



Examination of Health Care Providers' Use of Language in Diabetes Care: A Secondary Qualitative Data Analysis

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The purpose of this secondary qualitative data analysis was to assess the frequency and context of stigmatizing language used by health care providers (HCPs). The authors conducted content and thematic analysis of in-depth face-to-face and telephone interviews with HCPs in southeastern Ohio. Participants frequently used labeling language, such as “diabetic” and “noncompliant,” as well as language with negative connotations, such as “control,” “testing,” and “regimen.” These findings offer a real-world glimpse of how HCPs communicate about people with diabetes in this region of the country.

Diabetes is a chronic metabolic condition characterized by high blood glucose levels resulting from the body's inability to produce and/or use insulin (1). Its management requires individuals to follow specific self-care recommendations, including eating healthful foods (2), engaging in regular physical activity (3), monitoring blood glucose levels (4), taking medication (5), attending clinical appointments (6,7), and coping with stress (8,9). The significant role self-care behaviors play in the management of diabetes has perpetuated a stigma that diabetes is self-inflicted or caused by lifestyle mismanagement (10–12). Diabetes stigma refers to labeling, stereotyping, and discrimination toward people with diabetes (13,14). Research by Liu et al. (15) in 2017 found that 76% of people with type 1 diabetes and 52% of people with type 2 diabetes reported experiencing diabetes stigma. The most commonly reported stigma was “a character flaw or failure of personal responsibility.” This stigma was experienced regardless of type of diabetes (15).

Diabetes stigma has a negative impact on the psychosocial health, self-care, and clinical outcomes of people with diabetes. Gredig and Bartelsen-Raemy (16) in

2017 found that people with diabetes who perceived stigma reported higher levels of psychological distress, increased depressive symptoms, less social support, and lower quality of life. We know from prior research that higher levels of psychological distress, increased depressive symptoms, and lower quality of life are associated with fewer self-care behaviors (17,18), higher A1C values (18–22), and increased complications (23,24). Moreover, public stigma from family, friends, health care providers (HCPs), and employers may contribute to people with diabetes hiding their condition, developing a lower sense of self-worth, and internalizing stigma (25). People who internalize stigma (i.e., experience self-blame, guilt, and shame) may be more reluctant to engage in self-care behaviors and avoid or limit their participation in social activities (25). Furthermore, people with diabetes who internalize stigma may struggle to form meaningful relationships with others and feel disconnected from society (25).

Speight et al. (26) in 2012 and Dickinson (27) in 2018 showed that people with diabetes experience stigma from the language used regarding diabetes. HCPs, employers, family members, and friends may intentionally or unintentionally use language that introduces and/or reinforces diabetes stigma (11,12,25,27). The recognition that language is stigmatizing led multiple diabetes organizations to publish position statements addressing language use, including Diabetes Australia (26), the International Diabetes Federation (IDF) (28), the American Diabetes Association (ADA) and Association of Diabetes Care and Education Specialists (ADCES) (29), and Diabetes Canada (30). These position statements oppose language that 1) reflects unrealistic ideas about diabetes; 2) describes the person

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<https://doi.org/10.2337/cd21-0108>

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rather than the condition, behavior, or outcome; and 3) uses judgmental, blaming, or shaming language. In contrast, these position statements recommend language that 1) conveys empathy, compassion, respect, and hope; 2) promotes active engagement and aligns with the preferences of the person with diabetes; 3) addresses the type of diabetes; and 4) centers on the person with diabetes (26,28–30). Research is needed to examine HCPs' use of diabetes language to identify areas for targeted education. Thus, the purpose of this study was to conduct a secondary qualitative analysis of HCPs' use of language in diabetes. Specifically, we assessed the frequency and context of stigmatizing language in HCPs' interviews.

