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Diabetes self-management in a low-income population: impacts of social support and relationships with the health care system

Bonnie M Vest¹, Linda S Kahn^{1,2}, Andrew Danzo¹, Laurene Tumiel-Berhalter¹, Roseanne C Schuster³, Renée Karl⁴, Robert Taylor⁵, Kathryn Glaser^{2,6}, Alexandra Danakas⁷, and Chester H Fox¹

¹Primary Care Research Institute, Department of Family Medicine, State University of New York at Buffalo, Buffalo, NY, USA

²Department of Anthropology, State University of New York at Buffalo, Buffalo, NY, USA

³Division of Nutritional Sciences, Cornell University, Ithaca, NY, USA

⁴Colorado Community Health Network, Denver, CO, USA

⁵School of Medicine and Biomedical Sciences, State University of New York at Buffalo, Buffalo, NY, USA

⁶Roswell Park Cancer Institute, Buffalo, NY, USA

⁷AuroraCare of Western New York, East Aurora, NY, USA

Abstract

Objectives—This article reports on results of a qualitative study of social supports and institutional resources utilized by individuals living with diabetes in a high-poverty urban setting. The goal was to examine how access to social capital among low-income populations facilitates and impedes their self-efficacy in diabetes self-management.

Methods—Semi-structured interviews were conducted with 34 patients with diabetes from a safety net primary care practice in Buffalo, New York.

Results—Facilitators and barriers to successful self-management were identified in three broad areas: (1) the influence of social support networks; (2) the nature of the doctor-patient relationship; and (3) the nature of patient-health care system relationship. Patients' unmet needs were also highlighted across these three areas.

Discussion—Participants identified barriers to effective diabetes self-management directly related to their low-income status, such as inadequate insurance, and mistrust of the medical system. It may be necessary for patients to activate social capital from multiple social spheres to achieve the most effective diabetes management.

Keywords

Diabetes; self-management; social capital; qualitative; low-income populations

Racial and ethnic minority groups in the United States, especially those living in poverty, bear a greater burden from the growing prevalence of diabetes, making diabetes a key focus

for health disparities research.^{1–3} According to a 2004–2006 national survey, the age-adjusted prevalence of diabetes was 11.8% among non-Hispanic blacks and 10.4% among Latinos/Hispanic Americans compared to 6.6% for non-Hispanic whites.⁴

Diabetes is a complex chronic condition for which the burden of daily care falls upon the patient.^{5,6} Patient behaviors, including daily blood glucose monitoring, record keeping, medication, and lifestyle modifications related to diet and exercise, are critical to successful diabetes management. This considerable patient burden weighs heavily on disadvantaged populations that often experience difficulty with self-management due to limited access to health care resources, competing survival demands and other social, economic and cultural barriers related to poverty status.^{7–9} Refugees and recent immigrants may face even greater challenges adhering to recommended diabetes care due to a range of factors, including a lack of preventive health care in their home country, often resulting in late diagnosis and treatment.^{10,11} Cultural differences in beliefs about disease origin and treatment may also complicate diabetes care among refugee populations.¹²

Social support networks may mediate the impacts of economic and environmental disadvantages by promoting increased access to social capital, with a resulting increase in self-efficacy behaviors.¹¹ Social support has been examined in numerous forms, as it relates to the facilitation and hindrance of patients' self-management of chronic diseases, such as diabetes.^{13–18} Studies have demonstrated that families are a primary source of social support and often play a key role in the instrumental day to day tasks of diabetes care.^{14,19,20}

However, social support is a complex concept which corresponds to the multiple social networks (familial, occupational, community-based, institutional, etc.) surrounding an individual patient that exert positive and negative influences on a patient's ability to self-manage diabetes.^{14,15} Social support translates further into an individual's ability to activate their networks to leverage social capital.¹¹ Social capital derives from existing or potential formal or informal relationships and social networks pertaining to an individual or group²¹ and includes benefits and challenges individuals face as a result of their position within the structure of social relations and resulting available resources.^{11,21} The collective value resulting from cooperation among individuals within social networks can act both positively and negatively to influence self-efficacy, or confidence in one's ability to complete a task.¹¹ An individual's ability to leverage their positive social capital by asking for and receiving assistance from key individuals in various social positions (i.e. a family member who works in health-care, or an acquaintance who owns a vehicle) and thereby minimize barriers related to poverty status directly affects their ability to effectively manage a chronic illness.

