



Defusing Distress:

Helping Patients with Diabetes Distress

Advancements in Diabetes Webinar Series

October 16, 2024

Carol Greenlee MD MACP



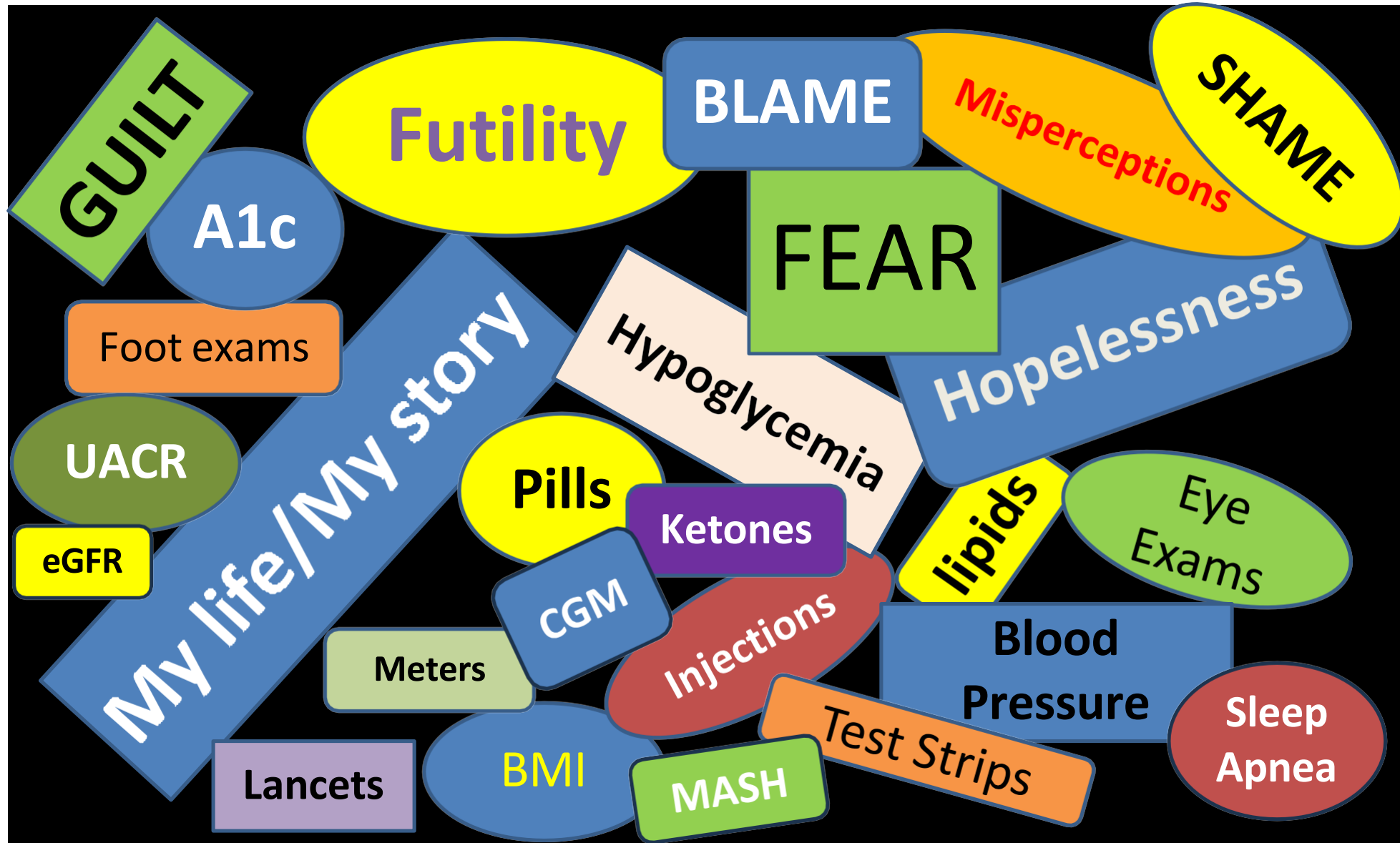
Learning Objectives

- Examine diabetes distress and how it impacts patients with diabetes
- Identify screening tools used to assess for and manage diabetes distress
- Consider how Behavioral Health Specialists can be part of the diabetes care team and help support people with diabetes to reduce diabetes distress.

What is
Diabetes
Distress?



Diabetes Distress – the Patient Experience



Diabetes Distress vs Depression

- Previous studies suggested many people with diabetes (2-3x those without diabetes) have depression.
 - More recent studies show 3-8% of people with diabetes have depression, about the same as people without diabetes --- but...
 - People with diabetes score higher on the PHQ9 –
 - This is picking up something, but it is not always depression, often diabetes distress (DD)
 - One study suggests ~70% of those with abnormal PHQ9 have DD not clinical depression
- Very different solutions
 - *“This distress cannot be treated with depression medications because...it is not depression!*
 - *Rather, it requires a greater focus on acknowledging and addressing the emotional and behavioral obstacles associated with diabetes.” W. Polonsky*

Depression vs Diabetes Distress

Depressive Disorder

- Hopelessness about life in general
- Pervasive & persistent mood problems (most of the day, more days than not)
- Interference with functioning across (work, relationships, health)

“I’m a failure. Everything is hopeless.”

Diabetes Distress

- Sadness & tough feelings about diabetes
- Persistent stressors related to diabetes.
- May affect diabetes self-management.

“I am failing at diabetes. My efforts at diabetes are hopeless.”

Diabetes distress is anchored in the day-to-day experience of living with diabetes (it is an expected reaction to diabetes), whereas depression is the generic feeling of depressed affect, which is not linked to a specific condition or experience.

How Common is Diabetes Distress?

“The rate of diabetes distress is far greater than is often appreciated”

- Diabetes Distress is common. Many people experience significant diabetes distress –
 - **about 40% of adults with either type 1 or type 2 diabetes report significant distress at any point in time**
 - over 50% report significant distress during any 12-month period.
- In the second Diabetes Attitudes, Wishes, and Needs (DAWN2) study, ***significant diabetes distress*** was reported by **45%** of the participants
 - No data on AI/NA populations

5-15% of people with diabetes overlap with both DD & clinical depression

Why is Diabetes Distress Important?

- Diabetes Distress is of significant clinical concern due its high prevalence and its *clinically significant relationship with*
 - disease management
 - lower self-efficacy
 - less optimal eating and exercise behaviors
 - lower medication adherence (problematic medication-taking behaviors)
 - glycemic control – higher A1c
 - reduced health-related quality of life



ADA 2024 Standards of Care-Diabetes Distress

- Recommendation 5.39
 - **Screen** people with diabetes **for diabetes distress at least annually**, and
 - consider **more frequent monitoring**
 - when treatment targets are not met,
 - at transitional times, and/or
 - in the presence of diabetes complications.
 - Health care professionals can **address** diabetes distress
 - may consider referral to a qualified behavioral health professional, ideally one with experience in diabetes, for further assessment and treatment if indicated. B

How do You Screen for DD?

- Be **AWARE** that people with diabetes may experience diabetes distress (the emotional burden arising from living with and managing diabetes)
- Look for signs:
 - suboptimal A1C or unstable blood glucose levels
 - missed clinic appointments
 - reduced engagement in diabetes self-care tasks
 - ineffective coping strategies
 - multiple life stressors
 - chronic stress
 - impaired relationships (personal or with health professionals)
 - appearing passive/aggressive during consultations

Not responding to
Antidepressant treatment

“Be curious, not furious”

How do You Screen for DD?

- Routinely **ASK** all people with diabetes about diabetes distress.
 - Use open-ended questions to explore the impact of diabetes on daily life and well-being
 - *“What is driving you crazy about diabetes?”*
 - *“Diabetes can be a lot to deal with, how are you doing with everything?”*
 - *“What is the hardest thing for you in dealing with diabetes?”*
 - *“What is the most difficult part of living with diabetes for you?”*
 - *“How is your diabetes getting in the way of other things in your life right now?”*
- If diabetes-related concerns are raised through AWARE (signs) and/or ASK → continue to **ASSESS**.

How do You Screen for DD?

