



A Review of the Mental Health Issues of Diabetes Conference

Diabetes Care 2015;38:333–338 | DOI: 10.2337/dc14-1383

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Individuals with type 1 diabetes are at increased risk for depression, anxiety disorder, and eating disorder diagnoses. People with type 1 diabetes are also at risk for subclinical levels of diabetes distress and anxiety. These mental/behavioral health comorbidities of diabetes are associated with poor adherence to treatment and poor glycemic control, thus increasing the risk for serious short- and long-term physical complications, which can result in blindness, amputations, stroke, cognitive decline, decreased quality of life, as well as premature death. When mental health comorbidities of diabetes are not diagnosed and treated, the financial cost to society and health care systems is catastrophic, and the human suffering that results is profound. This review summarizes state-of-the-art presentations and working group scholarly reports from the Mental Health Issues of Diabetes Conference (7–8 October 2013, Philadelphia, PA), which included stakeholders from the National Institutes of Health, people living with type 1 diabetes and their families, diabetes consumer advocacy groups, the insurance industry, as well as psychologists, psychiatrists, endocrinologists, and nurse practitioners who are all nationally and internationally recognized experts in type 1 diabetes research and care. At this landmark conference current evidence for the incidence and the consequences of mental health problems in type 1 diabetes was presented, supporting the integration of mental health screening and mental health care into routine diabetes medical care. Future research directions were recommended to establish the efficacy and cost-effectiveness of paradigms of diabetes care in which physical and mental health care are both priorities.

The Mental Health Issues of Diabetes Conference (7–8 October 2013, Philadelphia, PA) sought to provide a scholarly as well as a patient- and family-informed review of the state of mental health care primarily for people living with type 1 diabetes. The conference included stakeholders from the National Institutes of Health, people living with type 1 diabetes and their families, diabetes consumer advocacy groups, and the insurance industry, as well as psychologists, psychiatrists, endocrinologists, nurse practitioners, and educators, all of whom are internationally recognized experts in type 1 diabetes research and care. (The conference agenda and speaker list is available from <http://mhidglobal.org/october-2013-conference>.) The consensus among participants was that the mental/behavioral health comorbidities of type 1 diabetes are largely overlooked in our current system for the delivery of diabetes care. Here we provide an overview of this landmark conference.

Dr. Griffin Rodgers, Director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) set the tone for the conference by reviewing the rising incidence of type 1 diabetes. He emphasized the complex balance of behavioral tasks required to achieve optimal glucose control while avoiding hypoglycemia, part of the heavy disease burden of living with type 1 diabetes. Dr. Rodgers pointed out

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Received 2 June 2014 and accepted 2 November 2014.

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that adherence to the multiple daily tasks of a complex diabetes treatment regimen is negatively affected by mental health comorbidities that increase the risk for short- and long-term physical complications (1).

Because of the daily demand for self-management behaviors, the concept of behavioral health is especially appropriate when considering the psychological aspects of type 1 diabetes. Behavioral health was defined as promoting a philosophy of health that stresses individual responsibility in the maintenance of health and the prevention of illness (2). Mental/behavioral health challenges confront people and families with type 1 diabetes, irrespective of age, educational level, or socioeconomic status. These behavioral/mental health challenges are associated with poor adherence to treatment (3) and poor glycemic control (4), thus increasing the risk for serious short- and long-term physical complications.

The Mental Health Issues of Diabetes Conference provided an opportunity to critically review the evidence on mental/behavioral health issues in diabetes informed by personal stories of individuals living with type 1 diabetes and their family members. There was consensus that because of the devastating consequences of type 1 diabetes and comorbid depression, anxiety disorders, and eating disorders, new paradigms of diabetes care in which mental health care is an integral part of regular diabetes medical care are needed.

