



# Psychosocial Research and Care in Diabetes: Altering Lives by Understanding Attitudes

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The philosophers of antiquity and others through the ages recognized the connection of human emotion and thought with physiological processes and behavior (1). The relatively recent increases in the human life span and the prevalence of significant chronic illnesses have generated a greater appreciation of the relationship between human emotional, social, cognitive, and behavioral processes and health and wellness. However, understanding human behavior remains challenging, and in the presence of a significant chronic illness such as diabetes, that challenge becomes even more daunting. Specifically, the interaction of individual differences in emotional responses, attitudes, thought processes, preferences, beliefs, and social situations appear amplified with the increased complexities of new diabetes treatments. With the realization that other factors such as quality of life are equally important as physiological outcomes, the necessity of understanding behavioral and psychosocial processes is evident (2,3). Thus, the era of simply outlining a broad plan and sending it home for the patient to implement, if that era ever existed, is over. The era of placing the person with diabetes and family in the center of health care decisions and understanding their individual challenges and barriers has

begun. Given the emerging concepts in the psychosocial aspects of diabetes, the editorial committee of *Diabetes Care* wanted to highlight this area in this issue.

This special issue of *Diabetes Care* presents nine articles that represent a broad spectrum of behavioral and psychosocial issues that can influence treatment success and quality of life for those living with diabetes. Central to this topic and serving as the cornerstone of the special issue is the publication of the first Position Statement from the American Diabetes Association (ADA) for the psychosocial care of people with diabetes (4). This is followed by the presentation of a collection of articles that represent important aspects of psychological science spanning from the development of measures to assess psychological constructs (5) to community-based interventions to treat psychological outcomes of diabetes (6). These articles also represent work conducted with samples across the life span ranging from the experiences with artificial pancreas in children with type 1 diabetes and their parents (7) to adult couples with type 2 diabetes (8). Three articles address the emotional and affective experience of diabetes by examining 1) stigma associated with type 2 diabetes (5), 2) the course of depressive disorders in adults with type 2 diabetes (9), and 3) linkages

between emotional distress and self-care behaviors (10). Additional work examines the use of an Internet platform to deliver a behavioral intervention to address hypoglycemic unawareness in adults with type 1 and type 2 diabetes using insulin (11). Thus, the articles selected for this special issue highlight the range of interventions that have been developed by behavioral scientists working in diabetes.

As stated, the cornerstone article for this special collection is the ADA Position Statement “Psychosocial Care of People with Diabetes” (4). This Position Statement is the first comprehensive set of clinical practice recommendations for the psychosocial care of people with diabetes in the history of the ADA. These recommendations are grounded in more than 40 years of behavioral science that has systematically recorded and assessed the psychosocial experience of people with diabetes and their families and has used empirical data to develop innovative interventions to address the unique psychological, social, emotional, cognitive, and interpersonal issues that patients, families, and providers face on a daily basis. Distinct from the research articles devoted to advancing scientific knowledge, the Position Statement is designed to guide diabetes clinical practice and increase awareness

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See accompanying articles, pp. 2126, 2141, 2149, 2158, 2165, 2174, 2182, 2190, and 2197.

of all providers who work with people with diabetes and their families about the emotional and behavioral landscape of this disease. They are also intended to augment provider awareness that one size does not fit all when it comes to health care for people with diabetes. Each psychological factor discussed in these recommendations lies along a continuum ranging from normative/adaptive experiences (e.g., awareness of the risk of hypoglycemia associated with insulin use) to clinical symptoms/psychopathology (e.g., fear of hypoglycemia as a specific phobia that impairs diabetes self-management). Central to these recommendations is the recognition that the experience of diabetes differs across roles (i.e., patient vs. family member vs. health care provider), phase of the disease (i.e., new diagnosis, onset or exacerbation of long-term complications, end of life), stage of human development (i.e., childhood, young adulthood, middle age, older adulthood), accumulated experience of the disease over time, and the person's cultural, social, political, and economic context. Finally, this Position Statement recognizes that the psychological science of diabetes, like the search for a cure for diabetes, is a work in progress. Much work remains to be done to advance psychological interventions to support and treat people with diabetes and their families.