- **ASSESS** for diabetes distress using a *validated questionnaire*
- When to assess:
 - Annually
 - If AWARE or ASK indicates possible diabetes distress
- Use a validated questionnaire
 - ADA toolkit(multiple questionnaires)
professional.diabetes.org/sites/default/files/media/ada_mental_health_toolkit_questionnaires.pdf
 - *BDI: <https://diabetesdistress.org/>
 - Provides scoring: subscales/domains
 - Can download or print results

*Behavioral Diabetes Institute

BDI: Assessment of Diabetes Distress in Type 2 Diabetes:

- For adults with type 2 diabetes (regardless of medication regimen) - suggest ***the T2-Diabetes Distress Assessment System (T2-DDAS)*** in English or Spanish.
 - This recently developed system consists of **29 items** and yields **two sets of scores**:
 - an 8-item **CORE DISTRESS SCORE**, reflecting overall diabetes-related emotional distress
 - a 21-item set of seven **SOURCE SCORES**, reflecting different potential sources of distress
 - For type 1 diabetes – a 30 item T1-DDAS
- [How to use the T2-DDAS on the Website \(Diabetes Distress Assessment & Resource Center -https://diabetesdistress.org/\)](https://diabetesdistress.org/)
 - You can *download* a copy of the T2-DDAS in English or Spanish, along with scoring instructions.
 - *You may also ask patients to complete the T2-DDAS in English or Spanish **online**.*
 - Online administration will produce a **single CORE score, 7 SOURCES scores, and all item scores, which will be computed automatically.**
 - All scores will then be summarized in an accompanying **report**, available for download or printing.

Instructions for Patients

- DIRECTIONS: Living with diabetes can be tough. Listed below are many of the stresses and worries that people with diabetes often experience.
 - These are issues that can often be tough to acknowledge and to talk about, but please be as open and honest as you can.
- Thinking back over the past month, please indicate how much each of the following items were a problem for you by marking the appropriate column.
 - For example, if an item was not a problem for you over the past month, place a mark in the first column: "Not a Problem" (1). If it was a very tough problem for you, place a mark in the last column: "A Very Serious Problem" (5).

The Online Screening Tool

Not a Problem A Little Problem A Moderate Problem A Serious Problem A Very Serious Problem

1. I feel burned out by all of the attention and effort that diabetes demands of me.

1

2

3

4

5

2. It bothers me that diabetes seems to control my life.

1

2

3

4

5

3. I am frustrated that even when I do what I am supposed to for my diabetes, it doesn't seem to make a difference.

1

2

3

4

5

4. No matter how hard I try with my diabetes, it feels like it will never be good enough.

1

2

3

4

5

Interpreting & Using the Screening Scores

- How to Use the T2-DDAS
 - Use the **T2-DDAS** to identify three levels of specificity of diabetes distress information for use in clinical care:
 1. Use the **CORE** score to begin a conversation about a *patient's overall level of diabetes distress* and current general feelings about living with diabetes.
 2. Review each of the 7 **SOURCE** scores to identify *the highest reported source or cause of distress*.
 - Use this subscale to begin a conversation about more focused areas of concern.
 3. Identify the highest rated of the 29 T2-DDAS items. Use these **specific items** to begin a conversation about *particular sources of diabetes distress*.
 - Mean score < 2.0 indicate little or no distress.
 - Mean score between 2.0 and 2.9 indicate moderate distress.
 - Mean score \geq 3.0 indicate high distress
 - Any subscale score \geq 2.0 is considered *clinically significant*



Case Patient - Tony

- 55-year-old man
- Diagnosed with T2D mid-40s – strong family history of T2D & CVD
- Works in grocery delivery, in & out of truck & stores all day on workdays
- A1c is 8.4% on max doses of metformin, sitagliptin & empagliflozin; rarely uses meter to check BGs
- He is on statin with LDL of 62, lisinopril with BP 118/74, UACR 20, eGFR 78
- He has had regular diabetic eye exams with mild to moderate cataracts noted bilaterally, no DME or DR
- BMI 33; Nonsmoker, occasional alcohol on weekends and social outings
- He seems to be reliable at taking his prescribed medications and coming to appointments for follow up of diabetes but had to cancel his last appointment and now is several months overdue when he comes in today.

Case Patient - Tony



The Medical Assistant (MA) comments, as she rooms Tony, that she is glad to see him back for follow-up & notes his reply *“Thanks, but I am not sure what good it does”*

MA: *“It sounds like you are discouraged with things or at least with the diabetes?”*

Tony: *“Just seems like a lot of medications and appointments, gets hard to keep it up, just wondering if it will make a difference.”*

MA: *“Dr. Brown will be in to see you shortly. While you are waiting, would you be willing to take a survey on how diabetes is impacting you? – it could help us sort things out for you.”*

Provides tablet with the T2DDAS open and reviews the directions with him. Asks him to signal her when he is done, and she will take it from there.

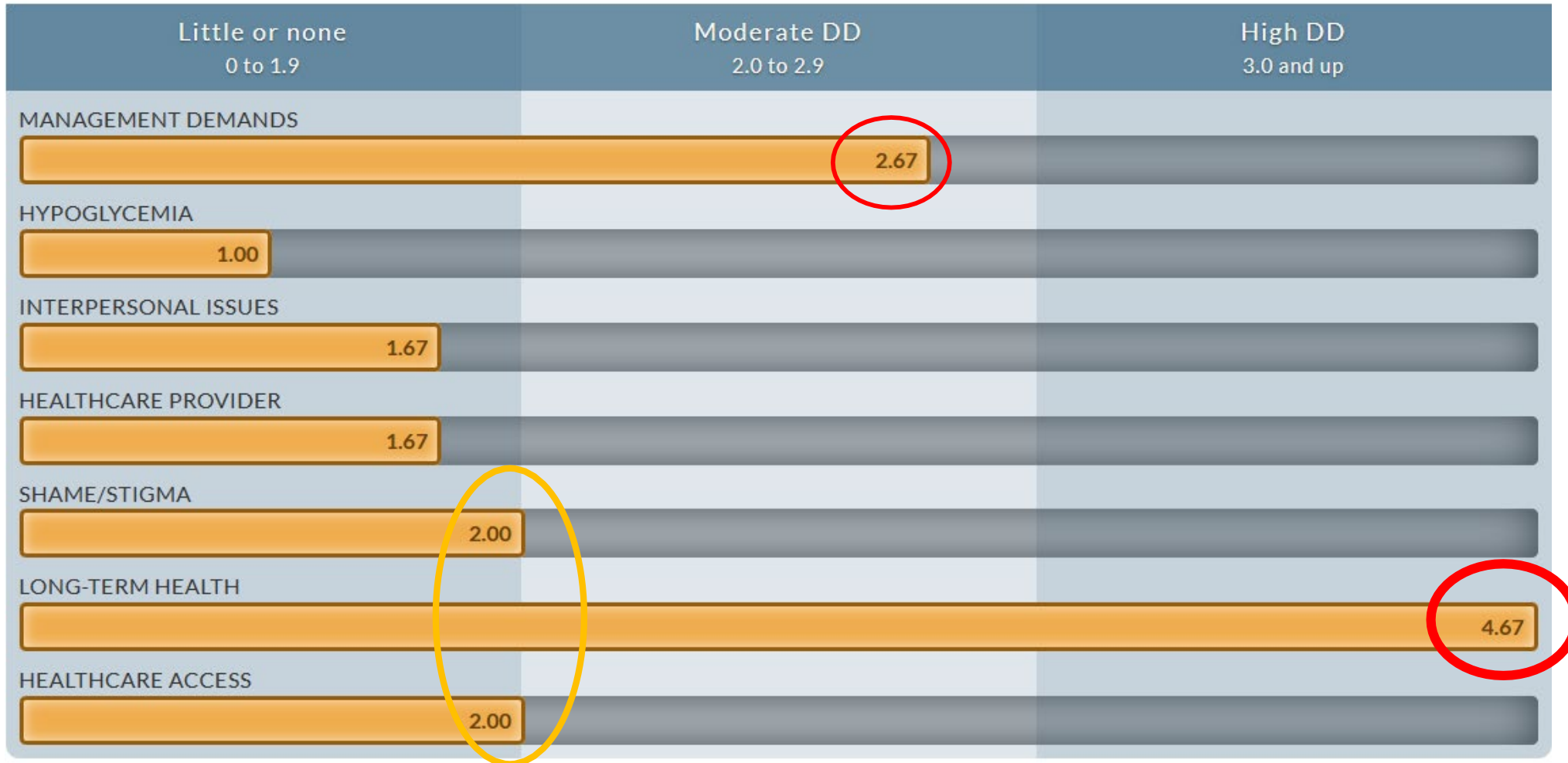
She prints the Core & Source Summary Reports (Mean score > 3.0 indicate high distress)

Your CORE T2-DDAS Summary Report



What is the main source of his DD?

