

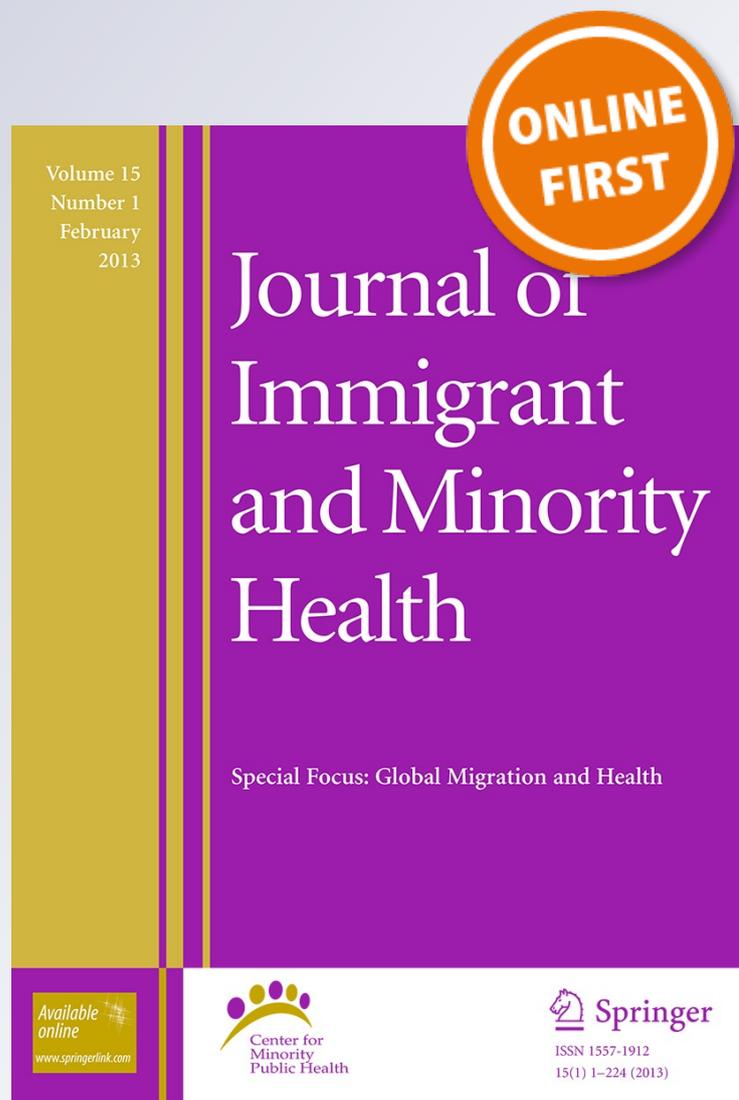
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**Govinda Dahal, Adnan Qayyum,
Mariella Ferreyra, Hussein Kassim &
Kevin Pottie**

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Immigrant Community Leaders Identify Four Dimensions of Trust for Culturally Appropriate Diabetes Education and Care

Govinda Dahal · Adnan Qayyum · Mariella Ferreyra · Hussein Kassim · Kevin Pottie

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Abstract This paper explores immigrant community leaders' perspectives on culturally appropriate diabetes education and care. We conducted exploratory workshops followed by focus groups with Punjabi, Nepali, Somali, and Latin American immigrant communities in Ottawa, Ontario. We used the constant comparative method of grounded theory to explore issues of trust and its impact on access and effectiveness of care. Detailed inquiry revealed the cross cutting theme of trust at the “entry” level and in relation to “accuracy” of diabetes information, as well as the influence of trust on personal “privacy” and on the “uptake” of recommendations. These four dimensions of trust stood out among immigrant community leaders: entry level, accuracy level, privacy level, and intervention level and were considered important attributes of culturally appropriate diabetes education and care. These dimensions

of trust may promote trust at the patient-practitioner level and also may help build trust in the health care system.

Keywords Immigrants and refugees · Diabetes · Trust · Migrant health · Ethnicity · Culturally appropriate diabetes education and care

Introduction

Immigrants of South Asian, Latin American, and African ethnicity have two-to-four times greater risk for developing type 2 diabetes compared to their native-born Canadian counterparts [7] and often experience poorer health outcomes [18]. Contributory factors cited for these disparities include genetic susceptibility [5]; higher rates of sedentary lifestyle [9]; changing food habits from their country of origin [23]; low health literacy [11]; and relative deprivation and low socio-economic status [11, 14]. Disparities in access to diabetes health services are also likely to contribute to poorer health outcomes.

