Successful Parent-Child Transition of Responsibility for the Management of Type 1 Diabetes during Adolescence: A Longitudinal Perspective

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Abstract of the Dissertation

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Type 1 diabetes requires complex day-to-day management to reduce the risk of severe medical complications. Problems with adherence and glycemic control are especially common in adolescence. During this time, the primary responsibility for diabetes management shifts from parent to child. This may be problematic if the transition of responsibility occurs too early or too quickly, or if parents and youths disagree on the division of responsibilities. The present study employed a longitudinal approach using multilevel growth curve modeling to examine characteristics of successful parent-youth transition of responsibility for diabetes management. The first study aim was to characterize developmental trajectories in levels of youth autonomous responsibility and in parent-youth discrepancies about responsibility for diabetes management. The second aim was to examine how trajectories of youth responsibility levels and parent-youth discrepancies were related to trajectories of diabetes regimen adherence and glycemic control. The third aim was to examine whether family characteristics predicted responsibility levels and parent-youth discrepancies. At four times over two years, 87 youths with type 1 diabetes (10 to 16 years old at study entry) and their parents reported on the division of diabetes management responsibilities, and provided assessments of adherence. Glycemic control was indexed by laboratory measures of HbA_{1c} taken during regular doctor visits. Characteristics of family functioning were assessed at study entry. Results showed that youths' levels of responsibility for diabetes management increased with age. Parent-youth discrepancies showed no consistent developmental trend; youths' perceptions of their responsibility exceeded parents' perceptions across all ages. However, trajectories of youth responsibility levels and of parent-youth discrepancies were diverse across individual families. Higher discrepancies, but not responsibility levels, were related to worse adherence and glycemic control at study entry. Moreover, an increase in discrepancies over the study period, but not change in responsibility levels, was related to worsening in adherence over time. Families with favorable communication patterns and little home chaos showed less discrepancy at study entry. The findings highlight the importance of understanding the successful transition of diabetes self-care responsibility during adolescence as a dynamic, interactive process. This may facilitate the development of family interventions to improve diabetes care in adolescence.

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Introduction

Type 1 diabetes mellitus is among the most common pediatric diseases. It is most frequently diagnosed during childhood or early adolescence, and occurs in about 1 in 600 youths, with an estimated incidence of 19 cases per 100,000 children per year (Centers for Disease Control and Prevention, 2008). The incurable illness results from inflammatory destruction of the beta cells of the pancreas and the consequent inability to synthesize and release insulin, and requires insulin replacement therapy for a lifetime. Type 1 diabetes has many short-term complications (associated with episodes of severe hypo- and hyperglycemia) and long-term health risks. Long-term complications include heart disease, stroke, blindness, kidney failure, and nerve damage. The life expectancy of individuals with type 1 diabetes is significantly reduced (American Diabetes Association, 2002).

A profound event in recent diabetes care was the release of the Diabetes Control and Complications Trial (Diabetes Control and Complications Trial Research Group, 1993), a controlled, prospective trial following more than 1,400 adults and adolescents with type 1 diabetes over an average of 6.5 years. The results provided strong evidence that the maintenance of blood glucose at near normal levels through the use of intensive treatment regimens effectively delays the onset and slows the progression of both microvascular and cardiovascular long-term complications (Diabetes Control and Complications Trial / Epidemiology of Diabetes Interventions and Complications Study Research Group, 2005; Diabetes Control and Complications Trial Research Group, 1993; White et al., 2001). As a consequence, achieving glycemic control as close to normal as possible and as early in life as possible has become the primary goal of medical diabetes management, and intensive treatment regimens have become the standard of type 1 diabetes care (Silverstein et al., 2005).

The everyday management of type 1 diabetes with intensive regimens is complex. Over the course of an average day, a patient must monitor the kind and amount of food consumed, must frequently test blood glucose levels, administer the correct amount of insulin accordingly throughout the day, and anticipate the effect of physical activity on blood glucose levels (Gonder-Frederick, Cox, & Ritterband, 2002; Wysocki, 2006). It is during adolescence that patients with diabetes show the greatest difficulty adhering to this demanding regimen (Johnson et al., 1992; Kovacs, Goldston, Obrosky, & Iyengar, 1992), and many adolescents have poorer glycemic control than do children or adults (Levine et al., 2001; Luyckx & Seiffge-Krenke, 2009; Mortensen et al., 1998). Thus, promoting optimal management of diabetes during the adolescent developmental period remains critical for research and clinical practice.

One factor that has often been implicated as playing a central role in facilitating favorable diabetes outcomes during adolescence is the successful transition of responsibility for the management of the illness from parent to the developing youth (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Anderson, Brackett, Ho, & Laffel, 1999; Beveridge, Berg, Wiebe, & Palmer, 2006; Cameron et al., 2008; Nansel, Rovner et al., 2009; Wysocki & Greco, 1997). Younger children are unable to provide their own diabetes care, such that parents are initially responsible for the day-to-day management of their children's disease. Over the course of adolescence, a key task for youths and their parents is to adjust and renegotiate the distribution of responsibility within the family as youths increasingly become responsible for managing their illness independently.

Determining the appropriate balance of parental involvement and youth autonomous responsibility for diabetes management can be extremely difficult. For one, the transition of responsibility may occur too early or too quickly, such that parents reduce their involvement prematurely, and youths take over responsibility before they are ready to meet the demands of managing the illness independently. Alternatively, if parents do not reduce their involvement to the extent that youths claim more autonomous responsibility for themselves, the resulting parent-youth disagreement and competition for authority may hamper adequate disease management.

A number of studies have suggested negative diabetes-related consequences of each of these two aspects — the premature transfer of responsibility (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Hsin, La Greca, Valenzuela, Taylor Moine, & Delamater, 2010; La Greca, Follansbee, & Skyler, 1990; Palmer et al., 2004; Wiebe et al., 2008; Wysocki, Taylor et al., 1996), and discrepancies between youths and parents about the division of responsibilities (Butner et al., 2009; Cameron et al., 2008; Lewandowski & Drotar, 2007; Lewin et al., 2006; Miller & Drotar, 2003). However, few studies have examined the unique and combined implications of these two aspects simultaneously, and previous research has almost exclusively relied on cross-sectional study designs. Consequently, the dynamic longitudinal processes characterizing the parent-youth transition of responsibility for diabetes management are still only poorly understood. To overcome this limitation of previous research, the present study used a longitudinal study design to examine developmental changes in youth autonomous responsibility and in discrepancies between youth and parent perceptions of responsibility for diabetes management, and investigated how these changes relate to the successful management of type 1 diabetes during adolescence.

Autonomy and control during the adolescent developmental period

Adolescence is a period of fundamental changes and developmental transformations. A pivotal life task of an adolescent is to create a personal identity that is both individually satisfying and absorbing, but at the same time is in accord with the goals of adult life instead of focusing on the immediately pleasurable activities of childhood (Csikszentmihalyi & Larson, 1984). This development is also accompanied by a transformation in parent-youth relationships. Young children's relationships with their parents are necessarily asymmetrical in terms of power, in that parents have authority over most tasks and decisions. As youths mature over time and their capabilities for independent action and decision making increase, establishing more autonomy from their parents becomes an important developmental task, and adolescents often expect greater symmetry of power and authority. At the same time, parents may feel the need to stay in control and provide the necessary guidance to ensure the safety and well-being of the adolescent. Eccles and colleagues (Eccles, Buchanan, Flanagan, & Fuligni, 1991; Eccles et al., 1993) suggest that optimal developmental outcomes may result from a fit between the youth's desires for autonomy and the parents' provision of opportunities for autonomy and independence, such that parents must gradually reduce control to the extent that a youth's desire for independence increases. However, finding the right balance in a relationship that encourages the adolescent's independent contributions in decision making, while not overburdening the child and still maintaining appropriate involvement often translates into a difficult "dance" for many families (Beveridge & Berg, 2007; Steinberg & Silk, 2002).

Parent-youth collaborative responsibility for the management of type 1 diabetes

For a family with a child having type 1 diabetes, the responsibility of managing the chronic illness on a daily basis adds a unique and especially challenging aspect to the autonomy-authority balance between parent and youth: a balance must be found between medical adaptation to the illness and the adolescent's normal developmental needs (Seiffge-Krenke, 1998). On the one hand, diabetes is a life-threatening illness, and failure to maintain optimal diabetes control during adolescence can result in serious long-term complications. Hence, it may be important for parents to maintain considerable levels of authority and control over the management of the medical condition, and conventions of autonomy granting that may be optimal for healthy adolescent life tasks may not apply. On the other hand, it may be equally important for parent and youth to be in mutual agreement about power and authority for diabetes management tasks: parental control to an extent that exceeds a youth's desire for autonomous diabetes management responsibility may interfere with the youth's normal progression of autonomy during adolescent development and may disrupt positive parent-youth collaboration necessary for successful illness management. As stated in the most recent standards for the care of children and adolescents with type 1 diabetes of the American Diabetes Association (Silverstein et al., 2005), "the challenge is to find the degree of parental involvement that is comfortable for all involved, without risking deterioration in glycemic control from over- or underinvolvement" (p. 190).

Importance of sustained parent responsibility for diabetes management

Because type 1 diabetes is typically diagnosed before puberty, parents are initially in charge for most aspects of illness management. Paralleling the shift in authority that occurs during healthy adolescent development, responsibility for diabetes self-care begins to be transferred from parent to youth in early adolescence, such that adolescents are generally expected to take on increasing levels of responsibility for diabetes care as they mature (Anderson et al., 1997; La Greca et al., 1990).

There are good reasons, however, for parents to remain substantially involved in diabetes care during the years of adolescence. Diabetes is a life-threatening disease. Its management is complex, and youths might lack the necessary cognitive abilities and problem-solving skills to make all the right choices and judgments involved in diabetes-related tasks (Miller & Drotar, 2007; Wysocki, Iannotti et al., 2008). Adolescents also often experiment with different lifestyles, and spend more time away from home together with their peers; the erratic schedule sometimes associated with this may interfere with the precision and regularity required for conventional diabetes regimens, and may make it difficult to make appropriate adjustments to self-care behavior when needed. Hormonal changes associated with puberty make it even more difficult to manage the illness and maintain tight glycemic control (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986). Furthermore, adolescents are often less likely to make choices based on concerns about their health (Chassin, Presson, & Sherman, 1987), and they may tend to view themselves as invulnerable to long-term effects of the disease (Hanson & Onikul-Ross, 1990). Concerns that are often more salient during adolescence may be at odds with optimal diabetes management: for example, an adolescent might not adhere to recommended dietary behaviors and meal planning because of social pressures and the desire for peer acceptance (Hains, Berlin, Davies, Parton, & Alemzadeh, 2006; Hains et al., 2007; Thomas, Peterson, & Goldstein, 1997), or because of concerns about physical appearance (Meltzer et al., 2001). For these reasons, scholars have argued that transferring responsibility from parent to youth prematurely or too abruptly may be one major reason for suboptimal disease regulation, and have advocated that parents should maintain substantial involvement in the daily management of the illness throughout the course of adolescence (Anderson et al., 1997; Wysocki, Taylor et al., 1996).

A number of studies have empirically supported the notion that greater parental involvement and less youth responsibility for diabetes management are associated with more favorable diabetes self-care outcomes (see Wysocki & Greco, 2006). Anderson et al. (1997; 2002) found that greater parental involvement was related to more frequent blood glucose testing, which, in turn, was related to better glycemic control in youths aged 8 to 17 years. Similarly, La Greca, Follansbee, and Skyler (1990) reported that preadolescents who assumed more independent responsibility for glucose testing and insulin administration had poorer glycemic control than those with less responsibility. Wiebe et al. (2005) showed that youths aged 10 to 15 years who viewed their mother as being relatively uninvolved in dealing with diabetes problems reported poorer adherence; greater participation and child monitoring by mothers and fathers related to better adherence and glycemic control (Berg et al., 2008; Horton, Berg, Butner, & Wiebe, 2009; Wiebe et al., 2008). Furthermore, studies by Wysocki et al. (1996; 2006) and by Palmer et al. (2004; 2009) suggest that youths with inordinate diabetes self-care autonomy relative to their pubertal status and psychological maturity have poorer self-care outcomes and more hospitalizations compared with youths with fewer autonomous responsibilities. In other studies, lower degrees of parental involvement in diabetes management were found to be associated with more emotional adjustment problems, lower psychological well-being, and lower diabetes-related quality of life (Berg et al., 2007; Horton et al., 2009; Weissberg-Benchell & Glasgow, 1997; Wiebe et al., 2005).

These findings were all based on cross-sectional study designs. However, a longitudinal study by Helgeson, Reynolds, Siminerio, Escobar, & Becker (2008) also found that child reports of greater parent responsibility for diabetes tasks predicted an improvement in self-management behavior from one year to the next, whereas greater child responsibility predicted a deterioration of glycemic control over time. Moreover, interventions aiming at greater parental involvement in daily diabetes management showed longitudinal benefits in terms of improved metabolic control (Anderson et al., 1999; Laffel, Vangsness et al., 2003).

Importance of parent-youth agreement in perceptions of responsibility

Notwithstanding the theoretical and empirical importance of parents maintaining a high degree of participation in diabetes management during adolescence, it may be similarly pivotal for parent and youth to be in mutual agreement about power and authority for diabetes management tasks. If parent and adolescent are "not on the same page," such that levels of parental involvement exceed and oppose a youth's desire for independent responsibility taking, this may undermine successful family management of diabetes for several reasons.

For one, discrepancies about diabetes management responsibilities may lead to family conflict (Holmbeck, Graber, Brooks-Gunn, & Petersen, 1996), which, in turn, may interfere with successful diabetes management (Miller-Johnson et al., 1994). Developmental research on conflicts about authority in families has shown that most arguments occur over relatively mundane issues, such as cleaning one's room, and over prudential concerns of safety, comfort, and health (Smetana, 1988, 1989; Smetana & Asquith, 1994). As they get older, adolescents increasingly tend to define such issues as matters of personal jurisdiction and under their own control, whereas parents continue to define them as matters of social convention and as issues for which a parent would have some right to establish rules. Most tasks related to the management of diabetes are relatively mundane parts of a daily routine, making this a likely area of disagreement and youth-parent conflict about authority.

Furthermore, intrusive parental involvement may undermine adolescents' self-esteem and motivation to adhere to the diabetes regimen. Developmental research suggests that, with age, young adolescents increasingly tend to interpret parental assistance as a reflection of their own incompetence (Pomerantz & Eaton, 2000). Pediatric research has found that parents of chronically ill children and adolescents commonly overestimate illness-related limitations and impairments (de Wit et al., 2007; Levi & Drotar, 1999) and are more likely to display intrusive overprotection than parents of able-bodied youths do (Holmbeck et al., 2002). As such, problems from intrusive parental assistance may be especially prevalent in families with a chronically ill child, given that parents may perceive their child as being particularly vulnerable and may be overly protective to ensure the child's safety (Thomasgard & Metz, 1995; Thomasgard, Shonkoff, Metz, & Edelbrock, 1995).

Anderson and Coyne (1991) outlined a model of "miscarried helping" for understanding the interactive processes by which a parent's well-meant attempts to help and protect a chronically ill child can backfire and undermine the very positive self-care behaviors they are intended to foster. Initially, both parent and youth may be equally invested in achieving the best possible treatment outcomes. However, if a parent's efforts to help disregard the youth's need for autonomy, the youth may naturally view the parent's involvement as intrusion of personal space. Hence, the youth may react by demanding more personal freedom and control over the treatment while feeling that *not* adhering to the parent's demands for treatment compliance is justified and even important to preserve personal autonomy. According to the miscarried helping model, this can set an interactive cycle in motion, in which parent and youth struggle over power instead of supporting each other's contribution to the management of the illness: the child's non-adherence behavior may elevate fear of treatment failure in the parent, raise doubts about the child's illness management competence, and further increase parents' level of involvement. This, in turn, may lead to more child resistance, excessive attempts to gain autonomous responsibility for diabetes tasks, and more maladaptive treatment outcomes.

Empirical research supports the notion that parent-youth discrepancies in perceptions of authority for diabetes management tasks are associated with worse glycemic outcomes (Anderson et al., 1990), and that agreement about diabetes-related responsibilities relates to better diabetic outcomes (Anderson et al., 2009). A study by Butner et al. (2009) examined intrafamilial discrepancies in perceptions of the adolescent's competence and independence for diabetes management in a sample of 185 youths aged 10 to 14 years and their parents. Results showed that parent-youth discrepancy — mothers viewing the adolescent as less competent and independent than the adolescent did — was significantly associated with poorer glycemic control in the youth and poorer mental well-being of the mother. Similar results were obtained in a study by Cameron et al. (2008) examining differences in parent-youth perceptions of diabetes management responsibility in a large sample of 2,062 adolescents aged 11 to 18 years and their parents: to the extent that youths claimed to be more autonomously responsible than the parent viewed them to be, they reported greater parental over-involvement in diabetes self-care activities, and showed significantly worse glycemic control. Other studies have confirmed that discrepant parent-youth opinions about authority over diabetes management decisions relate to poorer diabetic control (Lewandowski & Drotar, 2007; Lewin et al., 2006), greater oppositional child behavior (Lewandowski & Drotar, 2007), and greater family conflict (Miller & Drotar, 2003), whereas parent-youth collaboration in diabetes management and parental appreciation of the youth's autonomy needs relate to better diabetes-related outcomes (Berg et al., 2008; 2007; Butler, Skinner, Gelfand, Berg, & Wiebe, 2007; Wiebe et al., 2005).

Limitations of previous research

To summarize, previous research suggests the importance of two aspects of establishing a successful balance between parent and youth responsibility in the management of type 1 diabetes during adolescence: (a) the importance of continued parental involvement without premature transfer of responsibility for illness management to the adolescent, and (b) the importance of adolescent-parent agreement about the distribution of responsibility and authority for diabetes management tasks. Correspondingly, recent family intervention programs for adolescents with type 1 diabetes attempt to facilitate parent-youth collaborative involvement in diabetes management and "teamwork" among family members (Anderson et al., 1999; Ellis et al., 2005; Laffel, Vangsness et al., 2003; Nansel, Anderson et al., 2009; Wysocki et al., 2007; Wysocki, Harris, Buckloh, Mertlich et al., 2006; Wysocki, Harris et al., 2008).

There are two general limitations of past observational research that the present study seeks to address. For one, previous studies have commonly focused either on the *level* of adolescent (versus parent) responsibility, or they have focused on parent-adolescent *discrepancies* in perceptions of the distribution of responsibility for diabetes management tasks, but few studies have examined these two aspects simultaneously. Thus, little is known about their importance for successful diabetes management relative to each other and in combination with each other.

Second, previous research examining responsibility for diabetes management has almost exclusively relied on cross-sectional study designs. Cross-sectional designs can only capture differences in responsibility at a given point in time, but they cannot capture the magnitude and direction of *changes* in responsibility over time. Accordingly, previous work has largely treated the parent-youth division of diabetes responsibilities as a relatively static family characteristic. This disregards the fact that the transfer of responsibility from parent to youth is a dynamic developmental process during which parent and youth must frequently renegotiate their authority over the treatment tasks. Hence, the longitudinal processes underlying the successful parent-youth transfer of responsibility for diabetes management during adolescence are only poorly understood.

Study overview

The purpose of the present study was to investigate characteristics of successful parent-youth transition of responsibility for the management of type 1 diabetes during adolescence using a longitudinal study design. Specifically, the study examined longitudinal trajectories in (a) the level of youth autonomous responsibility and (b) discrepancies between youth and parent perceptions of responsibility for diabetes management, and investigated their associations with outcomes of diabetes self-care.

The study addressed three specific aims: the first aim was to characterize age-related trajectories in levels of responsibility and in parent-youth discrepancies throughout the course of adolescence, and to examine the extent to which these trajectories are relatively uniform or substantially varied across individual families. The second aim was to examine how trajectories in levels of responsibility and in parent-youth discrepancies are related to trajectories in diabetes self-care outcomes, namely, adherence and glycemic control. The third aim was to examine the role of baseline family characteristics in predicting differential trajectories in the level of youth responsibility and in youth-parent discrepancies about responsibility.

Operationalization of trajectories in responsibility levels and parent-youth discrepancies

Research has faced longstanding difficulties with the operationalization of change in individuals and the operationalization of discrepancies between dyad members, for very similar reasons. In particular, the use of an observed difference score (for change and discrepancies alike) has been widely criticized due to its inability to separate random measurement error from true change in individuals and from true discrepancies in dyads (Cronbach & Furby, 1970; McArdle, 2009; Rogosa, 1988). In the present study, a multilevel modeling approach was used to generate estimates of latent change and latent discrepancies that are "cleaned" from measurement error. The approach is an amalgam of individual growth curve analysis for the analysis of change and a multilevel model for the analysis of matched pairs (Barnett, Marshall, Raudenbush, & Brennan, 1993; Kenny, Kashy, & Cook, 2006; Lyons & Sayer, 2005; Lyons, Zarit, Sayer, & Whitlatch, 2002; Raudenbush, Brennan, & Barnett, 1995).

At four times during the 2-year study period, youths (10 to 16 years old at study entry) and parents provided parallel measures indicating how the responsibility for diabetes management was partitioned amongst them. As shown in Figure 1, both dyad members indicated the proportion of responsibility they attributed to themselves versus the other (my parent / my child). Individual growth curves of youth responsibility levels and of parent-youth discrepancies were simultaneously estimated based on the dyad members' responses. Specifically, the *level* of youth autonomous responsibility for diabetes management was operationally defined as the *latent average* of youth and parent reports of the youth's responsibility. This definition was based on the assumption that the reports of both dyad members contain information about the "actual" level of youth responsibility, expressed in the shared variance of the reports. The parent-youth *discrepancy* in perceptions of youth responsibility was operationally defined as the *latent difference* between youth and parent reports of the youth's responsibility. This provided an estimate of the "actual" discrepancy in perceptions, and it is not implied that either parent or youth subjectively perceive discrepancies or experience a sense of disagreement. Positive discrepancies denote that youths attribute more responsibility to themselves than parents attribute to their child.

Specific aims

Aim 1: Characterization of developmental trajectories of responsibility

Given the dearth of longitudinal research on the parent-youth transfer of responsibility for diabetes management, the developmental dynamics underlying this transition are not well understood. Thus, the first aim of the study was to describe and characterize age-related trajectories in the level of youth responsibility and in parent-youth discrepant perceptions of responsibility throughout the course of adolescence. The use of multilevel growth curve analysis allows modeling both average change and individual differences in rates of change simultaneously. Accordingly, the two goals were to characterize the developmental pattern of change on average across all families, and to examine the extent to which these patterns are relatively uniform or substantially varied between individual families.

Average developmental trajectories in responsibility levels and discrepancies

Developmental change in levels of youth responsibility. Previous research has consistently shown that older adolescents have more autonomous responsibility for diabetes care than do younger adolescents, with age commonly explaining between 25% and 50% of the variance in responsibility levels in cross-sectional studies examining age-heterogeneous samples (Anderson et al., 1990 [6 to 21-year-olds]; Anderson et al., 1997 [10 to 15-year-olds]; Anderson et al., 2002 [8 to 17-year-olds]; Cameron et al., 2008 [11 to 18-year-olds]; La Greca et al., 1990 [7 to 17-year-olds]; Ott, Greening, Palardy, Holderby, & DeBell, 2000 [11 to 18-year-olds]; Palmer et al., 2009 [10 to 14-year-olds]; Palmer et al., 2004 [10 to 15-year-olds]; Weissberg-Benchell & Glasgow, 1997 [5 to 18-year-olds]). However, the cross-sectional nature of these studies leaves open the possibility that age differences in the levels of youth responsibility have resulted from cohort effects rather than reflecting true developmental changes. Regimens for the treatment of type 1 diabetes are continually being upgraded due to technical advances (e.g., invention of the insulin “pump”), such that different cohorts of research participants may have developed differentially because of the type of “standard care” that was in place for each cohort. The longitudinal design of the present study made it possible to disentangle between-person (cohort) and within-person influences of age, in that age of the participants varied at the beginning of the study (10 to 16-year-olds), and also changed over the course of the study (2 years). In individual growth curve analysis, a person’s initial (baseline) status and a person’s rate of change are modeled simultaneously. This way, it could be examined whether observed cross-sectional age differences in youth responsibility are replicated in the average rate of change in responsibility levels within subjects over time (Biesanz, Deeb-Sossa, Papadakis, Bollen, & Curran, 2004; Mehta & West, 2000). Given the considerably strong age effects found in previous studies, it was hypothesized that cross-sectional age differences in youth responsibility would replicate in within-subject analyses of change in responsibility, such that youths on average would show an increasing amount of autonomous responsibility over time.

In addition, it is unclear from previous research whether the parent-youth transition of responsibility for diabetes care follows a constant rate (i.e., is strictly linear) across the adolescent years. Rates of parent-youth transfer of responsibility may generally be faster during early adolescence and slow down during late adolescence, or they may potentially be especially pronounced during late adolescence when the youngsters get ready for adult life. Thus, this study examined linear and explored curvilinear age trends in levels of youth responsibility for diabetes management.

Developmental change in parent-youth discrepancies. Developmental theory suggests that adolescence is often a time of opposition between youth autonomy seeking and parental autonomy granting, and developmental research has shown that adolescents commonly view themselves as more competent and autonomous than their parents do (Daddis & Smetana, 2005; Dekovic, Noom, & Meeus, 1997; Holmbeck & O'Donnell, 1991). Similarly, previous pediatric diabetes research suggests that adolescents typically claim more autonomous responsibility for diabetes management than their parents grant them (Butner et al., 2009; Laffel, Vangsness et al., 2003; Lewandowski & Drotar, 2007; Mansfield, Addis, Laffel, & Anderson, 2004; Miller & Drotar, 2003; Palmer et al., 2009). Accordingly, it was hypothesized that parents' and youths' perceptions, on average, would disagree in the direction that youths attribute more responsibility to themselves than parents attribute to their child (and parents attribute more responsibility to themselves than youths attribute to their parent), such that parent and youth would each claim overlapping areas of diabetes management as under their personal jurisdiction.

Whether discrepancies in perceptions of responsibility for diabetes management generally tend to become larger or smaller during the course of adolescence is not clear. A decrease in discrepancies would be expected to the extent that parent and youth opinions about responsibility usually tend to converge during adolescence, and an increase in discrepancies would be expected to the extent that opinions typically tend to diverge during adolescence. Previous cross-sectional work has yielded inconsistent results, finding that parent-youth discrepancies are negatively associated with age

(Anderson et al., 1990 [6 to 21-year-olds]; Anderson et al., 2009 [9 to 14-year-olds]), positively associated with age (Beveridge et al., 2006 [10 to 15-year-olds]), or not associated with age (Butner et al., 2009 [10 to 14-year-olds]). Theories of autonomy development indicate that parent-youth disagreement may generally increase during early adolescence as youths seek more autonomy in their decision making than is provided by parents (Eccles et al., 1991; 1993) but may decline later in adolescence as parent-youth conflict declines (Laursen, Coy, & Collins, 1998), suggesting the possibility of a curvilinear trend of parent-youth discrepancies across adolescence. Thus, exploratory analyses examined evidence for linear and curvilinear age-related changes in parent-youth discrepancies in perceptions of responsibility for diabetes management.

Variability in responsibility trajectories between families

Examining average trajectories across all families captures only one aspect of the developmental dynamics underlying the transfer of diabetes management responsibilities. In addition, it is similarly important to ask to what extent individual families differ from one another in patterns of change. That is, are changes in the level of youth responsibility and in parent-youth discrepancies relatively uniform across families, suggesting homogenous developmental processes, or do rates of change substantially vary between individual families?

Traditionally, research has focused on individual differences between families at a given point in time (or at a given age). At any given age, some youths may be expected to have more autonomous responsibility for diabetes care than others, and some families may be expected to show greater discrepancies than other families. Such individual differences of initial status *at one point in time*, however, provide no information about individual differences in the magnitude and direction of changes *over time*. In other words, they do not tell us whether the *rate of transfer* of responsibility from parent to youth is relatively uniform across families (even though some families may start the transition at earlier ages than others), or whether some families transfer responsibility at significantly faster rates than others, such that some youths gain autonomous responsibility more rapidly than other youths. Similarly, they do not tell us whether change in parent-youth discrepancies follows a homogenous trend across all families, or differs markedly between families, such that views about responsibility tend to converge in some families and diverge in other families over time.

Examining the extent to which families differ in rates of change over time makes it possible to evaluate whether differences between families observed initially (i.e., differences in initial or baseline status) are based on a relatively consistent and stable family "disposition," or whether such differences are more short-lived and situationally determined. Previous research has documented considerable and significant individual differences in growth rates of behavioral autonomy in healthy adolescents and adolescents with spina bifida (DeLucia & Pitts, 2006; Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009), and significant differences of change in family conflict during adolescence (Herrenkohl, Kosterman, Hawkins, & Mason, 2009). Accordingly, it was hypothesized that families would significantly vary in rates of change in youth autonomous responsibility for diabetes management, and that families would significantly vary in changes in perceptual discrepancies about responsibility.

Relationship between initial status and change in responsibility

As a final descriptive aspect in characterizing the developmental trajectories of parent-youth responsibility, the relationship between individual differences at study entry and individual differences in rates of change was explored. Examining the way in which families' individual starting point (i.e., their initial status at baseline) relates to families' rates of change can provide valuable information for understanding the underlying nature of developmental trajectories (Klein & Muthén, 2006; Raudenbush & Bryk, 2002; Seltzer, Choi, & Thum, 2003; Wilson et al., 2002). It addresses the question: if we know how families start relative to other families, can we predict how they will progress in comparison with other families? An advantage of the individual growth curve approach used in this study is that initial status and rate of change are treated as simultaneous outcomes, and the relationship between them is explicitly estimated. A positive relationship between initial status and change indicates that initial individual differences tend to be magnified over time, and a negative relationship between initial status and change indicates that initial individual differences tend to be diminished over time.

With regard to youth levels of responsibility, it is unclear to date whether having relatively high autonomous responsibility at a given age predicts faster or slower subsequent growth in responsibility (i.e., whether the transfer of responsibility takes place at a faster pace in those youths who show high levels of responsibility initially, or whether youths with initially lower levels of responsibility tend to "catch up" over time). With respect to parent-youth discrepancies, the developmental and clinical literatures convey controversial predictions: theories of adolescent development suggest that initial parent-youth discrepancies may often be a natural outgrowth of healthy development, and generally tend to be resolved over time (Holmbeck et al., 1996; Lerner & Spanier, 1980; Steinberg, 1990). By contrast, clinical models such as the "miscarried helping" model (Anderson & Coyne, 1991) outlined earlier suggest that initial discrepancies may be the starting point of an interactive cycle of "escalation," such that they may tend to exacerbate over time.

Given that the current status of the empirical literature did not afford specific predictions, the analysis of relationships between initial status and change in levels of responsibility and in parent-youth discrepancies were exploratory.

Aim 2: Relationships between responsibility trajectories and diabetes self-care outcomes

A central goal of the study was to identify aspects of the parent-youth transfer of responsibility that relate to the successful management of diabetes during adolescence. Accordingly, the second aim was to examine how trajectories in levels of youth responsibility and parent-youth discrepancies in perceptions of responsibility are associated with trajectories in diabetes self-care outcomes (i.e., adherence to the diabetes regimen and glycemic control).

The multilevel growth curve approach used in this study made it possible to estimate how initial status and change on one variable relates to initial status and change on other variables, thus allowing for a comprehensive analysis of the dynamic interplay between youth levels of responsibility, parent-youth discrepancies in perceptions of responsibility, and diabetes self-care outcomes. Figure 2 illustrates the different types of relationships that were addressed. First, cross-sectional (baseline) associations between initial status in responsibility and initial status in self-care outcomes were examined (path

A in Figure 2). The second type of analyses addressed whether initial status differences in responsibility predicted changes in self-care outcomes (path B in Figure 2). The third type of analyses addressed whether changes in responsibility were associated with changes in self-care outcomes (path C in Figure 2).

Initial status in responsibility in relation to initial status in self-care outcomes

As discussed previously, prior cross-sectional studies have found that higher levels of youth responsibility and parent-youth discrepancies in perceptions of responsibility are both associated with worse self-care outcomes, but few studies have examined these two aspects of responsibility together. Thus, expanding upon prior cross-sectional work, this study evaluated their combined and relative contribution to understanding concurrent differences in adherence and glycemic control. It was hypothesized that at any given age, relatively higher levels of youth responsibility and greater parent-youth discrepancies are both uniquely associated with concurrently poorer adherence and glycemic control.

Initial status in responsibility as a predictor of change in self-care outcomes

An obvious limitation of prior cross-sectional work is that it does not afford any conclusions about the directionality of influences. According to many models of human development including developmental contextualism (Lerner, 1998), the ecological development perspective (Bronfenbrenner, 1979), and the lifespan development perspective (Baltes, 1987; Lerner & Spanier, 1980), development is the result of bidirectional influences occurring between individuals and their environmental contexts. Theoretically, it has been assumed that a positive parent-youth distribution of responsibilities influences (i.e., causes) more successful self-care outcomes of diabetes.

One longitudinal study (Helgeson et al., 2008) found that greater initial levels of parent responsibility for diabetes care predicted an improvement in self-care behavior over the following year; the extent to which parent-youth discrepancies at a given time predict diabetes self-care outcomes in the long-run remains to be determined empirically (Butner et al., 2009).

To overcome this limitation of previous cross-sectional research, this study examined whether initial status in responsibility levels and in parent-youth discrepancies *precipitate changes* in diabetes self-care outcomes. It was hypothesized that higher levels of youth responsibility and greater parent-youth discrepancies at any given age are both uniquely associated with unfavorable subsequent change in adherence and glycemic control.

Changes in responsibility in relation to changes in self-care outcomes

Given the dynamic developmental nature of the parent-youth transition of responsibility for diabetes management, it is also crucial to examine how *changes* in the level of youth responsibility and in parent-youth discrepancies relate to *changes* in self-care outcomes.

