The Use of Language in Diabetes Care and Education

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Language is powerful and can have a strong impact on perceptions as well as behavior. A task force, consisting of representatives from the American Association of Diabetes Educators (AADE) and the American Diabetes Association (ADA), convened to discuss language in diabetes care and education. This document represents the expert opinion of the task force. The literature supports the need for a language movement in diabetes care and education. There are effective ways of communicating about diabetes. This article provides recommendations for language used by health care professionals and others when discussing diabetes through spoken or written words—whether directed to people with diabetes, colleagues, or the general public, as well as research questions related to language and diabetes.

It has been well established that diabetes is a complex disease that is challenging to manage on a daily basis. There has been abundant discussion recently (1,2) about the patient experience, communication, and questions about how to make life better for people with diabetes. While information exists on how to interact more effectively with people living with diabetes (3), there is very little discussion about the language we use in these encounters. People experience both diabetes and the language of diabetes in context. Language is the principal vehicle for the sharing of knowledge and understanding (4). Words are immediately shaped into meanings when people hear or read them (5,6), and those meanings can affect how a person views him or herself.

Language lies at the core of attitude change, social perception, personal identity, intergroup bias, and stereotyping. The use of certain words or phrases can intentionally or unintentionally express bias about personal characteristics (e.g., race, religion, health, or gender). Words have the power to “elevate or destroy” (7). This is also true of language referring to persons with diabetes, which can express negative and disparaging attitudes and thereby contribute to an already stressful experience of living with this disease. On the other hand, encouraging and collaborative messages can enhance health outcomes (8). How we talk to and about people with diabetes plays an important role in engagement, conceptualization of diabetes and its management, treatment outcomes, and the psychosocial well-being of the individual. For people with diabetes, language has an impact on motivation, behaviors, and outcomes (9).

A task force, consisting of representatives from the American Association of Diabetes Educators (AADE) and the American Diabetes Association (ADA), convened to discuss language in diabetes care and education. The task force reviewed the literature regarding language used in the delivery of diabetes care and education and made recommendations to enhance the communication process. This document represents the expert opinion of the task force. The task force members defined and adopted four principles that guided the work and served as a core set of beliefs for this article. Table 1 presents the guiding principles.

A language movement in health care is not a new concept. Psychologists, clinicians, and even the lay community have been discussing the language of health for decades,
and evidence exists demonstrating that language will change over time. For decades, a substantial amount of the language around diabetes has been focused on negative outcomes and laden with judgment and blame, and it has not adequately considered individual needs, beliefs, and choices. As our knowledge of diabetes has expanded and as more effective treatments have emerged, we are moving into a more personalized approach to diabetes care and education. As such, it is time for the language around diabetes to reflect this evolution.

Diabetes Australia, upon identifying that language in diabetes can be “inaccurate and harmful,” published a position statement calling for a “new language for diabetes,” summarizing negative emotional and behavioral outcomes of some language choices in diabetes (10). The International Diabetes Federation published a Language Philosophy because of the belief that there is a “responsibility to set an example about appropriate language to others” (11).

This article provides recommendations for language related to diabetes that is respectful, inclusive, person centered, and strengths based (see detailed definitions in Table 2) to diabetes clinicians, diabetes educators, researchers, journal editors and authors, and other professionals who communicate about diabetes (e.g., authors of patient education publications). These recommendations are consistent with the American Psychological Association style guidelines for nonhandicapping language, which originated in the Committee on Disability Issues in Psychology (the following is adapted from http://www.apastyle.org/manual/related/nonhandicapping-language.aspx): Nonhandicapping language maintains the integrity of individuals as whole human beings by avoiding language that

- implies that a person as a whole is disabled (e.g., diabetic child)
- equates a person with his or her condition (e.g., diabetic)
- has superfluous and negative overtones (e.g., unmotivated, suffering with/from diabetes)
- is regarded as a judgment (e.g., noncompliant, nonadherent, poorly controlled)

