



Moving the Journey Towards Independence: Adolescents Transitioning to Successful Diabetes Self-Management¹



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Adolescent;
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Purpose To gain a greater understanding of adolescent's experiences living with Type 1 diabetes mellitus (T1DM) and create a theoretical paradigm.

Methods: Grounded theory as described by Glaser was used. Fifteen in-depth interviews were conducted with adolescent's ages 11–15 with T1DM. Symbolic interactionism is the theoretical framework for grounded theory. Data were collected; transcribed, coded, and analyzed simultaneously using constant comparative analysis and findings were grounded in the words of participants.

Results: A theoretical model was created with the concept of “normalizing”. Normalizing was defined as the ability to integrate diabetes into one's daily life to make diabetes ‘part of me’. Phase four of the model, and the focus of this manuscript was “Moving the Journey towards Independence” and included: 1) taking over care, 2) experiencing conflict with parents, and 3) realizing diabetes is hard. The major task for adolescents in this phase was separating from parents to independently manage diabetes. The normalizing task for this phase was: “taking on the burden of care”. Adolescents described challenges with independent care and increased parental conflict including: fearing needles, forgetting insulin, feeling embarrassed and believing that diabetes was a burden in their life. Additionally, juggling the multiple responsibilities of home, school and work along with managing a chronic illness during adolescence is challenging.

Conclusions: Transitioning to diabetes self-management is a challenge for adolescents. This model advances understanding of the moving processes in adolescents transitioning; additionally, hypotheses are presented that may be used for developing interventions to promote success in self-management.

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TRANSITIONING TO DIABETES self-management (DSM) is a challenging time for most adolescents (Ingerski, Anderson, Dolan, & Hood, 2010). Many adolescents take on increased independence in their diabetes management tasks as early as age 9–10 with the majority of care being done by the adolescent by age 11–13 (Dashiff, McCaleb, & Cull, 2006; Ingerski et al., 2010). As adolescents take on more of their own care, hemoglobin A1C (A1C) rises and blood

glucose self-monitoring decreases (Rausch et al., 2012; Ziegler et al., 2010) leading to increased risk for diabetic ketoacidosis (DKA) (Ziegler et al., 2010). Transition is difficult for both the parent and the adolescent and a greater understanding is needed to assist families during transition to DSM. While a number of research studies have been undertaken to address diabetes management with adolescents, none have focused on developing a paradigm from the perspective of the adolescent that help to predict, describe, and explain behaviors (Channon et al., 2007; de Wit et al., 2008; Lehmkuhl et al., 2010; Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010; Svoren, Butler, Levine, Anderson, & Laffel, 2003; Wysocki et al., 2007) as was

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the aim of this study. The purpose of this research project was to gain a greater understanding, of the adolescent's perspective, of their experiences in living with diabetes, and associated challenges and management issues they may face. Findings are of value to families and adolescents, nursing practice, as well as the advancement of nursing science in the understanding of adolescent management of diabetes.

Adolescents with Type 1 diabetes mellitus (T1DM) learn to self-manage their diabetes gradually starting in childhood. The first steps of DSM are often learning the tasks of blood glucose monitoring and giving insulin injections (Hanna & Decker, 2010). Diabetes self-management is very complex with over 600 tasks needed to manage diabetes effectively (Coffen, 2009) and include not only the physical tasks needed for glycemic control, but emotional adjustment to having a chronic illness. DSM also includes needed skills in decision making, and problem solving (Wysocki et al., 2008). The adolescent's perception of their self-efficacy has been shown to be an important factor in not only DSM but also glycemic control (Berg et al., 2011; Iannotti et al., 2006). In adolescents and parents with a good relationship there is better adherence to diabetes care and metabolic control than for those with poor relationships (Berg et al., 2011). Despite this, collaboration with parents drops off dramatically between ages 14 and 15 while problem solving skills increase throughout the adolescent period (Keough, Sullivan-Bolyai, Crawford, Schilling, & Dixon, 2011). Risk factors for poor adherence to care include increasing age, single-family homes, lower socio-economic status (SES), high family conflict, poor family communication and problem solving skills, and poor social skills and coping methods (Wysocki, 2006). Adolescent females tend to have better communication than males with their parents, their friends, and their providers about their diabetes (Keough et al., 2011). While there are several theories that describe self-management of chronic illness and the risk and protective factors that improve outcomes it is difficult for adolescent's to achieve successful self-management of their diabetes during these transition years (Grey, Knafl, & McCorkle, 2006; Ryan & Sawin, 2009). Parents have described frustration and worry over their adolescent's self-management of their diabetes but state that reminding their adolescent and granting more freedom are helpful during this time (Dashiff, Riley, Abdullatif, & Moreland, 2011).

