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Original Research

Journal of Primary Care & Community Health
Volume 13: 1–6
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DOI: 10.1177/21501319221126281
journals.sagepub.com/home/jpc
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Qualitative Exploration of Geospatially Identified Bright Spots and Priority Areas to Improve Diabetes Management

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Abstract

Background: Type 2 diabetes (T2DM) results in significant morbidity and mortality and is associated with disparities in prevalence, treatment, and outcomes. GIS can identify geographically based disparities. In the focused Rapid Assessment Process (fRAP)—a novel mixed-method study design—GIS is combined with qualitative inquiry to inform practice interventions and policy changes. **Methods:** Using fRAP, areas with poor T2DM outcomes (priority areas) as well as areas with positive T2DM outcomes (bright spots) were identified, focus groups were conducted, and responses analyzed for intervention opportunities. Focus group participants were English- and Spanish-speaking patients with T2DM living in one of the identified areas. Qualitative analysis consisted of initial coding with a priori themes from the focus group question guide, followed by identification of emergent themes within each defined category. **Results:** The a priori categories included Facilitators, Barriers, Strategies, and Impact of Diabetes Diagnosis. Emerging recurrent themes were Interactions with Medical Professionals, Medications, Lifestyle Management, Family Motivators and Support, Self-Efficacy, and Social Needs and Community Resources. **Conclusions:** Thematic results from focus groups can be used by practices to improve T2DM care through educating patients about chronic disease and nutrition, connecting them to diabetes-specific services, learning how diabetes fits in the context of patient lives, and eliciting patient values and motivations to improve diabetes self-management. Findings also may be used by health care professionals to inform community-based advocacy efforts, interventions, and future research.

Keywords

diabetes mellitus, geographic information systems, disparities, qualitative methods, focused rapid assessment process, community health, focus groups, lifestyle change, mixed methods

Dates received: 26 July 2022; revised: 27 August 2022; accepted: 29 August 2022.

Introduction

Type 2 Diabetes (T2DM) is one of the largest public health issues in the United States (US), causing significant amounts of morbidity and mortality yearly.[1,2] The Centers for Disease Control and Prevention (CDC) estimates that as of 2019 more than 37 million people living in the US have T2DM, while an additional 96 million adults have prediabetes.[3] Unfortunately, disparities in T2DM prevalence, treatment, and outcomes exist across the country.[4]

The connection between health status and the communities in which patients live is well documented.[5] Geographic Information Systems (GIS) have been shown to be effective in identifying geographic regions facing health disparities.[6-8] Using GIS to map patient addresses contained within clinical registries can reveal areas where pockets of individuals who are most in need of intervention live. Many initiatives have focused on the use of data that is publicly available, while others have used electronic medical record (EMR) or claims-based data to conduct localized analyses.

Using a novel method combining geolocation and subsequent rapid qualitative inquiry, our study team sought to

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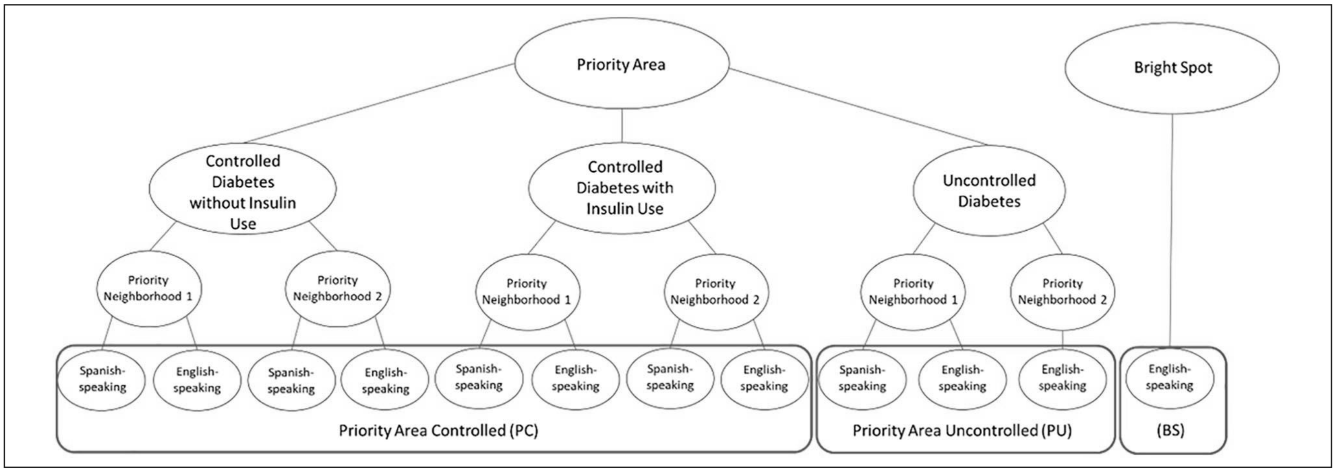