The ADA “Standards of Medical Care in Diabetes—2017” (12) calls for “a patient-centered communication style that uses active listening, elicits patient preferences and beliefs, and assesses literacy, numeracy, and potential barriers to care” in order to “optimize patient health outcomes and health-related quality of life.” The AMA Manual of Style (13) calls for authors to do the following:

Avoid labeling (and thus equating) people with their disabilities or diseases (e.g., the blind, schizophrenics, epileptics). Instead, put the person first. Avoid describing persons as victims or with other emotional terms that suggest helplessness (afflicted with, suffering from, stricken with, maimed). Avoid euphemistic descriptions such as physically challenged or special.

In an effort to build on those ideas and further define effective communication in diabetes, the task force developed five evidence-informed recommendations (see Table 3) for person-centered and strengths-based communication as well as a list of words and phrases that have potentially negative connotations, along with suggestions for alternatives (see Table 4). This article emphasizes the rationale, based on expert consensus, for a reevaluation of the way we talk about diabetes, even if the meanings of particular words change over time.

Language is important for health care professionals to consider as they work to build and strengthen therapeutic relationships with their patients (14). Awareness of language also applies to family members and caregivers of people with diabetes, corporate spokespeople, and members of the media who are in a position to speak and write about diabetes. This article is not meant to suggest how people living with diabetes talk or write about themselves as individuals. In addition, other key aspects of communication, including design and layout of information, health literacy, and health numeracy are beyond the scope of this article and have been discussed elsewhere.

**RECOMMENDATIONS**

1. **Use Language That Is Neutral, Nonjudgmental, and Based on Facts, Actions, or Physiology/Biology**

In health care, the way in which something is said is equally important as what is actually being said (15,16). Words, which “are inseparable from the concepts they refer to” (5), are powerful. Medical language has an influence over patients and plays a central role in defining experience and understanding. How one hears and interprets language related to disease has an impact on one’s perception of their health and themself as a person (5). Words that start out as simple descriptors can take on positive or negative connotations over time (17).

Judgmental words and messages can inflict shame, leading a person to pull

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**Table 1—Guiding principles for communication with and about people living with diabetes**

- Diabetes is a complex and challenging disease involving many factors and variables
- Stigma that has historically been attached to a diagnosis of diabetes can contribute to stress and feelings of shame and judgment
- Every member of the health care team can serve people with diabetes more effectively through a respectful, inclusive, and person-centered approach
- Person-first, strengths-based, empowering language can improve communication and enhance the motivation, health, and well-being of people with diabetes

**Table 2—Key definitions**

<table>
<thead>
<tr>
<th>Word/phrase</th>
<th>Definition</th>
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<tr>
<td>Strengths-based language</td>
<td>Opposite of a deficit approach; emphasizing what people know and what they can do (7). Focusing on strengths that can empower people to take more control over their own health and healing (103). Example: Lee takes her insulin 50% of the time because of cost concerns (instead of Lee is noncompliant/nonadherent).</td>
</tr>
<tr>
<td>Person-first language</td>
<td>Words that indicate awareness, a sense of dignity, and positive attitudes toward people with a disability/disease. Places emphasis on the person, rather than the disability/disease (88). Example: Lee has diabetes (instead of Lee is a diabetic).</td>
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away from other people and situations (18). Adults living with diabetes who participated in a focus group study \( n = 68 \) reported that they experience judgment and blame through the language used by health care professionals, friends, family, and the general public (16). It is preferable in patient and professional education, research, publishing, and health care to use words that are factual, neutral, and nonjudgmental rather than words that impose blame or imply negative attitudes (19–21).

Possibly because of perceived judgment from health care professionals, people with diabetes sometimes alter or underreport blood glucose levels (22) or omit information during health care provider visits (23). Adolescence is an especially vulnerable time for communication and self-care (24). Therefore, adolescence is an important period when effective, nonjudgmental messages may help establish trusting relationships, which then foster open and honest communication (16).

