its impact on their health and well-being. Our goal was identifying key themes to help policy-makers, providers, and researchers understand and measure these types of programs.

METHODS

We conducted telephone interviews with 102 patients who completed an intake visit for the intervention.

Intervention. A collaboration between CCHS and the nonprofit organization Health Leads, the intervention pilot embedded trained volunteer patient advocates in a large primary care clinic to help patients access community resources.³³ The pilot and evaluation were funded by the Kaiser Foundation Health Plan, Inc. The WCHC is one of 11 health clinics run by CCHS to serve as safety net clinics for the county's most vulnerable residents. In 2018, the WCHC provided over 140,000 patient visits to the community across a variety of services including primary care, women's health, and specialty services.

The Health Leads volunteer advocate model and WCHC included a full-time Program Manager and two Program Fellows who managed and supervised the advocates. Staff recruited advocates through local universities. Interested individuals applied to be an advocate, a process that included both a written application, an in-person interview, and commitment to volunteer for at least 10 hrs a week for at least 2 semesters (~8 months). Advocates were given 2 days of onboarding training, 4 weeks of on-the-job training with an experienced volunteer, and ongoing weekly trainings. They were supervised by paid staff and carried a caseload of patients that were assigned based on who is on shift when a patient indicated an interest in the program. Many advocates had an interest in a future career in health care, but this was not a requirement for the position.

Patients were referred to advocates based on responses to a paper screening tool developed by Health Leads to assess social needs³⁴ and given to patients by front desk staff at check-in during predesignated times (e.g., daily from 9–10 am). If patients indicated or health care teams determined needs through patient interaction, providers explained the program, orchestrating warm handoffs to advocates if possible. Patients could self-refer. Advocates conducted in-depth phone or in-person needs assessments and helped patients access resources. After initial encounters, advocates were expected to follow-up via phone, text, or in person to determine if patients successfully accessed resources, needed help addressing barriers, and had additional needs. Advocate work was recorded in a database developed by the Health Leads to manage resources and document patient encounters.

Sample. Purposive recruitment aimed for respondents with key demographics similar to those in the Health Leads program.³⁵ Using the database, we identified potential interviewees meeting inclusion criteria¹: enrolled in the intervention June 2014 through April 2016, and² at least one "closed need" (indicating that the advocate had completed their work with the patient) during that time. Exclusion criteria were not speaking English or Spanish or under 18 years old. The sampling plan stratified for two variables for which we established quotas for completed interviews¹: successfully met needs (target was 50% of sample with one or more successfully met needs) and² Spanish speaker, defined as patient's preferred language (target was 30% Spanish speaking, proportional to distribution in the program), and three prioritized variables without quotas¹: date of case closure, prioritizing more recently served patients to improve recall²; number of social needs met, ensuring inclusion of patients with multiple needs; and³ gender. We had data on respondents' age but did not have specific recruitment goals for this variable. Potential interviewees were identified in batches of 50–100 with priority given to those with the most recent experiences with the program to improve recall. This project was reviewed by the

of advocates' knowledge of resources, comfort working with advocates, and quality of intervention services. Initial reactions to being offered the services were overwhelmingly positive and often patients were surprised.

I haven't heard of it before and I wasn't expecting it. But that was nice that that's right there, because not only are you getting your health care, you can also go get some additional care and it's more convenient because it's right there. (#17, Female, English speaker, success)

Respondents appreciated the intervention. Prominent positive themes that emerged about the service included (1) convenience of embedding the service in primary care, (2) level of support provided, and (3) follow-up calls and texts. Respondents appreciated individualized attention from advocates. The theme of persistence and follow-up of patient advocates surfaced repeatedly in several contexts.

Many respondents praised the personal qualities and actions of advocates, most of whom were volunteers from local colleges. Qualities and actions highlighted included compassion, caring, listening skills, honesty, respectfulness, and persistence.

It's really kind of surprising, because they're all college-age kids, basically. I'm almost 60, and the compassion and understanding that they have is remarkable. (#15, Male, English speaker, success)

...He was just an angel. I give him a hundred marks every way you can mark a person. He was so caring... he gave me the impression he was very sincere and he was extremely persistent. He would call me over and over again, and follow up and send me information...Yeah, he cared more about me than I did for myself. (#31, Female, English speaker, no success)

I was well received in the office; she treated me well. She was very attentive, very cordial, very friendly, and she inspired trust...(#S17, Female, Spanish speaker, no success)

Many patients reported that interactions with the program and the advocates made them feel respected and cared for, manifesting in patients feeling listened to and supported in ways that were unique and special.

...it just made it feel like there were others out there that had a genuine interest in helping you help yourself.