Research Design and Methods

Research Design

We conducted a secondary qualitative analysis to explore the use of language in diabetes care among HCPs. The aim of the original qualitative study was to identify HCPs' perceived barriers and supports for the management of diabetes in rural southeastern Ohio (31). We used focused ethnography to conduct in-depth face-to-face and telephone interviews with HCPs who cared for people with diabetes in the region. Focused ethnography is a qualitative approach designed to access beliefs and practices to improve our understanding of factors surrounding health and disease (32). Furthermore, HCPs shared beliefs and practices about diabetes, including the diagnosis of diabetes, self-care behaviors (e.g., blood glucose monitoring and physical activity), beliefs about diabetes (e.g., the need to lower or prevent hyperglycemia), and language used in diabetes management (e.g., insulin, glucose, lancets, and ketones).

Sample

We used maximum variation sampling, a form of purposive sampling (33), to recruit a wide range of participants from different medical backgrounds. Inclusion criteria included HCPs who were ≥ 18 years of age who could read and speak in English and practiced in southeastern Ohio, with at least 5% of their practice consisting of people with diabetes, to ensure experience with treating diabetes. Participants were recruited via emails, telephone calls, and word of mouth.

The Ohio University Office of Research Compliance approved the protocol (Institutional Review Board #16-E-342) and all recruitment procedures and materials. Written (during face-to-face interviews) or verbal (during telephone interviews) informed consent was obtained from all participants.

Data Collection

One trained qualitative researcher (E.A.B.) conducted all interviews, asking participants broad, open-ended questions about diabetes in the region, diabetes management, and barriers and supports to diabetes care. No questions about diabetes language were included in the interview guide; thus, the diabetes language used in the interviews may reflect how the HCPs discuss diabetes with their patients, colleagues, and community. The interview guide has been published elsewhere (31).

In-depth interviews were conducted either in-person at medical offices or university spaces or via telephone per participants' preference. Interviews were audio-recorded and lasted 30–90 minutes each. Interviews were conducted in the spring and summer of 2017. Data were collected until saturation was reached (i.e., when no new information emerged from the interviews) (33).

All interviews were digitally audio-recorded and transcribed verbatim, with names and identifiers removed to protect participant confidentiality. The research team, consisting of two behavioral diabetes researchers and one medical student, performed quality checks of the transcribed files by listening to the audio-recordings to validate the transcriptions.

Qualitative Analysis

The multidisciplinary research team used content and thematic analyses to analyze the data using NVivo software (34). Specifically, members of the research team performed content analysis (35,36) by independently coding key words and phrases in the transcripts to identify language not recommended by the following organizations: Diabetes Australia (26), IDF (28), ADA and ADCES (29), and Diabetes Canada (30). The coders met to review the coded data; discrepancies were reviewed, discussed, and resolved through consensus (37). The Cohen κ coefficient for intercoder reliability was 0.981, indicating almost perfect agreement (38,39). Finally, the research team met to identify themes or abstract concepts linking substantial portions of the interviews together. The themes described participants' use of diabetes language that occurred multiple times, both within and across transcripts.

Rigor

We used analyst triangulation to support the credibility (validity) of the data by limiting selective perceptions and cognitive biases in the analysis (40). Next, we used thick descriptions and verbatim quotations to support the

transferability (external validity) of the data (41). Finally, we conducted an inquiry audit to support dependability (reliability) of the data. Specifically, a researcher not involved with the study examined the research process and product to determine whether the findings and conclusions were supported by the data (42).

Results

A total of 42 HCPs participated in in-depth interviews (23 in person and 19 via telephone). The average age of participants was 45.1 ± 12.0 years. Two-thirds of the participants self-identified as cisgender women ($n = 28, 66.7\%$) and 15 (35.7%) identified as primary care physicians. On average, participants had 17.7 ± 11.5 years of clinical experience and an estimated diabetes caseload of $46.8 \pm 29.6\%$ (Table 1). Transcript identifiers are used with quotations indicating participant number and provider type. Three themes emerged and are discussed below.

