THE EMOTIONAL SIDE OF DIABETES: IMPLICATIONS FOR CLINICAL CARE

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No conflicts of interest to report.

Percentage of Patients Achieving ADA Treatment Targets

Casagrande et al. 2013

Behavior Change Ain’t Easy

- Habits are hard to change.
- It takes time and energy to make changes.
- We often don’t know what else we need to do that we have not already done before.
- Life gets in the way.
- HCPs: Even if we had the extra resources (45 minutes with a patient), what would we do differently?

HCP Attributions Regarding Problem Patients

HCP top 5 complaints about patients with diabetes:
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
The Costs Are High
- Increased complications
- More frequent health care visits.
- More frequent hospitalizations and ER visits.
- Increased mortality.
- Higher health care costs.
- More pain and suffering.

How The Process Works

Tools For Behavior Change
Important & Effective Components:
- Education – provide information.
- Behavioral tools: e.g., SMBG, monitoring.
- Behavioral direction: provide the how-to’s.
- Community resources.
- Action planning, goal setting, review obstacles.
- Reminders and ticklers.

Efficacy Of Action Planning

<table>
<thead>
<tr>
<th>Follow-up</th>
<th>Remembered the action plan</th>
<th>Goal achieved and behavior sustained</th>
<th>Goal achieved, behavior not sustained</th>
<th>Goal not achieved, some behavior change</th>
<th>Other behavior change</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 weeks (n = 240)</td>
<td>95%</td>
<td>71%</td>
<td>2%</td>
<td>19%</td>
<td>44%</td>
</tr>
<tr>
<td>4 weeks (n = 232)</td>
<td>94%</td>
<td>66%</td>
<td>3%</td>
<td>22%</td>
<td>34%</td>
</tr>
<tr>
<td>12 weeks (n = 229)</td>
<td>88%</td>
<td>53%</td>
<td>3%</td>
<td>21%</td>
<td>45%</td>
</tr>
<tr>
<td>At all 3 follow-ups</td>
<td>70%</td>
<td>33%</td>
<td>3%</td>
<td>21%</td>
<td>40%</td>
</tr>
</tbody>
</table>

DeWalt et al, 2000
How The Process Works

Actions & behavior are necessary but not sufficient for some patients.

Qualitative Study

- 40 adults with poorly controlled T2DM.
- Mixed gender, ethnicity, age, DM duration.
- One-hour audio-taped interview with each.
- Questions: A diabetes conversation.
  - What is it like living with DM?
  - How do you think and feel about DM?
  - What happens to you as a person as you take care of your disease?
  - What stops you from doing what your HCP asks you to do and what you may know you need to do?

Five Very Good Reasons For NOT Following Through

- Mental health challenges
- Discouraging results
- Environmental influences
- Expectations
- Social influences

Mental Health Challenges

- Depression
- Substance use
- Eating disorders
- Anxiety disorders

How many T2D adults have clinically diagnosable disorders?

Mental Health Challenges

- Depression: 4%
- Substance use: 2%
- Eating disorders: 3%
- Anxiety disorders: 3%

Many of above have dual diagnoses.
A small but significant contributor.

Discouraging Results

- Insignificant weight loss (weight gain).
- No significant drop in A1C.
- Side effects of medications.
- Don’t feel any different.
- No change in blood sugars.

A lack of perceived value.
Environmental Influences
- Cost.
- Work & financial stress.
- Competing priorities: e.g., family, finances.
- No time.
- Culture: conflicting influences/preferences.
- Safety.
- Availability.

Personal Expectations
- I need to be perfect.
- I should be better at this by now.
- It never worked before, so why should it now?
- Can I trust my HCP?
- My poor A1C will be my fault.
- It will never be enough.
- If I start this now I can never take a break.
- I did this to myself anyway.

Social Influences
- Nobody understands.
- I have to take care of my family first.
- Others nag me.
- My family blames me.
- My family always tells me what to do – the "diabetes police."
- I don’t want to stand out.
- It will be embarrassing to ‘fail’ again.

Five Very Good Reasons For NOT Following Through
- Mental health challenges
- Discouraging results
- Environmental influences
- Expectations
- Social influences

These reasons are understandable and to be expected!

