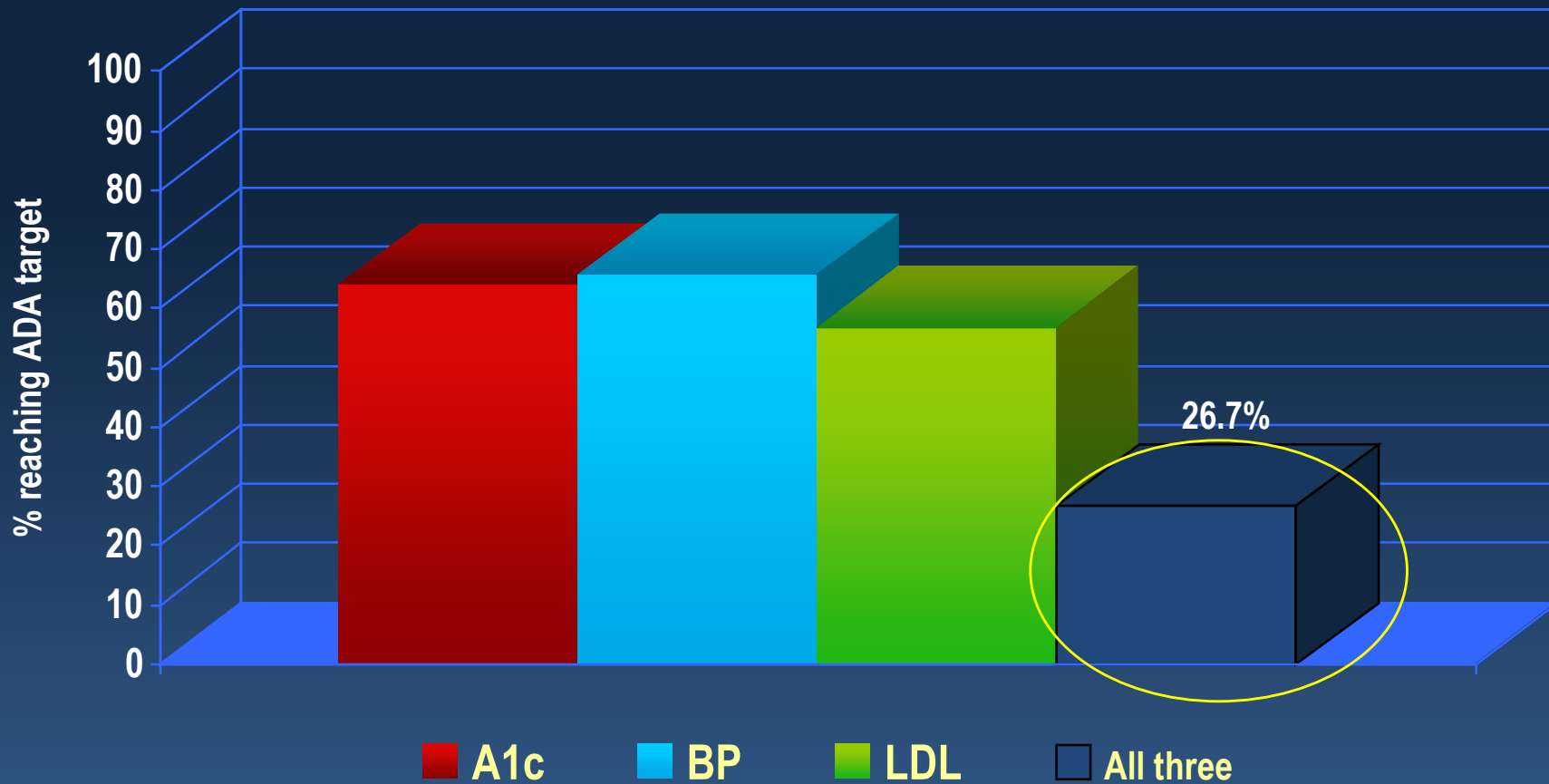# **Engaging the Disengaged**:

## Strategies for Promoting Behavior Change in Diabetes

William H. Polonsky, PhD, CDE

whp@behavioraldiabetes.org

# Percentage of Patients Achieving ADA Treatment Targets

NHANES data: Ali et al, 2014

# Why Such Poor Cardiometabolic Outcomes?

➢Macroeconomic factors (e.g., poverty)

➢Limitations of currently available tools

➢HCP behavior (e.g., clinical inertia)

➢Patient behavior (e.g., self-management)

# An Illustration

3295 insulin-naïve T2Ds were identified who had been recommended insulin:

➤984 (29.9%) declined

➤Of the 984 who declined, 374 (38%) eventually started insulin

➤Of the 374 who finally initiated, mean time to insulin initiation was 790 days.

