The Role of Community-Based Organizations in Improving Chronic Care for Safety-Net Populations

Kim Hanh Nguyen, ScD, MPH, Jessica D. Fields, BA, Anupama G. Cemballi, MA, Riya Desai, MPH, Anjali Gopalan, MD, MS, Tessa Cruz, BA, Aekta Shah, PhD, Antwi Akom, PhD, William Brown III, PhD, DrPH, Urmimala Sarkar, MD, MPH, and Courtney Rees Lyles, PhD

Introduction: Social determinants of health (SDoH) influence health outcomes and contribute to disparities in chronic disease in vulnerable populations. To inform health system strategies to address SDoH, we conducted a multi-stakeholder qualitative study to capture the multi-level influences on health for those living in socio-economically deprived contexts.

Methods: Varied qualitative inquiry methods – in-depth interviews, participant-led neighborhood tours, and clinic visit observations – involving a total of 23 participants (10 patients with chronic illnesses in San Francisco neighborhoods with high chronic disease rates, 10 community leaders serving the same neighborhoods, and 3 providers from San Francisco’s public health care delivery system). Qualitative analyses were guided by the Chronic Care Model (CCM).

Results: Several key themes emerged from this study. First, we enumerated a large array, neighborhood resources such as food pantries, parks/green spaces, and financial assistance services that interact with patients’ self-management. Health service providers leveraged these resources to address patients’ social needs but suggested a clear need for expanding this work. Second, analyses uncovered multiple essential mechanisms by which community-based organizations (CBOs) provided and navigated among many neighborhood health resources, including social support and culturally aligned knowledge. Finally, many examples of how structural issues such as institutional racism, transportation, and housing inequities are intertwined with health and social service delivery were elucidated.

Conclusion: The results contribute new evidence toward the community domain of the CCM. Health care systems must intentionally partner with CBOs to address SDoH and improve community resources for chronic care management, and directly address structural issues to make progress. (J Am Board Fam Med 2021;34:698–708.)

Keywords: Chronic Disease, Disease Management, Health Resources, Minority Health, Qualitative Research, San Francisco, Self-Management, Social Determinants of Health, Vulnerable Populations

Background and Significance
Chronic diseases disproportionately affect people of lower socioeconomic status (SES) and racial/ethnic minorities.1-3 Excessive burden of social and economic risk factors (i.e., structural racism, low SES,4 language barriers) and adverse neighborhood environments (i.e., limited healthy food access, unsafe places, low social cohesion) contribute to these problems.
disparities. Social determinants of health (SDoH)—the conditions in which people live, work, and play—are linked to the development, progression, and severity of chronic diseases. To improve chronic disease outcomes, individuals require consistent health care access, effective health care provider interactions, and the ability to perform self-management tasks (i.e., medication adherence, healthy behaviors). Unmet social needs (i.e., food insecurity, homelessness) interfere with individuals’ opportunity and capacity to manage chronic conditions, exacerbating inequities.

A 2019 National Academies committee report called for the health sector to increase attention on upstream contributors to health inequities, aligned with interest in integrating SDoH into clinical care and value-based payment models incentivizing population health. Sustained health improvements among complex patients will likely require partnerships between health systems, public service agencies, and community organizations addressing patients’ social needs. This qualitative study aims to capture the experiences of chronic disease patients within socio-economically deprived contexts and the role of community resources in supporting their health management. We focus on residents of high-risk neighborhoods with chronic conditions, primarily diabetes, cared for in an urban safety-net health system, and we integrate the perspectives of local community leaders (CLs) and health care providers.

Methods
This work was the first phase of a National Library of Medicine-funded R01 entitled Mapping to Amplify the Vitality of Engaged Neighborhoods (MAVEN). We used varied qualitative inquiry methods—interviews, clinical observations, and participant-led neighborhood tours—for triangulation to inform the future creation of a mobile application to improve how community members and leaders in underserved neighborhoods interact with existing community health resources.

