

CHANGING THE LANGUAGE OF DIABETES

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OBJECTIVES

- 1. Identify problem language in diabetes
- 2. Locate resources for changing diabetes messages.
- 3. Discuss strategies for changing messages in diabetes.

Special Diabetes Program for Indians

Changing the Course of Diabetes: **Charting Remarkable Progress**

Tremendous improvements in diabetes outcomes are happening for American Indian and Alaska Native people.

Read the Special Diabetes Program for Indians 2020 Report to Congress to learn more.

Diabetes Prevalence



Diabetes decreased from 15.4% in 2013 to 14.6% in 2017 in adults

14.6%

Diabetes-Related Deaths

Decreased 37% from 1999 to 2017



Diabetes-Related Kidney Failure



New cases decreased by 54% from 1996 to 2013 in adults

Diabetic Eye Disease

Decreased by >50% since 1990s in adults



Hospitalizations for **Uncontrolled Diabetes**



Decreased 84% between 2000 and 2015 in adults





These improvements have huge implications for quality of life and health care costs. The Special Diabetes Program for Indians has been, and continues to be, key to this remarkable progress." - Ann Bullock, MD (Ojibwe)





BACKGROUND

Common messages in diabetes:

- Rules
- •Judgment
- •Blame/shame

INACCURATE BELIEFS ABOUT "POOR ADHERENCE"

("strongly agree" endorsements by physicians)

Poor self-discipline	53.2 %
Poor willpower	50.0%
Not scared enough	36.9%
Not intelligent enough	16.3%

WHAT HCPS SAY ABOUT "POOR CONTROL"

HCP top complaints:

- 1. Patients say they want to change but not willing to make the necessary changes
- 2. Not honest/only tell me what they think I want to hear
- 3. Diabetes not a priority/ "in denial"/don't care
- 4. Don't listen to my advice

Effective HCP communication is built on a better understanding of the real problem.

EVIDENCE — WHAT WE KNOW

Feelings

Messages

Labels

Trust

WHAT WORDS NEGATIVELY AFFECT YOU?

Six Themes

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

MESSAGES AT DIAGNOSIS (INTRODIA)

Type of message	Outcomes
Encouraging	Positive impact
Collaborative	Positive impact
Discouraging	Negative impact
Recommend resources	No impact

THOUGHTS FROM FUTURE HEALTH PROFESSIONALS...

Patients are "noncompliant"

- "I have no patience for people who cause themselves to become ill, lose limbs, and disregard their medication/diet regimen. I'd become overwhelmingly frustrated working with this group of patients all day every day."
- "From what I've seen thus far, many of those who have diabetes are noncompliant and don't take care of themselves. That would be extremely frustrating for me."

IF HCPS STOPPED USING JUDGMENTAL, SCARY, LABELING, OVERSIMPLIFIED, DISCONNECTED, AND DIRECTIVE WORDS...

They would feel respected, listened to, supported, and comfortable.

They would trust their HCPs and feel more confident and willing to work with them.

PROBLEM LANGUAGE IN DIABETES

High (more negative feelings)	Neutral
Non-compliant	Diabetic
Preventable (T1)	Preventable (T2)
In denial	Suffered (just above neutral)
Unmotivated	
Failed	
Should	
Uncontrolled	
What did you do wrong?	
You could end up blind or on dialysis	

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EXPERIENCE OF STIGMA IN T2D

T2D
Not on insulin
49%

T2D on Intensive Insulin 61%

GUILT, SHAME, BLAME, FEAR, EMBARRASSMENT

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



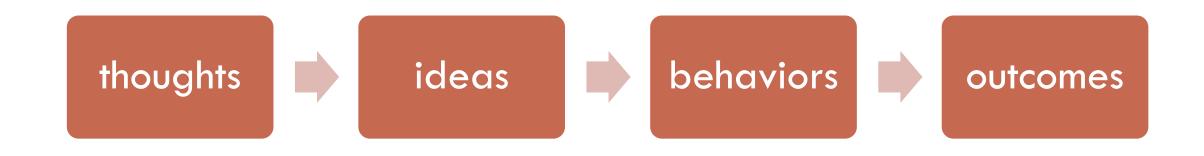
MESSAGES AND THERAPEUTIC INERTIA

The evidence...

