DEVELOPING RESILIENCE
Positive coping strategies for living successfully with diabetes

Diana Naranjo Ph.D ● March 5, 2017 ● Bay Area Diabetes Summit
OBJECTIVES

▪ Challenges + Risks
▪ Resilience + Protection
▪ Behavioral Strategies
▪ Devices + Technology
MYTH OR FACT?
ONE DAY YOU WILL MASTER DIABETES AND IT WILL BECOME EASY
DIABETES IS TOUGH.
MANAGEMENT IS DEMANDING.

- Complex, unrelenting, always there.
- Blood sugars don’t always go as planned or make sense
- Self-management often translates into feeling 100% responsible
- Arguments about diabetes are exhausting.
- Worries and fears can be all-consuming.
CHALLENGES/RISKS
RISK HAPPENS

Psychological & Behavioral Risks:
- Depression
- Anxiety
- Disordered eating

Family Risks:
- Conflict
- Uninvolved
- Over-involved
- “Miscarried helping”

Environment & Systems Disparities:
- Poverty/SES
- Race
- Insurance
- Access to healthcare
VARIATIONS IN EMOTIONAL DISTRESS

- Distress
  - Burdens of daily diabetes care
  - Stresses and worries
  - Feeling overwhelmed
  - Feeling judged

- Burnout
  - Feeling chronically overextended by demands of living with diabetes
  - At the point of giving up on diabetes care
  - Irritability, conflict

- Depressive Symptoms
  - Any symptoms of depression that do not reach diagnostic levels
  - Content may be related to diabetes or other stresses

- Depression
  - MDD and other depressive disorders meeting DSM criteria
  - Content may or may not be related to diabetes

Fisher et al., 2014
Hilliard 2016
DEFINITION DIABETES DISTRESS & BURNOUT

Diabetes burnout is a collection of feelings and behaviors

Hood, 2016
DEFINITION

Diabetes burnout is a collection of feelings and behaviors that occur after taking care of diabetes

Hood, 2016
DEFINITION

*Diabetes burnout* is a collection of feelings and behaviors that occur after taking care of diabetes *over and over again without a break*. 

Hood, 2016
DEFINITION

Can look and feel a lot like *depression*

almost every person with diabetes, parent, and caregiver will experience diabetes distress or burnout at some point in time

Hood, 2016
The demands take a toll.

- Frustrated, feel out of control
- Feeling overwhelmed
- Burnout
- Distress
- Dealing with caring yet intrusive people
- Worries for the future
- Fears about complications
- Burden
- Exhausted
RESILIENCE HAPPENS, TOO.
WHAT DOES RESILIENCE MEAN TO YOU?
A (TRADITIONAL) DEFINITION

Oxford English Dictionary says:

*resilience* (mass noun)

1. The capacity to recover quickly from difficulties; toughness.
   ‘the often remarkable resilience of so many British institutions’

2. The ability of a substance or object to spring back into shape; elasticity.
   ‘nylon is excellent in wearability, abrasion resistance and resilience’
RESILIENCE AS A DYNAMIC OUTCOME

What happens when people overcome extremely stressful or difficult situations* and do better than expected**.

*the kinds of situations that would be expected to throw everything off-track, like exposure to war, trauma, or major disease like diabetes

**this can vary across different outcomes, circumstances, or time

Luthar, 1993; Masten, 2001
THE MOST COMMON OUTCOME

WHAT DOES **RESILIENCE** MEAN TO YOU IN THE CONTEXT OF T1D?