Figure 1. Focus group stratification.

better understand diabetes disparities in our health network's patient panel. The focused Rapid Assessment Process (fRAP)[9] is a 3-phase, mixed-methods approach to evidence-informed clinical practice shifts; fRAP harnesses the power of GIS mapping to (1) identify geographic areas for (2) in-depth qualitative inquiry, leading to (3) practice intervention and policy change.[9] This paper describes the results and clinical practice implications of the qualitative investigation of local pockets identified as having a high prevalence with high rates of poorly controlled T2DM (priority areas) and high prevalence with high rates of well-controlled T2DM (bright spots).

Methods

This study used GIS mapping followed by qualitative data collection from individuals with T2DM. The first phase of the fRAP method[9] determined which neighborhoods in the primary-care coverage area had poor disease outcomes (priority areas) and positive outcomes (bright spots). Priority areas were defined as those with top quartile T2DM prevalence and outliers for poor A1c control (more than 2 standard deviations [SDs] worse than the mean). Bright spots were neighborhoods in the top quartile T2DM prevalence and outliers for good A1c control (more than 2 SDs better than the mean). Detailed descriptions of the mapping procedure, study inclusion/exclusion criteria, and neighborhood demographics can be found in a previously published report.[10]

Study participants were primary care patients with T2DM living in one of the identified priority areas or bright spots. Participants were recruited by mailed letter and telephone to participate in focus groups designed to collect patient-identified facilitators and barriers to receiving appropriate diabetes management services. The study coordinator (NB) confirmed that individuals met inclusion criteria. Recruitment was based upon a proposed stratification design by ZIP code grouping, diabetes control (uncontrolled, controlled with insulin, or controlled without insulin), and language preference (Spanish vs English), as outlined in Figure 1.

Five focus groups were conducted in Spanish and 7 in English based on primary language of participants. Participants completed an informed consent process and received a $25 gift card, and a meal was provided during each focus group session. Facilitators (MJ, NB) used a focus group question guide to conduct each session. Spanish-speaking focus groups utilized a question guide translated into Spanish by a certified interpreter and had a bilingual facilitator (NB). All focus group sessions were audio recorded, then transcribed (and translated into English when needed) by a third party. Transcriptions were imported into NVivo qualitative analysis software (Version 10, released in 2014, QSR International Pty Ltd, Melbourne, Victoria, Australia).

Three members of the research team (ESB, SEH, AKE) conducted qualitative analysis. Analysis began with *a priori* coding of each transcript based on high-level categories developed from the focus group question guide. Then, the transcripts were aggregated and stratified by ZIP code, diabetes control status, and language preference. The coded data sets were extracted from NVivo for the analysis team to explore independently for emergent themes within each *a priori* category. For the second phase of analysis, the coding team utilized Microsoft Excel (Office 365) to create a matrix coding grid for a frequency analysis to determine which themes appeared in each ZIP code data set. After each team member independently coded each data set, they met for comparison coding sessions. When coding decisions were not unanimous, the analysis team reached consensus through discussion.

Results

We conducted 12 focus groups including 54 participants across 5 ZIP codes, which were ultimately coalesced into 3 geographic areas. Demographic information for the priority areas and bright spots can be found in a previously published report.[10] The *a priori* categories based on the focus group guides included Facilitators, Barriers, Strategies, and Impact of Diabetes. Recurrent themes emerged from the data sets: Interactions with Medical Professionals, Medications, Lifestyle Management, Family Motivators and Support, Self-Efficacy, and Social Needs and Community Resources. Abbreviations after the exemplar quotes contained in this section refer to the focus group participant type, as noted in Figure 1 (PC = priority area controlled T2DM; PU = priority area uncontrolled T2DM; BS = Bright Spot).

Interactions With Medical Professionals

Participants discussed interactions with the medical system as both barriers and facilitators to managing their T2DM.

Participants in the priority areas discussed the impact of multiple appointments and difficulty with transportation: "*There's the neurologist, there's a cardiologist—I got the incontinence, OK?—So I'm seeing a lot of doctors. In fact, I'm busier seeing doctors now than I was when I was working*" (PC). Participants from the bright-spot areas specifically reported that they did not have difficulty with transportation.

