Investigating Dimensions of Trust in Public Discussions of Diabetes Led by Certified Diabetes Educators

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ABSTRACT: The givens of “trust” and “credibility” are often glossed over in research concerning the efficacy of community-based approaches to health issues. This research focuses on one type of community intervention aimed at increasing citizens’ interest in acting to address diabetes: a series of community discussions led by Certified Diabetes Educators (CDEs). We take a critical discourse analysis approach to answering several questions including: How does the discourse between CDEs and participants work to establish or hinder the CDEs’ credibility?

KEYWORDS: certified diabetes educators, credibility, diabetes, health communication, public meetings, trust

1. INTRODUCTION

Recent years have seen a trend to move away from deficit models of science and health communication, which is characterized by experts imparting knowledge to an uninformed public, to more participatory or dialogue models, creating discursive space for the recognition and value of people’s lived experiences and community knowledge. But is this really practical or possible in realms that rely heavily on technical or medical expertise? Trench (2008), in reviewing literature across the field, makes a strong argument that the move from a deficit to a dialogue model may be more theoretical than real. He concludes: “the deficit model survives as the effective underpinning of much of science communication” (p. 130).

Others would argue even further that any dialogic or deliberative model of public communication is flawed because, in the end, who will be listened to, who will be silenced, and who will ultimately have authority to make decisions and determine what is ‘legitimate
knowledge’ will depend on power: power based on access to information and resources and ability to control the discourse because of historical precedent and systematic procedures of prohibition (Foucault, 1970/1981; Mouffe, 2000; Peters, 2000).

These ideas regarding the need for the expert and who is an expert are integral to an understanding of how trust and credibility figure into community-based approaches to public health issues. A cursory review of articles related to collaborative or community-based approaches to health issues suggests that the effectiveness of these approaches hinges on participants’ trust in healthcare providers and the system in which they operate as well as the belief that the information they have access to is accurate and useful (Aveling, Martin, Herbert & Armstrong, 2017; Genuis, 2012; Rosales, Coe, Stroupe, Hackman & de Zapien, 2010; Schuller, Jenkins & Neal, 2007; Smith, Dixon, Trevena, Nutbeam & McCaffrey, 2009).

In regard to diabetes education and care specifically, Dahal, Qayyum, Ferreyra, Kassim, and Pottie (2014) argue that successful interventions to educate and treat vulnerable populations who may experience high rates of diabetes require attention to building trust between “the vulnerable patient and the practitioner” (p. 978). Dahal, et al. also identify four dimensions of trust in relation to diabetes care: entry trust, accuracy trust, privacy trust, and intervention trust. Entry trust refers to initial feelings of acceptance and/or the perception of the ability to access a service; accuracy trust refers to confidence in sources and information provided; privacy trust refers to not only feeling information disclosed will remain confidential, but also that disclosing information will not cause anxiety; and intervention trust refers to confidence that the actions, interventions, and behaviors prescribed by the healthcare provider will actually improve one’s health and quality of life.

While the dimensions of trust identified by Dahal et al. (2014) offer an excellent starting point for the present study, several limitations must be noted. First, Dahal et al.’s study focused on one-on-one relationships between a patient and a healthcare provider, not community interventions. Second, this study is based on focus groups with immigrant communities in Ottawa, Canada, and therefore, may not lend itself well to application in rural parts of the United States, such as, in the case of this study, Arkansas. Finally, while the dimensions were identified by asking community leaders general questions about their perceptions of diabetes, the problems they thought immigrant populations faced accessing services related to diabetes, and ways to raise awareness about the disease, no examples of how each of these dimensions of trust might be created through patient-practitioner interactions were offered. Despite these limitations, we see Dahal et al.’s work as an excellent starting place for investigating dimensions of trust important to creating effective public communication related to health issues in general, and diabetes in particular.

