

# **Diabetes Distress Learning Center**

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# Acknowledgement

- A significant part of this web site is based on publications by and communications with Larry Fisher PhD
- AASP protocol personal communication L. Fisher
- Fisher et al, AASAP protocol- Patient Education and Counseling 2012;86:372-377
  
- Fisher et al Diabetes Care 2007;30:542–548
- Fisher et al, Diabetes Care 2010;33:23–28
- Fisher L et al, Diabetes Care 2012;35(2):259-264
- Fisher et al, Diabetes Care 2013;36:2551–2558
  
- Fisher et al Diabe. Med 2009; 26: 622–627
- Fisher et al Diabe. Med 2014 ;31(7):764-72

*All these references can be accessed on line at [www.diabetesuniversitydmcp.com/diabetes-distress-learning-center.html](http://www.diabetesuniversitydmcp.com/diabetes-distress-learning-center.html)*

# Objectives of Learning Center

- **Help nurses, medical assistants and others understand Diabetes Distress (DD).**
- **Assist with understanding and use of the 2 question DD screening survey.**
- **If either screening questions is scored 3 or more assist with utilization of the 17 question Diabetes Distress Survey DDS 17.**
- **Assist nurses, medical assistants and others with helping patients and their families diminish the emotional burden of diabetes distress**
- **Understand how the demands of diabetes self management lead to Diabetes Distress**
- **Provide a certificate of completion (see next slide)**

# Diabetes Distress Learning Center Certificate

- After reading all the material in this slide set you have the option of taking an on line test.
- A certificate (if requested) will be sent if you pass the test and indicate the scores of 2 patients who have taken the screening test and 2 patients who have taken the full test.
- The test is set up for you to pass. If you give a wrong answer it takes you to the correct answer.
- Link to on line test at the end of this presentation
- If you wish to have a certificate email me ([eshahady@att.net](mailto:eshahady@att.net)) indicating you have completed the test and wish a certificate

# Diabetes Distress Learning Center Certificate

## Jane Doe MA

*This certificate indicates that the above person has participated in the Diabetes Distress Learning Center, passed a test indicating their basic knowledge about Diabetes Distress and the ability to administer the Diabetes Distress Questionnaires. This knowledge can be used to explain Diabetes Distress and help patients deal with the distress. The Diabetes Master Clinician Program congratulates and thanks you for your willingness to help the many patients in your area with Diabetes Distress.*

Edward Shahady MD  
Medical Director  
Diabetes Master Clinician Program



Edward Shahady MD



# Agenda



- **Definition of Diabetes Distress**
- **Questionnaires for Diabetes Distress**
- **Discuss Diabetes Distress from the perspective of the patient, family and provider.**
- **Diabetes Distress vs Depression**
- **Discuss the AASAP protocol a program to help patients deal with diabetes distress**
- **Additional Tips to help patients with Diabetes Distress**

# Agenda

- **Definition of Diabetes Distress**

# **Diabetes the Most Difficult Chronic Disease**

- Living with diabetes is a challenge. Multiple medications, finger sticks, physician visits, dietary restrictions and the need to be physically active.**
- Life includes a complex and sometimes confusing set of directives that may lead to anger, frustration, and feeling overwhelmed.**
- This may lead to conflict with loved ones and strained relationship with health care providers.**
- As a result motivation for self care may be impaired.**



# Definition of Diabetes Distress

**Diabetes distress (DD) refers to the unique, often hidden, emotional burdens and worries that a patient experiences when they are managing a severe chronic disease like diabetes. High levels of DD are common and distinct from clinical depression**

*Gonzalez et al Diabetes Care 2011; 34:236-239*

# Diabetes Distress (DD)

- **The distress results from unsuccessful diabetes self management over time**
- **The distress leads to narrowing of attention span, limiting of creative solutions and a spiral of poor management and poor coping.**
- **This pattern hampers the ability to gain new knowledge and skills, accelerates development of unrealistic goals and expectations, development of inaccurate personal beliefs and perceptions that are self defeating.**
- **All the above are common reactions for a distressed patient facing a demanding chronic disease like diabetes.**

# **Diabetes Distress (DD)**

- **The challenges of self-management of diabetes are recognized by healthcare providers, but the psychological toll associated with these challenges may not be recognized.**
- **Diabetes Distress (DD). DD describes the emotional burden created by the pressures of diabetes self-management. The emotional burden is scored with a 17 question survey (DDS17).**
- **This emotional burden impacts patients, their families and the health care providers involved in diabetes care**
- **The DDS17 measures 4 areas of distress**