Participants spoke about how physicians and other health care professionals helped them better understand their illness, including diabetes symptoms, interpretation of lab values, and self-management. Many participants cited diabetes-specific services (such as nutritionists, cooking classes, educators, and support groups) they had found helpful. "*What happens with the body part. . .or how my sugar affects these body parts. So that really kinda opened my eyes because I didn't know that having diabetes affected so much in your body*" (PU). Some remembered moments of emotional support they had received, "*[My doctor], like, pushed me to be, like, the best person I could be*" (PU). Some participants also recalled frustrating interactions, "*My doctor always made it look like the—it was my fault for not listening*" (PC).

Medications

Participants from the priority areas discussed concerns about cost and gaps in insurance coverage for diabetes medications, "*All my medications that I'm on, including my insulin, is almost $5,000 per month. So how can I afford 5 grand? No way. I only make 8*" (PU) and "*My needles alone, I still pay out of pocket almost 50 bucks*" (PU). Some participants from the bright-spot areas agreed, noting the high cost of a glucometer and test strips, although they did not mention difficulties with affording medications.

Participants from the priority neighborhoods frequently discussed medication side effects, including hypoglycemia ("*And I kept feeling worse, dizzier and I sweated a lot. . . When I checked my sugar, it was 59*" [PC]), diarrhea, weight gain ("*My biggest problem is I didn't want to take my insulin because I didn't want to gain the weight*" [PU]), and fear of needles ("*That was the hardest, you know, 'cause I don't like needles*" [PU]). Priority neighborhood participants also brought up how their careers interfered with taking medication, "*like doing a double shift*" (PU) or "*When I worked at the jail . . . I'm not keeping my insulin out in the car with the heat, I wanna take it in my locker, but then I have to watch what sharps I'm bringing in*" (PU).

Lifestyle Management

Participants discussed nutrition, physical activity, and knowledge in the context of both facilitators and barriers to diabetes management.

Participants in all areas said they struggled with the cost of healthy foods. However, in priority areas, the high cost was considered prohibitive—"*We got that gift card. That's gonna go for [groceries], but if it wasn't for that, I'd be eating rice for the rest of the month till I get my next Social Security check*" (PC)—while in bright spots it was challenging but manageable, "*Because now you're getting the whole wheat bread, which is a lot more expensive than the white bread*" (BS).

Participants also struggled with competing dietary restrictions, "*They're both bad for you. . .it's like, now, which one do I buy? The one without the carbohydrate or the one without the salt?*" (PC). Participants across areas noted food preferences, habits, and cultural impact on food choices: "*That's what we did back in the day. Every day after dinner, it's you have a dessert*" (PU). Only participants in the priority areas identified a deficit of knowledge about nutrition: "*I wasn't taught that by my mother because she was never taught it. And how far does it go back, you know? And what kind of foods we should be eating and shouldn't be eating, you know?*" (PC).

Physical activity came up frequently as a means to improve diabetes control, but not all participants were able to access safe places to exercise, as exemplified by comparing "*We belong to SilverSneakers at the Y*" (PU) with "*So I mean there's a Planet Fitness right up the street, but I don't have the, the 20 bucks to cover for it*" (PC). Other limitations that interfered with exercise also were discussed, "*My leg is so bad they won't let me walk*" (PC).

Family Motivations and Support

Facilitators for diabetes control included motivation to stay healthy to be there for family members, "*I have 6 grandchildren and 1 great-grandchild, and I wanna be here to see what's going on with those guys*" (BS). In every focus group session with individuals who T2DM was well controlled, participants discussed wanting to avoid poor health outcomes they had witnessed in others with diabetes, "*I want to take care of myself. And after watching my brother lose toes and then his feet and then his legs . . . if I don't take care of me, nobody else is going to, you know?*" (PC).

Family members also helped participants with diabetes control in other ways, "*[My husband] taught me how to read labels . . . He goes, 'You know you don't need that. Put it back.' . . . So he kinda keeps me . . . in line*" (PU) and "*My son calls me every night, 'Ma, you took your pills*?'" (PC).

In contrast, there were also examples of how family and friends hindered the participants' self-management efforts, "*Birthdays are the worst, and weddings. You know, you tell people, 'No, thank you.' . . . And they're like, 'Oh, well it won't hurt to have one little piece.' No, you don't get it, that one little piece might hurt.*" (BS).

