

# Diabetes and Behavior in the 21st Century: Things That Make You Go “Hmmm . . .”

Tim Wysocki

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**Editor's Note:** This article is adapted from the address Dr. Wysocki delivered as the recipient of the American Diabetes Association's Richard R. Rubin Award for 2018. This award recognizes a behavioral researcher who has made outstanding, innovative contributions to the study and understanding of the behavioral aspects of diabetes in diverse populations. Dr. Wysocki delivered the address in June 2018 at the association's 78th Scientific Sessions in Orlando, Fla.

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I am so honored to have been selected as the 2018 recipient of the American Diabetes Association's (ADA's) Richard R. Rubin Award, especially since I was fortunate to have gotten to know Dick quite well over the 25 or so years of our friendship and collegiality. Dick was truly one of the finest, most centered people I have ever known, and I tried in my lecture to emulate some of the unique style he brought to his role as a highly accomplished speaker and motivator. I strongly encourage you to learn more about him in his 2008 autobiographical article in *Diabetes Spectrum* (1) and in Mark Peyrot's touching memorial to Dick that was published in *Diabetes Care* in 2017 (2), a few years after Dick's untimely passing in 2013. You can also hear directly from him in a YouTube video that ADA produced when Dick was ADA President, Health Care & Education, in 2006–2007 (3).

Dick Rubin lives on in the hearts and minds of thousands of people with diabetes and clinicians who have benefitted from his wisdom and compassion over the years. He dedicated most of his career to improving the psychological experiences of people with diabetes, and I hope I can help

readers develop some of his passion for contributing something of yourselves to behavioral science research in diabetes and to advocate for its broad dissemination into clinical practice.

In approaching this task, it became clear that I am not very comfortable with the concept of individual awards for accomplishments in a clinical/scientific domain such as this one, in which the major steps forward consist increasingly of transdisciplinary and multicenter collaborations, stakeholder engagement, and international arrangements. Acknowledging the droves of fine people—my loving wife, Marcia; kids with diabetes, their parents, and families; countless pediatric endocrinologists, diabetes educators, nurses, and dietitians; my colleagues in psychology, psychiatry, and various behavioral sciences, especially the 13 past recipients of this award who are listed in Table 1; industry representatives; and advocates within ADA, JDRF, the International Society for Pediatric and Adolescent Diabetes, the International Diabetes Federation, and the National Institutes of Health who have bolstered my ability to contribute to this science and its clinical application—would consume all of my available space. So, let me just

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**TABLE 1. Past Recipients of the Richard R. Rubin Award and Its Predecessor, the Lilly Lecture**

2005	Daniel J. Cox, PhD
2006	Russell E. Glasgow, PhD
2007	Suzanne B. Johnson, PhD
2008	Rena R. Wing, PhD
2009	Patrick J. Lustman, PhD
2010	Richard R. Rubin, PhD
2011	Barbara J. Anderson, PhD
2012	Lawrence Fisher, PhD
2013	Margaret Grey, PhD, RN
2014	William H. Polonsky, PhD
2015	Robert M. Anderson, PhD
2016	Elizabeth A. Walker, PhD, RN
2017	Michael A. Harris, PhD

thank all of you collectively because this award is really a credit and honor to all of you as much as it is to me.

My intention for this published version of my lecture is to try to take a broad perspective of behavioral and psychological research in diabetes by cataloging some of the major past achievements, evaluating our current evidence base, commenting on several ongoing developments in our field, and forecasting some directions the field might take in the coming decade or so. This will not be an exhaustive review. Rather, I will try to offer a high-level perspective of our field, its contributions to elevating diabetes care, and its immediate and near-term future. Although I will mention a few exemplary studies along the way, I selected them as illustrations of the scope of our field and of the levels of sophistication and refinement that have been achieved in our short history as a focus of scientific inquiry and collaboration. I hope that these will acquaint some readers with the scope and depth of behavioral science focused on the complexities of living with diabetes. I'll conclude with some questions and observations that perplex me about the prospects for our little scientific niche—issues that may also make you go, “Hmmm . . .”

