Screening for Diabetes Distress and Depression:
What Should the Diabetes Educator Do?

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Objectives

- To review the recommendations and rationale for screening and evaluating psychosocial outcomes in clinical practice based on the ADA Position Statement for the Psychosocial Care of People with Diabetes.
- To discuss considerations for selection, administration and interpretation of screening and evaluation measures.
- To discuss considerations in sharing results and clinical decision making based on screening and evaluation procedures.

Origins of the ADA Position Statement

- Deborah Young-Hyman, Ph.D., National Institutes of Health and Mark Peyrot, Ph.D., Loyola University, were asked by the American Diabetes Association to collate evidence-based recommendations for clinical practice in 2007.
- Solicited 16 chapters from 27 experts in behavioral diabetes research and clinical practice.
- Content included behavioral health, self-management, implementation of treatment technology and life course issues.
- Five years and 282 pages later...

In 2014, Drs. Young-Hyman and Peyrot assembled a smaller writing group to tackle the task of synthesizing 40 years of psychosocial/behavioral research in diabetes into practice recommendations.

- Mary de Groot, Ph.D., IU School of Medicine
- Felicia Hill-Briggs, Ph.D., Johns Hopkins School of Medicine
- Korey Hood, Ph.D., Stanford University School of Medicine
- Jeffrey Gonzalez, Ph.D., Albert Einstein School of Medicine
Goals of the ADA Position Statement

• To synthesize the extant literature to formulate evidence-based practice recommendations.
• Standards of care that represent current best practices
• Aspirations for future care delivery
• General recommendations that transcend specific practice settings or patient populations
• Recommendations for specific psychosocial presentations.

Goals of the ADA Position Paper

• To codify the role and contribution of psychosocial aspects of the diabetes disease experience so that the needs of patients may be addressed and supported by provider care teams using evidence-based best practices.
• Recognize the interdisciplinary nature of diabetes care.
• No single provider can or should do it all.

Process of Determining Recommendations

• Writing team defined the scope of 'behavioral diabetes practice'
• A 92-page Table of Evidence was assembled by all authors. Strength and rigor of evidence was graded (A-E).
• Treatment recommendations were synthesized from the evidence by all authors.
• Recommendations were formulated in concert with existing national standards of care (e.g. Institute of Medicine, ACSM, etc.)

Assumptions within the Standards

• Psychosocial factors exist along a continuum that spans adaptation/health to problematic/diagnosed disorders.
  — Example: Fear of hypoglycemia
• There is a reciprocal relationship between psychosocial factors and diabetes
• There are, by necessity, different roles that members of the diabetes care team can and should play.
• There are different issues that arise across the lifespan.
Assumptions within the Standards

- These standards represent a landmark advance in the field of diabetes care by identifying key psychosocial elements that affect patients and can be addressed by their care.
- These standards do not speak to implementation.
- There are as many ways/models that these standards can be incorporated into practice as there are models of practice.

General Considerations

- Integrated psychosocial care within patient-centered care provided to all patients and their families with diabetes.
- Consider assessment with validated tools:
  - Diabetes-related distress
  - Depression
  - Anxiety
  - Disordered eating behaviors
  - Cognitive capacities
- Monitor patient performance of self-management behaviors and psychosocial factors that influence self-management

Psychosocial Issues Impacting Diabetes Self-Management

- Diabetes education and training should be delivered (8) at:
  - Time of diagnosis
  - Annually
  - If/when diabetes complications arise
  - At times of transitions in care
- Directly assess self-management behaviors
- Providers should consider the burden of treatment and patient levels of confidence in their ability to perform self-care tasks and levels of social/family support for the patient (E).
Diabetes Distress

- Diabetes-related distress should be routinely monitored (B).
- Distress should be monitored when treatment targets are not met.
- Distress should be monitored with the onset or exacerbation of diabetes complications.

Depression

- Consider annual screening for depression with all patients and routine screening for those with a history of depression (B).
- Screen for depression at the onset of complications or changes in medical status (B).
- Refer to a mental health provider for follow-up assessment and, if needed, treatment (B).
- Collaborative care for depression using evidence-based treatments is recommended (e.g. cognitive behavioral therapy) (A).