Hosomura et al, 2017

# Number of Patients Who Avoid Sharing Information with Their HCP

| Type of Information | Ever Avoided Informing the Clinician, No. (%) | |
| --- | --- | --- |
| | MTurk (n = 2011) | SSI (n = 2499) |
| Disagreed with clinician's recommendation | 918 (45.7) (n = 2010) | 785 (31.4) (n = 2497) |
| Did not understand clinician's instructions | 638 (31.8) (n = 2009) | 607 (24.3) (n = 2497) |
| Had unhealthy diet | 493 (24.5) (n = 2009) | 506 (20.3) (n = 2491) |
| Did not take prescription medication as instructed | 453 (22.5) (n = 2011) | 439 (17.6) (n = 2491) |
| Did not exercise | 446 (22.2) (n = 2008) | 538 (21.6) (n = 2495) |

Levy et al, 2018

# HCP Attributions Regarding Poor Adherence in Diabetes

HCP top 5 complaints:

1. Patients say they want to change, but are not willing to make the necessary changes
2. Not honest/Only tells me what they think I want to hear
3. Don't listen to my advice
4. Diabetes not a priority/Uninterested in their condition/"In denial"/Don't care/Unmotivated
5. They do not take responsibility for self-management

Edelman et al, 2012

# Why Avoid Sharing Information?

**Table 2. Percentage of Times a Reason Was Selected for Avoiding Telling the Clinician Collapsed Across Types of Information[a]**

| Reason | % (95% CI) | |
|---|---|---|
| | MTurk | SSI |
| I didn't want to be judged or get a lecture about my behavior. | 81.8 (79.8-83.9) | 64.1 (61.5-66.7) |
| I didn't want to hear how bad [insert behavior] is for me. | 75.7 (73.5-78.0) | 61.1 (58.5-63.8) |
| I was embarrassed to admit that I [insert item]. | 60.9 (58.9-62.9) | 49.9 (47.8-52.1) |
| I didn't want the health care provider to think that I'm a difficult patient. | 50.8 (48.7-52.9) | 38.1 (36.0-40.3) |
| I didn't want to take up any more of the health care provider's time. | 45.2 (42.6-47.9) | 35.9 (33.2-38.7) |
| I didn't think it mattered. | 38.6 (36.6-40.6) | 32.9 (30.9-35.0) |
| I didn't want the health care provider to think that I'm stupid. | 37.6 (35.7-39.6) | 30.6 (28.6-32.7) |

Levy et al, 2018

# Real Life with Diabetes

1.  Living with diabetes can be tough
    - It is a time-consuming job

Russell et al, 2005

**TABLE 2**

### Estimated time required for recommended care*

| Task | Minutes/day |
|---|---|
| *ADA recommendations* | |
| Home glucose monitoring | 3 |
| Record keeping | 5 |
| Taking oral medication | 4 |
| Foot care | 10 |
| Oral hygiene, flossing | 1 |
| Problem solving | 12 |
| Meal planning | 10 |
| Shopping | 17 |
| Preparing meals | 30 |
| Exercise | 30 |
| **ADA SUBTOTAL** | **122** |
| *Other desirable self-care* | |
| Monitoring blood pressure | 3 |
| Stress management | 10 |
| Support group | 2 |
| *Administrative tasks* | |
| Phoning educators, doctors | 1 |
| Scheduling appointments | 1 |
| Insurance dealings | 2 |
| Obtaining supplies | 2 |
| **TOTAL TIME** | **143** |

*Estimates for patients with stable diabetes who are taking oral agents and self-monitoring blood glucose once

# Real Life with Diabetes

1. Living with diabetes can be tough
   - It is a time-consuming job
   - It is a balancing act that requires vigilance and an ability to deal with frustration