The current study builds on the work of Dahal et al. to investigate how trust is created or undermined in a series of community discussions about diabetes led by Certified Diabetes Educators (CDEs), a specific community intervention aimed at increasing citizens’ interest in engaging in individual and collective actions to curb rising rates of diabetes. Specifically, we seek to address the following questions:

RQ1: How does the discourse between the CDEs and other participants work to establish or hinder trust across the four dimensions identified by Dahal et al.?
RQ2: How might the investigation of trust creation in interaction increase understandings of dimensions of trust related to public communication concerning health issues in general and diabetes education and care specifically?

RQ3: How important is trust between the expert and participants in determining participants’ perceptions of the usefulness of community interventions in addressing increasing diabetes rates?

2. METHOD

The data set presented here is part of a larger study sponsored by the Kettering Foundation comparing three different types of communication interventions to address diabetes: Lectures by CDEs; a series of facilitated community conversations led by trained facilitators who were not health providers or experts; and single community conversations led by trained facilitators followed by training on how to facilitate similar conversations.

For the intervention covered in this study, Certified Diabetes Educators (CDEs) were recruited to serve as the “experts” for a series of lectures in five Arkansas communities. The events were framed as a series of “discussions” rather than a “lecture series,” given local feedback on how best to attract people to the events.

The CDEs were trained to follow roughly the same topics in their presentations and discussions as the topics that would be discussed in the two other interventions that were part of our larger study. Topics included the following:

- A general overview of the prevalence of diabetes in the state and in the particular county in which the lectures were offered, as well as basic information about the disease itself and how to manage it, such as the types of diabetes, effects of diabetes on the body, ways to manage diabetes through diet and exercise
- How to prioritize diabetes in Arkansas through changing individuals’ behaviors
- How to prioritize diabetes in Arkansas through improving system of care
- How to prioritize diabetes in Arkansas through creating cultures of wellness
- Resources available in the community to prioritize diabetes
- Individual and community actions needed to prioritize diabetes and lower rates of the disease

CDEs were also instructed to limit the time for each event to an hour or less as feedback from previous diabetes awareness work done by one of the authors suggested people often do not attend events when they are perceived to be too long (45-60 minutes). Participants were recruited using a variety of outreach methods, including newspapers articles, flyers at local businesses, flyers at the locations where the events would be held, creation of Facebook events, and emails to local contacts that helped with earlier work related to diabetes. Events were held at two public libraries, a church, a community room at a hospital, and a community room at a community college.

All events were conducted between July and December 2017. Total attendance for all events was 218 with 30 participants attending two or more lectures. Repeat attendance varied widely across the state as evidenced in the following table:
Table 1. Repeat participants by region

<table>
<thead>
<tr>
<th>Region</th>
<th>Total Attendance</th>
<th>Repeat Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northwest</td>
<td>69</td>
<td>12</td>
</tr>
<tr>
<td>Southeast</td>
<td>51</td>
<td>7</td>
</tr>
<tr>
<td>Central</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>Northeast</td>
<td>33</td>
<td>4</td>
</tr>
<tr>
<td>Southwest</td>
<td>25</td>
<td>3</td>
</tr>
<tr>
<td>TOTAL</td>
<td>218</td>
<td>30</td>
</tr>
</tbody>
</table>

Events were audio recorded and transcribed simply with pauses and inflection noted, but without attention to false starts or verbal fillers. The researchers used an iterative process (constant comparative analysis) to ensure rigorous and consistent analysis of the transcripts. This process included individual coding of the transcripts until a consensus was reached concerning codes and themes and continued discussion and reflection on the data to ensure consistency and depth of analysis.

Questionnaires were also distributed at the end of each event. Questions focused on participants’ perception of the effectiveness of the event in increasing their understanding of the issue of diabetes in their community, their willingness to engage in future individual and collective actions to address diabetes in their community, and specific items concerning what these actions might be. Data from Likert Scale scores were averaged and compiled by location. Observational data were also recorded through field notes and discussed among the research team at weekly data sessions.

While events led by CDEs were conducted in five communities, the current study focuses on events in two regions of the state: the Northeast and the Central regions. These two regions were selected for analysis here because they attracted the same number of repeat participants and were led by different CDEs.