Theoretical Approach
Using the Chronic Care Model (CCM), we explored aspects of the community and their relationships with chronic disease management, with a long-term goal of informing self-management interventions. The CCM posits that productive interactions between informed, activated patients and a prepared, proactive health care team are essential to improved health outcomes. Two overlapping domains influence these interactions: (1) health system organization and (2) community resources and policies. Much research addresses chronic disease management within health systems, yet often neglects the less robustly defined community sphere. We aimed to build on the CCM’s community sphere with qualitative insights about community-level influences relevant for chronic care.

We used physically defined neighborhoods for participant recruitment and to assess the physical characteristics within distinct geographic spaces. In interviews and analyses, we conceptualized ‘community’ as a sense of identification and emotional boundedness with other members. We recognize that these community boundaries are symbolic and may be centered around a sense of common identity—sometimes but not always linked to a geographic neighborhood. During interviews, we more deeply explored community as collective identity and emotional connection to other members.

Study Sample and Setting
The study sample consisted of 10 patients, 10 CLs, and 3 health service providers, with multiple data collection points across participant groups averaging 3 to 4 hours per participant. We recruited patients with diabetes or prediabetes living in 1 of 5 San Francisco (SF) neighborhoods with high diabetes prevalence (Mission, Bayview/Hunters Point, Excelsior/Visitacion Valley, Tenderloin, Western Addition), using SF Planning Department’s neighborhood definitions. These patients were receiving care from the San Francisco Health Network (SFHN), SF’s public health care delivery system. We identified patients via primary care provider review of prediabetes and diabetic patient panels followed by phone screening by staff, as well as purposeful snowball sampling from patients suggesting additional participants. We then called patients living in the SF neighborhoods listed above to seek their participation in the study – focusing on English speakers and those who owned or previously owned a smartphone, given the study scope.

We recruited CLs from health and social service community-based organizations (CBOs) in the above neighborhoods using snowball sampling,
beginning with a city-wide coalition of CBOs focused on chronic disease prevention.

We interviewed SFHN health service providers (2 primary care physicians and 1 system leader in SDoH screening and referrals) about workflows to address patients’ social needs and the role of community resources in promoting patients’ health. In addition, we conducted 4 patient clinic visit observations to gain broader insights into health provider perspectives.

We obtained informed consent from all participants. The UCSF Institutional Review Board approved the study (#18-25696).

Data Collection
KHN, AGC, JDF, RD, and CRL conducted semi-structured, in-person interviews and participant-led neighborhood tours tailored to each participant group (patients, CLs, health service providers, see Table 1). Patients described their experiences living with chronic disease, what being healthy means to them, their motivations and strategies for staying healthy, barriers to meeting their health goals, and where they find health information. They recounted places and resources in their neighborhoods that do and do not contribute to health, where they spend time with family and friends, and whether they feel a sense of community. CLs discussed their professional background and role, experience in their local community and neighborhood, relationships with clients, perspective on what health means to them and their clients, and barriers and facilitators to their clients’ health. Providers described their experience helping safety-net patients manage chronic conditions, identifying and addressing patients’ social needs, and the process for coordinating care within and outside the health care system.

In neighborhood tours, patients and CLs led study staff through their neighborhoods (where patients lived or most strongly identified; where CLs’ organizations were located, sometimes overlapping with where they lived), describing activities they do, places they go, and people with whom they interact.

In-person clinic visit observations for 4 of 10 patients and their primary care providers allowed an independent view of interactions described by participants, useful in uncovering insights about roles, processes, and patterns between providers and patients.24 Study staff interviewed patients after each clinic visit observation about their perceptions of the visit, their relationships with their health care providers, and what information about their neighborhood they felt would be useful for their health care providers to know.

All patients completed a survey including demographic information, self-reported health, chronic conditions, physical activity, diet, and technology access and use. Interviews, neighborhood tours, and clinic visits were audio recorded. Each interview lasted 90 to 120 minutes and each neighborhood tour 60 to 120 minutes.