Randomized controlled trials are as important in behavioral science as they are in other components of clinical research, and in this special issue, we feature three trials, each of which includes an aspect of a behavioral intervention that can be delivered remotely or by self-study. Trief et al. (8) describe a well-designed, three-armed randomized controlled trial that compares a 4-month telephonic couples behavioral intervention ( $n = 104$ ) with individual calls ( $n = 94$ ) and diabetes education ( $n = 82$ ) for adults with type 2 diabetes who were above glycemic targets. They reported that A1C improved in all three groups with no difference between arms at 12 months. However, only the telephonic couples intervention led to lower A1C among those whose A1C ranged from 8.32 to 9.2% (middle tertile). Fortunately, for those whose A1C was  $\geq 9.3\%$  (highest tertile), A1C improved in all intervention groups. In

their thoughtful discussion, the authors reflect on possible mechanisms of improvement for the telephonic group and discuss the value of diabetes education in supporting those who are in very poor control ( $A1C \geq 9.3\%$ ) to improve glycemia. They point out that participants in this group realized a 1.7-point A1C improvement without achieving target levels. Thus these participants may need concurrent intensification of medical approaches in order to achieve target levels.

The Decision-making Education for Choices In Diabetes Everyday (DECIDE) study (6) used a four-armed randomized controlled design to investigate the usefulness of three methods for delivering a problem-solving diabetes and cardiovascular disease education intervention among urban African Americans with type 2 diabetes. Using usual care as a comparison, they studied clinical outcomes resulting from self-study, group, and individual delivery methods. A total of 182 participants completed the study with a relatively high retention rate of 87%. Although the three DECIDE groups showed improvement in A1C and other clinical outcomes immediately after intervention, none were able to maintain an improvement compared with enhanced usual care at 6-month follow-up. However, all three groups improved in problem-solving knowledge compared with enhanced usual care. Importantly, for those with  $A1C \geq 7.5\%$ , the self-study group achieved improvements in A1C, blood pressure, and lipid outcomes. We must interpret the subgroup analysis findings with caution, yet they do support the value of self-study as a potentially useful methodology for intervention.

Rondags et al. (11) discuss a 6-month study examining the effectiveness of a brief, partially web-based group intervention addressing severe hypoglycemia among insulin-treated patients ( $n = 137$ , 88% with type 1 diabetes). The authors report a difference in the amount of severe hypoglycemia from a median of 2.5 events in the control group versus one event in the intervention group during the 6-month study period. The intervention group also improved distress levels compared with controls. If these preliminary results are supported in future studies, the intervention has the potential to broaden

the reach to a greater number of people suffering from hypoglycemia unawareness. This type of intervention has the potential to reduce costs both to the patient and to health care systems, and these factors should be examined.

New technologies have an important potential to improve glycemia safely while reducing or controlling the amount of hypoglycemia. Troncone et al. (7) used structured interviews and surveys to investigate the experience of 33 Italian children aged 5–9 years (and that of their parents) wearing an artificial pancreas for 3 days at a summer camp. This study is an example of the benefits of qualitative and quantitative data collection that provides researchers and science consumers with a robust understanding of the phenomena at hand. While parents had a positive attitude toward the artificial pancreas in the presence of significant medical and technical support, they also had some skepticism. This finding is consistent with qualitative data from an insulin pump study that found that those in good glycemic control thought of the pump as a somewhat flawed but very useful tool (12). The authors conclude that children who participated were more intrigued with the technology while their parents focused on risks and benefits such as the safe management of hypoglycemia, particularly at night and at school. The importance of this study rests on the need for understanding the psychosocial and quality-of-life implications of the exciting new technology.

The study by Sereika et al. (13) examines the impact of preconception counseling in adolescence on family planning vigilance in adult women with type 1 diabetes. Unplanned pregnancies can result in maternal-fetal complications that can be significantly reduced or avoided with intentional family planning efforts. In this study, a sample of 102 women aged 18–38 years were enrolled using a retrospective online survey design. Preconception counseling received in adolescence was correlated with initiating discussion with health care professionals in advance of pregnancy. In addition, women who were vigilant about family planning had fewer episodes of diabetic ketoacidosis and hospitalizations, as well as improved diabetes self-management and health outcomes. These findings demonstrate that preconception counseling for young women with type 1

diabetes serves as the first step in promoting family planning vigilance and communication with health care providers.

