The language that we use as healthcare professionals in our conversations with patients can have a profound impact in both positive and negative ways. Many words that are commonly part of the diabetes vocabulary are associated with feelings of judgment, fear, blame, guilt and shame. Some words inappropriately label people with diabetes and perpetuate misunderstandings.

Research drawn from other fields indicates that language does have an impact on the patient-provider relationship and may likely affect diabetes self-care behaviors and ultimately blood glucose levels and other clinical outcomes. For example, lessons learned from expectancy theory research indicates that when students are labeled in a certain way, they are more likely to perform to match that label.

The American Diabetes Association and the American Association of Diabetes Educators convened a Task Force to look more deeply at the literature and identify recommendations regarding the use of language in diabetes care and education. A paper was prepared and jointly published in December 2017 that presents five recommendations:

1. Use language that is neutral, non-judgmental and based on facts, action or physiology/biology.
2. Use language that is free from stigma.
3. Use language that is strengths-based, respectful, inclusive and imparts hope.
4. Use language that fosters collaboration between patients and providers.
5. Use language that is person-centered.

The paper also presents a table of words with potentially negative connotations and suggests replacement language along with the rationale for doing so. While the paper was published with the healthcare professional audience in mind, the goal is to get the message out to a much wider audience including pharmaceutical industry professionals, the media and people affected by diabetes.

The audience is encouraged to identify specific steps to both identify problematic words/phrases in their own language (spoken and written) and discuss steps towards making revisions that are more in line with the recommendations.

References


Resources from AADE:

- Quick Guide for Healthcare Professionals: Speaking the Language of Diabetes

WORDS MATTER: 
THE USE OF LANGUAGE IN DIABETES 
CARE AND EDUCATION

A Discussion About Making a Difference

Melinda D. Maryniuk MEd, RDN, CDE
Senior Consultant; Maryniuk & Associates
Diabetes Education & Nutrition Consultants
Boston, MA

Objectives

- Identify words that may be “problematic” as we talk about diabetes
- Discuss the 5 recommendations from the ADA/AADE Paper on Language
- Practice turning “problematic” words and phrases into ones that are “preferred”
- Explore some “next steps”

Presenter Disclosure Information

In compliance with the accrediting board policies, the American Diabetes Association requires the following disclosure to the participants:

Melinda Maryniuk
Research Support: none
Employee: self-employed
Board Member/Advisory Panel: Foodicine Health
Stock/Shareholder: none
Consultant: Diabetes – What to Know
Other:

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Share some words or phrases that you find problematic
Research: Does Language Affect people?

Meet Susan Guzman, PhD
Director of Clinical Education Services – Behavioral Diabetes Institute
www.behavioraldiabetes.org

Expectancy Theory

Expectancy Effects: 4 Main Factors

- The *emotional climate* was affected by expectations. Teachers were warmer toward students they expected to do well.
- The *behaviors* of teachers were different. Teachers gave "spurters" more difficult study materials.
- The *opportunities to speak out* in class were different. Teachers gave "spurters" more opportunities to respond and more time to answer questions.
- The *level of detailed feedback* about performance was different. Teachers gave "spurters" more informative feedback.

(Rosenthal, 1994)

Uncontrolled

Diabetes Stigma
People with diabetes perceived as...

- Having a character flaw or a failure of personal responsibility.
- Being a burden on the healthcare system.
- Being weak, fat, lazy/slothful, overeaters/gluttons, poor, bad, and not intelligent.


Does diabetes come with social stigma?

- Type 1: 24% No, 76% Yes.
- Type 2: 48% No, 52% Yes.


Guilt, shame, blamed, fear embarrassment

- Avoidance/Hiding
- Additional Barriers
- Disengagement
- Isolation
- Depression
- Health Outcomes

Rhee, Chronic Illn 2014
Weinger, Arch in Med 2011

On a scale of 1-5, how strongly do you feel our words can impact patient’s emotions, attitudes, behaviors and ultimately — outcomes? (5 = very strong)

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HCP communications

Messages at diagnosis

- IntroDia: Conversation Elements

  36 “Told me that with good care and effort, odds are good that I can live a long and healthy life with diabetes.”
  22 “Told me that a lot can be done to control my diabetes.”
  35 “Told me that if someday I need to take insulin, it would be my own fault.”
  27 “Told me that diabetes is mostly my fault because of the way I had been living my life.”
  17 “Encouraged me to attend diabetes-related programs in the community that could help me.”
  13 “Helped to make a treatment plan that I could do in my daily life.”
  10 “Encouraged me to go to a specific group or class to help me cope with diabetes.”
  14 “Helped to plan ahead so I could take care of my diabetes even in hard times.”

(Polonsky et al, 2017)
Conversation elements

Key Messages

- Language conveys meaning that can determine expectations. Expectations can lead to bias that affects outcomes (even if we aren’t aware of it).

- Messages that convey stigma, judgment, fear, and misunderstanding can lead to disengagement, avoidance and distress

- HCPs have an important role in defining this experience by communicating collaborative and encouraging messages

Meet Jane Dickinson

Qualitative Research on Language

- **Purpose:** To identify common words that have a negative impact on people living with diabetes
- **Focus groups - Adults**
  - 2 online, 2 live focus groups = 68 participants
  - Questions included:
    - What diabetes-related words have a negative impact on you?
    - How do you feel when you hear those words?
    - If you could ask your HCP to stop using one word – what would it be?
    - How do you think not using those words would affect your diabetes experience?