WHAT ARE GOOD OUTCOMES?
DIABETES RESILIENCE MODEL

Hilliard et al., 2012

Risks and Assets

Social/Context
Family
Individual

Protective Skills & Behaviors

Behavioral Resilience Outcomes

Diabetes Self-Management
Good QOL

In-range A1c
No complications

Health Resilience Outcomes

In context of general developmental tasks (social, academic)
# ASSETS FOR RESILIENT OUTCOMES

**Individual:**
- Cognitive Skills, IQ
- Self-Efficacy
- Optimism, Positive Outlook
- Sense of Humor
- Talents
- Faith/Meaning

**Family & Relationships:**
- Close relationships with caring others
- Predictable home environment
- Supportive family interactions
- Prosocial peer group

**Environment & Community:**
- Good schools/work
- Public safety
- Health care access
- Financial resources

Masten, 2001
THINK POSITIVE…

How do you **assess** your or your child and families’ strengths?

What do you do to **build strengths** and **promote resilience** in yourself or your children?
BREAKING DOWN RESILIENCE

**Adversity**
- Overwhelming diabetes management demands
- Diabetes burnout, distress
- Pain/blood
- Constant management

**Asset**
- Optimistic outlook
- Diabetes online community
- Tech savvy
- Years of experience

**Protective Skill**
- Cognitive restructuring
- Seeking support
- Repeat what works, like exercise
- Have fun sharing experiences

**Resilient Outcome**
- Good mood
- Hopefulness
- Better management and glycemic control
SO, WHAT SHOULD WE DO?

Behavioral Strategies
BREAKING DOWN RESILIENCY

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Goal is to build skills that promote resilient outcomes
FIND YOUR STRENGTHS + USE THEM.

▪ What do you enjoy doing?
▪ What are you good at?
▪ What is going well in diabetes care?
▪ How can you build on what is going well?
▪ How can you use your strengths for diabetes?
WATCH YOUR LANGUAGE!

Say this…

- BG checking or monitoring
- High or low BG/A1c
- In- or out-of-range numbers
- Diabetes management (behavior)

… not this

- BG testing
- Good or bad numbers
- Diabetes control (biology)
“If you call someone non-compliant, then you are judging that person, intentionally or otherwise. Support and encouragement are much more constructive.”

–Jessica Collins (http://diatribe.org/art-compliance)

“The reason it’s easier to be honest with my endocrinologist now is because she views my pancreas as non-compliant, not me.”

–Kerri Sparling (http://sixuntilme.com/wp/2014/05/08/lies/)
“DIABETES IS NOT DIY”
HELPFUL AND NON-HELPFUL SUPPORT FROM FAMILY

Try this....

▪ Calm, supportive communication
▪ Acknowledge what’s going well
▪ A few reminders
▪ Clear about goals
▪ Problem-solving together

Not that...

▪ Angry communication
▪ Blame & Shame
▪ Negative confirmation bias
▪ Punishing out-of-range numbers
▪ Denying fears and worries
▪ Nagging
WHY NAGGING DOESN'T WORK

Stop overeating, stop drinking, stop staying out late, stop fighting, stop worrying, stop eating sweets, stop gambling...

What did the doctor say? I don't know... I stopped listening.
SET REALISTIC GOALS

• Major changes can be daunting
• **Small changes**, one step at a time
• Focus on **behavior** goals
• Each step achieved will reinforce self-management behaviors
• **Celebrate each success!**
• Praise behaviors not numbers
WHEN IT COMES TO PARTNERS FILL THEM IN:

- What does partner need to know about diabetes? How much do they want to know?
- What language works best in your family?
- What specifically can partner do to help PWD?
- Attend medical or educational appointments?
- Participate in self-management?
- How can partner check in about concerns without becoming “diabetes police”?
SUPPORT AND COMMUNITY

▪ Local organizations like CarbDM!
▪ Real-time access at your fingertips
▪ Blogs, community forums, online groups:  
  ▪ www.TuDiabetes.org (Diabetes Hands Foundation)
  ▪ www.ChildrenWithDiabetes.org
  ▪ www.SixUntilMe.com
  ▪ Check out their links to other blogs
▪ Twitter, tweet-chats  
  ▪ Diabetes social media advocacy @DiabetesSocMed  
  ▪ Wednesdays 9:00 pm Eastern  
  ▪ Follow #dsma to observe, answer questions, join conversation
PLAYING NICE WITH YOUR DIABETES DEVICE
IMPACT OF TECHNOLOGY