Anxiety Disorders

- Consider screening for anxiety in those exhibiting anxiety symptoms, excessive worry about complications, insulin administration and/or hypoglycemia that interferes with self-care.
- Look for fear, dread, irrational thoughts, avoidance behaviors, excessive repetitive behaviors and/or social withdrawal (B).
- Blood Glucose Awareness Training is recommended for treatment of those with hypoglycemic unawareness and fear of hypoglycemia (A).

Disordered Eating Behavior

- Providers should consider re-evaluating the treatment regimen of patients who present with disordered eating behaviors, eating disorders (e.g. anorexia, bulimia) or disrupted patterns of eating (B).
- Screen for disordered or disrupted eating using validated measures when hyperglycemia and weight loss are unexplained by self-reported self-management. A review of the medical regimen is recommended to identify potential treatment-related effects on hunger/caloric intake (B).

Serious Mental Illness

- Annually screen individuals for pre-diabetes/diabetes who are prescribed atypical antipsychotic medications (B).
- Incorporate monitoring of diabetes self-care activities into treatment goals for people with diabetes and SMI (B).
### Youth and Emerging Adults

- At diagnosis and during routine care, assess psychosocial issues and family stresses that could impact disease management. Provide referrals to mental health professionals with experience in childhood diabetes (preferred) (E).
- Monitor youth and their parents about social adjustment (peer relationships) and school performance to determine whether further evaluation is needed (B).
- Assess for diabetes-related distress by ages 7-8 years (B).

### Youth and Emerging Adults

- Encourage developmentally appropriate family involved in diabetes self-care, recognizing that premature transfer of care can result in poor self-management and decreased glycemic control (A).
- Consider inclusion of children in the consent process as early as developmental level indicates understanding of health consequences (E).
- Adolescents may have time by themselves with care providers starting at age 12 years (E).

### Youth and Emerging Adults

- Initiate discussions of care transition to adolescent medicine/transition clinic/adult medicine 1 year prior to transfer, starting preferably in early adolescence (~ age 14 years) (E).
- Monitor support from parents/caretakers of emerging adults and encourage instrumental support (e.g. ordering supplies) and collaborative decision making among caregivers (E).
- Preconception counseling should be incorporated into routine care for all females starting at puberty (A).
- Consider counseling males for adoption of healthy lifestyles to reduce the risks of sexual dysfunction starting at puberty (E).

### Adults

- In adults with childbearing potential, discuss life choices that could be impacted by diabetes self-management such as pregnancy and sexual functioning (B).
- Providers should assess social support (e.g. family, peers) that may facilitate self-management behaviors, reduce burden of illness and improve diabetes and general quality of life (B).

### Older Adults

- Annual screening for early detection of mild cognitive impairment and/or dementia is indicated for adults age 65 and older (B).
- Assessment of neuropsychological function and dementia should use standardized evaluation approaches (E).
- Within primary care settings, the collaborative care model that incorporates a nurse case management system, is recommended to treat depression in older adults with diabetes (A).

### Diabetes Complications and Functional Limitations

- Consider routine monitoring for chronic pain associated with diabetes complications and impact on quality of life (B).
- Appropriate pain management interventions including referral to behavioral health providers for pain management strategies should be provided (B).
Bariatric Surgery

• Comprehensive mental health assessment by a professional familiar with weight loss interventions is recommended for patients presenting for bariatric surgery.
• If psychopathology is evident (e.g. suicidal ideation, depression), postponement of surgery should be considered so that patient suffering can be addressed before adding the burden of recovery and lifestyle adjustment [E].
• Consider assessment of ongoing mental health services to assist patients with medical and psychosocial adjustment post-surgery.

Diabetes Distress and Burnout

Definition:
• Loss of motivation for self-care behaviors
• Inability to maintain an intensive regimen 24/7/365 indefinitely; Decrease in self-care behaviors (Polonsky, 1999)

Prevalence:
• 38-45% of adults report moderate to high levels of diabetes distress at any given time (Fisher et al., 2013).