Theme 1: Use of Labeling Language

The majority of HCPs referred to people with diabetes as “diabetic.” Thirty of the 42 participants (71.4%) used the label “diabetic” in their interviews a total of 167 times, with some participants using this term more than 20 times (Table 2). For example:

*“It almost seems like everybody’s **diabetic**. It’s almost a given. Even when I was a home health nurse, that was the majority of reasons that you were dealing with this person. Whether it was for some reason they were in the hospital and then discharged home, DKA [diabetic ketoacidosis], and then you’re following up with home health or something like that. It was always usually **diabetic-related**.” (ID 28, registered nurse)*

*“I continue to see that our numbers for prevalence are rising with diabetes as well as the prevalence of unmanaged **diabetics**. One of my other areas here in [the] **diabetic** department is we do have inpatient services, and so we’re continuing to see very complex concerns regarding DKA.” (ID 32, exercise physiologist)*

In the context of the interview questions, participants were asked to describe barriers to diabetes care and reasons for not achieving diabetes targets. Participants’ responses attributed unmet targets to not performing self-care behaviors. These participants did not use

TABLE 1 Participant Demographic Characteristics (N = 42)

Variable	Participants
Age, years	45.1 ± 12.0
Gender	
Female	28 (66.7)
Male	14 (33.3)
Other	0 (0)
Prefer not to answer	0 (0)
Race	
American Indian or Alaska Native	1 (2.4)
Asian	1 (2.4)
Black or African American	0 (0)
Hispanic or Latinx	0 (0)
Native Hawaiian or Pacific Islander	0 (0)
White	40 (95.2)
Two or more races	0 (0)
Another race not listed	0 (0)
Provider type	
Physician	15 (35.7)
Registered nurse	10 (23.8)
Nurse practitioner	5 (11.9)
Pharmacist	3 (7.1)
Clinical psychologist	3 (7.1)
Registered dietitian	3 (7.1)
Exercise physiologist	2 (4.8)
Emergency medical technician	1 (2.4)
Practice experience, years	17.7 ± 11.5
Employment status	
Part-time	2 (4.8)
Full-time	40 (95.2)
Estimated proportion of patients with diabetes, %	46.8 ± 29.6

Data are mean ± SD or n (%).

person-centered language but rather used labeling language, as shown in the following examples.

*“And the other thing too is, **diabetic** patients aren’t just **diabetics**; they’re **obese**, they’re **smokers**, they have high blood pressure, they have [an] endless bucket list of things that they have going on. So, if it was just the single diagnosis of diabetes, I think it would be a bit easier, maybe, to manage. But there’s so many things, so many comorbidities that are piled on top of that.” (ID 6, nurse practitioner)*

*“I think it’s taken somewhat serious, but it doesn’t change their diets much. Their trends don’t change a lot, you know what I mean? Because I’m down here going to the basketball banquets and stuff and, look over—your **diabetics** are eating the same exact stuff everybody else is eating; they’re eating their desserts,*

TABLE 2 Frequency of Use of Nonrecommended Language in Diabetes (N = 42)

Term	Frequency of Use, n	Recommended Term(s) or Replacement Language*
Noncompliant/compliant	42	“Person with diabetes experiences side effects to taking metformin.”
Nonadherence/adherence	19	Engagement, participation, medication-taking
Control/glycemic control	82	A1C, management, blood glucose levels, glycemic targets
Diabetic/nondiabetic/prediabetic	167	Person with diabetes or a person’s preference for identity
Regimen	15	Plan, choices
Test	20	Monitoring blood glucose levels, checking blood glucose levels
Prevent	31	Reduce the risk, delay
Suffer/victim	3	Diagnosed with diabetes, lives with diabetes
Fail/failure	5	“Medication was not adequate to reach A1C target.”
Unmotivated	5	“Person experiences barriers to performing self-care behaviors.”