# Agenda

- Questionnaires for Diabetes Distress



# Questions discover Distress in 4 Areas

- **Emotional Burden-** *personal reactions like feeling scared, angry, or diabetes controls my life*
- **Physician Related Distress-** *Dr. does not give clear directions or take me seriously*
- **Regimen Related Distress-** *too many meds and finger sticks-not confident in my ability to care for my diabetes*
- **Interpersonal Distress**— *Friends and Family do not appreciate how difficult it is and may not provide support*

# Review of the Diabetes Distress Questionnaire

- Go on line at <http://www.diabetesuniversitydmcp.com/diabetes-distress-learning-center.html> to review the Questionnaire. Note it is in both English and Spanish.
- Emotional Burden EB is discovered through Questions 1, 3, 8, 11, 14
- Physician Related Distress PD is discovered through Questions 2, 4, 9, 15
- Regimen Related Distress RD is discovered through Questions 5, 6, 10, 12, 16
- Interpersonal Distress ID is discovered through Questions 7, 13, 17

# Scoring the Diabetes Distress Questionnaire

- Also review the last page of the questionnaire
- Note how the questionnaire is scored
- For example
  - Regimen-related Distress:
    - a. Sum of 5 items (5, 6, 10, 12, 16) \_\_\_\_\_
    - b. Divide by: 5 (number of questions)
    - c. Mean item score: \_\_\_\_\_

If the mean score is 3 or greater it indicates regimen related diabetes distress and you place an x next to the score.

Note that the other three areas of distress have a similar way of scoring

# **When is Diabetes Distress (DD) score Clinical Meaningful**

- **Establishment of a reliable cut point is needed to define high DD to indicate when further evaluation and treatment is needed**
- **Significant curvilinear relationships exist between DDS scores and measures for glycemic control, diabetes self efficacy and physical activity**
- **The comparative scores indicate the following scale for measuring level of Diabetes Distress**
  - **Little or no distress  $<2$**
  - **Moderate Distress 2-2.9**
  - **High distress  $\geq 3$**



# Agenda

- **Discuss Diabetes Distress from the perspective of the patient, family and provider.**



# **Diabetes Distress (the patient)**

- **Life changes dramatically when the patient receives a diagnosis of Diabetes.**
- **Food choices are now changed and some of their favorite food choices may be limited, physical activity is no longer an option but a requirement for their health, multiple medications are required to sustain life, finger sticks are now required to guide their treatment, and visits to the doctor and other health care providers is now changed from an occasional to a frequent occurrence.**
- **All of these changes are coupled with the knowledge that if the disease is not controlled you may face loss of vision, heart attack, stroke, amputation and kidney failure.**
- **Self management is the key to success but the patients reaction to self management directions may lead to an inability to self manage.**

# **Diabetes Distress (the patient)**

- It is not unusual for patients with diabetes to feel overwhelmed with the demands of self management.**
- Feelings of frustration, fatigue, anger, burnout, poor mood and depression are common.**
- It is difficult to keep up with a complicated routine when you have all the above feelings**
- Diabetes distress makes it difficult to self manage and results in poor diabetes control.**

# **Diabetes Distress (family and friends )**

- Families of patients with diabetes may or may not understand all of these issues and their lack of understanding may place an additional burden on the patient.**
- Family meals are an example. If appropriate options are not available the patient does not want to inconvenience other family members. It helps if the family understands issues about diabetes and discusses them openly.**
- Diabetes is a genetic disease and other family members may have diabetes or are at risk of developing diabetes. Open discussion about the challenges of the disease and the psychological burden benefit the patient and the family.**

# **Diabetes Distress (family and friends )**

- Patients with diabetes benefit by discussing their fears and concerns with individuals and groups they can trust. Family and friends are usually the patients most trusted associates.**
- But communication with family, friends and spouse about diabetes is not easy for the patient, they may be embarrassed or do not want to burden family and friends with their problems.**

# Diabetes Distress (the provider)

- **Diabetes creates significant challenges for all health care providers (HCP) not just physicians. HCP are driven by the fear of diabetes complications and the knowledge that achieving goals for HbA1c, LDL B/P reduces complications.**
- **This fear produces behaviors in HCP that may interfere with diabetes self-management. HCP feel guilty if a patient is not achieving diabetes goals. The guilt may lead to a culture of blame—where someone has to be blamed and the patient is usually the target of the blame.**

# Diabetes Distress (the provider)

- The common reaction to blame is labeling the patient non-compliant. A more productive way to face this issue is to replace the concept of compliance with the concept of barriers to adherence
- Barriers to Adherence include:
  - past emotional health,
  - lack of support from family and friends
  - misconceptions about their disease and its treatment
  - inability to understand, purchase and use medications
  - understanding and availability of appropriate food choices
  - and an environment that is not conducive to physical activity.

