

Behavioral Health and Psychology

Vision

Build resilience and foster strengths, reduce the psychosocial challenges, and engender optimism to manage the chronic condition throughout the lifespan with type 1 diabetes (T1D), and ultimately improve overall health outcomes.

Mission

Create a sustainable Behavioral Health / Psychology program within JDRF that informs science, trains health professionals, increases access to psychosocial services, and educates the diabetes community.

Rationale

The challenges of living with T1D are complex, vast and individualistic. From diagnosis and therapy confusion to emotional and physical burden, many challenges exist that can be addressed in the psychosocial plain. By approaching the unique issues related to a life-long journey and challenging the norms of care delivery to include consideration of emotional and psychological factors, we will improve lives and diabetes outcomes.

Included in the American Diabetes Association (ADA) Standards of Care, psychological care in diabetes has long been recognized as beneficial, but practice has not kept step with the recommendations. The following are key conclusions and opportunities outlined in the 2016 ADA and American Psychological Association (APA) Position Statements on Psychology and Diabetes:

- “Collaborative care shows the most promise for supporting physical and behavioral health outcomes.”
- “There is a need for more psychologists with diabetes training to meet the growing care needs. Psychologists also have an important role to play in research...”
- “The integration of screening into clinical settings, with appropriate referrals to qualified mental health professionals for reasons noted, can improve outcomes.
- “Challenges...include too few qualified mental health professionals who understand living with diabetes... “
- “The integration of psychosocial care and ensuring access to services will benefit the PWD and the care team.”

JDRF recognizes the benefit of psychological intervention and the need for further research, increased community education, support of professional training and education, increased access to psychosocial services, and improved collaboration across the diabetes spectrum. The establishment of Behavioral Health / Psychology as a category within the research portfolio exemplifies our recognition of the challenges and our commitment to a total health approach in diabetes, including the development of effective interventions that can be disseminated into the diabetes community. The diabetes literature also illustrates this value convincingly.

JDRF's approach will be focused in 3 general areas: HCP Training and Education, Research, and Community Intervention. This triple thread weaves in the value of the patient voice and the needs of the HCP community in complex health delivery settings. Research will aid in gathering the specific data to further and to support initiatives that hold promise for improving access to clinical psychology services, individual and family adjustment, overall well-being, transition of care, reduction of burden, and much more.

The value of investment in behavioral health / psychological care has been demonstrated by the Cystic Fibrosis Foundation (CFF) and their multi-year, multi-prong approach to understanding psychological issues, creating mechanisms for assessing patient challenges and progress, investing in infrastructure and evaluating outcomes. Initial CF research showed symptoms of depression in 10% of adolescents with CF, 19% of adults with CF, and over 30% of parent caregivers; the prevalence of symptoms of anxiety was even higher (Quittner et al., 2014). Elevated levels of anxiety or depression in people with CF are associated with worse health-related quality of life, more engagement in risky behaviors (misuse of alcohol and other substances), higher rates of missed appointments, and increased health care costs. Individuals with CF reporting elevated symptoms of depression in the TIDES landmark CF study had significantly increased mortality at 5 years following screening: 14.4% vs. 8.7% in those without depression (McColley et al., 2017 and Schechter et al.).

Following the collection of research data, the Cystic Fibrosis Foundation invested in psychological care at 138 centers. The 3 year grants to the 138 centers included an expectation of a sustainability plan at the end of the grant term. The end result has been the development of a robust collaborative care model (Quittner et al., 2015).

This example could be considered in the framework of Type 1 diabetes. It is a shining example of the benefit of investment in behavioral health / psychology and why JDRF should further consider engagement.

Strategy

Over the last five years, JDRF has conducted 3 national meetings on Psychology and Diabetes. Each meeting yielded compelling results. The meetings followed an iterative process of identifying gaps, recommending interventions and identifying broad opportunities for JDRF to consider that would advance psychosocial science in the diabetes community.

Below are the gaps identified and recommendations offered from the collective 2013-2018 sessions:

- **Research Integration**
 - Invest in research that is compelling and communicates the value proposition of behavioral health to multiple stakeholders such as decreasing overall healthcare costs, building resilience, preventing psychological issues (ex: distress, depression, anxiety, and suicide), improving glycemic and other outcomes
 - Incorporation of psychosocial markers in ongoing and prospective clinical observational and interventional studies in the JDRF research programs, such as but not limited to understanding barriers to adoption of therapeutics, patient preferences and choices for treatments, rate limiting factors impeding adherence, Patient Reported Outcomes (PRO) and Quality of Life (QOL) assessments
- **Healthcare Professional Training and Engagement**
 - HCP training in diagnosis and treatment of psychosocial issues
 - Create broader access to effective programs/interventions
 - Promote HCP reimbursement for diagnosis and treatment of psychosocial issues
- **Community Interventions**
 - Create a directory of resources for healthcare providers, patients, and families
 - Evaluate cost effectiveness research on interventions to inform health policy