Your SOURCE T2-DDAS Summary Report



A score of 2.0 or higher on any scale suggests significant diabetes distress. 0

More Detailed Look – at Core Issues

Your T2-DDAS Summary Report

Here is how you scored each item.

| Question | Not a Problem (1) | A Little Problem (2) | A Moderate Problem (3) | A Serious Problem (4) | A Very Serious Problem (5) |
|--|-------------------|----------------------|------------------------|-----------------------|----------------------------|
| Core Level Of Distress | | | | | |
| I feel burned out by all of the attention and effort that diabetes demands of me. | | | | ✓ | |
| It bothers me that diabetes seems to control my life. | | | ✓ | | |
| I am frustrated that even when I do what I am supposed to for my diabetes, it doesn't seem to make a difference. | | | | ✓ | |
| No matter how hard I try with my diabetes, it feels like it will never be good enough. | | | | | ✓ |
| I am so tired of having to worry about diabetes all the time. | | | ✓ | | |
| When it comes to my diabetes, I often feel like a failure. | | | | ✓ | |
| It depresses me when I realize that my diabetes will likely never go away. | | | ✓ | | |
| Living with diabetes is overwhelming for me. | | | ✓ | | |

Main message = sense of **futility, hopelessness** –

- No matter what I do, bad things are going to happen
- What I do doesn't make a difference, I am 'doomed'
- I am doing a lot of stuff for nothing (no benefit)

More Details- Sources of Distress

| Management Demands | | | | |
|--|---|---|---|---|
| It frustrates me that my eating often feels out of control. | | | | ✓ |
| I worry that I don't pay enough attention to my diabetes. | | | ✓ | |
| It bothers me that I don't get as much exercise as I should. | ✓ | | | |
| Hypoglycemia | | | | |
| I am scared that I might have a serious low glucose event when I am out in public. | ✓ | | | |
| I worry a lot that I could have a serious low glucose event. | ✓ | | | |
| I worry about having a serious low glucose event when I'm alone. | ✓ | | | |
| Interpersonal Issues | | | | |
| When it comes to family and friends, it disappoints me that I am pretty much on my own with diabetes. | ✓ | | | |
| It frustrates me that people in my life tempt me to eat foods or do things that are not good for my diabetes. | | ✓ | | |
| It hurts me that many people in my life don't understand what living with diabetes is really like. | | ✓ | | |
| Healthcare Provider | | | | |
| When it comes to medical care, it upsets me that I am mostly on my own with diabetes. | | ✓ | | |
| It upsets me that I'm not really heard or understood by my healthcare provider. | | ✓ | | |
| It upsets me that my healthcare provider seems to care more about my glucose levels than about me as a person. | ✓ | | | |

Eating Distress

Maybe some ambivalence
(distress over how much time
diabetes requires & that it
doesn't make a difference AND
Guilt/distress over not doing more)

Some sense of
"in it all alone"

More Details- Sources of Distress

| Shame/Stigma | | | | |
|---|--|---|---|---|
| It makes me feel bad that I must hide my diabetes from others. | | ✓ | | |
| It upsets me that people in my life think less of me because I have diabetes. | | ✓ | | |
| I often feel ashamed or embarrassed when other people know about my diabetes. | | ✓ | | |
| Long-term Health | | | | |
| I worry a lot about developing serious complications from diabetes. | | | ✓ | |
| I can't escape this sinking feeling that diabetes is eventually going to get me. | | | | ✓ |
| No matter what I do, I fear that serious complications from diabetes will happen to me. | | | | ✓ |
| Healthcare Access | | | | |
| I worry that I won't be able to pay for my diabetes care, medicines or supplies. | | ✓ | | |
| I worry that I can't get the healthy food I need for my diabetes. | | ✓ | | |
| I worry about how hard it is get to my healthcare appointments or pharmacy. | | ✓ | | |

Mild/Moderate Shame & stigma

The Big One
Futility and hopelessness

Mild/Moderate Access Distress

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

Now What?

- What do you do? What *can* you do?
- If diabetes distress is *not managed*, it can get worse over time. It may lead to “burnout”—this is when a person feels ***emotionally exhausted and overwhelmed by the demands of their diabetes.***
- They try to cope with this by ***giving up*** on taking care of their diabetes.
- *For the most part, **distress interventions typically do not require the expertise of a mental health professional, which can be costly and, in most cases, unavailable. With planning they can be incorporated into regular diabetes care by well-trained, sensitive diabetes clinicians.*** Fisher & Polonsky

What can you do to help patients with Diabetes Distress?

- Good news – **just acknowledging DD & talking about it/normalizing it helps reduce it**
 - Improvement seen just by *MONITORING* DD
- For some items – diabetes education is helpful
 - Most effective to ***first address emotional distress*** & then provide the self-management education
 - Identifying ***misperceptions & capacity issues*** can help address emotional distress – examples:
 - Thinking it is necessary to eat “no sugar” – really don’t know what to eat
 - Not knowing what BG is normal – e.g., should be 100 all the time
 - Not sure how to use pen or use insulin scale, etc.
 - Numeracy & literacy issues
- Reducing diabetes stigma & shame in the clinic (clinicians & staff) – words matter
- Address hopelessness & futility (*“no matter what I do, bad things are going to happen”*) – provide Evidence-based hope
 - Avoid scare tactics – provide strategies
 - Share updated research data on outcomes (*“not your grandfather’s diabetes”*)
 - Use “discovery learning” – CGM a great tool
 - “what you do does make a difference”
 - Being Perfect is not required to improve outcomes & do well with diabetes

Antidepressants are Not the Answer for DD

- The **demands of self-management might exceed their capacity**
 - diabetes adds several hours per day of an unasked-for “job” per day –
 - no pay, no vacation – this **adds a lot** extra to balance with life, especially when there are additional life demands (competing priorities)
 - they **might not know or understand why or how** to do some of the expected self-management
 - not everyone has the same capacity for self-management and the necessary skills

Patient Capacity for Self-Care



Over 2 hours per day is required for diabetes self-care
Diabetes is hard ...

“When individuals do not feel able to follow the advice, recommendations or instructions given, this is likely to increase distress rather than motivate action.”

Consider patient’s capacity when doing Shared-Decision Making

Diabetes Education can Help

Improve Capacity & Reduce Misperceptions & Self-blame

- Ensure necessary skills (how to xxx) – teach back (*“show me how you...”*)
- Assess numeracy skills – make it easier, less intimidating
 - *“Many people tell me they aren’t good at math, how comfortable are you with math? – how are you with adding, dividing...?”*
 - *“Do you have any questions about what all the numbers mean?”*
- Explain what is normal
 - Normal blood glucose range and fluctuations
 - High BG not always “your fault”
 - E.g., Stress hormones make everyone need more insulin/more insulin needed to help fight infection
- Explain expectations
 - *“Diabetes gets worse even if you do everything right”* – beta cells “wear out” over time and make less insulin [from inside] (key message – *“it is not your fault”*)
 - *Therapeutic heterogeneity* – not every treatment works the same for every person – need to find what works for any individual (*precision* medicine) [the patient didn’t fail]
 - For safety need to start with small dose and gradually increase – *the starting dose is not the “right” dose* that was expected to do the job (you did not fail)

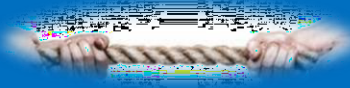
- Fear of med side effects
- Fear that Insulin therapy *causes* complications

Diabetes Stigma – What is *Your* Mental Model of Diabetes?