Putting It All Together: Common Feeling Scenarios
- Hopelessness
- Overwhelmed
- Demoralized
- Frightened
- Angry
- Ashamed
- Embarrassed
- Distrustful
- Self-critical
- Why me?
- Avoidant
- Self-blaming
- Guilty

How The Process Works
Feeling, Expectations (Distress) → Actions → Diabetes Numbers → Long & Healthy Life
Conflicting Motivations

Reasons For Not Following Through:
- Diabetes Distress
- Mental Health Challenges
- Discouraging Results
- Environmental Concerns
- Expectations
- Social Influences

Reasons For Following Through:
- Good For Me
- Live Longer
- No Complications
- Healthier

Diabetes Distress (DD):
The Emotional Side Of Diabetes

Definition: DD refers to the expected worries, concerns, fears, and threats that are associated with struggling with a demanding and progressive chronic disease, its management, threats of complications, loss of functioning, etc.

Characteristics Of DD
- DD reflects a broad range of affective experience (all the Common Feeling Scenarios listed earlier).
- Anchored: DD focuses on an emotional experience (distress) linked to the specific situational contexts that produced it (diabetes): implies etiology, context and source, it directs intervention.
- DD is viewed as an expected response to a health threat: does not imply psychopathology, is not viewed as a co-morbid disorder or condition.
- Many patients & HCPs are unaware of the emotions underlying DD – not part of our usual conversations.

DDS: T2DM Diabetes Distress Scale
- 17 items developed from the patient interviews.
- Four subscales:
  - Regimen distress: Maintaining a good diabetes regimen.
  - Interpersonal distress: Obtaining diabetes-related emotional support.
  - Emotional burden: Managing the emotional demands of DM.
  - Physician distress: Concerns and worries about health care for diabetes.

Prevalence of DD
Current & clinically meaningful (> moderate):
- Type 2 adults (n = 503): 35%
- Type 1 adults – new scale with 7 sub scales (n = 386): 39%

DD & Depression Fact Sheet

- Significantly associated with HbA1C
- Significant co-variation with HbA1C over time
- Significantly associated with diet, medication adherence and physical activity
- Interventions to reduce DD also reduce depression (PHQ9)

Summary Of The Story So Far

- We all have problem patients who have major difficulties with disease management.
- We tend to address disease management by focusing exclusively on behavior and behavior change (education, action planning, etc.).
- These are necessary but not sufficient for many patients.
- The missing link in the process is the emotional side of diabetes – diabetes distress.
- Where do we go from here? How to address the emotional side of diabetes in clinical care?

Time to Practice #1

Can you think of a healthy change you’d like to make in your life, but you just haven’t made it yet; haven’t gotten around to it yet?

Practice #1: Persuasive HCP

- Explain why he/she should make this change.
- Give at least three specific benefits that would result from making the change.
- Suggest how to make the change.
- Emphasize how important it is for him/her to change.
- Tell him/her to just do it; and you will be checking up over time.
- You have many things to suggest to make it work, so interrupt often.

Time to Practice #2

Can you think of a healthy change you’d like to make in your life, but you just haven’t made it yet; haven’t gotten around to it yet?

Practice #2: Journalist HCP

1. Clearly identify the area for behavior change.
2. Get the details, stay neutral, listen carefully.
   - Ask for 2-3 good reasons why they might want to make this change.
   - Ask for 2-3 good reasons why they might NOT want to make this change. Help identify and label them clearly. Repeat and emphasize ‘feeling’ words.
   - Given the reasons for and the reasons against, ask how they might go about it, in order to succeed?
3. Summarize and feed back each part of the story you have heard. Let patient decide what to do.

DO NOT OFFER ANY HELP, DIRECTION OR ADVICE

The Internal Tug-Of-War

On the one hand …. One the other hand …
An Emotional Tug-Of-War

ON THE ONE HAND:
Want to be healthy.
Want to participate.
Want to lose weight.
Want to exercise.
Want better HbA1c.
Don’t want compls.

ON THE OTHER HAND:
Fear of failure.
Angry.
Hopeless.
Avoidant.
Distrustful.
Ashamed.

DIABETES AMBIVALENCE

Diabetes Distress

- Not pathological
- Not unexpected
- Not uncommon

But the feelings and expectations can block behavior change if not addressed!

