Diabetes Daze: How Patients are Affected by Messaging

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WILL – AGE 5
AGE 13
- Blood glucose meter
- Blood glucose test strips
- Ketone strips
- Lancing device
- Lancets
- Continuous Glucose Monitor & Sensor
- Alcohol swabs
- Syringes
- Insulin pump supplies
- Batteries
- Glucose tablets
- Glucagon kit
- Waterproof tape
- Adhesive remover
- Frio cooling wallet
- Snacks

**Factors That Affect BG**

<table>
<thead>
<tr>
<th>Food</th>
<th>Biological</th>
<th>Environmental</th>
<th>Behavioral &amp; Decision Making</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3. Fat</td>
<td>22. Recent hypoglycemia</td>
<td>41. Decision-making biases</td>
</tr>
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<td></td>
<td>4. Protein</td>
<td>23. During-sleep blood sugars</td>
<td>42. Family relationships and social pressures</td>
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<td></td>
<td>5. Caffeine</td>
<td>24. Dawn phenomenon</td>
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<td></td>
<td>6. Alcohol</td>
<td>25. Infusions set issues</td>
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<td></td>
<td>7. Meal timing</td>
<td>26. Scar tissue and lipodystrophy</td>
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<td></td>
<td>8. Dehydration</td>
<td>27. Intramuscular insulin delivery</td>
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<td></td>
<td>9. Personal microbiome</td>
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<tr>
<td>Medication</td>
<td>10. Medication dose</td>
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<td></td>
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<tr>
<td></td>
<td>11. Medication timing</td>
<td></td>
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<td>12. Medication interactions</td>
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<td></td>
<td>13. Insulin administration</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>14. Niacin (Vitamin B3)</td>
<td></td>
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<tr>
<td>Activity</td>
<td>15. Light exercise</td>
<td>34. Expired insulin</td>
<td></td>
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<tr>
<td></td>
<td>16. High-intensity and moderate exercise</td>
<td>35. Inaccurate BG reading</td>
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<td></td>
<td>17. Level of fitness training</td>
<td>36. Outside temperature</td>
<td></td>
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<tr>
<td></td>
<td>18. Time of day</td>
<td>37. Sunburn</td>
<td></td>
</tr>
<tr>
<td></td>
<td>19. Food and insulin timing</td>
<td>38. Altitude</td>
<td></td>
</tr>
</tbody>
</table>
Ambiguous Loss

Theory first coined by Pauline Boss, PhD

"An unclear loss defies closure...often times it does not have validation or clarification."

Knowing That You Won’t Have Clear Answers

- “The human experience is never one of certainty or predictability, but with the support of caring family members, friends, and neighbors, as well as the comfort that some derive from spiritual beliefs, we learn to hang on during such inevitable emotional rides.” – Boss, 1999
Goodbye Without Leaving

What is Ambiguous Loss?

Physically present but emotionally absent
- Extramarital affairs
- Mental illness/addictions
- Workaholic
- Dementia
- Brain injuries
- Severe medical issues
- Children with severe disabilities
Camp Needlepoint

National Youth Advocate
Graduate school research
“It’s unbelievable how much you don’t know about the game you’ve been playing all your life.”
–Mickey Mantle

- Direct medical costs and reduced productivity from people with diabetes costs the United States $245 annually.
- Medical expenses for those with diabetes is 2.3 times higher than that of the average American.
Hemoglobin A1c

Blood test to indicate average blood glucose levels.

<7.5% A1c for pediatrics

<7.0% A1c for adults

“A1c of over 8.0% was associated with increased risk...”.

American Diabetes Association Standard of Care, 2017
National Health and Nutrition Examination Surveys from 1988-2011

Diabetes control & complications trial – Type 1 diabetes

1982 – present
2 - 75 years old
Found that 13-17 year olds:
  Decreased A1c from 9.5% to 9.0%.
Type 1 diabetes involves self-directed care 90-95% of the time.

Modern day medical advances have resulted in slight A1c drops.

Limited research on how communication messages affect self-efficacy of type 1 diabetes management.

**Research questions**

**RQ1:** What communication messages from diabetes medical professionals, family and peers affect self-efficacy in adolescents with type 1 diabetes? If so, how?

**RQ2:** Does any group of influencers (medical professionals, family, peers, media) have a more significant effect on diabetic's self-efficacy? How?

**RQ3:** Does any group of influencers (medical professionals, family, peers, media) have a negative effect on a diabetic's self-efficacy? In what ways?
Petrie, Jago, Devcich define illness perception as, “the organized cognitive representations or beliefs that patients have about their illness” (p. 164).

Greatest impact is their perceived ability that they’ll get to still have a ‘normal’ life (Hale, Treharne, Kitas, 2007).

- Albert Bandura
- Perceived self-efficacy is conceptualized as perceived operative capability.
- “Human behavior has often been explained in terms of unidirectional causation, in which behavior is shaped and controlled either by environmental influences or by internal dispositions” (2001, p. 265).
- Scare tactics are ineffective.
Communication and uncertainty management

- Brasher’s Research:
  - Forecasting complications and morbidity rates.
  - Problematic for the patient because their future seems uncertain.
  - “…engaging in or avoid communication so that they can manipulate uncertainty to suit their needs” (p. 491).

Peer impact

- “Diabetic adolescents might thus lack adequate support from their peers in dealing with the illness emotionally” (Seiffge-Krenke, 2001, p. 166).
- A common disease fostered a bond and lowered feelings of isolation, but did not facilitate closeness. (Embuldeniya, Veinot, Bell, E., Bell, M., Nyhof-Young, Sale, and Britten, 2013).
Family impact

How a parent models coping with the stress, will depend on how the child does (Seiffge-Krenke, 2001).

Mother is in position as main communicator.