Current diabetes psychology literature illustrates these needs well. It is clear that evidence-based behavioral interventions promote diabetes management in individuals with T1D and their families, yet so many still struggle. Part of the reason for the struggle is the lack of trained psychology professionals available in medical clinics (Hilliard, 2016). Our partner national organizations have called for improvement, JDRF's presence in this debate is critical. In addition, it is clear from the literature that more needs to be done related to the intersection of psychology with life stage planning, transitions and specific interventions (Weissberg-Benchell, 2017). Finally, the literature indicates that with specific psychosocial intervention, remarkable life and specific financial savings can be realized in the most at-risk youth with T1D. Psychosocial interventions like the Novel Interventions in Child Health (NICH) program in Oregon that aim to resolve challenges beyond A1c are necessary and effective (Wagner et al., 2017).

JDRF Psychology Program Objectives:

- **Support research initiatives** related to psychosocial factors in Type 1 diabetes that promote optimal health outcomes by preventing poor psychosocial functioning
- **Train health care professionals** in psychology related constructs within the Type 1 diabetes field to improve education of and patient access to qualified health professionals.
- **Support health care professional education** opportunities related to psychosocial factors associated with Type 1 diabetes care to improve adherence to standards of care recommendations.
- **Educate individuals and families** about the psychosocial impact of living with Type 1 diabetes to improve family functioning, reduce adverse events, teach resilience, and improve overall diabetes outcomes.

Critical Gaps

1. Interventions

We don't have empirically supported interventions that addresses the population health need related to psychosocial factors in diabetes. Economic / value-based research is a potential solution, as it provides evidence of value of psychology.

- Bend the cost curve with innovative care delivery for the most fragile
- Establish evidence for need

2. Access

We have significant barriers in access to psychological care. Telehealth is a potential solution.

- Issues related to access to facilities
- Issues related to access to providers – there are not enough providers
- Reduction in medical costs of care delivery

3. Health Care Professional Training

There are not enough psychologists / behaviorists trained in diabetes care. Funding training initiatives is a potential solution.

- There are no other diabetes psychology fellowship training programs
- The only complimentary program is a 12-hour CE offered by ADA for any mental health professional
- Health systems struggle with funding positions for psychologists in diabetes

4. Exposure

There is a need for broader exposure of psychology in diabetes. Enhancing the profile of psychology is a potential solution.

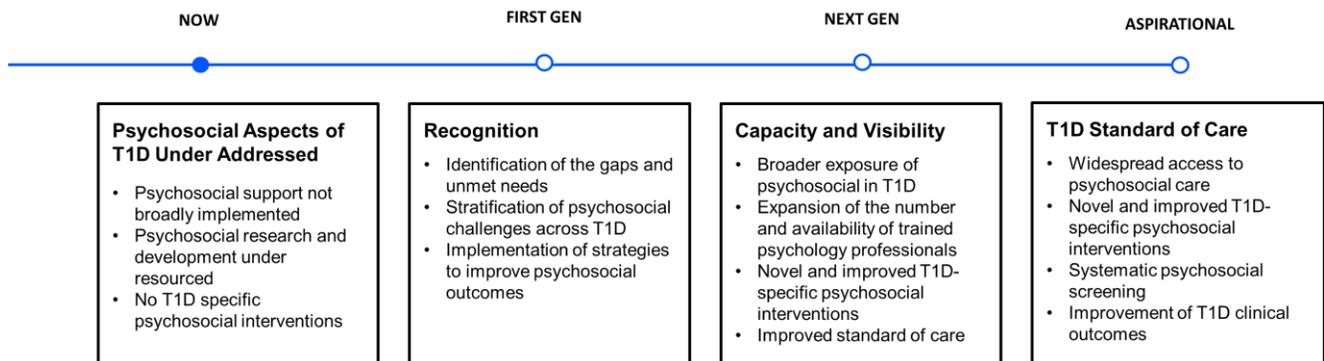
- Few multi-year initiatives are funded in diabetes psychology
- Few research projects and interventions are funded by NIH
- NIH does not fund pilot interventions
- Our peer organizations are also interested in this topic, but lack the scientific rigor of JDRF

5. Networking

There is a need for networking improvement amongst psychology professionals and traditional health professionals.

- The ADA diabetes standards of care identify clear pathways and recommendations, yet few health professionals are following the guidelines.
- Identifying a way to incentivize compliance with the established standards is a potential solution.

Roadmap



Additional Gaps for the Future

Future opportunities in the psychosocial arena include the following broad concepts:

Psychosocial Screening Tool Intervention / Standard of Care Development

Consider an initiative to implement systematic psychosocial screening during diabetes care visits. This screening may include measures such as depression, diabetes distress, resilience, quality of life and social support. Accompanying the measures would be a “script” for professionals to offer guidance about appropriate action.

The specific project could utilize technology in clinics. The results would be delivered to the health professional before the visit and would prompt the health professional to ask certain questions based on the screening results. The health professional would then be prompted to refer the patients in need to local mental health professionals with diabetes knowledge and provide information on evidence-based interventions for the identified psychosocial concerns (ADA Directory).