- Assumptions/beliefs that
 - people with diabetes are “non-compliant” - don’t do as told
 - they don’t care, they aren’t trying
 - the diabetes, hyperglycemia & complications are their fault
 - treating diabetes is easy, if they would only do it
 - they would be fine if they ate right
- Many people with diabetes get *weight stigma* along with diabetes stigma

Some Mental Models of Diabetes from HC workers

- *“Many of those who have diabetes are noncompliant and don’t take care of themselves.”*
- *“That patient is so undisciplined.”*
- *“People with diabetes cause themselves to become ill, lose limbs, and disregard their medication/diet regimen.”*
- *“Diabetes is a disease of gluttony and sloth – they bring it on themselves.”*
- *“If she wasn’t so lazy...”*
- *“Well, it is kind of his fault, right?”*
- *“They don’t do what they are supposed to – they are not even trying to get better.”*
- *“They just don’t care...their noncompliance, nonadherence, whatever it is, is so frustrating, why don’t they just do what I tell them to do?”*



Words Matter:



Studies shows importance of language choices in diabetes care

- **“Negative terms”** e.g., *“nonadherent”* or *“noncompliant”* → **negative health outcomes**
- Blame, Shame, provide Directives (*should, need to vs an option would be_*), *“Control”* (*manage, outcomes*), *“Test”* (*check, measure*) → **disengagement, diabetes distress, sub-optimal diabetes self-management**
- The effects of being referred to as **“a diabetic”** vs **“a person with diabetes (PWD)”**
 - Effect on *health care professional/staff* mindset & approach
- Carefully chosen language can have a positive effect
 - Use language to **support** patients' diabetes self-management and psychosocial well-being – **on the same side - fighting for, not against**
 - *“There are things we can do together to help you stay healthy/prevent complications with diabetes”* [or prevent from getting worse]



Words Matter



Fear of Complications → large contributor to Diabetes Distress

Scare Tactics Don't Help & Can Be Harmful



- **Loss-framing** (e.g., "having diabetes is the leading cause of blindness & amputations") with few if any **risk reduction strategies** offered (often scare tactics: e.g., "if you don't do better, you could go blind and lose your feet") → **hopelessness**

vs

- **Gain-framing** ("early diagnosis & treatment of diabetic retinopathy can prevent up to 98% of severe vision loss") plus **strategies** ("get annual eye exam") → **more effective** (evidence-based hope – how to stay healthy)
 - Instead of "you need to take care of your feet" (directive, blame) → "I want to be sure you know what we can do to help keep your feet safe" (do foot exam explaining findings to patient, teach self-foot care) [care team activity]

True or False

- Diabetes is the leading cause of adult blindness, amputations and kidney failure.

FALSE

- *Poorly Managed Diabetes* is the leading cause of adult blindness, amputations and kidney failure.
- *Well Managed Diabetes* is the leading cause of... **Nothing.**

"The 'leading cause of nothing' doesn't mean 'nothing bad can happen'...[but] research shows that with good care, odds are good that you can live a long and healthy life with diabetes."

W. Polonsky

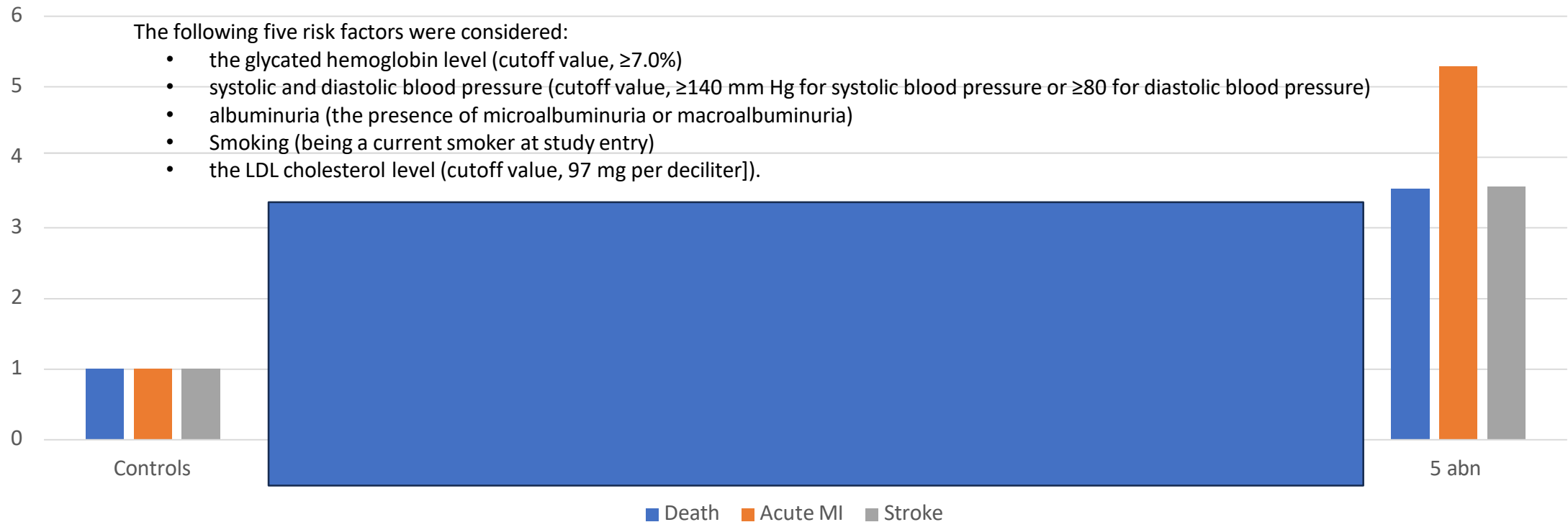
"Not only have treatments for diabetes improved, so have treatments for complications."

Help show their efforts are not futile - provide *Evidence Based Hope*

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

Swedish National Diabetes Register *n engl j med* 379;7 August 16, 2018

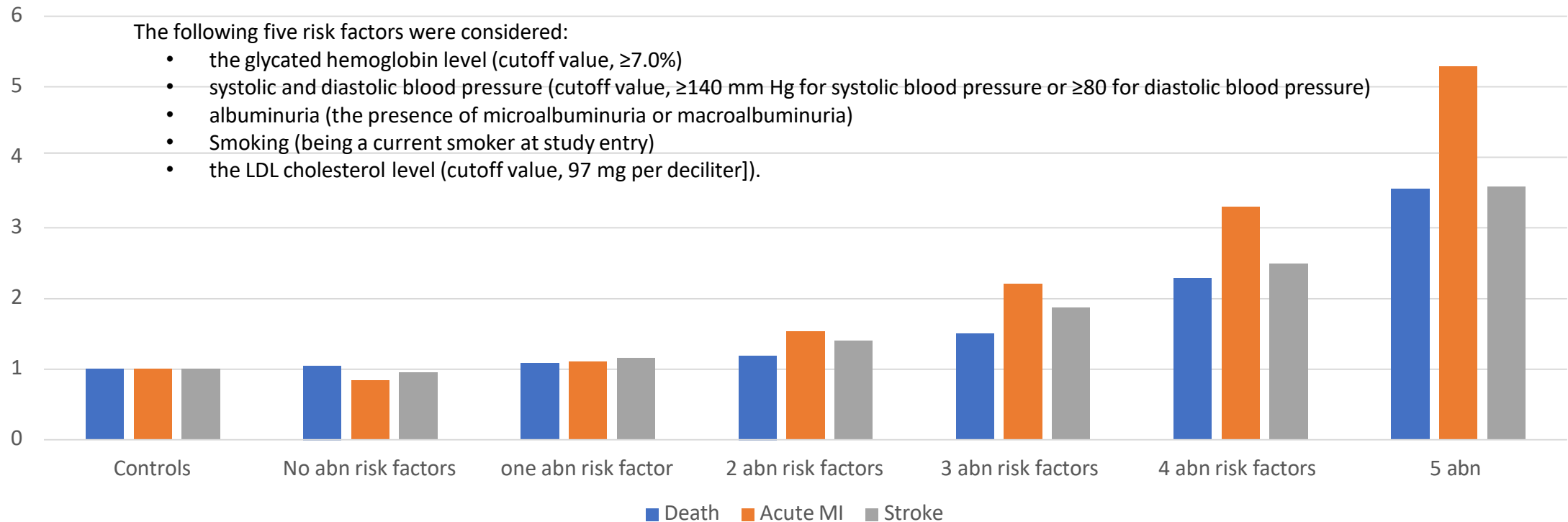
Risk of Death or CV event People with Diabetes vs Controls (People without Diabetes)



