2019 UCSF Mini Medical School

*Speaking the Language of Diabetes*

Maureen McGrath, MS, PNP-BC, BC-ADM
Associate Clinical Professor
Director, Diabetes Minor
UCSF School of Nursing
Ms. McGrath has over 25 years caring for youth with type 1 and type 2 diabetes. She helped found UCSF’s first pediatric diabetes clinic in the mid-1990s. A 1995 graduate of the UCSF School of Nursing’s Advanced Practice Pediatric Nurse program she returned as faculty in 2012 to begin the nation’s first minor in diabetes for advanced practice nurses. She oversees diabetes projects in Haiti, Chiapas, and Navajo Nation. For the past 35 years she has been involved in diabetes camps. In 2015, the Masters class awarded her with the Excellence in Teaching award. In 2016, she received the UCSF SON Excellence in Teaching Award for Educational or Curricular Innovation for the Behavior Lab she designed.
Disclosure to Participants

- Notice of Requirements For Successful Completion
  - Please refer to learning goals and objectives
  - Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours

- Conflict of Interest (COI) and Financial Relationship Disclosures:
  - Presenter Maureen McGrath has no COI/Financial Relationship to disclose.

- Non-Endorsement of Products:
  - Accredited status does not imply endorsement by UCSF or Office of CME of any commercial products displayed in conjunction with this educational activity

- Off-Label Use:
  - Participants will be notified by speakers to any product used for a purpose other than for which it was approved by the Food and Drug Administration.
GENERAL CHANGES

In alignment with the American Diabetes Association’s (ADA’s) position that diabetes does not define people, the word “diabetic” will no longer be used when referring to individuals with diabetes in the “Standards of Medical Care in Diabetes.” The ADA will continue to use the term “diabetic” as an adjective for complications related to diabetes (e.g., diabetic retinopathy).
The Use of Language in Diabetes Care and Education

https://doi.org/10.2337/dci17-0041

http://care.diabetesjournals.org/content/40/12/1790

AADE's resources and the HCP handout on the AADE website

Position Statement
A new language for diabetes
Improving communications with and about people with diabetes

Summary

- Diabetes is the fastest growing chronic condition in Australia, affecting 1.7 million Australians. It is a progressive condition, which can reduce both quantity and quality of life, and requires daily self-care. On average, people with diabetes have higher levels of emotional distress than those without diabetes. Distress can continue throughout life with diabetes.

- The way language is used – both verbal and written – reflects and shapes our thoughts, beliefs and behaviours. Language has the power to persuade, change or reinforce beliefs, discourse and stereotypes – for better or for worse. Words do more than reflect people’s reality: they create reality.

- Language needs to engage people with diabetes and support their daily self-care efforts. Importantly, language that de-motivates or induces fear, guilt or distress needs to be avoided and countered.

- Diabetes Australia believes optimal communication increases the motivation, health and well-being of people with diabetes; furthermore, that careless or negative language can be de-motivating, is often inaccurate, and can be harmful.

- The aim of this position statement is to encourage greater awareness of the language surrounding diabetes, and identify potential improvements.
“Words are, of course, the most powerful drug used by mankind”

Rudyard Kipling
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.

Key Definitions

- **Strengths-based language**
  - Opposite of deficits approach; emphasizing what people know and what they can do
  - Focusing on strengths that can empower people to take more control over their own health and healing

- **Person-first language**
  - 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

Recommendations

Use language that:

- is neutral, nonjudgmental, and based on facts, actions, or physiology/biology
- is free from stigma
- is strengths based, respectful, inclusive, and imparts hope
- fosters collaboration between patients and providers
- is person centered

Avoiding Judgment

- Camp policy re: campers showing BG on meter
- School RN accepting verbal report from student
- Meter download reconcile with written log (1995 clinical)
- Use of control solution or checking friends’ or pets’ BG
- Mother of one of my patients “taking off 100 points” of BG
- All of the above are examples of protective behaviors to avoid
  - Judgment, punishment, shame, feelings of failure
Adolescent Management

- 29% of the 144 subjects reported fabricating BGs to give lower numbers
- 25% of the subjects reported forgetting injections/boluses
- Belief that certain injections are not needed
- Teens fabricated blood tests because of perceived pressure from family and physicians to produce good results
- Skipped blood sugars so as to appear in better control

Qualitative Study

- Primary author of language paper
- Conducted focus groups (live and virtual)
- Virtual was done in the DOC- Diabetes Online Community
- Adults with type 1 and type 2 diabetes
Qualitative Study

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?
Qualitative Study

• Question 1 & 2- What diabetes-related words have a negative impact on you? How do you feel when you hear those words? Six themes emerged from analysis of question 1 and 2

  – **Judgement** - “non-compliance”, “uncontrolled”, “good/bad”, “can/can’t”, “should/shouldn’t”

  – **Fear and Anxiety**- “seizure”, “complications”, “DKA”, “blindness”, “death”

  – **Labels, reminders, and assumptions**- “diabetic”, ”disease”, “brittle”, ”suffer”

Qualitative Study- Quest 1 & 2 themes

• Question 1 & 2- What diabetes-related words have a negative impact on you? How do you feel when you hear those words?

