
Diabetes Care paper from ADA/AADE details importance of language in diabetes, explains rationale for changing vocabulary - October 19, 2017

Executive Highlights

- In a new, innovative paper [published in Diabetes Care](#) and in [The Diabetes Educator](#), the ADA and AADE have shared a set of specific recommendations about language used in diabetes care and education. Kudos to the group for such collaboration!
- The article notes that when talking about diabetes, HCPs, caregivers, and the media can (and should) adopt empowering, non-judgmental, non-stigmatizing vocabulary to motivate, educate, and foster patient/provider collaboration. For example, "adherence" and "compliance" (especially, compliance!) can be replaced with "engagement," "participation," or "involvement." This one example, in particular, has been weighing on our minds for quite some time now, and we're so happy to see a consensus on getting rid of "compliance" in particular.
- In an interview with very impressive lead author Dr. Jane K. Dickinson, she highlighted that AADE has already created a freely accessible language guide based on this paper, which she hopes to see utilized by healthcare professionals, family members, and the general public. She also hopes that writers, industry leaders, and other stakeholders will be in contact for assistance in changing the language used in their own work. Moreover, she wishes for HCPs to see the value in focusing on patient strengths and needs, rather than their own agenda, and in approaching patients as experts in their own health.
- Dr. Dickinson alluded to the fact that there's much work to be done, still, in spreading this message. Indeed, in a talk at [AADE 2017](#), she shared an anecdote of HCPs at a recent dinner using the word "non-compliant" fluidly in conversation, despite all the progress that's being made on this front. This Diabetes Care publication is an incredibly important advance, and we recognize that changing habits of all the people who talk about diabetes (providers of all specialties, members of the general public, the media) will require ongoing, concerted effort - fortunately, there are powerhouse advocates like Dr. Dickinson behind this vital movement!

*Diabetes Care just [published a new paper](#) (simultaneously published in AADE's *The Diabetes Educator*), spearheaded by Dr. Jane K. Dickinson, suggesting specific language to be used when talking or writing about diabetes. "The Use of Language in Diabetes Care and Education" was put together by representatives from the ADA and AADE. Dr. Dickinson's team was motivated by the fact that little attention has been placed on language - in talking to patients or talking about patients - despite other strides forward in diabetes care, such as a growing emphasis on patient experience, quality of life, and patient- (or rather, person-) centered approaches. Language referring to people with diabetes can be unintentionally negative and disparaging, influencing conceptions of the disease, outcomes, and individual wellbeing. The authors acknowledge prior work that has been done in language and diabetes: Diabetes Australia has called for a "new language for diabetes" based on the behavioral and emotional outcomes associated with language, and IDF has published a *Language Philosophy*. To take this to another level and to reach a wide audience with this key message, the authors put forth four guiding principles in communicating about diabetes:*

(i) Diabetes is a complex and challenging disease involving many factors and variables;

(ii) Stigma that has historically been attached to a diagnosis of diabetes can contribute to stress and feelings of shame and judgment;

(iii) Every member of the healthcare team can serve people with diabetes more effectively through a respectful, inclusive, and person-centered approach; and

(iv) Person-first, strengths-based, empowering language can improve communication and enhance motivation, health, and wellbeing of people with diabetes.

The meat of this paper is in its practical recommendations for "respectful, inclusive, person-centered" language, and the authors have created their own evidence-based recommendations for communication: Use language that (i) is neutral, non-judgmental, and based on facts, actions, or physiology/biology, (ii) is free from stigma, (iii) is strengths-based, respectful, inclusive, and imparts hope, (iv) fosters collaboration between patients and providers, and (v) is person-centered. In accordance with these principles, the authors produced a four-page table of words and phrases that can carry negative connotations, side-by-side with superior alternatives. Importantly, the paper also lists the rationale for replacing these words in talking about diabetes - we found this to be quite compelling, and we hope real-world HCPs are similarly moved. Below, we detail the recommendations for communication and provide a table of, in our opinion, the most important language changes suggested in the paper. Notably, these recommendations are intended for family, caregivers, corporate spokespeople, HCPs, and other members of the media who write and speak about diabetes. They are not suggesting how people with diabetes should talk about themselves.

As disclosure, we note that Kelly Close is an author on this paper.

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Evidence-Based Recommendations