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

Swedish National Diabetes Register *n engl j med 379;7 August 16, 2018*

Risk of Death or CV event
People with Diabetes vs Controls (People without Diabetes)



Message: “not your grandparents’ diabetes” “What you do does make a difference”
“don’t need to be perfect to see benefits” “not futile, not hopeless”

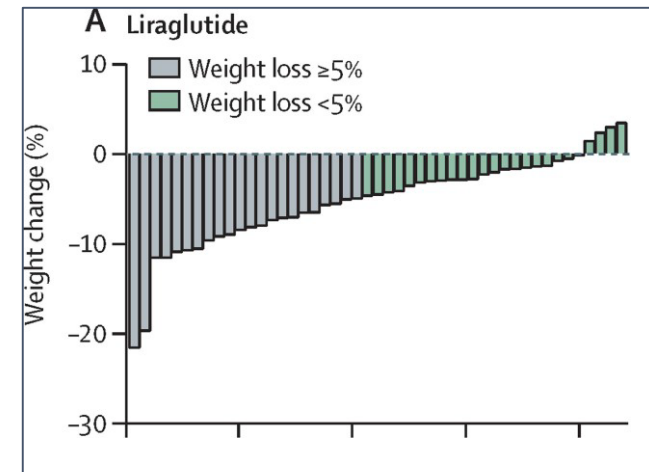
Establishing Treatment Efficacy

(What you do does make a difference)

- Discovery learning
 - E.g.: Utilize SBGM/ CGM to “discover” blood glucose effects of
 - Exercise / activity
 - Meal choices (type or quantity of foods)
 - Stress / stress reduction
 - Medication changes (increased dose, added medication, change from one med to another, change in timing or injection site)
 - Need *before & after data*
 - **This is *not* a test!!** (you are not “testing” the *patient*) – having them *help discover* what works for them (treatment efficacy) and what doesn’t
- Win-win benefits
 - Helps reduce futility
 - Helps care team identify efficacy of treatment for that individual (*therapeutic heterogeneity*)

Therapeutic Heterogeneity (not everyone responds the same)

- Based on our individual make-up, some things work better or not as well for some of us- this includes:
 - Type of foods/meal plan (low fat, low carb, low glycemic index, intermittent fasting, etc.)
 - Glucose lowering
 - Weight loss
 - Exercise (aerobic, strength training)
 - Glucose lowering
 - Weight loss
 - Fitness
 - Medications
 - for example, the research reports the average A1c lowering or weight loss with a medication but in the study group of patients, some had a greater than average response and some had less than average or worsening
 - E.g., ~10-15% non-responders to weight loss for semaglutide & tirzepatide



Case Patient - Tony



Dr. Brown asks Tony about the results of the survey & his sense of futility – “The survey suggests that you feel like you are doomed by the diabetes – can you tell me more about that?”

“My grandfather and father both had diabetes so it seemed inevitable that I would get it – and that I will end up the same way – strokes & heart attacks take us out early, before age 60 –”

“How has that impacted the way you take care of yourself with diabetes?”

“Not sure what I do makes a difference or will change what happens to me – it doesn’t seem like the expensive meds do anything – I hate to pay the higher copay if they aren’t working (the sitagliptin and SGLT2i), so I don’t take them every day. Also, it is hard to cut out all foods that have sugar in them , especially if it is not going to make a difference, so I know I don’t eat healthy and eat too much.”

So how can we help Tony?

- Pick the next best step
 - A. Tell him he needs to eat better, and take his diabetes medicine, or he will indeed end up like his father and grandfather.
 - B. Refer him to see a dietician.
 - C. Add basal insulin.
 - D. Clarify misperceptions, provide some evidence-based hope, and offer a professional CGM as an option to learn what does work for him.

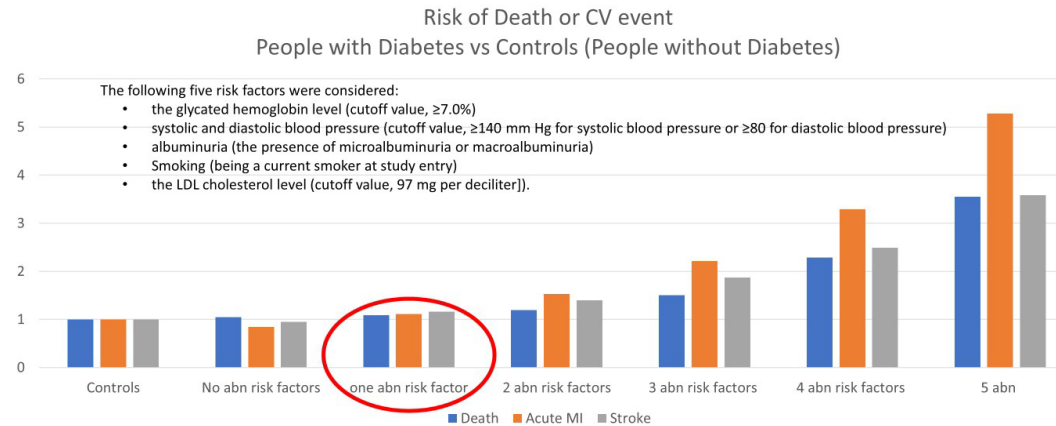
Case Patient - Tony



“I can understand why you might feel like you are doomed, I have also heard that from other PWD.”

“ First, I want to assure you that we know more now than when your grandfather or even your father was diagnosed with diabetes - I want to show you some results:

“As you can see, doing those things that we know help people with diabetes stay healthy does make a difference! – you are in range on everything but your A1c, so you have already greatly reduced your risk of heart attack and stroke.”



“I also want to assure you that we don’t want you to cut out all sugar – that would be very hard, and it is not necessary – but what you eat can make a difference on how easy it is to manage the diabetes and on how healthy you stay. [referral option - *“It might be helpful to meet with a diabetes educator/dietician”*]

Also, not all meds work the same for everyone. It sounds like we need more information on what works best for you. One option would be to get blood glucose readings at specific times using your meter or we have a device called a continuous glucose monitor (CGM) – we can use this to see what is happening with your BGs now and what happens when

How Can You Take Diabetes Distress On?

Avoid worsening “Diabetes Overwhelm”

- Just being aware is good first step
 - Asking about it, talking about it, normalizing it, monitoring it
 - Avoid scare tactics
 - Be on same side as patient
 - Reduce stigma/shaming in your practice
 - Don't confuse with depression / avoid polypharmacy (antidepressants “not working”)
 - Realize that DD is the cause of abnormal PHQ9 in most people with diabetes
- Benefits of structured assessment/scale
 - time-efficient
 - quantitative
 - can be used to monitor change over time
 - provides concrete findings that can be shared with people with diabetes
 - use of the entire scale helps identify variation in sources of distress among different individuals, as reflected by the various subscales, prompting different kinds of clinical conversations

Suggested Strategies for Approach to DD

- First are programs for individuals who are ***currently experiencing significantly high levels of diabetes distress***.
 - Group formats especially beneficial
- Second, a focus on diabetes distress when ***critical diabetes events*** occur may be particularly helpful.
 - An increase in medication dose or a transition to insulin or other injectables or devices, the emergence or exacerbation of a complication, the period following a severe hypoglycemic event, or a change in diabetes provider.
 - These are times when **both rational and irrational fears** may increase, self-evaluations may become distorted by **self-blame and fault**, and **worries about the future** may abound.
- A third strategy is ***to integrate*** information about diabetes distress into ***routine diabetes education*** seamlessly, both for newly diagnosed individuals and for those receiving a diabetes update or instructions for use of a new device or medication.
- Fourth, and perhaps most importantly, are strategies that ***integrate discussion about the emotional side of diabetes into all clinical encounters***.