*Based on recommendations included in refs. 26, 28, 29, and 30.

and you know what I mean? So, they don’t take it real serious.” (ID 8, physician)

Several providers used language that labeled people with diabetes as people who did not follow medical recommendations. Sixteen of the 42 participants (38.1%) referred to people with diabetes as “noncompliant” when discussing self-care recommendations, as shown in the following quotations.

*“Getting patients to come in on scheduled appointment times can be difficult; you know, your **noncompliant** patient is just **noncompliant** all-around.” (ID 7, nurse practitioner)*

*“First of all, the biggest barrier is obviously going to be **compliance**. Because unless there’s something really wonky going on, in which case it would warrant a referral to a diabetologist, we know how to get patients controlled. We know how to get their diabetes to the point where we’re going to minimize their morbidity and their mortality. But it’s really, really difficult to do that if they’re not being **compliant**.” (ID 17, physician)*

*“I don’t feel some of them actually grasp how it can affect them, you know, their whole body. I think they don’t—they just kind of think it’s a diagnosis; they don’t really understand the whole . . . There are very few that are very **compliant**, you know what I mean, that realize it can affect their whole body.” (ID 3, registered nurse)*

Theme 2: Use of Language With Negative Connotations

Several participating HCPs used judgmental language to describe people not engaging in self-care or not achieving A1C targets. For example, 25 participants (59.5%) referred to A1C levels with good or bad value judgments and/or placed an emphasis on achieving “control” (Table 2). For example:

*“But my ultimate goal, what I share with them, is getting our handle on the A1C, because it’s simple; it’s a blood test, they understand that, and actually it does define **good control**. And, if your **A1C is controlled**, then your risk for complications is a little bit less, like your proteinuria, and that sort of thing. So, for the most part, I try and define it as a **good A1C**.” (ID 4, physician)*

*“Over the past year, I have seen lots of those people. They don’t care about their sugar [glucose] **control**. I mean, those people may die sooner . . . If they don’t care about themselves, they often die sooner.” (ID 34, physician)*

In addition, participants used language with negative connotations when discussing self-care behaviors such as blood glucose monitoring. Fourteen participants (33.3%) used the term “testing” for blood glucose monitoring, which implies a pass/fail result. These participants used “test” and “testing” instead of monitoring, as shown in the following examples.

“Testing your blood sugar. I had a lady who just, I think it was yesterday, she’s supposed to test three to four times a day, and she does once a day. She’s on a lot of insulin, too.” (ID 28, registered nurse)

“I know that insurance doesn’t reimburse for people to test their blood sugar that often. And really, from what I remember, the evidence isn’t there at all for [people with] type 2 [diabetes] to test for their blood sugar if they’re not on insulin. You know, the best thing to do is just check them every 2 months.” (ID 13, registered nurse)

Eight participants (18.6%) also used “regimen” when discussing self-care behaviors, which is a term that may feel discouraging and/or limiting to people with diabetes. For example:

“I provide evaluation, management, and guidance for a variety of medical conditions and concerns, and then preventive health services, as well. So, I manage acute conditions or chronic illnesses, and then preventive care. Sometimes it’s starting medication, sometimes it’s continuing a regimen or working with the patient to adopt a preexisting regimen.” (ID 13, registered nurse)

“I think, obviously, one of the biggest barriers besides education is the cost of the disease. Even if they have government-assisted insurance, they’re still in situations where this medication regimen can cost them up to \$100.00 a month in just pharmacy bills out of pocket, which can be frustrating.” (ID 17, physician)

Seven participants (16.7%) used “adherence” when referring to “regimens” and self-care behaviors. Like compliance, the word “adherence” suggests that a person with diabetes is taking orders from someone else rather than making their own choices for self-care, as shown in the following example.