Analysis
Patient survey data were summarized. Transcripts of interviews, neighborhood tours, and clinic visit observations were read multiple times and independently coded by at least 2 study staff using Atlas.ti 8. Authors KHN, AGC, and RD met several times to discuss and reconcile codes. Through inductive thematic analysis, we established a final codebook used to code all transcripts.25 Authors KHN, AGC, RD, and JDF developed code-level summaries, and over several meetings, KHN, AGC, RD, JDF, and CRL developed and mapped themes onto the CCM. Illustrative quotes were selected for presentation in this article.

From patients’ and CLs’ interviews and tours, we cataloged key neighborhood sites and features identified as facilitators or barriers to health using the Streetwyze digital health platform.26 Neighborhood

Table 1. MAVEN Study Qualitative Data Collection Methods

<table>
<thead>
<tr>
<th></th>
<th>Interviews</th>
<th>Neighborhood Tours</th>
<th>Clinic Visit Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community leaders</td>
<td>10</td>
<td>8</td>
<td>N/A</td>
</tr>
<tr>
<td>Patients</td>
<td>10</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Health service providers</td>
<td>3</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
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N/A, not applicable; MAVEN, Mapping to Amplify the Vitality of Engaged Neighborhoods.
features were then summarized and organized into broad categories.

**Results**

**Participant Characteristics**
Table 2 shows participants’ demographic characteristics. Patients were majority Black, 67% were female, mean age of 62 years, had at least high school education, most earned less than $20,000 annually, and all except 1 reported at least 1 other chronic condition in addition to prediabetes/diabetes. CLs’ organizations included a public library, patient advisory council coordination center, health and wellness organization serving Black and other marginalized communities, a nonprofit cooking school, a social services center, a multi-ethnic family resource center, and a Latinx cultural organization. Providers included a nurse diabetes educator and 2 primary care physicians from SFHN.

**Overview of Findings**
Our analysis yielded 3 overarching themes. First, we describe neighborhood features that patients and CLs identified as important to health,
<table>
<thead>
<tr>
<th>Resource Category</th>
<th>Attribute/Specific Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FOOD</strong></td>
<td>Price, quality, and availability of food for purchase</td>
</tr>
<tr>
<td>(grocery stores, restaurants, food pantries, food assistance programs, farmer’s markets, free meals programs)</td>
<td>Patient 3 identified a social service agency that provides food tailored to diabetes-related dietary restrictions. Patient 7 explained that a grocery store is often messy and its prices can be twice the price of stores in other neighborhoods. <strong>Free groceries and meals</strong> Patient 1 noted that a church hands out free produce once a week.</td>
</tr>
<tr>
<td><strong>PUBLIC SPACE/RECREATIONAL PLACES</strong></td>
<td>Places where people congregate</td>
</tr>
<tr>
<td>(community gardens, public parks, libraries, pools, playgrounds, community and senior centers)</td>
<td>Patient 4 explained that there are activities for seniors in a park and a nearby area recently had a free health fair. <strong>Safety</strong> Patient 3 mentioned avoiding certain streets due to gun violence. <strong>Accessibility of public spaces</strong> Patient 2 identified a church as being handicap accessible.</td>
</tr>
<tr>
<td><strong>HEALTH</strong></td>
<td>Types and availability of local health services and programs</td>
</tr>
<tr>
<td>(healthcare facilities, community health centers, pharmacies)</td>
<td>Patient 1 explained how much she loved her diabetes education class. Patient 3 noted that it takes her a long time to get to her primary care clinic by bus. <strong>Specific services that can be requested at local clinics and pharmacies</strong> Patient 2 discussed how his pharmacy delivers medications with clear instructions.</td>
</tr>
<tr>
<td><strong>SOCIAL SERVICES</strong></td>
<td>Availability and accessibility of social services</td>
</tr>
<tr>
<td>(legal representation, mental health services, cultural resources, nutrition programs, access to government identification, homelessness programs)</td>
<td>Community leader 10 pointed out a family resource center. <strong>Free services available for vulnerable populations</strong> Community leader 5 explained that a social services agency hosts free computer classes, a needle exchange and gives out free phones. Patient 6 described a social services agency where he can get free socks helpful for his diabetes-related foot problems.</td>
</tr>
<tr>
<td><strong>EDUCATION</strong></td>
<td>Availability of child-focused programs</td>
</tr>
<tr>
<td>(schools, afterschool programs, libraries, city colleges, education initiatives)</td>
<td>Community leader 10 described an organization that provides culturally relevant services to low-income youth. <strong>Learning opportunities for adults</strong> Patient 6 described going to the public library to learn about health and meet people.</td>
</tr>
<tr>
<td><strong>TRANSPORTATION</strong></td>
<td>Service quality, accessibility, and reliability of bus lines</td>
</tr>
<tr>
<td>(public transportation, paratransit, bus/taxi voucher programs)</td>
<td>Patient 2 appreciated the reach of the public tram line but also explained that paratransit has long wait times and no same-day requests. Community leader 6 explained that the public tram line does not consistently stop in their neighborhood.</td>
</tr>
<tr>
<td><strong>HOUSING</strong></td>
<td>Housing displacement</td>
</tr>
<tr>
<td>(affordable housing communities, assisted living facilities, shelters, single residency occupancy hotels)</td>
<td>Patient 5 noted many buildings whose Black former owners were pushed out due to redevelopment policies and gentrification. <strong>Housing tailored to specific populations</strong> Community leader 8 noted a low-income housing community serving residents with special needs.</td>
</tr>
<tr>
<td><strong>ART</strong></td>
<td>Availability of art and cultural events</td>
</tr>
<tr>
<td>(cultural shows, murals, musical events, museums)</td>
<td>Patient 3 explained that a social services agency gives free tickets to the opera, ballet, and sports games. <strong>Appreciation of public art</strong> Patient 6 noted how much he liked a mural in his neighborhood.</td>
</tr>
</tbody>
</table>
alongside health service providers’ experiences facilitating patients’ use of community resources. Second, we discuss the central role of CBOs in the provision and navigation of community resources. Third, we outline structural domains of neighborhoods that influence chronic disease management. These examples illuminate the CCM’s community domain.