Patients' ability to activate social capital to leverage institutional resources can play a key role in their chronic disease management. One of the most frequently highlighted aspects is the doctor–patient relationship because the quality of this relationship can have a direct impact on patient adherence to diabetes care.^{3,18–20,22–24} Other aspects of the health care system have direct impact on diabetes self-care as well, particularly for underserved populations for whom access to care and the cost of care may present significant obstacles to achieving optimal self-management.^{19,22} It is in regard to these institutional barriers that self-efficacy, derived from an ability to successfully leverage social capital resources, may be especially important.

This article draws from a larger ethno-graphic project which explored the social and cultural contexts underlying diabetes health disparities on the West Side of Buffalo.²⁵ The project had two main objectives: (1) to explore patients' explanatory models for their diabetes, elucidating their understanding of the disease and responses to living with diabetes, and (2)

to explore the forms and potential impacts of social supports and institutional resources utilized by individuals living with diabetes in a high-poverty urban setting. This article explores the role of social supports (e.g. family, neighbors) and institutional resources (e.g. physicians, health care system) as facilitators of/or barriers to diabetes self-management in this community.

Methods

This was a pilot study designed to identify themes related to social support and institutional resources in diabetes self-management for further exploration in future qualitative and quantitative studies.

The setting

Study participants were recruited from a primary care practice on the West Side of Buffalo, which draws patients from an ethnically diverse, low-income neighborhood. The West Side is among the poorest sections of the city, containing almost half of the city's 10 most impoverished census tracts.^{25,26} The West Side is home to a population that is 16.5% Black or African-American, and 27.7% Hispanic or Latino²⁷ as well as immigrants speaking over 30 languages from 70 nations. The largest proportions of recent arrivals hail from Burma and Iraq. Other prominent countries of origin include Somalia, Sudan, Burundi, Congo, Ivory Coast and Cuba.²⁸

The primary care practice from which participants were recruited accommodates over 30,000 patient visits per year and is the largest provider of healthcare to the area's refugee population.²⁵ Approximately 70% of these patients have government health insurance (Medicaid) and 12% are uninsured. Some 46% of the patients spoke English as their primary language; other prominent languages include Burmese, Somali, Arabic, Spanish and Swahili. In 2010, there were approximately 500 patients with diabetes in the practice registry. The practice has a full-time certified diabetes educator (CDE) on staff.

The participants

Qualitative interviews were conducted with 34 patients who had a diagnosis of diabetes (ICD-9 250.xx) in their medical record for at least 1 year. The practice generated a registry of patients with diabetes who were coming in for regular appointments, and a member of the research team recruited patients when they arrived for their appointment.

A table detailing participant demographics has been previously published,²⁵ but it is important to note that the 34 participants represented a diverse sample, including refugees (14/34) from Somalia, Sudan, Burma and Cuba, African-Americans, Caucasians, Native Americans and Puerto Rican immigrants. Eighty-three percent (28/34) of study participants were ethnic minorities and were predominantly female (77% or 26/34). The mean age of participants was 58. Some 65% of participants were married or living with a partner, and 82% (28/34) reported living with a partner, child(ren), or other relative in various combinations. Nineteen out of 34 (60%) participants had less than a high school education. Only 5 participants were employed full-time, 3 were employed part-time and the majority (20/34) were either retired or disabled. For those who were employed, employment was predominantly in transportation, cleaning, or other labor-related jobs. Of 25 participants responding to a question on health insurance, 13 (52%) indicated they were on Medicaid, and 8 (32%) were covered under Medicare. Since Medicaid is only provided to people under a certain income threshold, we used this information as a proxy for low-income status. Participants' mean HbA1c was 8.4% (SD 2).

