Adolescents' Perceptions of Parental Roles and Involvement in Diabetes Management

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This descriptive qualitative study compared how 18 teens (aged 14–16 years) with higher (n = 11; HiA_{1c}) versus those with lower (n = 7; LoA_{1c}) hemoglobin (Hb) A_{1c} levels who met the standard of care viewed parental roles and involvement in diabetes management. Content analysis of the verbatim interview transcripts yielded five major themes. Teens in the LoA_{1c} group (average HbA_{1c} levels ≤8%) described their parents' monitoring roles more positively, whereas teens in the HiA_{1c} group (average HbA_{1c} levels >8%) were annoyed with reminders and described more conflict with their parents related to lack of adherence to their diabetes protocol. Clinicians need to assess the quality of parent–teen relationships and provide developmentally appropriate interventions to help teens and their parents effectively negotiate role transitions related to diabetes management during middle adolescence.

IN MODERN WESTERN cultures, adolescence is an extended period of transition providing time for teens to move from dependence on their parents to greater independence in meeting their own needs—emotional, physical, social, and financial. Physical growth and normative psychological conflicts and crises emerge in adolescence (Friedman, Connelly, Miller, & Williams, 1998). Adolescents are challenged to gain more independence and autonomy from parents and other older family members. Families also face challenges with regard to structure, roles, and relationships. The main task for families in this stage is to pave the way for adolescents to assume more responsibility and independence. This stage of family development focuses on the process of letting go (Friedman et al., 1998) where a balance between freedom and responsibility needs to be achieved as parents deal with a developing individual.

Renegotiation of roles is a significant developmental task for teens and parents alike during adolescence. For youth with Type 1 diabetes, changes in the management plan via parent and teen roles and responsibilities must begin early in this transition period as a teen is away from direct parental supervision for much of the day at school, participating in sports and other after-school activities as well as spending time with friends. During the time away from home, a teen must make many decisions about his or her diabetes care such as insulin dosing, glucose monitoring, diet, and exercise.

The necessary process of transferring the primary responsibility of diabetes care from parents to adolescents carries with it the potential of distress for both parties. In their examination of parental involvement in diabetes management, Hanna and Guthrie (2000) found issues of loss of control, authority, and supervision to be barriers to decision making for parents regarding adolescents' assuming diabetes management. In a previous study, Leonard, Jang, Savik, Plumbo, and Christensen (2002) suggested that adolescents who self-identified as having attention problems and delinquent and aggressive behavior and who saw their family lacking in emotional involvement and

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responsiveness were two times more likely to have poorer metabolic control than those who did not. This was true although their scores on the Youth Self-Report scale and the Family Assessment Device were almost all within normal limits. Even subtle increases in negative behaviors and perception of family dysfunction separated the adolescents with poorer control from those with better metabolic control (Leonard et al., 2002). These quantitative measures, however, could not explain the dynamics influencing the perturbations in these young people or why the teens viewed their families as dysfunctional.

Although there is substantial literature on family contributions to the health of youth with Type 1 diabetes from parents' point of view, there is relatively little research on teens' perceptions of family roles and parental involvement in diabetes management during middle adolescence. Understanding parental involvement in diabetes management from the teens' point of view is important because parental involvement has been associated with better outcomes among adolescents with Type 1 diabetes. Wysocki et al. (1996) investigated self-care autonomy among adolescents with diabetes and concluded that parental involvement was related to better outcomes. However, the authors did not provide information "about the precise nature of that involvement, the characteristics of families who demonstrate it, or the role of clinical and educational practices in its cultivation" (Wysocki et al., 1996, p. 123). Similarly, Anderson, Auslander, Jung, Miller, and Santiago (1990) found that conflicts between mothers and children regarding who assumed responsibility for diabetes management and adherence levels were significant predictors of hemoglobin (Hb) A_{1c} levels. Anderson, Ho, Brackett, and Laffel (1999) admonished clinicians not to assume that mothers and children communicate about diabetes management or about changes in expectations over time. In a recent qualitative study of parents of adolescent girls with diabetes, Mellin, Neumark-Sztainer, and Patterson (2004) found that parents were challenged in trying to account for all the factors affecting blood glucose and knowing what aspect of the regimen to adjust and how best to do it. Parents also spoke about their teen's complicated and busy life away from home and the difficulties this posed for diabetes management.

Because family roles must be renegotiated during adolescence, both parents and adolescents share a time of instability. Most families overcome this transition confusion and give their teenaged children more autonomy and independence (Preto, 1989). This normal transition may be more complicated for families with an adolescent with Type 1 diabetes. Adolescents have a need for autonomy, and this need may compete with parental concern for adherence to a medical regimen. Parents' concern over their child's well-being and health, along with adolescents' simultaneous drive for autonomy, triggers functional shifts and role revision within families (Preto, 1989). In their focus group study of adolescent–parent diabetes management-related conflict and support, Weinger, O'Donnell, and Ritholz (2001) found that parents were concerned about their adolescent's long-term well being whereas adolescents were concerned about their present situation, which created a source of conflict between the parents and adolescents. In another study, Hanna, Juarez, Lenss, and Guthrie (2003) found that parental support increased from early to middle adolescence but decreased from middle to late adolescence. Perhaps this change reflects the normal transfer of responsibility for diabetes management from parents to teens from early to late adolescence.

Dashiff (2003) examined the perceptions among adolescents and parents of their respective diabetes management responsibilities and concluded that there were significant differences in how fathers and mothers perceived each other's as well as their adolescent's diabetes management responsibilities. Mothers and adolescents did not differ in their views of the adolescent's role; however, they showed significant differences in how they perceived the mother's and father's responsibilities. Finally, the adolescents and the fathers did not differ in the perceptions of the father's role, but they differed in their views of the teen's and mother's responsibilities. These findings suggest a need to further investigate teens' views of both parents' roles in diabetes management during adolescence.

This study addresses a gap in the literature by investigating how teens between the ages of 14 and 16 years view their parents' roles and involvement in diabetes management.

Our aim is to compare findings between teens who meet the current American Diabetes Association standard of care of HbA_{1c} levels $\leq 8\%$ and those who do not to inform clinicians on how to tailor their interventions for families of adolescents who face different management challenges.