Breaking Down Barriers and Creating Partnership in Diabetes Self-Management

Addressing Diabetes-related distress and burnout

Tziporah Rosenberg, PhD, LMFT
Assistant Professor, URMC Depts of Psychiatry & Family Medicine
Objectives

- Review extant literature on facilitators and barriers to diabetes self-management
- Define diabetes-related burnout, its causes and symptoms
- Differentiate between burnout and other symptoms
- Identify our own contributions to successful interactions and prevention of burnout
- Build skills in empathic responding, eliciting, and supporting
Think of a patient you’ve treated who has diabetes
- who was routinely engaged in care
- who came to scheduled appts
- who asked good questions
- who had optimal or near-optimal glycemic control

What do you do to facilitate this patient’s engagement in care? What does the pt do?
Think now of a patient you’ve treated who has diabetes...

- who struggles with their healthcare
- who doesn’t always “show up”?
- who isn’t “adherent”?
- whose glycemic control is out of control?

What do you believe about this patient, their behaviors, or their commitment?
Our Collective Conundrum

- These patients are hard. And sometimes frustrating. Or worse.

- We have such good data about what behaviors potentiate improved outcomes, and reduced risk for life altering complications.

- We have excellent resources for patient education.

- We have effective treatments, and more and more emerging by the month.
What Does Optimal Management Look Like?

1) managing the disease (taking medications, following a diet, engaging in physical activity, self-monitoring)

2) maintaining one's daily life while living with chronic illness

3) dealing with emotional aspects of the disease, such as anger, fear, frustration, and depression

Core Ingredients?

1. Sufficient knowledge of the condition and its treatment

2. Skills to manage the condition and to maintain functioning (incl problem solving skills)

3. Motivation and buy in

4. Confidence in one's ability to successfully execute specific tasks (self-efficacy)

5. Adequate environmental support to initiate and sustain behavioral changes

6. Effective management of feelings
What Gets in the Way for Patients?

- Inadequate family/social support
  - Too much “support”?
- Health literacy concerns
- Attitudes and beliefs
- Culture/finances
- Lack of clear understanding about diabetes (markers, regimen, daily routines)
- Depression
- Low self efficacy/locus of control
  - confidence to carry out a behavior necessary to reach a desired goal
- Time
“It’s not that people are unwilling to change, it’s that they are unwilling to be changed”

- We naturally resist others’ efforts to change us (wouldn’t YOU?) as a way to preserve our autonomy
Diabetes Burnout and Impact on Overall Care

- A prominent diabetes researcher (Fisher) reported recently that in any 18-month period, between a third and a half of people with diabetes will experience diabetes distress or burnout.

- A 2010 study in Diabetes Care reported that people with higher distress levels were more likely to develop high blood glucose than those with less distress. The converse is also true.
How Do They Get Burned Out?

- Doing the same (BOATLOAD of) tasks and not achieving the results we want. Or the same results every time. Or understanding why not

- Feeling like “doing our best” isn’t good enough. And having myriad reminders to reinforce that

- Developing a sense of resignation or hopelessness, or getting stuck in a series of negative feedback loops

- Losing touch with a sense of autonomy and control
Signs of Disease-Specific Burnout

- Feeling that diabetes is controlling your life, and sometimes a sense of defeat or hopelessness.

- Worrying about not taking care of diabetes well enough, yet unable to make a change.

- Avoiding diabetes-related tasks that might give feedback about the consequences of poor control.

- Experiencing caregivers and health professionals as unable to truly understand.

- Feeling alone and isolated with diabetes.

