Language Use in Diabetes Care from the Perspective of the Patient-Professional

Living with diabetes

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Warning: strong language ahead.

Today I'm going to put you in your patient's shoes.

You may internalize some of my words.
You may disagree or get angry with me.
You may feel shame or denial of your personal choice of language.

But we are in this together.
And no one is expected to have all the answers.

We are evolving.
We are all responsible for taking a bold and inventive approach to patient care.

Because…
It's about time.

The evolution of language in diabetes

1552 BC until 1921 *death by dehydration/starvation/DKA*

1921 insulin injections begin! *"Carbs are bad"*

1930's brought *"diabetic food/diet"*, *artificial sweeteners*

- brought on *restriction* and increased *saturated fat*

1980-90s *SnackWell's* came to town

- *Low fat* vs. *sugar* - which one's worse?
- Research leans into cardiovascular health
- *Individual needs vs. uniform recommendations*

21st Century

Diet junkies
Supplements
Trends/Fads
Industry funded science

Attention is turning towards
our language and tone
within the standards
of medical care
in diabetes

Every patient has a story…

The Patient Perspective, *Evolved*

Words I <u>once</u> associated with T1D

- Shame
- Confused
- Incapable
- Anger
- Never good enough
- Poor body image
- Rebellious

Words I associate with T1D <u>today</u>

- Knowledge
- Ownership
- Powerful
- Fiber
- Exercise
- Self-sufficiency
- *Attitude is everything*

How did I get there?

A change in perception changed my attitude

What diabetes IS and what it is NOT

UPGRADED MY CARE TEAM

UPGRADED MYSELF

Accepted personal responsibility
&
took agency over my future

Chronic Care Model

CCM *core elements* (6)

1. Self-management support
2. Decision support

"individuals must assume an active role in their care"

For the person living with diabetes
language impacts perception & self-efficacy

- *Glucose*
- *Insulin*
- *Nutrition*
- *Exercise*
- *Brain, mental & emotional health*

Depth of Diabetes

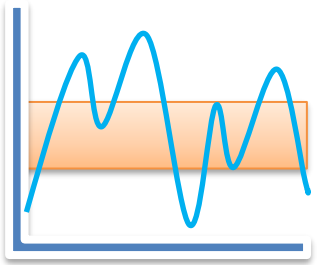
- Diabetes distress
- Isolation
- Distrust
- Depression
- Anxiety
- Obsession with control
- Perfectionism
- Self-worth tied to data
- Failure
- Disabled

The Illusion of balance & perfectionism

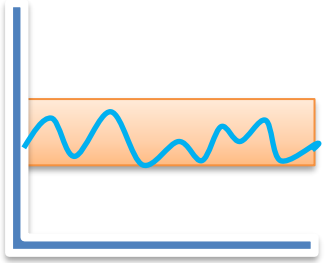
glucose, insulin, nutrition, exercise, mental & emotional health

1. No change
- unrealistic expectation
- not flexible
- diabetes is in charge

2. Elevator Effect
- reactive changes
- does not feel good
- chasing range all the time



3. Rolling in Range (70-180 mg/dl)
- mimics a body that makes insulin
- allows for flexibility
- demonstrates self-awareness



Patient perspective of T1D on social media: ***How low can you go***

What scares us the most?

Hypoglycemia

Unpredictability

Feeling helpless

Lonely in our decisions

Misunderstood

Judgement

- Additional health problems
- Actions fueled by fear or perfectionism
- Community engagement/support
- Seeking alternative counseling
  - *Inappropriate recommendations*
  - *Unreasonable measures*
  - *Abandonment of responsibilities*

Patient/Professional perspective:

we agree on the place we want to go, but have alternate ideas on how to get there

Disconnects in communication between patients and clinicians

- Sympathy vs. empathy
- Misunderstanding of facts and distrust
- Missed opportunities in communication
- Clinical priorities vs. individual needs

Review of literature: *experiences of adults and young adults, attitudes and barriers to exercise, eating disorders and weight gain in T1D, and perspectives of providers*

Diabetes Dilemma

Consequences of pessimism, hypercriticism, & comparing ourselves to others:

- Declining physical & mental health
- High rates of depression, anxiety, diabetes burnout
- Disordered relationship with food
- Medication avoidance
- Isolation

"Negative language drives poor outcomes"

Negative Undertones

- "Diabetic"
  diabetic food, diabetic education
  "you're a diabetic?"
- Threats of complications
  "you are going to lose your vision"
- Noncompliant/nonadherent
- Unmotivated/unwilling
- Poorly controlled
- Suffering/afflicted
- Sad/sucks
- Carbs are bad

Evidence of *The Problem*

August 2020,

I had the opportunity to publish an Op-Med about why language matters in diabetes care on Doximity, a blog with a large network of medical professionals.