# Motivation in Diabetes

- No one is unmotivated to live a long and healthy life

- The real problem: Obstacles to self-care outweigh possible benefits
  - And there are a TON of obstacles!
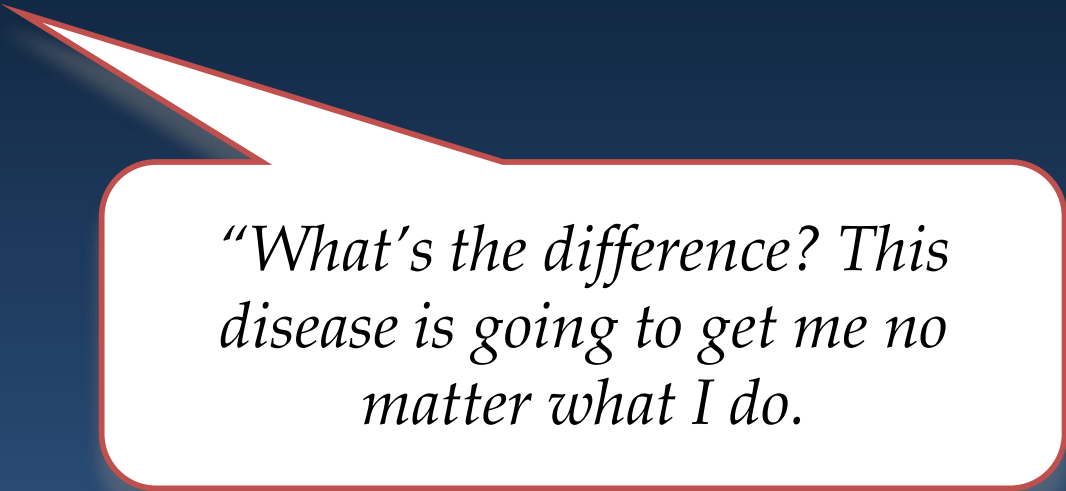  - The underlying theme to most obstacles is a lack of "worthwhileness"

# Lack of Worthwhileness

➢ An invisible and non-urgent disease

*"Look, I'll start worrying about my diabetes as soon as something something falls off."*

# Lack of Worthwhileness

➢ An invisible and non-urgent disease
➢ Hopelessness

*"What's the difference? This disease is going to get me no matter what I do."*

# Lack of Worthwhileness

➤ An invisible and non-urgent disease
➤ Hopelessness
➤ Discouragement

*"I did everything I was supposed to, and now you're telling me I have to take even more medications?!"*

# What Is Diabetes Distress?

➢ The felt burden of living with a tough, demanding disease

- Despair: "I will end up with serious long-term complications, no matter what I do"

- Discouraged: "I am often failing with my diabetes"

- Overwhelmed: "Diabetes is taking up too much of my mental and physical energy every day"

Polonsky et al, 1995; Polonsky et al, 2005

# Measuring Diabetes Distress

➤ **PAID (Problem Areas in Diabetes Scale)**
- 20 items, 5-point Likert scale, no subscales

➤ **DDS (Diabetes Distress Scale)**
- 17 items, 5-point Likert scale, four subscales

➤ **Reliability and validity are well-established**

Polonsky et al, 1995; Polonsky et al, 2005; Fisher et al, 2008

# Diabetes Distress

➢ Diabetes distress

  ▪ Type 1 diabetes (n = 224):          42%
  ▪ Type 2 diabetes (n = 36,998):       36%

➢ Linked to self-care and glycemic control

➢ Diabetes distress is often chronic

  ➢ Of those with elevated distress at baseline: 74% remain elevated levels at 9 months.