In a study of postoperative patients, negative words were associated with higher pain scores and higher levels of the stress hormone cortisol when compared with no words or positive words (25). Research has linked pain-related words to activating brain networks similar to unpleasant stimulation (26). Another study showed that participants undergoing venipuncture reported experiencing significantly more pain when hearing negative words such as “beware” or “sting” (27).

The perception of “control” has evolved over time. Use of “control” in diabetes came from clinical research and was reinforced with the Diabetes Control and Complications Trial (DCCT) (28). Over time it has come to be perceived as “ability to control” or “lack of control,” and there has been a strong emphasis on this word when discussing diabetes today (23,29). The conclusion of Broom and Whittaker (23) was that this type of messaging positions people with diabetes as “disobedient children” or as “wicked or foolish adults,” which is contradictory and confusing for people with diabetes. Broom and Whittaker suggested that there may be moral implications regarding people’s ability to “control” blood glucose levels, food choices, weight, physical activity, and one’s “self.” As a result, failure to control diabetes not only relates to health but also implies a moral failing (23).

The term “control,” when used in discussing diabetes management activities, places responsibility on the person with diabetes while also implying strictly following the advice of the health care professional who holds authority and knowledge. On the other hand, some people interpret “taking control” as purposely going against what providers suggest (23). In society there is value to being “in control,” while being “out of control” means failure. The frequent reference to “control” in diabetes forms a moral discourse surrounding the disease and may elicit feelings of shame. It may be more effective to serve those with diabetes without using language that places implicit or explicit judgment on them or blames them for their health-related problems (23). Diabetes conversations may not always include a discussion of the effort and/or intent on the part of the person managing the disease. A conversation about “control” that omits mention of a patient’s effort/intent puts the focus solely on the effect or expected outcomes of diabetes care. The goal, instead, is to use language that is neutral, nonjudgmental, and based on facts, actions, or physiology/biology (see Table 4).

Table 3—Recommendations

<table>
<thead>
<tr>
<th>Use language that</th>
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<tbody>
<tr>
<td>1. is neutral, nonjudgmental, and based on facts, actions, or physiology/biology</td>
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<tr>
<td>2. is free from stigma</td>
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<td>3. is strengths based, respectful, inclusive, and imparts hope</td>
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<td>4. fosters collaboration between patients and providers</td>
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<td>5. is person centered</td>
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2. Use Language That Is Free From Stigma

Stigma has been defined as labeling and identifying human differences via stereotyping in which the labeled person is linked to undesirable characteristics (30). Health-related stigma is a psychological factor that negatively influences the lives of people living with diabetes (23). In diabetes, “uncontrolled,” “diabetic,” “noncompliant,” and “nonadherent” can be stigmatizing terms that associate with stereotypes including “lazy,” “unmotivated,” “unwilling,” and “don’t care” (31).

Results from an online survey \( n = 12,000 \) to assess stigma related to diabetes and the associated psychological impact demonstrated that most people with type 1 diabetes (76%) and type 2 diabetes (52%) have experienced stigma (32). In fact, the most widely reported forms of diabetes-related social stigma were the perception of having a character flaw or a failure of personal responsibility (81%) and being a burden on the health care system (65%). Another study showed that people with diabetes reported perceptions of being weak, fat, lazy, overeaters or gluttons (33), poor or bad people, and not intelligent (34). While these characteristics are often perceived by people with type 2 diabetes, there is evidence that people with type 1 diabetes feel similar stigmatization (35,36).

Research has shown that people experiencing stigma are less likely to seek follow-up care (37) and are more likely to feel psychological distress (38). In a study of people living with diabetes \( n = 3,347 \), data from a self-administered questionnaire demonstrated that perceived stigma is associated with increased psychological distress, depressive symptoms, decreased social support, and decreased quality of life (39). These assessments were confirmed in a study where stigma related to diabetes was associated with elevated A1C; increased blood glucose variability; feelings of guilt, shame, blame, embarrassment, and isolation; and negative impacts on social life (32). A recent randomized controlled trial employing the Weight Bias Internalization Scale (40) demonstrated that higher weight stigma predicted increased odds of having high triglycerides (odds ratio 1.88 [95% CI 1.14–3.09]) and may heighten cardiometabolic risk (41).