### Where Have We Been?

In the past four decades or so, there has been an explosion of behavioral science research across the life span on how living with diabetes affects, and is affected by, a plethora of psychological processes and mechanisms at the levels of individual patients, family and spousal relationships, extra-familial social networks, the health care system, and broader communities. This extensive research has yielded a massive body of knowledge that provides many answers about how diabetes affects people's psychological adjustment and how psychological variables influence diabetes self-management behavior (4–13). Application of this knowledge has led to the development and validation of many psychometrically sound measures (14–17) and demonstrations of the utility and merits of routine psychosocial screening (18–20) of people with diabetes and their families.

Numerous longitudinal studies have identified putative affective, behavioral, cognitive, and social determinants of diabetes outcomes in varied clinical populations (21–28). Many of the mechanisms that have been specified in such studies have been targeted in trials of behavioral and psychological interventions (29–39).

These related bodies of evidence have matured to the point that the ADA and the American Psychological Association have collaborated to initiate a training program offering continuing education credits to qualified psychologists, mental health counselors, and psychotherapists that equips these mental health professionals to better meet the needs of patients across the life span who are living with diabetes (40,41). Further affirmation that this evidence base is gaining influence on health care policy and clinical practice is manifest in the level of attention to psychosocial issues that appears in current treatment guidelines issued by major organizations (42–45), as well as in standards for accreditation of diabetes

education programs (46) and certification of diabetes educators (47).

### Where Have We Fallen Short?

Although there have been major strides in developing and expanding the evidence base, there is also considerable room for improvement in the contributions made by behavioral scientists to improving the behavioral, affective, cognitive, and social lives of people with diabetes. So, I've summarized in this section a few targets that I think represent valuable near-term directions for the field.

Organizations that develop and disseminate guidelines for clinical practice use one of several evidence-grading systems (48). For example, in a recent ADA position statement (43) on psychosocial care for people with diabetes, only 5 of the 31 treatment recommendations put forth were supported by the highest level of evidence (grade A). Certainly, research that can yield the most credible levels of empirical evidence is difficult and expensive, but the field must move beyond subjective, self-reported outcome measures, small sample sizes, short follow-ups, and single-center studies to maximize its impact on health care policy. Researchers should plan their work with the intention of informing and influencing decision-makers and other key stakeholders.

In the past decade, science has become increasingly open and transparent (49,50), with grant agencies and scientific journals increasingly requiring investigators to share with their scientific peers their research data, statistical syntax and output files, data dictionaries, procedural manuals, and other materials to facilitate both the understanding and replication of their investigations. Given the complexity of behavioral science protocols, particularly for intervention trials, these steps can be challenging, labor-intensive, and costly for behavioral researchers. The sensitivity of confidential psychological data also entails ethical and

patient-protection considerations that tend to be far more salient in behavioral science research than in other domains of scientific inquiry. When studies are long since completed, the expectation that researchers can and will share such materials with others may run counter to commitments made in the informed consent process that may appear to prohibit the sharing of certain data. Moving forward, behavioral scientists working in diabetes should prepare to meet increased obligations to design and implement their research studies openly and transparently.

In my opinion, early behavioral research on diabetes was designed, conducted, and disseminated largely for the benefit of other behavioral scientists. It is time for the field to move beyond that perspective and toward a better understanding of how the accumulated evidence can now be brought to bear to improve the lives of people with diabetes and to minimize the adverse psychological impact of living with diabetes. The introspective stance that has characterized the field must now give way to research that penetrates clinical practice across the life span, normalizes the integration of medical and psychological care for people with diabetes, and demonstrates the conditions under which such services have favorable impact on clinical, financial, and patient-reported outcomes.

Relatively little behavioral research in diabetes to date could be classified as dissemination and implementation science (51). Such research includes rigorous economic analyses (51–53) of psychological screening, assessment, and intervention strategies; variables affecting the adequacy of communication of scientific methods and evidence base to clinical colleagues; and influences on the mobilization of stakeholder energy among patients, family members, parents, and clinicians to promote the dissemination of behavioral science research into clinical practice. Contributions in these directions will be necessary to move

this field to the next level, and early-career researchers should develop expertise in these critical methods.