Yeah, it didn't feel artificial or fake. It was really cool. (#23, Male, English speaker, success)

Well, just that somebody cared really was the biggest thing to me. Somebody cared, somebody wants to make you aware that these things were available. (#18, Male, English speaker, no success)

Respondents appreciated persistent follow-up attempts. Some acknowledged that when follow-up occurred, they were in stressful situations and had trouble being responsive. Nevertheless, they appreciated the efforts.

You know, they did the right thing. They didn't just drop me, you know, because some places when you call about something, they just say forget it...But they kept up with me, they called to see how I was doing. They didn't stop. (#4, Female, English speaker, no success)

...they were also persistent, because they called several times before I could get back to them. Again, I was in an extremely desperate situation. I was injured and I wasn't able to get back to them right away, and they continued to call until I did get back to them. (#15, Male, English speaker, success)

She would say, "I'll send you a message." And I would say, "That's great," because sometimes I do not have time to answer a call; the text facilitated the task...I do not know how she did it, but she sent me the texts in Spanish. (P14, Female, Spanish speaker, success)

Most respondents reported receiving follow-up calls that were a key component of their intervention experience. One respondent who did not receive follow-up communication expressed interest in more follow-up calls and more structured calls.

There was no like depth to the conversation. It was just her asking me what I needed information [about], and telling me she was going to send it out...I think at this point in my life I probably would have found it more helpful if they had called maybe a couple more times to say "well, hey, did you get an opportunity to check this out or check that out?" (#44, Female, English speaker, no success)

Some respondents could not connect with resources they were referred to or get their needs met but continued to value the service. Patients understood that sometimes there were no resources to meet their needs. Sometimes they blamed themselves for lack of success.

They tried their very best to help me, but they couldn't help me in that area. They tried really hard. (#17, Female, English speaker, no success)

At no time, in no way were they neglectful or at fault. Like I said, it seems like it was me who kind of dropped the ball in the long run. (#66, Male, English speaker, no success)

Respondents viewed the intervention as a resource they could easily access for other needs. This perspective was shared by patients who did not have needs resolved.

If I ever need to, I will call them and reach out to them. Because why? They helped me really fast and they're friendly, they understand me, and they just do their job. I like results, I don't like when I ask for help and they say "can I get back to you in a week?" I feel that person's not going to help me. But these people don't say that to me, they help me right away. (#19, Female, English speaker, success)

Some respondents expressed frustrations because resources were not tailored to their needs or because advocates did not seem to have the knowledge and skills to help them identify appropriate resources.

I was having trouble getting to the food pantry, bank or whatever, and a lot of that stuff she did mail the proper papers out, but I just didn't qualify for it. When I read through the papers and try to fill them out, I called certain numbers...every time I open the door, it kind of closed in my face. (#10, Female, English speaker, no success)

Patient Use of Resources. While most respondents reported that resources they were referred to were accessible, only about half reported using them (Table 2). We saw different rates of use for different resource types. Food resources were used the most and resulted in the most positive experiences. The use of other resources was limited with more negative experiences reported for services outside the four most frequently mentioned resource-referral categories.

Several respondents reported accessibility as a barrier to trying resources. Paperwork and negotiating program policies affected patients' ability to use resources. Respondents often gave up when the resource required them to make many calls or meet specific requirements or was unclear about who could answer questions.

The use of community resources was enhanced when advocates were willing and able to address patient barriers, for example by helping complete paperwork or calling organizations and making appointments.

The utility help was difficult to navigate. I couldn't have done it by myself. They totally helped me through it. (#15, Male, English speaker, success)

Almost one-third of English-speaking (25 of 70) and Spanish-speaking respondents (9 of 30) reported barriers to using referred services. Barriers included poor-quality products or services (e.g., low-quality food at food banks, dirty dental clinics), outdated or inaccurate information about a resource (e.g., phone never answered, location closed), or poor customer service from the resource.

I kind of let her know a lot of the places were nice, but some of the places, they sucked. And she was like thanks for that feedback. (#24, Female, English speaker, no success)

She gave me three numbers, I think. I left messages and I kept calling, but nobody called me back. Yeah, that

Table 2 Patient-Reported Perceptions About Referred Resources*

	Patient reported referrals	Used referral—positive experience	Used referral—negative experience/didn't work out	Used referral—neutral/other/unclear
Food	A.1.1.1.1.1.1.1.46. 61 A.1.1.1.1.1.1.1.51. 29	A.1.1.1.1.1.1.1.47. 24 A.1.1.1.1.1.1.1.52. 1	A.1.1.1.1.1.1.1.48. 2 A.1.1.1.1.1.1.1.53. 4	A.1.1.1.1.1.1.1.49. 2 A.1.1.1.1.1.1.1.54. 0
A.1.1.1.1.1.1.1.50. Housing	A.1.1.1.1.1.1.1.56. 19	A.1.1.1.1.1.1.1.57. 1	A.1.1.1.1.1.1.1.58. 0	A.1.1.1.1.1.1.1.59. 1
A.1.1.1.1.1.1.1.55. Utilities	A.1.1.1.1.1.1.1.61. 19	A.1.1.1.1.1.1.1.62. 5	A.1.1.1.1.1.1.1.63. 1	A.1.1.1.1.1.1.1.64. 0
A.1.1.1.1.1.1.1.60. Transportation	A.1.1.1.1.1.1.1.66. Unknown	A.1.1.1.1.1.1.1.67. 11	A.1.1.1.1.1.1.1.68. 9	A.1.1.1.1.1.1.1.69. 0
A.1.1.1.1.1.1.1.65. Other				