“So, with working with patients with diabetes, I do a couple of things. One is motivational interviewing about adherence to diabetes, to the diabetes treatment regimens, and, addressing ambivalence about adherence. Then creating change plans. You’re talking about behavioral planning in terms of increasing adherence, figuring out what their goals for adherence are and trying to increase adherence to treatment plans and increase health. Also, for behavioral modification. That’s really so much about creating [a] change plan and goals and addressing barriers to change and barriers to behavioral modification that they’re trying to make.” (ID 41, psychologist)

Theme 3: Recognition of the Need to Use Recommended Diabetes Language

Only one participant did not use any of the nonrecommended language during the interviews. Two participants, without prompting, noted that language could be stigmatizing and harmful to people with diabetes. These two HCPs stated that they did not like the use of the term “noncompliant.” One participant mentioned how using the term “noncompliant” in the medical chart could negatively affect future clinical care for a person with diabetes.

“I had a lady who . . . she’s supposed to test three to four times a day, and she does once a day . . . because she can’t afford to buy any more strips than that. So, she’ll go to the doctor and be labeled as noncompliant because she’s not testing any more than once a day. However, she would if she had the ability to. But a lot of people don’t understand that, and the next person that sees noncompliant on their chart, they may not know the story, and it’s almost [as if] there’s an opinion formed in your mind, and these people aren’t treated very well.” (ID 28, nurse)

The other participant commented that this term was frequently heard from other HCPs in rural southeastern Ohio and that its use in a clinical setting was not appropriate.

“In this area, the providers still use the word compliance, and they say, ‘This person is very noncompliant.’ That is a word that almost every provider I work with uses . . . and, in my head, I’m like ‘That’s not the appropriate term.’” (ID 11, pharmacist)

Discussion

In this secondary qualitative analysis of HCPs’ use of language in diabetes care, participants frequently used stigmatizing language when referring to people with diabetes. Participants spoke with labeling language and used language with negative connotations. Nearly three-fourths of participants used the label “diabetic” when referring to people with diabetes, and more than one-third used the label “noncompliant” when discussing self-care recommendations. In addition, participants emphasized achieving glycemic “control” and placed good or bad value judgments on A1C levels. Participants also used the terms “testing,” “regimen,” and “adherence,” which may be perceived as discouraging and limiting to people with diabetes. Importantly, one participant did not use any nonrecommended language

during the interview, and two participants recognized the negative impact language could have on people with diabetes. These findings offer a real-world glimpse of how HCPs talk about people with diabetes, given that the original aim of the study was not focused on the use of language.

Our findings align with the conclusions of prior qualitative research exploring the experiences of people with diabetes regarding nonrecommended language. Qualitative research by Speight et al. (26) in 2012 and Dickinson (27) in 2018 revealed that people with diabetes felt judged, stigmatized, blamed, and shamed by the language used by HCPs. Specifically, participants in these studies stated that certain terms made them feel as if their diabetes was being over-simplified or presumed to be easily managed (27). Participants also noted that the use of “noncompliant” implied that someone else was responsible for their health care decisions, which in turn removed autonomy from their own diabetes-related decisions (27). In our study, the participating HCPs used the term “noncompliant” to describe people with diabetes who were not following their medical recommendations, echoing the sentiments of the participants in the Dickinson study (27). Moreover, Speight et al. (26) found that people with diabetes want a more active role in their diabetes care and that being labeled as “noncompliant” left them feeling upset and unheard. In these two studies, participants requested that HCPs stop using harmful labels such as “diabetic” and “noncompliant” as well as judgmental terms such as “control” and “should” (27). They said they would feel more supported, comfortable, and understood by HCPs if these terms were no longer used (27). Finally, Dickinson (27) highlighted the need to address language broadly, arguing that new terms with the same meaning and intention could be used in place of current terms. Thus, widespread education to call attention to stigmatizing and harmful language is needed to improve care for people with diabetes.

Language affects views, perspectives, and practices (29). It can inflict harm and perpetuate stigma, whether intentionally or unintentionally (29). For these reasons, the American Psychological Association (43) and the ADA and ADCES (29) advocate for the use of person-first language, which emphasizes the person rather than a disabling or chronic health condition. In the context of diabetes, person-first language acknowledges that a person has diabetes rather than diabetes being who they are (e.g., “a person with diabetes” vs. “diabetic”).