### Diabetes and Behavior: What's Next?

There could not be a more exciting time to begin or nurture a career emphasizing the generation of behavioral science research in diabetes or its active dissemination into clinical practice for the benefit of people with diabetes everywhere. When I contemplate certain mega-trends that appear to be converging, I see a world of infinite possibilities and opportunities for behavioral scientists to make valuable contributions that can improve the lives of people with diabetes. Here are a few observations that support this optimism:

- Science is becoming increasingly collaborative and transparent, as manifest by the open science movement, growth in transdisciplinary research teams, multisite and international networks and collaborations, and data-sharing initiatives (49–51).
- There is likely to be continued growth of trends in clinical research that amplify the potential real-world relevance and value of that research, including stakeholder engagement in all phases of clinical care and research, shared medical decision-making, and patient- and family-centered care (54). Behavioral scientists are well-positioned to play a leading role in conducting research that embodies these developments.
- There are many potential applications of dissemination and implementation science in behavioral diabetes research, and this is the domain in which the most valuable contributions remain to be made.
- Technological advances in communication technology, glucose monitoring, insulin delivery, social media, and behavioral assessment may provide feasible, innovative

alternatives to self-reported measurement of study outcomes.

- There may be an increased role of simulation methods such as standardized patients, virtual reality, and avatar-based computerized training (55).
- Continued advances in quantitative methods that permit sophisticated analyses of complex multivariate and longitudinal relationships could enable researchers to pose more nuanced research questions and put forth more complex hypotheses (56). Rather than simple tests of aggregated effects of a specific behavioral intervention, researchers should be better prepared to put forth and evaluate questions such as, “Under what conditions does this intervention yield its most robust effects on the primary outcome?” and “What baseline characteristics differentiate people who derive clinically meaningful benefit from this intervention from those who do not?”

### What Makes Me Go “Hmmm . . .”?

Although the observations above may engender considerable optimism about behavioral science research in diabetes and its application to improve the lives of people with diabetes everywhere, some perplexing observations and questions remain.

- How can we more effectively mobilize patients, families, and other stakeholders to demand access to evidence-based mental health services?
- How can evidence derived from studies employing self-reported, subjective, recall-based measures influence policy and financing decisions in medical settings in which quantifiable, objective evidence is at a premium?
- What kind of evidence will convince administrators, insurers, and purchasers of health care coverage that meaningful integration of mental health services into diabetes care makes good sense from



financial, medical, and societal perspectives?

- Optimal delivery of evidence-based psychological and behavioral assessment and intervention services for diabetes patients typically requires time, expertise, and frequent contact, all of which are in short supply. Are there more creative financing strategies that could support the routine integration of those services into care for all people with diabetes? What sources of waste can be identified and eliminated and what efficiencies can be exploited?
- How can new diabetes technologies be introduced and disseminated in ways that reduce, rather than exacerbate, disparities in health care outcomes along racial, ethnic, socioeconomic, and health literacy dimensions?
- What messages to patients, families, and other health care providers will reduce the stigma associated with seeking, obtaining, and maintaining mental health services to promote healthy coping with diabetes?

A large segment of the population harbors considerable distrust of science and other “fact-based” professions and institutions, tending to view with suspicion any expression of expert opinion based on expertise and methods that are difficult for nonexperts to comprehend (57). These attitudes may well impede recruitment of study participants, fulfillment of research commitments among those who do enroll, retention of participants, translation of research findings into clinical practice, and the influence of research on health care policy. Current “self-policing” trends such as training investigators in the responsible conduct of research, the emergence of open science and data sharing, and the inclusion of stakeholders in all aspects of research from conceptualization through dissemination certainly can play constructive roles, but these may do more to con-

vince scientists of the credibility of one another’s work than to influence public opinion, policy decisions, and health care practice. Perhaps all scientists (and friends of science) share a responsibility to apply their energy and creativity to countering the anti-scientific perspective that stands to impede societal benefits from their valuable research.