Assessment:
• Problem Areas in Diabetes (PAID; Polonsky et al. 1996)
• Diabetes Distress Scale (Polonsky et al., 2005)

Depression in Diabetes: Prevalence

• Depression is 2 times more likely in people with diabetes than the general population (Lustman et al., Diabetes Care, 2000)
• 1 in 4 people with diabetes will have depression in their lifetime (Lustman et al., Diabetes Care, 2000)
  - Depressive symptoms: 21%–27%
  - Depressive disorders: 11%–15%
• Women with diabetes have 60% increased risk of depression (Anderson et al., Psychosomatic Medicine, 2001)
• Comparable rates of depression across ethnic groups with diabetes (de Groot et al., Diabetes Care, 2002)
  - Depressive symptoms: 21%–27%
  - Depressive disorders: 11%–15%

Impact of Depression and Diabetes

• Worsened glycemic control (Lustman et al., Diabetes Care, 2000)
• Greater severity of diabetes complications (Lustman et al., Psychosomatic Medicine, 2000)
• Decreased adherence to diabetes treatment regimens and increased medical costs (Lustman et al., Diabetes Care, 2000; de Groot et al., Arch Intern Med, 2000)
• Increased functional disability (Lustman et al., Psychosomatic Medicine, 2000)
• Increased rates of premature all-cause mortality (Lustman et al., Arch Intern Med, 2000)

Depression Screening

• Depression is consistently under-diagnosed and under-reported (Gary et al., Diabetes Care, 2000)
• When we ask, patients share (Robinson & Roter, Soc Sci Med, 1999)
• Ethnically diverse patients are hesitant to share depressive symptoms (Wagner et al., Fam Res. Clin. Pract., 2009)
• Patient attitudes are positive once treated (de Groot et al., Diabetes Care, 2000)
Recommendations for Screening and Evaluation

- Psychosocial factors impacting self-care (e.g., diabetes distress) and psychological states (e.g., depression, anxiety) should be routinely monitored.
- For all patients, monitoring should occur at the first visit and on a periodic basis.
- Screening and evaluation should also take place during disease (e.g., onset or significant exacerbation of complication), treatment (e.g., initiation of new devices) and life transitions (e.g., changes in work or social roles).
- Prospectively every 6 months through these transitions (Young-Hyman et al., 2016).

Rationale for Screening and Evaluation

- Psychosocial considerations affect every aspect of a patient’s life and can impact diabetes management and outcomes directly or indirectly (e.g., Hood et al., Pediatrics, 2009).
- Screening and evaluation allows clinicians to identify psychosocial barriers and resources to overcome these barriers.
- Not knowing an important barrier to self-care results in missed targets for intervention and improvement in patient health and well-being.

Rationale for Screening and Evaluation

Evaluation facilitates:
- Learning about barriers that would be otherwise unknown and unaddressed
- Confirming clinical observations with objective data.
- Inform treatment recommendations or changes in treatment.
- Accountability
  - For health care providers
  - For patients

Barriers to Psychosocial Screening and Evaluation

Common Concerns
- It takes time
- It’s complicated
- It’s “too academic”
- I might learn something I don’t want to know
- I might create a problem just by asking
- This is somebody else’s idea, not mine.

Counterpoints
- Can be done with patient flow
- Can take many simple forms
- Good evaluation is clinically useful.
- Response relies on established clinical procedures
- Asking may reveal a problem, but not create it.
- Externally imposed standards create opportunities to enhance clinical care

Considerations for Screening and Evaluation

Measure selection
Gathering the Data
Interpret the Data
Sharing Feedback with Patients and Providers
Use for Clinical Decision Making
Measure Selection

Considerations for selecting a measure:

• Use the right tool for the right job
  – Identify measures that assess what matters most to your practice and patient population.
  – Example: Diabetes Distress ≠ Depression
• Select measures that are valid and reliable for people with diabetes
• Select measures that have been developed for your patient population (e.g., pediatric, reading level, cultural subgroup, language)

PHQ-9

Over the last 2 weeks, how often have you been bothered by any of the following problems?