Fisher et al, 2016; Perrin et al, 2017

# So What To Do?

# Patient-HCP Communication

A video example………

# Step 1. Assess

- ➤ The informal approach:
  - ▪ "What's one thing about diabetes that's driving you crazy?"
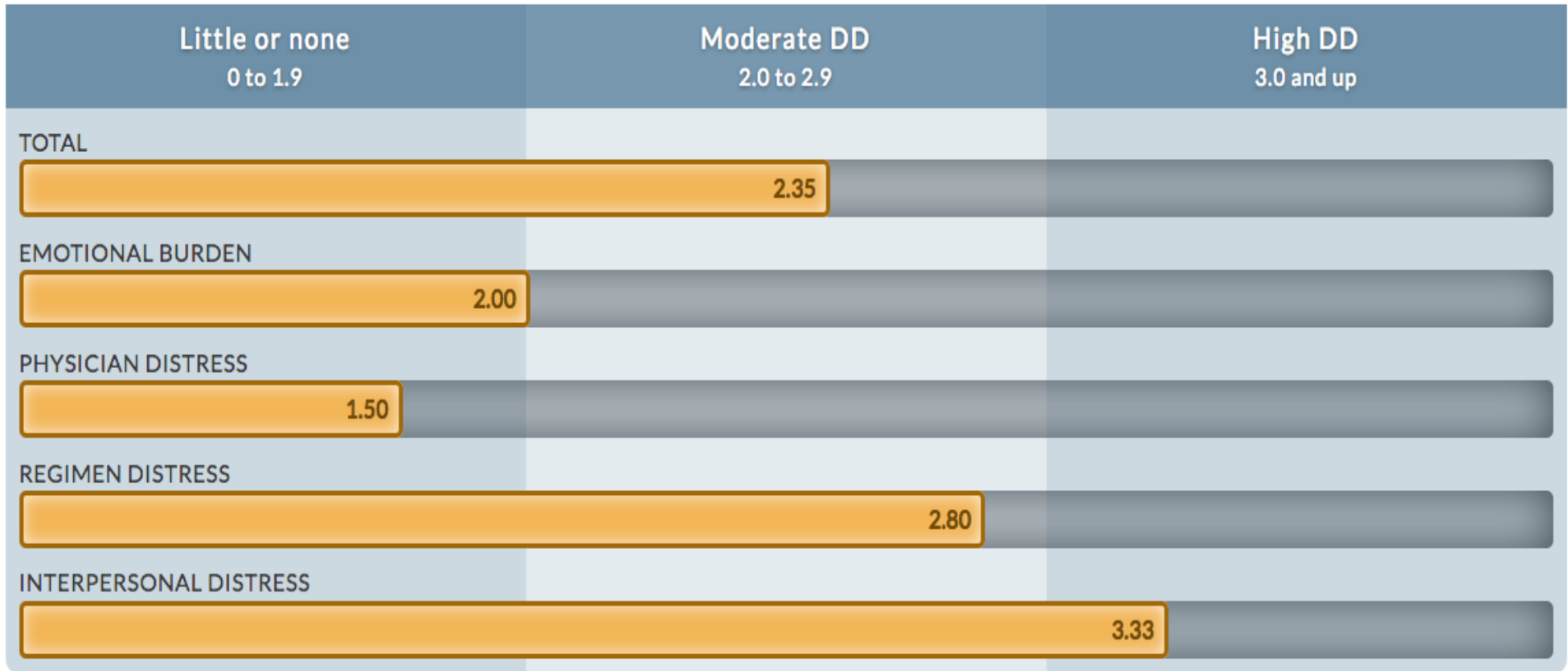- ➤ The formal approach:
  - ▪ Use self-report instruments

# Diabetesdistress.org



- T1-DDS & DDS in English & Spanish
- Automatically scored, with printable reports

# Diabetesdistress.org

## Your DDS Summary Report (page 1)

| Little or none<br>0 to 1.9 | Moderate DD<br>2.0 to 2.9 | High DD<br>3.0 and up |
| --- | --- | --- |

**TOTAL**

2.35

**EMOTIONAL BURDEN**

2.00

**PHYSICIAN DISTRESS**

1.50

**REGIMEN DISTRESS**

2.80

**INTERPERSONAL DISTRESS**

3.33

A score of 2.0 or higher on any scale suggests significant diabetes distress.