There is an increase in psychological distress during these years including poor self-esteem which is correlated with poor quality of life (Abolfotouh, Kamal, El-Bourgy, & Mohamed, 2011), increased parental conflict (Dashiff, Vance, Abdullatif, & Wallander, 2009; Ingerski et al., 2010), higher rates of depression and anxiety (Hoey, 2009; Insabella, Grey, Knafl, & Tamborlane, 2007). Adolescents believe their parents are overbearing and controlling (Carroll & Marrero, 2006; Hoey, 2009; Leonard, Garwick, & Adwan, 2005), and often do not want their parents involved (Hanna, Juarez, Lenss, & Guthrie, 2003) despite the benefits shown from increased parental support (Leonard et al., 2005). These adolescents often struggle

with peer relationships (Buchbinder et al., 2005) and do poorly in school (Northam, Lin, Finch, Werther, & Cameron, 2010).

In summary, the changes in supervision of care as well as the emotional distress associated with the adolescent years leads to a dramatic decline in blood glucose monitoring (BGM) with poor A1C's during this stage with only 17% of adolescents meeting the national recommendation for A1C < 7.5% (Cengiz et al., 2013; Professional Practice Committee, 2015). Despite the multitude of interventions that have been done with adolescents with T1DM no lasting changes have been made in improving glycemic control (Channon et al., 2007; de Wit et al., 2008; Lehmkuhl et al., 2010; Mulvaney et al., 2010; Svoren et al., 2003; Wysocki et al., 2007). This understanding of the adolescent's perspective of how they live and manage their diabetes gave a unique understanding of their challenges and allowed for the development of a theoretical paradigm on "normalizing" (Babler & Strickland, 2013). This paradigm provides information from the perspective of the adolescents on their experiences of living with diabetes.

In this manuscript, the focus is on one portion of the research, "moving the journey towards independence". This particular portion of the research contributes to a greater understanding of the transition to DSM for adolescents and thus is of value to health providers, parents, and adolescent's as they struggle with the challenges of addressing DSM at this important stage of adolescence. The theoretical model developed in this research also advances the science in DSM.

Methods

The purpose of this study was to gain an understanding of the adolescent's experiences in living with diabetes, their challenges and management issues, and to build a theoretical paradigm to create future interventions for adolescents with T1DM. In this manuscript, phase 4 of the theoretical model developed, "moving the journey towards independence" and separating from the parent was the focus. Further details of the methods, data analysis, and the full model are available and have previously been described (Babler & Strickland, 2015).

Study Design

This was a qualitative study utilizing traditional grounded theory as described by Glaser (Glaser & Strauss, 1967). Symbolic interaction is the theoretical framework for grounded theory (Blumer, 1969). Grounded theory was the most appropriate method for this study because it was congruent with the aims of the study which were to understand the experiences of adolescents with T1DM management, to build a theoretical paradigm, and to generate hypothesis for future interventional studies. Understanding more about the conditions that are present with certain behaviors assists in the design of interventions (Glaser, 1978; Glaser & Strauss, 1967).

Study Sample

The sample for this study was chosen from Caucasian adolescent's ages 11–15 years that had T1DM from western Washington State. There were 3 boys (27.3%) and 8 girls

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