What The Journalist Did

- Listened carefully – talked far less than usual.
- Reflected both sides of the tug-of-war.
- Rephrased with different language.
- Inserted feeling words.
- Allowed the patient to consider and ponder.
- Permitted periods of quiet.
- Asked questions to clarify & specify.
- Asked the patient to consider options and decide what might be best without an HCP value judgment.
- HCP available to provide tools & resources if requested.

 Intervention Rationale

Since:
- We cannot control what we feel.
- We often feel more than one way at once.
- Feelings are often out of our awareness.
- Feelings drive behavior.

Then:
- Acknowledging both sets of feelings publicly helps patients label what they feel and helps them recognize the impact of their feelings on their behavior.
Intervention Rationale

The goal is to label & normalize both sides of the ambivalence and thus make public and potentially defuse the distress and ambivalence that prevents many patients from entering into and engaging with programs to improve disease management (the missing link).

A STRUCTURED WAY TO BRING FEELINGS INTO THE CONVERSATION!

How To Make It Work In Clinical Care?

What We Need:
- A way to engage in a time-efficient conversation with the patient.
- Process to include the missing link: distress.
- Systematic and reasonably protocol-driven.
- Easily integrated into SMS activities.
- Easy to learn by ALL staff.

Two General Strategies For Implementation In Primary Care

1. Motivational interviewing (brief negotiation):
   - Popular.
   - Requires training and follow-up.
   - Somewhat unsystematic.
   - Can be time-consuming.
   - Not easily protocol-driven.
   - Effective.
   - Online mini course through Northern CA KP.

Two General Strategies For Implementation In Primary Care

2. AASAP
   - Anticipate feelings.
     “It must have been hard for you to come for this visit knowing you were unable to reach your weight goal."
   - Acknowledge and label the feeling.
     “You must have felt like a failure when your AIC went up.”
   - Standardize or normalize the feeling.
     “That happens to so many of my patients, so many people feel the same way when that happens.”

Two General Strategies For Implementation In Primary Care

2. AASAP
   - Accept & understand where the feeling comes from, what triggers it and how it affects behavior.
     “So when you feel that way you usually just give up.”
   - Plan how to respond to the feeling.
     “So on the one hand... And on the other hand... What should you do now?”

Two General Strategies For Implementation In Primary Care

2. AASAP
   - Evidenced-based
   - Requires only brief training.
   - Highly systematized and reasonably protocol-driven
   - Similar techniques significantly increased recruitment and decreased attrition in RCTs.
   - Training in DM education centers reduced no-show rates.
   - Training PC physicians, MAs, NPs, PAs to enhance SMS for adults with DM (5-hour workshop plus follow-up).

**Take-Home Messages**

- The lack of attention to the emotional side of diabetes reflects a major gap in engaging patients in the process of behavioral change.
- Most of the emotions we see are not part of a clinical depressive syndrome or mental health disorder but are reactions to the demands of having DM.
- The prevalence of DD is high.
- DD is significantly linked with management and A1C.

**Take-Home Messages**

- DD is not pathological, it is to be expected – it part of having diabetes.
- **Caution:** some DM patients are clinically depressed and need to be treated!!!
- Aspects of motivational interviewing (brief negotiation) and AASAP are useful tools for addressing the missing link in behavioral change.

**HCP’s Emotional Tug-Of-War**

<table>
<thead>
<tr>
<th>ON THE ONE HAND:</th>
<th>ON THE OTHER HAND:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Want pts. to be healthy.</td>
<td>Too much to do.</td>
</tr>
<tr>
<td>Want to help change behavior.</td>
<td>Already overwhelmed.</td>
</tr>
<tr>
<td>Want to help improve ABCs.</td>
<td>Don’t want to open a Pandora’s Box.</td>
</tr>
<tr>
<td>Want pts. to be happier.</td>
<td>Not comfortable with this stuff!</td>
</tr>
<tr>
<td>Want to feel successful.</td>
<td>Not what I am here to do - not me.</td>
</tr>
<tr>
<td>Want to feel less frustrated.</td>
<td>I feel too awkward.</td>
</tr>
<tr>
<td>Want to feel less demoralized &amp; hopeless.</td>
<td>I fear not having the right words.</td>
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</tbody>
</table>

**PRIMARY CARE AMBIVALENCE**