With respect to changes in responsibility levels, there is good reason to assume that an optimal transfer of responsibility may occur if adolescents *gradually* assume more autonomous responsibility for diabetes management rather than gaining responsibility *rapidly* and abruptly (Palmer et al., 2004; 2009). The most recent American Diabetes Association guidelines for care of children and adolescents with type 1 diabetes (Silverstein et al., 2005) state that "the goal should be a *gradual* transition toward independence in management" (p. 186, italics added for emphasis). Such a graduated approach to autonomous self-care may be essential for allowing youths to build the necessary confidence in their ability to master the demands associated with the diabetes treatment independently, rather than being overwhelmed by the complexity of the daily diabetes treatment (Holmes et al., 2006; Ott et al., 2000). Consequently, the extent to which the parent-youth transfer of responsibility takes place at a faster or slower pace may be uniquely important for understanding changes in self-care outcomes over time in addition to the youths' initial level of autonomous responsibility.

Similarly, changes in parent-youth discrepancies may play a vital role in successful self-care. From a developmental perspective, it has been suggested that the initial occurrence of discrepancies in perceptions between adolescents and their parents may not in all instances be dysfunctional in nature. Initial discrepancies may represent a natural outgrowth of the typical autonomy seeking of the adolescent and may even serve as a catalyst for positive child development if they are eventually reduced and resolved (Greenley, Holmbeck, & Rose, 2006; Holmbeck & O'Donnell, 1991; Lerner & Spanier, 1980; Ohannessian, Lerner, Lerner, & von Eye, 2000; Steinberg, 1990). On the other hand, the occurrence of discrepant opinions may be dysfunctional and maladaptive if it does not spur changes in the parent-youth relationship and if discrepancies persist or worsen over time (Butner et al., 2009). Similarly, the "miscarried helping" model outlined earlier suggests that increasing difficulties with diabetes management may be expected as the result of an interactive process in which parent and youth develop progressively divergent and opposing views about who is in charge for the treatment (Anderson & Coyne, 1991).

Accordingly, it was hypothesized that change in responsibility levels and change in parent-youth discrepancies are both uniquely associated with change in self-care outcomes, such that faster growth in youth responsibility and increases in discrepancies are associated with unfavorable changes in adherence and glycemic control. Furthermore, it was hypothesized that changes in responsibility and parent-youth discrepancies explain differences in change of self-care outcomes above and beyond what is explained by initial levels of responsibility and initial discrepancies.

Aim 3: Baseline family system characteristics predicting responsibility trajectories

The final aim of this study was to examine whether longitudinal trajectories in youth levels of responsibility and in parent-youth discrepancies can be predicted from characteristics of the family system assessed at study baseline. Determining aspects of the family system that may facilitate or impede optimal patterns of the parent-youth transfer of diabetes responsibilities may be important to preemptively identify families at heightened risk for poor illness management outcomes. Of particular interest here are "dispositional" aspects of family functioning that may be assumed to be relatively stable over time, given that such family characteristics may provide an enduring developmental context shaping a family's transition of diabetes responsibilities during adolescence.

In accordance with ecological systems theory (Bronfenbrenner, 1979), the family system can be conceptualized as comprising multiple subsystems that are hierarchically nested within each other, each of which may contribute to positive developmental outcomes individually or in combination. This study examined four hierarchically nested aspects of the family system: (a) socializing behaviors of the parent, (b) parent-youth dyadic communication, (c) support from family members in general, and (d) the home environment. Figure 3 illustrates the family characteristics under study and the expected relationships. To investigate the long-term influence of these family characteristics on the transition of responsibility, it was examined how each of them related to both *initial status* and *change* in youth responsibility levels and in parent-youth discrepancies about responsibility for diabetes management.

(A) Parental socializing behaviors: Dimensions of authoritative parenting. On the level of parenting behavior, a large body of research has suggested that an authoritative parenting style is associated with favorable adolescent developmental and socialization outcomes (Darling & Steinberg, 1993; Steinberg & Silk, 2002). Maccobi & Martin (1983) conceptualized authoritative parenting as a function of two dimensions that were examined in this study: high demandingness and high responsiveness. Demandingness refers to setting disciplinary boundaries and supervising a child’s activity to maintain structure and regimen in the child’s life. Responsiveness refers to parental warmth and acceptance, recognition of the child’s individuality, and acquiescence to the child’s demands and needs (Darling & Steinberg, 1993).

(B) Parent-youth interaction: open parent-youth communication. On a dyadic level of parent-child interaction, the extent to which parent and youth are able to openly communicate their changing preferences, needs, and feelings with each other appears to be particularly important during the adolescent years. Barnes and Olson (1985) advocate that communication is a central mechanism for optimal family functioning, in that it allows family members to maintain cohesion and connectedness while at the same time facilitating the family’s adaptability and positive reorganization in response to changing developmental demands. Thus, open parent-youth communication may be a central

ingredient for consensual involvement and collaborative management of diabetes during adolescence.

(C) Family relationships: family support. On a more global intrafamily level, the extent to which a youth experiences supportive relationships from family members in general was considered. The perceived availability of social support is often acknowledged as a key resource promoting successful coping with developmental stressors and favorable adjustment in adolescence (Gottlieb, 1991; Sandler, Miller, Short, & Wolchik, 1989). The youth's awareness and experience that social support from family members is available when needed may facilitate the ability of parents to remain involved in the daily management of diabetes, while enabling the youth to appraise parental involvement as constructive rather than intrusive (Nansel, Rovner et al., 2009).

(D) Home environment: chaos at home. On the most general level considered here, homes and households vary in the extent to which they are organized or "chaotic," that is the extent to which they are characterized by high levels of confusion, agitation, crowding, noise, and a consistent sense of rush and pressure (Matheny, Wachs, Ludwig, & Phillips, 1995). Evidence suggests that home chaos is related to, but distinct from other social and psychological constructs involving the family environment (Dumas et al., 2005). Homes that are disorganized and chaotic may not offer an environment that facilitates the routines and regularities necessary for responsive parental discipline, adequate parental involvement in the youth's everyday life tasks, and optimal parent-youth interactions (Nelson, O'Brien, Blankson, Calkins, & Keane, 2009; Valiente, Lemery-Chalfant, & Reiser, 2007).

Each of the different family system characteristics (adaptive parenting, open parent-youth communication, family social support, and the absence of home chaos) may potentially facilitate the positive development of diabetes self-care autonomy during adolescence. Accordingly, it was hypothesized that adaptive parenting, open parent-youth communication, family social support, and the absence of home chaos are each associated with lower initial levels of youth responsibility and lower initial parent-youth discrepancies, as well as with slower increase of youth responsibility and reduction of discrepancies over time.

Summary of hypotheses

The study hypotheses are summarized in the following.

Hypotheses for Aim 1, developmental trajectories in responsibility for diabetes management:

- *Hypothesis 1a:* Older youths will have higher levels of autonomous responsibility than younger youths; this effect will replicate in within-subject analysis of change in responsibility, such that youths on average will have increasing levels of responsibility over time.
- *Hypothesis 1b:* On average, youths' and parents' perceptions of responsibility for diabetes management will be significantly discrepant, such that youths will attribute more responsibility to themselves than the parents attribute to the youths.
- *Hypothesis 1c:* Families will significantly vary in trajectories (initial status and change) of youth responsibility levels, and in trajectories (initial status and change) of parent-youth discrepancies in perceptions of responsibility for diabetes management.

Hypotheses for Aim 2, relationships between responsibility for diabetes management and diabetes self-care outcomes:

- *Hypothesis 2a:* Higher initial levels of youth autonomous responsibility and greater initial parent-youth discrepancies in perceptions of responsibility will both be uniquely associated with concurrently poorer initial levels of adherence and glycemic control.
- *Hypothesis 2b:* Higher initial levels of youth autonomous responsibility and greater initial parent-youth discrepancies in perceptions of responsibility will both be uniquely associated with unfavorable change in adherence and glycemic control.
- *Hypothesis 2c:* Faster increase of youth responsibility and increase in parent-youth discrepancies will both be uniquely associated with unfavorable change in adherence and glycemic control.
- *Hypothesis 2d:* Changes in responsibility and in parent-youth discrepancies will explain differences in change of self-care outcomes above and beyond what is explained by initial responsibility levels and initial discrepancies.

Hypotheses for Aim 3, relationships between responsibility for diabetes management and baseline family system characteristics:

- *Hypothesis 3a:* Adaptive parenting, open parent-youth communication, family social support, and relative absence of home chaos will each be associated with lower initial levels of youth responsibility and lower initial parent-youth discrepancies, as well as with slower increase of youth responsibility levels and reduction of discrepancies over time.

Methods

Procedure

All data were collected in the period from February 2003 through August 2006 as part of the National Institutes of Health (NIH) protocol "Developmental Influences on Family Management of Type 1 Diabetes" [Protocol # 3-CH-N088], conducted at the Prevention Research Branch of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). The protocol was approved by the Institutional Review Boards (IRBs) of the NICHD and the participating clinical site.

Sample inclusion criteria

Youth subject inclusion required diagnosis with type 1 diabetes for a minimum of 1 year; and youth age between 10 and 16 years. Exclusion criteria were the presence of a comorbid chronic illness requiring daily medical treatment, mental retardation, attention deficit disorder or attention deficit hyperactivity disorder, pregnancy, current inclusion in other medical research protocols, or low English reading/writing skills of parent/youth to an extent that would complicate the administration of standard interview questions. The parent/legal guardian who was most involved with the youth's diabetes care was recruited along with each youth.

Recruitment

Recruitment took place at an urban university medical center pediatric outpatient clinic. All families of adolescents who were receiving medical care by one of two pediatric endocrinologists at the clinic, and who met the inclusion criteria, were approached to participate in the study. The flowchart of participant recruitment and retention is shown in Figure 4. Based on electronic clinic files, 182 patients with type 1 diabetes who were in the in the age range of 10 to 16 years were identified. Fifty patients were found to be ineligible by inspection of medical records, and 132 families were sent a brochure and invitation letter, and contacted via telephone for screening and participation in the study. Out of these, 12 were found to be ineligible, and 33 families declined participation, resulting in a baseline study sample of 87 families. Out of these, 80 families were successfully retained for 6-month follow-up, 78 for 12-month follow-up, and 44 for 24-month follow-up assessments, respectively.

Data collection

The assessments were completed during face-to-face interviews (with the exception of 12- and 24-month follow-up interviews, which were completed via telephone) and administered by trained interviewers. All families were given the choice to be interviewed either at their homes or at another convenient location selected by the parent (e.g., a public library near their homes). Prior to interview administration, youths provided informed assent; parents provided informed consent and authorization for disclosure and use of health information from the child’s medical records in accordance with HIPAA regulations. Parent and youth were interviewed simultaneously, but separately by two interviewers. The participants were asked if they preferred to have the questions read to them or to have assistance with writing responses to those instruments requiring brief written responses. Each participant (parent and youth) was given an incentive of $25 for completion of each interview.

Measures

Demographic characteristics

Basic demographic characteristics of the family (e.g., youth age, gender, race, socio-economic status) and youth medical characteristics (e.g., illness duration, diabetes regimen characteristics) were assessed during parent interviews.

Parent-youth distribution of responsibility for diabetes management tasks

The distribution of responsibility for diabetes management tasks was assessed with parallel self-report measures from both youth and parent. For each of 40 diabetes management tasks taken from the Diabetes Independence Survey (Wysocki, Meinhold et al., 1996) and the Diabetes Behavior Rating Scale (McNabb, Quinn, Murphy, Thorp, & Cook, 1994), the respondent is asked to indicate "whose job it is in the family to see that it is done" (e.g., "remembering or deciding when to check blood sugar"). Responses are given on a 5-point scale, with response options for youth report ranging from "it's all my job" to "my parents and I share" to "it's all my parent's job," and response options for parent report ranging from "it's all my job" to "my child and I share" to "it's all my child's job." The respondent also has the option of checking that it is "no one's job" if a given diabetes management task is no one's responsibility. For the purposes of the present analyses, all responses were scored such that higher values indicate greater responsibility of the youth, and were scaled from 0 to 100, such that they can be interpreted as the percent of responsibility assumed by the youth (i.e., a score of 0 indicates that the youth has 0% responsibility, 50 indicates that the youth and parent equally share 50% of the responsibility, and 100 indicates that the youth has full responsibility for 100% of the tasks). The measure has demonstrated adequate internal consistencies in previous research, with Cronbach's alphas of .93 for youth report and .93 for parent report, respectively (Robinson et al., 2009).

Diabetes self-care outcomes

Adherence to the diabetes regimen. Both parent and youth individually completed a modified version of the Diabetes Self-Management Profile (DSMP; Harris et al., 2000; Iannotti, Nansel et al., 2006), a structured interview assessing adherence to the type 1 diabetes regimen. The original DSMP uses an open-ended format. In the modified version (Iannotti, Nansel et al., 2006), interview administration and scoring are standardized to facilitate administration by nonmedical interviewers and to make the instrument more suitable for interviewing younger youths separately from parents. The measure was designed to assess the extent to which diabetes is adequately managed by the family, regardless of who is responsible for managing the tasks. Participants are instructed to report the extent to which certain tasks are done, regardless of who (parent or youth) does them.

The interview includes a total of 29 items assessing adherence in the areas of insulin administration, meal planning, exercise, blood glucose testing, and self-care adjustments. An overall score is derived by averaging the scores from these five adherence domains, and represents the percent of adherence relative to "optimal" diabetes management (possible scores of 0 to 100), with higher scores reflecting greater adherence. The instrument has shown to exhibit sound psychometric characteristics and adequate internal consistency, with Cronbach's alphas of .70 for youth report and .75 for parent report, respectively (Iannotti, Nansel et al., 2006). The measure has demonstrated criterion validity in relation to glycemic control (Schneider et al., 2007), and has demonstrated theoretically expected relationships with self-efficacy and self-esteem for diabetes (Iannotti, Schneider et al., 2006; Schneider et al., 2009).

Glycemic control. Youths' metabolic control was indexed via glycosylated hemoglobin (HbA_{1c}) levels, assessed as part of the patients' routine clinic visits during the study period, and transcribed from the patients' medical records. HbA_{1c} is an indicator of a patient's average blood glucose levels over the preceding 3 months (Sacks et al., 2002).

Measures of family systems variables

Youth reports of parenting style. The Authoritative Parenting Index (Jackson, Henriksen, & Foshee, 1998) consists of two subscales representing dimensions of parenting style: responsiveness (9 items) and demandingness (7 items). Items are rated on a 4-point scale indicating the degree of agreement or disagreement with descriptive statements about the parent (e.g., "my parent listens to what I have to say," for responsiveness; "my parent has rules that I must follow," for demandingness). Previous studies have supported the two-factorial structure of the scale, convergent relationships with adolescent risk behaviors, and acceptable internal consistencies of the responsiveness (Cronbach's alphas commonly exceeding .80) and demandingness (Cronbach's alphas commonly exceeding .70) subscales across a variety of samples (Jackson et al., 1998).

Youth reports of social support from family. A version of the Perceived Social Support Scale (Procidano & Heller, 1983) modified by DuBois, Felner, Sherman & Bull (1994) was used to assess youth perceptions of family support. The measure consists of 30 items and yields separate scores for levels of perceived social support received from family, peers, and school personnel, respectively. Each item is a declarative statement (e.g., “My family notices and gives me help when I need them to”), which the respondent is asked to rate on a 3-point scale (*no, sometimes, yes*). For the present purpose, only the 10-item subscale referring to support from family members was examined. Prior research has provided support for the reliability of the measure, with Cronbach’s alpha levels generally exceeding .80 (DuBois et al., 2002; DuBois, Felner, Brand, Phillips, & Lease, 1996; DuBois et al., 1994).

Parent reports of parent-adolescent communication. The 20-item Parent-Adolescent Communication Scale (Barnes & Olson, 1982) has two subscales. The Open Family Communication subscale (10 items) measures the exchange of information between family members; higher scores denote more openness. The Problems in Family Communication subscale (10 items) measures negative feelings about communication and the absence of sharing emotions or selectiveness in exchange of information. Scores on the problem communication scale are reversed, such that higher scores denote fewer problems. Items are declarative statements (e.g., “I find it easy to discuss problems with my child”), and are rated on a 5-point scale ranging from *strongly disagree* to *strongly agree*. The two-factorial structure, as well as reliability of the two subscales has been supported, with Cronbach’s alpha reliabilities of .87 (Open Communication) and .78 (Problems with Communication), and 4-week test-retest reliabilities of .78 (Open Communication) and .77 (Problems with Communication).

Parent reports of order and confusion at home. The Confusion, Hubbub, and Order Scale (CHAOS; Matheny, Wachs, Ludwig, & Phillips, 1995) is a self-report measure of environmental confusion in the home, including noise, crowding, and environmental “traffic patterns” such as the number of people coming and leaving the home. It consists of 15 true or false statements about chaos and disorganization in the home environment (e.g., "There is often a fuss going on at our home"). The scale has previously demonstrated adequate internal consistency (Cronbach's alpha of .79), test-retest reliability (r = .74 over a 12-month interval), and construct validity established by demonstrating relationships with directly observed traffic patterns at home (Matheny et al., 1995).

Analytic strategy

Prior to testing the hypotheses, the data were inspected for missing values, outliers, and deviations from normality. Psychometric properties (means, standard deviations, skewness, kurtosis) and internal consistencies (Cronbach's alpha) of all self-report measures were examined for each wave of assessment.

Multilevel modeling data analysis framework

Multilevel modeling was the primary analytic strategy used for hypothesis testing in this study. This strategy has several advantages when working with developmental and dyadic data, but has not yet been frequently applied in pediatric psychology research (DeLucia & Pitts, 2006) and in the analysis of dyadic data in family research (Lyons & Sayer, 2005). Multilevel modeling takes into account the fact that repeated observations are nested within individuals and that parents and youths are nested within families, and appropriately adjusts the standard errors of parameter estimates for this nonindependence of observations. For dyadic data, it permits the comparison of family members' responses on average across all families and between individual families (Barnett et al., 1993). For longitudinal and developmental data, it permits the study of population average change and individual differences in change over time (Singer & Willett, 2003). The longitudinal multilevel model for change, or "individual growth curve analysis," fits a latent trajectory (a weighted regression line) through time for each individual, thus allowing for unbalanced designs: individuals can be observed at different time points, as opposed to assuming that the number and spacing of the measurements is the same across all families. A final advantage of multilevel modeling is the use of direct maximum likelihood parameter estimation, which allows inclusion of all participants in the analyses even if some people have missing data. It is possible for only one family member to contribute data at one or more time points or for the pattern of missing responses to be different for each family member (Atkins, 2005). Under the assumption that the data are missing at random (i.e., ignorable, in that they can be modeled as a function of nonmissing data), the maximum likelihood approach preserves the available data and permits valid conclusions where traditional strategies (e.g., listwise deletion) may be biased (Jeličić, Phelps, & Lerner, 2009; Schafer & Graham, 2002).

Multilevel model for trajectories of youth responsibility levels and parent-youth discrepancies

The analytic approach used in the present study is based on the combination of a multilevel model for individual growth curve analysis and a multilevel model for dyadic (i.e., parent and youth) data. Theoretically, there are various alternative parametrizations possible for representing the information contained in longitudinal and dyadic data in a multilevel model, which yield formally identical models but different interpretations of the estimated parameters (see Atkins, 2005; Kenny et al., 2006; Lyons & Sayer, 2005; Lyons et al., 2002; Raudenbush et al., 1995; Singer & Willett, 2003). For the present purpose, the parameters were specified to provide direct estimates of the initial status and change (for the repeated measures data) of the parent-youth mean and the parent-youth discrepancy (for the dyadic data) in ratings of the youth's responsibility level. In this multilevel model, the Level 1 ("within-family") submodel describes the initial status and change in the dyad mean and in the dyad discrepancy in each family, and a Level 2 ("between-family") model describes how each of these estimates varies across families.

The general model can be expressed as

Level 1: $Y_{ij} = (\text{D\_MEAN})_{ij}\,[\pi_{A0i} + \pi_{A1i}\,(\text{TIME})_{ij}] + (\text{D\_DISC})_{ij}\,[\pi_{B0i} + \pi_{B1i}\,(\text{TIME})_{ij}] + \varepsilon_{ij}$

Level 2: $\pi_{A0i} = \gamma_{A00} + \gamma_{A01}\,(\text{AGE})_i + \zeta_{A0i}$

$\pi_{A1i} = \gamma_{A10} + \zeta_{A1i}$

$\pi_{B0i} = \gamma_{B00} + \gamma_{B01}\,(\text{AGE})_i + \zeta_{B0i}$

$\pi_{B1i} = \gamma_{B10} + \zeta_{B1i}.$

At Level 1, Y_{ij} is the rating of youth responsibility for diabetes management made by either youth or parent at time *j* in family *i*. The $(\text{D\_MEAN})_{ij}$ term is coded as 1 for both dyad members' ratings, and replaces an intercept term. It estimates the *dyad mean* rating of the *level* of youth responsibility, that is, the latent average of youth and parent reports of the youth's responsibility level. The $(\text{D\_DISC})_{ij}$ term is coded as 0.5 for the youth and –0.5 for the parent, and represents a linear contrast (slope) between parent and youth perceptions of responsibility. It estimates the *dyad discrepancy* in ratings of the youth's responsibility, that is, the latent difference of youth and parent reports of the youth's responsibility (see Cano, Johansen, & Franz, 2005; Cheung, 2009; Lyons et al., 2002; Mounts, 2007; Newsom, 2002). The $(\text{TIME})_{ij}$ term is a linear contrast taking on the time of the measurement since baseline. Therefore, the first set of parameters π_{A0i} and π_{A1i} characterize initial status (intercept) and change (linear slope) of the dyad mean for family *i*, and the second set of parameters π_{B0i} and π_{B1i} characterize initial status (intercept) and change (linear slope) of the dyad discrepancy in family *i*. The ε_{ij} term represents random measurement error within the family.

Given that two parameters (dyad mean and dyad discrepancy) are estimated based on two observations (parent and youth) at each time point, the model would normally assume that the dyad mean and dyad discrepancy are measured without error at a given point in time. To circumvent this problem, two observations were included for each respondent and time point by forming parallel parcels with similar variance from the responsibility items (see Barnett et al., 1993; Cano et al., 2005; Lyons & Sayer, 2005; Lyons et al., 2002; Raudenbush et al., 1995). This way, the dyad mean and dyad discrepancy represent latent constructs at each time point and the ε_{ij} term corrects for measurement error at a given point in time.

At Level 2, the Level 1 coefficients (πs) serve as latent multivariate outcome variables. The Level 2 γs represent the population averages (i.e., fixed effects) of the latent trajectories for the dyad mean and dyad discrepancy. The $(\text{AGE})_i$ term represents a youth's age at baseline, centered above 10 years of age (the youngest study participant). Thus, the intercept terms (γ_{A00} and γ_{B00}) indicate the average dyad mean and dyad discrepancy at 10 years of age, the Level 2 fixed effects of the AGE predictor (γ_{A01} and γ_{B01}) indicate the cross-sectional age differences in the dyad mean and dyad discrepancy, and the linear slope terms (γ_{A10} and γ_{B10}) indicate the average change in the dyad mean and in the dyad discrepancy over time.

The Level 2 ζs characterize the variation (i.e., random effects) of individual families' trajectories above those average trajectories. The random effects for the intercept terms (ζ_{A00} and ζ_{B00}) represent the variance in initial status for the dyad mean and dyad discrepancy that is not explained by baseline age (i.e., deviations from the statistically "expected" average initial status at a given age). The random effects for the linear slope terms (ζ_{A10} and ζ_{B10}) represent the variance in change above average changes in the dyad mean and dyad discrepancy. Finally, the covariances between the ζs indicate the linear associations between families' initial status and change in the dyad mean and families' initial status and change in discrepancy.

Supplemental multilevel model for trajectories of youth and parent perceptions of responsibility

The multilevel model specified above provided direct tests of the study hypotheses. However, it is also illustrative to inspect the trajectories of youths' perceptions and parents' perceptions of youth responsibility within dyads, given that these are the underlying components of the dyad mean and the dyad discrepancy. Therefore, trajectories of youth and parent perceptions of youth responsibility were also estimated in supplementary analyses. The Level 1 model can be expressed as

$$Y_{ij} = (\text{YOUTH})_{ij}\,[\pi_{A0i} + \pi_{A1i}\,(\text{TIME})_{ij}] + (\text{PARENT})_{ij}\,[\pi_{B0i} + \pi_{B1i}\,(\text{TIME})_{ij}] + \varepsilon_{ij}.$$

In this model, the $(\text{YOUTH})_{ij}$ term is coded as 1 for youths and as 0 for parents, to yield estimates of the initial status and change for youths, and the $(\text{PARENT})_{ij}$ term is coded as 0 for youths and as 1 for parents, to yield estimates of the initial status and change for parents. Apart from the difference in interpretations of these parameters, the model is identical with the model for trajectories of dyad means and dyad discrepancies.

Specific analyses

The described multilevel models served as the basis for the analyses involved in the three specific aims. HLM 6 (Raudenbush, Bryk, & Congdon, 2004) was used for the analyses.

For analyses addressing aim 1, average developmental trajectories of the dyad mean and dyad discrepancy in perceptions of responsibility were examined by testing the Level 2 fixed effects for age at baseline and for linear change over time. Evidence for curvilinear age trends were explored variously by adding quadratic terms for baseline age, and by testing the interaction between baseline age and change over time. The significance of variation in the trajectories (initial status and change) of the dyad mean and dyad discrepancy was examined with likelihood-ratio tests comparing the deviance statistics of restricted models and unrestricted models.

For analyses addressing aim 2, the multilevel model was expanded by an additional multivariate outcome representing initial status and change in adherence or glycemic control. Separate models were estimated for each of the diabetes management outcomes, that is, youth-reported adherence, parent-reported adherence, and HbA_{1c}. To examine the unique contribution of the dyad mean and dyad discrepancy in perceptions of responsibility for understanding initial status and change in diabetes management outcomes, latent variable regression analyses available in HLM 6 were conducted. This approach allows for multiple regression analyses based on the Level 2 random effects variances and covariances in multilevel models, and provides estimates that are appropriately corrected for the Level 1 residual variances.

To address aim 3, each of the family systems characteristics (parenting style, parent-youth communication, family social support, and home chaos) were entered individually as time-invariant (i.e., Level 2, “between-families”) predictor variables of initial status and change of the dyad mean and dyad discrepancy in perceptions of responsibility.

Statistical power considerations

Power to detect population average change

Statistical power analysis for multilevel growth curve models is substantially more complex than for traditional designs. The power to detect change within subjects depends not only on the magnitude of change, sample size, and alpha level, but also on additional factors including the number and spacing of measurement occasions, random effects variances (variances and covariance of initial status and individual change), growth curve reliability, and amount of missing data (Raudenbush & Xiao-Feng, 2001).

The magnitude of within-subject change in levels of youth responsibility for diabetes management that could be reliably detected given the present data was estimated via simulation, using a set of SAS macros by Zhang and Wang (2009). The simulation was based on 1000 replications of likelihood ratio tests to evaluate the null hypothesis of no average change within subjects given a sample size of 87, four measurement occasions, and 15% randomly missing data. Youth responsibility was scaled from 0 to 100. Assuming a mean initial status of 50, random effects standard deviations of 15 (for initial status) and 5 (for change), and no random status-change covariance, the mean yearly rate of change detected with a power of 80% at a significance level of .05 (two-tailed) is 2.0 scale-points [corresponding estimates apply for change in parent-youth discrepancies and change in self-care outcomes]. For comparison, la Greca et al. (1990) found levels of youth responsibility for diabetes differing by 3.4 points (on a 100-point scale) per year of age in between-subjects (cross-sectional) analyses.

Power to detect individual differences in change and correlated change

To date, relatively little information is available about the power to reliably detect individual differences in change and correlations between growth curves. Existing recent simulation studies (Hertzog, Lindenberger, Ghisletta, & von Oertzen, 2006; Hertzog, von Oertzen, Ghisletta, & Lindenberger, 2008) suggest that statistical power in these analyses depends to a very large extent on the reliability of the individual growth curves. Power is greatly enhanced if multiple indicators per variable are specified to represent a latent construct at each measurement occasion, such that growth curves are corrected for random measurement error occurring at each occasion (Hertzog et al., 2006; 2008). Using this approach, Raz et al. (2005) were able to detect medium sized effects of differences in change and correlations between growth curves (r = .35) using only 2 measurement occasions and a sample size of 72 individuals. Thus, in accordance with recommendations by Raudenbush et al. (1995) and Hertzog et al. (2006; 2008), parallel parcels (ensuring equal variance of scores across parcels) of responsibility scores were used for the estimation of individual growth curves.

Results

Study sample

Sample characteristics at baseline

Baseline demographic and medical characteristics of the participating youths and their parents are shown in Table 1. The study sample included approximately equal numbers of boys (44.8 %) and girls (55.2%), and the majority of youths were White (71.3 %). The mean age was 13.44 years (*Mdn* = 13.40), with approximately one third of the youths between the ages of 10 to 11 years (32.2%), 12 to 14 years (37.9%), and 15 to 16 years (29.9%). Most youths came from a high socio-economic background: thirty-five (40.2%) lived in families with a total household income of at least $100,000, and more than half of the interviewed parents/caregivers (*n* = 49; 56.3%) had at least a college graduate degree. For most of the families (*n* = 75; 87.0%), mothers completed the parent/caregiver interviews, followed by fathers (*n* = 9; 10.5%) and grandmothers (*n* = 2; 2.3%).

The average diabetes duration in the sample was 6.3 years (*Mdn* = 5.8 years), ranging from one to fifteen years. The insulin regimen of the majority of youths (*n* = 54; 62.1%) involved multiple daily injections (between 2 and 5 per day) without long-acting basal insulin. The remaining youths used a combination of basal- and short-acting insulin (*n* = 10; 11.5%) or insulin pump therapy (*n* = 23; 26.4%).

Comparison of youths retained versus not retained at 24-month follow up

Whereas a substantial percentage of the families participating at baseline were successfully retained for 6-month (92%) and 12-month (90%) follow-up assessments, only 51% of the families were available for the final 24-month follow-up. For this reason, whether families who completed the 24-month assessment systematically differed from those who were lost at 24-month follow-up was examined. As shown in Table 2, there were no significant differences between these two groups on youth age, gender, time since diagnosis, as well as on the socio-demographic variables ethnicity, family income, and parent education.

Traditional methods of handling missing data, such as listwise and pairwise deletion, require a strong assumption that data be missing completely at random (MCAR), such that the observed values are a random sample of all the values that could have been observed had there been no missing data. The fact that there are systematically more missing data at 24-month follow-up does not support the assumption that the present data are MCAR. One of the advantages of multilevel modeling using direct maximum likelihood parameter estimation is that individual growth models are sound as long as the unobserved values are missing at random (MAR), a much less restrictive assumption. When data are MAR, the probability of missingness can depend on any observed values for either the predictors or the outcome (Jeličić et al., 2009; Singer & Willett, 2003). As Singer and Willett (2003) noted, "The allowance for dependence upon observed outcome data can account for a multitude of sins, often supporting the credibility of the MAR assumption even when MCAR … assumptions seem far-fetched" (p, 158). The MAR assumption would be violated if youths were less likely to be interviewed at a given wave because they had especially high or low levels of responsibility for diabetes management at that particular point in time. It seems unlikely that many youths or parents would be unwilling to participate because of the youth's responsibility level at a given occasion. Thus, despite attrition, the multilevel analyses are based on all 87 families who had some outcome data.

Assessment of responsibility for diabetes management tasks

The parent-youth division of responsibility for diabetes management was assessed with a set of 40 items addressing a broad spectrum of diabetes management tasks. The tasks addressed in the items of this newly developed scale were taken from the Diabetes Independence Survey (Wysocki, Meinhold et al., 1996) and the Diabetes Behavior Rating Scale (McNabb et al., 1994). To identify items that should potentially be deleted from further analyses, descriptive characteristics of the responses to the pool of 40 items were inspected first. Subsequently, psychometric properties of the scale scores were examined.

Item selection

Table 3 shows the frequency distribution of parent and youth responses for each item at the baseline assessment. Scores on all items showed considerable variability: with few exceptions, the range of responses covered all 5 possible response choices (from "it's all my job" to "it's all my parent's / my child's job"), and all standard deviations exceeded two thirds of a scale-point (*SD*s averaged 1.13, ranging from 0.67 to 1.44 for youth reports, and *SD*s averaged 1.02, ranging from 0.71 to 1.42 for parent reports).

For each item, respondents were also given the option to indicate that a task is "no one's job" in the family. Given that available treatment regimens for type 1 diabetes are continuously changing due to medical and technological advances, this option was added to identify self-management tasks that may not apply to families using current treatment approaches. As shown in Table 3, this option was infrequently used by youths or parents for most items. However, for five items more than 10% of the participants (youths and parents) indicated that these tasks would be "no one's job" — this was evident at each wave of assessment. Out of these items, 4 pertained to testing ketones from the urine (items 7, 8, 9, and 29), and one item asked about remembering to wear diabetes identification (item 37). One additional item ("calling the doctor in case of severe symptoms that you cannot correct") was not administered at follow-up assessments. These six items were eliminated from further analyses and the remaining 34 items were included in subsequent analyses.

Scale scores — psychometric properties

Scale scores for youth and parent perceptions of the youth's autonomous responsibility for diabetes management were computed by averaging the relevant items for each wave of assessment. The scores were transformed to a scale ranging from 0 to 100, such that they may be interpreted as the *percentage* of responsibility independently assumed by the youth. The scale scores showed high internal consistency for both youth- and parent-report forms at each assessment wave (Cronbach's alphas ranging from .94 to .96). Descriptive characteristics and intercorrelations between parent and youth report and assessment waves are shown in Table 4.

These descriptive data suggest that scores of youth autonomous responsibility on average increased over the four measurement occasions for both youth and parent report. Intercorrelations between youth and parent report were generally moderate (*r*s ranging from .58 to .72). Intercorrelations between assessment waves were moderate to high for both youth report (*r*s ranging from .72 to .82) and parent report (*r*s ranging from .81 to .90). As shown in Figure 5, the scores were fairly normally distributed at each occasion, showing minimal skewness and kurtosis and no evidence of floor or ceiling effects.