Living with a stigmatizing disease can have a psychological impact that can be detrimental to self-care (38). Several factors contribute to diabetes-related stigma, including blame, fear, disgust, social norms, and avoidance of disease. While stigma is experienced by people with both type 1 and type 2 diabetes, it tends to be perpetuated even within the diabetes community. People with type 1 diabetes have reported beliefs about those with type 2 diabetes being responsible for their disease, which creates an “us vs. them” dynamic (36).
<table>
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<tr>
<th>Language with potentially negative connotations</th>
<th>Suggested replacement language</th>
<th>Rationale</th>
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<tbody>
<tr>
<td>Compliant/compliance, noncompliant, adherent/nonadherent, adherence/nonadherence</td>
<td>“He takes his medication about half the time.” “She takes insulin whenever she can afford it.” “He eats fruits and veggies a few times per week.” Engagement Participation Involvement Medication taking</td>
<td>The words listed in the first column are inappropriate and dysfunctional concepts in diabetes care and education. Compliance and adherence imply doing what someone else wants, i.e., taking orders about personal care as if a child. In diabetes care and education, people make choices and perform self-care/self-management. Focus on people’s strengths—what are they doing or doing well and how can we build on that? Focus on facts rather than judgments.</td>
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<tr>
<td>Control (as a verb or adjective) Controlled/uncontrolled, well controlled/ poorly controlled</td>
<td>Manage “She is checking blood glucose levels a few times per week.” “He is taking sulfonylureas, and they are not bringing his blood glucose levels down enough.”</td>
<td>Control is virtually impossible to achieve in a disease where the body no longer does what it is supposed to do. Use words/phrases that focus on what the person is doing or doing well. Focus on intent and good faith efforts, rather than on “passing” or “failing.” Focus on physiology/biology and use neutral words that don’t judge, shame, or blame.</td>
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<tr>
<td>Control (as a noun) Glycemic control, glucose control, poor control, good control, bad control, tight control</td>
<td>A1C Blood glucose levels Blood glucose targets Glycemic target/goal Glycemic stability Glycemic variability</td>
<td>Focus on neutral words and physiology/biology. Define what “good control” means in factual terms and use that instead.</td>
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<tr>
<td>Diabetic (as an adjective) Diabetic foot Diabetic education</td>
<td>Foot ulcer, infection on the foot Diabetes education</td>
<td>Focus on the physiology or pathophysiology. “Diabetic education” is incorrect (education does not have diabetes). Put the person first. Avoid using a disease to describe a person. Avoid describing people as a disease.</td>
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<tr>
<td>Diabetic person “How long have you been diabetic?” Diabetes patients</td>
<td>Person with diabetes “How long have you had diabetes?” Patients with diabetes</td>
<td></td>
</tr>
<tr>
<td>Diabetic (as a noun) “Are you a diabetic?”</td>
<td>“Do you have diabetes?” Person living with diabetes Person with diabetes Person who has diabetes</td>
<td>Person-first language puts the person first. Avoid labeling someone as a disease. There is much more to a person than diabetes. When in doubt, call someone with diabetes by their name.</td>
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<tr>
<td>Nondiabetic, normal</td>
<td>Person who does not have diabetes Person without diabetes</td>
<td>See above. The opposite of “normal” is “abnormal”; people with diabetes are not abnormal.</td>
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<td>Imperatives Can/can’t, should/shouldn’t, do/don’t, have to, need to, must/must not</td>
<td>“Have you tried….” “What about….” “May I make a suggestion….” “May I tell you what has worked for other people….” “What is your plan for…” “Would you like to consider…”</td>
<td>Words and statements that are directives make people with diabetes feel as if they are being ordered around like children. They can inflict judgment, guilt, shame, and blame.</td>
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<tr>
<td>Regimen, rules</td>
<td>Plan Choices</td>
<td>Use words that empower people, rather than words that restrict or limit them.</td>
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<tr>
<td>Words/phrases that focus on the provider “I got him/her to…” “I want you to…” Let people…</td>
<td>“He started taking insulin…” “She lost 25 pounds…” “May we make a plan for…” “May I make a suggestion…” Facilitating identified goals and creating a plan with… Self-directed goals</td>
<td>Give the person with diabetes credit for what they accomplished. Make it about the person with diabetes and choices, rather than making it about the provider.</td>
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Continued on p. 1794
Changing the language of diabetes could serve as an “advocacy campaign” to reduce diabetes-related stigma (36).