Self-Efficacy

Many participants talked about self-reliance and the ways they independently sought out knowledge for diabetes control, "*I got books . . . from the hospital*" (PC); "*I went to the University of Google*," (BS); and "*I'm always at it, I'm always finding out new things*" (PC). When asked about who helps them with managing their diabetes, the answers often reflected self-efficacy: "*Myself*" (PC) and "*Diet, medicine, and willpower—willpower more than anything*" (PC). Participants discussed motivations, such as, "*I want to stay active and healthy as long as I can*" (BS). They also talked about the things they still wanted to do, "*I don't want diabetes to be the reason my life ends . . . I gotta die on a roller coaster and die happy*" (BS).

Social Needs and Community Resources

Several participants living in priority areas discussed socioeconomic challenges, including eviction and food insecurity. They named community resources they relied upon, such as mobile medical clinics—"*Like, twice a year, they bring, like, a bus and they check you for, for diabetes, they check your blood pressure*" (PC)—and food banks. However, participants noted that food options were often limited, "*Now it's mostly just bread. They used to give meat*" (PU). Another contextual challenge was the lack of security in priority-area neighborhoods, which prevented participants in those areas from utilizing delivery services offered by local pharmacies, "*I just don't trust packages coming to my house in my neighborhood*" (PC). None of the bright-spot participants brought forth these types of concerns.

Thematic Differences Between Groups

Evaluation of thematic differences between groups revealed that participants who live in priority neighborhoods struggled more than bright spot participants with transportation to multiple medical appointments, the cost of medications, medication side effects, job circumstances interfering with taking medication, the cost of healthy foods, nutritional knowledge, and other socioeconomic challenges (Figure 2). Participants with controlled diabetes frequently discussed the motivation of wanting to avoid poor health outcomes that they had witnessed in others, which was rarely discussed by participants with uncontrolled diabetes.

Facilitator Observations

Focus group facilitators made observations that could not otherwise be quantified, "*It seemed eye opening for some, and they realized they were not alone living with diabetes, and that there are others out there struggling with similar circumstances*" (NB). In addition, facilitators observed that some participants appeared excited to have the opportunity to share their experiences in ways that might help other focus group participants, "*But for the medicines, I suggest going to either a financial [inaudible] or ask your doctor for the link to go here or contact the manufacturer themselves and see if the manufacturer has any programs*" (PC).

Discussion

Many themes were similar to previous studies including: stress,[11] co-morbidities,[11] financial resources,[11] work environment,[11] transportation,[11] and interaction with medical professionals,[11] motivation,[11,12] knowledge,[11,12] family support,[13] and dietary preferences.[14] Unlike previous studies, participants discussed the cost and timing of medication, but did not express a general desire to avoid medication[14] or a barrier of medication regimen complexity.[12] Prior studies of South Asian and Arabic populations identified a strong barrier in language discrepancy between patients and health care clinicians.[14,15] This was not a barrier identified by the Spanish-speaking focus groups in the present study. Mobile apps and other technology are currently being evaluated as tools to improve diabetes self-management and outcomes.[16] Other than general internet searches for self-education, participants in this study did not discuss technology in the conversation of knowledge or diabetes-specific services as either a barrier or facilitator to their diabetes management.

Strengths of this study include use of fRAP to combine EMR data, GIS mapping, and qualitative data collection, as well as the inclusion of Spanish-speaking participants. A significant limitation of this study is that enrollment for focus groups was lower than anticipated (N = 54). This limited the ability to identify differences between groups across multiple variables (ie, ethnicity, language, and insulin use).

The findings of this study will be useful for clinicians caring for patients with diabetes. Importantly, clinicians cannot assume health literacy, especially with respect to diabetes and nutritional interventions. Many patients need help understanding diabetes as a chronic progressive disease and