A lack of involvement between parent and child led to, “…collaboration is associated with less depressive symptoms and more positive emotion, with support associated with less depressive symptoms for children” (Berg et al., 2007, p. 1001).

Health care professionals

- A physician’s level of education is critical (Hale, Bennett, & Probst, 2010).
- Doctor’s advice focuses on the success of self-directed care in diabetes clinics, it tends to be successful (Rugh, 2011).
- Choice of words.
- Motivational interviewing.
Media

- Nearly 88 percent of those between 18-29 use social media (Greenwood, 2016).
- Diabetes Online Community
  - Access of high-speed internet and smart phones.
  - Rising costs of healthcare.

Research methodology

- Survey Monkey
- Parent or guardian consent
  - Two questions: Age of diagnosis and current age.
- Adolescent assent
  - Eight quantitative questions
  - Six qualitative questions
PARTICIPANTS

Age at Diabetes Diagnosis

Age of Participants

NUMBER OF PARTICIPANTS

AGE

PARTICIPANTS

NUMBER OF PARTICIPANTS

AGE
results

How important is taking care of your diabetes?

Participants selected one (not important) to 10 (very important).

Do you believe managing your diabetes will enhance your overall lifespan?

Participants selected one (don’t believe) to 10 (strong believe).
Q: 11 negative experience

18 - regarded negative lifestyle choice.

2 - included a meme.

6 - being perceived as different than a typical healthy adolescent, or a misunderstanding of the illness.
Q12: How helpful is your diabetes medical team in helping you with the management of your diabetes?

- **15** - very helpful
- **10** - pretty good or fair
- **7** – responded with criticism

Q13: What best motivate you to take better care of your diabetes? Why is that?

- **11** - Extra-curricular activities
- **5** - Post high school graduation goals
- **7** - Overall healthy life/living longer
- **5** - Negative consequences
- **1** - Other people
Q14: Are your parents helpful?

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, yeah, or good.</td>
<td>26</td>
</tr>
<tr>
<td>Not helpful.</td>
<td>5</td>
</tr>
<tr>
<td>Used “Mom” in the involvement of their self-management.</td>
<td>11</td>
</tr>
<tr>
<td>Used “they” or “parents”.</td>
<td>19</td>
</tr>
<tr>
<td>Neither.</td>
<td>1</td>
</tr>
</tbody>
</table>

1 participant mentioned dad by saying, “My dad does nothing”.

Do you have any friends living with type 1 diabetes?

<table>
<thead>
<tr>
<th>Response</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15</td>
</tr>
<tr>
<td>No</td>
<td>13</td>
</tr>
<tr>
<td>Response was vague.</td>
<td>4</td>
</tr>
</tbody>
</table>

If you answered yes, how important to you are these relationships?

- 14 - high importance
- 1 - “Good??”.
- 1 - didn’t see an impact.
- 1 - they used to but not anymore.
- 1 - don’t care.
Research results challenge the hypothesis.

Adolescents place their greatest information source with diabetes medical professionals.

Negative messages came from multiple sources.

The results showed that not all adolescents had optimum control of their diabetes currently (45 percent were at 8.1 percent or higher for their A1c).

Nearly 97% agreed that better diabetes management would allow them to live longer.

75% told of a person having misinformation.

40.6% reported that they had a negative experience where they were called overweight.

71% say a motivating factor in improving self-management is curability/controllability.
As a health care professional or caregiver of a person living with diabetes, the choice of words you use is critical.

Think before you speak.

Choose your words wisely.

Work with the person with diabetes on perceptions of their illness and diagnosis.

Involving the patient in self-management decisions, regardless of age.

Take time to build resiliency with the patient.

Involved all members of a person’s family.

Continue with educating yourself on diabetes and current research.

Speak about the elephant in the room.
<table>
<thead>
<tr>
<th>Scare tactics.</th>
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</thead>
<tbody>
<tr>
<td>Blame and shame.</td>
</tr>
<tr>
<td>Good and bad to describe food, blood sugars, HbA1c, and weight.</td>
</tr>
<tr>
<td>Only thinking that diabetes in itself is motivating.</td>
</tr>
<tr>
<td>Hyper focus on lifestyle choices.</td>
</tr>
<tr>
<td>Diabetes jokes and/or diabetes memes.</td>
</tr>
</tbody>
</table>

5 best communication tips when talking to patients
#1Listen

- Feeling isolated.
- Misunderstood.
- Need a safe outlet to talk things out.
- Be a great listener & you will gain trust.
- Give your patient a choice in their care.

#2 no judgement

Patients have been told since their diagnosis terms such as...

- Good number & bad number.
- Good food & bad food.
- Good A1c & bad A1c.
- Good weight & bad weight.

NEVER scold – we live with this disease 24/7 and there’s a high rate of burnout.
#3 motivate

What's important to your patient (not diabetes or ED related)?

- Hobbies
- Interests
- Passions
- Future aspirations

#4 use humor

First diagnosed, I was so sad about the diagnosis. Tried to hide having diabetes.

Marcia taught me that I couldn’t internalize everything. With diabetes, just like with most things in life, I needed to find the humor in the disease when I could.
Patients with type 1 diabetes self-manage 90-95% of the time.

Preaching, rather than suggesting.

Power of perspective.

Six Themes

**Judgment** (non-compliant, uncontrolled, don’t care, should, failure)

**Fear/Anxiety** (complications, blindness, death, DKA)

**Labels/Assumptions** (diabetic, all people with diabetes are fat, suffer)

**Oversimplifications/Directives** (lose weight, you should, 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)

(Dickinson, 2018)
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.


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

Words are powerful

Words create meaning

Meaning can be positive or negative

We can choose positive, strengths-based language to send messages that empower

When our mindset changes to putting the person first, the language will follow


### 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>
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