Finally, three articles address the emotional and affective experiences of diabetes. The article by Browne et al. (5) represents the latest contribution to the canon of measures that have been developed by behavioral researchers to assess the emotional, attitudinal, and behavioral aspects of diabetes. These authors describe the development of the Type 2 Diabetes Stigma Assessment Scale (DSAS-2), designed to assess the level of perceived and experienced stigma in adults with type 2 diabetes. People with diabetes must manage their condition in all social situations and, as a result, can be recipients of negative attention, comments, or judgments from others (5). Moreover, misunderstanding and lack of accurate knowledge about the impact of diabetes on autonomy and daily functioning has repeatedly resulted in restrictions on children and adults with diabetes by many social institutions (e.g., schools, driving privileges). Thus, the authors engaged in a two-stage measurement development design, beginning with an initial item pool of 57 questions evaluated by 13 adults with type 2 diabetes using cognitive debriefing interviews, which was then completed by a sample of 1,064 adults with type 2 diabetes. The final scale consisted of 19 items that measure three dimensions of diabetes stigma: being treated differently by others, feelings of blame and judgment, and self-stigma. Analysis of this final pool of items demonstrated satisfactory levels of concurrent, convergent, and discriminant validity. This measure provides researchers with a valid and reliable tool to assess degree of stigma experienced by adults with type 2 diabetes and to explore the relationship of this important part of the diabetes experience to psychological and medical outcomes.

Emotional distress or diabetes-related distress has gained both scientific and popular acceptance among people with diabetes, their families, and health care providers. Diabetes-related emotional distress is defined as the emotional and psychological reactions to the burden and stress associated with continuous diabetes self-management. In the article by Gonzalez et al. (10),

the authors examine the linkages between emotional distress, depressive symptoms, and self-care behaviors in an ethnically diverse sample of 104 adults with type 2 diabetes over a 3-month period. The authors reported that both depressive symptoms and diabetes distress predicted nonadherence to medications using electronic monitoring of medication adherence. When depressive symptoms were categorized into somatic (e.g., changes in appetite, weight, sleep, fatigue) and cognitive-affective (e.g., depressed or anhedonic mood, decreased concentration or memory, feelings of worthlessness) subgroups, somatic symptoms were most predictive of medication nonadherence. These findings suggest that physical discomfort such as changes in appetite, sleep, and fatigue are important cues that patients with type 2 diabetes may use when making decisions about when and whether to take their diabetes medications. The findings from Gonzalez et al. (10) highlight the importance of these physical symptoms in medication nonadherence and point the way to the development of interventions that more effectively address distress and diabetes self-care.

Depressive symptoms and depressive disorders are comorbid in type 1 and type 2 diabetes (14). One in four patients with type 1 or type 2 diabetes experience elevated depressive symptoms, and 11–15% of these patients experience depression at the level of a clinical disorder (14). While depressive episodes have been documented to be recurrent (15) and depressive symptoms persistent (16,17), the naturalistic course of depression in adults with type 2 diabetes has been understudied. In this issue, de Groot et al. (9) examine the course of clinical depressive disorders in a well-characterized cohort of 50 adults with type 2 diabetes using a diagnostic psychiatric interview protocol. This article is the first to document the duration and pattern of recurrent depressive disorders from birth to date of study completion. Most notably, the authors observed that initial depressive episodes lasted nearly 2 years, which is an order of magnitude longer than depressive episodes in the general population. Subsequent depressive episodes were shorter in duration with less time between episodes, resulting

in prolonged exposure to depression over the life course. This finding is particularly troublesome when the association of depressive disorders to long-term diabetes complications and early mortality are considered (18,19).

The consideration of psychosocial factors is increasingly being recognized as a critical aspect of diabetes care. This special issue of *Diabetes Care* marks an important milestone in the research and clinical care of people with diabetes. The collection of articles contained in this issue is representative of the trajectory of psychosocial and behavioral research that has occurred in the service of improving the lives of people at risk for and with diabetes. There is much more that must be learned. However, our intent as an editorial committee was to underscore psychosocial factors and to provide additional thoughts on the next steps for the research in this area. Caring for the individual with diabetes is much more than obtaining blood tests, providing a prescription, and monitoring risk factors. As stated, the recognition that human emotion and thought plays an important role in physiological processes and behavior is a concept whose time has come. But is it really a new concept? William James (1842–1910), an American philosopher who wrote *The Principles of Psychology* in 1890 stated, “the greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind.” Clearly, those words ring true today and essentially epitomize the message we are trying to convey with this special issue of *Diabetes Care*.

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