The community effectiveness of interventions can be measured using four factors: access, diagnostics, provider compliance, and patient adherence [31]. “Effective access” depends on availability, accessibility, affordability, acceptability, and accommodation, which improves service utilization and thereby perceived/evaluated health status and/or consumer satisfaction, which in turn, increases “efficient access” [2]. Access can be a major barrier impacting the efficacy of a particular intervention [31] for vulnerable populations, and thus trust between a vulnerable patient and practitioner is an important consideration. Trust can be considered a global attribute of treatment relationships that encompasses: satisfaction, communication, competency and privacy. It also relates to the behaviours

G. Dahal
Institute of Population Health, University of Ottawa, 1 Stewart Street, Room 231, Ottawa, ON K1N 6N5, Canada
e-mail: gdahal@uottawa.ca

A. Qayyum
University of Ottawa, Ottawa, Canada

M. Ferreyra
Department of Family Medicine, University of Ottawa, Ottawa, Canada

H. Kassim
Carleton University, Ottawa, Canada

K. Pottie (✉)
Departments of Family Medicine and Epidemiology and Community Medicine, Centre for Global Health at the Institute of Population Health, University of Ottawa, 1 Stewart Street, Room 231, Ottawa, ON K1N 6N5, Canada
e-mail: kpottie@uottawa.ca

and attributes of the practitioner; such as, empathy, understanding a patients' individual experience and partnership [19]. While the presence of trust may indeed lead to improved physician-patient relationships, it does require a certain level of vulnerability on behalf of the patient and it frequently involves an assumption that the provider will act in accordance to the patient's best interest [10]. Although studies around this issue are rather limited, it appears that patients' levels of trust are shaped by experiences between them and their health providers [10, 13, 26, 34].

In this paper, we aim to better understand the care preferences and dimensions of "trust" of immigrant community leaders from Somali, Latin American, Punjabi and Nepali communities in regard to diabetes education and care.

Methods

Context

This study was the qualitative portion of a multifaceted Ontario Ministry of Health and Long Term Care-funded project aimed at improving access to community diabetes education and care for immigrants from communities at high risk for type 2 diabetes. One community champion from each of the Latin American, Punjabi, Somali, and Nepali communities—were selected as co-researchers based on submitted community proposals, interviews and references. Research ethics approval was obtained from the Ottawa Hospital Research Ethics Board.

Community Consultation Workshops

In collaboration with the community champions, we conducted four exploratory community consultation workshops between April and May 2011; one with each community. A total of 131 community members participated. The aim of these workshops was to understand the perceptions of community members regarding their concerns for effective diabetes education and care in Ottawa.

Recruitment and Sampling for Focus Groups

In collaboration with the community champions, a total of 34 community leaders (8–12 per community) were identified, based on their interest in working with their respective community members related to awareness raising for diabetes education and care. The venues for focus group interviews were community centres (Latin American and Somali groups), conference hall in the temple (for Punjabi group), and community house (for Nepalese group). The sex, age ranges and education demographics can be found in Table 1 below.

Data Collection

We conducted an interview guide (Table 2) for in-depth focus group discussions based on the collective perspectives from the community consultation workshops. We sought feedback on this interview guide from the project steering committee (25 members from academic and immigrant communities, public health, and diabetes service organizations). On the basis of the researchers' previous experience working with community leaders [17], we estimated that focus groups with 30–35 community leaders would achieve data saturation. We collected data from a total of 34 community leaders of four different focus groups of high risk communities (Table 1).

Data Analysis

The data from the interviews were transcribed verbatim from the audiotapes, and where necessary, translated. Transcripts were cross-checked for accuracy using field notes taken during the focus group discussions. Three research team members with varying professional backgrounds (Family Medicine (KP), Population Health (GD), and Education (AQ)) attended the focus groups and reviewed and re-reviewed the transcripts independently, using the constant comparative analysis and integration approach of grounded theory [1, 8] in the analysis of the interviews. The iterative analysis included identifying codes, quotes and writing notes and ongoing analytic reflections and discussions enabled the researchers to move

Table 1 Demographic characterises of focus group participants

Community	Male	Female	Education level	Age ranges (years)
Nepali	5	3	2 Undergraduate; 4 Masters of Arts; 2 Ph.Ds	27–50
Punjabi	6	3	6 Undergraduate; 3 Master of Arts	22–79
Latin American	3	6	2 Undergraduate; 7 Masters of Arts	18–65
Somali	5	3	2 Undergraduate; 6 Masters of Arts	35–56

deeper into practical and theoretical issues of trust and its impact on access and effectiveness of care. Thematic approach was also used to analyse the data. Preliminary themes related to the research questions were noted, discussed and debated to synthesize the results.

