THE EMOTIONAL BURDEN OF DIABETES AND HOW WE CAN HARNESS TECHNOLOGY TO HELP
**PSYCHOSOCIAL BARRIERS**

Outline

- Common challenges in diabetes
- Ways to address distress/burden
- How technology can impact wellbeing
- Harnessing the benefits of technology
PSYCHOSOCIAL BARRIERS

Diabetes Can Be Tough!

- Treatment takes both physical and mental energy
- Time-consuming
- Can disrupt daily life and activities
- No breaks
- No end
Burden of diabetes
Invisibility of diabetes

- I just don’t want to think about diabetes today
- I hate all my treatment options
- I’m going to cancel my endo visit—it’s just going to be more bad news.
- I don’t want to have to take insulin shots. In public
- I feel fine so I’m not going to take those pills today.
- I can’t check my blood sugar at work because I don’t want people to know I have diabetes.
- I know I should check, but I have a million other things to do
- I should cook something healthy but I just don’t have the time
- My feet hurt. Is this some sort of diabetes complication?
- I’m sick of people asking me questions or judging me?
Real world example
What do you see?
People with type 1 diabetes see this...

PROBLEM: Starting the Day

Diana Betes wakes up at 6:30 am with a Blood Glucose (BG) level of 60 mg/dL. She plans to have a cup of coffee with 4 oz milk on her 1/2 mile walk to work.

A) How many glucose tablets does Diana need to correct her BG level?
B) How many units of insulin does Diana need?

A) Target BG = 120 mg/dL
   Current BG = 60 mg/dL (LOW)

   needs to \[ \frac{-60}{60} \]

   1 carb = 5 pts
   x carbs = 60 pts

   \[ \frac{5x}{x} = \frac{60}{5} \]
   \[ x = 12 \text{ carbs} \]

   Diana needs 3 Glucose Tablets

B) Current BG = 120 mg/dL

   - Correction dose = 0 units
   - Dawn Phenomenon = 1 unit
   - Coffee with 4 oz milk
   - 3 carbs
   - 8 oz milk = 12 carbs
   - 4 oz milk = 6 carbs
   - 6 carbs = 1 unit of insulin
   - 1/2 mile walk = 1 BG 60 pts

   Diana needs 1 unit of insulin to start her day!
ARE YOU DEPRESSED BECAUSE YOU HAVE DIABETES OR IS DIABETES CAUSING YOUR DEPRESSION?

YES!
The demands take a toll.

Worries for the future

Distress

Frustrated, feel out of control

Feeling overwhelmed

Burnout

Conflict with loved ones about diabetes

Fears about complications

Burden

Fearing low blood glucose

Adapted from Hilliard, 2016
SOME DAYS...

DIABETES

ME
WAYS TO EASE THE BURDEN
Go Easy on Yourself

- Emotions around numbers/tasks can make diabetes feel harder
  - Numbers can feel like grades rather than data points
- There is no failure in diabetes
  - Nothing is perfect every day
  - Treat each day like a new chance to engage
PSYCHOSOCIAL BARRIERS

Eliminate Blame and Shame

- You are allowed to feel: angry, upset, sad, overwhelmed, overworked, tired, bored, irritated, and more.
  - All your emotions are valid!
- Emotions that can be concerning: ashamed, blamed, and hopeless
  - Never feel bad about asking for help
  - Give yourself credit for all the hard work you do
Finding benefit in an illness can help with acceptance of the illness and self, while improving physical and mental health.
PSYCHOSOCIAL BARRIERS

Remember...

- Small goals build up to long-term habits
- Be flexible and find what works for YOU
- Empower yourself and give yourself credit
- Eliminate blame and shame
- Find positives and reframe diabetes
- Accept who you are as a person with diabetes
HOW CAN DIABETES TECHNOLOGY HELP?
AND WHEN MIGHT IT GET IN THE WAY?
"Be honest with me, Doc. How much longer can I go on ignoring your advice to keep checking my blood glucose?"
3 ERAS of GLUCOSE MONITORING

Urine Sugar (pre-1977) → Blood Sugar (1980s) → CGM/AP (2003-)

Artificial Pancreas
Eras of **INSULIN PUMPS**
Get Your Insulin

Vial and syringe
or
Insulin pen

Know Your Glucose

Blood glucose meter

Advanced

Insulin Pump

Closed Loop
Get Your Insulin

- Vial and syringe
- Insulin pen

Know Your Glucose

- Blood glucose meter

Advanced

Insulin Pump

Closed Loop

Continuous glucose monitor (CGM)
Psychosocial Benefits of CGM and Pumps

- Improved quality of life
- CGM
  - Increased hypoglycemia awareness
  - Reduced diabetes distress
- Insulin pump
  - Flexibility and freedom
  - Enhanced experience in social situations
  - Improved daily management routines
- Both CGM & Pump
  - Can increase time in range
  - Can lower A1C