3. FINDINGS

Analysis of the Northeast and Central regions’ event transcripts suggest that using Dahal et al.’s (2014) dimensions of trust related to diabetes education and care to analyze public communication regarding health issues may be useful in initially unpacking what is being created in the interactions between experts and participants. However, analysis must go deeper to uncover how trust may ebb and flow in the course of repeated interactions between healthcare professionals and community members. Moreover, questionnaire results suggest that perhaps trust between the expert and participants is not as important as other factors in determining participants’ perception of the usefulness of an intervention in regard to their understanding of diabetes. We examine each of these claims more fully below.

3.1 Applying Dahal et al.’s (2014) Dimensions of Trust to Interactions between CDEs and Event Participants

For the most part, Dahal et al.’s (2014) dimensions of trust proved useful in parsing out what we had initially coded as ‘discourse to create identification’ or ‘discourse to create division’ (see Burke, 1969). Through application of Dahal et al.’s dimensions of trust, we were able to analyze
the discursive data in a more in-depth and nuanced way. While analysis of the discursive data of the CDEs revealed attempts to build trust in all four dimensions, two dimensions, entry and privacy, were reported here. Focusing on these two dimensions offered interesting insights into the complicated way trust may be created and transformed in the course of just a few utterances.

The Entry Dimension of Trust. As indicated earlier, the entry dimension of trust refers to attempts to create feelings of acceptance and a sense of accessibility. Dahal et al. (2014) define this dimension solely in terms of the patient feeling accepted and perceiving the service as accessible. They also suggest that to build entry trust providers not only need to be culturally competent, but should also adopt a person-centered approach when interacting with marginalized groups, such as immigrant populations. Further, they suggest that leaders within immigrant communities can serve as liaisons between community members and healthcare providers as entry trust can be built through those leaders.

Our analysis of the discourse of the CDEs here suggests that, within the context of public communication related to diabetes awareness and education, building entry trust is a complicated and dynamic process that involves more than participants’ feeling accepted or perceiving services as accessible, but that the CDE also needs to feel accepted and accessible while still being seen as an expert. In fact, most of the discursive work CDEs did related to entry trust was not necessarily to convey a general message of “I accept you,” as much as a message of “Accept me,” with that message containing at least two meanings. One seemed to be “Accept me as similar to you, like you” as seen in these examples:

CDE: My role here is simply to facilitate our conversation.

CDE: Personally, I don’t have diabetes, I am avoiding it. I am at risk [because I had very large babies] and so that’s my story. You do not have to be a person with diabetes to care about your health.

CDE: I use myself as an example a lot, for one, so it doesn’t sound like I’m putting blame or blaming it on someone else.

CDE: I’m a Certified Diabetes Educator, but I like to think of myself as a coach (long pause) sometimes.

CDE: [After soliciting a list of actions people with diabetes may need to take to stay healthy] Look at all of these motioning at previously stated actions she wrote on flip chart, these are all actions you have to take. No, not you (pause) we.

The above statements work to place the CDE somewhat in the same health space and, to some degree, the same level as the participants. One CDE, who had diabetes, started every event by iterating that fact. The other CDE continued throughout the series of events to emphasize she was at risk for diabetes because she gave birth to large children. The general message, then, is “trust me, I am like you;” however, the discourse of the CDEs also worked to convey a contradictory but equally important message regarding entry level trust: “Accept me, I know what I am talking about:”

CDE: I’ve had diabetes for 35 years and I have no complications. If you just kind of do the things that you need to and acknowledge that you have diabetes and take care of it, then it doesn’t have to be a death sentence like a lot of people unfortunately think it is.
CDE: I read a lot of studies... I would like to think that I am an exceptional person (like all of you). I realize I was not the exception, I have a human body like all of these people I’m reading about who are susceptible to diabetes, so it hit me, I needed to eat like this [low carbs, low fat, low sodium].