**Theme #1: Key Neighborhood Resources and Linkages from Health care Systems**

Patients and CLs shared information about neighborhood resources relevant to chronic disease management based on their life experiences and local knowledge (Table 3). Participants discussed the quality of local resources and services, how they use local resources (or how they refer clients to local resources), and ways these resources and spaces can improve.

**Health care System Linkages to CBOs**

Health service providers undertook numerous activities to link patients to community resources addressing social needs. For example, the diabetes educator described forging and maintaining relationships with CBOs that offered health-related services (e.g., food assistance, exercise classes), assessing social needs, and connecting patients to tailored resources to support diabetes management. However, she noted patients’ needs were often so complex that even once connected to resources, additional barriers prevented patients from using them. For example, a patient could obtain food from food banks, but their shelter lacked adequate appliances to store groceries or prepare meals. She also noted that CBOs were interested in connecting with health care providers to reach new clients:

“We give them the info [and] right now I feel like we’re hoping for the best when we make these social needs referrals whereas... ideally this would be a very consistent tool that we would use to facilitate proper social and medical care.” Provider 2

Building trust to discuss social needs was also an essential component for patients and providers:

“Hopefully I’m providing an environment [where patients] feel okay sharing... I think sometimes asking the [SDoH] screening questions without... knowing them for long enough it might make them guarded unintentionally because it’s like ‘why are you asking that?’” Provider 1

“I feel I can tell her [my doctor] anything. When I first met her, it was like I couldn’t... I had to have a feel of her and she’s feeling me... It took me a while... after I got used to her, I became open up to her more.” Patient 1

**Theme 2: CBOs Are Essential for Providing and Navigating Neighborhood Health Resources**

CBOs played 3 main roles in supporting patients’ chronic disease management.

**Health and Social Services Provision**

CBOs offer direct health services and additional social services that further support health. For example, the nonprofit cooking school provided nutrition, meal planning, and grocery shopping education “to empower people to know how to buy, cook, and eat good food every day.” Further, the librarians mentioned that many residents without internet access used the library to find health information. For example, a woman whose doctor prescribed a healthier diet called the librarians with questions like “How much vitamin C is in an orange?” and “I have to only take 7 grams of salt a day, so tell me what I should avoid.”