REVIEW OF CONFERENCE WORKING GROUPS

The “Standards of Medical Care in Diabetes—2014” position statement (5) recommends routine screening for psychosocial problems, such as depression and diabetes-related distress, anxiety disorders, eating disorders, and cognitive impairment. To address the gap between

these recommendations and the reality of diabetes care in the U.S., four scholarly working groups were formed at the Mental Health Issues of Diabetes Conference, with participation by all stakeholders led by scientists and clinicians in the area of type 1 diabetes research and clinical care (for the chairs and working group members, see <http://mhidglobal.org/october-2013-conference>). Here we summarize the working group recommendations (Table 1); following each group’s recommendations is a section that reports whether current research is congruent with, or conflicts with, the working group’s recommendations.

Working Group 1

What major mental/behavioral health issues of children and adolescents (0–18 years old) with type 1 diabetes and their families need to be an integral part of diabetes care? How can psychosocial support available to children and

Table 1—Summary of working group recommendations

Working group	Primary recommendations
Mental/Behavioral Health Issues of Children and Adolescents (0–18 Years) With Type 1 Diabetes and Their Families	<ol style="list-style-type: none"> 1. Mental/behavioral health issues of youth 0–18 years old must be addressed within a developmental framework. 2. Provide annual developmentally focused workshops for families that focus on the unique needs of children in specific stages of life. 3. Provide mental/behavioral health screening for youth and families at diagnosis and annually; refer for evidence-based treatments when needed.
Mental/Behavioral Health Issues of Patients With Type 1 Diabetes and Their Caregivers From Late Adolescence to Older Adulthood	<ol style="list-style-type: none"> 1. Because of the risk of depression, diabetes distress, anxiety disorders, and eating disorders, carry out preventive mental health visits at key life transition points and focus visits on adult issues, such as family conflict, fear of hypoglycemia, sexuality, finances, and insurance. 2. Promote more mental health professionals who are knowledgeable about mental/behavioral health issues of adults with diabetes.
A Model for Screening for Mental Health Comorbidities in Type 1 Diabetes	<ol style="list-style-type: none"> 1. Screening for children, adolescents, and adults with type 1 diabetes should be ongoing and incorporated into a program of “anticipatory guidance.” 2. After screening, the mental health professional should work in active collaboration with the diabetes team to ensure that patients determined to be at risk are referred for evidence-based therapies.
Future Research and Resources That Will Be Needed to Assess Paradigms of Care for Persons With Type 1 Diabetes in Which Mental and Physical Health Care Are Both Priorities	<ol style="list-style-type: none"> 1. Research designed to assess the cost-effectiveness and efficacy of integrated care should be conducted in rigorous randomized controlled trials that assess mental health outcomes, cost-effectiveness, quality of life, and patient satisfaction. 2. Research should focus on patients who are newly diagnosed and who are extensive users of medical services and other vulnerable subgroups to develop interventions tailored to unique patient subgroups. 3. National Institutes of Health and diabetes organizations should partner to fund this important research for new paradigms of diabetes care.

adolescents with type 1 diabetes and families be improved?

1. The key mental and behavioral health issues for youth with type 1 diabetes must be addressed within a developmental framework.
2. Multidisciplinary workshops focused on the developmental needs of children and families at specific stages of child and adolescent development should be offered as part of routine pediatric diabetes care.
 - a. For parents of children with type 1 diabetes younger than age 6, coping with the fear of hypoglycemia and with feeding struggles are the major mental/behavioral health issues.
 - b. For elementary school-aged children, major issues for the child and family include sharing the diagnosis of type 1 diabetes with others, making a good adjustment to school, maintaining positive family interactions around diabetes, and preventing type 1 diabetes from interfering with daily activities.
 - c. The primary behavioral health issues facing adolescents with type 1 diabetes and their families are balancing the desire for independence with the continuing need for parental support and supervision of type 1 diabetes management.

Diabetes education and care are best delivered within a developmental framework (6,7). Parents of young children with type 1 diabetes experience emotional distress (8). Currently, there are opportunities to improve glycemic control using intensive management tools including small, programmable insulin pumps and continuous glucose monitoring systems. Even with these tools, however, there continues to be significant psychosocial burdens that confront the young person and family living with type 1 diabetes (9,10). Parents of young children with type 1 diabetes are at high risk for severe fear of hypoglycemia (11). The threat of serious hypoglycemic episodes and “parental fear of hypoglycemia” are a constant burden for families living with type 1 diabetes (12).