These utterances are fascinating in that they work to convey the message of “expertise,” not by disclosing credentials or training, but by communicating idea that “I am like you but I have ‘overcome’ the ‘threat’ of this terrible disease.” These are messages that set the CDE apart from the participants as someone in some ways better at handling diabetes than the average person, rather than sending the message that they accept or are the same as the participants. As such, these utterances allow the CDE into the discussion with some degree of power that their credentials alone would not afford them.

If we extend this to Habermasian (1989) conceptions of the public sphere, the argument can be made that the CDEs’ discourse related to successful management of their diabetes is their most compelling evidence that they have license to enter the discussion. The participants’ license to enter the discussion is more of a given as the discussion is in their community—their (metaphorical) public house or salon. The CDEs, however, enter that space truly as strangers and thus have to work more vigorously to gain acceptance and the right to speak.

This suggests that unlike the patient who enters the doctor’s office the focus of Dahal et al.’s (2014) investigation of trust in diabetes care and education looking for acceptance and deems the health care professional trustworthy if she is culturally competent and person-centered, in public settings where diabetes care and education is discussed, entry trust may also be perceived as requiring relationship-building beyond the traditional expert/patient dichotomy. In other words, the discourse of the CDEs, in some ways, worked to level the balance of power: “I am like you;” but also worked to keep that balance of power: “I am like you in some ways, but in other ways I am not.”

*The Privacy Dimension of Trust.* Dahal et al. (2014) present this dimension of trust as a feeling that a disclosure will be kept in confidence. Further, they suggest that privacy trust becomes important once someone is diagnosed with diabetes because of “issues around stigma and family dynamics” (p. 782). They go on to argue that health care providers are better positioned to provide confidentiality because of the “level of familiarity among other community members” (p. 782).

Our analysis of the discourse in the community discussions of diabetes led by CDEs suggests more nuanced and complicated aspects of this dimension of trust. Consider, for example, the following exchange:

Participant asks another participant: Can I ask you, who is your doctor?

CDE responds: Well, that’s a little ground rule we have here. If we could leave our doctor’s names out, they’re not here to defend themselves. Out in the parking lot, I don’t care.

This sort of exchange happened several times during the course of the series of events. In regard to the privacy dimension of trust, it seems that the CDE’s talk works to protect the privacy of participants’ doctors within in the public space of the event, while also granting permission for the disclosure to happen in a more private space—the parking lot. Compare the previous exchange to the following utterances by another CDE at a separate event:
If you have things that you would like to bring up privately, I can stick around afterwards too, if that would be of assistance to you…Growin’ up I didn’t know anything. I was a slave to the insulin. It told me if I had low blood sugar, high blood sugar. [I] became a nurse and figured out how to have a normal life and that’s kinda what I try to help everybody else do, so if you have questions—specific questions about yourself—I am happy to stay afterwards and help you figure some stuff out.

Again, the discourse works to set up a dichotomy between public disclosure of personal medical information and private disclosure. The CDE also positions herself here as a “nurse,” a title that suggests a more medical position than a “Certified Diabetes Educator.” It is through the role of “nurse” that she will keep confidence.

The above examples suggest a construction of privacy trust as a matter of not sullying or valorizing a doctor’s reputation publicly or disclosing private medical information. A final exemplar points to another way privacy trust was constructed in the discourse of the CDEs:

Growing up, diabetes wasn’t something I was proud of. It was personal and not something I shared with people, it was private. So your grandparents may have had it and you might not have known it. You were a child and they might not have told you that they had it.

This utterance and others similar to it relate to the stigma of diabetes. There is a perception of diabetes as a “silent disease,” as something you do not talk about, as something that you suffer in private was pervasive through the events (Brower et al., 2012; Kohinor et al., 2011; Oleson et al., 2017). As with the utterance above, CDEs worked to create a safe space for participants to talk about their own struggles with diabetes by disclosing their own and the stigma attached to it. They did not leave the shame of the disease unspoken, they named it, and in doing so, not so much generated privacy trust as something more akin to trust built in consciousness raising groups through recognizing similar patterns across lived experience (see, Mansbridge, 1980). This aspect of the construction of trust seems most pertinent to interpreting participants’ perceptions of the useful events.

