



Family Perspectives of Components of a Diabetes Transition Program^{1,2,3}



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Purpose: To evaluate the perspectives of adolescent/parent dyads about a diabetes program on: (1) perception of knowledge, self-efficacy, importance of transition behaviors and ability to self-manage diabetes, (2) the congruency of knowledge and skills important for transition, (3) program specifics families determined helpful for transition, and (4) the relationship of adolescents' self-efficacy to self-management behaviors (SMB) and Hemoglobin A1C (HbA1C).

Methods: The individual and family self-management theory guided this prospective cross-sectional study. Sample included 45 dyads from a pediatric diabetes program. Dyads independently completed questionnaires related to knowledge, self-efficacy, the importance of specific diabetes knowledge and skills, and behaviors helpful for self-management and transition readiness. Analysis included frequencies, correlations, Cronbach's alpha, and paired t-tests.

Results: Knowledge was high and self-efficacy even higher in the dyads. However, they did not agree on behaviors important for transition such as, knowing what the HbA1C should be, accurately counting carbohydrates, how to check ketones, how alcohol and drugs affect diabetes, or consistent documentation of blood sugar, carbohydrates and insulin doses. Adolescents indicated talking with providers and program materials as helpful, but attending regular visits and talking with parents as most helpful for transition. Adolescent and parent assessment of adolescent self-efficacy and self-management behaviors were strongly correlated. Family dyad's perceptions of adolescent self-efficacy were similar but not related to HbA1C.

Conclusion: A diabetes transition program has the opportunity to impact an adolescent's ability to self-manage their chronic illness by increasing self-efficacy and recognizing the strengths of the parent, adolescent and provider in the transition process.

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TYPE 1 DIABETES mellitus (T1DM) is a life-altering chronic illness that is usually diagnosed during childhood. As children move through different developmental stages it is recommended that they increasingly assume primary responsibility for their diabetes care (Hanna, 2012). In addition, the adolescent with diabetes is expected to transition their care

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from a pediatric health care team to an adult health care team with 60% transferring between ages 16–18 years (Begley, 2013). This shift coincides with an expectation of an increased level of self-management, decreased oversight from the provider and less supervision from parents (Garvey, Markowitz, & Laffel, 2012; Peters, Laffel, & American Diabetes Association Transitions Working Group, 2011). Concurrently, during the developmental stage of adolescence there is a sense of invincibility, increased influence of peers, more risk-taking behaviors and general fatigue of dealing with diabetes (Borus & Laffel, 2010). The combination of these factors often leads to a notable deterioration in glycemic control for many youth (Peters et al., 2011; Rausch et al., 2012).

Adolescence is a stressful time as adolescents face changes in their lifestyles, peer and familial relationships and increasing independence (Fleming, Carter, & Gillibrand, 2002). Adding the need to find the time and motivation to successfully control their diabetes and prepare for transition to an adult health care team can be difficult (Fleming et al., 2002). Specific diabetes-related behaviors that adolescents may struggle with during these years include choosing appropriate nutrition, demonstrating adequate frequency in blood glucose monitoring, or not using their insulin appropriately for their food choices (Peters et al., 2011). Unfortunately, inability to take on independent diabetes self-management behaviors can lead to further complications such as poor glycemic control and loss to follow up care (Garvey, Markowitz et al., 2012). In a study conducted by Garvey et al. (2013) that examined health care transition experiences of young adults, 26% stated that they were not seen for > 6 months, and 6% waited > 12 months before they saw an adult provider after their last pediatric diabetes visit. Youth with T1DM ages 20–29 are four times more likely to die than their peers without diabetes (Rapley & Davidson, 2010).

Acknowledging that worsening glucose control can occur during this period places an increased level of responsibility of successfully preparing the adolescent to transition to independent care with adequate glycemic control. Factors that can influence the successful transition of the adolescent with diabetes have included the pediatric health care team (Bowen, Henske, & Potter, 2010; Peters et al., 2011), the use of transition classes or programs (Bowen et al., 2010; Peters et al., 2011), the adolescent's level of self-efficacy (Kaye, Rapley, Babel, & Brown, 2013; Stupiansky, Hanna, Slaven, Weaver, & Fortenberry, 2013) and the individual's family (Bowen et al., 2010; Jaser, 2011; Weissberg-Benchell, Wolpert, & Anderson, 2007). The position statement from the American Diabetes Association recommends that the pediatric health care team work with the adolescent and the family for a minimum of 1 year during the adolescent years prior to the transfer of care to the adult healthcare provider (Peters et al., 2011). Despite this recommendation over 60% of parents report that they had not discussed transition with their adolescents (ages 15–17) or with their current diabetes team despite anticipating the transfer to adult care between ages 17 and 19 years (Hilliard et al.,

2014). In centers with transition plans, 4% of respondents felt completely unprepared for transition while 7% stated they were mostly unprepared and 26% were neutral in how prepared they felt for transition (Garvey, Wolpert et al., 2012). In a review of multiple studies of adolescent transition outcomes, in pediatric centers without a formal transition process 20–25% failed to seek follow up care in the 2–4 years after leaving the pediatric practice (Daneman & Nakhla, 2011).

The term self-management has been used in multiple different contexts. For the purpose of this study, the concept of self-management will be based on the individual and family self-management theory (IFSMT) (Ryan & Sawin, 2009). Used within this paradigm, self-management combines the individual and family, but recognizes that the contribution of each shifts over time and each will assume different roles which fits well with the concept of transition (Ryan & Sawin, 2009). Using the IFSMT (Figure 1) in transitioning of care for diabetes, the ability to self-manage is based on contextual factors (complexity of diabetes, access to diabetes care and the developmental stage of the adolescent), process factors (self-efficacy, ability to self-regulate, factual information, goal congruence, self-monitoring and decision making), interventions and proximal outcomes (performing diabetes-related management behaviors) that leads to distal outcomes (health status, quality of life or cost of healthcare) (Ryan & Sawin, 2009). The IFSMT concepts evaluated in this study include the contextual factor—"complexity of T1DM and its treatment". The process factors explored are knowledge as well as the family and adolescent's perception of the adolescent's self-efficacy to successfully manage their diabetes. The intervention is the diabetes transition program. According to the theory, the intervention is aimed at both the context and process factors, and together they contribute to understanding of the proximal outcomes—the adolescent's performance of self-management behaviors. Each of these components of the theory then contribute to understanding the distal outcomes of improved health status, which is exemplified by the HbA1C (Figure 1).

Currently, in one midwestern children's hospital the standard recommendation is that patients are seen every 3–4 months by the interdisciplinary team that includes physicians, nurse practitioners, diabetes educators, and registered dietitians. Additional resources include a pediatric psychologist and social worker used on an as needed basis. This pediatric diabetes program includes 1826 patients, with 1659 diagnosed with T1DM. In this program, the preparation of the adolescent and family to transition care is addressed through multiple mechanisms including routine clinic visits, provision of a diabetes team-created educational binder, and optional transition classes.

The adolescent–adult transition program at this midwestern children's hospital was developed with the goal to provide anticipatory guidance and thereby prevent the declines in diabetes care and control that frequently occur during this transitional period. The program promotes adolescent involvement in

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