Conversely, disability culture and its scholars challenge the notion of person-first language and recommend the use of identity-first language (44). Identity-first language places the disabling or chronic condition first by recognizing that it is an integral part of a person’s identity. Identity-first language is considered empowering because people acknowledge that their disabling or chronic condition is essential to who they are as a person. Furthermore, disability scholars argue that person-first language endorses stigma by implying that the disabling or chronic condition is problematic (45). For example, a 2017 analysis by Gernsbacher (45) showed that person-first language in scholarly writing was used more frequently to refer to children with the most stigmatized disabilities (e.g., intellectual disability) compared with children with less stigmatized disabilities (e.g., deafness).

To address this bias, some experts recommend that HCPs refer to all people, regardless of the presence of a disabling or chronic condition, with person-first language (45). However, other experts recommend the use of identify-first and person-first language interchangeably to acknowledge both people with and without disabling and chronic conditions (44). They argue that the use of both identify-first and person-first language is more inclusive and addresses the issues raised by disability culture and scholars (44).

People with diabetes are diverse, and what applies to one person may not apply to another. For this reason, HCPs cannot predict what any single individual might prefer. Therefore, HCPs should ask each person about their preferred terminology.

Limitations

Study limitations included homogeneity of the sample with regard to gender, race, and geographical region. Thus, our qualitative findings may not be transferable or generalizable to people not represented in the sample. Furthermore, data from one geographic area (i.e., southeastern Ohio) may not reflect the diabetes language used by HCPs in other regions of the country. Future research should examine HCPs’ language use in different geographical regions. Importantly, our findings are consistent with the qualitative findings from Speight et al. (26) and Dickinson (27).

Next, the qualitative interviews were conducted in the spring and summer of 2017, which is when the ADA and ADCES published their position statement (29). Thus, the participating HCPs may have been less

familiar with their recommendations against using some terms. On the other hand, the use of language has been a topic of discussion for more than two decades in the diabetes literature (46,47), and Diabetes Australia (26) and the IDF (28) published their recommendations in 2012 and 2014, respectively.

An additional limitation to this secondary qualitative analysis was we did not ask participants specific questions about language use in diabetes. Participants responded to questions about diabetes management and barriers and supports to diabetes care from a previous qualitative study, which may explain the use of language with negative connotations. Despite the emphasis on barriers and diabetes management, participants had the opportunity to use terms other than “noncompliant,” “control,” or “test.” Another important consideration was that the participants in the study may have used different language when speaking to their patients with diabetes; future research exploring HCPs’ language use via qualitative interviews and video-based observation of patient-provider interactions may be useful methods to answer this question. Finally, as a secondary data analysis, we did not perform member checking, which involves asking participants to review the findings as a technique to improve the accuracy of the findings. To address this limitation, the qualitative coders included behavioral diabetes researchers and one member from the diabetes community.

Conclusion

In this study, the participating HCPs frequently used stigmatizing language when discussing people with diabetes and their outcomes. We know from prior research that people with diabetes report feeling judged, stigmatized, blamed, and shamed by the words used by HCPs and that those feelings are associated with psychological distress and negative health outcomes. Thus, HCPs must strive to use diabetes language that is free of bias and avoids perpetuating stigma, blame, and shame. Continuing medical education is the ideal platform to disseminate national and international diabetes language recommendations to promote rapid uptake of best practices. Increasing HCPs’ awareness and knowledge of recommended diabetes language has the potential to improve patient-provider communication, relationships, and health outcomes.

Acknowledgment

The authors thank the HCPs who participated in this study.

Duality of Interest

No potential conflicts of interest relevant to this article were reported.

Author Contributions

All authors provided substantial contributions to secondary data conception, design, and analysis; contributed to the interpretation of data; drafted and revised the article critically for important intellectual content; and read and approved the final version of the manuscript for publication. E.A.B. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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