- **Recommendation 1: Use language that is neutral, non-judgmental, and based on facts, actions, or physiology/biology.** The authors establish that words are inextricable from the concepts they refer to, and they thus maintain that how a person hears and interprets disease-related language impacts his/her perception of personal health and identity. Simple descriptors can develop specific connotations due to their use. Judgmental words can cause shame, and blame is commonly felt by adults living with diabetes due to the language used to describe them. For example, the use of "control" in diabetes came from research, reinforced by the DCCT, and has become perceived as "ability to control" or "lack of control," equating patients to "disobedient children" or "wicked or foolish adults." Failure to control diabetes spurs a sense of moral failing. Instead, conversations can highlight a patient's effort and intent, not just the expected outcome of diabetes care.
- **Recommendation 2: Use language that is free from stigma.** Health-related stigma negatively influences people living with diabetes, and commonly used terms (uncontrolled, diabetic, non-compliant, non-adherent) carry false stereotypes - lazy, unmotivated, or unwilling. Surveys show that people with diabetes frequently feel they have character flaws, are failures of personal responsibility, or are burdens to the healthcare system. Perhaps most harmfully, the authors note that stigma causes patients to be less likely to seek follow-up care and more likely to experience psychological distress, depressive symptoms, and decreased quality of life. Diabetes-related stigma has even been associated with higher A1c, blood glucose variability, as well as guilt, shame, blame, embarrassment, and isolation. Moreover, research has demonstrated an expectancy effect, in which labeling of individuals creates expectations that become self-fulfilling prophecies. HCPs are more likely to delay insulin therapy for patients perceived as "less adherent," and patients who see themselves as such are less likely to be willing to initiate insulin. AACE released survey results [last year](#) that reflect this expectancy phenomenon, providing a concrete example of how damaging this

bias can be on population-scale health. The survey found that 55% of people with type 2 diabetes wanted to intensify their treatment regimen to reach target A1c more efficiently, but only 18% of diabetes care providers believed this about their type 2 patients, causing significant clinical inertia and allowing hyperglycemia to persist.

- Recommendation 3: Use language that is strengths-based, respectful, inclusive, and imparts hope.** Language that focuses on what is working for patients conveys a belief in patients and their capabilities, rather than causing shame - a sense of self-efficacy goes a long way for people living with chronic disease. Negative or judgmental language can lead to diabetes distress, which is independently associated with higher A1c. People with diabetes commonly fear hypoglycemia and hyperglycemia, and HCPs can use language that instills confidence and prompts patients to overcome these fears and manage their diabetes successfully. This recommended approach to language is intended to empower: Effective communication highlights patient-identified goals to encourage action and mastery over self-identified challenges.
- Recommendation 4: Use language that fosters collaboration between patients and providers.** Patient/provider interactions can encourage or discourage engagement and collaboration, and respectful, effective communication is key to building trusting relationships. Disease can disrupt a person's identity, and his/her experience with a disease and the language used by HCPs combine to influence a person's "self-talk." Patients and providers do not use a common language, and HCPs can avoid evoking a power differential by avoiding words like "allowed/not allowed," "should/shouldn't," or "cheat." Rather than reinforcing the compliance model, the patient/provider relationship can support mutual engagement, collaboration, and dialogue - a "meeting of experts." We've noticed increasing commentary from diabetes thought leaders on the importance of shared decision-making (just yesterday we heard this message from [Dr. Robert Ratner](#)), and it's easy to see why language fostering collaboration is at the crux of this goal - down the line, as we push slowly but surely toward personalized medicine in diabetes, patients will have to feel comfortable sharing preferences, thoughts, and fears with their care team in order to settle on an optimal individualized treatment plan.
- Recommendation 5: Use language that is person-centered.** The authors point out that "patient-centered care" has been a part of the literature for more than 50 years, but more recently, the diabetes field has been transitioning to "person-centered care," which recognizes the whole person, not just their medical needs. Person-centered care invokes quality of life, satisfaction, and amelioration of symptoms. Language can directly boost this goal, with messages of support, compassion, and caring. Key to this is the use of "person with diabetes" rather than "diabetic person." This acknowledges that a disease is only one small part of an individual - disease, and even chronic disease, is not the dominant factor in a person's identity (not by a long shot!). In diabetes, person-first language promotes an active role in self-management, so that individuals are more than "passive recipients" in their own care.

Sample Alternative Word Choices

Below, we include a small sample of alternative word choices as suggested in the *Diabetes Care* paper. See the [full article](#) for an extensive list of problematic vs. preferred words/phrases.

Problematic	Preferred	Rationale
<p>Compliant/compliance/ non-compliant/non-compliance</p> <p>Adherent/non-adherent/ adherence/non-adherence</p>	<p>"She takes insulin whenever she can afford it."</p> <p>Engagement/participation/ involvement/medication-taking</p>	<p>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</p>

		strengths - what are they doing or doing well, and how can we build on that? Focus on facts rather than judgments.
Control (as a noun) Glycemic control/glucose control/ poor control/ good control/bad control/ tight control	A1c/blood glucose levels or targets/glycemic target or goal/ glycemic stability or variability	Focus on neutral words and physiology/biology. Define what "good control" means in factual terms and use that instead.
Diabetic (as a noun) "Are you a diabetic?"	Person living with diabetes/ person with diabetes/person who has diabetes "Do you have diabetes?"	Person-first language puts the person first. Avoid labeling someone as a disease. There is much more to a person than diabetes.

Interview with Dr. Jane K. Dickinson

Q: What do you envision as the down-the-line applications for this work? The paper mentions a media style guide and resources for HCPs - do you have any more specifics in mind?