Creation of parallel parcels

The magnitude of individual differences in growth curve analysis can be severely underestimated if parameter estimates are based on a single indicator (i.e., a scale score) at each occasion, because this assumes that the construct is measured without error at a given point in time (Hertzog et al., 2006; 2008). For the subsequent multilevel modeling analyses, the scale scores of responsibility for diabetes management were divided into two parallel parcels to adjust the growth curve estimates of responsibility for random measurement error, and in accordance with previous cross-sectional and longitudinal studies using a multilevel modeling approach to dyadic data analysis (Barnett et al., 1993; Cano et al., 2005; Lyons & Sayer, 2005; Lyons et al., 2002; Raudenbush et al., 1995). Specifically, the 34 responsibility items were divided into two groups of 17 items for each respondent and each occasion, such that each family had a record of up to 16 observations for the multilevel modeling analyses (two for parent and youth for each of four time points). To create the two parcels, matched pairs for the 34 items were formed based on their standard deviations, and the items of each pair were then randomly assigned to one of the two parcels (see Barnett et al., 1993; Raudenbush et al., 1995). This randomization procedure was performed on the youths' baseline scores, and the resulting assignment of items to parcels was applied to the remaining measurement occasions, and to parent reports. As shown in Table 5, the procedure created two parallel parcels with approximately equal variance and internal consistencies. In addition, the two parcels were highly correlated at each measurement occasion (*r*s ranging from .90 to .94 and *r*s ranging from .92 to .95 for youth report and parent report, respectively), indicating high split-half reliability.

Aim 1: Characterization of developmental trajectories of responsibility

The first aim of this study was to provide a description of the developmental course of the levels of youth autonomous responsibility for diabetes management, and in parent-youth discrepancies in perceptions of youth responsibility, using a multilevel modeling approach. As a first step, a baseline ("unconditional means") model without covariates was examined for comparison of parent and youth reports irrespective of developmental changes. Second, linear developmental effects based on (between-subject) age and (within-subject) change over time were examined. Third, the possibility of curvilinear developmental trends was explored.

Unconditional means models

Prior to examining the multilevel model for change, it is useful to fit a model that does not include age or time as predictor variables. Such an "unconditional means model" implicitly aggregates each participant's responses across measurement occasions, and provides a baseline to establish whether there is any meaningful variation between families and within families over time that is worth examining in individual growth curve analysis (Singer & Willett, 2003).

Unconditional means were estimated simultaneously for youth and parent reports as multivariate outcomes. This also allowed for an overall comparison of youth and parent perceptions of responsibility regardless of possible changes during the adolescent years, to address the hypothesis that youth and parent perceptions would be discrepant from each other. It was hypothesized that, on average, youths would attribute more responsibility to themselves than parents attribute to the youth.

Table 6 displays the results for two different parameterizations of this model, as outlined in the analytic strategy. In Model A, parameter estimates for youth and parent perceptions of youth responsibility are shown. Model B shows the results for the dyad mean and dyad discrepancy in perceptions of youth responsibility. Models A and B are formally identical, such that they yielded the same deviance statistic (-2*Log Likelihood = 8484.02).

As shown in the random effects portion of Table 6, perceptions of responsibility varied significantly among youths ($SD = 14.26$, $p < .001$) and among parents ($SD =$

14.35, $p < .001$), as well as within youths and within parents over time ($SD = 8.01$, $p < .001$) [1]. Youth and parent perceptions were strongly correlated ($\hat{\rho} = .77$; $p < .001$). In Figure 6, the model-based (empirical Bayes) estimates for individual youths are plotted against their parents, illustrating the correlation.

This close correlation does not mean, however, that youth and parent perceptions do not differ on absolute levels. As shown in the fixed effects portion of Table 6 (Model A), youths on average perceived themselves as having 67.6% of the responsibility, and parents on average perceived their child as having 54.4% responsibility for diabetes management. Thus, as shown in Model B, the youths' judgment on average exceeded parents' judgment by 13.2% ($p < .001$), a highly significant discrepancy between youths and parents.

Families varied significantly on dyad means ($SD = 13.45$, $p < .001$) and dyad discrepancies ($SD = 9.74$, $p < .001$) in perceptions of youth responsibility. The dyad means and discrepancies were uncorrelated ($\hat{\rho} = -0.01$; $p = .93$), indicating that the magnitude of discrepancies did not differ between families in which the youth had relatively high versus low (dyad mean) levels of responsibility.

Figure 7 shows the dyad discrepancies plotted against the dyad means in each family, consistent with the methods for assessing agreement proposed by Bland and Altman (1986). In this figure, a value of zero indicates perfect agreement between youth

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[1] A model in which the within-subjects variance was allowed to differ between youth and parent did not yield a significantly better fit than a model that assumed the within-subjects variance to be equal for youth and parent ($\chi^2 = 0.5$, $df = 1$, $p = .52$). Moreover, models that allowed for heterogeneous variances of the two parallel parcels did not yield a significantly better fit than models that assumed variance homogeneity of the parcels for youth report ($\chi^2 = 0.9$, $df = 1$, $p = .34$) and parent report ($\chi^2 = 0.9$, $df = 1$, $p = .34$). Therefore, a single within-subjects variance term was estimated.

and parent, and positive values indicate that the youth's perception of their responsibility exceeded their parent's judgment. As can be seen, almost all families showed differences in perception above zero. Assuming a normal distribution of discrepancies, it can be estimated that the 95% of the parent-youth differences were between +32.3 and -5.9 percent points (mean ± 1.96 times the square root of the between-dyad variance in discrepancies in Table 6), indicating the "limits of agreement" as per Bland and Altman (1986; see Figure 7). Although it is plausible that some families were negatively discrepant (such that parents perceived the youth to have more autonomous responsibility than the youths did), this pattern can be estimated to occur only in 8.9% of the families.

In conclusion, the hypothesis that the youths on average will view themselves as having more autonomous responsibility for diabetes management than their parents view them to have was supported. Moreover, while there was significant variation in the magnitude of discrepancies between families, the youths' judgment exceeded their parents' judgment in the vast majority (92.1%) of the families.

Longitudinal responsibility trajectories

The next analytic step was to examine developmental trajectories in youth responsibility for diabetes management in multilevel growth curve analyses. Given that the youths' age varied at the beginning of the study (10 to 16-year-olds), and also changed over the course of the study (2 years), there are several choices for scaling the age term in the multilevel model. One option frequently employed in research on developmental change is to use a single predictor of age/time, representing the actual age of each participant at each measurement occasion. Even though this approach is parsimonious, the resulting estimates may confound cohort effects and temporal effects of age (Mehta & West, 2000). To circumvent this problem, two separate predictor variables were used: the youths' age at the baseline assessment was entered as a between-subject (Level 2) predictor, and time since baseline was entered as a within-subject (Level 1) predictor of responsibility for diabetes management. This made it possible to examine to what extent between-subject (i.e., cross-sectional) age differences in responsibility for diabetes management are replicated in within-subject changes of responsibility over time.

Youth *age* at baseline (the between-subject predictor) was centered on 10 years, the age of the youngest study participant. The *time* predictor (the within-subject predictor) was coded as the time in years that had passed since baseline, based on the actual dates that the assessments took place. This ensured that changes in responsibility were precisely estimated even if follow-up assessments were not taken exactly at 6, 12, and 24 months after the baseline assessment. In fact, the actual average time lags were 6.64 months (*SD* = 0.48, range = 5.75 to 8.28 months), 12.77 months (*SD* = 0.87, range = 11.51 to 17.39 months), and 27.13 months (*SD* = 1.75, range = 24.32 to 34.22 months) following the baseline assessments.

The results are displayed in Table 7 and illustrated in Figures 8 to 12. In the following sections, results for fixed effects (i.e., pertaining to population average trajectories) are described first, followed by results for the random effects (i.e., pertaining to individual differences above the average trajectories). It was hypothesized that, on average, older youths would have more autonomous responsibility for diabetes management than younger youths would, and that youths on average would gain increasing responsibility over time. In addition, it was hypothesized that families would show significant heterogeneity in patterns of the parent-youth transition of responsibility.

Results for population average trajectories (fixed effects). With age and time included as predictors in the model, the intercept of the initial status can be interpreted as the average youth responsibility at an age of 10 years. At this age, youth perceptions of their responsibility were estimated as 50.8%, and parent perceptions were estimated as 37.3%. Thus, paralleling the results from the unconditional means model, youth and parent perceptions were estimated to differ from each other on average by 13.6% ($p < .001$) at 10 years of youth age.

The between-subject effect of *age at baseline* was highly significant for both youth and parent perceptions of youth autonomous responsibility: for each year that a youth's age was higher at study entry, youth perceptions of responsibility were greater by 4.2% ($p < .001$), and parent perceptions were greater by 3.8% ($p < .001$). Correspondingly, the dyad mean perception of youth autonomous responsibility was greater by 4.0% ($p < .001$) for each year that a youth's age was higher at study entry. This replicated the results from previous cross-sectional research suggesting older youths have higher levels of autonomous responsibility for diabetes management than younger youths.

Age at baseline did not significantly predict dyad discrepancies in perceptions of youth responsibility for diabetes management ($p = .49$, see Table 7). Thus, there was no evidence that dyad discrepancies would differ between younger and older cohorts at study entry.

The effects for *average rates of change* in responsibility (i.e., the fixed effects of time) were also highly significant: for each year post study entry, youth perceptions of responsibility on average increased by 3.3% ($p < .001$), and parent perceptions of their child's responsibility increased by 5.8% ($p < .001$). Accordingly, the dyad mean perception of youth responsibility increased by 4.5% per year ($p < .001$). This confirmed the hypothesis that levels of autonomous responsibility *change* (i.e., increase) as youths get older, irrespective of any potential cohort effects. It is also interesting to note that the regression coefficients for cross-sectional age at baseline (estimate = 4.0) and for rates of change over time (estimate = 4.5) predicting the dyad mean were very similar in magnitude. Figure 10 shows the estimated levels of responsibility for cohorts of 10, 12, 14, and 16 years of age, together with the estimated rate of change over the subsequent 2 years for each cohort (bold lines in the figure). As can be seen, for each cohort, the predicted level of responsibility two years post baseline corresponds very closely with the predicted initial status of the next cohort. Indeed, when the fixed effects for baseline age and change over time predicting the dyad mean perception of responsibility were constrained to be equal, this did not significantly change the model fit ($\chi^2 = 0.4$, $df = 1$, $p = .54$), indicating that temporal and cohort effects of age did not significantly differ from each other. It can be estimated that for the average youth, the level of autonomous responsibility increased from 44.0% at age 10 to 77.2% at age 18, a considerable increase of 33.2% over the course of 8 years.

As shown in Table 7 and illustrated in Figure 11, the parents' perceptions of youth responsibility on average showed a faster increase than the youths' own perceptions of their responsibility. As a consequence, the average family in the study showed a significant reduction of discrepancies by 2.5 points (p = .009) per year over the study period (see Figure 12).

To summarize, the results supported the hypothesis that levels of autonomous responsibility generally increase during adolescent development as a function of youth age. No such developmental pattern was evident for parent-youth discrepancies in perceptions of responsibility, even though these discrepancies on average longitudinally decreased significantly over the study period.

Results for individual differences in trajectories (random effects). As shown in the random effects portion of Table 7, families differed substantially from each other in their *initial status*: highly significant variances in initial status were evident for youth perceptions (SD = 14.63, $p < .001$) and parent perceptions (SD = 12.63, $p < .001$), as well as for initial status in dyad means (SD = 12.24, $p < .001$) and dyad discrepancies (SD = 12.16, $p < .001$) in perceptions of youth responsibility. Given that age was included as a predictor of initial status in the model, these effects are statistically controlled for baseline age. That is, individual families' initial status varied considerably above what would be expected based on the youth's age at baseline. Initial status estimates were significantly correlated between youth and parent perceptions ($\hat{\rho}$ = .61; $p < .001$), but not between dyad means and discrepancies ($\hat{\rho}$ = .18; p =.13).

In addition, the *rates of change* also evidenced significant variability between families for youth perceptions (SD = 6.94, $p < .001$) and parent perceptions (SD = 4.11, $p < .001$) of youth responsibility, as well as for dyad means (SD = 4.61, $p < .001$) and dyad discrepancies (SD = 6.71, $p < .001$). Estimated rates of change were significantly positively correlated between youth and parent perceptions ($\hat{\rho}$ = .35; $p < .05$). Rates of change in the dyad mean and in dyad discrepancies were also positively associated ($\hat{\rho}$ = .51; $p < .01$), such that the decrease in dyad discrepancies was more pronounced in families in which the dyad mean perception of responsibility increased less rapidly.

The smoothed individual trajectories for each family are shown in Figures 8 to 10 and Figure 12. The individual trajectories in these figures are organized so that their starting points equal the youth's age at study entry, and the length of each line relative to the x-axis indicates the years of observation for that family. Overall, a considerable amount of heterogeneity is evident in the individual paths of change. Even though the dyad mean of youth responsibility increased over time in almost all families, some youths exhibited a much faster growth in responsibility than others (see Figure 10). Moreover, parent-youth discrepancies decreased in some families and increased in other families, despite the overall decline in discrepancies found on average across all families (see Figure 12).

In sum, the hypothesis that families will show significant diversity in patterns of the parent-youth transition of responsibility was supported. Not only did families significantly differ from each other in youth responsibility levels and parent-youth discrepancies at study entry, but they also varied significantly in rates of growth in youth responsibility, and in the direction and magnitude of change in parent-youth discrepancies.

Rates of change dependent upon initial status. The relationships between initial status and subsequent change in perceptions of youth responsibility were also examined. The patterns of individual trajectories displayed in Figures 8 to 10 and Figure 12 suggests consistently negative associations: in fact, the correlations between initial status and change (estimated from the random effects variances and covariances) were significantly negative for youth perceptions of responsibility ($\hat{\rho}$ = -.65; $p < .001$), parent perceptions of youth responsibility ($\hat{\rho}$ = -.31; p =.04), the dyad mean ($\hat{\rho}$ = -.50; $p < .001$), and dyad discrepancies ($\hat{\rho}$ = -.63; $p < .001$). This indicated that initially higher values preceded subsequently slower (or more negative) rates of change, whereas initially lower values preceded subsequently faster (or more positive) rates of change.

Conditional rates of change based on different values of initial status may further illustrate these relationships. In terms of the dyad mean, for each 10% that a youth had more responsibility than expected based on his or her age at baseline, the subsequent yearly growth in responsibility was predicted to be 1.9% slower, such that the yearly increase in responsibility was predicted to be 6.8% (SE= 0.83; p <.001) for youths with initially low responsibility (one standard deviation below the average initial responsibility), but only 2.25% (SE= 0.83; p = .009) for youths with initially high responsibility (one standard deviation above the average initial responsibility). In terms of dyad discrepancies, for each 10% that the parent-youth discrepancy was greater than expected based on the youth's age at baseline, the subsequent yearly change in discrepancies was predicted to be 3.5% more favorable, such that a yearly *increase* in discrepancies by 1.72% (SE= 1.27; p = .18) was predicted for families with initially low discrepancy (one standard deviation below the average initial discrepancy), whereas a yearly *decrease* in discrepancies by 6.77% (SE= 1.27; p < .001) was predicted for families with initially high discrepancy (one standard deviation above the average initial discrepancy). [2]

Examination of curvilinear age trends in responsibility for diabetes management

Up to this point, the analyses considered only strictly linear age trends in youth responsibility for diabetes management. However, it is also possible that youth responsibility levels and parent-youth discrepancies follow *curvilinear* developmental trends.

This possibility was examined in two different ways: First, a quadratic term for youth age at baseline was added as a Level 2 fixed effect to the previous model; evidence for this effect would indicate that the relationship between responsibility for diabetes management and between-subjects age differed across the adolescent years. Second, an alternative method for testing curvilinear developmental trends, the cross-level interaction between youth age at baseline (Level 2) and time since baseline (Level 1), was examined; evidence for this effect would indicate that rates of change in responsibility differed between younger and older youths.

Effects of quadratic baseline age. When a quadratic age term was entered into the model, it did not significantly predict youth perceptions of responsibility (estimate = 0.32, SE = 0.35, p = .37) or parent perceptions of responsibility (estimate = 0.16, SE = 0.37, p = .67). Moreover, the quadratic age term did not significantly predict the dyad

[2] Latent variable regression analyses in HLM were conducted to obtain these estimates, where latent rates of change were regressed on the latent initial status. To obtain standard errors and p-values for conditional rates of change predicted from high versus low initial status, the outcome variables were centered on one standard deviation above and below the estimated average initial status, based on the fixed effects and Level 2 random effects components of the initial status.

mean (estimate = 0.24, *SE* = 0.33, *p* = .47) or the dyad discrepancy (estimate = 0.16, *SE* = 0.30, *p* = .60) in perceptions of responsibility.

Effects of baseline age by time cross-level interaction. The cross-level interaction term between baseline age and time did not significantly predict youth perceptions of responsibility (estimate = 0.36, *SE* = 0.42, *p* = .40) or parent perceptions of responsibility (estimate = -0.22, *SE* = 0.29, *p* = .47). Moreover, the baseline age by time interaction did not significantly predict the dyad mean (estimate = 0.07, *SE* = 0.29, *p* = .81) or the dyad discrepancy (estimate = 0.57, *SE* = 0.45, *p* = .21) in perceptions of responsibility. Taken together, the findings did not support curvilinear developmental trends in levels of youth responsibility or in parent-youth discrepant perceptions about responsibility for diabetes care.

Effect of disease duration

Even though these results suggested that levels of youth autonomous responsibility for diabetes management may increase as a linear function of youth age, it is theoretically possible that disease duration is more closely related to responsibility levels than chronological age. Youths who were diagnosed with type 1 diabetes many years ago may have gained more autonomous responsibility for managing the illness because they had more time to develop the necessary skills and have more experience than youths who were diagnosed more recently. Thus, in supplementary analyses, youth age at baseline was dropped from the model and replaced by disease duration as Level 2 predictor of responsibility. Disease duration did not significantly predict youth perceptions (estimate = 0.14, *SE* = 0.41, *p* = .73), parent perceptions (estimate = 0.12, *SE*

= 0.41, *p* = 77), the dyad mean (estimate = 0.13, *SE* = 0.39, *p* = .73) or the dyad discrepancy (estimate = 0.02, *SE* = 0.29, *p* = .94) in perceptions of responsibility.

Summary of findings

In sum, the analysis of developmental trajectories of youth responsibility for diabetes management produced several major findings. For one, the results suggest that the *levels* of youth autonomous responsibility show a steady increase during the adolescent years as a function of age. On average, youth autonomous responsibility increased within families over time, corresponding with differences found between cohorts. Second, with regard to parent-youth *discrepancies* in perceptions of responsibility, the findings showed that youths' perceptions of their autonomous responsibility were almost always greater than their parents' perceptions. Discrepancies between youths and parents did not show a clear developmental trend, although discrepancies on average decreased during the study period. No curvilinear age-related trends in responsibility levels or parent-youth discrepancies were evident. Moreover, the results confirmed that trajectories in levels of responsibility and parent-youth discrepancies did not follow a uniform and homogenous developmental pattern, but were considerably varied across individual families.

Aim 2: Relationships between responsibility trajectories and diabetes self-care outcomes

The second aim of this study was to examine how trajectories of youth responsibility for diabetes management relate to trajectories of diabetes self-care outcomes, that is, youth-reported adherence, parent-reported adherence, and glycemic control. First, descriptive characteristics of these self-care outcomes were inspected.

Second, individual growth curve analyses were conducted to identify developmental trajectories of these outcomes, and to examine the extent to which they were related to each other. Finally, relationships between trajectories of youth responsibility for diabetes management and trajectories of self-care outcomes were examined.

Descriptive statistics for adherence and glycemic control

Descriptive characteristics for parent-reported adherence and youth-reported adherence for each wave of assessment are shown in Table 8. Adherence scale scores demonstrated adequate internal consistencies, with Cronbach's alphas ranging from .70 to .79. Intercorrelations were generally moderate between youth- and parent-reported adherence (*r*s ranging from .19 to .62), and between assessment waves (*r*s ranging from .40 to .70 for youth-reported adherence, and from .38 to .76 for parent-reported adherence, respectively).

Glycemic control was indexed by laboratory measures of percent HbA_{1c}, which were taken during regular doctor visits. Given that the scheduling of doctor visits was not linked to the administration of self-report measures, and was idiosyncratic to each family, it was not useful to examine means and intercorrelations of HbA_{1c} values across different waves of measurement. The average number of HbA_{1c} measures available for the analyses was 3.07 per youth (SD = 1.41, range = 1 to 6 measures per youth). The average time interval between HbA_{1c} measures was 6.14 months (SD = 3.69, range = 0.10 to 23.87 months). Across all youths and time points, the mean HbA_{1c} value in this sample was 8.22% (SD = 1.53).

Developmental trajectories of adherence and glycemic control

Developmental trajectories of the self-care outcomes (youth-reported adherence, parent-reported adherence, and HbA_{1c}) were examined next. Paralleling the previous analytic strategy used to examine trajectories of youth responsibility for diabetes care, the youths' age at the baseline assessment was entered as a between-subject (Level 2) predictor (centered on 10 years of age), and time since baseline was entered as a within-subject (Level 1) predictor of each of the self-care outcomes. A multivariate multilevel model was estimated with youth-reported adherence, parent-reported adherence, and HbA_{1c} as simultaneous (i.e., correlated) outcomes in order to evaluate how the trajectories of the three self-care outcomes were related to each other. Level 1 residual variances were assumed to be heterogeneous (i.e., separate residual variances were estimated for each of the three outcomes). In the following sections, results for fixed effects (i.e., population average trajectories) are described first, followed by results for the random effects variances (i.e., individual differences above the average trajectories) and random effects covariances (i.e., the relationships among the outcome variables).

Results for population average trajectories (fixed effects). The results are shown in Table 9 and illustrated in Figures 13 to 15. Adherence at 10 years of age (the initial status intercept term) was estimated to be 69 points based on youth report and to be 70 points based on parent report; these estimates did not significantly differ from each other (χ^2= 0.84, df = 1, p = .36), indicating that youths generally did not tend to report more favorable adherence than their parents. Youth-reported adherence was negatively associated with age at baseline (estimate = -0.95, SE = 0.42, p = .028), but also showed a significant increase within subjects over time (estimate = 1.76, SE = 54, p = .002).

Parent-reported adherence did not significantly differ by youth age, nor did it significantly change over time (ps ≥ .15).

The average HbA_{1c} value estimated for a youth at 10 years of age was 7.7%, indicating reasonably good glycemic control for the youths at this age. However, HbA_{1c} was positively associated with age at baseline (estimate = 0.14, $SE = 0.07$, $p = .06$), and significantly increased within subjects over time (estimate = 0.51, $SE = 0.12$, $p < .001$). This suggests that glycemic control generally worsened across the adolescent years (higher HbA_{1c} values indicate *poorer* glycemic control). For the average youth, HbA_{1c} was estimated as 7.7% at age 10 versus 9.4% at age 18, a sizeable difference of 1.7% over the course of 8 years. For comparison, the American Diabetes Association (Silverstein et al., 2005) recommends HbA_{1c} values below 7.5% over the course of adolescence (between 13 and 19 years of age).

The possibility of curvilinear developmental trends in the self-care outcome variables was also explored. A quadratic term for age at baseline did not significantly add to the prediction of youth-reported adherence (estimate = 0.40, $SE = 0.24$, $p = .10$), parent-reported adherence (estimate = 0.07, $SE = 0.27$, $p = .79$), or HbA_{1c} (estimate = -0.02, $SE = 0.04$, $p = .71$). Similarly, the cross-level interaction between age at baseline and change over time did not significantly predict youth-reported adherence (estimate = -0.40, $SE = 0.25$, $p = .13$), parent-reported adherence (estimate = 0.12, $SE = 0.32$, $p = .70$), or HbA_{1c} (estimate = -0.06, $SE = 0.06$, $p = .29$).

Results for individual differences in trajectories (random effects). As shown in Table 9, the random effects variances showed highly significant individual differences on the initial status of youth-reported adherence, parent-reported adherence, and HbA_{1c} (ps <

.001). Rates of change also differed significantly between individuals for youth-reported adherence, parent-reported adherence, and HbA_{1c} (ps $\leq .05$). The smoothed individual trajectories shown in Figures 13 to 15 illustrate the amount of variability in paths of change for each outcome variable. Thus, it was justified to examine how these individual differences in self-care outcomes relate to individual trajectories in responsibility for diabetes management.

Correlations between random effects. The correlations between the random effects for the three self-care outcome variables were inspected next. Initial status estimates of youth- and parent-reported adherence were significantly positively intercorrelated ($\hat{\rho} = .63$; $p < .001$), and both showed significantly negative associations with the initial status of HbA_{1c} ($\hat{\rho} = -.40$, $p = .004$ for youth-reported and $\hat{\rho} = -.32$, $p = .02$ for parent-reported adherence, respectively). Thus, cross-sectionally, higher adherence scores reported by youths and parents were associated with better glycemic control.

The correlations between initial status and change were significantly negative for both parent-reported adherence ($\hat{\rho} = -.63$, $p = .04$) and youth-reported adherence ($\hat{\rho} = -.46$, $p = .05$). Thus, initially higher adherence preceded a subsequent decrease in adherence, whereas initially lower adherence preceded subsequent improvement in adherence. This pattern was not evident for HbA_{1c} ($\hat{\rho} = .09$, $p = .66$).

Initial status in youth- and parent-reported adherence did not significantly predict subsequent change in HbA_{1c}, nor did the initial status in HbA_{1c} predict subsequent change in youth- or parent-reported adherence (ps $> .10$). Finally, rates of change were significantly positively correlated between youth-reported and parent-reported adherence ($\hat{\rho} = .62$, $p < .001$), but not between youth-reported adherence and HbA_{1c} ($\hat{\rho} = .13$, $p =$

.72), or between parent-reported adherence and HbA_{1c} ($\hat{\rho}$ = -.15, p = .63). Thus, longitudinally, improvement in adherence over time was not associated with concurrent improvement in glycemic control.

Summary of findings. Taken together, the analyses of developmental growth curves for adherence and glycemic control produced three major findings. First, population average trajectories were not uniform across the self-care outcomes. A consistent developmental trend was evident only for glycemic control, which worsened from 10 to 18 years of age both from a between- and a within-subjects perspective. Youth-reported adherence was lower in older cohorts, but improved within youths over time, and parent-reported adherence on average showed no longitudinal trends. Second, longitudinal changes in each of the self-care outcomes varied significantly between individuals. Third, adherence reports by youths and parents were positively related both cross-sectionally and longitudinally, whereas adherence and glycemic control were only cross-sectionally related.

Relationships between responsibility for diabetes management and self-care outcomes

A central goal of the present study was to investigate how individual trajectories in self-care outcomes are associated with trajectories in levels of youth responsibility and in parent-youth discrepancies in perceptions of responsibility. To examine this question, the multilevel growth curve models for diabetes responsibility and for the self-care outcomes were combined. That is, multivariate multilevel models were specified in which latent initial status and rates of change in perceptions of responsibility (the dyad mean and dyad discrepancy) and latent initial status and rates of change in the self-care outcomes were estimated as simultaneous (i.e., correlated) outcomes. A separate model was estimated for each of the three self-care outcomes (youth-reported adherence, parent-reported adherence, and HbA_{1c}).

Latent variable regression analyses available in HLM 6 were performed to address the specific hypotheses. This approach allows for multiple regression analyses based on the Level 2 random effects parameters (i.e., initial status and change parameters) in multilevel models, and provides estimates that are appropriately corrected for measurement error (the Level 1 residual variance). First, multiple regression analyses were conducted to examine the hypothesis that higher *initial status* in the dyad mean and dyad discrepancy of responsibility would be associated with a poorer *initial status* of each of the self-care outcomes. In the second set of analyses, the hypothesis was addressed that a higher *initial status* in the dyad mean and dyad discrepancy of responsibility would predict unfavorable *change* in the self-care outcomes. The third set examined the hypothesis that faster *increase* in the dyad mean and *increase* in the dyad discrepancy would be associated with unfavorable *change* in the self-care outcomes. Finally, the fourth set addressed the hypothesis that *increases* in the dyad mean and dyad discrepancies would explain *change* in the self-care outcomes above what would be expected from the families' initial status.

Tables 10 to 21 show the results for the series of latent multiple regression analyses. In each table, regression estimates for the *dyad mean* and *dyad discrepancies* are shown in Model B. In addition, regression estimates for *youth perceptions* and *parent perceptions* of youth responsibility predicting the self-care outcomes are shown in Model A to illustrate the underlying contribution of youth and parent perceptions to the pattern of results.

Initial status of responsibility predicting initial status of self-care outcomes. Results for the latent variable multiple regression analyses predicting the initial status of each of the self-care outcomes from the initial status in the dyad mean and dyad discrepancy in perceptions of responsibility are displayed in Tables 10 to 12. Given that age at baseline was included as a (Level 2) predictor of initial status, the between-subjects effect of age was statistically controlled in these analyses.

The initial status of youth-reported adherence was not significantly predicted by the dyad mean perception of responsibility ($p = .88$), but the initial status in dyad discrepancies emerged as a significant negative predictor ($p = .05$) in the multiple regression analysis (Table 10, Model B). Youth-reported adherence was predicted to be 1.9 points lower per 10% greater parent-youth discrepancy at study entry. Figure 16 illustrates the estimated relationship, and shows youth reports of adherence predicted for families with a high discrepancy of 25.7% (one *SD* above the mean discrepancy of 13.6%) and for families with a low discrepancy of 1.4% (one *SD* below the mean): the predicted initial youth-reported adherence was 66.4 points in families with an initially high discrepancy versus 71.1 points in families with an initially low discrepancy.

Similar results were obtained in the regression predicting the initial status of parent-reported adherence (Table 11, Model B): the dyad mean showed no significant effect ($p = .63$), but the effect of the initial status in dyad discrepancies was highly significant ($p = .002$). Parent-reported adherence was estimated to be 3.2 points lower per 10% greater parent-youth discrepancy at study entry. As shown in Figure 17, the estimated initial status of parent-reported adherence was 66.5 points in families with an initially high discrepancy versus 74.3 points in families with an initially low discrepancy.

Corresponding results were also found for the initial status of glycemic control (Table 12, Model B): the dyad mean showed no significant effect (*p* = .80), but the effect of the initial status in dyad discrepancies was highly significant (*p* = .01) in the regression predicting HbA_{1c}. Youths were predicted to have 0.34 higher percent HbA_{1c} values (indicating poorer glycemic control) per 10% greater parent-youth discrepancy at study entry. As shown in Figure 18, an HbA_{1c} value of 8.09% was estimated for families with a high discrepancy as opposed to an HbA_{1c} value of 7.26% in families with a low discrepancy.

It is also informative to examine the simultaneous effects of *parent perceptions* and *youth perceptions* of youth responsibility (i.e., the component variables of the dyad mean and dyad discrepancy) in latent variable multiple regression analyses predicting each of the self-care outcomes. This is useful to determine whether the effects of dyad discrepancies are predominantly driven by the perceptions of one respondent (parent or youth), or whether both equally contribute to the effect (Glasnapp, 1984; Griffin, Murray, & Gonzalez, 1999). The results of these regression analyses are shown in Tables 10 to 12, Model A. As can be seen, in each of the regression models, youth and parent perceptions had opposite effects on each of the self-care outcomes, and the coefficients were similar in magnitude. For adherence outcomes, the regression coefficients of youth perceptions were consistently negative, whereas the coefficients of parent perceptions were consistently positive (the reversed pattern was found for glycemic control, given that higher HbA1c indicates poorer glycemic control). Thus, each of the self-care outcomes was predicted to be better to the extent that youths reported having lower responsibility levels (while holding parent reports constant) and to the extent that parents reported their child to have higher responsibility levels (while holding youth reports constant) — this is the exactly the combination for which parent-youth discrepancies are lowest.

Taken together, the results showed that dyad discrepancies (but not dyad means) in perceptions of responsibility were concurrently associated with worse adherence and glycemic control.

Initial status of responsibility predicting change of self-care outcomes. Tables 13 to 15 show the results for the regression analyses predicting change in the self-care outcomes from the initial status of responsibility for diabetes management. As can be seen, neither the initial status in the dyad mean nor the initial status in dyad discrepancies significantly predicted subsequent change in youth-reported adherence, parent-reported adherence, or HbA_{1c} (all *p*s > .23). Similarly, neither initial youth nor initial parent perceptions of youth responsibility individually predicted change in the self-care outcomes (*p*s > .18).

Change in responsibility predicting change of self-care outcomes. The results for the regression analyses predicting change in the self-care outcomes from change of responsibility for diabetes management are shown in Tables 16 to 18. The between-subjects effect of age was not controlled in these analyses, given that age at baseline was not included as a predictor of change in the multilevel model.

Change in youth-reported adherence was not significantly associated with change in the dyad mean perception of responsibility ($p = .34$), but change in dyad discrepancies showed a highly significant negative effect ($p = .01$) in the multiple regression analysis (Table 16, Model B). Youth-reported adherence was predicted to increase by 3.1 points per year for each 10% yearly decrease in parent-youth discrepancies. Figure 19 illustrates the predicted relationship. Also shown in this figure are the estimated yearly changes in youth-reported adherence for families with a relatively high yearly discrepancy *decrease* (-6.7%; i.e., one standard deviation below no change in discrepancy), and for families with a relatively high yearly discrepancy *increase* (6.7%; i.e., one standard deviation above no change in discrepancy). Youth-reported adherence was estimated to increase by 3.15 points per year in families with a high discrepancy decrease, and to decrease by 0.95 points per year in families with a high concurrent discrepancy increase.

Corresponding results were also found for change in parent-reported adherence (Table 17, Model B): change in the dyad mean showed no significant effect ($p = .13$), but change in dyad discrepancies had a highly significant effect ($p < .001$) in the expected direction. Parent-reported adherence was predicted to increase by 4.7 points per year for each 10% yearly decrease in parent-youth discrepancies. As shown in Figure 20, an increase in parent-reported adherence by 2.22 points per year was estimated in families with a high discrepancy decrease, and a decrease by 4.10 points per year was estimated in families with a high concurrent discrepancy increase.

As shown in Table 18, change in HbA_{1c} was not significantly associated with change in the dyad mean or with change in dyad discrepancies in regression analysis (ps > .42).

It is again informative to examine the unique effects of change in *parent perceptions* and change in *youth perceptions* of youth responsibility in regressions predicting change in the self-care outcomes (Tables 16 to 18, Model A). As can be seen, for changes in adherence outcomes, the regression coefficients of youth perceptions were consistently negative, whereas the coefficients of parent perceptions were consistently positive (all *p*s < .05). Thus, more favorable change in adherence was predicted to the extent that youths reported slower growth in responsibility (while holding change in parent reports constant) and to the extent that parents reported faster growth in their child's responsibility (while holding change in youth reports constant) — this is the condition under which parent and youth perceptions converge (and discrepancies decrease) over time. For change in HbA_{1c}, neither change in youth nor change in parent perceptions of youth responsibility showed a significant effect (*p*s > .62).