# **Diabetes Distress (the provider)**

- **Dealing with these barriers leads to better outcomes and less distress in both patient and the HCP**
- **Unfortunately education of HCP does not usually include recognition of their reaction to patients and how patients react to them.**
- **The Diabetes Distress questionnaire has questions that describe how the patient perceives the care from their physician—these questions can be extended to all HCP that provide care to the patient.**
- **Hopefully this learning center provides some guidance**



# Agenda

- **Diabetes Distress vs Depression**



# Diabetes Distress vs Depression

- **There are inconsistencies that question our understanding of the relationship between diabetes and depression.**
- **Association with self management based on Diabetes Questionnaires—is not always a reliable way to Dx Depression**
- **When the gold standard for depression diagnosis—the structured clinical interview—is used--no relationship is found with diabetes self management.**
- **Dx of Depression requires the presence of well defined diverse symptoms (5/9 on DSM-V)**

# Diabetes Distress vs Depression

- **Major Depression is one of the few diagnosis in medicine defined exclusively by symptoms and not by cause or disease process.**
- **Major Depression does not distinguish what may be an expected reaction to a significant life stressor like diabetes.**
- **Diabetes Distress captures the worries, concerns and fears among those who struggle with a progressive and demanding chronic disease—diabetes.**
- **Distress is an expected response to perceptions of health threats balanced against available coping resources**

# **Diabetes Distress vs Depression**

## **Implications for Care**

- **All patients with diabetes, even those with minimal distress, profit from education and support that considers distress an expected part of diabetes.**
- **Incorporate distress education at critical times like when starting insulin or onset of complications**
- **Minimal inexpensive interventions lower distress levels and improve disease management no matter the level of distress**
- **With moderate and higher levels of distress use of other health professionals may be beneficial**

# **Rx of Diabetes Distress not Depression associated with Glycemia Control**

- **Many patients with Diabetes are Depressed. Depression is associated with poor outcomes**
- **A study of 506 type 2 diabetic patients found no association between improvement in Major Depressive Disorder and improvement in glycemic control.**
- **But relationships were found between diabetes distress and improvement of A1C.**
- **What has been called “depression” among type 2 diabetic patients may really be two conditions, depression and diabetes distress. Depressive symptoms may be a reflection of distress.**
- **Treatment of the depression is important but to change the A1C-- treatment of the Diabetes Distress is needed**

# **Predicting Diabetes Distress in Type 2 Diabetes**

- **High levels of Diabetes Distress (DD) in T2 diabetes are common with a prevalence of 18-35% and an 18 month incidence of 38 to 48%**
- **Predictors of DD include being female, prior episode of major depression, experiencing more negative life events, more complications, poor diet and less exercise**
- **As the number of predictors increased the chance of DD increases**

# Agenda

- Discuss the AASAP protocol a program to help patients deal with diabetes distress (*obtained from L Fisher personal communication*)



# AASAP

- **AA=Anticipate and Acknowledge—expect and label the distress—patients feel the distress in different ways--it can present as discouraged, overwhelmed, guilty, hopeless or I do not think it will work.**
- **The first step after acknowledge is define it more clearly by reflection like “Sounds like your feeling or How would you describe these feelings”**
- **The next step is to identify the Ambivalence.**
- **Example “On one hand you feel like you really want to lose weight/change your diet/exercise more but feel you might fail again”**
- **Identify both feelings**



# AASAP

- **S=Standardize it—normalize the feelings—tell them they are not alone and many patients with Diabetes feel they same way—this is typical-common-expected—does not surprise me**
- **Also standardize the ambivalence by normalizing the desire to improve and the road blocks that are preventing improvement**
- **“Most people with diabetes feel this way; they want to improve but they often feel that ...”**

# AASAP

- The first three steps Anticipate, Acknowledge, Standardize form the basics of the program and are used most frequently during clinical encounters.
- The remaining steps are used with patients having more difficult problems with distress that require further attention.
- These steps may be used as new tools for patients to consider.