Dr. Dickinson: AADE has already created a media guide and a handout that can be accessed on their website (here's the link: https://www.diabeteseducator.org/practice/educator-tools/diabetes-language-paper?utm_source=Internal&utm_medium=MAST&utm_campaign=LanguageGuide) that summarizes the messages in the paper and can be shared with any and all. My hope is that these important messages about positive, empowering language and communication in diabetes will not only be shared with health professionals, but also with family members and the general public. We hope that writers, industry leaders, researchers, and other stakeholders will contact us for assistance in changing the language used in their specific settings/work.

Q: How does this work build on Diabetes Australia's position statement and the IDF's Language Philosophy? What specifically does this work add to the language movement?

Dr. Dickinson: Diabetes Australia did the ground-breaking work of publishing a language position statement back in 2012. That paper was certainly motivation for working toward a language movement here in the United States. While the joint language paper from the AADE and ADA is not modeled after either the Diabetes Australia or the IDF statements, the purpose and goals of publishing this paper are certainly similar: to change the language used when speaking to or about people with diabetes and to improve the experience of those living with diabetes through positive messaging. While becoming aware of and changing our language in diabetes is quite simple (and cheap), it's not easy. We live in a large country with an overwhelming amount of diabetes and a very established communication style. Publishing a paper here in the U.S. was needed in order to increase awareness of the problem and motivation for change.

Q: We often hear people describe themselves as diabetic (e.g. on patient panels) - we once heard a provider ask a panel of people with type 1 diabetes who had been referring to themselves as "diabetic" how they felt about the issue/being labeled as diabetic and they were pretty nonchalant about the issue; they generally said that they were all older, or used to it, or they didn't think anything of it. What is your reaction to that?

Dr. Dickinson: As we stated very clearly in the paper, the purpose of the language paper is not to suggest how people with diabetes refer to themselves. People living with diabetes have been hearing - and in many cases using - the term "diabetic" for decades. Again, we are not asking anyone to change how they refer to

themselves. We are asking health care professionals and others in the community to become aware of the labels used in diabetes and work to change that practice.

Q: It seems that a change needs to occur at the level of patient-provider interactions, but it would also seem to me that what HCPs are being told needs to change. We often hear speakers at conferences use "compliance," and "adherence" is so incredibly ingrained in the literature. How do you think a shift can happen in the information that is being fed to HCPs? Do you think that "control" and "adherence" can be eliminated from the literature? I imagine many see a practical utility to these words.

Dr. Dickinson: Once again, these words have been used for decades - lifetimes! - in the health care arena. In the late 1980s and early 1990s there was an attempt to eliminate the word "compliance" and all that happened was people tried to replace it with "adherence," which still means doing what someone else wants. Our goal with this language work is to help health care professionals see the value in approaching people with diabetes as experts in their health and care and avoid making it about what the health care professional wants, but rather what the person needs. We are also asking health care professionals to focus on people's strengths; what they are doing or are able to do. When we change our mindset this way, empowering and strengths-based language follows, because the old words like "compliance" and "adherence" and "control" no longer make sense.

Q: Of all changes to make language in diabetes, the transition from "diabetic" to "person with diabetes" has largely occurred - when I do hear someone say "diabetic," they often correct themselves. How and why do you think that switch has been successful?

Dr. Dickinson: It's hard to say. There is a lot of talk about eliminating the word "diabetic" and not labeling people, and I'm glad it's catching on. I hope it's because of the emphasis on person-centered language that is becoming more and more pervasive in health care. The autism community has wholeheartedly taken this on. It is rare to see "autistic person" anymore - now we see "person with autism." We are even seeing this change with the language around obesity - "person with obesity." Putting the person first is another change in our way of thinking about people with diabetes. It's what we have, not what we are. We are not numbers, we are not a level of "control," we are not a disease: we are people. We still have a lot of work to do in terms of getting this message out to a broader audience.

Q: With respect to getting people to switch from "obese" to "person with obesity," in what ways do you find this more challenging than the diabetic/person with diabetes transition? Or do you think it's just a matter of time?

Dr. Dickinson: I imagine it's a matter of time and exposure. Many people have not heard this message yet. I see "person with obesity" more and more in the literature, but I don't hear it spoken a lot yet.

Q: We recall hearing you mention at AADE that you'd like to see "prevent diabetes" replaced with "delay diabetes" (of course, please let us know if that is inaccurate!); I don't believe this was mentioned in the paper, but we would be so interested in hearing more of your thoughts on this.

Dr. Dickinson: I usually say "reduce risk for diabetes." We included "prevent/prevention" in the word list that is part of the language paper (see Table 4). I've had conversations with people who did everything they were told to "prevent" diabetes and they still got it. The bottom line is that there is no guarantee of prevention. We do know that taking certain actions can reduce someone's risk for diabetes or delay the onset of diabetes, so it really makes more sense to use these words. Saying that type 2 diabetes is preventable is misleading and can cause people to experience unnecessary shame and stress (which doesn't help them manage diabetes).

-- by Ann Carracher, Ben Ose, Lisa Maslak, Payal Marathe, and Kelly Close