CBOs also deliver social interventions that support clients’ health, including transportation, caregiver support, housing, senior services, public assistance program access (i.e., disability, social security income), clothing and laundry services, employment training, and language interpretation. CBOs often tailored these services to meet clients’ language, cultural, and health literacy needs, allowing for greater openness in conversations about clients’ health and social needs: “If English is your second language in that situation, you might just be easier and more comfortable to pretend that you understand [what your doctor says].”

Further, many CBOs help clients access and navigate more specialized social care services. For
example, a CL from the Mission noted her organization “opens a door for many services,” many of which residents had not realized exist within the neighborhood. The public library employs a full-time social worker who connects marginally housed patrons to “where they could take a shower and get food. Nothing like what books to get.” Overall, CLs described an extensive network of CBOs encompassing many more organizations than those in our study.

Activated Space for People with Psychosocial Vulnerabilities to Meet, Connect, and Feel Belonging
CBOs are key sources of social support and connection within neighborhoods—particularly important in light of the high rates of mental health needs within our sample. Over half of the patient participants self-reported depression and/or anxiety, and almost all described psychosocial difficulties adjusting to their chronic condition(s). A patient with diabetes and lupus stated, “I am dealing with a whole lot of stuff...mentally, emotionally, and spiritually.” The absence of social support and close, positive family relationships also affected patients’ ability to cope with everyday life. A disabled patient living in a single-room occupancy hotel was unable to leave his room unless someone came to aid him: “I could not get out unless somebody else could get [me] out. I was not leaving my room for months at a time.” CLs suggested patients’ loneliness and lack of social support may have led some to seek interactions with social service and health care providers: “They come for that human connection, just that human support.”

CBOs also serve as free, safe spaces for social interaction. Both CLs and patients noted that CBOs offer clients a sense of belonging. One patient said her favorite thing about her neighborhood was a wellness organization serving Black communities: “I am here more than I am any place else.” A CL explained that people, particularly the most marginalized, come to her organization because they desire to be with others and feel valued: “They just want to have time and space with each other.” Another CL said, “It is part of our job that they feel comfortable coming here, they feel happy.” Similarly, CBOs held community and cultural events, providing broader opportunities for social engagement.

CLs have close, trusting relationships with clients and follow up with them frequently, providing ongoing support and encouragement. “We have been here more than 10 years...to build this trust with the clients it takes time, but later they feel so comfortable coming here...the relationship is like a familia.”

Unique Positioning of CBO Staff to Connect Patients with Health Resources
CLs reflect the sociodemographic diversity of the communities they serve, understand the social needs of community members, and act as advocates for individuals and communities. CLs, for example, often share the same racial/ethnic, linguistic, and cultural background as their clients; some even grew up in the same neighborhoods in which they now work. One CL, born and raised in the Bayview, described her experiences of systemic anti-Blackness and challenges overcoming barriers related to living in an economically depressed neighborhood. She connected this experience with her passion for helping others facing similar obstacles. Another CL who grew up in the Tenderloin and now lives there “by choice,” recounted that her childhood experience navigating the health care system for her Spanish-speaking immigrant mother motivated her passion for helping others access health care: “[Clinics are] always moving forward to improve the patient experience. Coming from a background where that was not the case...it just drives me.” A CL from Mexico expressed understanding the cultural alienation and loneliness felt by immigrant clients as well as being able to overcome the multiple barriers that otherwise may have prevented Latinx patients from accessing services.

Theme 3: Structural Issues Are Intertwined with Health and Social Service Provision and Delivery
Structural issues within under-resourced neighborhoods emerged throughout our data collection. Participants emphasized that the greatest social needs were related to exclusion and lack of integration into the larger community, often due to structural barriers. These broader factors are centered around sociohistorical processes (i.e., institutional racism, economic inequality) that shape local contexts such as housing and transportation policies and ultimately impact individuals’ abilities to obtain the necessary resources to maintain their health. For example, patients and CLs explained that Black residents were deterred from entering certain neighborhoods or places (i.e., restaurants, grocery stores) because they felt unwelcomed or perceived as a threat, thus limiting their ability to access health-promoting resources and services. Additional examples of these structural domains—
including structural racism, transportation and housing inequity, gentrification and displacement, and neighborhood safety—are shown in Table 4.