There are several studies that have investigated preferred terms for describing obesity, a risk factor for developing type 2 diabetes. People have identified “obesity” as an undesirable (19,20,42–44) and highly stigmatizing term (44) that...
implies a “moral or esthetic failing” (42). People experiencing or fearing health-related stigma may avoid treatment or future health care appointments (30,45) and have reported feeling bad about themselves and an increased likelihood of avoiding exercise (45). Stigma can lead to embarrassment and/or shame, and shame can lead to decreased motivation (37) and nonattendance at structured diabetes education (46).

The label “noncompliant” is value-laden and represents an authoritarian patient-provider relationship. “Noncompliant” is a label that can travel with a person (47), for instance, in their chart or in conversations, so that providers have preconceived ideas about patients. Expectancy theory has shown that when individuals are labeled, expectations are set that can become self-fulfilling prophecies (48,49). Beginning with their landmark study, Rosenthal and Jacobson (50) demonstrated the expectancy effect in a variety of contexts. This research shows the expectancy effect is not only important; it is a robust effect that occurs in many situations, including business management (where the biasing effect is the expectations of employers about their employees), courtrooms (where the biasing effect is the expectations about the defendant’s guilt or innocence), and nursing homes (where the biasing effect is the expectation a resident will get better or worse). This effect has also been shown in athletic ability, where coaches’ expectations were set about the skill of the athletes (49).

Expectancy effects revealed four main factors of learning-related labeling in the classroom setting (48). In a randomized controlled trial, where typical students were randomly labeled as “spurters,” changes were seen in emotional climate, teacher behaviors, student opportunities to speak, and level of detailed feedback. When teachers expected students to do well, they were warmer toward them, gave them more difficult study materials, gave them more opportunities to respond and/or ask questions, and provided more informative feedback. The teachers’ expectations affected learning outcomes; students who were randomly labeled “spurters” performed better than “nonspurters” (48).

If expectancy theory is applied to the patient-provider relationship in diabetes, people labeled as “noncompliant,” “poorly controlled,” “unmotivated,” or “unwilling,” may find that these expectations become true. Potential evidence for this effect may be seen in patient and provider resistance to initiation of insulin therapy. Several studies have found that about half of nurses and general practitioners (50–55%) reported that they delay insulin therapy until “absolutely necessary” and are significantly more likely to do so when they perceive patients as “less adherent,” “unwilling,” or “uncontrolled” (51–53). The presumption that patients will be “noncompliant” or “unwilling” may result in a self-fulfilling prophecy. In fact, people with type 2 diabetes commonly report being “unwilling” to start insulin (17–39%) (54–56).

In a separate study, people who were given a new prescription for insulin fell into two groups: those who started taking the insulin and those who did not. Those who did not start taking insulin were significantly more likely to blame themselves and believed their prior lack of successful self-management caused the current need for insulin (54). This suggests that when providers label patients as “noncompliant” or “unwilling” and when patients see themselves as “noncompliant,” people with diabetes are less likely to be willing to start taking insulin.