• Themes continued:
  – **Oversimplification and directives**- “you’ll get used to it”, “at least it’s not ….”, “exercise more”
  – **Misunderstanding, misinformation, or disconnection**- “reverse”, ”you’re fine”, “are you still using insulin?”
  – **Body language and tone**- “I felt like a lot of it was my fault”
Question 3- What particular experiences do you recall that involved words and diabetes?

Three themes emerged from this question

- **General public** (friends, colleagues, family, teachers, and strangers)- “food police”
- **HCPs**- seeing “uncontrolled” in the medical record
- **Media**- perpetuates stereotypes
Question 4 & 5- If you could ask your diabetes care professionals to stop using one word, what would it be? If there is another word(s) that you’d like them to stop using, please share it (them) as well. Three themes emerged:

- **Stop Judging**- “anything that begins with ‘should’”, “sigh, control. I think that’s just an illusion”

- **Stop labeling**- “diabetic”, “noncompliance”

- **Stop discussing complications**- “I don’t want to hear about the complications at EVERY visit. I totally heard it the first time”
Qualitative Study

• Question 6- How do you think not using those words would affect your diabetes experience?

• Three themes emerged:

• **Suggestions for HCPs**- “focus on the person, not the diagnosis. You’ll treat both more effectively that way”

• **These words will be replaced with other words**- “people use words to pigeonhole us instead of actually seeing and listening to the person”

• **If HCPs stopped using these words**- increase feelings of respect or being listened to, relief, supported, and comfortable…

Qualitative Study

“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)

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

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

- **Interventions**
  - Blood Glucose is data by which therapies can be adjusted
  - Reinforce self-management behaviors, not results
  - The only “bad” number is one that doesn’t exist
  - There are no “good” or “bad” blood glucoses
  - Use “in range”; “above range”
  - Use “check” BG, instead of “test” BG
<table>
<thead>
<tr>
<th>Problematic</th>
<th>Preferred</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compliant/compliance/non-compliant/non-compliance</td>
<td>Engagement Participation Involvement Medication taking</td>
<td>- 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.</td>
</tr>
<tr>
<td>Adherent/non-adherent/adherence/non-adherence</td>
<td>“She takes insulin whenever she can afford it.”</td>
<td>- Focus on people’s strengths – what are they doing or doing well and how can we build on that?</td>
</tr>
<tr>
<td>Control (as a verb or an adjective) controlled/uncontrolled, well controlled/poorly controlled</td>
<td>Manage</td>
<td>- Focus on facts rather than judgments.</td>
</tr>
<tr>
<td></td>
<td>“She is checking blood glucose levels a few times per week.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“He is taking sulfonylureas, and they are not bringing his blood glucose levels down enough.”</td>
<td></td>
</tr>
<tr>
<td>Control (as a noun) glycemic control; glucose control; poor control; good control; bad control; tight control</td>
<td>A1C Blood glucose levels/targets Glycemic target/goal Glycemic stability/variability</td>
<td>- Control is virtually impossible to achieve in a disease where the body no longer does what it’s supposed to do.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Use words/phrases that focus on what the person is doing or doing well.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Focus on physiology/biology and use neutral words that don’t judge, shame, or blame.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Focus on neutral words and physiology/biology.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Define what “good control” means in factual terms and use that instead.</td>
</tr>
<tr>
<td>Problematic</td>
<td>Preferred</td>
<td>Rationale</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>---------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Diabetic (as an adjective)</strong></td>
<td>Foot ulcer; infection on the foot</td>
<td>• Focus on the physiology or pathophysiology.</td>
</tr>
<tr>
<td>diabetic foot</td>
<td>Diabetes education Person with diabetes</td>
<td>• “Diabetic education” is incorrect (education doesn’t have diabetes).</td>
</tr>
<tr>
<td>diabetic education</td>
<td>“How long have you had diabetes?”</td>
<td>• Put the person first.</td>
</tr>
<tr>
<td>diabetic person</td>
<td></td>
<td>• Avoid using a disease to describe a person.</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Diabetic (as a noun)</strong></td>
</tr>
<tr>
<td><strong>“Are you a diabetic?”</strong></td>
<td>Person living with diabetes Person</td>
<td>• Avoid labeling someone as a disease. There is much more to a person than</td>
</tr>
<tr>
<td></td>
<td>with diabetes Person who has diabetes</td>
<td>diabetes.</td>
</tr>
<tr>
<td></td>
<td>“Do you have diabetes?”</td>
<td><strong>Non-diabetic; normal</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• The opposite of “normal” is “abnormal”; people with diabetes are not</td>
</tr>
<tr>
<td></td>
<td></td>
<td>abnormal.</td>
</tr>
</tbody>
</table>
The Diabetes Minor at UCSF SON

- N296A- Advanced Clinical Management of Pediatric Diabetes (2 units)

- N296B- Behavioral Approaches to Diabetes Across the Lifespan (1 unit)

- N301.5- Lab to N296B (1 unit)

- N296C- Advanced Clinical Management of Adult Diabetes (2 units)
Diabetes Youth and Family (DYF) Family Camp 2015
Diabetes Nurse Fellows (2015-16) Piloting an In-service for School Nurses
PUMP TIME: Peds Class
“Words are, of course, the most powerful drug used by mankind”

Rudyard Kipling