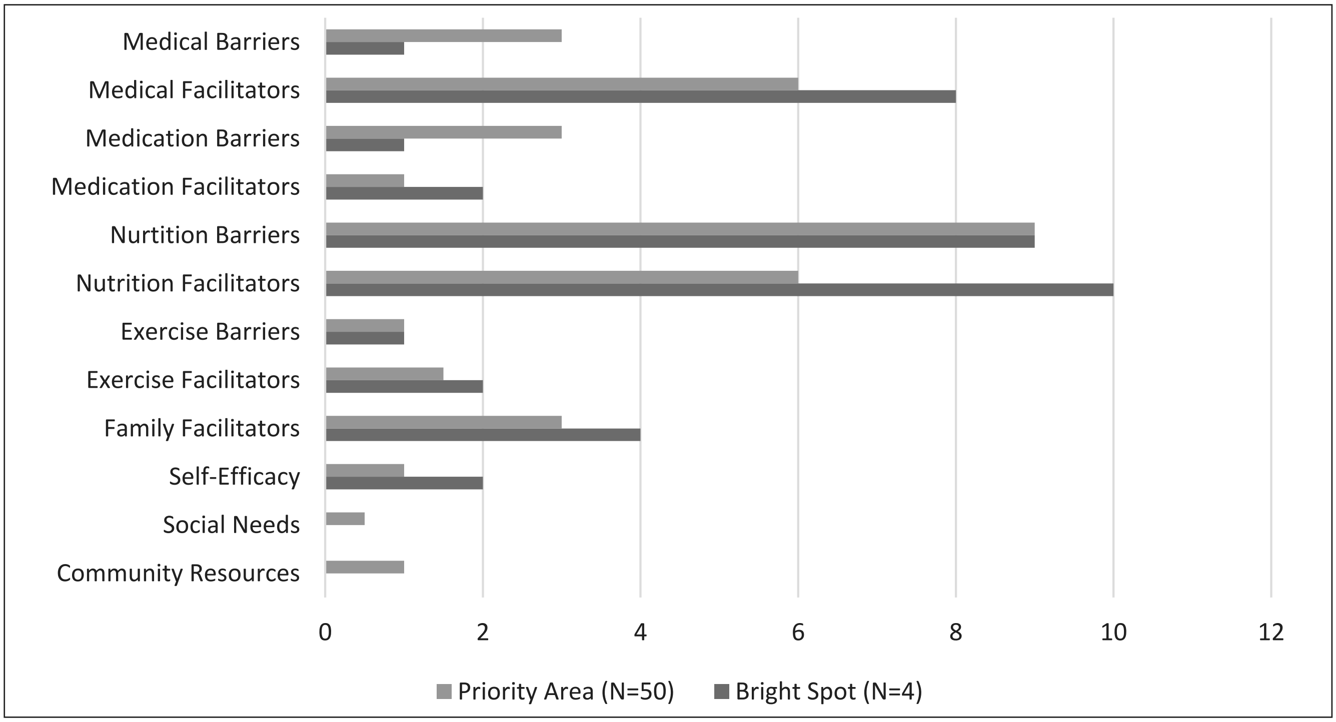

Figure 2. Relative frequencies of responses by geographic location type (number of unique responses divided by number of group members).

its impact on the body. Clinicians should consider referring patients to diabetes-specific services such as nutritionists, educators, cooking classes, and support groups. In some cases, primary care offices also can accept mail-ordered medications on behalf of patients so they may make use of this service.

Participants expressed comfort in discussing challenges with diabetes management with their clinicians, though they may not offer this information without prompting. It is appropriate for clinicians to ask questions about how diabetes fits into the context of patients' lives, which may include access to transportation, access to healthy foods, and neighborhood security, as well as opportunities to connect patients with available community resources. Clinicians also may need to ask specific questions about ability to afford medications, side effects experienced, and timing of dosing related to work schedules to collaboratively develop a realistic medication treatment plan. Primary care clinicians may be uniquely poised to help relieve the burden of frequent appointments by providing comprehensive care and care coordination for patients with multiple conditions.

Health care professionals including clinicians as well as diabetes educators, nutritionists, and community health workers can connect care plans to patient values and foster self-efficacy. Participants' statements often suggested fear, despair, and frustration. They also revealed the importance of family connections and self-reliance. By inviting patients to voice their own fears and frustrations, as well as their motivations for improving health status, health care workers may be able to help patients recognize the relevance of clinical recommendations to their own values.

Health care professionals are also poised to advocate on behalf of patients with diabetes. This may include partnering with government or non-profit agencies to ensure healthy options in food assistance programs and access to safe places to exercise.

Next steps for the study team include dissemination of these important take-aways to the primary care practices in this health network with the highest number of patient participants from both priority and bright spot areas. Practice-level interventions targeted for geographic practice specific differences will be developed in collaboration with clinicians who serve those areas. Future research may include combining GIS data with qualitatively measured neighborhood factors such as safety, access to healthy foods, and social support,[17] and community-based participatory research studies to improve diabetes management resources and disease outcomes.

In summary, the findings of this study produced the following key recommendations for health care workers to use neighborhood context to improve the care of patients with T2DM by: (1) addressing health literacy by asking what patients know, educating them about chronic disease, and connecting them with diabetes-specific services; (2) asking how diabetes fits into the context of their lives, including specific questions about neighborhood, transportation, employment, and medications; and (3) eliciting patient stressors, emotions, and motivations to connect care plans to patient values; (4) advocate on behalf of patients to improve the access to healthy lifestyle options.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by a Dorothy Rider Pool Health Care Trust Research and Development grant.

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