For some people, noncompliance may be a way of trying to gain control over their own lives, yet this psychological protection can actually lead to physical harm (57). There are many reasons for noncompliance in diabetes management (58,59), and the messages can be adjusted to reflect an understanding of these factors. The word “adherence” was used to replace “compliance” in the 1990s; however, “adherence” has a similar meaning and may have a similarly negative connotation. Therefore, neither “compliance” nor “adherence” is consistent with an empowerment, strengths-based approach in diabetes (57,60–62). The goal is to use language that is free from stigma (see Table 4).

3. Use Language That Is Strengths Based, Respectful, Inclusive, and Imparts Hope

Strengths-based language focuses on what is working rather than what is wrong, missing, or abnormal. This approach indicates a belief in people and their capabilities, talents, abilities, possibilities, values, and hopes (7). Language that focuses on what is wrong, on the other hand, may elicit a sense of shame, an emotion associated with an intense physiological response and that evokes a person’s weakness rather than potential (18).

Ward et al. (15) found that when physicians were perceived as disrespectful, insincere, or emotionless, African Americans with weight problems were less likely to engage in behavior change or seek the help they need. African American study participants wanted health care providers to demonstrate respect, nonjudgment, and concern for their well-being (15).

Language that is negative or judgmental can contribute to diabetes distress (9). Diabetes distress is defined as all of the worries, concerns, and fears that are associated with a demanding and complex disease like diabetes and the threat of possible complications (63). Diabetes distress is common (64,65) and independently associated with elevated A1C in diabetes (63,64,66,67).

Health care professionals are encouraged to seek skills in “attentive and empathic listening, sensitive verbal inquiry, and use of thoughtful and reflective comments—skills that are the hallmarks of good clinical care” (63). Fear of hypoglycemia and fear of not meeting blood glucose targets are common for people living with diabetes (24) and can contribute to undue stress. Fear of hypoglycemia can lead to keeping blood glucose levels elevated for long periods of time. Health care professionals can use language that instills confidence and encourages people to use their strengths to overcome these fears and manage successfully.

Stress has a negative influence on the body in general (68,69) and even more so for those with diabetes. Health care professionals have an important role in the context of diabetes. As it is difficult to separate language from context (6), negative language and messages can contribute to a stressful disease experience (9). Stress has an impact on blood glucose levels and self-care behaviors, and differences in psychosocial resources including support and coping will affect a person’s response to stress (70).

Empowerment involves identifying needs, taking action, and gaining mastery over issues that are self-identified as important (3). Language that is respectful, inclusive, and strengths based conveys an empowerment approach in diabetes
education and clinical care (71). Saying “I empower patients so they will be compliant” is not consistent with empowerment; language focused on goals identified by patients rather than imposed by health professionals is consistent with empowerment.

Everything that surrounds a person makes up their context. In the case of people with diabetes, that includes the words, attitudes, and behaviors of health care professionals. In fact, context may influence the outcomes of medical treatments (6). Benedetti and Amanzio (72) explained that one of the most basic and controllable contexts is words. Their research examined the placebo and nocebo effects. People who received an intervention that had no therapeutic effect in a verbal context that was hopeful and trust inducing had reduced pain symptoms (placebo effect), while those receiving the intervention in a fearful and stressful context had increased pain symptoms (nocebo effect) (72).

Awareness of language and communication behavior can help health care professionals have more effective conversations (15). A survey study asking patients about their experience with health care providers at the time of diagnosis with type 2 diabetes (n = 172) found that messages of hope, delivered right at diagnosis, have a lasting impact (at least 1 to 5 years) on patients’ attitudes and diabetes management behaviors and significantly mitigate diabetes distress (73). Using language that is strengths based, respectful, inclusive, and imparts hope can facilitate more empowering, productive communication (see Table 4).