Suggestions for the Behavioral Health Specialist – Part of the Diabetes Care Team

- Enhance your understanding of diabetes & its management requirements
 - put yourself in their shoes and think what it would be like for you to manage diabetes 24/7
 - <https://professional.diabetes.org/journals-resources/behavioral-health-resources>
- Enhance your understanding of diabetes distress
 - Behavioral Diabetes Institute
 - www.behavioraldiabetes.org
 - Become familiar with the DD
 - www.diabetesdistress.org
 - assessment tools
 - the core & subscale distress items

Diabetes Education 101 for the Behavioral Health Professional

This program is intended for behavioral health providers who treat people who are at-risk or living with diabetes. Learn about the unique challenges of living with diabetes and how to incorporate supportive terminology into your practice.

- 8 CE Credits (APA, ASWB, Certificate of Participation)
- Cost of the program: FREE
- Option to apply to be in the

Exploring Mental Health and Diabetes Through Case Studies

Explore our asynchronous modules, zeroing in on how behavioral health professionals can assist individuals from diverse cultures in managing diabetes. Dive into interactive sessions featuring patient videos and access valuable free resources. This program is geared toward the behavioral health professionals.

- 6 CE Credits (APA, ASWB, Certificate of Participation)

Behavioral Health in Diabetes Care

This program is designed for health care professionals (certified diabetes care and education specialists, social workers, and other members of the diabetes care members) to help integrate behavioral health best practices into clinical environments. Earn up to 5.25 credits and help people with diabetes overcome behavioral health challenges.

- 5.25 CE Credits (APA, ASWB, Certificate of Participation)
- Cost of the program: FREE

Suggestions for the Behavioral Health Specialist If Referred a Patient with Diabetes Distress (DD)

- Focus on
 - Emotional issues (shame, guilt, hopelessness, anger, fear, self-blame, etc.)
 - Social support issues
 - Communicate & coordinate with medical provider/care team, especially if uncover components of or misperceptions about the diabetes care plan that might be worsening emotional distress
- Help with the *Explain & Normalize* and *Explore* steps
 - Provide resources for the patient on DD (www.behavioraldiabetes.org)
- In patients with severe DD, utilize approaches that have been found effective/successful in diabetes:
 - Cognitive behavioral therapy
 - Motivational interviewing
 - Brief solution-focused therapy
- Help sort out if the patient is experiencing DD vs clinical depression, anxiety, or general psychological distress (or other MH issues) or BOTH
 - The person may be experiencing other life stressors that are causing general distress and affecting their diabetes self-management and outcomes.
 - Also consider DD in patients with diabetes referred with other psychological problems (e.g., depression or anxiety)
 - Consider having patient complete a DD assessment survey

Key Points

- Diabetes distress (DD) is common – it impacts outcomes & quality of life for PWD
- DD is distinct from clinical depression – it is the emotional side of diabetes
- DD does not respond to treatment with antidepressant medication but is very responsive to acknowledgement & support
- Screening can be initiated by clinician & care team awareness of and asking about issues in dealing with diabetes
- There are advantages to using a validated questionnaire to help identify specific areas of distress and to better allow monitoring.
- A basic approach goes a long way in preventing and reducing DD – includes:
 - asking about & normalizing diabetes-related emotional distress
 - avoiding scare tactics & directives
 - being on the same side as the patient
 - identifying & clarifying misperceptions
 - helping PWD see that their own actions can make a positive difference (“discovery learning”)
 - providing “evidence-based hope”
- Behavioral Health Specialists can play a valuable role in reducing DD in patients with diabetes.

Important Considerations

- *Entire staff* needs to
 - be aware of Diabetes Distress as normal & expected part of living with diabetes
 - avoid diabetes stigma
 - be on same side as patient/avoid scare tactics & punitive or directive approach
- Overlap with impact of
 - Historical loss
 - Intergenerational trauma
 - Individual trauma(s)/ PTSD
 - Epigenetic effects & learned behavior
 - Role of connection with/restoration of culture, community
 - Need for holistic approach

Billing & Coding Considerations

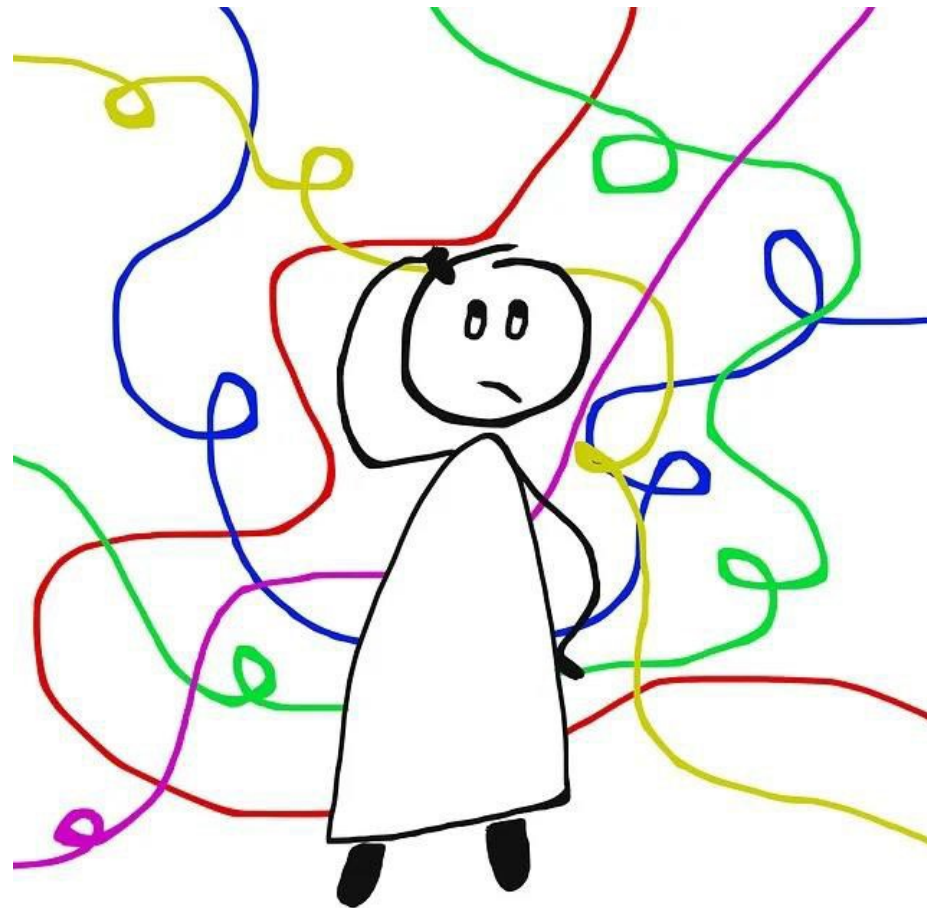
- Since it is not a “diagnosis”, there is no code. But you can code how it may show up as a psychological stressor.
- For some people, it may reach criteria for:
 - F54 Psychological Factors affecting a medical condition or
 - F43.20 Adjustment Disorder

Susan Guzman, PhD

Director of Clinical Education

Behavioral Diabetes Institute

Questions, Comments, Clarifications, etc.



References & Resources

Additional Slides on BH role in helping reduce Diabetes Distress

From ADA workbook

BH Specialist can help Explain & Normalize DD

- Explaining and normalizing diabetes distress is the first step to addressing it
 - Explain what diabetes distress is and that many people with diabetes experience it.
 - Explain the signs and consequences of diabetes distress (e.g., the impact on their daily self-management and well-being).
 - Acknowledge the significant daily efforts required to manage diabetes—this by itself may reduce the distress.
 - “Normalize” negative emotions about diabetes (an expected, normal reaction to diabetes).
 - If a person is self-blaming (e.g., “I am useless at ___” or “I can never get it right”), explain that diabetes outcomes are not a reflection of who they are as a person; diabetes is not about being “good” or “bad” or “a failure.”
 - Instead remind them that diabetes can be difficult to manage,
 - Explore what is going well and in what aspect(s) of diabetes management does the person feel confident?
 - Highlight their strengths and skills, which could be applied to address their current problems.
 - Offer the person opportunities to ask questions about what you just discussed.
 - Make a joint plan about the “next steps” (e.g., what needs to be achieved to reduce diabetes distress and the support they may need).