For school-aged children with type 1 diabetes, evidence supports the importance of good adjustment to school, avoidance of diabetes-specific family conflict, and continued involvement of

parents in diabetes management for optimal glycemic outcomes (7). Contemporary research with adolescents documents the importance of parent-adolescent collaboration in diabetes management tasks (13), as well as identifying depression, diabetes distress, and disordered eating symptoms (6) for positive health outcomes.

3. Mental health screening should occur for youth and family at diagnosis and annually; those in the at-risk range for depression, diabetes distress, or disordered eating should be referred for evidence-based therapies.

A recent meta-analysis reported that rates of depression are higher among youth with type 1 diabetes compared with nondiabetic controls, though the differences are smaller than reported previously (14). In contrast to adult primary care settings, in which models of collaborative care for depression and diabetes have been extensively implemented and evaluated (15–17), integrated, collaborative depression care has not yet been implemented in pediatric diabetes care. Diabetes-specific distress is common among children and adolescents and their family members (18). Diabetes-related distress is a major barrier to optimal diabetes management that clinicians can identify and improve. Higher diabetes distress in adolescents is strongly related to poorer glycemic control (19).

Adolescent girls with type 1 diabetes are 2.4 times more likely to develop an eating disorder and 1.9 times more likely to develop subclinical eating disorders than female adolescents without diabetes (20). Less is known about eating disorders among adolescent boys and men with diabetes. Disturbed eating behaviors in adolescent girls and adult women with type 1 diabetes include binge eating and caloric purging through insulin restriction (20).

Working Group 2

How can the major mental and behavioral health needs of patients and caregivers from late adolescence to older adulthood be an integrated part of diabetes care?

1. Because of the high risk of depression and diabetes distress, anxiety

disorders, and eating disorders, preventive mental health visits should occur at a prescribed frequency after diagnosis of type 1 diabetes.

The most serious mental health comorbidity of diabetes is major depressive disorder. While the psychiatric condition of major depressive disorder affects 6.7% of U.S. adults ≥ 18 years old, major depression is twice as likely to be diagnosed in U.S. adults with diabetes (21,22). However, behavioral scientists working in type 1 diabetes research and care have identified another serious mental health comorbidity of type 1 diabetes, diabetes distress, which is different from major depressive disorder or an anxiety disorder (12). According to the diabetes distress screening instrument (23), diabetes distress is defined as distress linked specifically to diabetes and its management (24). Four areas of disease-related distress were identified: emotional burden, physician-related distress, regimen-related distress, and interpersonal distress (25). Diabetes distress in individuals with type 1 diabetes occurs much more frequently than major depression and is associated with poor adherence to treatment, poor glycemic control, higher rates of diabetes complications, and impaired quality of life (22). Therefore, in addition to the traditional mental health comorbidities of diabetes—depression, anxiety disorders, and eating disorders—diabetes distress represents a significant behavioral health comorbidity of diabetes.

Increased anxiety in people with diabetes can occur both at diagnosis and at the onset of complications (26). Fear of hypoglycemia, the most common severe anxiety for people with diabetes, can drive some patients to maintain blood glucose concentrations above recommended targets, increasing their risk for diabetes complications (12). Hypoglycemia unawareness, in which the warning symptoms of impending hypoglycemia are not detected in time to obtain help, can occur at any age (27). While advanced diabetes management technologies can help manage and predict blood glucose concentrations, dangerous fluctuations still occur. Moreover, neurological and neuropsychological evidence documents out-of-range blood glucose concentrations as

well as blood glucose fluctuations that impact the brain and cognition of both youth (28,29) and adults with type 1 diabetes (30). Finally, disordered eating behaviors, such as binge eating and caloric purging through insulin restriction, persist and worsen over time. Adult women with type 1 diabetes and eating disorders have poorer glycemic control and higher rates of hospitalizations, retinopathy, neuropathy, and premature death compared with women of a similar age with type 1 diabetes without eating disorders (31).