Data collection

Data were collected via semi-structured interviews consisting of open-ended questions about participants' experiences with diabetes. Interview questions about social support and institutional resources are listed in Table 1. All of the interviews were held at a time and location of the patient's choosing. The majority (21/34) were held in the patient's home and the remainder (13/34) were undertaken in a private room at the practice. Interviews were conducted by three members of the research team, an anthropologist (LK), a medical student (RT), and an undergraduate pre-medical student (AD) using a standard set of questions, which were slightly modified in some cases to assist with translation for non-English speaking participants.²⁵ Due to funding limitations, volunteer translators from the practice were used for non-English speaking refugees. The practice maintained a list of reliable volunteer translators, and shared the list with the research team. Each volunteer translator signed an IRB-approved statement attesting to their trustworthiness in undertaking the translation. Participants were also asked to respond to a short demographic question-naire and for permission for the research team to review their medical charts for diabetes-related measures. All interviews were audio-taped. Interviews were de-identified and all portions of the conversations that took place in English were transcribed verbatim. Human Subjects approval for this study was granted by the University at Buffalo Health Sciences Institutional Review Board and all participants provided informed consent.

Data analysis

Qualitative analysis of the interview transcripts was conducted using a content-driven immersion-crystallization approach where researchers continuously and intensively review the data for emerging themes.²⁹ Themes were identified as relevant to the research questions based on the depth of the individual responses, reflecting potentially significant facets of individual experiences. While researchers looked for themes that were common across many accounts, themes that were reported by only a few participants were also retained and reported as potentially significant facets of the patient experience, which may be further assessed in future qualitative and quantitative studies.

Data analysis was undertaken in three phases in a collaborative manner to ensure consistency of identified themes across the members of the research team.²⁵ Data were initially analyzed in 2010 by three members of the research team (LK, RT, AD). These preliminary analyses were then vetted in a more comprehensive analysis with a larger team including three anthropologists (LK, KG, RK), a community health researcher (RCS) and an epidemiologist (LTB), during which time the investigators met regularly to discuss the transcripts, resolve discrepancies and develop a comprehensive codebook of identified themes. Interviews were then coded by hand, and themes and corresponding quotations were organized into tables. A final review of the full transcripts was completed separately by another anthropologist (BV) to ensure the consistency of the themes and identify salient quotes for each identified theme. A primary care physician from another practice (CHF) was consulted throughout the project to verify study findings and their clinical relevance.

Results

Facilitators and barriers to self-efficacy in diabetes self-management were identified across three main areas (Table 2): (1) the influence of social support networks, including family, friends, neighbors, co-workers and other acquaintances who work in healthcare; (2) the nature of the doctor–patient relationship; and (3) the patient–health care system relationship. A sub-theme, patients' unmet needs, was also identified as a component of both the doctor–patient and patient–health care system relationship. Many of the facilitators and barriers cut

across the diverse ethnic groups in this study, indicating factors that may be universally important to low-income populations, regardless of race or ethnicity.

The influence of social support networks

Patients' various social support networks interacted in many ways to either facilitate or hinder their diabetes self-management. Family, friends, neighbors, co-workers and acquaintances with medical knowledge formed a network around each patient. Family emerged in many interviews (21/34) as playing the most salient role in both day-to-day instrumental tasks and also in providing emotional support and motivation. Family members were reported to facilitate diabetes self-management in three main ways: (a) by assisting in the day-to-day care, (b) by providing moral/emotional support, and (c) by serving as motivators to 'set the example.'

Respondents stated that family members, particularly spouses and children, were integral in their daily self-management of their diabetes (16 of the 21 who reported family as a main source of support), by reminding them to take their medicine, assisting with blood sugar monitoring and recording, preparing meals, and providing transportation to medical appointments and grocery stores. Patients expressed a sense that they would not be able to take care of themselves properly without these reminders and daily assistance. For example, one woman said that if her fiancé did not check her sugar, 'it won't get checked' [P20, Caucasian female]. Two others described themselves as forgetful with regard to their diabetes self-care, and relying on spouses and/or children to 'act as a memory.' [P16, Caucasian female]. In addition to these more instrumental tasks, family members also provided emotional and moral support for the participants, encouraging them to take care of themselves, exercise and eat well. Finally, concern for the health of family members motivated the patients to better self-manage their own diabetes and promote healthy behaviors within the family. In this way a few patients tried to 'set the example' and took on an advocacy role in the family.

