

The Experience of Diabetes-Related Language in Diabetes Care

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■ ABSTRACT

Objective. The goal of this study was to understand how adults with diabetes experience the words used in diabetes care.

Methods. This qualitative study guided by Critical Theory used two virtual and two in-person focus groups conducted by the same facilitator. A total of 68 focus group members participated. The facilitator transcribed and coded focus group data using individual responses as the unit of analysis. The facilitator used constant comparison to analyze responses and developed a research summary of themes that emerged. A second coder confirmed the themes originally identified, and participants provided feedback on the summary.

Results. Many negative and stigmatizing words are used in diabetes care. Several themes emerged from the data, including judgment; fear and anxiety; labels, reminders, and assumptions; oversimplification and directives; misunderstanding, misinformation, and disconnection; and body language and tone. Participants reported experiencing negative diabetes-related words in the general public, with their health care providers (HCPs), and in the media. Participants made suggestions for HCPs to replace negative words; they raised a concern that current negative words will be replaced by others with similar negative connotations; and they said they would feel more like a partner in their care if HCPs stopped using these words.

Conclusion. The language used in diabetes care has an impact on people who live with the disease. Awareness is the first step in eradicating stigma in diabetes care. HCPs can improve patient-provider communication and contribute to a more positive experience for people living with diabetes by choosing words that empower.

The negative effect of language in health care is a topic that has been discussed for more than half a century (1); however, it is just recently beginning to gain some momentum. In 2017, the American Association of Diabetes Educators and the American Diabetes Association published a joint statement on the use of language in diabetes care and education (2). In recent years, Diabetes Australia published a position statement on language (3), the International Diabetes Federation published a language philosophy (4),

and The Obesity Society published a statement about using “people-first language” (5). People with diabetes are exposed to the language health care providers (HCPs) use both in speaking and writing, and those words may contribute to an already stressful illness experience.

For almost two decades, diabetes professionals have been discussing the inappropriateness of words such as “compliance” and “adherence” in diabetes care (3,6,7), yet these words are still used frequently (1). Diabetes professionals embrace an empower-

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ment model for delivering education and care, yet the language being used in diabetes care and education is not always consistent with that approach. The spoken and written words HCPs use contribute to the context in which people live with and manage their diabetes. Through context, people create meaning (8,9); therefore, negative words can lead to negative meaning.

Research to date has not examined language and diabetes care. Words can increase stress (10), and stress can lead to elevated blood glucose levels, decreased wound-healing, and increased risk for infection (11); therefore, understanding the impact of words and making efforts to change the words used in diabetes care could decrease stress and improve outcomes for people with diabetes.

Research on weight stigma has revealed that people may feel bad about themselves and be less likely to attend health care visits, exercise, and take care of themselves when they hear stigmatizing terms such as “obese,” “fat,” and “morbidly obese” (12,13). Although weight stigma and diabetes stigma have been linked in previous studies (14), there is a need for more research on diabetes stigma specifically. In fact, studying the “experiences, causes, and consequences” of diabetes-related stigma has been identified as an urgent research priority (15). Studies that illuminate the effect of stigma on people living with diabetes (16,17) encourage HCPs to find more effective approaches to care. One of these approaches could include changing the language they use with their patients with diabetes.

Critical Theory was chosen as the framework for this study because of its focus on human experience and awareness. Critical Theory research involves self-reflection, which can lead to an awareness of contradictions in beliefs and practices, with the hope that this awareness will inspire change (18). Critical Theory researchers often employ multiple methods (18) to

understand human experiences (19). Critical Theory–guided research endeavors to identify inequalities and facilitate change; it is often considered “consciousness raising” (20).

Research that elucidates how diabetes-related language is experienced by people living with diabetes is the first step in separating language that is and is not consistent with empowerment, improving patient-provider communication, and potentially improving health outcomes. The purpose of this Critical Theory–guided study, therefore, was to identify negative words used in diabetes care and explore the impact of those words on people with diabetes and their relationships with HCPs.

Design and Methods

The goal of qualitative research is to gain an understanding of participants’ experience through exploring, describing, and interpreting their own responses (21). Focus groups are often used to gather information on a phenomenon that has not been previously studied. This qualitative study utilized focus groups to elucidate the experience of diabetes-related words for adults with diabetes. The study included two virtual focus groups and two in-person focus groups. All were conducted by the same facilitator, a registered nurse and certified diabetes educator. The intention was to gather input from adults with diabetes in three different, yet representative, settings to identify common words that have a negative impact on people living with diabetes.