### Duality of Interest

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

### References

1. Rubin RR. Diabetes: a personal history. *Diabetes Spectr* 2008;21:54–56
2. Peyrot M, Richard R, Rubin, PhD: an ambassador for behavioral science in diabetes. *Diabetes Care* 2017;40:435–439
3. American Diabetes Association. Richard R. Rubin, PhD, CDE: President, Health Care and Education. Posted 28 June 2013. Available from [www.youtube.com/watch?v=bC\\_CJ-DZE\\_U](http://www.youtube.com/watch?v=bC_CJ-DZE_U). Accessed 5 May 2018
4. Peyrot M, McMurry JF Jr, Kruger DF. A biopsychosocial model of glycemic control in diabetes: stress, coping and regimen adherence. *J Health Soc Behav* 1999;40:141–158
5. Lin A, Northam EA, Rankins D, Werther GA, Cameron FJ. Neuropsychological profiles of young people with type 1 diabetes 12 yr after disease onset. *Pediatr Diabetes* 2010;11:235–243
6. Tonoli C, Heyman E, Roelands B, et al. Type 1 diabetes-associated cognitive decline: a meta-analysis and update of the current literature. *J Diabetes* 2014;6:499–513
7. Hilliard ME, Wu YP, Rausch J, Dolan LM, Hood KK. Predictors of deteriorations in diabetes management and control in adolescents with type 1 diabetes. *Adolesc Health* 2013;52:28–34
8. Fisher L, Hessler D, Polonsky W, Strycker L, Masharani U, Peters A. Diabetes distress in adults with type 1 diabetes: prevalence, incidence and change over time. *J Diabetes Complications* 2016;30:1123–1128
9. Lawrence JM, Standiford DA, Loots B, et al. Prevalence and correlates of depressed mood among youth with diabetes: the SEARCH for Diabetes in Youth study. *Pediatrics* 2006;117:1348–13458
10. Herzer M, Hood KK. Anxiety symptoms in adolescents with type 1 diabetes: association with blood glucose monitoring and glycemic control. *J Pediatr Psychol* 2010;35:415–425
11. Iturralde E, Weissberg-Benchell J, Hood KK. Avoidant coping and diabetes-related distress: pathways to adolescents’ type 1 diabetes outcomes. *Health Psychol* 2017;36:236–244
12. Wysocki T, Taylor A, Hough BS, Linscheid TR, Yeates KO, Naglieri JA. Deviation from developmentally appropriate self-care autonomy: association with diabetes outcomes. *Diabetes Care* 1996;19:119–125
13. Northam EA, Lin A, Finch S, Werther GA, Cameron FJ. Psychosocial well-being and functional outcomes in youth with type 1 diabetes 12 years after disease onset. *Diabetes Care* 2010;33:1430–1437
14. Wysocki T, Nansel TR, Holmbeck GN, et al. Collaborative involvement of primary and secondary caregivers: associations with youths’ diabetes outcomes. *J Pediatr Psychol* 2009;34:869–881
15. Young V, Eiser C, Johnson B, et al. Eating problems in adolescents with type 1 diabetes: a systematic review with meta-analysis. *Diabet Med* 2013;30:189–198
16. Varni JW, Burwinkle TM, Jacobs JR, Gottschalk M, Kaufman F, Jones KL. The PedsQL™ in type 1 and type 2 diabetes: reliability and validity of the Pediatric Quality of Life Inventory™ generic core scales and type 1 diabetes module. *Diabetes Care* 2003;26:631–637
17. La Greca AM, Bearman KJ. The Diabetes Social Support Questionnaire–Family Version: evaluating adolescents’ diabetes-specific support from family members. *J Pediatr Psychol* 2002;27:665–676
18. Schwartz DD, Cline VD, Axelrad ME, Anderson BJ. Feasibility, acceptability, and predictive validity of a psychosocial screening program for children and youth newly diagnosed with type 1 diabetes. *Diabetes Care* 2011;34:326–331
19. Coroathers SD, Kichler J, Jones NHY, et al. Quality report: improving depression screening for adolescents with type 1 diabetes. *Pediatrics* 2013;132:e1395–e1402
20. Hilliard ME, Herzer M, Dolan LM, Hood KK. Psychological screening in adolescents with type 1 diabetes predicts outcomes one year later. *Diabetes Res Clin Pract* 2011;94:39–44
21. Bryden KS, Peveler RC, Stein A, Neil A, Mayou RA, Dunger DB. Clinical and psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. *Diabetes Care* 2001;24:1536–1540
22. Hood KK, Huestis S, Maher A, Butler D, Volkening L, Laffel LMB. Depressive symptoms in children and adolescents with type 1 diabetes: association with diabetes-specific characteristics. *Diabetes Care* 2006;29:1389–1391
23. Kovacs M, Feinberg TL, Paulauskas S, Finkelstein R, Pollock M, Crouse-Novak M. Initial coping responses and psychosocial characteristics of children with insulin-dependent diabetes mellitus. *J Pediatr* 1985;106:827–834