# A T1-REDEEM Participant

" It was totally unexpected and surprising. I have had diabetes for 35 years. In all that time no one has ever asked me what it was like for me to have diabetes and what it was about diabetes that I found most distressing. And even if they did ask, I doubt that they would have taken the time or had the interest to listen carefully to my answer."
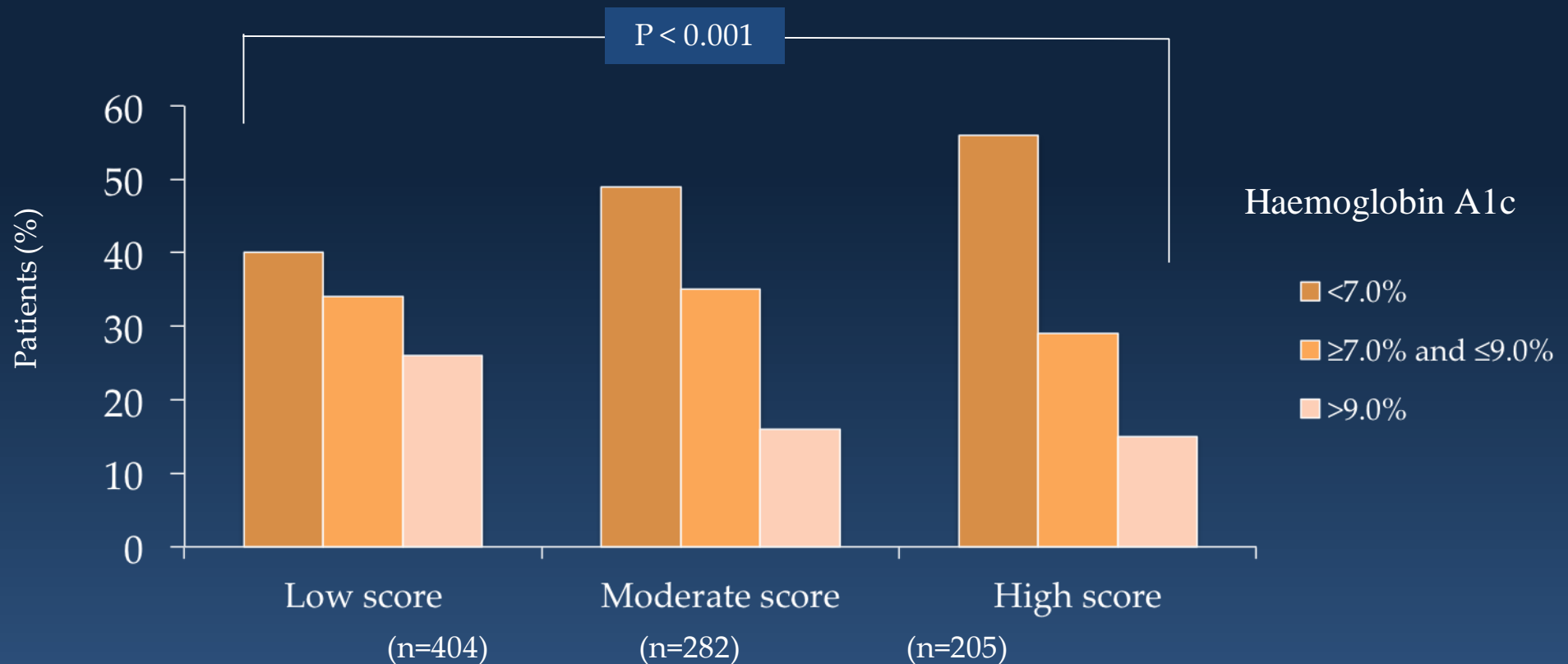
# Step 2. Respond with Empathy

➤ Don't try to fix your patient's difficult feelings

➤ Instead, acknowledge and normalize

- "Given the nature of diabetes, feeling this way is perfectly reasonable and many other people feel the same."

# Step 2. Respond with Empathy

A1c results for 891 patients, treated between 2006-2009, by levels of their HCP' empathy



P < 0.001

Patients (%)

Haemoglobin A1c

■ <7.0%
■ ≥7.0% and ≤9.0%
■ >9.0%

Low score (n=404)
Moderate score (n=282)
High score (n=205)

Hojat et al, 2011

# HCP Empathy and Health Outcomes

A recent literature review included 7 studies (UK, US, and the Netherlands):

➢"There is a good correlation between HCP empathy and patient satisfaction and a positive relationship with strengthening patient enablement. Empathy lowers patients' anxiety and distress and delivers significantly better clinical outcomes"

Derksen et al, 2013

# Step 3. Make the Invisible Visible

| Back on Track Feedback | | | Name: *Molly B.* | |
|---|---|---|---|---|
| <u>Tests</u> | <u>Your Targets</u> | Last Results | **FID #:** | |
| | *Your score should be* | | ***SAFE**: At or better than goal* | ***NOT SAFE**: Not yet at goal* |
| A1C | 7.0% or less | *8.7%* | | x |
| Blood Pressure | 130/80 | *125/75* | *x* | |
| LDL | 100 or less | *116* | | *x* |

# Step 3. Make the Invisible Visible

➢ Be non-judgmental.
- Fear tactics may be counterproductive:
- "Do you want to go blind, do you?"
- "If you don't do better, you'll end up on insulin. Is that what you want, is it?!"
- Rather than describing numbers as "good/bad" or "high/low", use "safe/unsafe".