Settings

The Diabetes Online Community (DOC) was started in the mid-2000s (22) and consists of websites, blogs, and social networks by, for, and about people living with diabetes. DOC is a place where people with diabetes can discuss their experiences and concerns, ask questions, or simply get support from others who are living with diabetes. Two DOC groups were chosen as sites for the virtual focus groups because adults with diabetes

are readily available and familiar with discussing diabetes topics in these settings.

The first virtual focus group took place in the chat room of Tudiabetes (www.tudiabetes.org), a diabetes social network. Tudiabetes calls itself “a community for people touched by diabetes” (23) and was formerly a program of the Diabetes Hands Foundation, a nonprofit organization founded in 2008. It is now a program of BeyondType1 (24). Tudiabetes hosts regular live interviews and other programs through which members can ask questions and participate in a live chat.

The second virtual focus group took place in a weekly Diabetes Social Media Advocacy (DSMA) live Twitter chat. DSMA started its weekly Twitter chats in July 2010 (25) and has continued to host these events every Wednesday night. DSMA “is involved with and promotes social media in all its forms to empower people affected by diabetes and to connect them with each other to foster support and education” (25). DSMA is part of a nonprofit organization called Diabetes Community Advocacy Foundation.

The two in-person focus groups took place in a private room of a community library in Northwest Colorado.

Participants

Adults who have diabetes or care for someone with diabetes took part in this study. Members of Tudiabetes were invited to join the first virtual focus group. People who chose to attend DSMA’s weekly live Twitter chat were invited to join the second virtual focus group. Both virtual focus groups included people living with or caring for someone with any type of diabetes. Because of the lack of privacy in the two virtual study settings and because the purpose of the study was to illuminate the experience of adults with any type of diabetes, demographic information was not collected.

Virtual focus group participants were recruited through promotion of the event on the Tudiabetes website and in email messages sent to Tudiabetes members from the group's community manager. DSMA has a regular following of people who participate on Wednesday evenings and does not conduct routine promotion for its weekly Twitter chats; therefore, participants were not recruited in advance. Nineteen adults participated in the Tudiabetes chat; 40 adults participated in the DSMA Twitter chat.

Residents of a community in Northwest Colorado who were living with diabetes and had participated in the local diabetes education program were contacted via telephone and asked to participate in an in-person focus group. Nine adults participated in the in-person focus groups, bringing the total number of participants in all focus groups to 68.

Ethics

This study was approved by the institutional review board at Teachers College Columbia University (protocol number 15-036). At the beginning of both virtual focus groups, the facilitator explained the informed consent process and gave participants the opportunity to ask questions and opt out of the chat. The facilitator also gave participants the opportunity to stay and observe the chat without participating in the focus group. Those who chose to participate typed their consent into the chat. Some people remained in the discussion without providing consent. It is possible, although not known, that others may have observed the discussion without participating. Responses of those who did not type in their consent were not included in the data analysis. Before each of the in-person focus group sessions, the facilitator gave participants the informed consent details. After reading and signing the consent form, they were offered a copy to keep.

Procedure

Focus groups lasted 1 hour each and included six questions:

1. What diabetes-related words have a negative impact on you?
2. How do you feel when you hear those words?
3. What particular experiences do you recall that involved words and diabetes?
4. If you could ask your diabetes care professionals to stop using one word, what would it be?
5. If there is another word(s) that you'd like them to stop using, please share it (them) as well.
6. How do you think not using those words would affect your diabetes experience?

Analysis

The two virtual focus groups had chat transcripts available immediately after the sessions, which the facilitator printed for analysis. The facilitator audio-recorded the two in-person focus groups and transcribed the recordings verbatim after the sessions.

Kidd and Parshall (26) suggested that either the individual or the group can be the unit of analysis in focus group research. In this study, individual responses were considered the unit of analysis. Group interaction was especially prevalent in the virtual focus groups, during which participants often indicated agreement through the chat or by retweeting or liking other comments. However, the researcher did not include retweets as separate responses.