Initial status and change in responsibility predicting change of self-care outcomes. To recapitulate, the presented results indicated that (a) initially higher discrepancies were concurrently associated with initially poorer adherence and glycemic control, and (b) decreases in discrepancies were associated with concurrent increases in self-reported adherence, but not glycemic control, over time. Given that decreases in discrepancies were more likely to occur if discrepancies were initially high, and increases in adherence were more likely to occur if adherence was initially poor (as indicated by the negative associations between initial status and change on these variables), it may be possible that the observed relationships between change in discrepancies and change in adherence are merely a function of initial status differences at study entry. Therefore, the following analyses examined whether the associations between changes in responsibility and changes in self-care outcomes remained significant when statistically controlling for the initial status in responsibility and the initial status in the self-care outcomes.

The results of these multiple regression analyses are shown in Tables 19 to 21. Change in dyad discrepancies still showed a significant, negative effect on change in youth-reported adherence ($p = .044$) and a highly significant negative effect on change in parent-reported adherence ($p = .002$) in these analyses (see Tables 19 and 20). The effects of change in the dyad mean, initial status in the dyad mean, and the initial status in discrepancies, remained nonsignificant (*p*s > .10). The effects of initial status in adherence and change in adherence also dropped below significance (*p*s > .10). Thus, the relationships between change in discrepancies and change in adherence could not be explained by initial status differences at study entry.

As in the previous analyses, change in HbA_{1c} was not predicted by any growth parameter of the dyad mean or dyad discrepancies in responsibility (*p*s > .65, see Table 21).

Summary of findings

To summarize these findings, no empirical evidence was found to support a relationship between individual trajectories in the *levels* (as represented by the dyad mean) of youth autonomous responsibility for diabetes management and individual trajectories in self-care outcomes. However, the results partially supported the hypothesized relationships between trajectories of parent-youth *discrepancies* and trajectories in self-care outcomes. For one, initially greater discrepancies were associated with initially poorer adherence and glycemic control. In addition, change in discrepancies was associated with change in adherence: both youth- and parent-reported adherence improved in those families in which discrepancies were reduced over time, and this effect could not be explained by the tendency of initial status differences in discrepancies and adherence to diminish over time.

Aim 3: Baseline family system characteristics predicting responsibility trajectories

The final aim of this study was to examine whether characteristics of the family system assessed at the baseline interview predicted the initial status and rates of change in youth responsibility levels and in parent-youth discrepancies about responsibility. Descriptive statistics of the family systems variables are presented first, followed by the results of the multilevel models.

Descriptive statistics of the baseline family characteristics

Table 22 shows descriptive statistics and intercorrelations between the baseline family characteristics, that is, parent responsiveness and demandingness, openness and problems with parent-youth communication, family social support, and home chaos. All scales were scored such that higher values indicate more favorable family attributes, with higher scores representing relatively few parent-youth communication problems and relatively low home chaos (see Table 22). For each of the six family characteristics, the mean scores of the sample were somewhat above the midpoints of the scales, reflecting that youths and parents overall tended to view their family in a favorable light. However, the scores varied considerably between families, with scores spanning most of the possible range for each scale.

Internal consistencies were adequate for all six measures: Cronbach's alpha coefficients ranged from .72 to .88 (see Table 22). The scale scores were all positively associated with each other, but the magnitude of these associations was generally moderate to low. With the exception of a substantial correlation between youth reports of responsive parenting and youth reports of family support ($r = .75$, $p < .001$), the intercorrelations ranged from $r = .00$ ($p = .99$) to $r = .43$ ($p < .001$). Thus, the baseline family characteristics were sufficiently distinct from each other to justify their separate consideration in the following multilevel models.

Baseline family characteristics as predictors of responsibility trajectories

Individual growth curve analyses were conducted to examine the utility of the family characteristics in predicting trajectories of responsibility for diabetes management. In a series of six multivariate multilevel models, each of the family characteristics was entered separately as Level 2 (time invariant) predictor of the initial status and change in the dyad mean and in dyad discrepancies of perceived youth responsibility. As in the previous analyses, youth age at baseline was statistically controlled (i.e., entered as Level 2 predictor). All family characteristics were centered above the sample mean prior to entry in the model, such that the interpretation of the intercepts for initial status and change remains identical to the individual growth model without family characteristics entered (results for this model are shown in Table 7).

For each model, the hypothesis was that higher (i.e., more favorable) scores for a given family characteristic would predict a lower initial status in the dyad mean and in dyad discrepancies of perceived youth responsibility, and slower increase in the dyad mean and improvement in dyad discrepancies over time. When significant effects were found, the magnitude of the effect was quantified by examining how much of the corresponding (initial status or change) Level 2 variation was explained by inclusion of the family characteristic into the model. Specifically, the proportional reduction of the corresponding Level 2 random effects variance component was calculated as one minus the ratio of the residual variance in the conditional model to the variance in the unconditional model (Singer & Willett, 2003).

The results are shown in Tables 23 to 28. To inspect the underlying dynamic of the effects on the dyad mean and on dyad discrepancies (Model B in each table), effects of family characteristics in multivariate models predicting youth and parent perceptions of youth responsibility were also estimated (Model A in each table).

Parenting style: parent responsiveness and parent demandingness. As shown in Table 23, parent responsiveness did not significantly predict the initial status or rate of change of the dyad mean or of dyad discrepancies in perceptions of responsibility for diabetes care. Likewise, parent responsiveness did not significantly predict the initial status or rate of change in youth or parent perceptions of responsibility (all ps > .21). Corresponding nonsignificant results were obtained for parent demandingness (all ps > .18, see Table 24).

Parent youth social interaction: open communication. Openness in parent-youth communication significantly predicted the initial status of dyad discrepancies in perceptions of responsibility ($p = .006$; see Table 25, Model B), accounting for 10.3% of the corresponding initial status variance. As hypothesized, higher openness was associated with lower discrepancies. To illustrate the nature of this effect, Figure 21 shows the predicted initial status of youth and parent perceptions of responsibility for high (one standard deviation above the mean) and low (one standard deviation below the mean) scores of openness in communication. Youths' perceptions of their responsibility exceeded their parents' perceptions by 17.7% in families with low openness, and only by 9.8% in families with high openness in communication. Figure 21 also shows that this effect was unilaterally driven by openness predicting parents' perceptions, but not by youths' perceptions of responsibility: for each scale point that openness in communication was higher on the 5-point scale, parents were predicted to attribute 7.0% more responsibility to the youth (p = .003), while youths concurrently attributed 0.5% more responsibility to themselves (p = .85; see Table 25, Model A). No significant association was evident between openness in communication and the dyad mean in perceptions of responsibility (see Table 25).

Whereas these results partially supported the hypothesized effect of openness for the initial status of responsibility, openness did not predict rates of change in perceived responsibility beyond these initial status differences (all ps > .61, see Table 25). Thus, the hypothesis that greater openness would predict a slower increase in responsibility and further improvements in dyad discrepancies over time was not supported. However, an interesting exploratory question is whether the significant effect of openness in communication on dyad discrepancies was *maintained* over time; that is, would openness in communication assessed at baseline still predict dyad discrepancies two years later? To evaluate this question, the individual growth curve model shown in Table 25 was reconfigured such that time (the Level 1 predictor of change) was centered on two years after the baseline assessment; this yields identical parameter estimates for change, and provides estimates for the 2-year follow-up status (instead of the initial status, see Singer & Willett, 2003). As illustrated in Figure 21, openness in communication assessed at baseline significantly predicted the 2-year follow-up status of dyad discrepancies (estimate = -5.33, SE = 2.55, p = .041). Youths' perceptions of their responsibility still exceeded their parents' perceptions by 12.0% in families with low openness versus 5.5% in families with high openness in communication. Thus, the effect on dyad discrepancies was maintained over time.

Parent youth interaction: problems in communication. Parent-reported problems with parent-youth communication were also significantly associated with the initial status of dyad discrepancies (p = .048; see Table 26, Model B). Fewer communication problems predicted lower dyad discrepancies, accounting for 4.5% of the initial status variance. The effect is illustrated in Figure 22. Youths' perceptions exceeded their parents' perceptions by 16.3% in families with many communication problems, and by 10.6% in families with few communication problems. As shown in Table 26 (Model A), for each scale point on the 5-point scale that communication problems were lower, parents were predicted to attribute 3.2% *more* responsibility to the youth (p = .12), while youths concurrently attributed 0.8% *less* responsibility to themselves (p = .72).

Problems with parent-youth communication did not predict rates of change in perceived responsibility (all ps ≥ .10, see Table 26). Moreover, as shown in Figure 22, the significant effect of problems with communication on initial dyad discrepancies was not maintained over time, such that baseline communication problems did not significantly predict the 2-year follow-up status of dyad discrepancies (estimate = -0.02, SE = 2.26, p = .940).

Family relationships: social support. As shown in Table 27, youth perceptions of support from family members did not significantly predict the initial status or rate of change of the dyad mean or of dyad discrepancies in perceptions of responsibility. Likewise, social support did not significantly predict the initial status or rate of change in youth or parent perceptions of responsibility (all ps > .11).

Home environment: chaos at home. As shown in Table 28 (Model B), parent reports of fewer chaos at home was significantly associated with lower dyad mean (p =

.010), as well as with lower dyad discrepancies (*p* = .013) in the initial status of youth responsibility. Home chaos explained 9.0% of the variance in the initial status of the dyad mean, and 7.8% of the variance in the initial status of dyad discrepancies. The nature of these effects is illustrated in Figure 23. The dyad mean estimate of youth responsibility at 10 years of age was 47.7% where home chaos was high versus 40.8% where chaos was low. Youths' perceptions of their responsibility exceeded their parents' perceptions by 17.3% where home chaos was high, and by 10.3% where chaos was low.

Home chaos also significantly predicted rates of change in the dyad mean (*p* = .048), and there was a trend for chaos to predict change in dyad discrepancies (*p* = .092) in perceived responsibility (Table 28). Entering home chaos into the model explained 7.6% of the variance in change of the dyad mean, and 4.2% of the variance in change of dyad discrepancies. However, the direction of these effects was opposite to the hypotheses, in that lower home chaos predicted a faster increase in dyad mean ratings of responsibility and a less favorable change in dyad discrepancies. As a consequence, the significant effects of home chaos observed for the initial status were not maintained over time, such that home chaos assessed at baseline did not significantly predict the 2-year follow-up status of the dyad mean (estimate = -5.81, *SE* = 6.77, *p* = .394) or of dyad discrepancies (estimate = -1.66, *SE* = 7.92, *p* = 0.835) in perceptions of youth responsibility for diabetes management (see Figure 23).

Summary of findings

To summarize, the results provided modest support for the hypothesized role of baseline family systems characteristics as predictors of trajectories of responsibility for diabetes management. Only lower home chaos was concurrently associated with generally lower levels of youth responsibility (as suggested by its relationship with the dyad mean), but also predicted a faster increase in youth responsibility, a finding contrary to hypothesis. Somewhat more support was found for the hypothesized relations between family characteristics and parent-youth discrepancies in perceptions of responsibility: discrepancies at baseline were found to be concurrently lower in families with more open parent-youth communication, fewer problems with communication, and lower home chaos. However, none of these family characteristics predicted further improvement in parent-youth discrepancies over time, and only the effect of openness in communication was sustained over time.

Discussion

Optimal day-to-day management of type 1 diabetes during adolescence is crucial to reduce the risk of severe short- and long-term medical complications and to increase life expectancy (White et al., 2001). Despite numerous technological advances, however, problems with adherence and glycemic control continue to be common and are exacerbated during the adolescent years relative to childhood and adulthood (Bryden, Dunger, Mayou, Peveler, & Neil, 2003; Bryden et al., 2001; Kovacs et al., 1992; Mortensen et al., 1998). Given that diabetes care during this developmental period rests upon the successful interplay of all family members, the identification of modifiable family factors to promote sustained adherence and glycemic control during adolescence remains critical for research and practice (Anderson et al., 2009; Butler et al., 2008). This study addressed one family factor that has often been ascribed a key role in diabetes care: the successful transition of responsibility for the daily diabetes management from parent to youth.

The clinical literature has emphasized two features as central for this transition process: (a) the avoidance of premature or abrupt transfer of high levels of responsibility for illness management to the adolescent, and (b) the establishment and maintenance of adolescent-parent agreement about the distribution of responsibilities (Wysocki, 2002; Wysocki & Greco, 2006). However, previous empirical work in this area has almost exclusively relied on cross-sectional research designs, and the dynamic processes underlying the transition of responsibility for diabetes management during adolescence are only poorly understood. To overcome this limitation, the present study employed a longitudinal approach using individual growth curve analysis. The goals of this study were to characterize longitudinal trajectories of the levels of youth responsibility and of discrepancies between parent and youth perceptions of their responsibility, to investigate associations with trajectories of diabetes self-care outcomes, and to examine whether baseline family characteristics predicted differential responsibility trajectories. In the following sections, findings pertaining to youth responsibility *levels* will be discussed first, followed by a discussion of findings pertaining to parent-youth *discrepancies* in perceptions of responsibility.

Levels of youth responsibility for diabetes management

Given the theoretical importance that has been ascribed to avoiding premature and rapid increases in youth autonomous responsibility for diabetes care, one focus of this study was to examine longitudinal trajectories of youth responsibility levels, and their relationships with successful diabetes self-care outcomes.

Characteristics of developmental trajectories of levels of youth responsibility

As hypothesized, the levels of youth autonomous responsibility for diabetes management were found to commonly increase over the course of adolescence in growth curve analyses. In a linear fashion, youth responsibility evidenced considerable growth at a rate of about 4% per year between the ages of 10 and 18 years. Importantly, almost identical results were obtained based on between-person (cohort) and within-person (temporal) effects of age. This finding expands prior cross-sectional findings, and reinforces the notion that previously identified age differences in youth responsibility for diabetes management evidence a true developmental trend. On average, youth responsibility levels increased from 44% at age 10 to 77% at age 18. It is noteworthy that the average 10-year old youth had only slightly less than 50% responsibility for diabetes management, which suggests that the transition of responsibility from parent to youth typically starts well before early adolescence. Also, the findings indicate that the transition of responsibility was generally not fully concluded at age 18, yet only small further gains may be expected in late adolescence (e.g., from 18 to 21 years of age).

The age-related increase in youth responsibility for diabetes management is consistent with prominent developmental theories — including socio-cognitive theory (Smetana, 1988), sociobiological theory (Steinberg, 1990), individuation theory (Youniss & Smollar, 1985), and psychoanalytic theory (Blos, 1979) — which commonly suggest that youths strive for and gain increasing independence from their parents during adolescence. Previous longitudinal research with healthy adolescents has shown that youths generally develop toward more independence in decision making within the family (Friedman et al., 2009; Pinquart & Silbereisen, 2002), and that they become increasingly less likely to endorse the legitimacy of parental authority across various life domains (Darling, Cumsille, & Martinez, 2008; Smetana, 2000). The present results indicate that a corresponding process of youth "individuation" operates in the day-to-day management of chronic illness, possibly as a natural extension of normative autonomy development during adolescence.

Apart from this overall developmental trend, significant diversity was evident in individual trajectories of growth in responsibility for diabetes management. For one, individual youths deviated considerably in their initial responsibility levels at study entry from what would be the expected or "normative" levels of responsibility at their age. In addition, even though responsibility levels increased in most youths over the study period, some youths exhibited a sharp gain, whereas others showed only modest and gradual gain in responsibility over time.

The wide variability in individual paths suggests that the transition of responsibility from parent to youth is not uniform and exclusively determined by age, but a heterogeneous process that is likely modified by a variety of developmental, social, and environmental influences.

Given that individual youths varied significantly in initial status and in rates of change of responsibility for diabetes management, an interesting question is whether and how initial status and change in responsibility are related to each other. This question is infrequently asked in the literature, in part because many longitudinal studies have only two measurement occasions, and observed individual differences in change are often biased as a consequence of "regression to the mean." The regression to the mean phenomenon occurs because of measurement unreliability: when initial values are measured with error, they tend to regress toward the population mean in repeated testing, such that the measurement error appears with a negative sign in the estimate of change (Campbell & Kenny, 1999; Willett, 1997). As a result, the initial level of functioning has often been viewed only as a source of error in estimating change rather than a further source of information about the dynamics of individual change (Cronbach & Furby, 1970; Rogosa, 1988). However, individual growth parameters in multilevel models take all measurement points into account simultaneously (not only pairwise measurement points): if the growth model is specified correctly (e.g., if the assumption of strictly linear change is correct, see Raudenbush & Bryk, 2002, p. 364), true changes are distinguished from measurement error, such that estimates of change are not confounded with regression to the mean effects (Gmel, Wicki, Rehm, & Heeb, 2008; Willett, 1997). Given that initial status differences precede differences in change, they may be viewed as predictors or putative causes of rates of change (Klein & Muthén, 2006).

In the present sample, initial levels of responsibility (statistically controlled for baseline age) showed a significantly *negative* association with subsequent rates of change in responsibility: to the extent that a youth had initially more responsibility than other youths at that age, subsequently slower growth in responsibility was predicted, and to the extent that a youth had initially less responsibility than other youths at that age, subsequently faster growth in responsibility was predicted. Initial status differences accounted for 25% of the variance in subsequent rates of change. This contrasts with *positive* associations between initial status and change that have been reported for the development of academic achievement (Raudenbush & Bryk, 2002; Seltzer et al., 2003; Williamson, Appelbaum, & Epanchin, 1991) and emotional functioning (Blandon, Calkins, Keane, & O'Brien, 2008; Miner & Clarke-Stewart, 2008) during adolescence, domains in which individual differences at a given age tend to magnify over time.

How can the negative association between initial status and change in levels of youth responsibility be explained? In part, ceiling effects may have contributed to the finding. An alternative, substantive interpretation is that the parent-youth transition of responsibility may be characterized by an underlying process in which phases of faster growth in youth responsibility alternate with phases of slower growth. That is, relatively high responsibility at a given age may be followed by a phase of slower growth to result in relatively low responsibility at a later age, which would be followed by a phase of faster growth to result in relatively high responsibility at a later age, and so on. Hence, even though the developmental progression of responsibility for diabetes management may be linear for youths on average, one might speculate that the transition of responsibility in individual families is characterized by a rather complex pattern of shifts at changing rates over the course of adolescence. Research using more frequent assessments and longer follow-up periods will be needed to better understand the nature of these dynamics, but these results suggest that cross-sectional data can provide very limited and possibly misleading information about the developmental progression of youth responsibility levels in individual families.

Relationships between youth responsibility levels and self-care outcomes

A central goal of this study was to identify whether trajectories of levels of youth autonomous responsibility for diabetes management contribute to understanding outcomes of diabetes self-care during adolescence. The analyses of average growth curves for adherence and glycemic control showed no consistent developmental trend for youth- and parent-reported adherence. However, glycemic control was found to deteriorate between 10 and 18 years of age, an effect that was evident for both between-person (cohort) and within-person (temporal) effects of age. For the average youth, HbA_{1c} levels were estimated to increase from 7.7% at an age of 10 years to 9.4% at an age of 18 years, a sizeable and clinically significant difference of 1.7% over the course of 8 years. Clinical guidelines recommend that HbA_{1c} values should be kept below 7.5% in patients between 13 and 19 years of age. The present finding is in accord with accumulating longitudinal evidence indicating that glycemic control generally worsens during this age period, with HbA_{1c} levels tending to peak during late adolescence (Bryden et al., 2001; Helgeson, Siminerio, Escobar, & Becker, 2009; Helgeson et al., in press; Levine et al., 2001; Luyckx & Seiffge-Krenke, 2009).

Thus, two parallel developmental trends were evident in this sample: youths' autonomous levels of diabetes management responsibility on average increased across the adolescent years, while glycemic control simultaneously decreased on average during this period. However, to suspect a relationship between these coinciding longitudinal trends would be an error of interpretation based on the "ecological inference fallacy": inferences about individuals cannot be drawn from aggregate characteristics of the group to which they belong (Robinson, 1950). Significant individual differences were evident in the trajectories of levels of youth responsibility and in trajectories of each self-care outcome, which made it possible to examine the extent to which they were related to each other.

Contrary to the hypotheses, individual differences in youth responsibility levels at study entry were not found to be significantly associated with concurrent adherence and glycemic control. This is at odds with a number of previous cross-sectional studies reporting poorer self-care outcomes among youths with relatively higher levels of responsibility for diabetes management (see Dashiff, Hardeman, & McLain, 2008; Wysocki & Greco, 2006; Wysocki et al., 2009). Moreover, youth responsibility levels at study entry did not predict subsequent change in self-care outcomes, in contrast to a recent study showing such a prospective relationship (Helgeson et al., 2008).

Importantly, this was the first study to empirically examine whether differences in individual youths' *change* in autonomous responsibility over time contribute to understanding change in self-care outcomes. It has repeatedly been speculated that a gradual and slow transfer of diabetes responsibilities would contribute to positive self-care outcomes during adolescence (Palmer et al., 2004; 2009; Silverstein et al., 2005; Wysocki, 2002), which can only be addressed by examining rates of change in youth responsibility. However, no significant evidence was found in this study to suggest that faster or slower growth in youth responsibility levels would be associated with worsening or improvement of adherence or glycemic control.

Several factors may have contributed to these unexpected null results. One potential explanation is that the statistical power was too low to detect significant relationships due to the modest sample size and the limited number of assessment points per family.

In addition, differences in the measurement of the parent-youth division of responsibilities across studies may have accounted for the inconsistent findings. Previous research has varyingly operationalized this concept by relying on parents' perceptions of youth responsibility (La Greca et al., 1990; Weissberg-Benchell & Glasgow, 1997), by relying on youths' perceptions of their own responsibility (Ott et al., 2000), or by asking youths to *evaluate* the appropriateness of their mothers' level of responsibility and involvement in daily diabetes care (Wiebe et al., 2008; 2005). In the present study, the latent average of youth and parent reports of the division of responsibilities was used. The reason for this approach was to obtain an estimate of the "actual" level of youth versus parent responsibility that is "cleaned" from error variance included in the unique subjective perception of each respondent. Youth and parent reports were positively intercorrelated cross-sectionally and longitudinally, supporting the viability of this approach. However, the extent to which the latent average of youth and parent reports appropriately captures the *actual* division of responsibilities for diabetes management would have to be established and validated in future work employing objective measures, such as behavioral observations.

As an additional potential reason for the null results found in this study, clinical recommendations regarding the level of youth autonomous responsibility for diabetes management generally caution against a *premature* transition of responsibility from parent to youth. The concept of a premature transition of responsibility involves the notion that youths' autonomous responsibility levels should not exceed their capability or maturity level, such that they are not exposed to more responsibility than they can successfully manage. In the present study, a youth's level of responsibility was gauged against the average (i.e., normative) level of responsibility of youths at the same *age*, but age is an imperfect marker of developmental maturity (Steinberg & Silverberg, 1986) and of an adolescent's ability to manage diabetes independently (Ott et al., 2000). Wysocki et al. (1996; 2006) have previously attempted to address this complex issue by forming the ratio between a youth's self-care autonomy and an index of the youth's "psychological maturity" (a composite measure comprised of scores on an intelligence test, a social-cognitive skills test, and an academic achievement test). Higher scores on this autonomy-maturity ratio were concurrently associated with worse adherence, higher HbA_{1c} levels, and more frequent hospitalizations when statistically controlling for differences in age. Similarly, Palmer et al. (2004; 2009) have found higher levels of youth responsibility to relate to worse glycemic control only in concert with concurrently low self-efficacy for diabetes management (Palmer et al., 2009) and in concert with a low sense of self-reliance and low pubertal status (Palmer et al., 2004). As an extension of this cross-sectional work, it may be important in future longitudinal research to consider the developmental progression of individual youths' psychological maturity in addition to age to gauge the appropriateness of individual trajectories of youth self-care autonomy. This may provide a more refined understanding of the importance of changes in youth self-care autonomy for successful diabetes self-care during adolescence.

Family characteristics as predictors of trajectories of youth responsibility levels

In view of the significant and pronounced heterogeneity in individual patterns of change in the youths' levels of responsibility for diabetes management, it was also an important question to ask which factors may influence these different trajectories. In the present study, family characteristics involving parents' socializing behaviors, the quality of communication between youths and parents, the provision of general social support from family members, and environmental disorganization in terms of "chaos" at home were examined as predictors. The selected family characteristics showed surprisingly little utility in predicting levels of youth autonomous responsibility (as expressed in the latent mean of youth and parent reports) both cross-sectionally and longitudinally. Lower levels of initial youth responsibility were found in families with less home chaos; however, levels of youth responsibility were also found to increase more rapidly in these families, a finding contrary to the hypothesis. Prior longitudinal research with healthy adolescents has similarly found little evidence that family characteristics assessed at study entry predicted differential rates of decline in parental authority over time (Darling et al., 2008). Contradictory patterns of association between family functioning and concurrent levels of parental control versus change in parental control have also been found (Greenley et al., 2006).

The selection of the family characteristics was guided by two assumptions: for one, they were assumed to be fairly stable and unchanging (such that they could be reliably captured by a single baseline assessment); in addition, it was assumed that their influence on youth responsibility levels would be consistent across periods of adolescent development. However, these assumptions may not be tenable. Parenting strategies as well as family communication and support patterns are likely in flux and evolve over time within each family. Moreover, the influence of given parental or familial factors on youth autonomy development may change from early adolescence to late adolescence (Holmbeck, Paikoff, & Brooks-Gunn, 1995).

In addition, it is possible that the transfer of greater responsibility for diabetes management from parent to youth is largely triggered by developmental-ecological changes rather than being influenced by psychological characteristics of the family system. As youths spend more time away from their parents during adolescence, parents must naturally reduce involvement in diabetes management, and this process may be driven by concrete events, such as the youth visiting a new school, changes in the parents' occupation, or changes in the family's schedule. Considering these factors in future research may help to gain a better understanding of the factors influencing the parent-youth transfer of responsibility for diabetes management during adolescence.

Parent-youth discrepancies in perceptions of youth responsibility

A second major focus of this study was to examine longitudinal trajectories of discrepancies in youth versus parent perceptions of diabetes management responsibilities, and their relationships with successful diabetes self-care outcomes.

Characteristics of developmental trajectories of discrepancies

Descriptive analyses of parent-youth discrepancies in perceptions of responsibility revealed that adolescents perceived themselves as having more autonomous responsibility for diabetes management than their parents attributed to them in the vast majority of the families, supporting the hypothesis. The pediatric clinical literature has sometimes cautioned against discrepancies in the opposite direction, which occur when parents overestimate the degree to which the adolescent assumes responsibility of diabetes self-care tasks independently, resulting in potential "diffusion of responsibilities" (Anderson et al., 1990; Naar-King, Ellis, Idalski, Frey, & Cunningham, 2007). However, the present study findings suggest that this pattern of discrepancies may be the rare exception, in accordance with results from previous studies (Butner et al., 2009; Lewandowski & Drotar, 2007). Developmental theories similarly suggest that youths are the predominant driving force in striving for gains in freedom and autonomy from their parents, whereas parents themselves tend to be more reluctant to this and try to keep some control over the youths' behaviors and decisions (Eccles et al., 1993; Holmbeck et al., 1996; Smetana & Asquith, 1994).

Whether parent-youth discrepancies in perceptions of youth responsibility generally become more or less pronounced over the course of adolescence remained unclear: no differences with age were found based on between-subject (cohort) analyses, whereas within-subject (temporal) effects of age showed that parent-youth discrepancies on average declined over the study period. It may be speculated that the observed reduction of discrepancies within families over time can be attributed to an effect of repeated testing. It is possible that the repeated assessments increased the accuracy of responses by stimulating youths and parents to monitor their behavior more closely. Moreover, even though youths and parents completed the measures independent from each other, the assessments were administered at the same time and day. This may have triggered parents and youths to exchange their perspectives about the distribution of responsibilities for diabetes management within the family, and may have stimulated some families to reconcile eventual differences in opinion.

Apart from these results for the “average” family, however, individual families markedly differed from each other in disagreement at study entry, such that youth and parent perceptions were drastically at odds in some families, whereas in other families they were not discrepant at all. Importantly, discrepancies in families also varied significantly in their course, such that views about the division of responsibility for diabetes management converged between youth and parent in some families (such that discrepancies decreased), and diverged in other families (such that discrepancies increased) over the course of the 2-year study period. This indicates that parent-youth discrepancies in opinions about responsibility are not well understood as a stable and "trait-like" feature of a family; instead, parent-youth discrepancies demonstrated pronounced plasticity and dynamic change over time.

The clinical and developmental literatures convey somewhat contradictory positions concerning the nature of change in parent-youth discrepancies in perceptions of autonomy and authority (Butner et al., 2009). The clinical literature generally emphasizes the possibility that initial discrepancies may successively lead to greater discrepancies over time. For example, the "miscarried helping" model (Anderson & Coyne, 1991) describes the dynamic of an interactive "vicious cycle:" the model suggests that if parents' attempts to help lead them to take more responsibility for the youths' illness management than the youths' need for personal freedom affords, adolescents may commonly oppose the parents' attempts to help and increase their own striving for independence, which, in turn, may trigger parents to even intensify their own involvement, such that initial discrepancies may escalate over time. By contrast, the developmental literature suggests that initially discrepant perceptions between parents and youths are part of normative and healthy adolescent development, such that they are typically reduced over time (Holmbeck et al., 1996; Holmbeck & O'Donnell, 1991; Lerner & Spanier, 1980; Steinberg, 1990). The results of the present study are in accordance with this developmental perspective: initial status and change in parent-youth discrepancies showed a significantly negative relationship, such that initially low discrepancies tended to increase, whereas initially high discrepancies showed a strong tendency to decrease over the 2-year study period. This pattern is also consistent with a previous study on developmental change in family conflict during healthy adolescent development, in which rates of parent-youth conflict at the age of fourteen showed a negative relationship with change in conflict over the next 4 years (Herrenkohl et al., 2009). Thus, even though it cannot be excluded that some families in the present sample showed a clinical pattern of "escalation" in discrepancies over time, the typical pattern of individual trajectories is more in accordance with the developmental notion that parent-youth discrepancies at a given point in time may serve to precipitate positive changes, and are followed by a phase in which perceptual gaps are reduced.

Relationships between parent-youth discrepancies and self-care outcomes

The examination of relationships between parent-youth discrepancies and diabetes self-care outcomes showed several significant findings that both replicated and expanded upon previous research.

As hypothesized, greater parent-youth discrepancies in perceptions of responsibility for diabetes management at study entry were significantly associated with concurrently worse self-care outcomes. This corroborates results from previous pediatric diabetes studies that have reported similar cross-sectional associations (Anderson et al., 2009; Butner et al., 2009; Cameron et al., 2008; Lewandowski & Drotar, 2007). Importantly, the results were robust, in that greater discrepancies were significantly related to lower youth-reported adherence, lower parent-reported adherence, and poorer glycemic control. Estimated HbA_{1c} percentages differed by 0.83 points between families with a high (one standard deviation above average) versus low (one standard deviation below average) discrepancy at study entry. For comparison, psychological interventions to improve glycemic control have been meta-analytically shown to achieve an average reduction in percent HbA_{1c} by 0.33 points (Hampson et al., 2001) to 0.48 points

(Winkley, Ismail, Landau, & Eisler, 2006). This underscores the notion that the present results may be clinically meaningful.

Expanding upon extant work, results of the longitudinal analyses also showed that *changes* in parent-youth discrepancies were significantly associated with *changes* in adherence over time in the hypothesized direction. Adherence worsened in families in which youths' perceptions of their responsibility grew faster than parents' perceptions (such that youths' and parents' perceptions diverged over time), whereas adherence improved in families in which youths' perceptions of their responsibility grew more slowly than parents' perceptions (such that youths' and parents' perceptions converged). Corresponding results were found for both youth-reported and parent-reported adherence, which bolsters confidence in the findings being robust, and not an artifact of reporting bias.

Changes in glycemic control neither showed significant longitudinal associations with parent-youth discrepancies, nor with adherence reported by youth or parent. Although this may seem perplexing, many plausible factors may dilute these associations, including a lack of temporal congruity between adherence and glycemic control, the possibility of non-linear effects, and the fact that glycemic control is influenced by a variety of biological, hormonal, and environmental factors (Harris et al., 2000). To date, almost all research on associations between adherence and glycemic control has been cross-sectional (Hood, Peterson, Rohan, & Drotar, 2009), and the few prospective studies available have failed to find significant effects longitudinally (Helgeson, Escobar, Siminerio, & Becker, 2010; Helgeson et al., 2009).

The initial status of parent-youth discrepancies at study entry did not significantly predict subsequent change in adherence, whereas changes in parent-youth discrepancies and changes in adherence were correlated. Thus, the present study failed to demonstrate the possibility of a causal effect of parent-youth discrepancies on self-care outcomes; however, the pattern of findings may also speak to the underlying nature of the relationships between parent-youth discrepancies and adherence. Note that the analyses examined whether initial discrepancies predicted the course of adherence over the subsequent *years*; evidence for this effect would suggest a distal causal process, in which discrepancies exert a lagged influence on adherence over a prolonged period (Cole & Maxwell, 2003; Shrout & Bolger, 2002). By contrast, the significant correlation found between changes in parent-youth discrepancies and concurrent changes in adherence speaks for a more contemporaneous timing of effects. For example, a reduction in parent-youth discrepancies might affect adherence somewhat immediately, improvements in adherence might reduce family discrepancies at the next day or over the next month, or both could exert reciprocal effects in relatively brief time periods. Pending replication of the findings, it will be important to understand more closely the psychological mechanisms that generate the linkage between changes in parent-youth discrepancies and changes in adherence in future research. Based on prior cross-sectional work, potential candidates are changes in family stress and conflict (Holmbeck et al., 1996; Miller & Drotar, 2003), changes in oppositional youth behavior (Lewandowski & Drotar, 2007), and changes in youths' sense of self-confidence and efficacy for managing diabetes (Ott et al., 2000; Pomerantz & Eaton, 2000).