CDE Training Program (Certification) on Psychosocial Factors and Behavioral Health

This is similar in concept to the ADA training program for mental health providers, but shorter and targeted to a different audience. This would allow CDE's to acquire advanced training on psychosocial screening practices, identification and assessment of psychological disorders or challenges, and referral practices. This project would be done in collaboration with organizational partners.

Transition Care Delivery and Standardization

Engage with psychologists to create two standard programs (for HCPs and for the community) on healthy adolescent transitions in diabetes and distribute the program nationally to health care professionals and institutions. Advocate for formal inclusion of the program in Standards of Care.

National Behavioral Health Services Catalogue

Presently there is no authoritative resource that outlines the “who, where and what” related to mental health and psychological care in diabetes. We could create such a catalogue that indicates the type of care offered at diabetes care delivery destinations. Presently, we know that the ADA standards of care on psychology are not being met, but there is no national data. (Preliminary research published in 2018 by Nicole Johnson and JDRF Psychology Fellow Samantha Barry.)

Health Care Professional Education and Recognition

Award program for HCPs who display exceptional practice of medical management of diabetes and psychosocial care. These awards could be given regionally and then the regional winners be considered for a national award given at a large JDRF event. This is a great opportunity for the chapters to engage with psychology professionals in localities and for JDRF national to identify leaders to speak at our national marquee events. The aim is to normalize psychological care in diabetes settings. (Those not doing it would be the ones who are different.)

Psychosocial Standardization in Population Screening

Explore ways to increase and standardize psychosocial consideration in population screening projects. Review evidence of past large screening campaigns and determine best practice standards for future projects.

Collaboration with Complications Portfolio

There are many natural connections between the psychosocial and complications portfolios. There should be a collaborative relationship between the JDRF teams managing both portfolios to identify ways to increase overall effectiveness and impact.

Regulatory / Policy

Psychosocial issues have a natural tie with our advocacy and regulatory departments. As programs and products are developed many will require engagement with the patient, provider and payer communities. The Psychology/ Behavioral Health program will have a strong tie with JDRF Advocacy in order to keep the teams informed of research progress and opportunities to engage. On the horizon, the NICHD program will have the most immediate need in this area. The program has a proven track record of Medicaid cost reduction and is in negotiations with state governing bodies to explore statewide implementation. JDRF Advocacy can play a role in socializing the emerging research evidence with the broader payer community to further bolster the program and the potential for broader implementation. In addition to this specific project, on a broader level there will be significant opportunities and need for engagement with the patient community in creating and validating T1D age and stage specific PROs, for eventual discussion with the FDA and other regulators. NIH and the FDA have begun thinking about this topic, but have yet to formalize policy or process. Opportunities abound for JDRF and JDRF's influence in this area.

References

- Harris M. A. (2018). Your Exclusion, My Inclusion: Reflections on a Career Working With the Most Challenging and Vulnerable in Diabetes. *Diabetes spectrum : a publication of the American Diabetes Association*, 31(1), 113–118. doi:10.2337/ds17-0080
- Hilliard, M. E., Powell, P. W., & Anderson, B. J. (2016). Evidence-based behavioral interventions to promote diabetes management in children, adolescents, and families. *The American psychologist*, 71(7), 590–601. doi:10.1037/a0040359
- Young-Hyman, D., de Groot, M., Hill-Briggs, F., Gonzalez, J. S., Hood, K., & Peyrot, M. (2016). Psychosocial Care for People With Diabetes: A Position Statement of the American Diabetes Association. *Diabetes care*, 39(12), 2126–2140. doi:10.2337/dc16-2053
- McColley SA, Schechter MS, Morgan WJ, Pasta DJ, Craib ML, Konstan MW. (2017). Risk factors for mortality before age 18 years in cystic fibrosis. *Pediatr Pulmonol*. 2017 Jul;52(7):909-915. doi: 10.1002/ppul.23715. Epub 2017 Apr 24.
- Quittner, A.L., Goldbeck, L., Abbott, J. et al. (2014). Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study across nine countries. *Thorax* published online September 21, 2014 doi: 10.1136/thoraxjnl-2014-205983
- Quittner AL, Abbott J, Georgiopoulos AM, et al. (2015). International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety. *Thorax* Published Online doi:10.1136/thoraxjnl-2015-207488
- Schechter et al. *Pediatric Pulmonology* 52 Suppl 47: 404-5
- Weissberg-Benchell and Shapiro. (2017). A Review of Interventions Aimed at Successful Transition Planning and Transfer to Adult Care Among Youth with Chronic Illness. *Pediatric Annals*.
- Wagner, D. V., Barry, S. A., Stoeckel, M., Teplitsky, L., & Harris, M. A. (2017). NICHD at Its Best for Diabetes at Its Worst: Texting Teens and Their Caregivers for Better Outcomes. *Journal of diabetes science and technology*, 11(3), 468–475. doi:10.1177/1932296817695337

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