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Helping Adolescents with Type 1 Diabetes “Figure It Out”

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Purpose: The aim of this study was to gain an understanding of adolescent’s experiences living with diabetes and build a theoretical paradigm for future interventions in adolescents with type 1 diabetes mellitus (T1DM). The adolescent’s quest for independence, balancing blood sugars, and integrating diabetes led to increased conflict with parents which contributed to difficulty coping. One code in this study, “**figuring it out**”, is the focus of this manuscript.

Methods: Grounded theory with 15 in depth interviews were conducted with adolescents ages 11 to 15 with T1DM.

Results: A theoretical model about the concept of “**normalizing**” was identified. Normalizing was defined as the ability to integrate diabetes into the background of one’s daily life to make diabetes ‘part of me’. The fifth phase of normalizing was “**Figuring it out**” which had 4 sub codes: (1) learning to accept diabetes, (2) believing it’s possible to manage their diabetes, (3) showing responsibility, and (4) staying on track, and the normalizing task was “**accepting the new normal**”.

Conclusions: Adolescents with T1DM develop the understanding that diabetes is their ‘new normal’. The use of motivational interviewing, goal setting, and promotion of self-management may be important interventions in supporting adolescents with T1DM to normalize their life.

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CHILDREN WITH TYPE 1 diabetes mellitus (T1DM) who reach adolescence struggle with maintaining their hemoglobin A1C (A1C) in a safe range (Hoey, 2009) recommended for their age and dramatically decrease testing blood glucose (BG) and administering insulin (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997). There are approximately 208,000 children under the age of 20 with T1DM (ADA, 2014), and diabetes is the 7th leading cause of death in the United States. The total cost for people diagnosed with diabetes in 2012 was \$245 billion, and it is estimated that \$69 billion was due to decreased productivity (CDC, 2014). Multiple interventions and utilizing a psychological and/or behavioral approach have been

employed to improve outcomes in this age group with no long term improvements in A1Cs (Grey, Boland, Davidson, Li, & Tamborlane, 2000; Hood, Peterson, Rohan, & Drotar, 2009; Hood, Rohan, Peterson, & Drotar, 2010; Nansel et al., 2009). The purpose of this study was to gain an understanding of adolescents’ experiences in living with diabetes and build a theoretical paradigm to create future interventions for adolescents with T1DM. Findings are of value to health care providers and educators aiming to support adolescents with T1DM in successfully normalizing their life with diabetes.

During adolescence only 10% of adolescents are still testing their BG the recommended four times daily (Anderson et al., 1997). Studies have shown that a decrease in BG monitoring leads to higher A1C levels (Anderson et al., 1997; Evans et al., 1999; Iannotti et al., 2006; Ingerski, Anderson, Dolan, & Hood, 2010; Ziegler et al., 2010) and an increased risk for hospitalization due to diabetic ketoacidosis

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(DKA) (Levine et al., 2001; Ziegler et al., 2010). Hospital admissions are approximately 40% of the total overall cost of diabetes care (Holmes-Walker, Llewellyn, & Farrell, 2007). Higher rates of anxiety, depression, problems coping, and poor self-esteem (Grey, Cameron, & Thurber, 1991; Grey, Whittemore, & Tamborlane, 2002; Hood et al., 2006; Kovacs, Goldston, Obrosky, & Bonar, 1997; Kovacs, Obrosky, Goldston, & Drash, 1997) are seen in adolescents with T1DM. Adolescents with T1DM also struggle with relationships with their peers (Buchbinder et al., 2005; Grey et al., 1991) and parents (Anderson et al., 2002; Dashiff, Vance, Abdullatif, & Wallander, 2009; Davidson, Penney, Muller, & Grey, 2004; Ingerski et al., 2010) which leads to increased levels of conflict (Anderson et al., 2002; Dashiff et al., 2009).