*Data source for this table was the qualitative interviews

service wasn't very good. (#14, Female, English speaker, success)

Some patients found few resources to address their needs. This was especially true for housing.

Like I say, I was disappointed. I had high hopes, thinking they were really going to help me find a spot, because the way they kind of put it out is they can help you find housing. Maybe it was worded wrong. And I got really excited about it, but then I was let down and I went into this depression. (#54, Female, English speaker, no success)

And at both they told me the same, that because I don't speak English, that the trainings were with English-speaking professors. That's why I didn't go. (#S7, Male, Spanish speaker, no success)

When asked what prevented participants from accessing services, responses clustered around two key domains: (1) systems barriers, linked to inequitable distribution of and access to resources and (2) individual barriers that were unique limitations experienced by the patient. Figure 1 summarizes the key barriers that emerged from interviews and illustrates an interrelationship between domains.

Patients almost universally identified advocates as facilitators and praised their help overcoming system and individual barriers. Patients noted that barriers were often pervasive and persistent and ultimately prevented them from fully resolving their behavioral and social needs.

Impacts on Patients. Many patients reported concrete changes in their lives from support provided by advocates. In some cases, the referral resolved their immediate food, transportation, or healthcare need.

When I fill[ed] out the form, I don't know exactly what it's all about, but when I do receive the card and the expla[nation], it was really, really so helpful indeed for me. Especially my medication, I pay a high price sometimes, \$84 or \$104, but now I pay nothing. (#11, Male, English speaker, success)

I know where more pantries are, so food is more readily available for me now. I can go to different pantries, so everything is fine and dandy. (#34, Male, English speaker, success)

She told me to go to San Pablo Career Center and that's where I found out my job, that I'm at now, had an

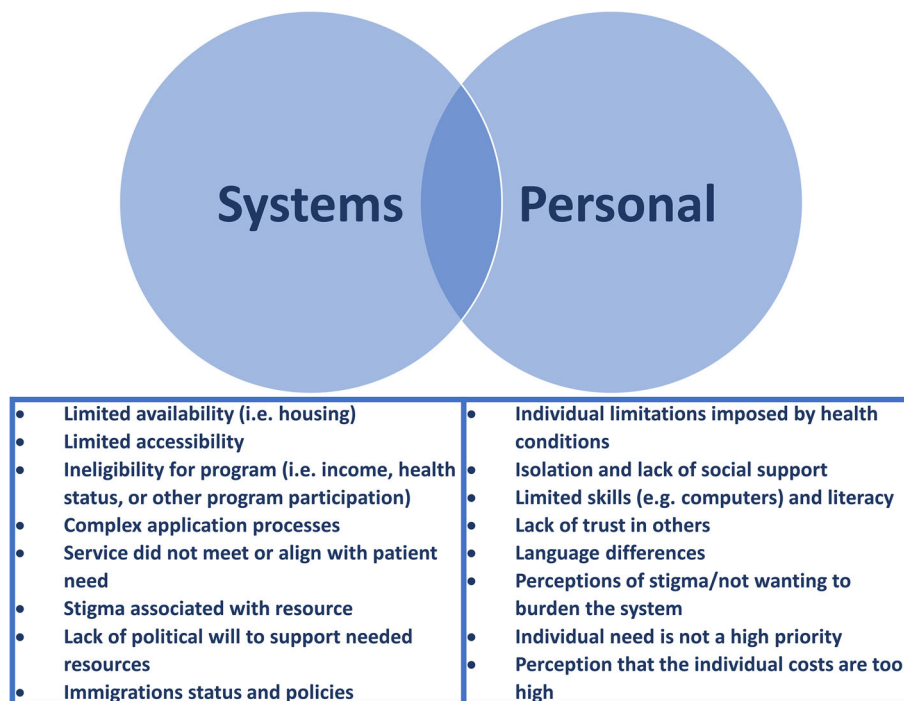


Figure 1 Summary of barriers to accessing referred resources. Barriers identified by interviewees who used patient advocate services were in two domains, system and personal. Shown are specific types of barriers associated with the domains.

orientation and was hiring. (#53, Female, English speaker, success)

We explored the impact on patients of engaging with the intervention beyond resolving needs through community resources. Most patients did not connect help or support from the intervention to notable changes in overall health. When asked if or how the program influenced their life, patients generally articulated the immediate and straightforward impact of a resource—for example, transportation assistance helped them more easily access the clinic.