1. Little interest or pleasure in doing things
2. Feeling down, depressed, or hopeless
3. Trouble falling or staying asleep, or sleeping too much
4. Feeling tired or having little energy
5. Poor appetite or overeating
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down
7. Trouble concentrating on things, such as reading the newspaper or watching television
8. Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual
9. Thoughts that you would be better off dead or of hurting yourself in some way

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all Somewhat difficult Very difficult Extremely difficult

Not at all Several days More than half the days Nearly every day

0 1 2 3
Measure Selection

- Assessment can be done at multiple levels:
  - Patient level
  - Clinic/provider level
  - Organizational Level
  - Health care delivery
  - Health care quality
- Make it useful: What do you want to know?
  - There’s a measure for that! (Young-Hyman et al., Diabetes Care, 2016)
  - Patient Reported Outcomes Measurement Information System (PROMIS; www.nihpromis.com)

Process of Screening and Evaluation

- Make it easy
  - Select a measure with an easy format for delivery and scoring.
- Go with the flow
  - Where is the patient most likely to have the most time before or during their visit?
  - Which collection format works best for your setting?
    - Clinical query
    - Pencil and paper form
    - Electronic interface
- Patients are already socialized to provide information.

Process of Screening and Evaluation

Create a process that requires the least amount of effort and the greatest yield.

- Train staff: Staff attrition affects all aspects of care. Measure collection must be included in training efforts.
- Chart the path of information from the patient to the provider.
- Determine who will review and score the measure (Provider? Medical Staff?).
- Measures help to identify who needs further assessment; not diagnosis per se.
- Incorporate into the health system business model.

Interpretation of Screening and Evaluation Outcomes

- Interpretation of the measure: What scores suggest further assessment?
  - Example: Depressive symptoms and the PHQ-9
    - The 'score' is a sum of all of the items circled by the patient.
    - A score of > 10 = depressive symptoms that require additional assessment.
- Identify standard clinical procedures that will be used when immediate action is needed
  - Example: PHQ-9 Item 9 assesses suicidal ideation, intent and plan.
  - Determine a safety protocol for scores of 2 or greater.
  - Follow-up evaluation by a clinician; referral to emergent care as needed.

Sharing Screening/Evaluation Outcomes with Patients

Patients can benefit from the same information as providers:

- Explain the purpose and value of screening and evaluation.
  - How does this help the patient?
  - How does it help you, the provider?
- Provide feedback to the patient about the screening/evaluation outcomes
  - Share how the score informs the need for further evaluation, possible medical recommendations and next steps.
  - Share with the patient that this information is helpful in their care.

Clinical Decision Making

For Provider and Patient Teams:

- Measures will assist identification of barriers to diabetes self-care or medical outcomes.
- Consider the patient’s priorities and what resources are needed to address this problem
  - Referral sources are available within and beyond my practice.
- Consider steps needed to facilitate the referral
- Referral Follow-Up: Checking back with the patient to identify gaps in care. Did the referral make a difference in the measured outcome? If not, why not?
Summary

- Psychosocial concerns have the capacity to affect every aspect of diabetes self-care and medical outcomes.
- Use of screening and evaluation tools can take many forms ranging from brief clinical queries to electronic or manually distributed surveys.
- Use of these tools can be successfully incorporated into clinical practice and decision making.
- Screening and evaluation represents an important opportunity to identify barriers and facilitate dialogue and joint decision-making to support to people with diabetes and their families.

Time for Self-Reflection...

- What forms of screening and evaluation for diabetes distress and depression already exist in my practice?
- How could I augment my practice to learn more about the patients who need this screening most?
- What measures will work best for my practice to learn more about diabetes distress and depression?
- To whom and how will I make referrals for patients who screen positively?

Implications for Diabetes Educators

- Diabetes educators are frontline providers for people with diabetes and their families.
- Well-positioned to recognize psychosocial aspects and barriers to regimen adherence.
- Diabetes educators are critical referral agents to assist patients to receive advanced behavioral health assessment and treatment services when indicated.

Implications for Diabetes Educators

- You are a critical member of the treatment team.
- The ADA Standards of Care were created to support your best work in clinical care.
- The first step to implementation of these standards is to identify what elements you do already.
- Your creative solutions can make a difference to your patients, your provider colleagues and your health care organization.