# Step 3. Make the Invisible Visible

➢ Be non-judgmental.

➢ Offer congratulations when possible.

"Your A1C is still too high. Don't you understand the consequences? Why aren't you working harder on this?"

VS.

"Its great that you took the time to get your A1C done today. The numbers haven't moved much, which tells us that something different is needed."

# Step 3. Make the Invisible Visible

➢ Be non-judgmental.

➢ Offer congratulations when possible.

➢ Provide a path forward.

- ▪ "Let's work together to get these important numbers to a safe place for you".

# Appealing to Fear: A Meta-Analysis of Fear Appeal Effectiveness and Theories

- 248 independent samples, n = 27,372
- Fear appeal:                                    d=0.21
- Fear appeal + efficacy message     d=0.43

Tannenbaum et al, 2015

# Step 4. Share the Good News

Q. Diabetes is the leading cause of adult blindness, amputation, and kidney failure. True or false?

A. False.  To a large extent, it is *poorly controlled* diabetes that is the leading cause of adult blindness, amputation and kidney failure.
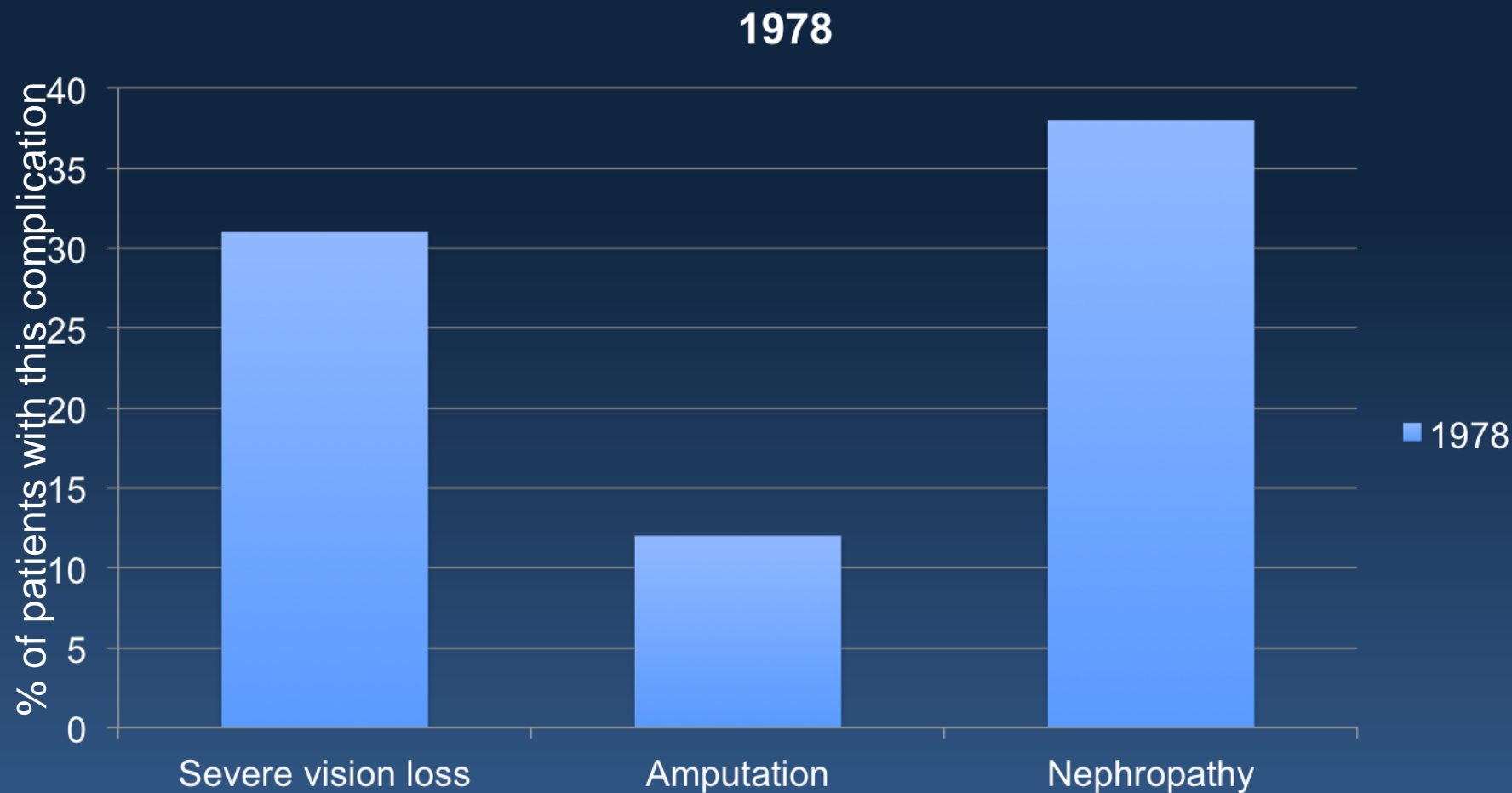
Well-controlled diabetes is the leading cause of… NOTHING!