However, some patients described physical or mental and emotional health benefits associated with engaging with the intervention or resources. Benefits frequently referenced a healthier diet, decreased stress or worry, or increased feeling of stability.

Oh, my health is way better...I eat different now. I probably lost 20, 30 pounds...Because I can afford better food. I'm eating better now. When you take stress off of you, you can afford the rent, you know where your next dollar is coming from—life is easier... Actually, I got a part-time job too. I'm working in a real nice place. It's all good. (#39, Male, English speaker, success)

I felt like it actually gave us less stress and less worry. So it kind of helped us a lot to just not worry about having to always look online for food banks and everything. (#58, Female, English speaker, no success)

Well, I feel less burdened, because as I told you, the bill was coming close to \$100 and sometimes I could not pay it. The bills would stack up for the next month and now I feel less burdened because it is only \$40 or less. (#S14, Female, Spanish speaker, success)

Patients indicated that interactions with advocates increased confidence or motivation to act in other life areas or investigate other resources or services. Some stated that introduction to a new resource by advocates prompted them to consider other options.

Yeah, honestly I do think it was beneficial because it was almost like this—I knew I needed help, I kind of didn't know where to begin and the steps, and they actually helped me in a way get to a point of creating steps and then having a little bit more of "oh hey, I'm going to make this

plan for myself." (#64, Female, English speaker, success)

My family told me, "this is gonna take a year or more." But...I myself took the reins and said "No, I'm gonna keep going"...Now I understand that one has to be decided, if someone wants to start something they have to keep at it, no? Until they find the result. (#S24, Female, Spanish speaker, success)

DISCUSSION

Patients who used the patient-advocate program appreciated the services provided, especially the follow-up. They described advocate assistance in filling out forms, calling community resources, and other navigations as critical to being able to use referred resources. Beyond these practical support activities, patients commented that interacting with advocates created a sense of being listened to and cared for. Patients felt they had a place to go should additional needs arise.

Our sample was chosen so at least half of respondents did not report resolution of a need within the intervention period, to ensure diversity of experiences. Barriers identified by interviewees to getting their needs met included lack of available resources, an issue of interest to other researchers.^{38, 39} Housing was particularly difficult to address. Understanding and addressing barriers to patients using resources are critical if programs are to be successful. Patient barriers to using intervention services included working with less-experienced advocates and referral to community resources that were hard to access or poor quality. Nonetheless, interviewees rarely faulted the advocate program.

Our finding that patients valued relationships with advocates is consistent with the well-established concept of therapeutic relationships^{26–28, 31, 32, 40} or working alliances. A variety of tools to measure therapeutic relationships or alliances consistently show positive effects over multiple studies. Findings associate therapeutic relationship/alliances with increased treatment/medication adherence,^{26, 30, 32, 41} better mental health outcomes,^{31, 40} and decreased pain.^{42–44} Although brief, this patient-centered intervention resulted in relationships that exhibited key components of therapeutic relationships—collaboration, empathy, and positive regard. Therapeutic relationships may increase patients' feelings of trust and respect and feeling cared for that positively affect relationships with other team members. We are not aware of work that explores linkages between establishing a therapeutic relationship with patients and effectiveness and impact of interventions to address social needs by embedding advocates in primary care settings. Research needs to explore if intermediate outcomes linked to development of therapeutic relationships can be used to assess the impact of these activities in healthcare settings.

Our study's limitations include that, as with all qualitative data, our findings are not generalizable to all patients in this or other programs, sites, or populations. Instead, qualitative data generates new insights and details ideas, events, and experiences. Nonresponse bias can affect data that rely on voluntary participation; our representation of key demographic variables indicates a robust cross-section of patients was sampled Table 1.

Our key learnings can help improve the design and impact of interventions that connect primary care patients to community resources. Despite concerns about patients' receptivity to this type of service in primary care, interviewees were open to and saw the value of these embedded services, even when needs were not met. When well executed, these services may provide patients with a therapeutic relationship that positively impacts their ability to problem solve and address barriers to their overall health and well-being. Our findings show these interventions must robustly and continuously vet resources and address structural barriers such as those that limit housing. Some interviewees benefitted from exploring and learning to navigate resources and advocate for themselves, suggesting that patients may benefit from interactions that emphasize activation, action planning, and self-advocacy. Our findings suggest new avenues for improving measurement of the impact of these interventions and ensuring provision of patient-centered, whole-person care. Finally, interventions that use primary care-embedded advocates to address social needs must identify and assess ways to help patients overcome personal-level and system-level barriers.

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