- Anger about the demands, or other negative feelings.
What is our role in assessing for and responding to burnout or distress?
Assessing Burnout: The Diabetes Distress Scale (Fisher & Polansky)

- Fisher and Polansky developed a series of scales to assess for burnout, incl one each for T1 and T2.
  - Regimen distress
  - Concerns about the future
  - Worries about quality and cost of care
  - Social burden or interpersonal distress

### Assessing Burnout: The Diabetes Distress Scale (Fisher & Polansky)

<table>
<thead>
<tr>
<th></th>
<th>Not a Problem</th>
<th>A Slight Problem</th>
<th>A Moderate Problem</th>
<th>Somewhat Serious Problem</th>
<th>A Serious Problem</th>
<th>A Very Serious Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feeling that my doctor doesn't know enough about diabetes and diabetes care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2. Feeling that diabetes is taking up too much of my mental and physical energy every day.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3. Not feeling confident in my day-to-day ability to manage diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4. Feeling angry, scared and/or depressed when I think about living with diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6. Feeling that I am not testing my blood sugars frequently enough.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
Anytime is the Right Time for Burnout

- For some, it may be a natural reaction to caring for diabetes for a long time.
- May coincide with a difficult life period or transitions, even normal, expected, or good ones.
- May occur when another friend, family member or acquaintance experiences a complication (or worse) attributed to diabetes.
- Receiving news of one’s own complications, while for some people can lead to a renewed motivation for self-care, for others can lead to a hopelessness.
Burnout is Not Depression

- Diabetes burnout is different from depression.

- Burnout is a **rational response** to the demands of living with a long-term illness.

- Depression leads a person to have negative thoughts about themselves, others and hopelessness about the future.

- Burnout involves feelings focused specifically on diabetes, and the person may not seem particularly low to an outside observer.
Rates of depression and anxiety are higher among those with diabetes.

Symptoms of depression can be ascertained with validated screening tools (plus empathy!).

Effective and evidence-informed treatments for depression and anxiety include

- CBT
- Behavioral activation
- Family therapy
What Solutions Can We Recommend?

- Treat the Illness
- Treat the Distress
- Build a trusting relationship
What Solutions Can We Recommend?

- Normalize feelings of burnout. They are real.
- Challenging all or nothing thinking.
  - Focus on effort, not just outcome
  - Notice trends
  - Praise periods of “better” and find out how they are happening
- Treat glucose levels as data points, not personal evaluations (or personal attacks)
- Encourage support beyond the office.
- Encourage other forms of self care.
Outpatient Partnerships

• **Ask-Tell-Ask**
  • 1) **Ask**: find out what patients already know, as well as additional information they would like to know
  • 2) **Tell**: provide new information or advice, giving choice about how much
  • 3) **Ask**: encourage patients to interpret and react to the information or advice and tailor responses accordingly.

• **Encourage experimentation**
  • what does and doesn’t work?
  • all data are useful
  • what did they do? How did it go? What did they learn? What next?

• **Self-management education (incl problem solving)**
In the Office, Establish Partnership.

- Ask open ended questions:
  - “tell me about how it’s going with your diabetes care...”; “tell me more about that...”; “what do you understand about how your diabetes is doing?”

- Invite discussion about how your patient is handling the diabetes demands
  - “how are you managing the day to day tasks?”

- Invite discussion about how your patient is handling non-diabetes demands in the setting of having diabetes
  - “what other demands are you managing in addition to diabetes?”; “how do these relate with how you take care of your health?”
In the Office, Establish Partnership.

- Ask what their diabetes-related concerns are
  - “what concerns you most about your diabetes today?”; “where would you like to start with managing your health?”

- Validate frustrations. And sadness. And loss. And fatigue. And anger.
  - “It’s understandable that you’d feel __________ with all that you’re managing”; “I have other patients who feel the same way; you’re not alone”

- Ask about successes
  - “what is going pretty well with your diabetes right now?”; “what has worked in the past when you tried to __________?”
In the Office, Establish Partnership.

- Assess for depression and anxiety, disease-related and not
- Don’t presume the problem is lack of information
- Break down too-large goals into smaller, more manageable ones (even/esp when pts have a long haul ahead)
- Discuss time as a resource, prioritize behavior changes or goals accordingly
- Lead with listening
Questions/Comments

- Any and all. 😊