Here are a few impressions from the article…

“People with diabetes that do nothing for themselves, expect drugs to do it (if they’re even “compliant”) and after years of living with this, they still don’t want to make changes… How long do we keep softening our language before telling them that if they don’t step up they’ll lose limbs and/or die?”
-PA

“Patient centered will not move the needle on obesity and diabetes because it makes $$$ for pharmaceuticals... We are trained in the 10 min visit and here is your Rx.”
-DO, Family Medicine

“I’d be happy to call any patient with diabetes anything they want if they keep away from the donuts, Blizzards and Oreos.”
–MD, internal medicine

Response from a medical student:
“I know you mean this comment to be funny, but as someone with T1D, I don’t find it particularly funny. And I think I’d find it even less funny if I had T2D not caused or exacerbated by poor diet…There’s got to be a better way to laugh.”

MD reply: “didn’t mean to offend and of course I was referring to T2D.”

“A lack of cultural congruence between the provider and the patient, exacerbates racial disparities. It also seems to remove the responsibility from the physician and places blame on the patient, when in fact, the two should be working together.”
-MD, Family Medicine

MD, Family Medicine reply: “A1c values don’t care what race you are or what race your doctor is or HOW nice they were. Numbers don’t lie.”

“The pang in someone’s heart when you use the word “diabetic” triggers their conscious, which might be a good thing… Not everything that hurts temporarily is bad for you.”
-MD, Family Medicine

“Why do we have to sugarcoat everything and treat patients like they are weak adults?” -MD, Family Medicine

“How dare you tell me how to practice medicine.”
-MD, Internal Medicine

“I would like to have a job where I get paid to write such drivel.”
-MD Family Medicine

“Wow, medicine is becoming PC? Instead of trying to hand hold and not offend anyone, why can’t we just be honest and forthcoming like they pay us to do?
–MD Internal Medicine

MD, Gastroenterology reply: “Becoming? It became PC a long time ago and only getting worse. We cannot hurt anybody’s feelings even at the expense of the truth.”

“If you actually think gymnastic verbiage will drop A1c in underserved populations with complex socioeconomic factors then I have a bridge to sell you. This is the sort of article one writes when all your patients have time shares in Monaco. Next…”
–MD, Internal Medicine

“My mother was diagnosed with DM1 at age 11. She let the disease define her as a person. She was a diabetic first and foremost and played the victim role. She would have benefited from a person first approach. I think this approach is especially helpful with DM2 since it is potentially reversible with lifestyle changes.”
-MD Family Medicine

If words have the power to elevate or destroy, they also have the power to inspire hope & growth

"With over 460 million people on the planet living with diabetes, and fewer than half meeting A1c goals, maybe it's worth taking a look at the patient perspective rather than revolving on the same wheel."

Optimistic Coaching

Inspires: self-efficacy & individual agency

Goals identified by our patients help

us direct care

them prioritize values

Collaborative care

Patient Perspective: *our words and thoughts inspire action*

- Pain is a catalyst for change
- Transform fear into wisdom
- Rewrite internal dialogue by building personal power
- Determine your experiences with positive self-talk

Apply person-centered language

1. ***"Catch the thread"* to provide resources**
2. **Listen for negative self-talk to intervene**

(Depth of Diabetes)

- *Diabetes distress*
- *Depression*
- *Anxiety*
- *Obsession with control*
- *Perfectionism*
- *Self-worth tied to data*
- *Failure*

Optimistic coaching

Build upon a thread to establish trust

- Individualized
- Targets the root
- Out of the box thinking
- Builds on personal strengths
- Challenges the skillset of health educators
  - *Deep questions*

Reframing self-blame *the impact of words*

“I can’t lose weight.” (failure)

“I’m so bad with food.” (distress)

“My parents are diabetic; I’m doomed.” (hopelessness)

“My A1c is bad. Diabetes sucks.” (seeking confirmation)

What we perceive, we believe

Living With Diabetes

Our words enhance the lived experience

- Build a bridge from patient to professional (empathy)
- Discover individual core values (motivation)
- Positivity from the moment of diagnosis (insight)
- Exchange authority for knowledge (therapy; healing)
- Identify knowledge gaps that a person agree to prioritize (taking action)

Community health groups are culturally crucial

cooking classes, open forum discussions, moderated QA

Life is not over with a diabetes diagnosis.

For some, it's just the beginning of a story…

THANK YOU

for your attention

QA

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