Polonsky et al., 2017; Payk et al., 2017
Diabetes Device Use in Adults With Type 1 Diabetes: Barriers to Uptake and Potential Intervention Targets

Molly L. Tanenbaum,1 Sarah J. Hanes,1 Kellee M. Miller,2 Diana Naranjo,3 Rachel Bensen,1 and Korey K. Hood1

Diabetes Care 2017;40:1–7 | DOI: 10.2337/dc16-1536
<table>
<thead>
<tr>
<th>Barrier</th>
<th>% Yes</th>
</tr>
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<tbody>
<tr>
<td><strong>Non-Modifiable</strong></td>
<td></td>
</tr>
<tr>
<td>Cost of supplies</td>
<td>61.3</td>
</tr>
<tr>
<td>Cost of device</td>
<td>57.4</td>
</tr>
<tr>
<td>Insurance coverage</td>
<td>57.3</td>
</tr>
<tr>
<td><strong>Modifiable</strong></td>
<td></td>
</tr>
<tr>
<td>Hassle of wearing devices all of the time</td>
<td>47.3</td>
</tr>
<tr>
<td>Do not like having diabetes devices on my body</td>
<td>34.8</td>
</tr>
<tr>
<td>Do not like how diabetes devices look on my body</td>
<td>26</td>
</tr>
<tr>
<td>Nervous that the device might not work</td>
<td>20</td>
</tr>
<tr>
<td>Do not want to take more time from my day to manage diabetes</td>
<td>17.5</td>
</tr>
<tr>
<td>Nervous to rely on technology</td>
<td>17</td>
</tr>
<tr>
<td>Worries about what others will think about you</td>
<td>10.5</td>
</tr>
<tr>
<td>I do not like diabetes devices because people notice them and ask questions about them</td>
<td>10.4</td>
</tr>
<tr>
<td>Too busy to learn how to use a new technology or device</td>
<td>9.2</td>
</tr>
<tr>
<td>My diabetes care team has never talked with me about diabetes technology options</td>
<td>4.5</td>
</tr>
<tr>
<td>Do not understand what to do with the information or features of the devices</td>
<td>4.5</td>
</tr>
<tr>
<td>Not able to get your diabetes care team to write you a prescription</td>
<td>4.4</td>
</tr>
<tr>
<td>Not enough support from your family</td>
<td>3.7</td>
</tr>
<tr>
<td>Not enough support from my diabetes care team in using devices</td>
<td>2.9</td>
</tr>
<tr>
<td>Do not want to have more information about my diabetes</td>
<td>2</td>
</tr>
<tr>
<td>My family does not think diabetes devices are important for taking care of my diabetes</td>
<td>0.9</td>
</tr>
</tbody>
</table>
Table 2.
*Top responses to questions “Why did you stop using your CGM?” and “Why did you stop using your insulin pump?”*

<table>
<thead>
<tr>
<th>Reasons for discontinuing CGM (n=249)</th>
<th>% Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost of supplies</td>
<td>35.3</td>
</tr>
<tr>
<td>There were too many alarms</td>
<td>32.1</td>
</tr>
<tr>
<td>It wasn't accurate</td>
<td>30.1</td>
</tr>
<tr>
<td>Don't like diabetes devices on my body</td>
<td>29.7</td>
</tr>
<tr>
<td>Wearing a CGM took too much time and effort</td>
<td>28.9</td>
</tr>
<tr>
<td>It was uncomfortable or painful</td>
<td>28.1</td>
</tr>
<tr>
<td>Too hard to get it to work right</td>
<td>22.1</td>
</tr>
<tr>
<td>Cost of device</td>
<td>21.7</td>
</tr>
<tr>
<td>Made it hard for me to sleep</td>
<td>20.1</td>
</tr>
<tr>
<td>Didn't trust it</td>
<td>18.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reasons for discontinuing pump (n=72)</th>
<th>% Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't like diabetes devices on my body</td>
<td>45.8</td>
</tr>
<tr>
<td>It was uncomfortable or painful</td>
<td>44.4</td>
</tr>
<tr>
<td>Cost of supplies</td>
<td>20.8</td>
</tr>
<tr>
<td>Didn't trust it</td>
<td>20.8</td>
</tr>
<tr>
<td>Too hard to get it to work right</td>
<td>16.7</td>
</tr>
<tr>
<td>Cost of device</td>
<td>13.9</td>
</tr>
<tr>
<td>Caused other people to ask too many questions about my diabetes</td>
<td>12.5</td>
</tr>
</tbody>
</table>
Three Primary Themes:
1. Considerations of trust and control
2. System features
3. Concerns and barriers to adoption

Naranjo et al., 2017
Differing Priorities

- **Children**: concerns about device use in specific social situations and settings, such as school and with friends.

- **Adolescents**: focused on physical features, wearability, and comfort of devices.

- **Adults and parents**: predominantly concerned about device safety and reliability.
  - **Partners** also raised concerns about trust and control.