Expectancy Theory



MESSAGES AND THERAPEUTIC INERTIA



PROBLEM WORDS TO REMOVE/REPLACE

suffer diabetic control

regimen

adherence compliance

EMOTIONAL IMPACT OF NEGATIVE MESSAGING

Uncontrolled (%)

M (SD)	*p	% positive	% neutral	% negative	
T1DM 5.8 (1.4)	0.001 Hopeful	8.4	11.2	80.4	Hopeless
T2DM 5.3 (1.9)		19.1	11.8	69.1	
T1DM 5.5 (1.5)	0.052 Trusting	9.3	20.6	70.1	Not trusting
T2DM 5.0 (1.8)		20.9	18.2	60.9	
T1DM 5.9 (1.3)	<.001 Encourage	d 6.5	8.4	85.1	Blamed
T2DM 5.4 (1.9)		19.1	10.9	69.9	
T1DM 5.9 (1.4)	<.001 Understoo	d 5.6	13.1	81.4	Misunderstood
T2DM 5.1 (1.9)		21	13.6	65.4	
T1DM 6.0 (1.4)	<.001 Accepted	6.6	7.5	86	Judged
T2DM 5.4 (1.9)		20.1	8.2	71.8	
T1DM 5.6 (1.4)	0.003 Motivated	7.4	19.6	72.9	Not motivated
T2DM 5.0 (1.9)		21.9	15.5	62.7	

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EMOTIONAL IMPACT OF NEGATIVE MESSAGING

You could end up blind or on dialysis (%)

M (SD)	*p		% positive	% neutral	% negative	
T1DM 6.0 (1.4)	0.001	Hopeful	3.8	8.4	87.9	Hopeless
T2DM 5.6 (1.9)			16.4	7.3	76.4	
T1DM 5.7 (1.4)	0.001	Trusting	3.8	19.6	76.6	Not trusting
T2DM 5.2 (1.9)			19.1	14.5	66.3	
T1DM 6.1 (1.4)	<.001	Encouraged	3.7	11.2	85	Blamed
T2DM 5.6 (1.9)			16.4	10.0	73.6	
T1DM 5.9 (1.5)	0.002	Understood	5.6	16.8	77.5	Misunderstood
T2DM 5.3 (1.9)			18.2	14.5	67.2	
T1DM 6.0 (1.5)	<.001	Accepted	5.7	14.0	80.3	Judged
T2DM 5.5 (2.0)			19.1	7.3	73.6	
T1DM 5.4 (1.7)	0.012	Motivated	12.2	15.0	72.9	Not motivated
T2DM 5.1 (2.1)			26.4	7.3	66.4	

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SAMPLE REPLACEMENTS

Control



A1C; Time in Range

Adherence



medication taking

Diabetic



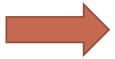
person with diabetes; diabetes-related

Suffer



experience; live with

Regimen



plan; approach

CHANGING WORDS VS. CHANGING MINDSET

Compliance to adherence vs.

compliance/adherence to engagement

Control to management vs.

defining "control" neutrally and factually

NEUTRAL AND FACTUAL...IS MORE HELPFUL

Fred's A1C is 9.5%; Fred's time in range is 35%

- •Fred has poor glycemic control.
- •Fred is uncontrolled.
- •Fred is poorly controlled.

Fred's A1C is 9.5% and he lost his job last month

NEUTRAL AND FACTUAL CONTINUED...

Fred takes his meds about half the time

- •Fred is nonadherent.
- •Fred is noncompliant.

Fred takes his meds about half the time because he lost his job and can't afford them.

LANGUAGE GUIDANCE RESOURCES

https://www.diabeteseducator.org/practice/practice-tools/appresources/diabetes-language-paper

General handout (Quick Guide for Health Care Providers)

Style guide for writers/speakers (Media Guide)

https://www.languagemattersdiabetes.com/

www.dstigmatize.org

STRATEGIES FOR MORE EFFECTIVE PATIENT-PROVIDER COMMUNICATION

- Use language/messages that are person-centered and strengthsbased.
- Use language/messages that are neutral and factual
- Practice radical acceptance and avoid judgment
- Acknowledge that diabetes is hard; ask how the person is doing
- Come from a place of partnership and curiosity
- Share the language guidance paper widely!
- Remove problem language/messages from your EHR

QUESTIONS?

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