Generally, patients reported positive effects of family support. The only negative aspect cited by participants was a fear of becoming a burden on family and friends, which led to a reluctance to ask for help or denial of the fact that help is needed, which could ultimately lead to a decline in self-efficacy in diabetes management. For example, one participant expressed:

For me being disabled basically, I'm on disability, for me to get to a place like that, I have to look for a driver ... Some people are more than willing to help you ... when you start becoming a burden to them or interfering with their thing ... it's kind of you're hindering, you're putting a fly in my ointment. [P28, *Native American male*]

Participants noted that their other social support networks had a positive effect on their diabetes self-management. Friends and co-workers served as another source of health information and helped remind participants about making healthy choices. Interestingly, some participants also told us that they elicited the advice of people within their social networks who have medical knowledge and experience. Family, friends, and other acquaintances who work in healthcare served as sources of information and support that participants viewed as helpful, though participants did not indicate how or whether they assess the quality and accuracy of this information. Such access may reflect the major role of the health care sector in the local economy.

Taken together, participants' social support networks generally facilitated successful diabetes self-management. While the sense of potentially burdening family and friends

inhibited help-seeking for some, interview results suggest that participants are actively seeking assistance and information from their existing social networks.

The doctor–patient relationship

The interviews elicited a range of responses regarding patient trust in their physicians, but patients who said they trusted their doctors seemed more likely to be satisfied with the care they were receiving for their diabetes. In general this more trusting relationship was expressed by the foreign-born participants. (Out of 10 patients who demonstrated trust in their doctor, 9 were foreign-born.) For example, P2 a Burmese refugee, exhibited a total faith in the ability of her doctor and his staff to help her:

She says that she doesn't know anything about that [taking care of diabetes] and she need help from the doctor or nurse who talk to her, if they can [give] advice, it's going to be okay for her. [P2, *Burmese female, via translator*]

A small group of American-born participants (6) seemed more likely to express some level of dissatisfaction with their doctor and question the doctor's authority. They expressed a desire to be less dependent upon their doctor for the management of their care, though this was not universal. While one patient described her doctor as a 'father type figure' [P20, Caucasian female] and another said they were 'buddies' [P27, Caucasian female] others expressed more ambivalent or even negative relationships. In contrast to the confidence and trust in the quality of medical care expressed by the refugee participants, American-born patients seemed to more readily question their doctors' recommendations. This difference may be a result of cultural differences in the patient–doctor relationship and the social status and authority of doctors in the refugees' home countries versus in the US:

[My doctor] told me "I want you to think about the surgery," but I told him I'm gonna get this weight off me 'cause I don't want anyone to cut on me. I said what do you recommend and he said he wants me to get the surgery, but I- no I'm gonna get this weight off me [P 3, *African American female*].

Sometimes, this distrust led to ambivalence towards medical care, hinting at a breakdown of the doctor–patient relationship with the potential to seriously impede successful diabetes management.

You get that thought in your head, well they're just after the money, they're not concerned about me, they just, they want to get that money and that they're driven by the money aspect and not about me. [P 28, *Native American male*]

However, in spite of potential barriers created by a poor doctor–patient relationship, other relationships also influence patients' perceptions of diabetes care. This included the positive influence of the diabetes educator. An African American male, P8, felt estranged from his doctors, but was still motivated to self-care by a caring educator.

I just now started talking with [educator]. Very nice lady ... She changed my perception, because no one else really seemed concerned. They all seemed like they were doing their job ... [she] makes it her life to wanna help. It seem like it's just because that's what she wants to do, she make it seem like she really cared. [P 8, *African American male*]

Participants expressed that they were happy with the overall quality of the treatment they were receiving, although a perceived lack of time spent in patient encounters and in answering questions was reported as a barrier.

Patient–health care system relationship

The patients' relationships to various aspects of the health care system tended to appear as barriers to their diabetes care, sometimes as a result of lacking health insurance or inadequate insurance coverage:

If she doesn't have the Medicaid, you know, she has to spend a lot of money for the diabetes. [P2, *Burmese female, via translator*]

A few times, I got sent back because my insurance card wasn't right. I'm like, dude I've got diabetes, you're supposed to see me regardless of whatever is going on. Bill me later, you know what I'm saying. You don't turn no one away ... That's why I stopped going. [P8, *African-American male*]

Patients with private insurance complained about costly co-pays and premiums, resulting in less than optimal care or periods without insurance coverage.