Naranjo et al., 2018
Common technology worries

- Fear of low BG
- Will my devices work?
- Fear of needles
- Social embarrassment
- Interference with daily life
- Anxiety about complications
- Dependence or burden on family
- Worries about taking insulin
Why people stop using devices

- Overall, people stop using when the balance tips toward more burden and little added-value.
  - Discontinued CGM and insulin pump use are associated with cost of supplies, bother from alarms, device inaccuracy, and not liking wearing them (Tanenbaum et al., 2017).
  - Discontinued hybrid closed-loop related to sensory issues, problems obtaining supplies, and fear of hypoglycemia (Lal et al., 2019).
- In an open protocol ecosystem, it is possible to prevent discontinued use by selecting a system that minimizes burden.
IMPROVING ENGAGEMENT AND EMPOWERING THE PERSON WITH DIABETES
Pathway to device/system use

<table>
<thead>
<tr>
<th>Aware</th>
<th>Understand</th>
<th>Trust</th>
<th>Commit</th>
<th>Adopt</th>
<th>Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Become aware of device/combo/system options</td>
<td>Understand how they work and advantages/disadvantages</td>
<td>Feel safe relying on the technology</td>
<td>Make a decision, obtain components and resources</td>
<td>Initiate initial use</td>
<td>Engage in continued use</td>
</tr>
</tbody>
</table>
ADDRESSING THE BARRIERS

Be Flexible

- Many options for treatment
  - Different pumps, different insulins, CGM, etc.
  - Consider what works best for YOU
  - Don’t be afraid to try new treatments

- Engage with your diabetes care team to help find the most effective treatment for you
  - And remember: mental and emotional health are important and substantial parts of physical health and diabetes care
MISSION & OBJECTIVES

Create a digital space to promote uptake and optimal use of devices

Do so with people with diabetes

Unbiased, free, straight talk that engages, nudges, and improves outcomes

Explore the options for treatment
  - Different pumps, different insulins, CGM, etc.
Helping You Find The Right Diabetes Devices For Your Life.

CHECKUP

DO YOUR DEVICES STILL WORK FOR YOUR LIFE?

Take a quick quiz to see what might be your next diabetes care upgrade.

Check Up
Check Up Results

It's serious and challenging to have diabetes. Let's take a look if there is a device that would help and not cause any new stress.

Because you said that your top priority when choosing diabetes devices is *avoid lows* and your top concern is *relying on technology* we are recommending that you consider switching your combo to **Meter & Pump**.

<table>
<thead>
<tr>
<th>CURRENT COMBO</th>
<th>COMBO TO CONSIDER</th>
<th>WHY WE SUGGESTED THIS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NO BELLS, NO WHISTLES</strong> Meter &amp; Injections</td>
<td><strong>FEWER INJECTIONS</strong> Meter &amp; Pump</td>
<td>Diabetes is tough, sounds like you're in the thick of it, don't forget that it comes in waves and the tough parts don't stay that way forever. An insulin pump may be a helpful device to consider. With an insulin pump you can have different settings during the each part of the day to match your body's needs. Things have come a long way since the first pumps, some are now tubeless and waterproof. Check out the wisdom below if you're interested in how others use a Meter and Pump, maybe you'll find a new tip or trick that someone else with the similar combo and concerns has discovered that would be helpful.</td>
</tr>
</tbody>
</table>

JDRF typeone nation summit
IMPROVING LIVES. CURING TYPE 1 DIABETES.
WISDOM

CHOOSING YOUR DEVICES IS AN INCREDIBLY PERSONAL DECISION. HERE ARE THE STORIES OF OTHER PEOPLE’S PRIORITIES AND CHOICES.

Different people choose different devices to fit their lifestyle, budget, and health needs. All of these stories are from real people. Learn from others and find out what’s right for you.

FILTER WISDOM BY PRIORITIES & CONCERNS

All  Avoiding Lows  Cost  Ease of Use  Comfort  Advanced Tech  Unwanted Attention  Trusting Tech  Data Overload

![Images of people using diabetes technology]
Summary

- Diabetes distress is common, expected, and needs to be addressed
  - Eliminating blame/shame, finding the positive, focusing on specific achievable and small goals can help
  - Seeking support from others (family, friends, providers) is also important
- Many believe technology is the “cure all” and there is a lot of benefit
  - Better quality of life and overall better health outcomes
- However there are still limitations
  - Overall, people stop using when the balance tips toward more burden and little added-value.
  - Discontinued CGM and insulin pump use are associated with cost of supplies, bother from alarms, device inaccuracy, and not liking wearing them (Tanenbaum et al., 2017).
  - Discontinued hybrid closed-loop related to sensory issues, problems obtaining supplies, and fear of hypoglycemia (Lal et al., 2019).
- Focus on access, realistic expectations, and supporting ongoing use
QUESTIONS?
Stanford Pediatric Endocrinology

www.stanfordchildrens.org/en/service/endocrinology
http://med.stanford.edu/pedsendo.html