Validation and Reliability

An external reviewer (ER) reviewed a random sample of transcripts from each community interview to ensure the internal consistency of themes and to ascertain inter-rater coding reliability [22]. ER identified minor inconsistencies in the coding which were later incorporated. The credibility (validation) of the results was assured through triangulation of results emerging from two different methods-grounded theory and content analysis approaches—which showed consistent results. We conducted member checking, presenting the research findings to community champions (leader of leaders) to confirm the credibility of the interpretation of the results. We also presented the near final results in a workshop of 131 community leaders and we later incorporated their feedback into the final interpretation. Finally, to mitigate the risk of researcher bias, three researchers from different backgrounds iteratively discussed and debated the codes and emerging theory.

Results

The community leaders identified a number of dimensions and barriers to trust in relation to diabetes care. Detailed inquiry on “preferred” provider characteristics (see Table 2) revealed the cross-cutting themes of trust at the entry level when immigrant community members first access service providers regarding issues around diabetes education and care. Trust also emerged as a key theme in relation to both accuracy of diabetes information, and

information to system navigation, and at the privacy level when an individual is diagnosed with diabetes. Finally, trust was also an issue at the intervention or change level when individuals must take action to follow a recommendation.

Entry Trust

Participants stated that “entry trust”—the initial feeling of acceptance or the patient experience associated with accessing a service—is essential to ensure a foundation for a trusting and productive educational or therapeutic relationship.

What’s so critical is the point of entry: If the person feels comfortable with the point of entry, then they will develop a relationship with you. Then, you can take it from there. (A male respondent from Somali focus group)

They go to clinics where the kids understand more than them [English]. So in the end they say, “This is not for me. Can be for my kids, but this is not for me.” You need them to have the confidence, and they lose confidence (trust) if they have to go through their kids. (A female respondent from Latin American focus group)

When we go to a doctor who doesn’t have knowledge of how we eat; for example, that creates a big barrier. You don’t have confidence. (A male respondent from Somali focus group)

Older generations of Punjabi people don’t trust in allopathic medication. When they go to India, they bring a whole bag of Ayurvedic medications including different oils to rub. (A female respondent Punjabi focus group)

Accuracy Trust

Participants expressed concern that after receiving medical or care navigation information, they were often not

Table 2 Key guiding questions

1. How do you perceive diabetes?
2. What problems is your community facing for accessing diabetes education and care services?
3. If someone from your community with diabetes came to you for help, what would you do?
4. What role can informal community health advocates play to raise awareness about diabetes in their communities?
5. What do informal community health advocates need to know in order to raise awareness about diabetes in their community?
6. Which individual from the following three scenarios do you consider the most useful in assisting informal community health advocates to provide the “best” diabetes education and care support for your community?
 - (a) A person from your community who knows your language and culture well and is trained to educate community people about diabetes prevention and care and has connections to community and Canadian health system, and (s)/he also knows where to go for diabetes education and treatment
 - (b) A person from your community who is a retired health professional and is living with your community but has no connection with the Canadian health system
 - (c) A person who is not from your community and does not know your language and culture but is a health professional working with the current Canadian health systemTM

confident about its accuracy unless they could trust the source or verify the information with trusted sources.

When I hear something, I just Google to see if there is an on-line Doctor. It depends on the generation; older persons compare opinions and verify with the available persons they trust, and younger person looks on line (A female respondent from Latin American focus group)

Role of community leader is knowledge brokering, bridging the system, and breaking it down into bits they can understand. Another role is a trusted information source (role in brokering trust). (A male respondent from Nepali focus group)

It is proven that going to a professional who has no cultural and linguistic background is useless for my family. (A female respondent from Punjabi focus group)

Even if it's the best information, without trust it is not effective (A male respondent from Nepali focus group)

Privacy Trust

Participants felt that upon disclosure of their illness, they become concerned about privacy matters. They did not want to disclose their illness to anyone but a trusted member of their community. Many participants also expressed that they felt more secure sharing their private information with professional health providers rather than general community members.