Explore the most appropriate support for the individual

- You can ask about the DD assessment/scores
 - *“How did you feel about answering these questions?”*
 - *“When looking at your scores, does anything stand out for you?”*
- Explore further
 - *“It sounds like you are struggling with several aspects of your diabetes care. Which of these would you most like to talk about today?”*
 - *“You said you feel angry and guilty when you think about your diabetes. Could you tell me what exactly makes you feel this way?”*
 - Explore whether these feelings are related to
 - the self-management tasks or the diabetes outcomes (e.g., high blood glucose levels)
 - how diabetes affects other aspects of their life (e.g., feelings of not being a “good” parent because of diabetes, or diabetes interfering with their work or social life).
 - *“According to your responses, you feel supported in some aspects of your diabetes management but not in others, is that correct? Can you give me an example of this?”*
 - *“You feel that you are not getting support from your partner or family/friends. Is this your overall feeling?”*

Help Tailor an Action Plan to Meet Specific Concerns, Needs & Preferences

- Examples: https://professional.diabetes.org/sites/default/files/media/ada_mental_health_workbook_appendix_c.pdf
- Explore whether—and how— **social support** could help in reducing diabetes distress:
 - Is there someone they can talk to?
 - Would they like to join a **peer support group**?
- Talk about **small behavioral changes** that could help—such as how to
 - remember to do certain tasks (e.g., taking medication or self-monitoring of blood glucose)
 - how to reduce the burden (e.g., a reward system).
- Acknowledge that well-intended support can often lead to frustration -Advise the person **to share with their partner or family/friends**:
 - how they feel about living with diabetes, and invite the other person to do the same
 - what help they would appreciate from their partner or family/friends.
- Encourage the person to **ask questions or seek clarification** (e.g., regarding their medical examination results, general health, or treatment).

Resources for BH Specialists

- <https://professional.diabetes.org/professional-development/behavioral-mental-health/MentalHealthWorkbook>
- <https://professional.diabetes.org/journals-resources/behavioral-health-resources>
- <https://www.youtube.com/@BDIviews>

References

- Lawrence Fisher, William H Polonsky , Danielle M Hessler, Umesh Masharani, Ian Blumer 5, Anne L Peters, Lisa A Strycker, Vicky Bowyer. Understanding the sources of diabetes distress in adults with type 1 diabetes. J Diabetes Complication. May-Jun 2015;29(4):572-7
- Fisher, L., Gonzales, J.S., Polonsky, W.H. The confusing tale of depression and distress in patients with diabetes: A call for greater clarity and precision. Diabetic Medicine, 2014, 31, 764-772.
- Risk Factors, Mortality, and Cardiovascular Outcomes in Patients with Type 2 Diabetes Swedish National Diabetes Register n engl j med 379;7 August 16, 2018
- William Polonsky , Cory Gamble, Neeraj Iyer, Mona Martin, Carol Hamersky. Exploring Why People With Type 2 Diabetes Do or Do Not Persist With Glucagon-Like Peptide-1 Receptor Agonist Therapy: A Qualitative Study. Diabetes Spectr. 2021 May;34(2):175-183.
- https://diabetesjournals.org/care/article/47/Supplement_1/S77/153949/5-Facilitating-Positive-Health-Behaviors-and-Well
- Diabetes Distress: Why It's Common and What We Can Do About It! (diatribe.org)
- Diabetesdistress.com
- Diabet. Med. 36: 803–812 (2019)

References

- Emotional Distress Predicts Reduced Type 2 Diabetes Treatment Adherence in the Glycemia Reduction Approaches in Diabetes: A Comparative Effectiveness Study (GRADE). Claire J. Hoogendoorn et al. *Diabetes Care* 2024;47(4):629–637
- Gonzalez JS, Bebu I, Krause-Steinrauf H, et al. Differential Effects of Type 2 Diabetes Treatment Regimens on Diabetes Distress and Depressive Symptoms in the Glycemia Reduction Approaches in Diabetes: A Comparative Effectiveness Study (GRADE). *Diabetes Care*. 2024;47(4):610619.
- T. C. Skinner, L. Joensen and T. Parkin. PSAD Special Issue Paper: Twenty-five years of diabetes distress research. *Diabet. Med.* 37, 393–400 (2020)
- L. Fisher, W. H. Polonsky and D. Hessler. Invited Review: Addressing diabetes distress in clinical care: a practical guide. *Diabet. Med.* 36: 803–812 (2019)

Diabet. Med. 37, 393–400 (2020)

- Diabetes distress is common among people with type 1 and type 2 diabetes, and is associated with lower levels of self-care, general emotional well-being and possibly metabolic outcomes of diabetes care.
- There is emerging evidence that ***the way healthcare professionals communicate with people with diabetes*** may be exacerbating the distress experienced by people with diabetes, or possibly contributing to its development.
- Healthcare professionals need to ensure that the way they communicate with people who have diabetes does not add to the distress that diabetes engenders.
- We need to embed the assessment and management of diabetes distress into the routine diabetes care services we offer people with diabetes.

Provide Details on the Medication at time of Prescribing

study on *Persistence* with GLP1 receptor agonist therapy

Continuers

- Perceived treatment efficacy
 - Glycemia
 - Weight loss
 - *“The knowledge of the cardiovascular benefit helped me stay on the GLP-1 [receptor agonist].”*
- Perceived treatment burden
 - Cost/insurance coverage
 - Ease of use
- Relevant information from healthcare team
 - explained that GLP-1 receptor agonist therapy would improve my blood glucose control [and other benefits]
 - explained the importance of **gradual dosage titration**
 - explained **how to manage food volume and fats**
 - [stop eating when feel full/ satiety – also bland foods, avoid carbonation & fatty or greasy foods]
 - my questions were answered by my health care team when I started on GLP-1 receptor agonist therapy.
 - I was provided information about GLP-1 receptor agonist medications.
 - my physician’s office called to check on my progress and ask if I had any additional questions.

Discontinuers

- Side Effects (GI, injection site)
- Cost
- Lack of benefit
 - **therapeutic heterogeneity:** *“lack of glycemic improvement, lack of weight loss, and/or intolerability of side effects may simply be an unmodifiable class effect in some participants, which could explain why 25% of discontinuers reported ‘numbers did not improve’ as their primary reason for discontinuation”*
- *Less likely to receive relevant information from healthcare team*



Continuers were more likely than discontinuers to receive clinically relevant information from their health care team, including facts about GLP-1 receptor agonist medications, likely treatment benefits, the importance of gradual dose titration, and the need to adjust diet after initiation.

Shared Decision Making preferable
Allows ownership

Diabetes distress: understanding the hidden struggles of living with diabetes and exploring intervention strategies

Berry E, et al. Postgrad Med J 2015;91:278–283.

- ...the importance of prompting discussion during appointments to present people with an opportunity to talk about which aspects of diabetes care are the most difficult.
- This does not require psychological expertise and does not require providing solutions there and then; indeed, the MIND Study suggests that simply monitoring diabetes distress can have beneficial effects.
- It is simply about initiating normal conversation, listening to and showing an understanding and awareness of the psychosocial and emotional issues embedded in diabetes, which often go unnoticed and grow.
- Practitioners should encourage patients to acknowledge their emotional difficulties and remind them that they are part of the process of adapting to living with diabetes.

The Potential Impact of CGM Use on Diabetes-Related Attitudes and Behaviors in Adults with T2D: A Qualitative Investigation of the Patient Experience

Taylor Clark, William Polonsky, Emily Soriano

- **Conclusions:** Participants reported a far-reaching impact of CGM on their daily lives, with many stating that CGM fostered a **greater understanding of diabetes and prompted positive behavior changes**. The observed **attitudinal and behavioral shifts** likely contributed synergistically to the significant glycemic benefits observed over the study period.
- This study highlights the technology's potential to bring about meaningful attitudinal and behavioral changes. Six primary themes emerged:
 - 1) Making the Invisible Visible, highlighting the newfound awareness of T2D in daily life;
 - 2) Effective Decision Making, emphasizing the use of real-time glucose data for immediate and long-term choices;
 - 3) Enhanced Self-Efficacy, describing a renewed sense of control and motivation;
 - 4) Diabetes-Related Diet Modifications;
 - 5) Changes in Physical Activity; and
 - 6) Changes in Medication Taking.