3.2 Questionnaire Results: Participants’ Perception of the Usefulness of the Events

As researchers, we spent much time analyzing the ineffectiveness of these events led by CDEs. We noted the inconsistency of the information they presented. We noted their tendency to cut off participants. We noted their vacillation between discourse to show they were like the participants and discourse that set up a clear division between themselves as experts and the participants as an unknowing public. Needless to say, we were quite surprised by the results from the post-event questionnaire items related to the effectiveness of the discussions.

Participants’ Perceptions of Effectiveness of CDE-led Discussion. In response to the question “Please rate the effectiveness of the lecture(s) in increasing your understanding of the issues related to diabetes in your community,” participants tended to rate the lectures as very effective. Overall, participants in all regions rated the effectiveness of the lectures as 4.52 on a scale of 1 to 5. Ratings varied across regions, with the lowest score being 3.88 and the highest 4.86. Participants in regions where attendance was highest tended to rate the lectures as more effective than those in regions where attendance was low. Participants who attended more than two lectures tended to rate the lecturers’ effectiveness similarly to those who attended less than twice.
Table 2. Effectiveness of lectures in increasing understanding of issue

<table>
<thead>
<tr>
<th>Region</th>
<th>Rating (All)</th>
<th>Rating (Repeat)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northwest</td>
<td>4.86</td>
<td>4.86</td>
</tr>
<tr>
<td>Southeast</td>
<td>4.77</td>
<td>4.78</td>
</tr>
<tr>
<td>Central</td>
<td><strong>4.29</strong></td>
<td><strong>4.25</strong></td>
</tr>
<tr>
<td>Northeast</td>
<td><strong>4.8</strong></td>
<td><strong>4.6</strong></td>
</tr>
<tr>
<td>Southwest</td>
<td>3.88</td>
<td>4.2</td>
</tr>
<tr>
<td>Average</td>
<td><strong>4.52</strong></td>
<td><strong>4.54</strong></td>
</tr>
</tbody>
</table>

The survey results suggest that perhaps the building of trust between the CDEs and participants was not as important as providing a space for the participants to come together to talk about their own experiences with diabetes.

This puts into perspective one of the issues we saw with this particular type of community intervention—these events tended to attract only people with diabetes, those who had relatives with diabetes, or others who worked with people with diabetes. No matter how much we emphasized that the events were open to all and would progress from emphasis on individual actions community members could take to curb rates of diabetes to collective actions community members could take to build a healthier community, the majority of attendees had a personal or professional connection to the disease.

Our preliminary thoughts were that this was a negative—a failing on our part to frame the events in a way people without diabetes would attend. However, having analyzed some of the discursive data from these events, our perceptions have changed to some degree. For one we, as a culture, hear that an event will be held about “diabetes,” and understand that event as an opportunity to learn about the disease. If we have no connection to it, why would we attend? More importantly perhaps, we had not considered the events as a space for people with a connection to diabetes to share their stories, to connect with others in their community that they may not have connected with before. That was a very positive outcome of these events and one that suggests they provided something different that an event in the frame of a deficit model of health communication.

4. CONCLUSION

In regard to investigating our initial research questions, the analysis suggests the dimensions of trust identified by Dahal et al. (2014) may be more complicated than simply training healthcare providers to be culturally competent and person-centered. Our findings also suggest that trust may be engendered in unexpected ways, particularly when the healthcare provider participant/patient encounter is transferred to a public arena.

One last observation has to do with Trench’s (2008) assertion that the deficit model still survives as the underpinning of much of science communication. While this may be true, taking an analytic perspective toward the study of science communication, another action advocated by Trench, may prove that those underpinnings can be transformed by publics who build trust among themselves and take the conversation beyond that expected by the experts.

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