I haven't taken my blood sugar at home in ages. The strips cost \$30 on the co-pay. I cannot afford that. My insulin is \$50. I can't afford it. I cannot afford it. I've got insurance ... but I can't afford those strips ... It's an expensive disease. [P26, *African-American female*]

Patients' unmet needs

Regardless of their relationship to the doctors or the health care system, participants expressed many needs that were not currently met. These unmet needs were perceived barriers to self-efficacy in diabetes self-management, and included: (a) patient education, (b) facilitation/instrumental support, and (c) understanding/empathy.

Patient education—In spite of receiving medical care for their diabetes, participants expressed a desire for more knowledge. This seemed to be particularly the case for refugees, who expressed uncertainty and confusion about doctors' guidelines:

The doctor told her nothing about that [eating right], but she knows herself.” [And] “She doesn't know exactly what to do. One thing she has to eat less food ... she said like someone could come and give her education about diabetes, to make diabetes better? Yes, she wants that. [P6, *Burmese female, via translator*]

Facilitation/Instrumental support—Education alone was not perceived as sufficient. Some participants expressed a desire to have a nurse or other health professional available to them at home, outside of their in-office medical care.

They give her help, but she feels that she wants more than they can give her. They don't assign a nurse and stuff. [P1, *Somali female, via translator*]

Another patient, P31, a Caucasian male, suggested that a nurse triage system would be beneficial where the nurses had continuity in the relationship so they would be more familiar with the patient's particular case details.

Understanding/Empathy—Finally, participants expressed a desire for greater understanding and empathy from their medical providers.

Just understanding really, no one seems to really understand nothing you talk about. It's like ... I don't even know how to put that. [P 8, *African American male*]

... looking at somebody's chart for five minutes and ... spending five minutes with you, it doesn't cut it. It doesn't. You can't possibly get a sincere relationship. [P28, *Native American male*]

These results point to the complex, and at times conflicting, nature of doctor–patient and patient–health care system relationships. A patient who feels comfortable with their doctor and trusts the doctor to provide quality care, may nonetheless lack self-efficacy in accessing that care due to financial barriers. These relationships both serve to promote self-efficacious health behaviors in some arenas and limit them in others.

Discussion

Our results suggest that a patient's ability to self-manage diabetes is profoundly influenced by an interweaving of social support structures with the doctor–patient relationship and the interaction with the health care system. Patients expressed many unmet needs in relation to these areas which they saw as impeding their self-management. Diabetes self-management is not a simple issue of deciding to follow clinically prescribed guidelines, but a complex interaction among the individual, their social networks, and their access to resources. Patients' access to social capital that allows them to increase their self-efficacy in diabetes management is intricately tied to their social relationships and their access to resources, including diabetic supplies, healthy foods, and medical knowledge. For example, individuals in our study exhibited a strong desire to draw upon their existing social support networks, particularly their families, to aid them in their diabetes self-management. However, the intricacies of the interpersonal relationships that comprise these social support networks have both positive and negative impacts on diabetes management.

While family can serve as an important source of instrumental day-to-day assistance and provide emotional and moral support, the fear of becoming a burden on the family may limit these positive impacts. It may be necessary to involve multiple social spheres to achieve the most effective diabetes management. This would entail activating social capital derived from broader networks that include family, friends, neighbors, co-workers and acquaintances with medical knowledge. Implicit in participants' statements of unmet needs was a desire for greater coordination between their existing social support networks and their formal medical care, either through integrating formal medical care into the home setting or including family members and social support sources in diabetes education.