4. Use Language That Fosters Collaboration Between Patients and Providers

The need for effective patient-provider communication is a common theme in the diabetes and health care literature (74–81). The ways in which health care professionals interact with people who have diabetes can encourage or discourage engagement and collaboration. Respectful and effective communication is the foundation of trusting relationships in health care (82).

According to Broom and Whittaker (23), people’s sense of identity may get disrupted when they have a disease such as diabetes. A person’s experience of diabetes can influence their self-talk, for example, someone might say “I’m a bad diabetic, because I don’t eat how I’m supposed to.” This “dialogue with the self” (23) is influenced by the words used by health care professionals, who are seen as knowledgeable and powerful. Communication between patients and providers is essential to the success or failure of these interactions (5); Fleischman supports the notion that health care professionals are ethically responsible for periodically reflecting on and critiquing the language they use: “what is clear is that [providers] and patients do not share a common language when talking about illness and disease” (5).

Language that evokes authority and implies a power differential, such as “naughty,” “cheat,” “allowed/not allowed,” “can/can’t,” “should/shouldn’t,” “good/bad,” “must/must not,” and “right/wrong” may result in people with diabetes feeling as though they are being talked to like children (83). Ritholz et al. (80) found that people with diabetes are less likely to discuss self-care information because of a fear of being judged and feeling shame. A randomized controlled trial (n = 222) demonstrated a mean 1-point A1C lowering when people with type 2 diabetes were taught how to reframe self-blame using more neutral, fact-based messages (84).

People naturally internalize the “compliance” model by being involved in the health care system and a part of society, where there are long-held beliefs about disease and health. The language of health care providers, therefore, can have a tendency to reinforce that model. Instead, the patient-provider relationship is an opportunity for mutual engagement, collaboration, and dialogue (62). It is important for providers to communicate with patients that difficulty reaching goals is not their fault; they are not to blame (85). Yelovich recommends approaching the patient-provider interaction as a “meeting of experts” (79).

Patient-provider communication is directly linked to how patients engage with and make the changes recommended by health care professionals (8, 76–78, 86). Providers who received education on collaborative communication reported better patient self-management outcomes (78). Trust in the health care professional is a critical element of the patient-provider relationship that can also improve patient engagement and self-care (16, 75). The goal is to use language that is consistent with collaborative interactions between people with diabetes and health care professionals (see Table 4).

5. Use Language That Is Person Centered

In 2001 the Institute of Medicine made a strong stand for supporting “patient-centered care.” The Institute of Medicine defined patient-centered care as “care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (87). Patient-centered care has been in the literature for more than 50 years (88). More recently, however, efforts have been made to recognize the whole person and therefore transition to “person-centered care” in order to include more than just clinical and medical needs and preferences (89).

Person-centered care involves a dynamic, collaborative relationship with relevant health care providers.

Indicators consistent with person-centered care include quality of life, amelioration of symptoms, and satisfaction (89). Language, an important part of this approach, contributes to effective communication, which relates to patient satisfaction (88). Qualities of person-centered care include support, compassion, and caring. Such qualities encourage patient activation, which leads to better outcomes (88). Messages of support, compassion, and caring can be communicated through the words health care providers choose.

Person-first language is “an essential starting point for conveying respect” (90), with its origin in the disability movement. Fleitas (91) suggested that defining people by their disease, for instance, “diabetic,” just because it is semantically convenient ought to give us pause. “When the words or some disease statement precede the subject of the sentence, an image is formed that prevents the listener or reader from thinking about the subject any other way” (91). She further suggested that descriptors such as “suffers from” and “victim of” can be socially destructive to those with the disease. She described the “linguistic landscape” as being full of landmines that need to be acknowledged and defused (91).

The Diabetes Attitudes, Wishes and Needs (DAWN) studies explored factors that influence active diabetes management (92) and favored shifting from an
acute or “compliance” model to a person-centered approach (93). Kalra and Baruah (94) recommended implementing a campaign toward changing attitudes about diabetes. Raising awareness of the impact of language and adopting person-centered communication could be some of the first steps in such a campaign.

