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Stressors in Teens with Type 1 Diabetes and Their Parents: Immediate and Long-Term Implications for Transition to Self-Management

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Purpose: Teens with Type 1 diabetes and their parents experience every day and illness-related stress; however, understanding of how these stressors relate to the transition to adulthood is limited. The purpose of this study was to identify stressors of teens with Type 1 diabetes (T1DM) and their parents related to the impending transition to adulthood.

Design and Methods: This study used open-ended questions to identify every day and illness-related stressors among 15 teens with T1DM and 25 parents seen in one pediatric diabetes clinic. Qualitative descriptive analysis identified themes in interview transcripts.

Results: The primary teen stressor related to impending transition centered on ineffective self-management, often when they were taking over responsibility for T1DM management. Parents' concerns included immediate and long-term negative outcomes of teen self-management as well as financial resources and health insurance for the teen. Teens and parents both expressed specific concerns about outcomes and prevention of nocturnal hypoglycemia, and identified uncertainties related to teen health and diabetes-focused health care when no longer living in the parent's home.

Conclusions: Teens with Type 1 diabetes and their parents understand that independent teen self-management is a component of transition to adulthood, but worry about teen self-management outcomes. Concerns specific to health care transition included health insurance, T1DM resources, and teens' abilities to handle new situations.

Practice Implications: Identifying current and future self-management concerns of individuals and families can facilitate targeted education and interventions to support successful transition to adulthood.

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NEARLY 75% OF Type 1 diabetes (T1DM) is diagnosed before age 18, highlighting the importance of lifelong pursuit of optimal physical and mental health (American Diabetes Association, 2015a). Successful medical management must be integrated into the broader context of everyday life. Starting at diagnosis, management plans should incorporate individual family dynamics, physical and emotional devel-

opment, and physiological differences, according to the *Standards of Medical Care for Diabetes* (American Diabetes Association, 2015b).

Developmental and life transitions, such as the transition to adulthood and taking responsibility for T1DM management, can affect achievement of optimal health (American Diabetes Association, 2015a). One critical transition shifts adolescents and emerging adults (AEAs; 18 to 30 years old) from pediatric to adult medical care. Despite established standards and protocols (American Diabetes Association,

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2015b; Betz, 2010; Sawyer & Ambresin, 2014), success rates vary, with nearly one-third of emerging adults not seen in an adult clinic a year after leaving pediatric care (Daneman & Nakhla, 2011; Hilliard, Harris, & Weissberg-Benchell, 2012). Those who transfer face difficulty with different approaches to care (Hilliard et al., 2012), and associated risk of poor metabolic control and acute complications (Peters, Laffel, & American Diabetes Association Transitions Working G., 2011; Rollo et al., 2014).

AEAs make multiple daily T1DM management decisions, a critical component of this transition. Appropriate, timely adoption of independent self-management and transfer to adult care are critical, occurring simultaneously with other major developmental changes in all areas of life (American Diabetes Association, 2015a; Daneman & Nakhla, 2011; Hamdani, Jetha, & Norman, 2011; Hilliard et al., 2012; Joly, 2015; Karlsson, Arman, & Wikblad, 2008; Peters et al., 2011). These changes can be stressful, with AEAs experiencing simultaneous shifts in disease management responsibility, health care, housing, geography, education and employment (Wang, McGrath, & Watts, 2010; Weissberg-Benchell, Wolpert, & Anderson, 2007). Diabetes-related and life stressors of teens with T1DM and their parents have immediate and long-term implications for developmental and health outcomes. These stressors influence T1DM self-management, achievement of glycemic control (Helgeson, Becker, Escobar, & Siminerio, 2012; Whittemore, Jaser, Chao, Jang, & Grey, 2012), and their biological and psychological effects (Halfon, Larson, Lu, Tullis, & Russ, 2014) increase risk of short- and long-term negative health outcomes.

Parental concern about AEAs' T1DM self-management and reluctance to discuss impending care transitions with teens (Hilliard et al., 2012) affects developmental and T1DM-related outcomes. Parents may limit college choices to ensure continued proximity or delay the AEA's move out of the family home (Arnett, 2000; Dubas & Petersen, 1996). Poor T1DM-related outcomes resulting from initial attempts at self-management may lead to a rapid shift back to parental management (Hamdani et al., 2011). AEAs with T1DM also worry about achieving independent self-management, particularly when parental support will be less readily available (Hilliard et al., 2012).

These difficulties occur even in the supportive and knowledgeable home environment. If not resolved they may be magnified during the transition to adulthood and adult based care, increasing the probability of transition failure and gaps in care (Daneman & Nakhla, 2011). In addition, few studies of strategies for successful transitions exist (Anderson & Wolpert, 2004; Hanna & Decker, 2010; Helgeson et al., 2012). A systematic review (Chu, Maslow, von Isenburg, & Chung, 2015) identified deficiencies in methods to evaluate transfer efficacy, including a lack of appropriate transfer metrics. Rather than planned gradual shifts to AEA self-management, more abrupt shifts may occur due to age, change in location, or clinic policy.

AEAs experience rapid changes in multiple aspects of life, which may generate additional stress, anxiety, and health risks. However, knowledge of parent and teen stressors in the context of T1DM, and their relationship to the transition to adulthood, is limited. A more comprehensive approach to transition would support better health outcomes. This holistic approach to transition, incorporating psychosocial, social network, and family factors, emphasizes the importance of integrating T1DM management into daily life (Betz, 2010; Betz, Nehring, & Lobo, 2015; Hamdani et al., 2011; Joly, 2015). This provides essential context for improving transfer to adult care, implementing appropriate interventions, and improving outcomes.

Achieving optimal mental and physical health throughout the life course requires identifying factors related to successful transition to adult-based T1DM care. Stress and anxiety directly affect the process and outcomes of transition. However, knowledge of stressors identified by teens with T1DM and their parents and their relationship to the transition to adulthood is limited. The purpose of this study was to identify stressors of AEA with T1DM and their parents relevant to the impending transition to adulthood.

Methods

Data were obtained using one-time semistructured telephone interviews with teens with Type 1 diabetes and their parents. Following ethical approval from the University of Iowa Institutional Review Board, participants provided written consent or assent.

Description of the sample and study procedures is in Table 1. Of 30 families who received information in clinic, 16 participated (one teen-only; one parents-only). Fifteen teens (12 to 18 years; four male) with Type 1 diabetes and 25 parents (15 mothers; 10 fathers) completed digitally-recorded telephone interviews with an experienced interviewer. Parent non-participation was most often due to separation or divorce. All participants self-identified as Caucasian, and 85% of parents were employed at least part time.

Open-ended questions identified everyday life and diabetes-related stressors (Table 2). The first three teens interviewed had difficulty interpreting "makes you anxious", so subsequent interviews used alternative wording of "stresses you out or worries you". Recordings were transcribed verbatim, verified, and deidentified. Transcribed text was uploaded into Atlas.ti (version 6) for analysis.

Qualitative descriptive analysis (Sandelowski, 2000) was used to describe parent and teen diabetes-related stressors with as little interpretation as possible. The first author read complete transcripts and identified topics discussed by parents and teens, generating the initial list of data codes. Codes identified stressors regarding moving from home to college and those related to health care transition. Transcripts were re-read and codes added for content not aligning with the initial list. An experienced second coder reviewed a random subset of transcripts to validate codes and ensure

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