Published in final edited form as:

Curr Diabetes Rev. 2015 ; 11(4): 208–209.

Editorial: Contemporary Faces of Diabetes Care for Youth and Young Adults in the 21st Century: Evolution in the Roles of Patients and Families, Healthcare Providers and Systems, Behavioral Health, and the Online Community

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“The chief business of a chronically ill person is not just to stay alive or keep symptoms under control, but to live as normally as possible despite symptoms and disease” [1]. Forty years after Glaser and Strauss first published these words, the essence of their message remains true: successful management of a chronic condition such as diabetes must focus on not only disease control but also – and perhaps more importantly – on supporting individuals and families to live happy, healthy, satisfying lives with diabetes. Since the start of the 21st century, changes in type 1 diabetes technologies and treatments have been rapid, yet progress toward a curative therapy has been frustratingly slow [2–3]. Diabetes care priorities have thus shifted toward patient-centered, behavioral approaches to living successfully with diabetes. Contemporary pediatric and young adult diabetes care increasingly recognizes the important roles of many team members toward achieving this goal: patients and families, medical providers, behavioral health providers, the healthcare system, and the growing diabetes online community. Indeed, the most recently published guidelines for diabetes care from the American Diabetes Association (ADA) [4] emphasize the important roles of numerous team members, including a highlight on behavioral care for people living with diabetes and their families. National experts in comprehensive diabetes care recently convened a conference, the goal of which was to organize professional, research, and practice efforts around systematically identifying and treating behavioral and mental health issues related to diabetes management [5–6]. Together, these actions represent a strengthening movement toward understanding our patients as individuals and families living with diabetes and providing care that equally prioritizes medical treatment and quality of life.

This goal of this thematic issue of *Current Diabetes Reviews* is to provide contemporary reviews on central aspects of today’s approach to diabetes management, with a focus on youth and families living with type 1 diabetes. Each of the six papers in this issue reviews recent literature related to the experiences of people with diabetes and their care providers and outlines practical applications to promote optimal health and well-being in diabetes. The authors are recognized leaders in their respective fields of clinical care, research, or

advocacy and contribute their expertise across numerous disciplines including behavioral science, clinical psychology, and endocrinology/medicine practice, as well as patient and family perspectives.

The first two papers in the special issue describe complementary components of clinical care for youth and young adults with type 1 diabetes: behavioral and medical care provision. First, Kichler and colleagues outline the numerous roles that pediatric psychologists and behavioral health specialists occupy in the care of people with diabetes from diagnosis until the transfer to adult care. In contrast to a traditional view of psychology filling a narrow role of treating youth with diabetes and emotional or behavioral disorders, the authors highlight a broad range of contributions by psychologists: prevention and well-being promotion, screening and treatment for significant psychosocial distress, program development, research, and advocacy. They also discuss the provision of psychological care across various care formats (e.g., individual, family, group) and settings (e.g., academic medical centers, inpatient and outpatient clinics, private practice, community organizations), with special attention to practical aspects of billing and integrated care approaches. Next, Powell and colleagues describe recent advances in patient-centered medical care for diabetes, with a highlight on communication strategies for providers to empower their patients related to health behavior change: shared decision-making and motivational interviewing. The authors also describe care delivery innovations, including providing patient care in shared medical appointments with a multidisciplinary team. Finally, this paper acknowledges the important aspects of diabetes care that occur outside of the medical setting and discusses how diabetes technologies, school health providers, and economic issues factor into clinical care. Together these two papers provide an updated view of the healthcare system issues that influence professional care of youth and young adults with diabetes and their families and offer practical strategies for success in today's healthcare climate.

The next two papers synthesize recent research surrounding developmentally relevant aspects of living with and managing type 1 diabetes across the pediatric and young adult age range. Markowitz and colleagues present a framework of shifting parent and youth roles and responsibilities in diabetes management from early childhood through late adolescence. The authors review general developmental milestones, illustrate how developmental shifts impact diabetes management, and review recent evidence for behavioral diabetes intervention strategies targeting the key developmental issues across each age range. With a focus on family teamwork and adherence, this paper highlights the collaboration and coordination needed for youth and families to successfully manage type 1 diabetes in the context of normative growth and development. Next, Monaghan and colleagues delve deep into the uniquely challenging period of transitioning from adolescence to adulthood with diabetes. With their foundations in the theory of "emerging adulthood" [7], the authors summarize a rapidly growing literature about the numerous shifts that occur during this age range and illustrate the impact on diabetes management. In addition to reviewing T1D management issues related to normative transitions in education, employment, family, social and romantic relationships, health risk behaviors, and psychosocial functioning, this paper also provides an updated review of pediatric to adult diabetes care transitions as well as novel intervention strategies to engage young adults with diabetes in care. Together,

Markowitz *et al.* and Monaghan *et al.* comprehensively review the key developmental and behavioral issues that influence and are influenced by life with type 1 diabetes across the pediatric and young adult population, with concrete implications for intervention and clinical support.

The final two papers in the special issue address diabetes management issues on a broader scale. Naranjo and colleagues present a model of the numerous contributors to disparities in diabetes care and outcomes. The authors review recent research about the individual, family, and healthcare system factors that place racial/ethnic minority youth and families at substantially elevated risk for poor diabetes outcomes. As with the other papers in this special issue, this paper focuses on interventions with a synthesis of recent findings on practical strategies to support the most vulnerable patients and families. Finally, Hilliard and colleagues shed light on an increasingly present force in many people's life with diabetes: the diabetes online community (DOC). The authors present the history of diabetes online, outline various potential benefits and risks of accessing diabetes resources online, and make recommendations for individuals, families, healthcare providers, and the diabetes healthcare industry to maximize the benefits of DOC participation. Quotes from DOC contributors illustrate each of these topics.

In sum, the following pages cover a great deal of information covering many aspects of living with diabetes in the 21st century. Our goal in compiling these reviews is to update readers about the key clinical, behavioral, developmental, and personal issues in contemporary life with diabetes in order to inform and enhance clinical research and practice. Perhaps beyond even Straus and Glaser's words, we believe that recent and ongoing advances in diabetes research and care can support people with diabetes in not only living as *normally* as possible *despite diabetes*, but in living as *well and fully* as possible, *with* diabetes.

ACKNOWLEDGEMENTS

Dr. Hilliard and Dr. Anderson's work on this thematic issue was supported by the National Institutes of Diabetes and Digestive and Kidney Diseases (1K12 DK097696, PI: B. Anderson).

Biographies

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