By focusing on person-first language, it may be possible to eliminate stereotypes, negative assumptions, and generalizations by respectfully addressing the whole individual; their disease is simply one part of their life experience (95). Person-first language evolved largely from organizations that serve people with disabilities. Over time, person-first language has been applied to people with other conditions, diseases, or population characteristics and demographics, such as medical diagnoses, age, and ethnicity (96). The American Psychological Association has long endorsed the person-first perspective in an effort to reduce stigma, stereotyping, and prejudice toward people with disabilities; this applies to those working in clinical practice, research, and education (96).

Barnish (97) found that health care providers and researchers may be more likely than not to refer to people with disabilities in terms that emphasize the disability rather than the person (e.g., “diabetic”). The Obesity Society formally adopted person-first language in 2013. For example, it is more acceptable to say “person with obesity” (98). As clinicians and others provide care and services to people with diabetes, it is important to recognize that possible biases and use of terminology may affect relationships with those who are served and ultimately the care they receive.

To date, there is no universal agreement on the use of person-first language (96,99), and there are organizations that espouse the use of “identify-first” language (e.g., “blind person”), including the National Federation of the Blind (100). However, in diabetes, person-first language is more consistent with having an active role in self-management rather than being a passive recipient (9) (see Table 4).

GAPS IN KNOWLEDGE IN LANGUAGE AND DIABETES

There is a paucity of research that directly addresses questions about language in diabetes care and education. Most of the existing literature reports qualitative methods used to illuminate issues of language and the experience of diabetes. There are several important questions that warrant further study.

- What is the relationship between language and stigma in diabetes?
- What is the effect of language in different types of diabetes, age-groups, and cultures?
- What is the role of expectancy theory in diabetes?
- What is the impact of language in the media on people with diabetes?
- What is the effect of language on patient engagement/motivation and diabetes outcomes?
- Does changing the language of diabetes improve outcomes?
- What is the effect of language on patient-provider relationships?
- What are effective ways to teach health care professionals about language?

CONCLUSIONS

Language cannot be separated from thought or experience. Language is part of every person’s context, and people create meaning from the messages they hear. The paradigm of diabetes care and education is moving past an approach that views the health care provider as the expert who tells people with diabetes what to do. It is moving toward an approach where people with diabetes are the central members of their care teams, experts on their experiences, and integral to the management of their disease. Diabetes professionals are working toward person-centered care that is based on respectful, inclusive, and empowering interactions. Health care professionals have an opportunity to reflect on the language used in diabetes and adapt strengths-based, collaborative, and person-centered messages that encourage people to learn about and take action to manage this complex disease. The ICD-9 Clinical Modification codes (ICD-9-CM codes) (101) linked with reimbursement included multiple codes for uncontrolled diabetes. Despite the removal of the modifier “uncontrolled” in the ICD-10-CM (102), the legacy of the ICD-9-CM system persists in medical records. Influencing culture and removing negative labeling will take time and determination.

The use of empowering language can help to educate and motivate people with diabetes, yet language that shames and judges may be undermining this effort, contributing to diabetes distress, and ultimately slowing progress in diabetes outcomes. This article serves as a starting point to acknowledge and avoid the potential pitfalls of the language used in diabetes. Its purpose is to engage health care professionals and those who prepare future health care professionals in a movement toward language that is consistent with an empowerment approach. The language movement that began decades ago has reached the diabetes community and requires support and implementation from all health care professionals, researchers, writers, and eventually society at large to be successful and sustainable. In addition, this article can serve as a guidepost for those in the media who communicate health messages to consider more carefully the language they use when writing about diabetes and other chronic diseases. It is also a call to action for scholars to further study and report on the impact of language on people with diabetes. The task force plans to follow up on this article by creating a media style guide and resources for health care professionals.

The time has come to reflect on the language of diabetes and share insights with others. Messages of strength and hope will signify progress toward the goals of eradicating stigma and considering people first.

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