It is important to distinguish diabetes distress from clinical depression or major depressive disorder

Diabet. Med. 36: 803–812 (2019)

- Most people with diabetes labelled as clinically depressed using common self-report inventories (e.g. Patient Health Questionnaire-9; PHQ-9) do not meet standard psychiatric criteria for major depressive disorder. When well-structured psychiatric interviews are undertaken with most samples of adults with diabetes, however, the prevalence of major depressive disorder distress falls to between 3.8% and 6%, which is similar to rates in the general community (note variation in this rate based on clinical setting and an individual's characteristics).
- Still, individuals with diabetes typically score higher on depression symptom measures than people who do not have diabetes, and although these higher scores may not be indicative of a depressive disorder, they do reflect the experience of significant emotional distress. In recent studies, depressive symptom scores, using the PHQ-9, have been found to correlate quite highly with diabetes distress scores (e.g. r as high as 0.60), pointing to a significant overlap between these two constructs.
- Furthermore, in one study, initial analyses indicated significant associations between depressive symptoms with management and HbA1c; but when diabetes distress scores were entered into the same analysis, depressive symptom scores were no longer significantly associated with these outcomes, whereas diabetes distress scores were.
- We suggest, therefore, that clinicians should not immediately assume that elevated depression symptom scores obtained from self-report inventories are indicative of a depressive disorder. Instead, it is likely that such scores reflect the emotional distress associated with diabetes. This is not to say that major depressive disorder does not exist in diabetes populations. When it is carefully documented and diagnosed, it needs to be treated accordingly. Fourth, although elevated levels of diabetes

Observations on Diabetes Distress in Glycemic Reduction Approaches; a Comparative Effectiveness Study (GRADE)

- 4 groups: Metformin + glimepiride or sitagliptin or liraglutide or glargine insulin
- Diabetes Distress was associated with reduced medication adherence.
- Levels of depressive symptoms and distress decreased over 1 year in all treatment groups:
 - The greatest reduction in distress observed in the glargine-treated & liraglutide-treated participants compared with the sitagliptin- and glimepiride-treated participants.
 - Given that *glargine was the most effective and liraglutide was similarly effective...one interpretation of these data is **that when people start a new medication to treat a medical condition, distress decreases when the medication is effective.***

Resources

- Behavioral Diabetes Institute (BDI) <https://behavioraldiabetes.org/>
 - <https://behavioraldiabetes.org/resources/health-care-professionals/professional-education-brief-video-series/>
- DIABETES DISTRESS (From Behavioral Diabetes Institute (BDI) & <https://diabetesdistress.org/>)
- [ADA https://diabetesjournals.org/care/article/47/Supplement_1/S77/153949/5-Facilitating-Positive-Health-Behaviors-and-Well](https://diabetesjournals.org/care/article/47/Supplement_1/S77/153949/5-Facilitating-Positive-Health-Behaviors-and-Well)
 - <https://professional.diabetes.org/professional-development/behavioral-mental-health/behavioral-health-toolkit>
- [How to make the diagnosis of type 2 diabetes less difficult \(youtube.com\)](#)
- <https://www.youtube.com/watch?v=6qtuO7Hq9WE> (evidence-based hope in diabetes)
- [Bing Videos](#) (diabetes distress vs depression)

ADA - Diabetes Distress in Diabetes

- <https://www.youtube.com/watch?v=8MTKa4PSp1c>
- [ada mental health toolkit questionnaires.pdf \(diabetes.org\)](#)
- [ada mental health toolkit handouts r3.pdf \(diabetes.org\)](#)
- [ada mental health toolkit 7as r2.pdf \(diabetes.org\)](#)
- ADA
https://diabetesjournals.org/care/article/47/Supplement_1/S77/153949/5-Facilitating-Positive-Health-Behaviors-and-Well
 - <https://professional.diabetes.org/professional-development/behavioral-mental-health/behavioral-health-toolkit>

Diabetes Stigma

- [Resources – dStigmatize](#)
- ['I'm not a druggie, I'm just a diabetic': a qualitative study of stigma from the perspective of adults with type 1 diabetes | BMJ Open](#)

Sources of Distress -T2D

- **Management Demands:**
 - Disappointment with your self-care efforts (for example, "It frustrates me that my eating often feels out of control").
- **Hypoglycemia:**
 - Concerns about severe hypoglycemic events (for example, "I worry a lot that I could have a serious low glucose event").
- **Interpersonal Issues:**
 - Disappointment that you are not getting the right type of support and help from family and friends about diabetes (for example, "When it comes to family and friends, it disappoints me that I am pretty much on my own with diabetes").
- **Healthcare Provider:**
 - Disappointment with your current health care professionals (for example, "It upsets me that I'm not really heard or understood by my healthcare provider").
- **Shame/Stigma:**
 - Concerns about the negative judgments of others (for example, "It upsets me that people in my life think less of me because I have diabetes").
- **Long-Term Health:**
 - Concerns about the potential harm that diabetes may cause over time (for example, "No matter what I do, I fear that serious complications from diabetes will happen to me"). [hopelessness]
- **Healthcare Access:**
 - Concerns that obtaining the medical care you need for your diabetes are, or will be, too difficult (for example, "I worry that I won't be able to pay for my diabetes care, medicines, or supplies").

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

n engl j med 379;7 August 16, 2018

- **CONCLUSIONS:** Patients with type 2 diabetes who had five risk-factor variables within the target ranges appeared to have little or no excess risk of death, myocardial infarction, or stroke, as compared with the general population.
- **The following five risk factors were considered:**
 - the glycated hemoglobin level (cutoff value, $\geq 7.0\%$)
 - systolic and diastolic blood pressure (cutoff value, ≥ 140 mm Hg for systolic blood pressure or ≥ 80 for diastolic blood pressure)
 - albuminuria (the presence of microalbuminuria or macroalbuminuria)
 - Smoking (being a current smoker at study entry)
 - the LDL cholesterol level (cutoff value, 97 mg per deciliter)].

Risk Factors, Mortality, and Cardiovascular
Outcomes in Patients with Type 2 Diabetes
n engl j med 379;7 August 16, 2018

- The following five risk factors were considered:
 - the glycated hemoglobin level (cutoff value, $\geq 7.0\%$)
 - systolic and diastolic blood pressure (cutoff value, ≥ 140 mm Hg for systolic blood pressure or ≥ 80 for diastolic blood pressure)
 - albuminuria (the presence of microalbuminuria or macroalbuminuria)
 - Smoking (being a current smoker at study entry)
 - the LDL cholesterol level (cutoff value, 97 mg per deciliter)].
- In the overall cohort, patients with type 2 diabetes who had no risk factor variables outside the target ranges had
 - a marginally higher risk of death than the controls (hazard ratio, 1.06; 95% confidence interval [CI], 1.00 to 1.12).
 - had a lower risk of acute myocardial infarction than the matched controls (hazard ratio, 0.84; 95% CI, 0.75 to 0.93).
 - Had a lower risk of stroke than controls (hazard ratio 0.95; 95% CI, 0.84-1.7)
- The results show a stepwise increase in the hazard ratios for each additional variable that was not within the target range among patients with diabetes,

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

n engl j med 379;7 August 16, 2018

In the overall cohort, **patients with type 2 diabetes who had no risk factor variables outside the target ranges had**

- a marginally higher risk of death than the controls (hazard ratio, 1.06; 95% confidence interval [CI], 1.00 to 1.12).
- had a lower risk of acute myocardial infarction than the matched controls (hazard ratio, 0.84; 95% CI, 0.75 to 0.93).
- Had a lower risk of stroke than controls (hazard ratio 0.95; 95% CI, 0.84-1.7)

Risk based on age group