The facilitator followed several steps consistent with the constant comparison method (27–30) to analyze the data. She read through the transcripts and assigned numerical codes to participants who gave consent. She highlighted responses from participants with consent and then read through the transcripts a second time for content. The researcher marked responses containing content with a check mark. She read through transcripts a third time for interactions (comments participants made to each other or retweets) and marked interactions with an asterisk. She also marked comments or questions about

the research with a question mark. The researcher made a copy of all transcripts, cut responses into individual strips, and coded them again by answers to each question.

According to Stewart and Shamdasani (31), marking relevant parts of the text and developing categories is integral to focus group analysis. They explain that in this scissor-and-sort technique, "the first step . . . is to go through the transcript and identify those sections of it that are relevant to the research questions."

During the analysis, questions 4 and 5 were combined because responses to them overlapped. Themes emerged from the data that allowed the words, feelings, and locations of participants' experiences to be placed into categories. Themes also emerged that categorized participants' suggestions for changes in language and thoughts regarding how such changes could help them.

A second coder analyzed the data in the same manner to confirm that the identified themes were, in fact, emerging from the data. To ensure that themes accurately reflected the discussions that took place in the focus groups, the researcher developed a narrative summary of the research findings and posted it on her website. She asked participants to read the summary and share feedback. At least one participant from each of the focus groups responded with feedback about the research summary.

Results

Participants revealed that words have an impact on how people with diabetes feel about themselves and how they experience living with and managing diabetes. Many words have a negative impact on people with diabetes.

Question 1 and Question 2

Six themes emerged for negative words or phrases that people with diabetes experience and how they feel when they hear them:

Judgment. Participants reported that they experience words and phrases that communicate judgment or question or blame them. Examples included “noncompliant/compliant,” “uncontrolled/control,” “good/bad,” “test,” “morbidly obese,” “can/can’t,” “should/shouldn’t,” “are you supposed to?,” “fault,” “lazy,” “burden,” “failure,” and “she didn’t care.” Findings revealed that words such as “noncompliant/compliant” and “uncontrolled/control” make people feel judged. These words also lead to anger. They make people with diabetes feel insulted, belittled, misunderstood, rebellious, annoyed, defeated, and frustrated.

“Noncompliant’ makes it sound as though someone else is responsible for my health decisions. Ultimately, the choices available are MINE to make.” (Participant 2)

Fear and anxiety. Words that lead to fear, anxiety, and stress included “complications,” “blindness,” “cataracts,” “seizure,” “DKA” (diabetic ketoacidosis), “ketones,” “podiatrist,” and “death.” Participants discussed that these words lead to feeling scared, sad, ashamed, alienated, worried, doomed, depressed, and guilty. They shared that these feelings do not, in fact, help to improve blood glucose levels.

“I feel alienated, worried, self-conscious, and hyperaware.” (Participant 51)

Labels, reminders, and assumptions. This theme included words that label people or communicate assumptions about people with diabetes and words that are simply reminders of all that people with diabetes have to deal with. Examples include the labels “diabetic,” “disease,” “brittle,” “postmenopausal diabetic,” and “special needs”; the reminders “diabetes,” “food,” “death,” “diet,” “chronic,” “insulin-dependent,” “weight,” and “risk”; and the assumptions “suffer”

and “all people with diabetes are fat.” Participants described labels as offensive, annoying, and a cop-out. They shared that labels do not put the person first; they feel impersonal. Similarly, words that make assumptions about people with diabetes are frustrating; they feel demeaning and patronizing. Participants also reported that hearing reminders about the demands and dangers involved in diabetes, or simply that they have diabetes, gets tiring.

“So, I think the word ‘diabetic’ has a stigma.” (Participant 62)

Oversimplification and directives. Participants shared that words that oversimplify or minimize how hard diabetes is, such as “you’ll get used to it,” “just,” “should,” “lose weight,” and “at least it’s not . . .” can make them feel dismissed. Words that are directives included “lose weight,” “exercise more,” “should/shouldn’t,” “can’t,” “no,” “stop,” “not allowed to,” and “don’t.” Participants said that directives, or words that tell people what to do, make them feel cranky, upset, hurt, and “like a failure with no self-control.” Some indicated that there is a constant concern about “getting caught,” whereas others said they simply lose interest when they hear these words.