24. Northam EA, Anderson PJ, Werther GA, Warne GL, Adler RG, Andrewes D. Neuropsychological complications of IDDM in children 2 years after disease onset. *Diabetes Care* 1998;21:379–384
25. Rohan JM, Rausch JR, Pendley JS, et al. Identification and prediction of group-based glycemic control trajectories during the transition to adolescence. *Health Psychol* 2014;33:1143–1152
26. Hilliard ME, Wu YP, Rausch J, Dolan LM, Hood KK. Predictors of deterioration in diabetes management and control in adolescents with type 1 diabetes. *J Adolesc Health* 2013;52:28–34
27. Helgeson VS, Vaughn AK, Seltman H, Orchard T, Libman I, Becker D. Trajectories of glycemic control over adolescence and emerging adulthood: an 11-year longitudinal study of youth with type 1 diabetes. *J Pediatr Psychol* 2017;43:8–18
28. Barnard K, Thomas S, Royle P, Noyes K, Waugh N. Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review. *BMC Pediatr* 2010;10:50
29. Grey M, Boland EA, Davidson M, Li J, Tamborlane WV. Coping skills training for youth with diabetes mellitus has long-lasting effects on metabolic control and quality of life. *J Pediatr* 2000;137:107–113
30. Grey M, Jaser SS, Whittlemore R, Jeon S, Lindemann E. Coping skills training for parents of children with type 1 diabetes: 12-month outcomes. *Nurs Res* 2011;60:173–181
31. Wysocki T, Harris MA, Buckloh LM, et al. Effects of behavioral family systems therapy for diabetes on adolescents' family relationships, treatment adherence, and metabolic control. *J Pediatr Psychol* 2006;31:928–938
32. Ellis DA, Frey MA, Naar-King S, Templin T, Cunningham P, Cakan N. Use of multisystemic therapy to improve regimen adherence among adolescents with type 1 diabetes in chronic poor metabolic control: a randomized controlled trial. *Diabetes Care* 2005;28:1604–1610
33. Mulvaney SA, Rothman RL, Osborn CY, Lybarger C, Dietrich MS, Wallston KA. Self-management problem solving for adolescents with type 1 diabetes: intervention processes associated with an Internet program. *Patient Educ Couns* 2011;85:140–142
34. Holmes CS, Chen R, Mackey E, Grey M, Streisand R. Randomized clinical trial of clinic-integrated, low-intensity treatment to prevent deterioration of disease care in adolescents with type 1 diabetes. *Diabetes Care* 2014;37:1535–1543
35. Whittlemore R, Jaser SS, Jeon S, et al. An Internet coping skills training program for youth with type 1 diabetes: six-month outcomes. *Nurs Res* 2012;61:395–404
36. Hood KK, Iturralde E, Rausch J, Weissberg-Benchell J. Preventing diabetes distress in adolescents with type 1 diabetes: results 1 year after participation in the STePS program. *Diabetes Care* 2018;41:1623–1630
37. Fisher L, Hessler D, Polonsky WH, et al. T1-REDEEM: a randomized controlled trial to reduce diabetes distress among adults with type 1 diabetes. *Diabetes Care* 2018;41:1862–1869
38. Trief PM, Fisher L, Sandberg J, et al. Health and psychosocial outcomes of a telephonic couples behavior change intervention in patients with poorly controlled type 2 diabetes: a randomized clinical trial. *Diabetes Care* 2016;39:2165–2173
39. Health Quality Ontario. Behavioural interventions for type 2 diabetes: an evidence-based analysis. *Ont Health Technol Assess Ser* 2009;9:1–45
40. American Diabetes Association. Mental health provider diabetes education program. Available from [professional.diabetes.org/meeting/other/mental-health-provider-diabetes-education-program](http://professional.diabetes.org/meeting/other/mental-health-provider-diabetes-education-program). Accessed 14 September 2018