Additionally, as Burke et al.¹¹ note, low-income populations confront numerous structural barriers that severely limit self-efficacy, such that providing information and activating social support, may still be insufficient to optimize individual self-management. Echoing findings in other studies,¹⁹ our participants expressed barriers to effective self-diabetes management, such as lack of health insurance coverage, expensive co-payments and mistrust of the medical system, that are directly related to their low-income status. Refugees in our population faced additional barriers related to limited knowledge of the English language, limited education in their home country, and a lack of understanding about the US healthcare system and preventive care.²⁵ These challenges need to be addressed on a much broader level within the US socio-economic system. In the meantime, study results point to a need for a wider lens on diabetes self-management, that takes into account not only individual patient behavior and clinical guidelines, but also the patient's social support networks, relationship with the health care system, community characteristics, and cultural background and beliefs.

Limitations

There were several limitations to the current study. This study enrolled patients at one primary care medical practice on the West Side of Buffalo New York. Future studies that incorporate patients across multiple practice settings will allow for more robust validation of the results presented here. Additionally, the sample, although ethnically diverse, was predominantly female. Each person was interviewed only once, and in many cases volunteer

translators were deployed. While these translators were vetted by the practice, the study team was unable to objectively verify the accuracy of their translations. Future studies might focus on the experience of diabetes among one particular refugee population and use professional translation services to ensure the most accurate understanding of participants' responses. Because of the small sample size within each ethnic group, it was not possible or meaningful to analyze each separately. However, the consistency of identified themes across all groups supports the validity of our findings.

Implications for clinical practice

Health professionals should strive to learn about and draw upon their patients' social support networks to better coordinate patients' medical care. This might include encouraging patients to utilize these networks and incorporating members of these networks into the patients' medical care and diabetes education. Diabetes affects entire families and communities, and therefore some of the patient's self-management education should take place at these levels, rather than at the individual patient level. In addition, the complex intricacies of interpersonal relationships between patients and their social support networks and between patients and their medical care teams, and the context-dependent nature of patients' ability to demonstrate self-efficacious behavior, underline the need for customized patient-centred care, rather than one-size-fits-all recommendations and protocols. The use of a diabetes educator as a liaison between the practice and patients might help address some of these needs.

Primary care providers' understanding of the context of patients' social support is critical to improving their health. Our data suggest that physicians might enhance their understanding of this context by incorporating a few simple questions into their patient visits such as: Who helps you to take care of your diabetes? Where do you go for information about diabetes? Is there anything that makes it harder for you to follow your diet, exercise or take your medicine? How would you like to receive information about diabetes? Collecting this information as part of routine care and documenting it in the patient history, can allow health care providers to more fully understand how diabetes plays out in the context of their patients' daily lives and make more sensitive and tailored recommendations that better fit patient's individual needs.

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Table 1**Interview questions around social support and institutional resources**

Questions around social support:

- What would make it easier for you to take care of your diabetes?
 - (a) Probes: knowledge or information; skills and/or equipment; family help/support
 - (b) Probe: based on their response to this question, elicit information on challenges
- Are you comfortable asking for help or support?
 - a) Probe: if no, why not?
 - b) If yes, whom do you ask?
- *[Ask only if respondent lives with a family member]* Because diabetes may necessitate changes in diet, how does that affect the rest of your family? Do your family members assist you?
 - a) Probe: what do they do?

Questions around institutional resources:

- Is there one particular clinic, health center, doctor's office or hospital emergency room that you usually go to if you are sick or need advice about your health?
 - a) What kind of place is it that you go?
 - What would make it easier to get to your doctor's office?
 - Do you feel comfortable talking to your doctor about your diabetes?
 - *[Ask immigrants]* What was your medical care like in your home country? Did you go to the doctors as often as you go here?
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Table 2**Summary of identified themes**

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- Influence of social support networks
 - Facilitate diabetes self-management by:
 - Assisting in instrumental day-to-day care
 - Providing moral/emotional support
 - Children as motivators to 'set the example'
 - Providing access to informal medical knowledge
 - Impede diabetes self-management by:
 - Fear of becoming a burden on family
 - Fear of losing independence
 - Nature of the doctor–patient relationship
 - Trusting relationships facilitate better management
 - Distrust can impede self-management
 - Patient–Health care system relationship
 - Frequently a barrier due to problems with lacking or inadequate insurance
 - Unmet needs
 - Educational materials
 - Facilitation/instrumental support
 - Understanding/empathy
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