“It varies from mild annoyance to sarcasm to RAGE.” (Participant 26)

Misunderstanding, misinformation, or disconnection. Words that indicate a lack of understanding or misinformation included “cure,” “reverse,” “have you tried . . .,” “you’re fine,” “normal,” “dead pancreas,” “you don’t look fat,” and “the bad kind.” Participants also discussed experiences with HCPs who appeared to be disconnected, as shown through phrases such as “you’re fine,” “are you still using insulin?,” and “have you checked your sugar recently?”

Participants reported that there is a large gap in knowledge and under-

standing about diabetes in general. Although participants acknowledged that people do care, they responded that comments based on misconceptions are frustrating and can lead to feeling defensive, impatient, or even angry. They shared their feelings of being tired of explaining and tired of hearing about cures or other options they know are not valid. Participants reported that comments and questions from HCPs that indicate a disconnection or lack of knowing the patient make them feel annoyed, exasperated, and irritated. They also said they feel tired, resigned, and not respected.

“We are all treated with words that suggest we’re mentally incompetent, medically illiterate, and failing at our job of staying alive.” (Participant 28)

Body language and tone. How things are said can be just as hurtful as what is said. Participants reported that body language and tone can send messages that are patronizing, impersonal, and accusatory.

“I felt like a lot of it was my fault.” (Participant 68)

Question 3

Three themes emerged from the Question 3 data regarding where participants hear these words:

General public (friends, colleagues, family, teachers, and strangers). Findings revealed that, although most people care, they are often misinformed about diabetes. In addition, hurtful words and phrases are used because that is what people hear and know.

“To be honest, I don’t know how to answer this. Unless someone is talking about how awesome I am in dealing with it, it’s usually bad.” (Participant 40)

Many participants discussed the “food police” and all the questions and comments people make about food.

“... nobody ever asks, ‘Should you be eating those carrots?’”
(Participant 33)

HCPs. Several participants discussed hearing upsetting words in health care settings. One particular problem is seeing “uncontrolled” on the health record.

“I’ve always felt like I’m the only one who can ‘judge’ my own feelings of control.” (Participant 23)

Media. Findings revealed that negative words are also used in print, broadcast, and social media, which only perpetuates the problem. The words that circulate through media can spread misconceptions, stigma, or simply bad information about diabetes and the people who live with it.

“Hey, you know what I saw on the news about diabetes?”
—INSTA-CRINGE.”
(Participant 20)

Question 4 and Question 5

Three themes emerged from the data about words or phrases participants would like their HCPs to stop using:

Stop judging. Participants suggested that HCPs could stop using words, phrases, body language, and tone that are judgmental or condescending or that lack investment in the person as an individual. Words that impart fault or guilt can be removed, especially “should,” “control,” “stop,” and “can’t.”

“Anything that begins with ‘should.’” (Participant 23)

“Sigh. Control. I think that’s just an illusion.” (Participant 50)

Stop labeling. Participants shared they would also like HCPs to stop addressing them as labels including “diabetic,” “noncompliant,” “average,” and “complicated.” Instead use their name.

“Labeling of any kind sucks big time.” (Participant 41)

Stop discussing complications. Hearing about complications is scary and stressful. It gets old and tiring to hear about them every time.

“I don’t want to hear about the complications at EVERY visit. I totally heard it the first time.”
(Participant 12)

Question 6

Three themes emerged from the data about how participants would feel if HCPs stopped using these words:

Suggestions for HCPs. Participants reported that they would like HCPs to listen to people with diabetes and focus on the person. They suggested treating people with diabetes like humans, partners, and as if they are competent. Acknowledge that diabetes is hard work and take an interest in what is going on for the individual. Do not blame.

“Focus on the person, not the diagnosis. You’ll treat both more effectively that way.”
(Participant 34)

These words will be replaced with other words. A few participants expressed worry that the current negative words will simply be replaced with different ones.

“... whatever words we use to replace the ‘problem’ words will grow to associate with the same issues.” (Participant 28)

The bigger problem is the messages these words send to people with diabetes and to the general public about people with diabetes. HCPs can take a different approach in working with people who have diabetes and maybe positive, empowering words will follow.

“In fact, you could almost boil the basic message of the past hour to the fact that people use words by rote to pigeonhole us instead of actually seeing and listening to the person.”
(Participant 3)

If HCPs stopped using these words. Participants discussed how they would feel if HCPs stopped using judgmental, scary, labeling, oversimplified, disconnected, and directive words, body language, and tone. These responses included feeling respected or listened to and that HCPs really care. They would feel relieved, supported, and comfortable.