41. American Diabetes Association. Mental health provider directory. Available from [professional.diabetes.org/mhp\\_listing](http://professional.diabetes.org/mhp_listing). Accessed 14 September 2018
42. American Diabetes Association. 6. Glycemic targets: *Standards of Medical Care in Diabetes—2018*. *Diabetes Care* 2018;41(Suppl. 1):S55–S64
43. Young-Hyman D, de Groot M, Hill-Briggs F, Gonzalez JS, Hood K, Peyrot M. Psychosocial care for people with diabetes: a position statement of the American Diabetes Association. *Diabetes Care* 2016;39:2126–2140
44. Delamater AM, de Wit M, McDarby V, et al. ISPAD clinical practice consensus guidelines: psychological care of children and adolescents with type 1 diabetes. Available from [www.ispad.org/forums/Posts.aspx?topic=1431341](http://www.ispad.org/forums/Posts.aspx?topic=1431341). Accessed 14 September 2018
45. Chiang JL, Maahs DM, Garvey KC, et al. Type 1 diabetes in children and adolescents: a position statement by the American Diabetes Association. *Diabetes Care* 2018;41:2026–2044
46. Beck J, Greenwood DA, Blanton L, et al., on behalf of the 2017 Standards Revision Task Force. 2017 national standards for diabetes self-management education and support. *Diabetes Care* 2017;40:1409–1419
47. National Certification Board for Diabetes Educators. 2018 certification examination for diabetes educators. Available from [www.ncbde.org/assets/1/7/Handbook\\_Current.pdf](http://www.ncbde.org/assets/1/7/Handbook_Current.pdf). Accessed 14 September 2018
48. Grades of Recommendation, Assessment, Development, and Evaluation (GRADE) Working Group. Grading quality of evidence and strength of recommendations. *BMJ* 2004;328:1490–1494
49. National Institutes of Health. NIH data sharing policy and implementation guidance. Available from [grants.nih.gov/grants/policy/data\\_sharing/data\\_sharing\\_guidance.htm](http://grants.nih.gov/grants/policy/data_sharing/data_sharing_guidance.htm). Accessed 14 September 2018
50. Weissgerber TL, Garovic VD, Sinham SJ, Milic NM, Prager EM. Transparent reporting for reproducible science. *J Neurosci Res* 2016;94:859–864
51. Glasgow RE, Vinson C, Chambers D, Khoury MJ, Kaplan RM, Hunter C. National Institutes of Health approaches to dissemination and implementation science: current and future directions. *Am J Public Health* 2012;102:1274–1281
52. Jeeva F, Dickens C, Coventry P, Bundy C, Davies L. Is treatment of depression cost-effective in people with diabetes? A systematic review of the economic evidence. *Int J Technol Assess Health Care* 2013;29:384–391
53. Herman WH, Hoerger TJ, Brandle M, et al., for the DPP Research Group. The cost-effectiveness of lifestyle modification or metformin in preventing type 2 diabetes in adults with impaired glucose tolerance. *Ann Intern Med* 2005;142:323–332
54. Institute of Medicine. *Patients Charting the Course: Citizen Engagement and the Learning Health System*. Washington, D.C., National Academies Press, 2011
55. Rizzo S, Koenig ST, Talbot T. Clinical virtual reality: emerging opportunities for psychiatry. *Focus* 2018;16:266–278
56. Wickrama K, Lee TK, O'Neal CW, Lorenz FO. *Higher-Order Growth Curves and Mixture Modeling with Mplus: A Practical Guide*. New York, N.Y., Routledge, 2016
57. Funk C. Real numbers: mixed messages about public trust in science. *Issues in Science and Technology* 2017;34. Available from [issues.org/34-1/real-numbers-mixed-messages-about-public-trust-in-science](http://issues.org/34-1/real-numbers-mixed-messages-about-public-trust-in-science). Accessed 14 September 2018