6 Themes Emerged in Analysis

- **Judgment**
  - non-compliant, uncontrolled, don’t care, should, failure
- **Fear/Anxiety**
  - complications, blindness, death, DKA
- **Labels/Assumptions**
  - diabetic, brittle, all people with diabetes are fat, suffer
- **Oversimplifications/Directives**
  - just, should, lose weight, you’ll get used to it, at least it’s not.
- **Misunderstanding/Misinformation/Disconnected**
  - cure, reverse, bad kind, you’re fine
- **Body Language and Tone**
  - no eye contact, accusatory tone

Hurtful words – heard everywhere

**General Public**

Unless someone is talking about how awesome I am in dealing with diabetes – what is said usually feels bad.

**Healthcare Providers**

I hate seeing “uncontrolled” on the health record. I’ve always felt like I’m the only one who can’t judge my own feelings of control.

**Media**

Hey, you know what I saw on the news about diabetes? – INSTA-CRINGE.
3 Themes – Please…

Stop Judging
Anything that begins with “should”.

Stop labeling
Labeling of any kind sucks big time.

Stop discussing complications
...not at every visit, I heard it the first time.

Suggestions for HCPs

- Acknowledge diabetes is hard
- Focus on the person, not the diagnosis
- Avoid judgement, labels
- It’s less about the word – than the meaning behind it
  - It’s not about just replacing one word (compliance) with another (adherence)
- Adopt a more person-centered, strength-based approach

So.... What to Do????

Look around….


One small step….

A much bigger step!

Committee

- Jane K. Dickinson, RN, PhD, CDE (chair)
- Susan J. Guzman, PhD
- Melinda D. Maryniuk, RD, MEd, CDE
- Catherine A. O’Brien, PhD
- Jane K. Kadohiro, DrPH, APRN, CDE, FAADE
- Richard A. Jackson, MD
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- Brenda Montgomery, RN, MSHS, CDE
- Kelly L. Close, BA, MBA
- Martha M. Funnell, MS, RN, CDE

Guiding principles

- 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 healthcare 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 motivation, health and well-being of people with diabetes.

Becoming aware of and changing our words

<table>
<thead>
<tr>
<th>Problematic</th>
<th>Preferred</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetic</td>
<td>Person living with diabetes</td>
</tr>
<tr>
<td>Test (blood glucose)</td>
<td>Check / monitor</td>
</tr>
<tr>
<td>Control (verb)</td>
<td>Manage; describe what the person is doing</td>
</tr>
<tr>
<td>Control (noun)</td>
<td>Define what you mean by control and use that instead (blood glucose level, A1C)</td>
</tr>
<tr>
<td>Good/Bad/Poor</td>
<td>Safe/unsafe levels; target levels; use numbers and focus on facts instead of judgmental terms</td>
</tr>
<tr>
<td>Compliant/Adherent</td>
<td>Takes medicine about half the time; Eats vegetables a few times a week; engagement; participation</td>
</tr>
</tbody>
</table>

- Recommendation #1
  - Use language that is neutral, non-judgmental and based on facts, action or physiology/biology.

  Instead of this….
  
  Your diabetes is not in good control. It seems that your efforts with meal planning, exercise and metformin have failed, so it’s time to add another medication.

  Say this….
  
  Your recent A1C level is 8.5. That is above the target goal of 7.0 we discussed. I’m thinking that adding another medicine that works in a different way could help. How does that sound?
Further study is needed!

- 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 outcomes?
- What are effective ways to teach HCPs about language?
Section 3: Comprehensive Medical Evaluation and Assessment: Patient-Centered Collaborative Care

• A patient-centered communication style that uses person-centered and strength-based language, active listening, elicits patient preferences and beliefs, and assesses literacy, numeracy, and potential barriers to care should be used to optimize patient health outcomes and health-related quality of life.

What can you do?

• Take a closer look at publications
  - Discuss/share with colleagues
• Think about your own language: spoken and written
  - Do a self-assessment (audio tape? Feedback from colleagues?)
  - Review PPTs / teaching resources
  - Review diabetes education tools
• Create a work group – Quality improvement
  - Create a “style guide” for writing
  - Share with all new employees
  - Discuss in student training programs
  - Get feedback from patients
• Talk with media/communications department
• Other:

From AADE.....

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Based on this presentation, which of the following actions will you consider taking?

Discussion

• Communications is less about speaking than it is about listening and observing
  - Barbara Anderson, PhD Former Joslin Psychologist

Questions/Comments: Melinda@MelindaMaryniuk.com
Real Life Examples

• What % of what you say to others is likely to be partially missed or misunderstood? 80-90%
• How much of what people listen to, in face-to-face communications is based on your:
  • words alone 7 __ %
  • tone of voice 35 ___ %
  • body language 58 ___ %
How long does it take before the average listener tunes out your message? 9 seconds

If HCPs stopped using these words…

• I would feel respected or listened to, that the HCPs really care.
• “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.”