“... like maybe I don’t have a chronic disease every second of my life.” (Participant 7)

They would trust their HCPs and feel more confident and willing to work with them.

“I would have more faith in my health care providers if they didn’t use words that I think convey a lack of information, sensitivity, or understanding of my experience.”
(Participant 1)

Participants reported they would feel more like a partner or team and less scared.

“... could get to meaningful conversation more quickly with less emotional obstacles and baggage.” (Participant 23)

It would reduce stress, anxiety, anger, and defensiveness and help them feel less judged.

“Better language would help shift the shame, blame, and self-loathing from the person to the disease. Allows for hope.”
(Participant 25)

There would be less medical stigma.

“Getting rid of stigmatized language would help me feel like a human being first. And it would help me feel like I’m seen as one.” (Participant 34)

If HCPs adopted an approach to working with people who have diabetes that includes sending messages of

understanding and hope rather than using negative, judgmental words, people may be empowered and feel better about their situation.

"I would feel less judged, less ashamed, less helpless, less annoyed, less defensive, less angry, and more likely to be happier."
(Participant 29)

Discussion

This study revealed that people with diabetes are aware of and bothered by the language used in diabetes care. Consistent with research on words and other health conditions, participants reported feeling judged, stigmatized, blamed, and shamed through the words used by HCPs, the media, and the general public. Negative words are part of messages that indicate an imbalance of power in the patient-provider relationship.

An article in an online diabetes newsletter (32) offered several suggestions for how HCPs can help people with diabetes feel more empowered and less stigmatized. Replacing negative messages was at the top of the list.

Diabetes distress, which is frequently discussed in the literature (33,34), is a response to the stressful demands of diabetes management and can result in diminished self-care and elevated blood glucose levels. The language of diabetes may be contributing to diabetes distress. Study participants responded that many words in diabetes care make them feel judged, blamed, and shamed. They also mentioned feeling fear and anxiety. These feelings could translate into distress and impair diabetes management efforts.

Broom and Whittaker (35) wrote about the damaging effects of the word "control" in diabetes. HCPs refer to managing diabetes as "controlling" diabetes. Blood glucose and A1C levels are often reported as levels of control: "glycemic control," "glucose control," "poorly controlled," "uncontrolled," "well controlled," "good control," and "bad/poor control." Diabetes requires an effort to

achieve control over something that cannot be controlled. Failing to "control" diabetes suggests not only poor health but also moral failure (35). Participants in this study consistently reported feeling like a failure, based on the word "control" and other words used in diabetes care. Instead of saying, "glucose control," HCPs could simply say "blood glucose levels" or "A1C" or use other neutral, fact-based terms (2,36).

Consistent with Critical Theory, this study sought to bring awareness to the problem of language in diabetes care. Participants disclosed that negative words used in diabetes care not only hurt them, but also hurt their relationships with HCPs. HCPs are often perceived as being in a position of power. Being aware of and working toward changing the language of diabetes care could improve HCPs' communication and relationships with patients. These findings could be used to form the basis of a language movement in diabetes care.

Limitations

Findings from this qualitative study cannot be generalized to all people with diabetes. Additional research is encouraged to validate these findings. In this study, participants did not identify whether they had type 1 or type 2 diabetes. Members of the virtual focus groups also could have been caregivers for people with diabetes. Another study could compare how people with the various types of diabetes (and their caregivers) respond when asked about diabetes-related language.

Conclusion

This study suggests that the time has come for a language movement in diabetes care, and the first step is awareness. Words are part of context, and through context, people with diabetes shape meaning and understanding. Participants in the focus groups described here shared their experiences with diabetes-related words that caused negative responses. They expressed a desire for better commu-

nication from and with their HCPs. An increasing number of HCPs are embracing approaches that empower people with diabetes. Using messages and words that are consistent with those approaches can improve communication and relationships between patients and providers. Beginning with the first encounter at diagnosis, using messages that impart strength and hope could make a difference in how people feel about and manage diabetes and their overall health.

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Duality of Interest

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

Author Contributions

J.K.D. was the sole author of this article. She is the guarantor of this work and, as such, had full access to all of 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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