The present findings have potentially important implications for family interventions aiming at improved type 1 diabetes self-care during adolescence. Several family interventions for diabetes have been developed to facilitate cooperative diabetes management, teamwork among family members, and increased skills for the negotiation of self-care responsibilities (Anderson et al., 1999; Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989; Laffel, Vangsness et al., 2003; McNabb et al., 1994; Nansel, Anderson et al., 2009; Wysocki et al., 1999). Even though interventions of this kind have shown to be successful in changing diabetes self-care behaviors, relatively little is known about the mediating processes that explain how these effects are achieved, and how they could possibly be enhanced. The present results suggest that changes (i.e., reductions) of parent-youth discrepancies in perceptions of responsibility for diabetes management may possibly be an important mediator to understand why psychological family interventions lead to improvements in adherence behavior.

An open question of potential clinical relevance is whether youths and parents are aware or unaware of discrepancies in their perceptions of responsibility for diabetes management (Welsh, Galliher, & Powers, 1998). Recall that this study used an indirect measure, in that discrepancies in perceptions were discerned from youths' and parents' individual reports of the division of responsibilities. If youths and parents commonly do not know that they differ in perceptions, a possibly important minimal intervention strategy would be to facilitate exchange in their perspectives. As mentioned above, parent-youth discrepancies on average declined over the study period, possibly because the simultaneous administration of the questionnaire was a sufficient trigger for some families to exchange their views and to reconcile differences in opinions. Along similar lines, investigators have previously recommended that "pediatric diabetes clinicians should initiate discussions with transitioning youth and their parents to clarify who in the family is taking responsibility for the many different tasks involved in managing diabetes" (Anderson et al., 2009, p. 150). On the other hand, clarification of discrepancies in opinion alone may not suffice to align conflicting motivations between youths' striving for autonomy and parents' striving for control in everyday life, and more intensive intervention strategies may be needed to facilitate mutual goal setting and cooperative family management of diabetes.

An additional question of clinical importance is whether the emergence of parent-youth discrepancies in perceptions of responsibility should be prevented at all times. From a developmental perspective, such discrepancies have been viewed as potentially adaptive in that they can spur important realignments in the parent-youth relationship, and can serve as an impetus for negotiating the balance between parent authority and youth autonomy during adolescence (Butner et al., 2009; Collins, Laursen, Mortensen, Luebker, & Ferreira, 1997; Miller & Drotar, 2003; Smetana, 1988). The present study showed that higher initial discrepancies were negatively associated with changes in discrepancies, such that initial discrepancies commonly precipitated a reduction in discrepancies, and this reduction in discrepancies was associated with improvements in adherence. This suggests that initial discrepancies might *indirectly* contribute to *favorable* changes in the successful family management of diabetes. In addition, if initial discrepancies are commonly reduced over time, this might be accompanied by additional benefits in youths' and parents' psychological adjustment and well-being not examined in this study. Future research will show whether parent-youth discrepancies in perceptions of responsibility for diabetes management should be accepted as a natural part of adolescent development, such that interventions should teach skills to facilitate the resolution of discrepancies when (i.e., after) they occur, or whether interventions should aim at the prevention and avoidance of parent-youth discrepancies to achieve sustained and long-lasting treatment benefits.

Family characteristics as predictors of trajectories of parent-youth discrepancies

To date, the predominant focus of research on parent-youth discrepancies has been on the *consequences* of discrepancies for youth and parent adjustment in general (Holmbeck & O'Donnell, 1991; Mounts, 2007; Ohannessian, Lerner, Lerner, & von Eye, 1995; Ohannessian et al., 2000; Welsh et al., 1998) and for adjustment to diabetes in particular (Butner et al., 2009; Lewandowski & Drotar, 2007; Miller & Drotar, 2003). Surprisingly little is known about potential antecedents of discrepant perceptions between parents and adolescents. In the present study, mixed evidence was found for the hypothesized role of family characteristics as predictors of parent-youth discrepancies regarding their responsibility for diabetes management. Cross-sectionally, significantly lower discrepancies at study entry were found in families who reported more favorable parent-adolescent communication (greater openness in communication and fewer problems with communication), and in families reporting less home chaos. The measures of family characteristics were not specific to diabetes, which lends partial support to the notion that general patterns of parent-adolescent interaction and the broader home environment may represent potentially important family "background" variables that contribute to the alignment of parents' and youths' views about their responsibilities for the daily management of diabetes.

However, no support was found for the utility of family characteristics in predicting change in discrepancies following study entry, a finding that greatly dampens enthusiasm about the importance of these family background variables for understanding the dynamic development of discrepancies over time. In addition, there was little evidence to suggest that the effects of the family predictors found at study entry were sustained over time. As mentioned previously, a potential weakness of the present study design is the reliance on a single (baseline) measure of the family characteristics. It may be important in future longitudinal research to collect data on general family functioning repeatedly over time to examine the relationships between changes in the family system and changes in parent-youth discrepancies in perceptions of diabetes responsibilities.

An alternative possibility worth considering in future research is whether characteristics of family function might *moderate* the relationship between initial status and subsequent change in discrepancies. In accordance with the developmental perspective, initial parent-youth discrepancies have been viewed as serving potentially adaptive functions in the long run *as long as* they are reduced over time. The ability to reduce discrepancies when they occur may be more pronounced in — or limited to — families that function well in general. That is, favorable family characteristics might represent resources necessary for parent and youth to resolve discrepant viewpoints more rapidly after their occurrence; in families that lack these resources, discrepancies in perceptions of responsibility for diabetes management may be more likely to persist over time.

Limitations

There are several limitations to the present study that should be noted and that may serve as an avenue for future research. A first limitation is the moderate sample size of this study, which may have left effects of smaller size but of potential clinical importance undetected. Similarly, even though the longitudinal design is a strength of this study, the use of only four waves of assessment and the relatively low retention rate at the final assessment wave may have limited the ability to reliably separate random variability from family-specific patterns of change, and to detect correlated growth patterns (Hertzog et al., 2006; 2008). Future studies should use more frequent assessments and should cover longer follow-up periods to more precisely characterize individual longitudinal trajectories of diabetes responsibilities over the course of adolescent development.

A second limitation concerns the characteristics of the participating youths and parents, who were predominantly Caucasian and from relatively high socioeconomic backgrounds. Thus, the results may not generalize to ethnic minority families and adolescents from lower-income families (Hsin et al., 2010). Research suggests that parents whose children reside in high-risk environments (who are often also poorer and minority families) feel obligated to use harsher or more controlling parenting to protect their adolescents (Dearing, 2004). Moreover, age-normative gains of autonomy during adolescence have been found to vary across different cultural backgrounds (Hasebe, Nucci, & Nucci, 2004; Qin, Pomerantz, & Wang, 2009). Additional research is necessary to determine if the present findings replicate in samples representative of a broader range of ethnicities, socioeconomic levels, and cultural contexts.

As a third limitation, this study only collected information from the primary caregiver who was most involved with the youth's diabetes care — for the most part, these were mothers. Therefore, the findings are not necessarily generalizable to the father-adolescent dyad or to other caregivers of youths with diabetes (e.g., grandparents). Even though fathers tend to play a relatively less active role in the daily management of diabetes compared to mothers (Seiffge-Krenke, 2002), recent research has documented the potentially unique importance of fathers' involvement in type 1 diabetes care during adolescence (Berg et al., 2008; Butner et al., 2009; Palmer et al., 2009; Wysocki & Gavin, 2006; Wysocki et al., 2009). Examining the distribution of responsibility among multiple family members (i.e., youth, mother, father, and potentially siblings) may be an important direction for future research.

As a fourth limitation, this study relied on self-reports of responsibility for diabetes management tasks and on self-reports of adherence to the diabetes regimen. The fact that results were similar across youth- and parent-reported adherence bolsters confidence in them not being an artifact of reporting bias. However, self-reports of responsibility and adherence may not reflect actual decision making and self-care behavior in everyday life. Future work may benefit from being supplemented with direct behavioral observation of parent and youth interactions regarding disease management tasks (Greenley et al., 2006; Holmbeck et al., 2002; Wysocki, Harris et al., 2008; Wysocki et al., 1999) and real-time assessments of adherence to the diabetes regimen (Fortenberry et al., 2009).

Finally, this study focused exclusively on adherence and glycemic control as indicators of the "successful" parent-youth transition of diabetes management responsibilities. Given the importance of these outcomes for medical short- and long-term complications and for *physical* health, they constitute the primary focus in most pediatric diabetes research. Nevertheless, it remains a pivotal task to understand more closely how the parent-youth transition of responsibility for diabetes management is implicated in the *psychological* adjustment of youths, as well as their parents. The limited data available in the literature suggests potentially important relationships between diabetes responsibilities and youths' mental well-being (Helgeson et al., 2008) behavior problems (Weissberg-Benchell & Glasgow, 1997) and quality of life (Laffel, Connell et al., 2003), as well as psychological well-being of the mothers (Butner et al., 2009). Achieving a healthy sense of autonomy is a major developmental goal during adolescence with profound implications for mental health (Steinberg & Silk, 2002), and families of youths with type 1 diabetes must balance the youth's medical adaptation and the youth's developmental needs (Seiffge-Krenke, 1998). Therefore, future research should consider both physical and mental health outcomes.

Conclusions

Guidelines for medical care of type 1 diabetes during adolescence stress the importance of an optimal parent-youth transition of responsibility for the day-to-day management of the illness (Delamater, 2009; Silverstein et al., 2005). However, the cross-sectional nature of most previous studies has limited empirical evidence to support this claim, in that it was only able to capture "snapshots" of the distribution of responsibilities in families at a single point in time. Pediatric investigators have repeatedly emphasized the need for longitudinal research designs to identify developmental trajectories in children's and families' adaptation to chronic illness

(Holmbeck, Franks Bruno, & Jandasek, 2006; Kazak & Drotar, 1997; Wallander & Varni, 1998). The longitudinal perspective of the present study and the use of individual growth curve modeling provided an opening for understanding the dynamic developmental processes underlying the transition of responsibility for diabetes management during adolescence.

The results of this study supported the notion of a "normative" increase in youths' levels of autonomous responsibility for diabetes management as a function of age, but also demonstrated that individual trajectories of growth in youths' responsibility varied substantially across families. Surprisingly, there was no evidence to suggest that deviations from "age-normative" trajectories of growth in youths' autonomous responsibility were implicated in diabetes self-care outcomes (i.e., adherence to the diabetes regimen and glycemic control). A possibly important contribution of this finding is that age may be an insufficient marker for judging the extent to which a youth's autonomous responsibility is *too* high or grows *too* rapidly. In other words, age alone may not tell us how much responsibility a youth is "ready" to assume. In future research, it may be imperative to consider gains in responsibility for diabetes management in the context of the developmental progression of psychological and environmental resources a youth has available. This may be necessary to more closely understand the potential consequences of *developmentally* appropriate or inordinate growth in responsibility for diabetes management during adolescence.

As a further strength of this study, the assessment of parent-youth dyadic data allowed taking into account that the transition of responsibility for diabetes management is not a unilateral process, in which the youth passively receives more responsibility as the parent decides to transfer responsibilities to the child, but a dynamic interactive process in which youth and parent continuously renegotiate their responsibilities. The results indicated that discrepancies in parent and youth perceptions were the norm. Across all ages, youths generally attributed more responsibility to themselves than the parent attributed to the youth. Importantly, the degree of discordance in individual families was consistently reflected in diabetes self-care outcomes. Adherence and glycemic control were found to be better in families with less discrepant perceptions at a given point in time; moreover, adherence improved to the extent that discrepancies were reduced over time. These findings corroborate that the successful transition of responsibility for diabetes management involves a formidable balancing act, in which the youth's desire for increasing autonomy and the parent's provision of opportunities for the youth's autonomous responsibility must co-evolve and develop in mutual accordance with each other. Facilitating a "fit" between parent and youth perceptions of responsibility for diabetes management may be an important strategy for family interventions targeting improvements of adherence and glycemic control during adolescence.

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Table 1
Baseline Demographic Characteristics of the Study Sample

	n	(%)	*M*	*(SD)*
Youth demographics				
Gender				
Female	48	(55.2)		
Male	39	(44.8)		
Age (years)			13.44	(2.06)
10 < 11	12	(13.8)		
11 < 12	16	(18.4)		
12 < 13	8	(9.2)		
13 < 14	12	(13.8)		
14 < 15	13	(14.9)		
15 < 16	14	(16.1)		
16 < 17	12	(13.8)		
Race / Ethnicity[a]				
African American	12	(13.8)		
Asian American	2	(2.3)		
European American	62	(71.3)		
Hispanic American	5	(5.7)		
Native American	3	(3.4)		
Other	2	(2.3)		
Socio-economic status				
Yearly household income[b]				
Below $50,000	10	(11.5)		
$50,000 to $69,999	10	(11.5)		
$70,000 to $99,999	27	(31.0)		
$100,000 to $149,999	24	(27.6)		
$150,000 or over	11	(12.6)		
Parent level of education[a]				
Some high school	4	(4.6)		
High school graduate / GED	25	(29.1)		
Grad. tech. school / trade school / 2-year college	8	(9.2)		
College graduate	31	(35.6)		
Grad. or professional school after college	18	(20.7)		

Note: [a] Data missing for one youth; [b] not reported by five parents/guardians.

continued

Table 1 (Continued)
Baseline Demographic Characteristics of the Study Sample

	n	(%)	*M*	*(SD)*
Youth medical variables				
Years since diagnosis[a]			6.3	(3.83)
> 1 – 3	25	(28.7)		
> 3 – 6	19	(21.8)		
> 6 – 9	19	(21.8)		
> 9	23	(26.4)		
Insulin regimen				
Insulin injections, conventional regimen	54	(62.1)		
Insulin injections, flexible regimen (with basal insulin)	10	(11.5)		
Insulin pump	23	(26.4)		
Hospitalized for diabetic ketoacidosis within year before baseline[b]				
One or more times	9	(10.3)		
Never	75	(86.2)		
Hypoglycemic episodes within year before baseline[c]				
One or more	8	(9.2)		
None	77	(88.5)		
Body mass index (kg/m^2)[a]				
Boys			23.1	(4.88)
Girls			20.8	(3.87)
Parent variables				
Interviewed caregiver[a]				
Mother	75	(87.0)		
Father	9	(10.5)		
Grandmother	2	(2.3)		
Marital status[a]				
Married / living together	69	(80.0)		
Separated / divorced	14	(16.1)		
Widowed	1	(1.1)		
Never married	2	(2.3)		

Note: [a] Data missing for one youth; [b] data missing for three youths; [c] data missing for two youths.

Table 2
Baseline Characteristics of Families Retained Versus not Retained at 24-Month Follow-up

	Retained at 24-month follow-up (*n* = 44)	Lost at 24-month follow-up (*n* = 43)	*p*
Mean age in years (SD)	13.46 (2.11)	13.42 (2.02)	.93
Mean years since diagnosis (SD)	6.35 (3.96)	6.31 (3.73)	.97.
Percent female	52.17	58.54	.67
Percent European American	80.43	65.00	.14
Percent high income (≥ $100,000)	50.00	29.27	.08
Percent parents with college education	71.74	60.00	.26

Note: *p*-values are for group differences based on independent samples t-tests (age, illness duration) or Fisher's exact test (gender, race/ethnicity, income, education).

Table 3
Percentages of Responses for Youth Diabetes Responsibility Items at Baseline by Respondent

		Percentage					
Item	*Respondent*	*A*	*B*	*C*	*D*	*E*	*F*
1. Remembering or deciding when to check blood	Youth	30	44	23	3	0	0
sugar.	Parent	13	21	53	12	0	1
2. Doing blood sugar checks.	Youth	72	16	10	1	0	0
	Parent	37	36	23	2	1	0
3. Recording results of blood sugar checks.	Youth	32	16	25	13	8	6
	Parent	23	16	23	13	15	9
4. Noticing the early signs of an insulin reaction.	Youth	45	16	21	11	6	1
	Parent	19	31	44	6	0	0
5. Carrying some form of sugar to take for insulin	Youth	33	22	32	8	2	2
reactions.	Parent	9	20	53	13	5	0
6. Treating insulin reactions.	Youth	33	23	29	10	3	1
	Parent	6	15	51	20	8	0
7. Remembering or deciding when to do urine	Youth	11	11	15	22	14	26
ketone tests.	Parent	5	3	17	36	20	19
8. Doing urine ketone tests.	Youth	48	9	8	5	5	25
	Parent	36	13	14	9	10	17
9. Recording urine ketone test results.	Youth	21	6	13	9	8	44
	Parent	7	6	19	19	20	31
10. Remembering or deciding when to inject /	Youth	43	15	32	5	6	0
bolus insulin.	Parent	19	28	41	9	3	0
11. Deciding how much insulin to inject / bolus.	Youth	34	18	30	8	8	1
	Parent	17	21	43	6	13	0
12. Adjusting insulin according to how high or low	Youth	37	13	22	14	13	2
the blood sugar is.	Parent	14	19	33	15	17	2
13. Drawing insulin into the syringe / filling the pump	Youth	53	13	20	5	10	0
reservoir	Parent	34	16	24	14	10	1
14. Choosing and rotating injection / pump sites	Youth	45	20	23	8	5	0
	Parent	30	17	36	10	6	0
15. Injecting insulin /programming pump basal rates	Youth	47	10	20	11	10	0

Table 3 (continued)
Percentages of Responses for Youth Diabetes Responsibility Items at Baseline by Respondent

		Percentage					
Item	*Respondent*	*A*	*B*	*C*	*D*	*E*	*F*
	Parent	29	22	20	13	15	1
16. Deciding what time to eat when at home.	Youth	23	17	40	13	5	2
	Parent	9	9	35	33	12	2
17. Deciding what time to eat when away from home.	Youth	38	18	32	7	1	3
	Parent	12	20	34	27	6	2
18. Deciding what and how much to eat at home.	Youth	23	21	41	8	5	2
	Parent	12	12	60	13	3	0
19. Deciding what and how much to eat away from home.	Youth	38	24	30	3	2	2
	Parent	17	23	44	12	2	1
20. Adjusting how much to eat according to how high or low the blood sugar is.	Youth	23	31	32	7	5	2
	Parent	15	13	49	17	6	1
21. Counting carbs.	Youth	25	23	36	7	0	9
	Parent	12	19	49	9	2	9
22. Adjusting insulin according to how much is eaten.	Youth	29	14	30	13	8	7
	Parent	14	12	35	22	9	8
23. Deciding when to exercise.	Youth	45	32	17	3	1	1
	Parent	17	38	31	7	1	5
24. Deciding what kind and how much exercise to do.	Youth	53	31	10	3	1	1
	Parent	26	43	21	5	1	5
25. Adjusting insulin based on exercise or activity level.	Youth	26	14	29	18	5	8
	Parent	13	16	28	23	12	8
26. Adjusting eating based on exercise or activity level.	Youth	29	26	34	6	1	3
	Parent	10	21	44	13	6	6
27. Adjusting amount of exercise if blood sugar is unusually high or low.	Youth	28	20	33	9	2	8
	Parent	12	17	42	19	6	5
28. Calling the doctor in case of severe symptoms that you cannot correct.	Youth	2	0	11	24	60	2
	Parent	0	0	5	21	72	2
29. Making sure that there is enough supplies for checking urine ketone.	Youth	8	7	20	18	26	21
	Parent	0	0	13	16	60	10

Table 3 (continued)
Percentages of Responses for Youth Diabetes Responsibility Items at Baseline by Respondent

		Percentage					
Item	*Respondent*	*A*	*B*	*C*	*D*	*E*	*F*
30. Making sure that there is enough insulin.	Youth	11	18	34	17	18	0
	Parent	1	2	20	19	58	0
31. Making sure that there are enough supplies for	Youth	13	23	39	13	13	0
testing blood sugar.	Parent	1	3	21	24	50	0
32. Checking expiration dates on diabetes	Youth	18	13	31	14	21	3
supplies.	Parent	1	1	14	21	62	1
33.Telling teachers, coaches, or other adults how	Youth	14	17	49	8	9	2
to treat low blood sugar.	Parent	1	0	28	28	42	1
34. Telling friends about diabetes.	Youth	60	24	9	0	0	7
	Parent	10	16	55	12	7	0
35. Remembering day of clinic appointment.	Youth	7	0	32	28	33	0
	Parent	0	0	13	22	65	0
36. Talking to the doctor about diabetes regimen	Youth	8	11	45	15	21	0
during clinic visit.	Parent	1	3	65	19	10	1
37. Remembering to wear bracelet or necklace as	Youth	45	11	13	1	1	29
diabetes identification.	Parent	29	21	17	5	3	24
38. Remembering to bring diabetes equipment	Youth	38	18	33	5	3	2
when going out.	Parent	5	20	55	12	9	0
39. Testing blood sugar every 3-4 hours when	Youth	24	11	40	9	8	7
having the flu or another illness.	Parent	2	7	41	31	17	1
40. Remembering to take extra liquids when	Youth	20	17	41	13	7	2
having the flu or another illness.	Parent	1	3	44	30	19	2

Note: *n = 87 for youth reports, n = 86 for parent reports.*
A = "it's all my job" (youth report) / "it's all my child's job" (parent report);
B = "it's mostly my job" (youth report) / "it's mostly my child's job" (parent report);
C = "my parents and I share" (youth report) / "my child and I share" (parent report);
D = "it's mostly my parent's job" (youth report) / "it's mostly my job" (parent report);
E = "it's all my parent's job" (youth report) / "it's all my job" (parent report);
F = "it's no one's job" (youth & parent report) / response missing.

Table 4

Pearson Correlations and Descriptive Statistics for Youth Responsibility Reported by Youth and Parent at each Assessment Wave

		Youth responsibility - youth report				Youth responsibility - parent report			
		Baseline	6-mo f/u	12-mo f/u	24-mo f/u	Baseline	6-mo f/u	12-mo f/u	24-mo f/u
	Baseline	-							
Youth	6-mo f/u	.82	-						
report	12-mo f/u	.77	.82	-					
	24-mo f/u	.72	.81	.84	-				
	Baseline	.61	.70	.70	.66	-			
Parent	6-mo f/u	.61	.70	.66	.72	.88	-		
report	12-mo f/u	.58	.66	.65	.65	.81	.82	-	
	24-mo f/u	.63	.69	.68	.68	.90	.86	.84	-
	N	87	80	78	44	86	80	78	44
	M	65.42	66.80	68.13	73.97	49.31	53.97	58.03	63.27
	SD	17.27	16.91	15.64	14.14	15.61	16.41	15.90	15.54
	Potential range	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100
	Actual range	17.5 - 100	19.7 - 100	28.0 - 93.4	34.1 – 96.9	15.9 – 85.3	14.4 – 95.6	17.2 – 90.4	23.1 – 94.1
	Coeff. alpha	.95	.95	.94	.94	.95	.96	.94	.95

Note: All correlation coefficients are significant at $p < .001$.

Table 5
Descriptive Statistics for Parallel Parcels of Youth Responsibility Reported by Youth and Parent at each Wave

	SD		Coefficient alpha		Correlation between parcels
	Parcel 1	Parcel 2	Parcel 1	Parcel 2	*r*
Youth report					
Baseline	17.81	17.10	.90	.88	.94
6-mo f/u	17.57	16.83	.91	.89	.94
12-mo f/u	16.37	15.46	.89	.86	.93
24-mo f/u	14.43	14.22	.88	.86	.90
Parent report					
Baseline	16.12	15.54	.89	.90	.92
6-mo f/u	16.58	16.17	.90	.91	.95
12-mo f/u	16.93	15.68	.87	.90	.93
24-mo f/u	16.46	14.84	.88	.90	.92

Table 6
Fixed Effects Estimates (Top) and Variance-Covariance Estimates (Bottom) for Unconditional Means Model of Youth Responsibility for Diabetes Management

Model A - Youth responsibility - Youth and parent perception			Model B - Youth responsibility - Parent-youth mean and difference		
Fixed effects	Coefficient	SE	*Fixed effects*	Coefficient	SE
Youth perception	67.62***	1.57	Dyad mean	61.01***	1.47
Parent perception	54.41***	1.58	Dyad discrepancy	13.20***	1.16
Random effects	Coefficient	SE	*Random effects*	Coefficient	SE
Between person			Between dyad		
Youth perception	203.22***	32.47	Dyad mean	180.82***	28.31
Parent perception	205.89***	32.98	Dyad discrepancy	94.94***	17.66
Covariance	157.09***	28.65	Covariance	-1.34	15.83
Within person			Within dyad		
Level 1 residual	64.19***	2.91	Level 1 residual	64.19***	2.91
-2*Log Likelihood	8484.02		-2*Log Likelihood	8484.02	

Note: *** $p < .001$.

Table 7

Fixed Effects Estimates (Top) and Variance-Covariance Estimates (Bottom) for Individual Growth Model of Youth Responsibility for Diabetes Manaegment

Model A - Youth responsibility - Youth and parent perception			Model B - Youth responsibility - Parent-youth mean and difference		
Fixed effects	Coefficient	SE	*Fixed effects*	Coefficient	SE
Initial status			Initial status		
Youth perception			Dyad mean		
Intercept	50.82***	2.66	Intercept	44.04***	1.97
Age	4.19***	0.62	Age	4.01***	0.58
Parent perception			Dyad discrepancy		
Intercept	37.26***	2.62	Intercept	13.56***	2.27
Baseline age	3.82***	0.64	Baseline age	0.37	0.44
Rate of change			Rate of change		
Youth perception			Dyad mean		
Intercept	3.28***	0.88	Intercept	4.54***	0.60
Parent perception			Dyad discrepancy		
Intercept	5.81***	0.61	Intercept	-2.53**	0.95
Random effects	Coefficient	SE	*Random effects*	Coefficient	SE
Initial status			Initial status		
Youth perception	213.94***	34.42	Dyad mean	149.73***	23.74
Parent perception	159.42***	26.25	Dyad discrepancy	147.78***	26.43
Covariance	112.79***	24.48	Covariance	27.26	17.93
Rate of change			Rate of change		
Youth perception	48.16***	9.88	Dyad mean	21.27***	4.50
Parent perception	16.88***	4.65	Dyad discrepancy	44.99***	11.13
Covariance	10.02*	4.96	Covariance	15.64**	5.31
Level 1 residual	37.47***	1.84	Level 1 residual	37.47***	1.84
-2*Log Likelihood	8100.65		-2*Log Likelihood	8100.65	

Note: * $p < .05$; ** $p < .01$; *** $p < .001$. Correlations between initial status and change are not shown but were also estimated and are presented in the text.

Table 8

Pearson Correlations and Descriptive Statistics for Adherence Reported by Youth and Parent at each Wave

		Adherence - youth report				Adherence - parent report			
		Baseline	6-mo f/u	12-mo f/u	24-mo f/u	Baseline	6-mo f/u	12-mo f/u	24-mo f/u
	Baseline	-							
Youth	6-mo f/u	.63	-						
report	12-mo f/u	.61	.70	-					
	24-mo f/u	.40[a]	.51	.46[a]	-				
	Baseline	.47	.49	.33[a]	.49	-			
Parent	6-mo f/u	.50	.55	.43	.45[a]	.76	-		
report	12-mo f/u	.42	.34[a]	.43	.51	.66	.70	-	
	24-mo f/u	.41[a]	.19[c]	.31[b]	.62	.38[a]	.45[a]	.59	-
	N	87	80	78	44	86	80	78	44
	M	65.57	65.80	69.39	70.08	67.40	69.39	68.58	68.87
	SD	10.11	10.79	9.83	8.80	11.01	10.43	10.42	10.70
	Coeff. alpha	.72	.74	.71	.70	.76	.75	.78	.79

Note: Correlation coefficients are significant at $p < .001$ with the exception of [a] $p < .01$, [b] $p < .05$, [c] not significant ($p > .05$).

Table 9

Fixed Effects Estimates (Top) and Variance Estimates (Bottom) for Individual Growth Models of Youth-Reported Adherence, Parent-Reported Adherence, and Glycemic Control (HbA_{1c})

	Youth-reported adherence		Parent-reported adherence		Glycemic control (HbA_{1c})	
Fixed effects	Coefficient	SE	Coefficient	SE	Coefficient	SE
Initial status						
Intercept	68.87***	1.81	70.44***	1.97	7.68***	0.30
Age	-0.95*	0.42	-0.68	0.47	0.14†	0.07
Rate of change						
Intercept	1.76**	0.54	0.16	0.66	0.51***	0.12
Random effects						
Initial status	78.19***	15.96	92.61***	17.39	1.81***	0.32
Rate of change	5.04*	3.09	16.42***	5.78	0.42***	0.17
Level 1 residual	38.17***	4.41	29.54***	3.55	0.51***	0.07
-2*Log Likelihood	4828.0					

Note: Estimates were derived from a single multivariate multilevel model with youth-reported adherence, parent-reported adherence, and glycemic control as simultaneous outcomes. Correlations among the Level 2 random effects are not shown but were also estimated and are presented in the text. † $p = .06$; * $p \le .05$; ** $p < .01$; *** $p < .001$.

Table 10

Latent Variable Multiple Regression Analysis Predicting Initial Status of Youth-Reported Adherence from Initial Status of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	-0.76	0.57	-1.34	Age	-0.76	0.57	-1.34
Initial responsibility				*Initial responsibility*			
Y perception	-0.20*	0.10	-2.01	Dyad mean	-0.01	0.09	-0.16
P perception	0.18	0.12	1.58	Dyad discrepancy	-0.19*	0.10	-1.96

Note: Y = youth, P = parent; * $p \leq .05$.

Table 11

Latent Variable Multiple Regression Analysis Predicting Initial Status of Parent-Reported Adherence from Initial Status of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	-0.76	0.58	-1.32	Age	-0.76	0.58	-1.32
Initial responsibility				*Initial responsibility*			
Y perception	-0.29**	0.10	-2.96	Dyad mean	0.04	0.09	0.48
P perception	0.34**	0.12	2.92	Dyad discrepancy	-0.32**	0.10	-3.25

Note: Y = youth, P = parent; ** $p < .01$.

Table 12

Latent Variable Multiple Regression Analysis Predicting Initial Status of HbA_{1c} from Initial Status of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	0.135	0.09	1.54	Age	0.135	0.09	1.54
Initial responsibility				*Initial responsibility*			
Y perception	0.033*	0.01	2.35	Dyad mean	-0.003	0.01	-0.26
P perception	-0.036*	0.02	-2.21	Dyad discrepancy	0.034**	0.01	2.51

Note: Y = youth, P = parent; * $p < .05$, ** $p < .01$.

Table 13

Latent Variable Multiple Regression Analysis Predicting Change of Youth-Reported Adherence from Initial Status of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	-0.10	0.20	-0.52	Age	-0.10	0.20	-0.52
Initial responsibility				*Initial responsibility*			
Y perception	0.07	0.05	1.34	Dyad mean	0.02	0.05	0.43
P perception	-0.05	0.06	-0.81	Dyad discrepancy	0.06	0.05	1.17

Note: Y = youth, P = parent;

Table 14

Latent Variable Multiple Regression Analysis Predicting Change of Parent-Reported Adherence from Initial Status of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	-0.06	0.23	-0.25	Age	-0.06	0.23	-0.25
Initial responsibility				*Initial responsibility*			
Y perception	0.08	0.06	1.23	Dyad mean	0.01	0.06	0.12
P perception	-0.07	0.07	-0.95	Dyad discrepancy	0.07	0.06	1.19

Note: Y = youth, P = parent;

Table 15

Latent Variable Multiple Regression Analysis Predicting Change of HbA_{1c} from Initial Status of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	0.05	0.04	1.24	Age	0.05	0.04	1.24
Initial responsibility				*Initial responsibility*			
Y perception	-0.011	0.01	-1.03	Dyad mean	-0.012	0.01	-1.21
P perception	-0.001	0.01	-0.07	Dyad discrepancy	-0.005	0.01	-0.48

Note: Y = youth, P = parent;

Table 16

Latent Variable Multiple Regression Analysis Predicting Change of Youth-Reported Adherence from Change of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Change in responsibility				*Change in responsibility*			
Y perception	-0.23*	0.09	-2.37	Dyad mean	0.16	0.17	0.96
P perception	0.39*	0.18	2.15	Dyad discrepancy	-0.31**	0.12	-2.63

Note: Y = youth, P = parent; * $p < .05$, ** $p \leq .01$.

Table 17

Latent Variable Multiple Regression Analysis Predicting Change of Parent-Reported Adherence from Change of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Change in responsibility				*Change in responsibility*			
Y perception	-0.33**	0.11	-2.99	Dyad mean	0.29	0.19	1.53
P perception	0.62**	0.21	2.99	Dyad discrepancy	-0.47***	0.13	-3.50

Note: Y = youth, P = parent; ** $p < .01$; *** $p < .001$.

Table 18

Latent Variable Multiple Regression Analysis Predicting Change of HbA_{1c} from Change of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Change in responsibility				*Change in responsibility*			
Y perception	0.009	0.02	0.43	Dyad mean	0.030	0.04	0.81
P perception	0.021	0.04	0.50	Dyad discrepancy	-0.006	0.03	-0.21

Note: Y = youth, P = parent;

Table 19
Latent Variable Multiple Regression Analysis Predicting Change of Youth-Reported Adherence from Initial Status and Change of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	-0.15	0.62	-0.24	Age	-0.15	0.62	-0.24
Initial adh.	-0.12	0.08	-1.48	Initial adh.	-0.12	0.08	-1.48
Initial responsibility				*Initial responsibility*			
Y perception	-0.02	0.07	-0.37	Dyad mean	0.01	0.05	0.29
P perception	0.04	0.06	0.64	Dyad discrepancy	-0.03	0.06	-0.54
Change in responsibility				*Change in responsibility*			
Y perception	-0.19	0.13	-1.53	Dyad mean	0.14	0.17	0.82
P perception	0.33	0.18	1.88	Dyad discrepancy	-0.26*	0.13	-2.05

Note: Y = youth, P = parent; * $p < .05$.

Table 20
Latent Variable Multiple Regression Analysis Predicting Change of Parent-Reported Adherence from Initial Status and Change of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	-0.07	0.74	-0.09	Age	-0.07	0.74	-0.09
Initial adh.	-0.14	0.09	-1.68	Initial adh.	-0.14	0.09	-1.68
Initial responsibility				*Initial responsibility*			
Y perception	-0.11	0.08	0.14	Dyad mean	0.00	0.06	0.05
P perception	0.11	0.07	1.62	Dyad discrepancy	-0.11	0.07	-1.67
Change in responsibility				*Change in responsibility*			
Y perception	-0.37*	0.15	-2.5	Dyad mean	0.24	0.18	1.30
P perception	0.61**	0.20	3.09	Dyad discrepancy	-0.49**	0.15	-3.30

Note: Y = youth, P = parent; * $p < .05$; ** $p < .01$.