# Fact Check

**FACTS** ✓

This doesn't mean: good care will **guarantee** that you will not develop complications

This does mean: with good care, **odds are good** you can live a long, healthy life with diabetes

# T1D Complications After 30+ Years



2009

# In Summary

"Historical reports of frequencies of serious complications in T1D patients are clearly outdated … rates of complications with 'intensive' treatment, or what would now be considered the standard of care, are substantially lower than in the past. This is indeed good news that should be openly shared with the newly diagnosed patient to help alleviate fears that may accompany the diagnosis.."

Nichols, 2009

# Risk Factors, Mortality, and Cardiovascular Outcomes in Patients with Type 2 Diabetes

Aidin Rawshani, M.D., Araz Rawshani, M.D., Ph.D., Stefan Franzén, Ph.D.,
Naveed Sattar, M.D., Ph.D., Björn Eliasson, M.D., Ph.D., Ann-Marie Svensson, Ph.D.,
Björn Zethelius, M.D., Ph.D., Mervete Miftaraj, M.Sc.,
Darren K. McGuire, M.D., M.H.Sc., Annika Rosengren, M.D., Ph.D.,
and Soffia Gudbjörnsdottir, M.D., Ph.D.

- **271,174 T2Ds, 1,355,870 matched controls**
- T2Ds "who had five risk-factor variables within target ranges appeared to have little or no excess risks of death, MIs, and stroke as compared with the general population."
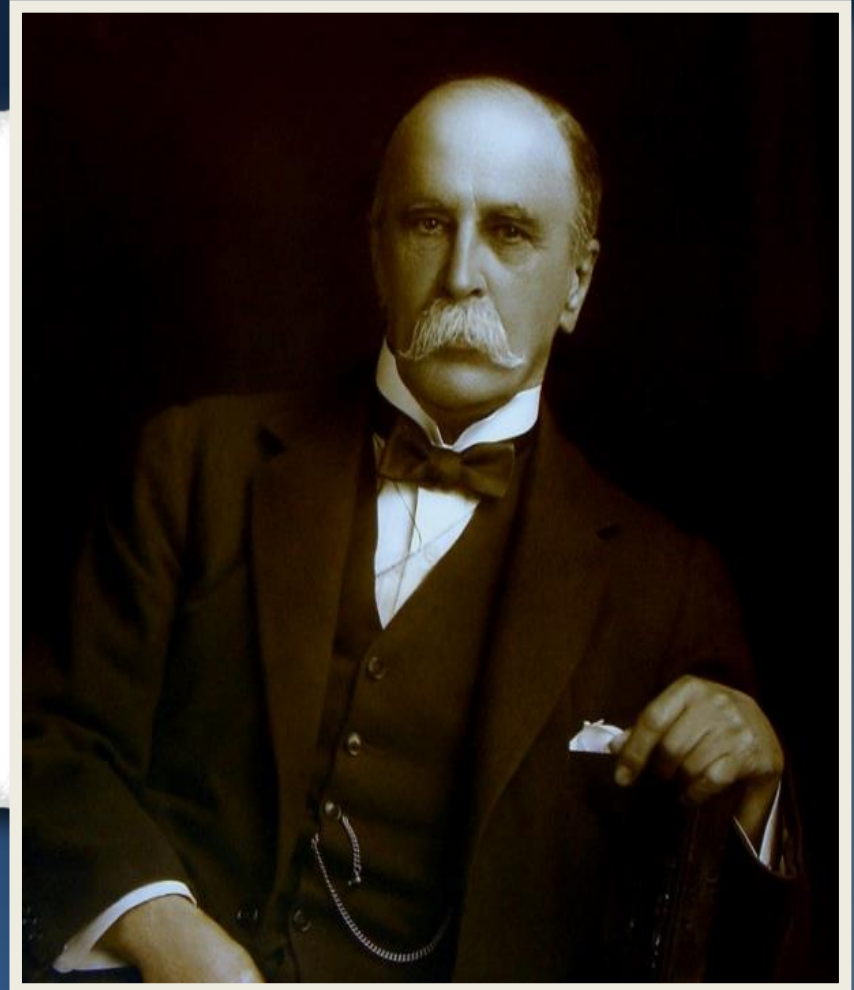
Rawshani et al, 2018