Pump

More freedom, flexibility
More demands, more stress
Can be more spontaneous
Need to be more vigilant

CGM

Alert Fatigue
Less anxiety, feel safer
Makes diabetes care easier
More collaboration, understanding
When to share?
TMI?
When to chime in, check up

Cemeroglu et al., 2010; Ritholz et al., 2014; Sullivan-Bolyai et al., 2004
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong># of respondents</strong></td>
<td><strong>1503</strong></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>35 years (SD=15; range=18-80)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>61% female</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td>90% Non-Hispanic White</td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td>20 years (SD=13; range=3-67)</td>
</tr>
<tr>
<td><strong>A1c (N=452)</strong></td>
<td>7.5% (SD=1.34)</td>
</tr>
<tr>
<td><strong>Current Management</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>25% Injections only</td>
</tr>
<tr>
<td></td>
<td>38% Insulin pump only</td>
</tr>
<tr>
<td></td>
<td>5% Injections + CGM</td>
</tr>
<tr>
<td></td>
<td>32% Insulin Pump + CGM</td>
</tr>
</tbody>
</table>

Hood, 2016
<table>
<thead>
<tr>
<th>Equipment</th>
<th>Multiple times a day / Daily / Every few days</th>
<th>Weekly</th>
<th>Monthly / Every few months</th>
<th>As Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insulin pump</td>
<td>- Carry supplies (infusion sets, insertion device, reservoirs, insulin, syringes, adhesives/tape)</td>
<td>- Charge battery (Tandem)</td>
<td>- Upload/send data to provider</td>
<td>- Manage sick days (i.e. follow blood glucose more closely; adjust settings; contact provider)</td>
</tr>
<tr>
<td></td>
<td>- Count carbohydrates</td>
<td></td>
<td>- Communicate w/MD or CDE re: basal/bolus adjustments</td>
<td>- Troubleshoot/manage/resolve infusion set failures</td>
</tr>
<tr>
<td></td>
<td>- Determine bolus type (standard/extended/combination)</td>
<td></td>
<td>- Replace battery (Medtronic, Animas, Omnipod, Roche)</td>
<td>- Check for/manage ketones</td>
</tr>
<tr>
<td></td>
<td>- Administer boluses</td>
<td></td>
<td>- Refill insulin prescription</td>
<td>- Troubleshoot pump issues (e.g. call customer service)</td>
</tr>
<tr>
<td></td>
<td>- Change infusion set</td>
<td></td>
<td>- Reorder supplies (infusion sets, reservoirs, adhesives, skin prep, etc.)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Change/fill reservoir</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Adjust basal/bolus settings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Adhesive/tape maintenance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CGM</td>
<td>- Monitor CGM values</td>
<td>- Change sensor (Medtronic)</td>
<td>- Upload/send data to provider</td>
<td>- Request replacement of failed sensors</td>
</tr>
<tr>
<td></td>
<td>- Respond to alerts</td>
<td>- Charge transmitter (Dexcom)</td>
<td></td>
<td>- Troubleshoot CGM issues (e.g. call customer service)</td>
</tr>
<tr>
<td></td>
<td>- Calibrate CGM</td>
<td>- Charge receiver (Dexcom)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Adhesive/tape maintenance</td>
<td></td>
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</table>