Table 21

Latent Variable Multiple Regression Analysis Predicting Change of HbA_{1c} from Initial Status and Change of Responsibility for Diabetes Management

Model A				Model B			
Predictors	Coeff.	*SE*	*t*-ratio	Predictors	Coeff.	*SE*	*t*-ratio
Age	0.030	0.13	0.17	Age	0.030	0.13	0.17
Initial HbA_{1c}	0.104	0.10	1.07	Initial HbA_{1c}	0.104	0.10	1.07
Initial responsibility				*Initial responsibility*			
Y perception	-0.016	0.02	-1.02	Dyad mean	-0.010	0.01	-0.90
P perception	0.006	0.01	0.40	Dyad discrepancy	-0.011	0.01	-0.78
Change in responsibility				*Change in responsibility*			
Y perception	-0.006	0.03	-0.19	Dyad mean	0.016	0.04	0.39
P perception	0.022	0.04	0.51	Dyad discrepancy	-0.014	0.03	-0.45

Note: Y = youth, P = parent;

Table 22

Pearson Correlations and Descriptive Statistics of Baseline Family Characteristics

	Responsive parenting	Demanding parenting	Open communication	(Few) communication problems	Family support	(Low) home chaos
Responsive parenting	-					
Demanding parenting	.34**	-				
Open communication	.26*	.15	-			
(Few) communication problems	.16	.00	.43***	-		
Family support	.75***	.31**	.27*	.28**	-	
(Low) home chaos	.27*	.13	.32*	.37***	.33**	-
N	87	87	86	86	87	86
M	3.14	3.19	4.02	3.68	2.63	1.77
SD	.51	.43	.61	.71	.35	.19
Potential range	1.0 – 4.0	1.0 – 4.0	1.0 – 5.0	1.0 – 5.0	1.0 – 3.0	1.0 – 2.0
Actual range	1.1 – 4.0	2.1 – 4.0	1.9 – 5.0	2.0 – 5.0	1.5 – 3.0	1.2 – 2.0
Coeff. alpha	.88	.72	.85	.76	.85	.79

Note: * $p < .05$; ** $p < .01$; *** $p < .001$.

Table 23
Individual Growth Model with Parent Responsiveness as Predictor of Youth Responsibility for Diabetes Management

Model A Youth and parent perception			Model B Dyad mean and discrepancy		
Fixed effects	Coeff.	*SE*	*Fixed effects*	Coeff.	*SE*
Initial status			Initial status		
Youth perception			Dyad mean		
Intercept	50.56	2.69	Intercept	43.65	2.39
Age	4.28	0.62	Age	4.14	0.58
Responsiveness	0.00	3.20	Responsiveness	1.49	2.65
Parent perception			Dyad discrepancy		
Intercept	36.74	2.62	Intercept	13.82	2.30
Age	3.99	0.65	Age	0.30	0.53
Responsiveness	2.98	2.76	Responsiveness	-2.99	2.76
Rate of change			Rate of change		
Youth perception			Dyad mean		
Intercept	3.25	0.88	Intercept	4.52	0.59
Responsiveness	1.74	1.73	Responsiveness	1.46	1.17
Parent perception			Dyad discrepancy		
Intercept	5.78	0.62	Intercept	-2.53	0.95
Responsiveness	1.18	1.24	Responsiveness	0.57	1.90
Random effects	Coeff.	*SE*	*Random effects*	Coeff.	*SE*
Level 2 Initial status			Level 2 Initial status		
Youth perception	216.47	35.00	Dyad mean	150.48	23.94
Parent perception	157.38	25.96	Dyad discrepancy	145.78	26.14
Level 2 Rate of change			Level 2 Rate of change		
Youth perception	47.45	9.78	Dyad mean	20.71	4.41
Parent perception	16.62	4.60	Dyad discrepancy	45.30	11.19
Level 1 Residual	37.50	1.84	Level 1 Residual	37.50	1.84
-2Log Likelihood	8082.95		-2Log Likelihood	8082.95	

Note: Significance levels of fixed-effects intercepts and age terms correspond with those in Table 7. Random-effects coefficients are significant at $p < .001$. Fixed effects for responsiveness are not significant.

Table 24
Individual Growth Model with Parent Demandingness as Predictor of Youth Responsibility for Diabetes Management

Model A Youth and parent perception			Model B Dyad mean and discrepancy		
Fixed effects	Coeff.	*SE*	*Fixed effects*	Coeff.	*SE*
Initial status			Initial status		
Youth perception			Dyad mean		
Intercept	50.88	2.65	Intercept	44.09	2.37
Age	4.19	0.61	Age	4.00	0.57
Demandingness	-5.03	3.77	Demandingness	-3.88	3.13
Parent perception			Dyad discrepancy		
Intercept	37.29	2.62	Intercept	13.60	2.30
Age	3.82	0.65	Age	0.36	0.53
Demandingness	-2.74	3.29	Demandingness	-2.28	3.31
Rate of change			Rate of change		
Youth perception			Dyad mean		
Intercept	3.27	0.88	Intercept	4.54	0.60
Demandingness	0.74	2.04	Demandingness	0.49	1.38
Parent perception			Dyad discrepancy		
Intercept	5.80	0.62	Intercept	-2.52	0.95
Demandingness	0.24	1.42	Demandingness	0.49	2.18
Random effects	Coeff.	*SE*	*Random effects*	Coeff.	*SE*
Level 2 Initial status			Level 2 Initial status		
Youth perception	211.78	34.28	Dyad mean	148.36	23.62
Parent perception	158.64	26.15	Dyad discrepancy	147.39	26.39
Level 2 Rate of change			Level 2 Rate of change		
Youth perception	48.41	9.93	Dyad mean	21.38	4.53
Parent perception	16.87	4.65	Dyad discrepancy	45.05	11.15
Level 1 Residual	37.50	1.84	Level 1 Residual	37.50	1.84
-2Log Likelihood	8084.90		-2Log Likelihood	8084.90	

Note: Significance levels of fixed-effects intercepts and age terms correspond with those in Table 7. Random-effects coefficients are significant at $p < .001$. Fixed effects for demandingness are not significant.

Table 25

Individual Growth Model with Open Parent-Youth Communication as Predictor of Youth Responsibility for Diabetes Management

Model A Youth and parent perception			Model B Dyad mean and discrepancy		
Fixed effects	Coeff.	*SE*	*Fixed effects*	Coeff.	*SE*
Initial status			Initial status		
Youth perception			Dyad mean		
Intercept	50.74	2.68	Intercept	43.85	2.34
Age	4.22	0.62	Age	4.07	0.57
Open comm.	0.51	2.71	Open comm.	3.76	2.21
Parent perception			Dyad discrepancy		
Intercept	36.97	2.49	Intercept	13.77	2.17
Age	3.92	0.61	Age	0.31	0.50
Open comm.	7.01**	2.23	Open comm.	-6.49**	2.26
Rate of change			Rate of change		
Youth perception			Dyad mean		
Intercept	3.29	0.88	Intercept	4.55	0.60
Open comm.	0.04	1.51	Open comm.	-0.25	1.03
Parent perception			Dyad discrepancy		
Intercept	5.80	0.62	Intercept	-2.51	0.94
Open comm.	-0.54	1.07	Open comm.	0.58	1.63
Random effects	Coeff.	*SE*	*Random effects*	Coeff.	*SE*
Level 2 Initial status			Level 2 Initial status		
Youth perception	216.16	34.95	Dyad mean	146.02	23.26
Parent perception	142.16	23.64	Dyad discrepancy	132.57	24.13
Level 2 Rate of change			Level 2 Rate of change		
Youth perception	47.97	9.86	Dyad mean	21.50	4.55
Parent perception	16.79	4.63	Dyad discrepancy	43.50	10.87
Level 1 Residual	37.54	1.84	Level 1 Residual	37.54	1.84
-2Log Likelihood	8071.61		-2Log Likelihood	8071.61	

Note: Significance levels of fixed-effects intercepts and age terms correspond with those in Table 7. Random-effects coefficients are significant at $p < .001$. ** $p < .01$.

Table 26

Individual Growth Model with (Few) Problems in Parent-Youth Communication as Predictor of Youth Responsibility for Diabetes Management

Model A Youth and parent perception			Model B Dyad mean and discrepancy		
Fixed effects	Coeff.	*SE*	*Fixed effects*	Coeff.	*SE*
Initial status			Initial status		
Youth perception			Dyad mean		
Intercept	51.12	2.68	Intercept	44.40	2.38
Age	4.12	0.62	Age	3.91	0.57
(Few) comm. probs.	-0.84	2.34	(Few) comm. probs.	1.16	1.93
Parent perception			Dyad discrepancy		
Intercept	37.68	2.59	Intercept	13.44	2.29
Age	3.71	0.64	Age	0.41	0.53
(Few) comm. probs.	3.16	2.00	(Few) comm. probs.	-4.00*	2.00
Rate of change			Rate of change		
Youth perception			Dyad mean		
Intercept	3.23	0.87	Intercept	4.51	0.59
(Few) comm. probs.	2.13	1.28	(Few) comm. probs.	1.17	0.86
Parent perception			Dyad discrepancy		
Intercept	5.80	0.62	Intercept	-2.58	0.95
(Few) comm. probs.	0.21	0.91	(Few) comm. probs.	1.92	1.39
Random effects	Coeff.	*SE*	*Random effects*	Coeff.	*SE*
Level 2 Initial status			Level 2 Initial status		
Youth perception	215.92	34.91	Dyad mean	150.26	23.91
Parent perception	155.14	25.61	Dyad discrepancy	141.08	25.43
Level 2 Rate of change			Level 2 Rate of change		
Youth perception	46.65	9.65	Dyad mean	20.48	4.38
Parent perception	16.71	4.62	Dyad discrepancy	44.78	11.12
Level 1 Residual	37.48	1.84	Level 1 Residual	37.48	1.84
-2Log Likelihood	8080.48		-2Log Likelihood	8080.48	

Note: Significance levels of fixed-effects intercepts and age terms correspond with those in Table 7. Random-effects coefficients are significant at $p < .001$. * $p < .05$.

Table 27
Individual Growth Model with Family Social Support as Predictor of Youth Responsibility for Diabetes Management

Model A Youth and parent perception			Model B Dyad mean and discrepancy		
Fixed effects	Coeff.	*SE*	*Fixed effects*	Coeff.	*SE*
Initial status			Initial status		
Youth perception			Dyad mean		
Intercept	50.92	2.67	Intercept	44.07	2.39
Age	4.17	0.62	Age	4.01	0.58
Social support	-5.89	4.58	Social support	-2.69	3.82
Parent perception			Dyad discrepancy		
Intercept	37.21	2.59	Intercept	13.70	2.28
Age	3.85	0.64	Age	0.33	0.53
Social support	0.51	4.01	Social support	-6.39	3.97
Rate of change			Rate of change		
Youth perception			Dyad mean		
Intercept	3.26	0.87	Intercept	4.52	0.59
Social support	3.42	2.53	Social support	2.29	1.71
Parent perception			Dyad discrepancy		
Intercept	5.79	0.62	Intercept	-2.53	0.94
Social support	1.16	1.80	Social support	2.26	2.76
Random effects	Coeff.	*SE*	*Random effects*	Coeff.	*SE*
Level 2 Initial status			Level 2 Initial status		
Youth perception	211.90	34.30	Dyad mean	150.11	23.89
Parent perception	159.87	26.34	Dyad discrepancy	143.10	25.74
Level 2 Rate of change			Level 2 Rate of change		
Youth perception	47.09	9.73	Dyad mean	20.72	4.42
Parent perception	16.61	4.60	Dyad discrepancy	44.54	11.07
Level 1 Residual	37.52	1.84	Level 1 Residual	37.52	1.84
-2Log Likelihood	8083.66		-2Log Likelihood	8083.66	

Note: Significance levels of fixed-effects intercepts and age terms correspond with those in Table 7. Random-effects coefficients are significant at $p < .001$. Fixed effects for social support are not significant.

Table 28
Individual Growth Model with (Low) Home Chaos as Predictor of Youth Responsibility for Diabetes Management

Model A Youth and parent perception			Model B Dyad mean and discrepancy		
Fixed effects	Coeff.	*SE*	*Fixed effects*	Coeff.	*SE*
Initial status			Initial status		
Youth perception			Dyad mean		
Intercept	51.18	2.56	Intercept	44.29	2.33
Age	4.10	0.60	Age	3.94	0.56
(Low) home chaos	-27.17**	9.55	(Low) home chaos	-18.01**	6.83
Parent perception			Dyad discrepancy		
Intercept	37.41	2.61	Intercept	13.77	2.26
Age	3.79	0.64	Age	0.31	0.52
(Low) home chaos	-8.85	7.37	(Low) home chaos	-18.22**	7.19
Rate of change			Rate of change		
Youth perception			Dyad mean		
Intercept	3.25	0.86	Intercept	4.52	0.58
(Low) home chaos	10.26*	4.48	(Low) home chaos	6.09*	3.04
Parent perception			Dyad discrepancy		
Intercept	5.80	0.62	Intercept	-2.55	0.34
(Low) home chaos	1.93	3.22	(Low) home chaos	8.34	4.90
Random effects	Coeff.	*SE*	*Random effects*	Coeff.	*SE*
Level 2 Initial status			Level 2 Initial status		
Youth perception	189.34	30.86	Dyad mean	139.20	22.22
Parent perception	157.20	25.93	Dyad discrepancy	136.28	24.70
Level 2 Rate of change			Level 2 Rate of change		
Youth perception	44.27	9.28	Dyad mean	19.66	4.25
Parent perception	16.59	4.60	Dyad discrepancy	43.08	10.84
Level 1 Residual	37.54	1.84	Level 1 Residual	37.54	1.84
-2Log Likelihood	8075.60		-2Log Likelihood	8075.60	

Note: Significance levels of fixed-effects intercepts and age terms correspond with those in Table 7. Random-effects coefficients are significant at $p < .001$. * $p < .05$; ** $p \leq .01$.

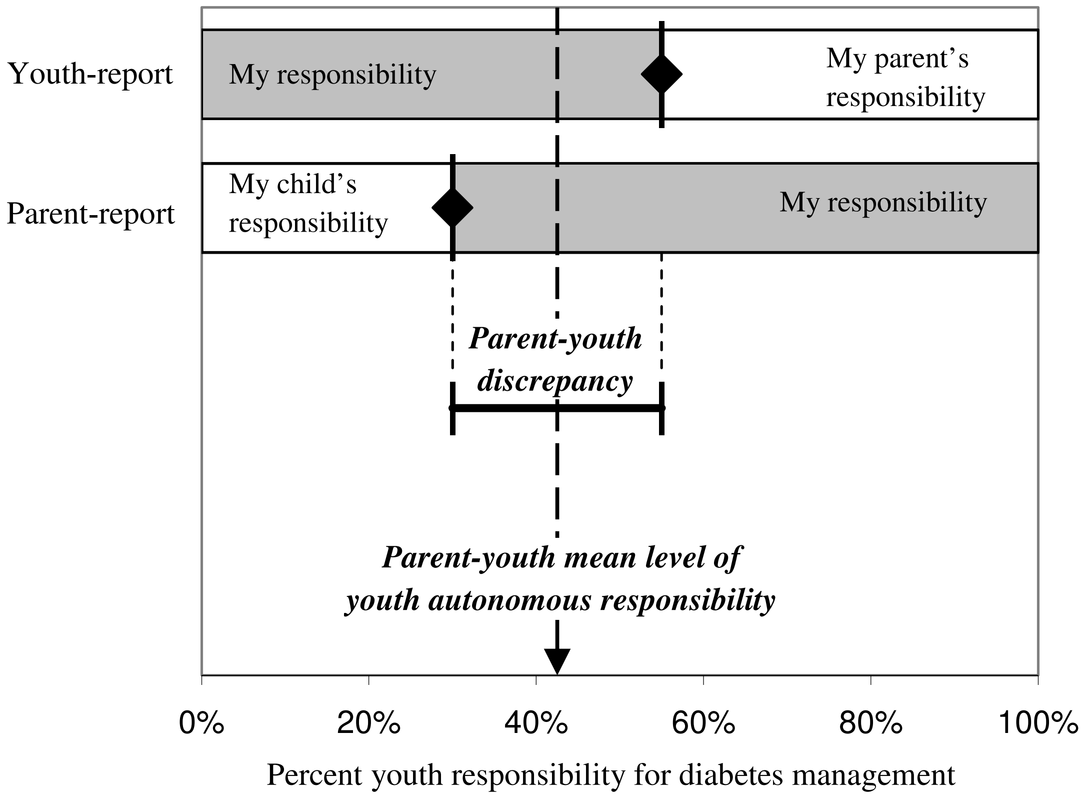

Figure 1. Conceptual diagram illustrating the operationalization of (a) the level of youth autonomous responsibility, and (b) youth-parent discrepancy in perceptions of responsibility for diabetes management.

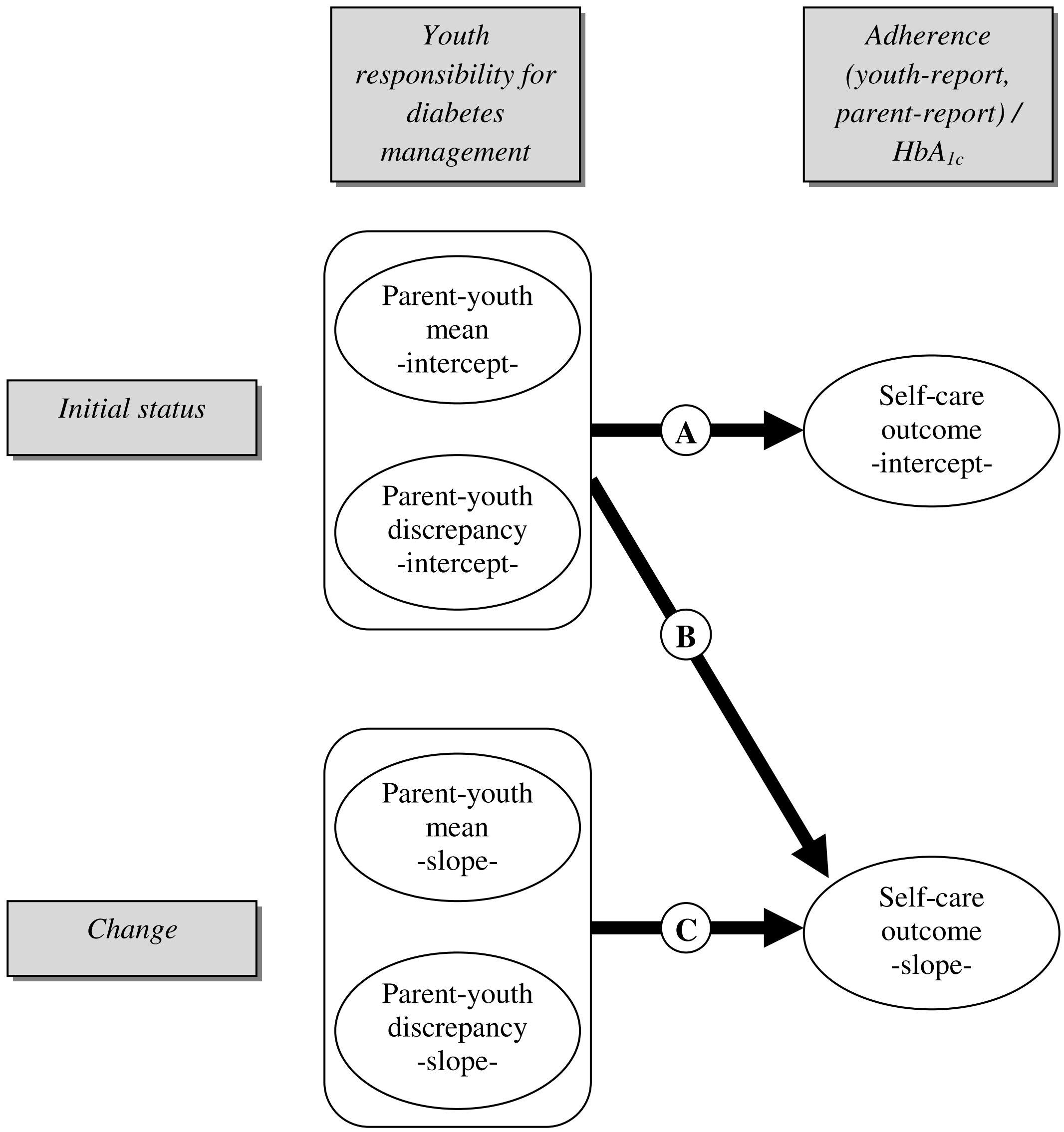

Figure 2. Diagram of the hypothesized associations between initial status (intercept) and change (slope) of the study variables.
Intercepts and slopes are latent variables; observed variables are omitted.

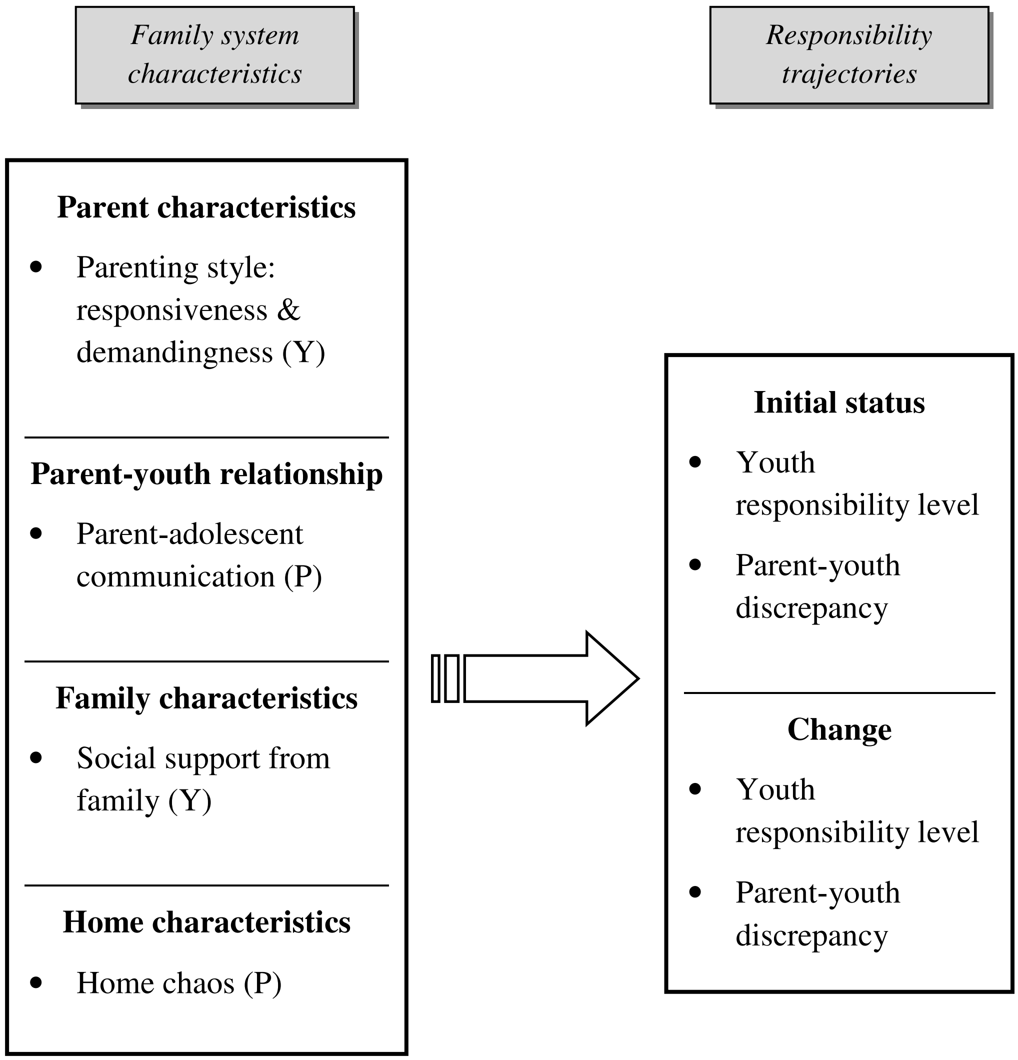

Figure 3. Hypothesized predictive relationships between family system characteristics and responsibility trajectories.
Y = youth report; P = parent report.

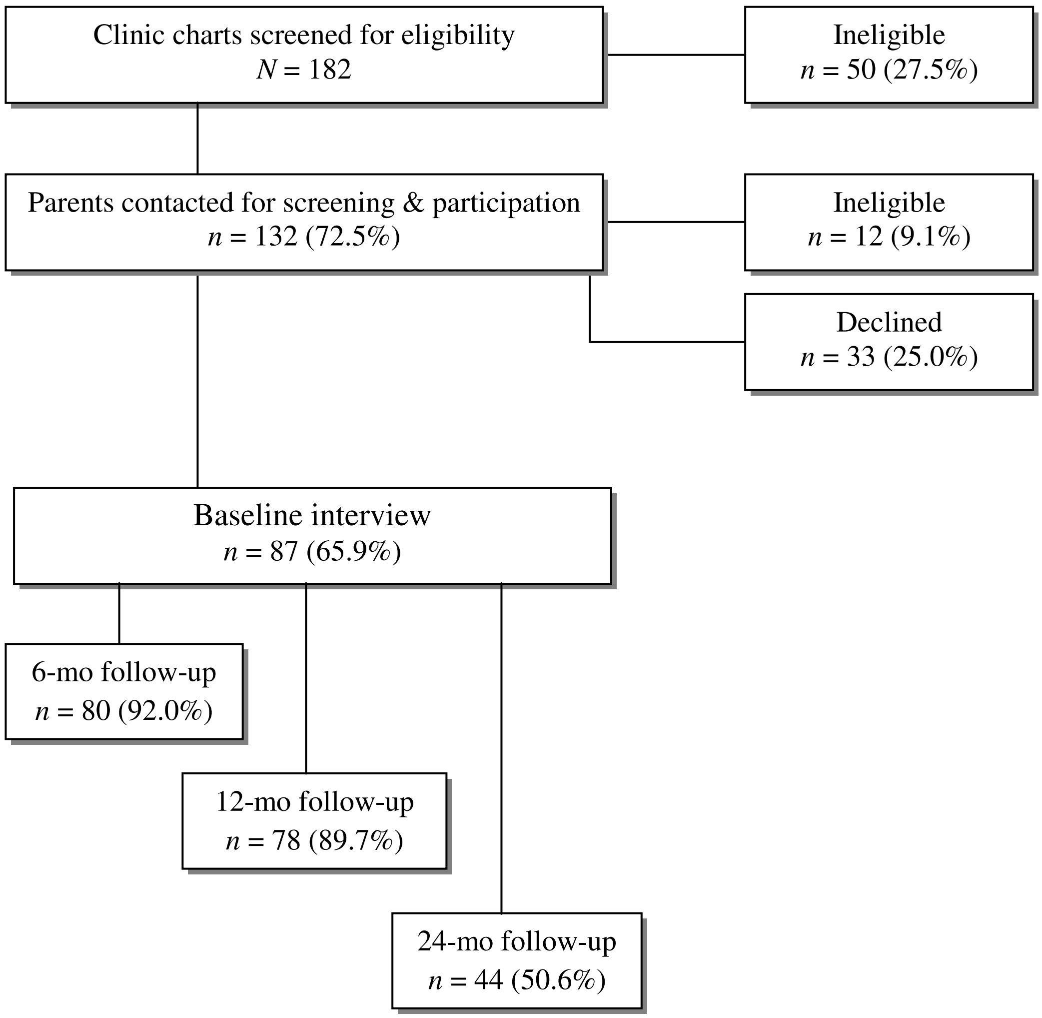

Figure 4. Flowchart of participant recruitment and retention.

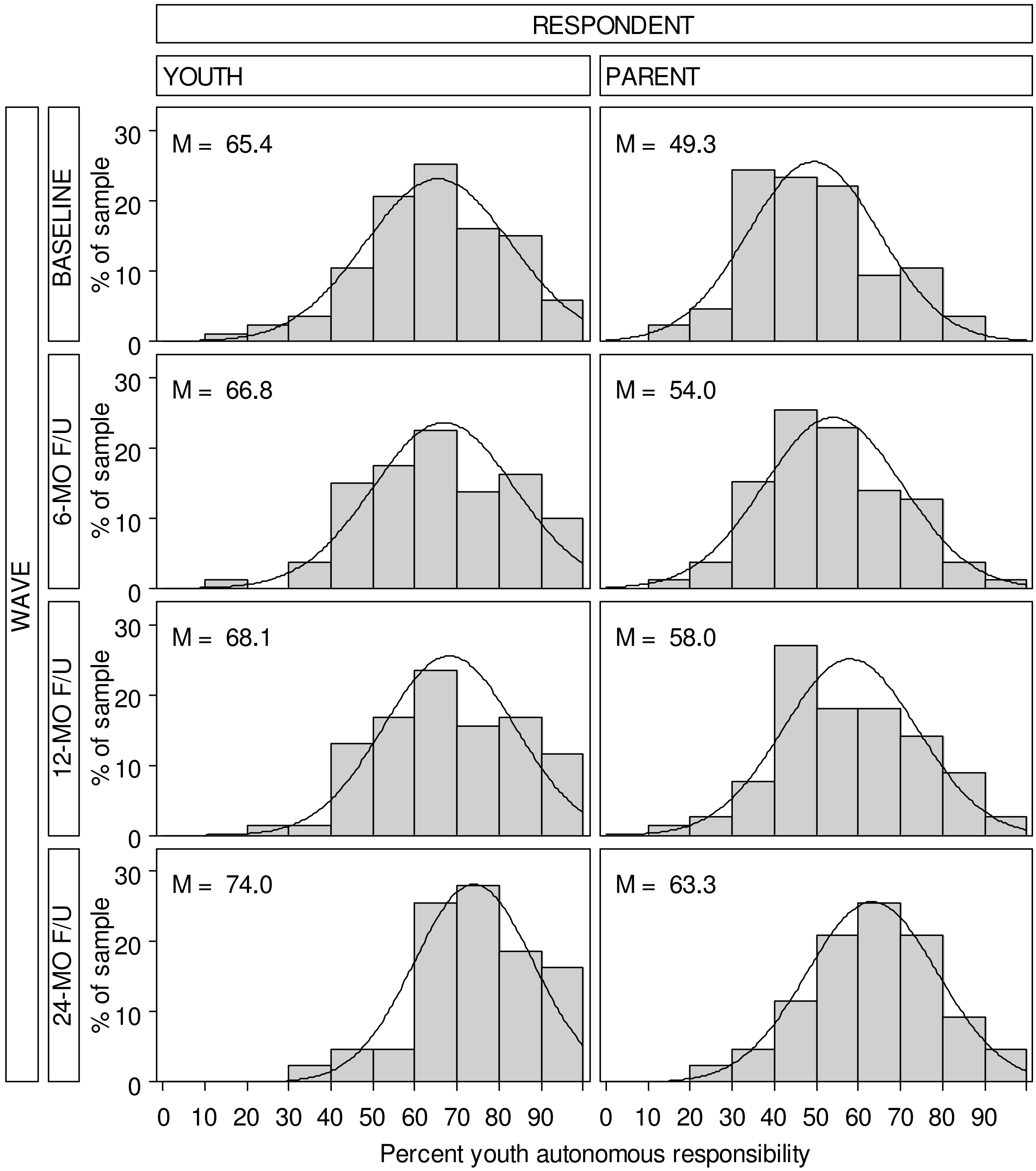

Figure 5. Histograms with normal distribution curves for scale scores of youth responsibility for diabetes management by wave and respondent.

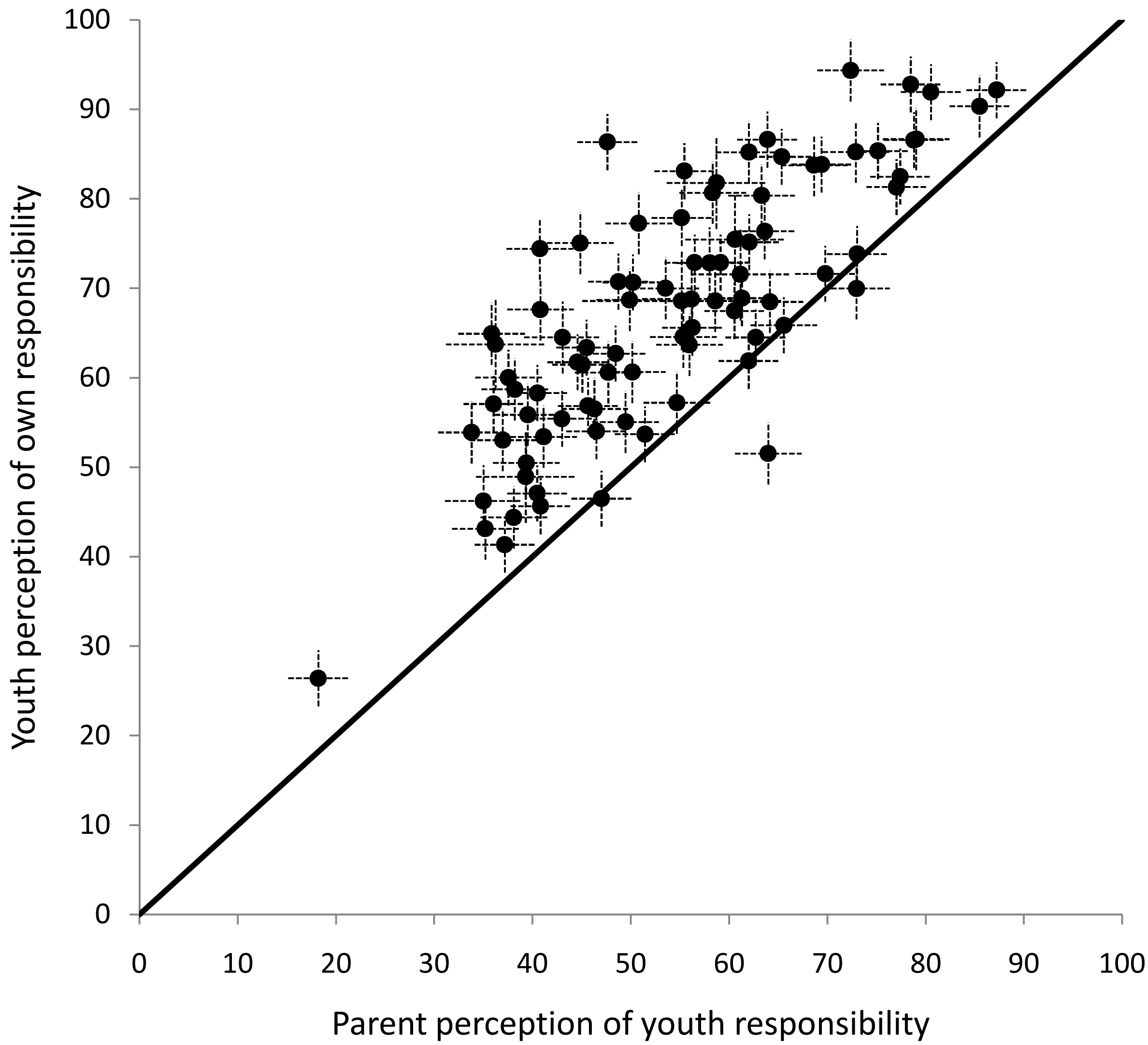

Figure 6. Model-based (empirical Bayes) estimates of youth perceptions of responsibility plotted against parent perceptions of youth responsibility, with line of equality.
Error bars represent standard errors of each estimate.