For some people it can be a question of privacy: it can be more important to discuss with a family doctor than a community member. (A male respondent from Somali community)

(When you are ill) you are looking for reassurance; you are looking for something that brings your anxiety down. There has to be a factor of relation or bond or trust. (A male respondent from Punjabi focus group)
There might be a lack of confidence and trust to share your private information with community leaders or any other members in your community (unless they are trusted). (A male respondent from Nepali focus group)

Intervention Trust

Participants expressed that it is very difficult for them to decide which recommendations or interventions to trust, because evidence from their perspective is changing over time, or between countries; new findings appear to continuously correct the flaws of old scientific evidence.

Science is still in competition with other ways of knowing. You question and you can go back to your own ways of knowing. There is a great deal of double-checking going on in the community. (A female respondent from Somali focus group)

The process of diabetes is such a long process of learning. That's the major issue. (A female respondent from Nepali focus group)

You have to establish relationships and be very consistent and follow up. If you are under illusion you will have impact in your first or second contact, it's very unlikely it will bring any shift in attitude. Need something long-term, cannot piecemeal it. (A female respondent from Somali focus group)

There were three primary options for these community members with regard to obtaining education, linking, and navigating appropriate diabetes services: One was a trusted community member, who can act as a cultural and language liaison with physicians. Option two was a retired health professional within their ethnic community. The third option was a locally licensed physician. Focus group participants stressed that using the knowledge and skills of each of these options, based on the person's needs, was important.

Discussion

Despite the availability of community diabetes education and care services and an acknowledged need within many communities, uptake of local services by immigrant communities at high risk for diabetes remains limited [12, 21, 24]. Language and cultural barriers are well documented in the literature [23], but our analysis clearly shows more attention needs to be placed on key dimensions of trust that are most important to immigrants.

Immigrants often describe culturally different understandings of health, and the provision of health care, as barriers to receiving care [33]. They also face access-to-care barriers due to unfamiliarity of the health care system and delivery process, perceiving the delivery of care as impersonal, rushed, and incomprehensive [3]. These experiences limit disclosure and trust. Engaging immigrant community leaders [30] and developing culturally appropriate diabetes programs have surfaced as effective supplementary steps to address disparities in relations to diabetes outcomes [15]. These unique characteristics likely play a role in influencing immigrant leaders' perceptions of trust.

Entry or access trust refers to the initial contact that an immigrant patient has with a practitioner. Most likely, for an immigrant facing language barriers and a new system this initial interaction is anxiety provoking. When

participants were presented with three scenarios, it was interesting to see that all four groups initially preferred to obtain diabetes-related information from a fellow community member, even if that individual was not a medical professional. Participants expressed their desire to communicate in their native language and refer to their cultural norms, all of which was conducive to a strong, trustworthy relationship. This concept has been the basis for incorporating cultural competency into medical practice as it has been associated with increased patient satisfaction and possibly improved health outcomes [4, 20]. However, given varying degrees of acculturation and differences within the multiple cultural groups, it has become increasingly challenging to adopt the “one-size-fits-all approach” when caring for a particular group. A *person-centred* approach to cultural competency [27], on the other hand, focuses more on the individual and takes into consideration other factors that may have contributed to the person’s understanding of illness and disease [29]. First impressions count, especially for an immigrant patient, and explicit attention to this detail could improve entry trust.

As the focus groups moved forward in their discussion, they all shifted their initial impulse of wanting to obtain information from a fellow community member to wanting to receive educational support from a Canadian licensed health professional, despite not sharing the same cultural background. Although participants agreed that trust would be harder to build with these professionals, they acknowledged the value of being connected to the local health care system and having access to various services. Similar findings emerged from US on Latin American populations [25]. All groups believed that a trusted community leader could help link the patient to a trusted Canadian health care professional. Addressing this *trust* component in this initial phase of information seeking is imperative and consistent with cross-cultural theory [16], as it is the starting point to obtaining diabetes prevention and care. Strengthening the relationship and collaboration between key community leaders and local health care providers may help build trust among communities and improve services utilization.