2. Mental health intervention is important at key life transition points for adults, such as entry to college, marriage, pregnancy, relocation, older age, and the onset of complications. Diabetes-specific adult issues such as family conflict, fear of hypoglycemia and hyperglycemia, sexuality and intimacy, pregnancy planning and management, and finances/insurance coverage must be addressed during regular diabetes clinic visits to promote optimal mental and physical health outcomes in adults.

Current evidence supports the importance of preventive interventions at life transition points (32). Older adolescents transitioning to young adulthood and young adults with type 1 diabetes are especially at risk for poor physical and mental health outcomes and premature mortality (33–35). Research with adults with type 1 diabetes identified four unique interpersonal challenges: 1) level of partner involvement and concerns about child rearing; 2) impact of hypoglycemia; 3) stress of potential complications; and 4) impact of technology (36). With respect to mental health comorbidities of adults with type 1 diabetes, adult patients in the T1D Exchange registry who reported a higher frequency of depressive symptoms had worse clinical outcomes than those adults who were not depressed (37).

Older adults with type 1 diabetes remain insufficiently studied. When health-related quality of life of older (≥ 65 years old) versus younger adults (30–64 years old) with type 1 diabetes was analyzed, older adults reported greater role limitations due to physical problems, better social functioning, less diabetes distress, and better ability to

cope with their diabetes (38). The *Type 1 Diabetes Sourcebook* (39) emphasizes that older patients with diabetes are a distinctly different population because of their heterogeneity (clinical, functional, and psychosocial) and the presence of coexisting medical conditions that interfere with self-care. Cognition in older patients with type 1 diabetes can be mildly to moderately disturbed (39), and a high incidence of impaired awareness of hypoglycemia in older adults has been reported (40).

3. There is a significant lack of mental health professionals who are knowledgeable about the mental health issues of people with diabetes, both in medical centers as well as in the community.

The lack of mental health experts trained to understand the behavioral issues unique to diabetes has been documented (41,42). However, there have been few efforts to build clinical training programs for mental health providers that include a focus on the unique mental/behavioral issues confronting people with type 1 diabetes and their families. Thus, this recommendation by Working Group 2 points out that initiatives are needed to correct the serious shortage of psychologists, psychiatrists, and social workers who are needed for integrated models of diabetes care.

Working Group 3

What would a model for screening for mental health comorbidities of type 1 diabetes, such as depression, suicide, and drug addiction, as well as anxiety and eating disorders, look like?

1. Screening for children, adolescents, and adults with type 1 diabetes should be ongoing and incorporated into a program of “anticipatory guidance.” Mental health screening should be conducted at diagnosis to determine strengths and risks based on prior experience and coping mechanisms that were successful and/or not helpful in prior challenging situations for the patient/family.
2. Screening and follow-up referral for evidence-based treatments are optimally delivered by a trained mental health professional with experience in the management of diabetes or,

at a minimum, experience in the care of serious chronic illness. The mental health professional should work in active collaboration with the diabetes team to ensure that patients screened to be at risk are referred for evidence-based therapies.

One of the few studies evaluating a screening program in diabetes found that psychosocial screening of youth with newly diagnosed type 1 diabetes is feasible, acceptable to families, and able to identify families at risk for early emerging adverse events and nonadherence (43). While both pediatric and adult guidelines (5,44) and others (45) have called for psychosocial screening at diagnosis and for depression screening on a routine basis, as yet there have been no efficacy or cost-effectiveness studies of screening programs. Establishing the efficacy and cost-effectiveness of screening is thus an important recommendation emphasizing that pressure must be put on funding agencies to make this research a high priority (46).

Working Group 4

What future research projects and resources are needed to assess paradigms of care for people with type 1 diabetes in which mental and physical health care are both priorities?

1. The efficacy of integrated care should be assessed in rigorous randomized controlled trials that assess mental health outcomes, cost-effectiveness, quality of life, and patient satisfaction.
2. Evaluate an integrated care approach in newly diagnosed patients to assess effects on preventing poor quality of life, lowering the risk of depression, and/or affecting medical outcomes.
3. Examine the cost of integrated care for pediatric and adult patients with type 1 diabetes to determine whether this results in long-term savings.
4. Develop interventions tailored to uniquely vulnerable patient subgroups such as patients who are heavy users of medical services.
5. Increase National Institutes of Health funding for integrated care using a trans-National Institutes of Health approach to support major outcome

investigations of the impact of integrated care on patient outcomes.