# AASAP

- **A=Accept and Understand –Understand where the distress comes from- an emotional struggle experienced when change not successful.**
- **“Change is hard work and distress occurs when goals that were anticipated are not achieved or harder than expected”.**
- **Ask questions like “why do you think these feelings are happening now”—if no response help them with examples like “some people tell us they feel \_\_\_\_\_ when they are not able to \_\_\_\_\_”**
- **Distressed does not mean they have to respond to it in ways that are harmful to change. Reframe it**
- **Once the patient “gets it” Distress then becomes something to understand and attend to as another goal**
- **Accept it—do not fight it or react blindly or discount it as not important**
- **“So you feel distressed but you feel you are able to continue to self manage”**

# AASAP

- **P= Plan to incorporate distress as part of the plan for behavioral change. i.e how to react to distress if it should come about**
- **If distress is experienced by discouragement with meal planning or exercise and this blocks performance use anticipatory problem solving. Be prepared and do something like look in the mirror and stick your tongue out—laugh at yourself and then realize how perceptive you are and addressing the distress a part of the change program.**
- **This re-frames or redefines the distress as something real and manageable the patient can control.**

# Agenda

- **Additional Tips to help patients with Diabetes Distress**



# Helping the Patient

- **Diabetes Distress is an emotional reaction to all the real and confusing demands of this disease.**
- **Many of these demands are placed by providers and are well meaning and scientifically sound but overwhelming and confusing.**
- **The result is the patient is not able to adhere to any recommendations**
- **This usually means we as HCP need to tone down our demands and go at a slower pace**

# Tips for Helping the Patient

- **Normalize their Feelings—let them know that many patients feel overwhelmed and frustrated—it is common and expected—they are not unique.**
- **Teach them how to deal with one thing at a time and as a provider do not expect changes in more than one area at a time**
- **Weight is one of the most frustrating issues and some medications like insulin, and other pills are associated with weight gain.**
- **Focus more on total calories as that is more within their control.**
- **Remember some diabetes medications are weight neutral or help with weight loss—consider using them if possible**

# Dealing with one Thing at a Time

- **Easy to say hard to do**
- **The provider has to decrease their expectations and allow the patient to choose their own goal and pace they want to achieve it**
- **Ask the patient on a scale of 1 to 10 the likelihood that they will be able to accomplish their goal in the next month (10 being I absolutely will be able to do it and 1 will not be able to do it) if they do not give it at least a 7 they will probably fail and need to reevaluate their goal**
- **Find the patients comfort zone**



# **Dealing with one Thing at a Time**

- Ask the patient to set an achievable Pace of change**
- As an example—if a patient goes from no exercise to a maximum exercise effort (like running) it may lead to sore muscles or a stress fracture that will cause them to stop any physical activity.**
- Set goals that are achievable and will create sustained behavior and be enjoyable.**
- Remember added activity competes with time.**
- A slow Pace of change enables new behaviors to be incorporated into every day lifestyle.**

# Putting it all together

- **Diabetes management changes with time. Changes occur in medications types and doses, and management requirements leading to what seems to be an endless series of tasks.**
- **These changes may lead additional frustration, anger and distress. Anticipate distress with any change—remember change includes personal and family issues.**
- **Putting it all together requires persistence, motivation, new knowledge, and collaboration with family, friends, HCP and all others who influence his/her life**

# Treatment of DD in T2 Diabetes

- In REDEEM study 33% of treated patients with high DD scores ( $\geq 3$ ) and 60% with moderate DD (2-2.9) at baseline reported little or no DD at 12 months.
- In the same study Regimen related (RD) created the most distress and demonstrated the greatest stress reduction with treatment.
- Other key findings in the study included
  - 31% of patients in the study had Regimen related distress
  - Older patients demonstrated reductions in distress earlier in the intervention than younger patients
  - Reductions in DD were maintained over time

*Fisher et al, Diabetes Care 2013;36:2551–2558*

# Treatment of DD in T2 Diabetes

**“Most distressed patients are highly responsive to clinical staff attention, concern, and support both with and without the formal programs to change behavior or enhance DD-related problem solving”**

**“Reducing distress, may have less to do with providing patients with programs of action and behavioral change and more to do with health care professionals listening to, understanding, acknowledging, and normalizing DD so that patients’ internal resources can become free of internal distress–related constraints”**

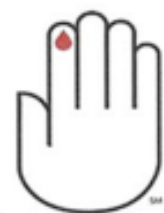
*Fisher et al, Diabetes Care 2013;36:2551–2558*

# Diabetes Distress Learning Center Certificate Jane Doe

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Edward Shahady MD  
NF SG Chapter ADA  
Medical Director  
Diabetes Master Clinician Program

*Edward Shahady MD*



Stop Diabetes



# Diabetes Distress Learning Center Certificate

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