# Diabetes and Your Health

"To live a long and healthy life, develop a chronic disease and take care of it."

- Sir William Osler

# Step 5. Address Discouragement

➤ Make behavioral success easier
- Plan for actions must be doable
- Focus on the behavior, not the outcome
- Collaborative agreement and commitment

*"So just to make sure we're on the same page, what's one diabetes-related action you're aiming to do over the next few months?"*

# One Step at a Time

# Step 5. Address Discouragement

➤ Make behavioral success easier

➤ Re-frame the medication conversation

# Step 5. Address Discouragement

➤ Make behavioral success easier

➤ Re-frame the medication conversation

- Taking your meds is one of the most powerful things you can do to improve your health.

- There are always pro's and con's; the con's are probably not as big as you think.

- More meds doesn't mean you're sicker, fewer meds doesn't mean you're healthier.

# Step 5. Address Discouragement

➢ Make behavioral success easier

➢ Re-frame the medication conversation

➢ Provide the tools needed to be successful
  ▪ Ongoing support

The Impact of Automated Brief Messages Promoting Lifestyle Changes Delivered Via Mobile Devices to People with Type 2 Diabetes: A Systematic Literature Review and Meta-Analysis of Controlled Trials

Carukshi Arambepola[1], MD; Ignacio Ricci-Cabello[2], PhD; Pavithra Manikavasagam[1], MBBS; Nia Roberts[3], MSc; David P French[4], PhD; Andrew Farmer[2], DM

# Step 5. Address Discouragement

➢ Make behavioral success easier

➢ Re-frame the medication conversation

➢ Provide the tools needed to be successful

- Ongoing support
- Medications
- Devices

# QOL and CGM

**Table 2—QOL outcomes by study arm from baseline to 24-week follow-up**

| | CGM group | | Control group | | P value |
|---|---|---|---|---|---|
| | Baseline | 24 weeks | Baseline | 24 weeks | |
| WHO-5 | 71.28 ± 14.71 | 70.47 ± 16.68 | 69.06 ± 14.89 | 67.32 ± 16.86 | 0.50 |
| EQ-5D-5L | 0.90 ± 0.11 | 0.89 ± 0.10 | 0.89 ± 0.11 | 0.88 ± 0.10 | 0.92 |
| Diabetes distress (DDS) | | | | | |
| Total | 1.78 ± 0.65 | 1.61 ± 0.48 | 1.69 ± 0.62 | 1.78 ± 0.65 | 0.03 |
| Regimen | 2.09 ± 0.87 | 1.81 ± 0.68 | 2.08 ± 0.99 | 2.05 ± 0.87 | 0.04 |
| Emotional burden | 2.06 ± 0.90 | 1.93 ± 0.80 | 1.91 ± 0.83 | 2.03 ± 0.95 | 0.09 |
| Interpersonal | 1.54 ± 0.81 | 1.43 ± 0.61 | 1.45 ± 0.70 | 1.73 ± 1.04 | 0.01 |
| Physician | 1.19 ± 0.63 | 1.09 ± 0.25 | 1.12 ± 0.25 | 1.18 ± 0.69 | 0.15 |
| Hypoglycemic confidence (HCS) | 3.27 ± 0.57 | 3.47 ± 0.55 | 3.15 ± 0.57 | 3.18 ± 0.63 | 0.03 |
| Hypoglycemia fear (worry subscale of HFS-II) | 15.75 ± 12.30 | 13.48 ± 10.63 | 17.30 ± 13.22 | 17.73 ± 14.92 | 0.15 |

Polonsky et al, 2017

# In Summary

➢ Assess

➢ Respond with empathy

➢ Make the invisible visible

➢ Share the good news

➢ Address discouragement

# Thanks for Listening!

www.behavioraldiabetes.org