In relation to these structural barriers, CBOs often served as advocates for social change:

“[T]o summa [rize the role that I believe I play in the community: I believe that I was seated at a table to where I am at least recognized and I am heard. I believe that that seat carries the weight and the stories of persons who I represent when I walk through the door. I carry my role in the community with great responsibility, understanding that other persons may not have been able to locate the access that I have in ways in which to be an advocate for more security across many different domains. I would say that my role is really probably firmly rooted in advocacy.” CL10

### Discussion

Study results provide evidence of the vast influence of SDoH on care experiences, with concrete examples of how community factors impact chronic care management, providing fruitful expansion of the CCM’s community domain. Our qualitative inquiry has made clear that a multi-level view of SDoH will be necessary for...
any health system interventions targeting social needs, including the central role of CBOs. Sustainable population health interventions in disadvantaged communities must also go beyond individual educational and behavioral approaches to focus on eliminating structural barriers. These findings also provide empirical data to support previously published recommendations on reconceptualizing the CCM model to (a) recognize SDoH, (b) bolster community participation and action, and (c) increase policies and programs that address societal inequities.20

Health care systems have begun to take on SDoH screening and referral, including more standardized questionnaires about patients’ social needs and direct provision of social services at the point of care (e.g., food banks at clinics,27,28 medical-legal partnerships).29,30 Some health care systems have invested in structural interventions, such as building or investing in affordable housing.31,32 Our findings provide additional focus areas for advancing this work, such as fostering a sense of belonging and supporting neighborhood-based advocacy for structural improvements.

These findings also show that CBOs do more than provide ancillary support, rather they are essential in chronic disease management. CBOs provide direct health services, linkages to additional social services, culturally relevant interpersonal connections with clients, and an understanding of the priorities for structural changes needed to improve health. This understanding of clients’ needs, coupled with knowledge of and leadership in social service environments, enables CLs to connect clients to the most relevant services. CLs have first-hand knowledge of local resources (i.e., buses, grocery stores) and an inherent awareness of patients’ local sociocultural context because they are members of these same communities.

This study supports the growing call to action for health care systems to partner more intentionally with CBOs33 to address SDoH and improve community resources for chronic care management.34,35 To date, many health interventions that engage CBOs either exist outside the health care system or involve adding community workers to existing health care self-management systems. While both approaches are useful, new ways of integrating health care systems and communities might better leverage the existing expertise of CBOs (e.g., interpersonal and social activation potential) within patients’ neighborhoods. Strategic partnerships between health care systems and CBOs are critical for identifying the social needs of communities and informing strategies to address domains that contribute to health disparities at each level of influence, including structural.36 Community-based participatory research principles should be incorporated for long-lasting, cross-sectoral partnerships to reduce disparities by addressing SDoH.37 The present study has limitations. We studied vulnerable patients from a single health system in a major metropolitan city, and findings may not represent other safety-net settings or regions with different demographics. Furthermore, 7 of 10 patients were English-speaking older adults in their 60’s who received care for their chronic condition(s) at SFHN; thus, limiting generalizability. Strengths of the study include participants who reflect the sociodemographic diversity of neighborhoods with high diabetes prevalence and in-depth qualitative data collection across participant groups on the complex reality of vulnerable patients living with chronic illness.

Amid renewed calls for racial justice and the stark disparities of the Coronavirus disease 2019 (COVID-19) pandemic, health care systems have been grappling with public health and health equity in new ways. While progress has begun in multiple domains, health care systems must value the expertise of patients navigating their health and health care and CBOs’ longstanding knowledge of how to promote population health and wellbeing. Rather than only developing chronic disease management solutions that emphasize single condition health education materials or narrow information exchange with community workers, we must re-envision health care–community partnerships to elevate community-based services and expertise that have been present in neighborhoods for decades.38,39

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To see this article online, please go to: http://jabfm.org/content/34/4/698.full.

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