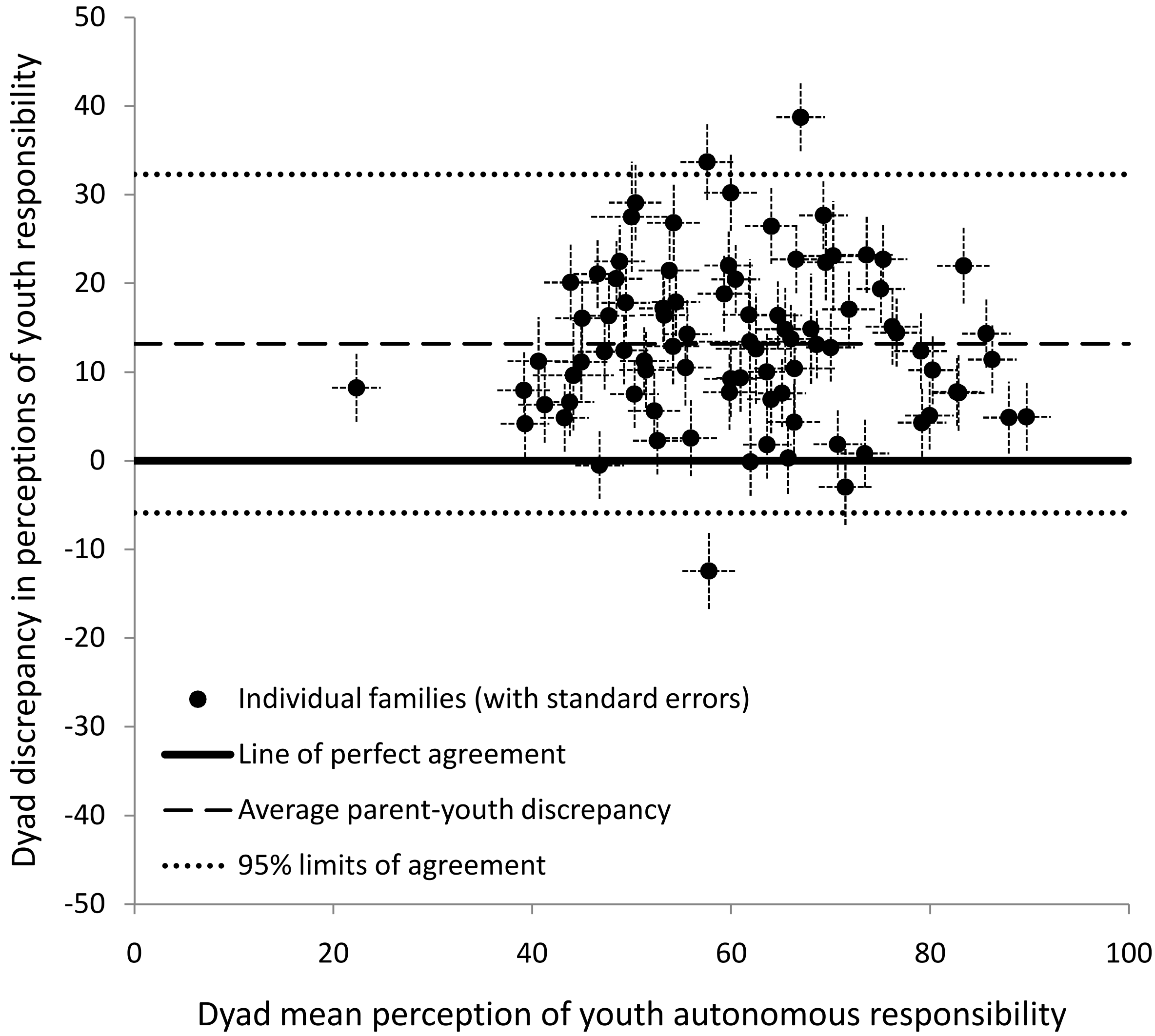

Figure 7. Model-based (empirical Bayes) estimates of dyad discrepancies plotted against dyad mean estimates of youth responsibility.
Error bars represent standard errors of each estimate.

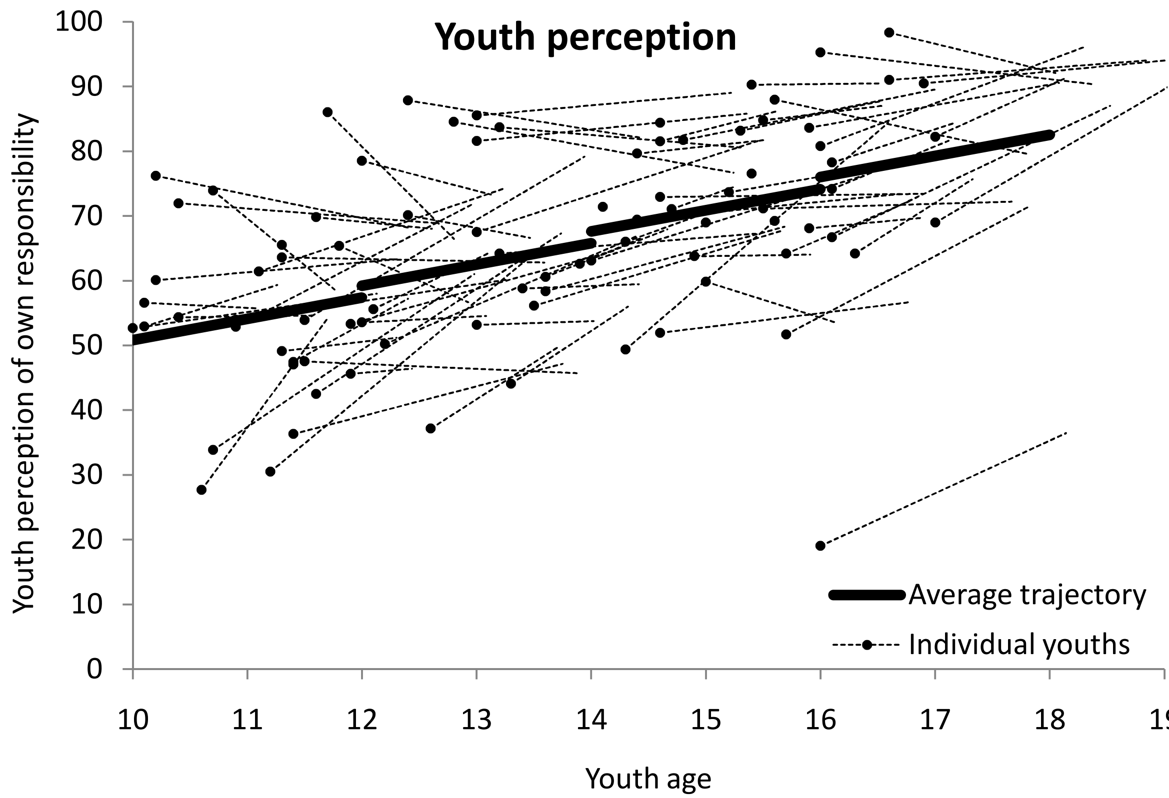

Figure 8. Predicted average trajectories of youth perceptions of their responsibility for diabetes management for cohorts of 10, 12, 14, and 16 years of age, with empirical Bayes estimates of trajectories for individual youths.

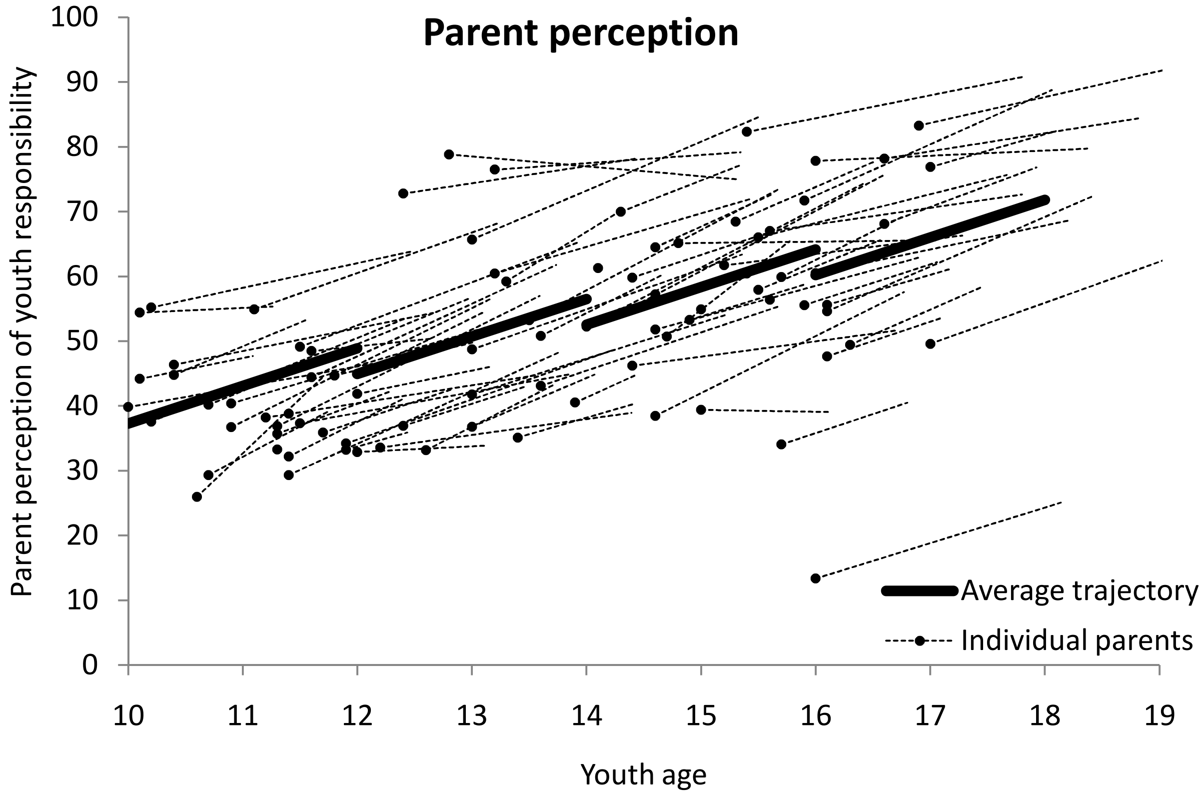

Figure 9. Predicted average trajectories of parent perceptions of youth responsibility for diabetes management for cohorts of 10, 12, 14, and 16 years of age, with empirical Bayes estimates of trajectories for individual parents.

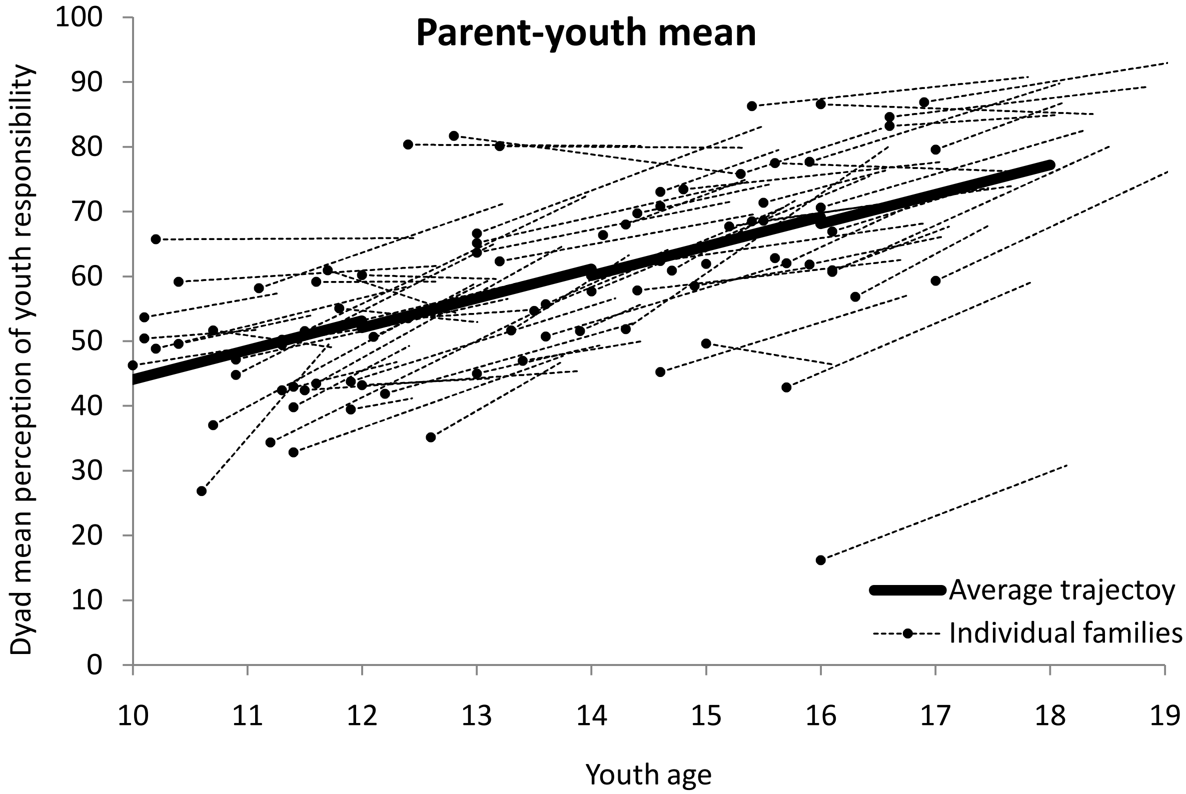

Figure 10. Predicted average trajectories of dyad mean perceptions of youth responsibility for diabetes management for cohorts of 10, 12, 14, and 16 years of age, with empirical Bayes estimates of trajectories for individual families.

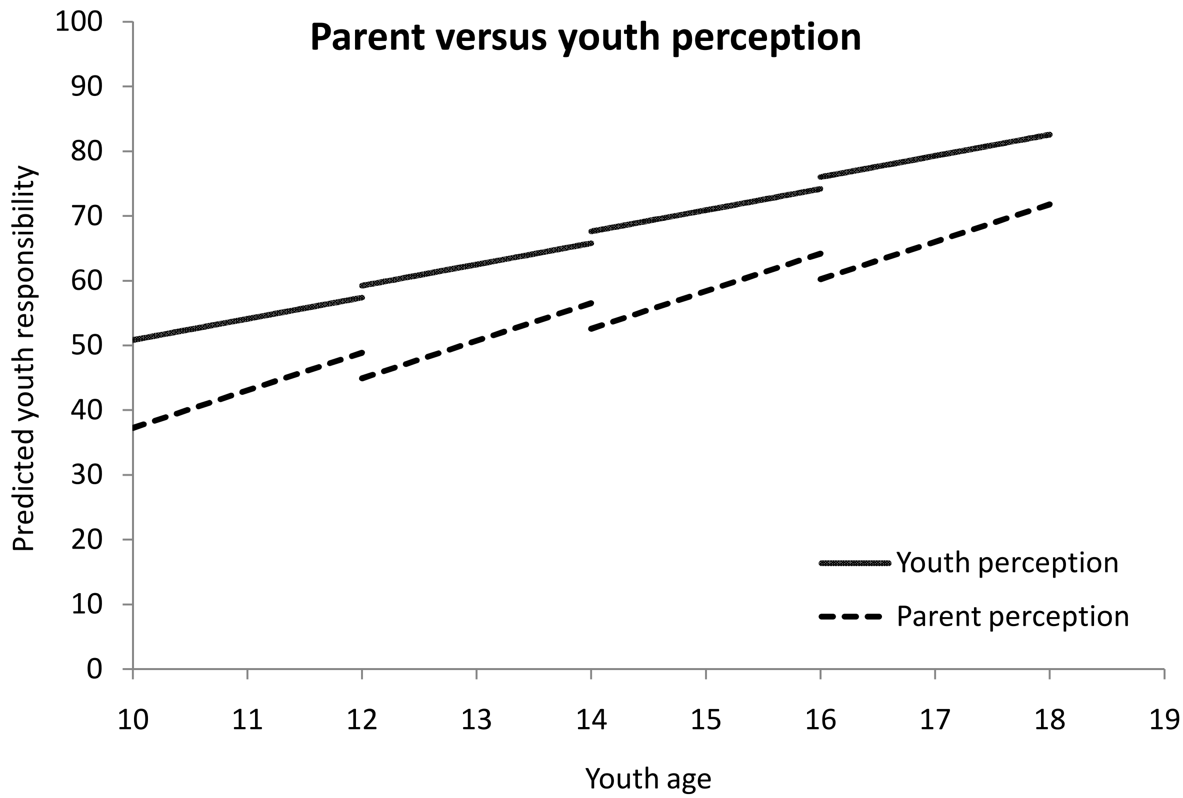

Figure 11. Predicted average trajectories of youth and parent perceptions of youth responsibility for diabetes management for cohorts of 10, 12, 14, and 16 years of age.

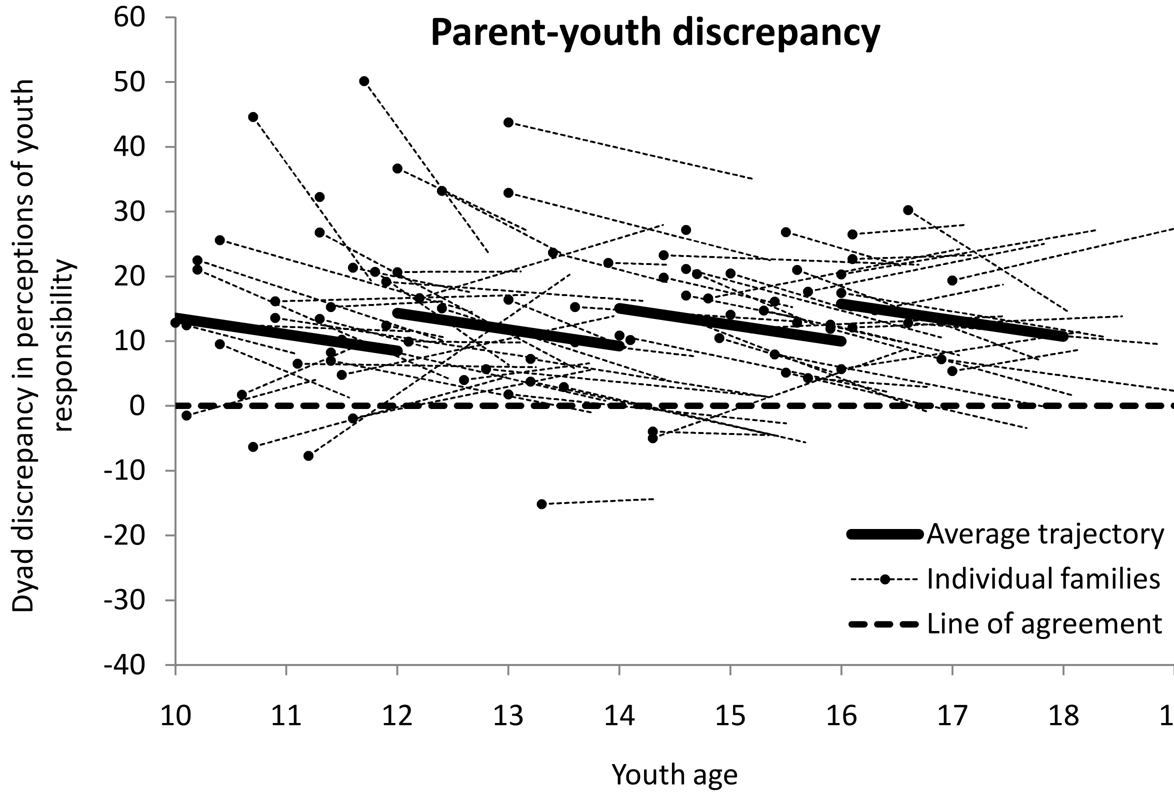

Figure 12. Predicted average trajectories of dyad discrepancies in perceptions of youth responsibility for diabetes management for cohorts of 10, 12, 14, and 16 years of age, with empirical Bayes estimates of trajectories for individual families.

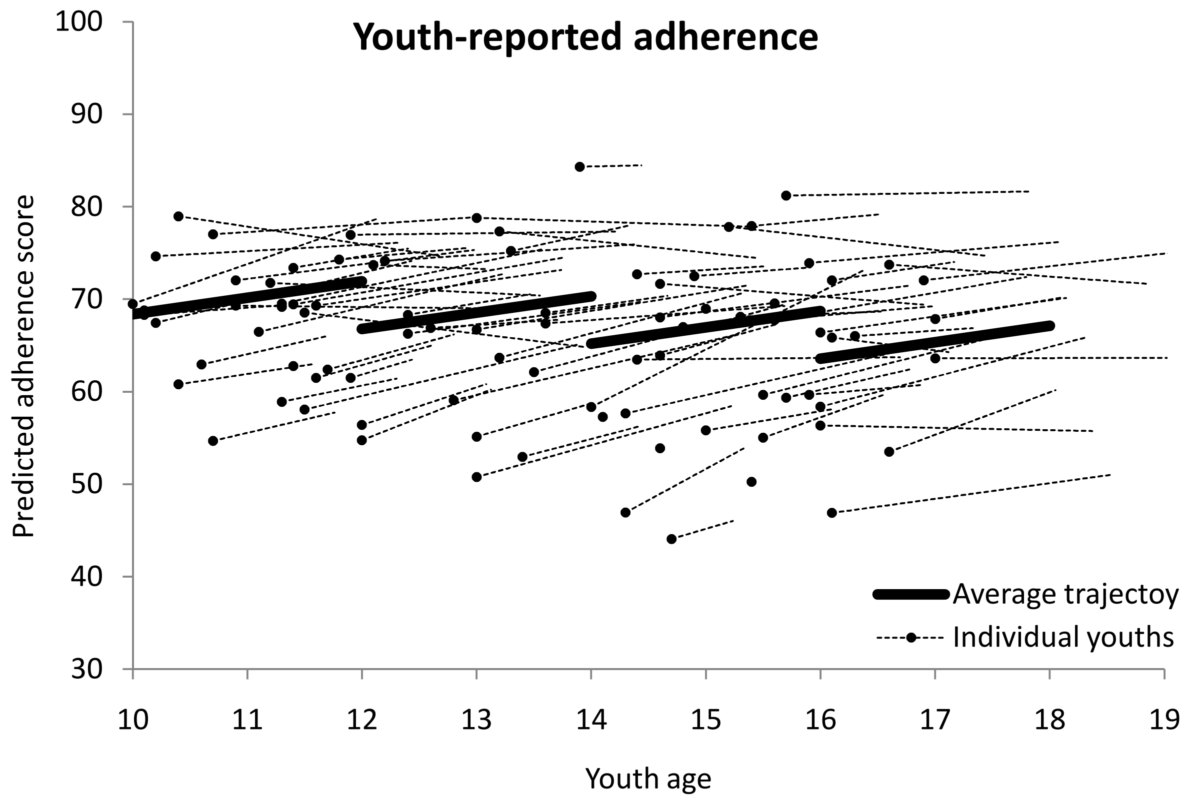

Figure 13. Predicted average trajectories of youth-reported adherence for cohorts of 10, 12, 14, and 16 years of age, with empirical Bayes estimates of trajectories for individual youths.

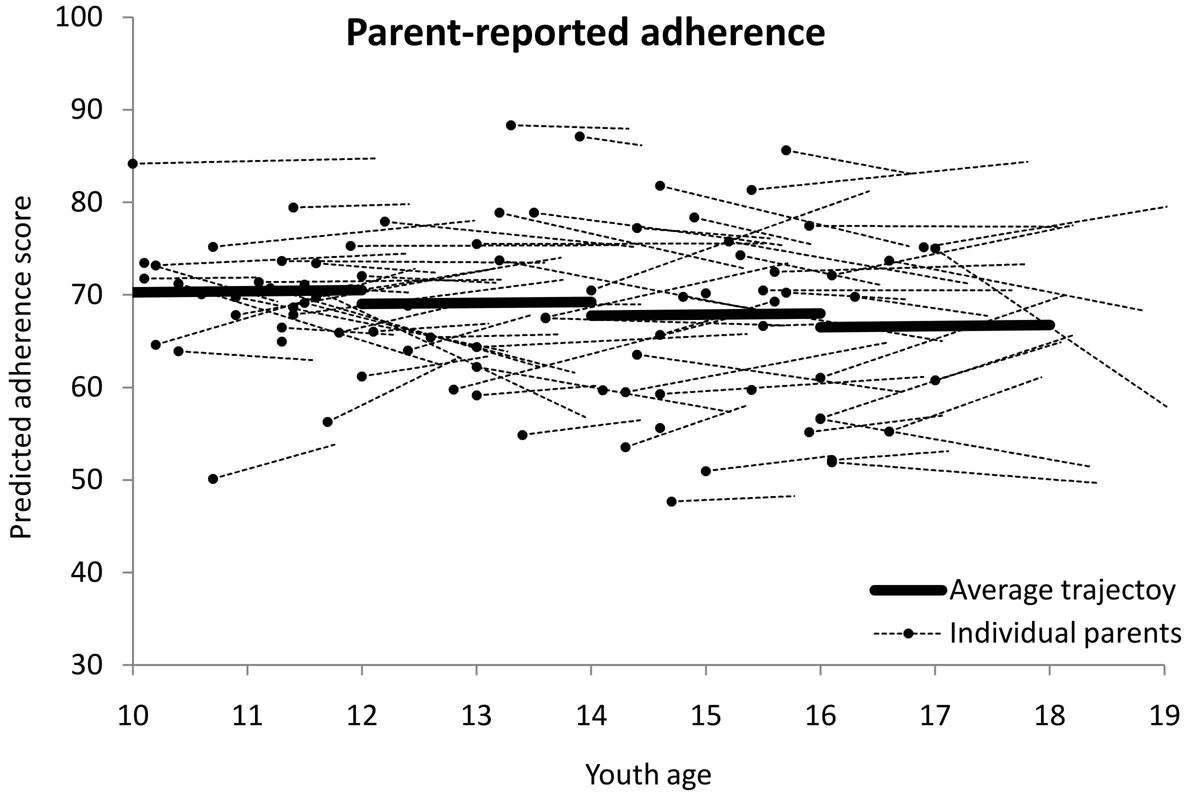

Figure 14. Predicted average trajectories of parent-reported adherence for cohorts of 10, 12, 14, and 16 years of age, with empirical Bayes estimates of trajectories for individual parents.

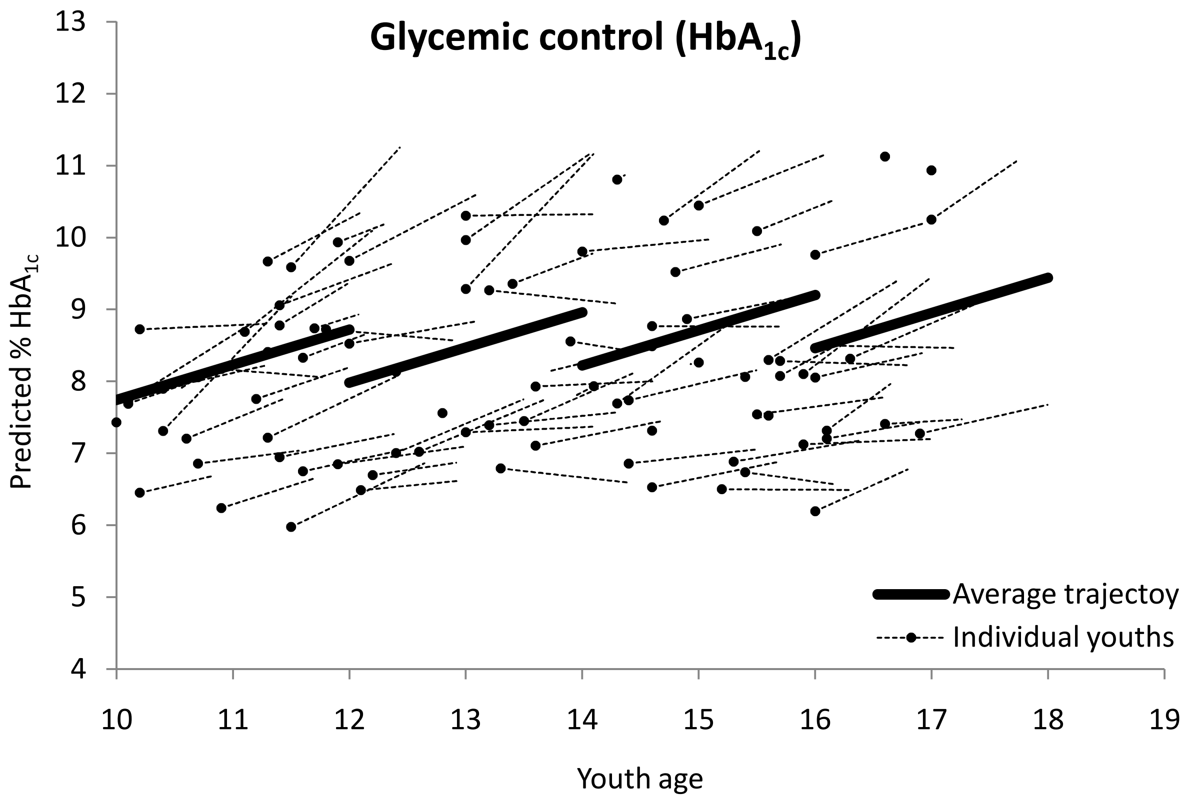

Figure 15. Predicted average trajectories of glycemic control (HbA_{1c}) for cohorts of 10, 12, 14, and 16 years of age, with empirical Bayes estimates of trajectories for individual youths.

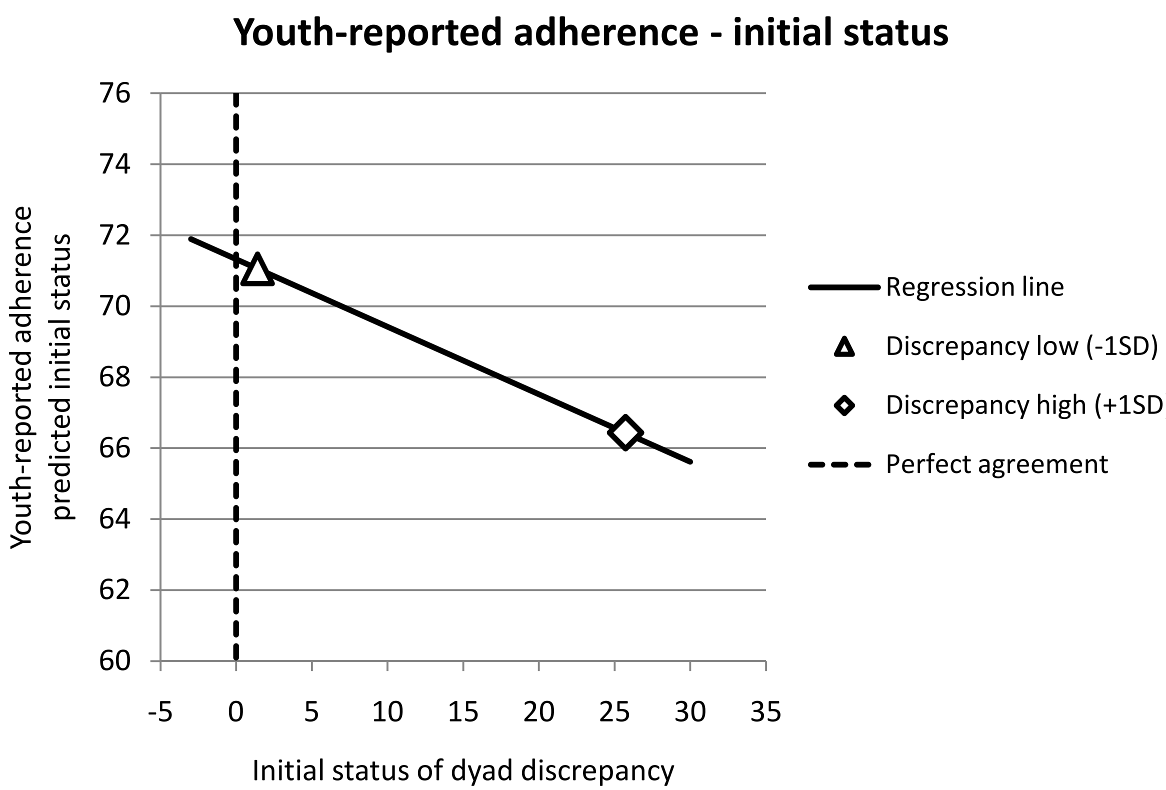

Figure 16. Initial status of youth-reported adherence predicted from initial status of dyad discrepancies in perceptions of youth responsibility for diabetes management, based on latent variable regression analysis.