Another dimension of *trust* is *accuracy trust*, described by participants as the ability to verify information that has been given to them from trusted sources. This was sometimes achieved by conducting Internet searches and consulting with friends, family, or other community members. Moments of discordance were identified when information given by a local health care professional differed from participants’ own views. Medical jargon in the presence of language barriers may exacerbate these concerns [3]. Patient-centred care studies [24, 25] have shown that patients are less likely to adhere to medication and follow medical advice when they disagree with the explanation of what is causing their illness or how it should be managed.

Conversely, involving patients in their own care following a shared decision-making process increases the effectiveness of an intervention [32]. In the case of diabetes education, for a condition highly dependent on education for prevention of complications, a culturally appropriate and collaborative approach is essential [14, 25].

Privacy trust gained importance primarily at the time that the diagnosis of diabetes was made. While participants felt comfortable openly discussing diabetes prevention and education topics as they pertained to the general population, they expressed concerns regarding privacy once they had been personally diagnosed with this condition. Arguably, this phenomenon may be present in the non-immigrant population as well, yet cultural and religious beliefs around illness etiology, as well as issues around stigma and family dynamics, could potentially exacerbate the negative consequences of a privacy breach in this population. As described by study participants, people with diabetes in their communities were hesitant to disclose medical information both to community leaders or health care providers if the element of privacy trust was not present. Because of the level of familiarity among other community members, participants felt formal health care providers were better positioned to ensure confidentiality in this setting. The distance commonly maintained by health care providers could potentially be beneficial in allowing disclosure on behalf of patients, along with facilitating open and clear discussions around management of diabetes.

The final level, *intervention trust*, refers to confidence that patients have in the management plan that has been presented to them, whether it involves lifestyle modification or use of medication. Both patients and health care providers encounter challenges when addressing this level, as it often requires cross-cultural negotiation and exploration of health care beliefs and expectations [20]. Participants agreed this level required time and often multiple visits to reach a common understanding of how a patient’s diabetes can be managed. A person-centred approach, taking into consideration contextual factors, may enhance the uptake of a particular intervention [25].

The importance of identifying these levels of trust lies in the apparent necessity for all levels to be addressed to ensure the effectiveness of an intervention [31]. For example, even if entry trust is secured, a patient may lose confidence if they are unable to verify the information that has been given to them with other trusted resources. Likewise, patients who are content with the information that has been provided to them may not necessarily agree to the management plan if intervention trust is lacking. Finally, all these levels may be ineffective if patients diagnosed with diabetes feel their privacy may be compromised when accessing care. All these levels were identified as essential components to securing a smooth

transition from diabetes awareness and education, to management and prevention of diabetes complications.

Implications for Diabetes Education and Care Programs

Immigrant community leaders from our four ethnic groups all identified four dimensions of trust: entry trust, accuracy trust, privacy trust, and intervention trust. Several attributes, and practitioner behaviours and characteristics, have been associated with trust [10, 19]. The four dimensions our immigrant community leaders identify represent a subset of these dimensions and this may be a significant finding. Minoritization amplifies fear, misunderstandings, risk of discrimination and thus mistrusts [3]. Paying close attention to these four elements of trust could enhance our understanding of person-centred care across cultures [14].

The research findings suggest that diabetes education and care must become more trustworthy if it is going to be effective for immigrants. Trustworthy does not indicate that the educational content and care is currently inaccurate. Rather, trust is about what health information users, such as immigrants, find trustworthy. Personal relationships may be an important key in helping to improve diabetes education and care. Social network analysis research [6] and adult education literature [28] have also indicated that personal relationships can be very important in changing health behaviour. Culturally appropriate programs, in conjunction with the self-care skills development approach implemented in partnership with local health provider, may help to reduce mistrust between ethnic minority patients and practitioners and increase access to essential diabetes education and services.

Limitations and Implications for Future Research

We have adopted a range of techniques to improve the reliability of the qualitative results of this study. However, as we engaged four different ethnic groups, the results of this study should not be used to determine cultural beliefs or practices and should be interpreted cautiously in relation to other immigrant populations.

Conclusions

Our results hone in on the dimensions of trust that are most important for marginalized populations. In appreciating these core dimensions of trust (entry, accuracy, privacy, and intervention) there is an opportunity to contribute to mainstream person-centred medicine and diabetes education and clinical care initiatives. Rather than focusing on cultural differences, our results provide an opportunity to highlight shared needs across all immigrant groups.

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Conflict of interest None.

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