6. Focus national diabetes-oriented scientific and clinical meetings on integrated care research studies.
7. Determine the efficacy and effectiveness of integrated care for adults and youth with type 1 diabetes through coordinated efforts among organizations and groups such as the American Diabetes Association, JDRF, NIDDK-sponsored Diabetes Centers, and Centers for Diabetes Translation.

Working Group 4 recommended increased funding for randomized controlled trials to evaluate the efficacy and cost-effectiveness of different models of integrated care. There is broad consensus among diabetes investigators and clinicians that this evidence is essential to support new models of diabetes care (47,48). Furthermore, an NIDDK strategic report, *Recent Advances & Emerging Opportunities 2014*, also called for changes in the delivery of diabetes clinical care and recognized the importance of mental health issues in diabetes (49).

In summary, the working groups' recommendations addressed improving mental/behavioral health care for people with diabetes for both primary prevention and secondary prevention. Primary prevention efforts aim to prevent mental health problems in people with diabetes and thus prevent poor health outcomes through routine mental health screening from diagnosis and at regular follow-up intervals. Secondary prevention approaches refer to the rapid referral for evidence-based treatments for those individuals with diabetes who screen in the at-risk level, including individuals with clinical diagnoses as well as individuals with elevated symptoms who do not reach the clinical threshold. The REDEEM (Reducing Distress and Enhancing Effective Management) Trial is an excellent example of a secondary prevention approach in which distressed, non-clinically depressed adults with type 2 diabetes were randomized to one of three interventions. Results revealed that interventions that enhance self-management also significantly reduce diabetes distress (50).

CONCLUSIONS

The diagnosis of type 1 diabetes increases the risk by two- to threefold

for comorbid mental health conditions, in particular depression, anxiety disorders, and eating disorders (51), as well as diabetes distress. Mental health disorders affect more than 80 million Americans and disrupt their ability to cope with activities of daily life. When psychiatric disorders are not treated in individuals without type 1 diabetes, the individual, family, and societal costs are staggering and include disability, unemployment, family dysfunction, homelessness, substance abuse, incarceration, and suicide (52). When mental health comorbidities of diabetes are not diagnosed and treated in individuals with type 1 diabetes, the financial cost to society and health care systems is even more catastrophic, and the individual and family suffering that results is even more severe (53).

In summary, the data reviewed here provide support for a paradigm of care for people with type 1 diabetes and their families in which both medical care and mental health care are critical. However, widespread transition to an integrated model of diabetes care demands bold and sustained leadership for additional rigorous scientific research. This requires partnerships among consumer organizations, professional training and education programs, insurers, professional societies, hospitals, and funding agencies. The goal is to design, build, staff, and evaluate competing care models to determine the cost-effectiveness of integrated care and whether it promotes optimal health and quality of life outcomes for individuals and families living with type 1 diabetes.

Funding. The Mental Health Issues of Diabetes: A National Conference (7–8 October 2013, Philadelphia, PA) was supported primarily by Universal Health Services, Inc., and cosponsored by the JDRF. L.H.P. was partly funded by the University of Chicago Diabetes Research and Training Center (P30-DK-020595 and 1U01-DK-103153-01). B.J.A. was funded in part by a grant (R01-DK-095373) from the National Institute of Diabetes and Digestive and Kidney Diseases.

Duality of Interest. No potential conflicts of interest relevant to this article were reported.

Author Contributions. L.D. chaired the Mental Health Issues of Diabetes conference, wrote the manuscript, and approved the final version. A.R. was honorary chair of the Mental Health Issues of Diabetes conference, reviewed and edited the manuscript, and approved the final version. L.H.P. cochaired the Mental Health Issues of Diabetes conference and wrote,

reviewed, and edited the manuscript and approved the final version. B.J.A. cochaired the Mental Health Issues of Diabetes conference, wrote the initial draft of the manuscript, edited the manuscript, and approved the final version.

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