Less than one third of adolescents are able to maintain their A1C in target range for their age (Hoey, 2009). Ongoing high BG levels, poor adherence to diet and exercise, and missing insulin doses persist into adulthood with only one third of adults able to maintain their A1C <7.5% and over 12% having very high A1C levels over 10% (Toljamo & Hentinen, 2001). As adolescents take on more self-care, they perceive diabetes to be a burden (Davidson et al., 2004) but often believe their parents are too controlling and do not want supervision for their care (Grey et al., 2009; Hoey, 2009). Parental support (Hanna & Guthrie, 2001; Kyngas & Rissanen, 2001; Leonard, Garwick, & Adwan, 2005) and peer (Kyngas, Hentinen, & Barlow, 1998; Kyngas & Rissanen, 2001) support have been shown to be helpful for adolescents in increasing BG monitoring and lowering A1Cs.

A recent meta-analysis of 15 studies with interventions to improve adherence (Hood et al., 2010) found a mean effect size of 0.11 for pre to post treatment group changes when comparing the control and intervention group, but did show that adding interventions around emotional, social, and family issues was better than behavior change alone. Two studies utilizing coping skills training showed minimal change in A1Cs (Grey et al., 2000, 2009). Additionally, a study on enhancing problem solving skills showed an increase in A1Cs during the study period (Nansel et al., 2009) and another with no change (Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010).

In summary, interventions aimed at improving diabetes self-management (DSM) for adolescents with T1DM have not had a major influence on A1Cs. Limited research has provided insights into the perspectives of adolescents experiencing T1DM. A theoretical model has also not been developed in this area to guide intervention design and practice as was the aim of this study. The theoretical paradigm of the concept of normalizing provides important information about strategies adolescents use as they **'figure it out'** (Babler & Strickland, 2013). This research builds on adolescent perceptions and strengths; it fosters understanding of the conditions present that allow adolescents success in DSM and helps move nursing science forward. These findings focus on positive reinforcement and the development of strategies to assist adolescents as they **'accept their**

new normal'. Hypotheses were generated for future interventional research to improve health outcomes for adolescents with T1DM.

Methods

The purpose of this study was to gain an understanding of adolescents' experiences in living with diabetes and build a theoretical paradigm to create future interventions for adolescents with T1DM. This paper provides more detail on phase 5 of the paradigm; the methods, data analysis, and full model were previously described in detail in previous work (Babler & Strickland, 2013, 2015) and will not be fully repeated here.

Study Design

This was a qualitative study that utilized grounded theory (Glaser & Strauss, 1967). Grounded theory was selected because it best supported the aims of this study which were to understand the adolescents' experiences in T1DM management, to build a theory model, and to generate hypotheses to support interventional design. Gaining insight into the conditions under which behaviors occur strengthens the theory and provides a deeper understanding of interventions that may be plausible (Bowers, 1988; Glaser & Strauss, 1967). The theoretical framework for grounded theory is symbolic interactionism (Blumer, 1969).

Recruitment

All eligible participants were mailed a recruitment letter, in clinic recruitment posters were displayed, and postcard handouts were provided. Parents interested in having their adolescents participate contacted the researcher directly and completed a verbal questionnaire to determine study eligibility. A \$25 gift card was given to study participants at the end of their interview.

Study Sample

The study sample was comprised of adolescents ages 11 to 15 (mean, 13.9) with T1DM. Average hemoglobin A1C of participants was 8.2% (range, 7.2%–9.2%; median, 8.4) per parent report. Sampling, coding, and data analysis were done simultaneously. A total of 15 in home private interviews with 11 participants (3 boys, 27.3% and 8 girls, 72.7%) were conducted each lasting approximately 1 hour. Interviews were digitally recorded and transcribed verbatim. Interviews were continued until data saturation had been reached. Data analysis followed the methods described by Babler and Strickland (2015) and Glaser and Strauss (1967) to create an integrated paradigm. First line coding was done on the interviews looking for gerund codes (-ing words) indicating behaviors that were occurring. This was followed by second line coding in which codes were grouped into clusters. Constant comparative analysis was used to understand the relationship of the various clusters or categories and to identify the core phenomenon that was occurring. The

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