Table created by Molly Tanenbaum, Regan Barley, Sarah Hanes, and Rebecca Adams
<table>
<thead>
<tr>
<th>Table 1. Barriers to Device Use Reported by Study Participants (n=1503)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barrier</strong></td>
</tr>
<tr>
<td>---------------------</td>
</tr>
<tr>
<td><strong>Non-Modifiable</strong></td>
</tr>
<tr>
<td>Cost of supplies</td>
</tr>
<tr>
<td>Cost of device</td>
</tr>
<tr>
<td>Insurance coverage</td>
</tr>
<tr>
<td><strong>Modifiable</strong></td>
</tr>
<tr>
<td>Hassle of wearing devices all of the time</td>
</tr>
<tr>
<td>Do not like having diabetes devices on my body</td>
</tr>
<tr>
<td>Do not like how diabetes devices look on my body</td>
</tr>
<tr>
<td>Nervous that the device might not work</td>
</tr>
<tr>
<td>Do not want to take more time from my day to manage diabetes</td>
</tr>
<tr>
<td>Nervous to rely on technology</td>
</tr>
<tr>
<td>Worries about what others will think about you</td>
</tr>
<tr>
<td>I do not like diabetes devices because people notice them and ask questions about them</td>
</tr>
<tr>
<td>Too busy to learn how to use a new technology or device</td>
</tr>
<tr>
<td>My diabetes care team has never talked with me about diabetes technology options</td>
</tr>
<tr>
<td>Do not understand what to do with the information or features of the devices</td>
</tr>
<tr>
<td>Not able to get your diabetes care team to write you a prescription</td>
</tr>
<tr>
<td>Not enough support from your family</td>
</tr>
<tr>
<td>Not enough support from my diabetes care team in using devices</td>
</tr>
<tr>
<td>Do not want to have more information about my diabetes</td>
</tr>
<tr>
<td>My family does not think diabetes devices are important for taking care of my diabetes</td>
</tr>
</tbody>
</table>

*Slide created by Molly Tanenbaum*
<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>
WHAT DO PEOPLE THINK ABOUT AUTOMATED INSULIN DELIVERY?

60 focus groups and 89 individual interviews were conducted. 294 participants.

Adults, children, and adolescents with T1D, and parents of youth with T1D and partners of adults with T1D.

A coding team analyzed transcripts from focus groups and interviews to identify main themes.
Burden associated with Automated Insulin Delivery (AID) systems

Concerns about AID systems

Features of AID systems

Financial Aspects of AID systems

Benefits of AID systems, including benefits on Glycemic Control

Context and Situations relevant to AID use

Human vs. System, or the ability to transfer control to a machine

Nighttime aspects of T1D management, and relevance to AID systems

Quality of Life aspects of AID systems

Relationships and how AID systems may impact them

Technology that is part of AID systems

Trust & Control related to AID systems
GROUP DIFFERENCES

Children = specific social situations and settings such as school and friends

Adolescents = physical features, wearability and comfort

Adults and parents = device safety and reliability

Similarly, partners raised trust and control themes

Hood, 2016
USER EXPERIENCE

High Expectations

Balance between perceived/realized burden and perceived/realized supports and benefits

Continuum of wanting to retain control over a system and trusting it fully

Hood, 2016
Trust in CL Systems

Control

- Potential advantages:
  - User engagement
  - Maintaining skills
- Potential disadvantages:
  - Want to override system
  - Use workarounds, (e.g. “fake meals”)
  - Want to input more detailed information

Trust

- Potential advantages:
  - Lower decision-making burden
  - Think about diabetes less
- Potential disadvantages:
  - De-skilling?
  - Less vigilance

Balance of Control & Trust

- Appropriate level of vigilance
- Ability to reengage with needed
- More trust in some situations; more control in others

Slide created by Molly Tanenbaum
CONCLUSIONS

Dramatic rise in uptake of health devices and technologies in general

Need to improve uptake and benefit of these devices

Enthusiasm for closed loop systems with preliminary efficacy and acceptability

Hood, 2016
NEXT STEPS

Develop interventions to address:
- Comfort with devices and technologies
- De-skilling that occurs while on closed loop
- Diabetes distress that interferes with optimal benefit from devices and systems
- Match expectations of devices to what devices can offer!

Hood, 2016
QUESTIONS? COMMENTS?
dnaranjo@stanford.edu