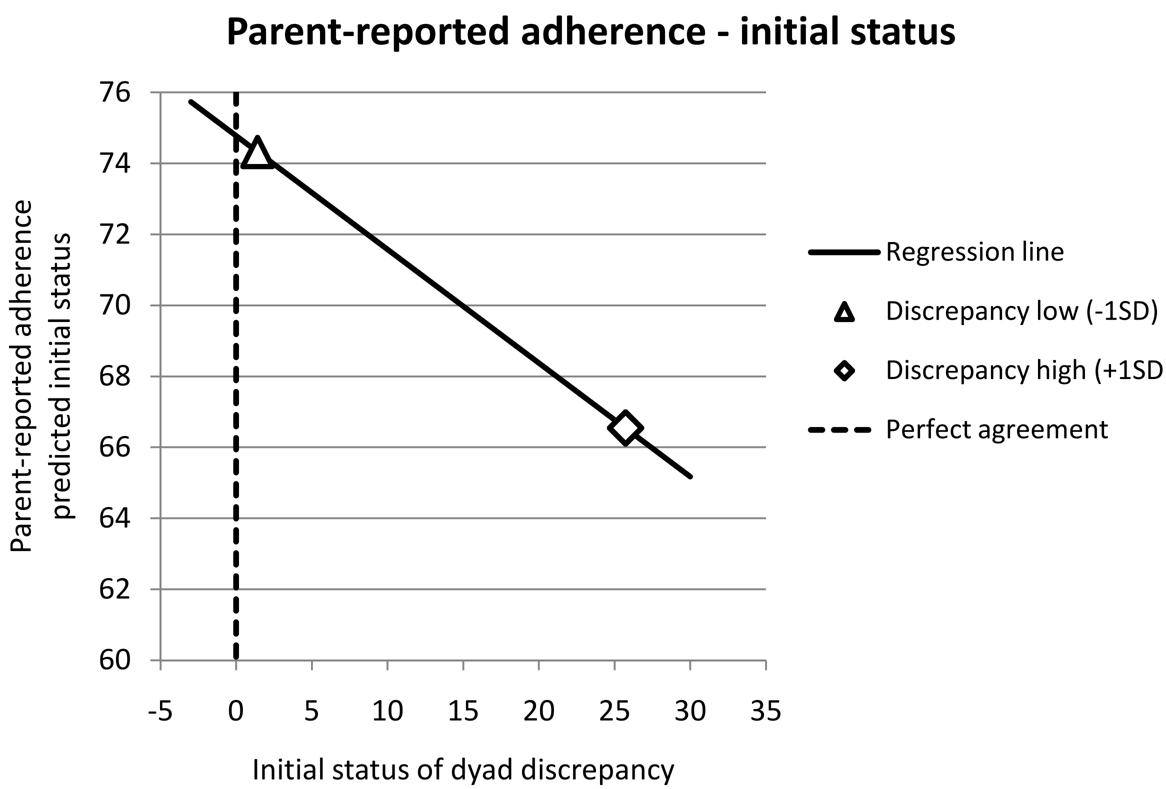

Figure 17. Initial status of parent-reported adherence predicted from initial status of dyad discrepancies in perceptions of youth responsibility for diabetes management, based on latent variable regression analysis.

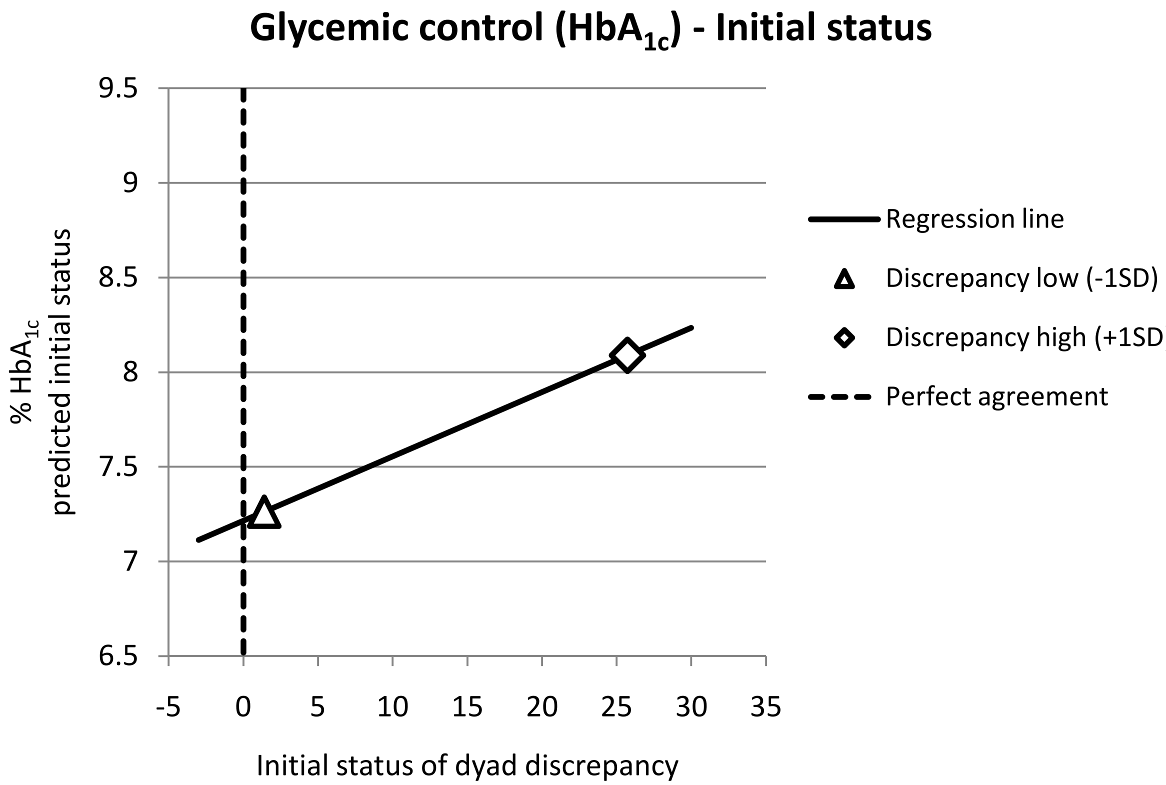

Figure 18. Initial status of HbA_{1c} predicted from initial status of dyad discrepancies in perceptions of youth responsibility for diabetes management, based on latent variable regression analysis.

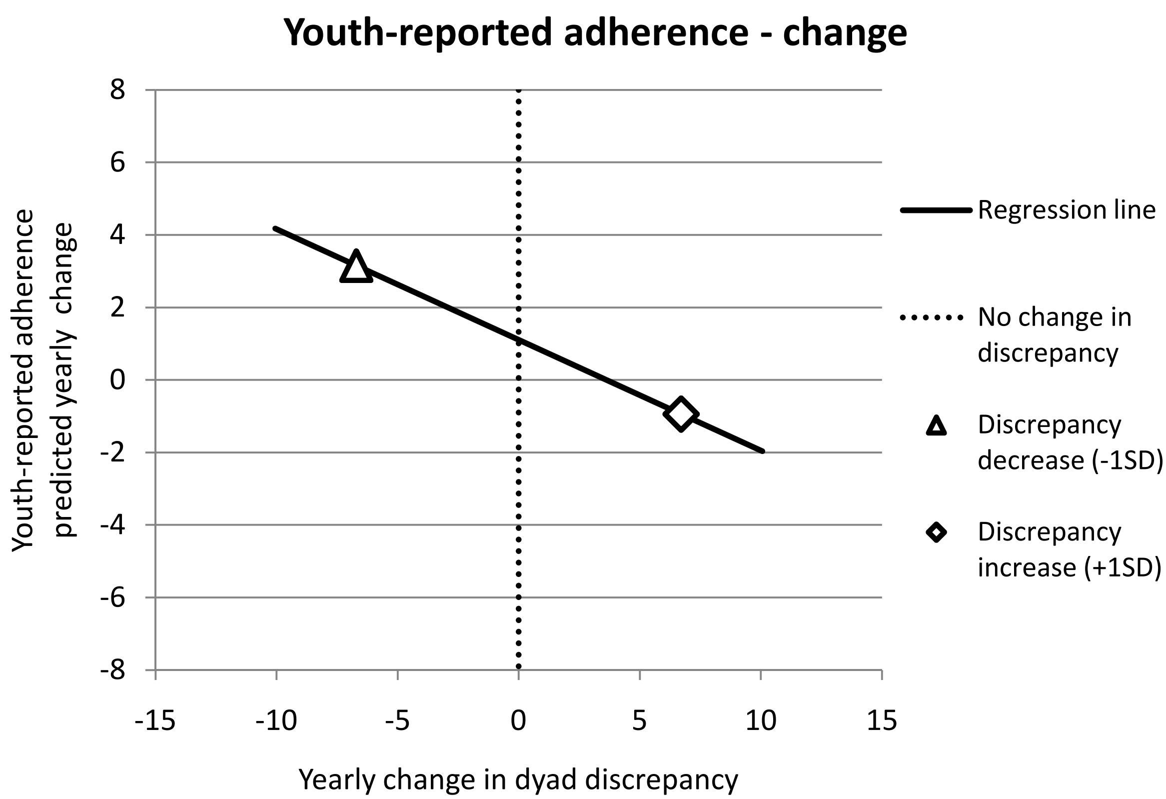

Figure 19. Yearly rates of change in youth-reported adherence predicted from yearly rates of change in dyad discrepancies in perceptions of youth responsibility for diabetes management, based on latent variable regression analysis.

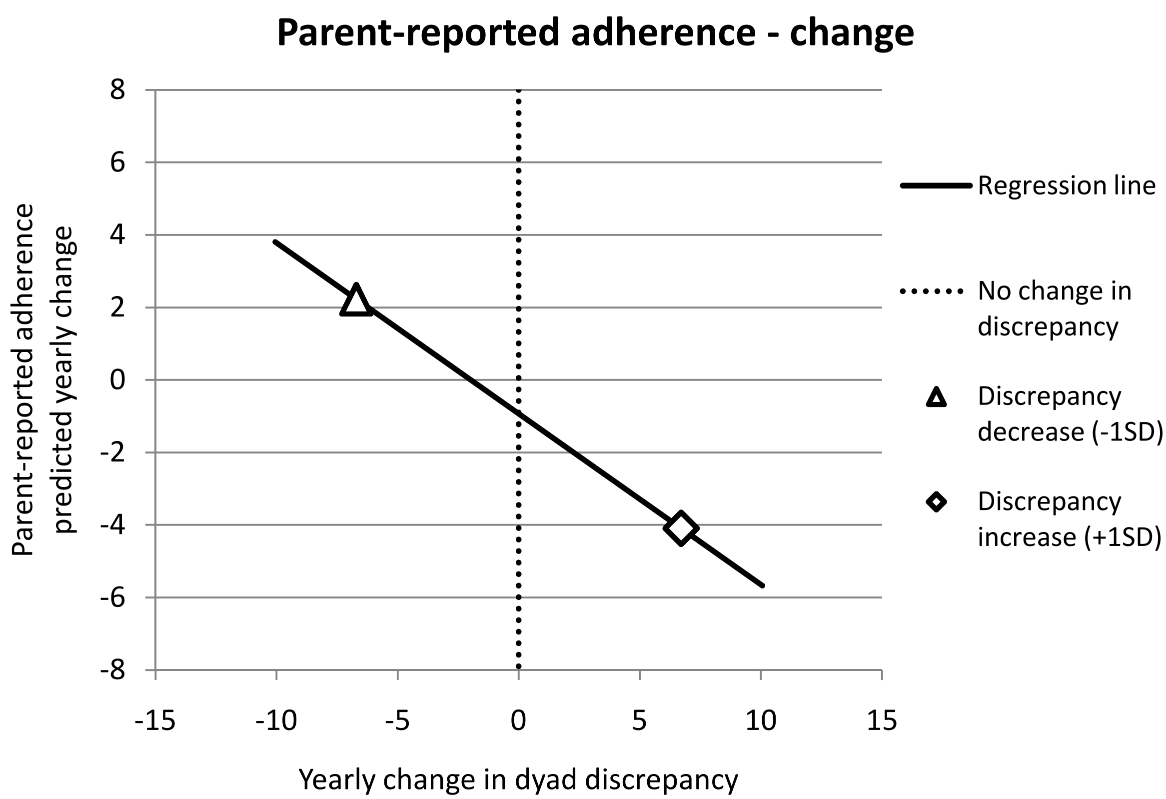

Figure 20. Yearly rates of change in parent-reported adherence predicted from yearly rates of change in dyad discrepancies in perceptions of youth responsibility for diabetes management, based on latent variable regression analysis.

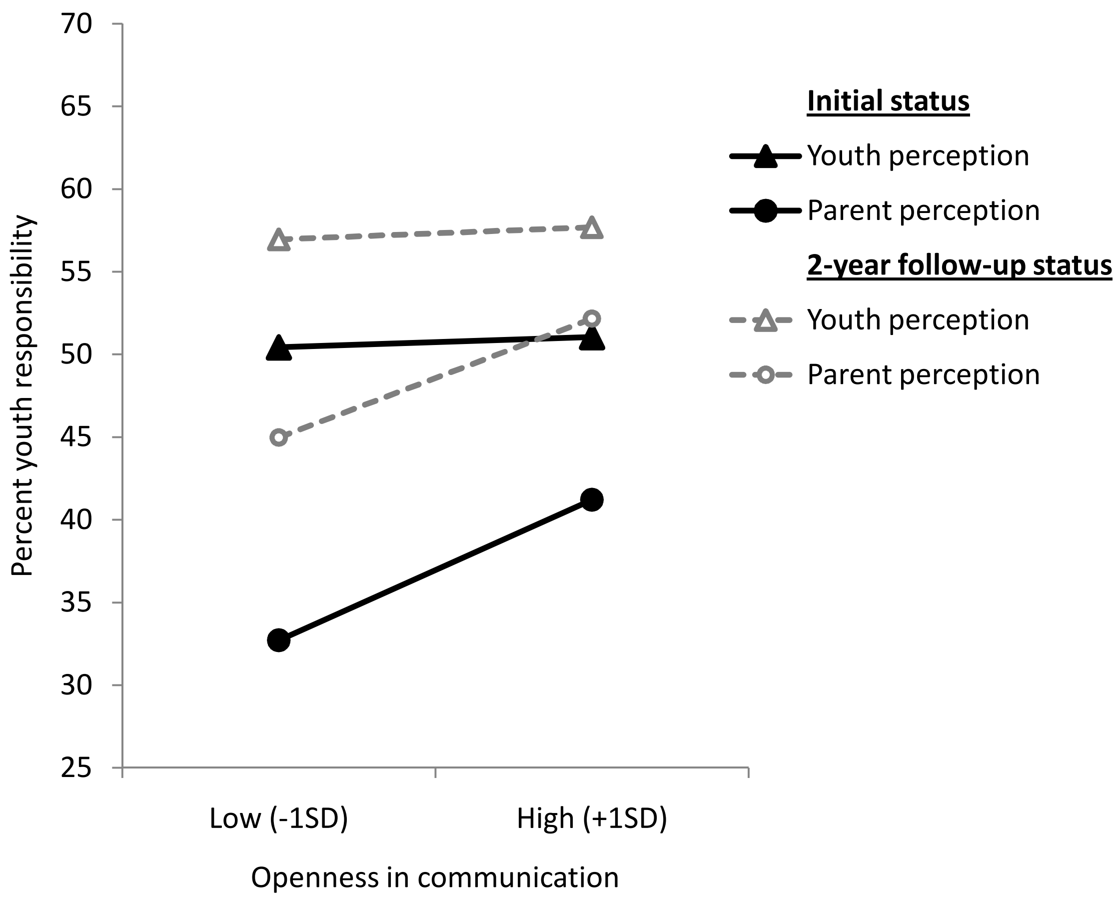

Figure 21. Predicted youth and parent perceptions of the youth's diabetes management responsibility for families with low (one standard deviation below the mean) versus high (one standard deviation above the mean) scores on openness in communication.

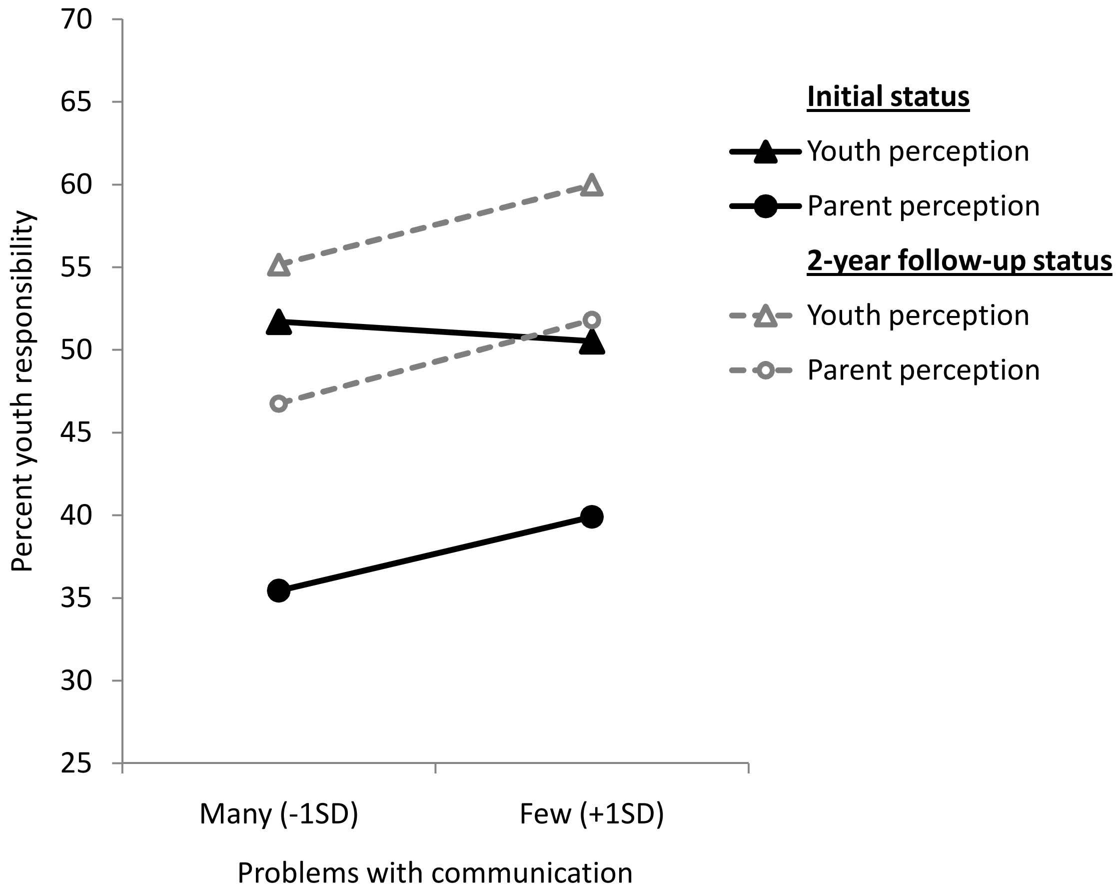

Figure 22. Predicted youth and parent perceptions of the youth's diabetes management responsibility for families with many (one standard deviation below the mean) versus few (one standard deviation above the mean) problems with communication.
The scale is scored such that higher scores express fewer problems.

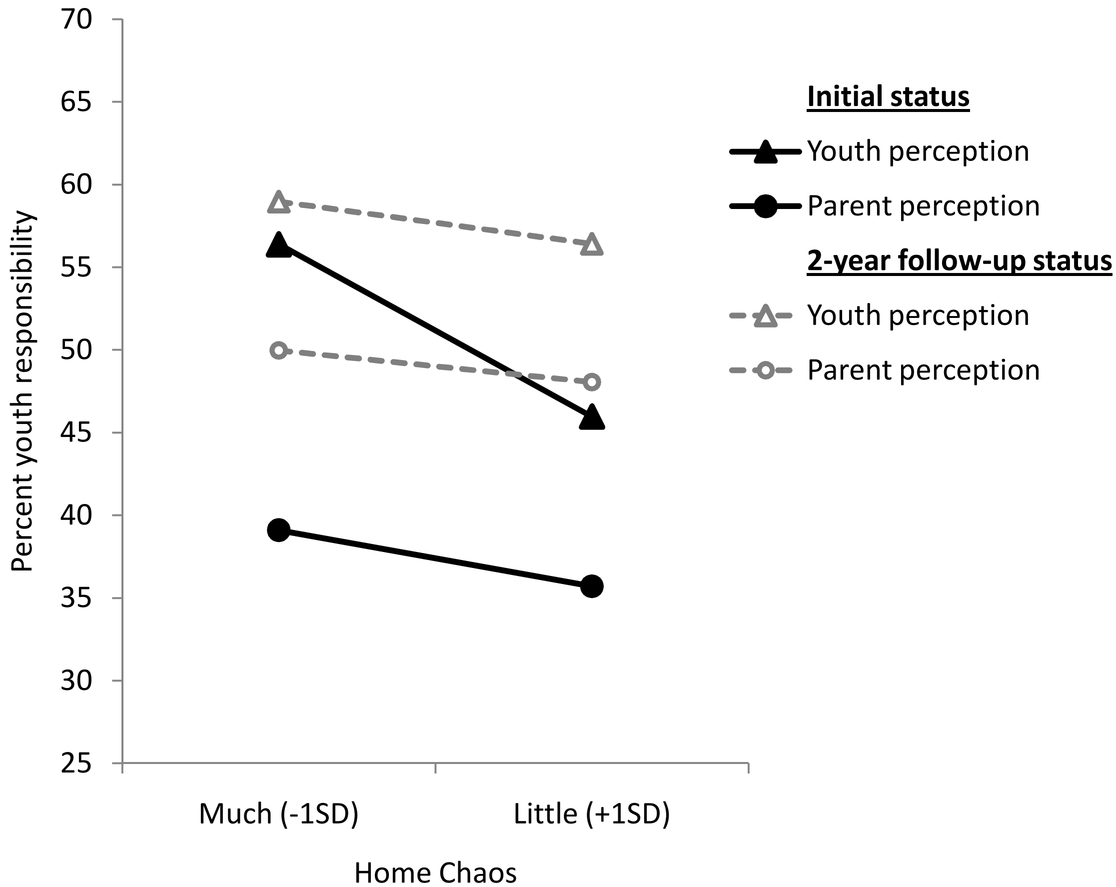

Figure 23. Predicted youth and parent perceptions of the youth's diabetes management responsibility for families with much (one standard deviation below the mean of scores) versus little (one standard deviation above the mean of scores) chaos at home. The scale is scored such that higher scores express less home chaos.

YOUTH ASSESSMENTS

PARENT-YOUTH DISTRIBUTION OF RESPONSIBILITY FOR DIABETES MANAGEMENT TASKS

Below are different tasks that relate to diabetes management. For each of the tasks, we would like to know whose job it is in your family to see that it is done. The answers range from the job is totally yours to the job is totally your parent's. The middle answer is that you and your parents share the job of seeing that it is done. For a task that is nobody's job in your family, place a mark at "it's no one's job".

	It's all my job	*It's mostly my job*	*My parents and I share*	*It's mostly my parent's job*	*It's all my parent's job*	*It's no one's job*
1. Remembering or deciding when to check blood sugar.	①	②	③	④	⑤	⓪
2. Doing blood sugar checks.	①	②	③	④	⑤	⓪
3. Recording results of blood sugar checks.	①	②	③	④	⑤	⓪
4. Noticing the early signs of an insulin reaction.	①	②	③	④	⑤	⓪
5. Carrying some form of sugar to take for insulin reactions.	①	②	③	④	⑤	⓪
6. Treating insulin reactions.	①	②	③	④	⑤	⓪
7. Remembering or deciding when to do urine ketone tests.	①	②	③	④	⑤	⓪
8. Doing urine ketone tests.	①	②	③	④	⑤	⓪
9. Recording urine ketone test results.	①	②	③	④	⑤	⓪
10. Remembering or deciding when to inject insulin.	①	②	③	④	⑤	⓪
11. Deciding how much insulin to inject.	①	②	③	④	⑤	⓪
12. Adjusting insulin according to how high or low the blood sugar is.	①	②	③	④	⑤	⓪
13. Drawing insulin into the syringe.	①	②	③	④	⑤	⓪
14. Choosing and rotating injection sites.	①	②	③	④	⑤	⓪
15. Injecting insulin.	①	②	③	④	⑤	⓪
16. Deciding what time to eat when at home.	①	②	③	④	⑤	⓪
17. Deciding what time to eat when away from home.	①	②	③	④	⑤	⓪
18. Deciding what and how much to eat at home.	①	②	③	④	⑤	⓪
19. Deciding what and how much to eat away from home.	①	②	③	④	⑤	⓪

	It's all my job	*It's mostly my job*	*My parents and I share*	*It's mostly my parent's job*	*It's all my parent's job*	*It's no one's job*
20. Adjusting how much to eat according to how high or low the blood sugar is.	①	②	③	④	⑤	⓪
21. Counting carbs.	①	②	③	④	⑤	⓪
22. Adjusting insulin according to how much is eaten.	①	②	③	④	⑤	⓪
23. Deciding when to exercise.	①	②	③	④	⑤	⓪
24. Deciding what kind and how much exercise to do.	①	②	③	④	⑤	⓪
25. Adjusting insulin based on exercise or activity level.	①	②	③	④	⑤	⓪
26. Adjusting eating based on exercise or activity level.	①	②	③	④	⑤	⓪
27. Adjusting amount of exercise if blood sugar is unusually high or low.	①	②	③	④	⑤	⓪
28. Calling the doctor in case of severe symptoms that you cannot correct.	①	②	③	④	⑤	⓪
29. Making sure that there is enough supplies for checking urine ketone.	①	②	③	④	⑤	⓪
30. Making sure that there is enough insulin.	①	②	③	④	⑤	⓪
31. Making sure that there is enough supplies for testing blood sugar.	①	②	③	④	⑤	⓪
32. Checking expiration dates on diabetes supplies.	①	②	③	④	⑤	⓪
33. Telling teachers, coaches, or other adults how to treat low blood sugar.	①	②	③	④	⑤	⓪
34. Telling friends about diabetes.	①	②	③	④	⑤	⓪
35. Remembering day of clinic appointment.	①	②	③	④	⑤	⓪
36. Talking to the doctor about diabetes regimen during clinic visit.	①	②	③	④	⑤	⓪
37. Remembering to wear bracelet or necklace as diabetes identification.	①	②	③	④	⑤	⓪
38. Remembering to bring diabetes equipment when going out.	①	②	③	④	⑤	⓪
39. Testing blood sugar every 3-4 hours when having the flu or another illness.	①	②	③	④	⑤	⓪
40. Remembering to take extra liquids when having the flu or another illness.	①	②	③	④	⑤	⓪

PARENTING STYLE

The next questions are about your parents or guardians.

I have a parent/guardian who...	*Strongly Disagree*	*Disagree*	*Agree*	*Strongly Agree*
1. Makes me feel better when I am upset.	①	②	③	④
2. Has rules that I must follow.	①	②	③	④
3. Is always telling me what to do.	①	②	③	④
4. Is too busy to talk to me.	①	②	③	④
5. Tells me what time I must come home.	①	②	③	④
6. Makes rules without asking what I think.	①	②	③	④
7. Listens to what I have to say.	①	②	③	④
8. Makes sure I say where I am going.	①	②	③	④
9. Likes me just the way I am.	①	②	③	④
10. Makes sure I go to bed on time.	①	②	③	④
11. Tells me when I do a good job on things.	①	②	③	④
12. Asks me what I do with friends.	①	②	③	④
13. Wants to hear about my problems.	①	②	③	④
14. Knows where I am after school.	①	②	③	④
15. Is pleased with how I behave.	①	②	③	④
16. Checks to see if I do my homework.	①	②	③	④

Social Support from Family

Instructions: The statements that follow refer to feelings and experiences which occur to most people at one time or another in their relationships with their FRIENDS, FAMILY MEMBERS, and ADULTS AT SCHOOL (teachers, club moderators, coaches, counselors, administrators, etc.). For each statement there are three possible answers: Yes, No, Sometimes. For each question, please mark the one best answer that describes how you feel.

The following questions are about MEMBERS OF YOUR FAMILY:	*No*	*Sometimes*	*Yes*
1. My family members back me up when I need them.	①	②	③
2. I get good ideas about how to do things from my family.	①	②	③
3. When I talk to the family members I am closest to about things that are important to me, I think they like it.	①	②	③
4. My family enjoys hearing about what I think.	①	②	③
5. I can count on my family for emotional support (help with feelings).	①	②	③
6. My family and I find it easy to talk to each other.	①	②	③
7. My family notices and gives me help when I need them to.	①	②	③
8. My family is good at helping me solve problems.	①	②	③
9. There are family members I can trust with personal things on my mind.	①	②	③
10. I wish my family was nicer to me.	①	②	③

DIABETES SELF-MANAGEMENT PROFILE
YOUTH VERSION

[For all questions, unless otherwise instructed, read the question and let the child answer. Then read response that most closely matches what they said and see if they agree with that answer.]

What we're trying to learn in this interview is what you and your family do to take care of your diabetes. Lots of kids have a hard time doing everything that their doctor told them to do for their diabetes. Your answers won't be shared with your parents or your doctor, so you don't have to say what you think **I want** you to say. Just try to be completely honest with me about what you do in taking care of your diabetes. Some of the questions ask about how often you do certain diabetes management tasks. For these questions, it doesn't matter who does them – you, your parent, or someone else. We want to know how often the tasks are done. So if your parent does them instead of you, then you can answer that they are done just the same as you would if you did them.

1. First, please tell me about how you take your insulin? Do you take insulin shots or do you use an insulin pump?

[If shots] Do you use Lantus/Glargine?

① Insulin pump *[complete #1a]*

② Insulin shots with Lantus/Glargine *[complete #1c]*

③ Neither pump nor Lantus/Glargine *[complete #1b and #1c]*

1a. *[If pump]* How long have you used an insulin pump?

_____ year(s) _____ month(s) *[proceed to question 2]*

☐ (77) don't know
☐ (88) injects insulin

1b. *[If neither pump nor Lantus/Glargine]* Which types of insulin do you take?

Types of insulin:____

(77) don't know
☐ (88) uses insulin pump

1c. *[If insulin shots]* How many insulin shots has your doctor recommended you take on a typical day?

Shots per day: _______

☐ (77) don't know
☐ (88) uses insulin pump or no recommendation

*<u>Interviewer</u>**:** Note for future questions if using pump vs. injections and if using Lantus/Glargine*

2. It is not possible to have the same blood sugar results every day. Most people with diabetes are happy with blood sugars that fall within a certain range most of the time. We would like to know the range of blood test results you would be happy with **in the next three months**.
Please tell me the upper limit and lower limit of blood sugar you would be happy with. Think about the range you consider good for **yourself**, not an absolute best.

Upper limit _________mg/dl

Lower limit _________mg/dl.

☐ (77) don't know

EXERCISE

In this part of the interview, I'll be asking about your exercise habits.

3. What kinds of exercise or physical activity do you get throughout the year?

____

____

4. On how many of the past 7 days did you exercise or participate in physical activity for at least **20 minutes** that made you sweat and breathe hard, such as basketball, soccer, running, swimming laps, fast bicycling, fast dancing or similar aerobic activities?

⓪ None	④ Four days
① One day	⑤ Five days
② Two days	⑥ Six days
③ Three days	⑦ Seven days

5. On how many of the past 7 days did you participate in physical activity for at least **30 minutes** that did not make you sweat and breathe hard, such as fast walking, slow bicycling, skating, or pushing a lawn mower?

⓪ None	④ Four days
① One day	⑤ Five days
② Two days	⑥ Six days
③ Three days	⑦ Seven days

6. On the days that you exercise **less than usual**, do you ever make any changes to your diabetes care routine (like changing the amount you eat or the amount of insulin you take)?

⓪ No *[skip to #7]*
① Yes *[complete #6a & #6b]*

☐ (88) never exercises less *[skip to #7]*

6a. What do you do? *[Mark all that apply.]*
① Take **less** insulin
② Take **more** insulin
③ Eat **less**
④ Eat **more**
⑤ Other (specify)

____

☐ (88) no change or never exercises less

6b. Think of the last 5 times that you got less exercise than usual. Out of the last 5 times you exercised less than usual, how many times did you make that change?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (88) no change or never exercises less

7. On the days that you exercise **more than usual**, do you ever make any changes to your diabetes care routine (like changing the amount you eat or the amount of insulin you take)?
⓪ No *[skip to #8]*
① Yes *[complete #7a & #7b]*

☐ (88) never exercises more *[skip to #8]*

7a. What do you do? *[Mark all that apply.]*
① Take **less** insulin
② Take **more** insulin
③ Eat **less**
④ Eat **more**
⑤ Other (specify)

____

☐ (88) no change or never exercises less

7b. Think of the last 5 times that you got more exercise than usual. Out of the last 5 times you exercised more than usual, how many times did you make that change?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (88) no change or never exercises less

[If uses insulin pump]

8. Do you ever take off your pump or decrease your basal rate when you exercise?
   ⓪ No
   ① Yes

   ☐ (88) N/A uses insulin shots

HYPOGLYCEMIA

Next, I have some questions about low blood sugar.

9. What do you feel when your blood sugar is too low? How can you tell when it is too low?

____

____

10. What do you usually do when you have a low blood sugar?

____

____

11. Do you eat or drink something **right away**?
⓪ No *[skip to #12]*
① Sometimes *[complete #11a-11e]*
② Yes *[complete #11a-11e]*

11a. What do you eat or drink? *[If drinks soda, probe for regular or diet soda.]*
____

☐ (88) does not eat or drink

11b. How much do you eat or drink?

____

☐ (88) does not eat or drink

11c. How many grams of carbs is that?
① 15 grams of carbs
② variable carbs based on blood glucose reading
③ unknown carbs *[consistent amount of food, but number of carbs unknown]*
④ variable carbs *[eating whatever is available]*
⑤ other _________________

☐ (88) does not eat or drink

11d. Do you check your blood sugar after you eat or drink?
① Rarely/Never *[skip to #12]*
② Sometimes *[complete #11e]*
③ Always/Almost always *[complete #11e]*

☐ (88) does not eat or drink

11e. How soon after you eat or drink do you check?
① less than 10 minutes
② 10-20 minutes
③ 21-30 minutes
④ more than 30 minutes

☐ (88) does not eat or drink/does not check blood sugar

12. How often in the past 7 days have you had something available to eat or drink in case your blood sugar got too low? Would you say almost never, less than half the time, half the time, more than half the time, or almost always?
⓪ Never/Almost never
① Less than half the time
② Half the time
③ More than half the time
④ Always/Almost always

13. Sometimes people get so hungry after a low blood sugar that they eat too much and end up with a high blood sugar. Think about the last five times you had a low blood sugar. How many of those times did you eat so much that your blood sugar went high?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

14. Do you ever wear or carry anything that identifies you as having diabetes, like a card or bracelet? *[Mark highest applicable response and use for subsequent questions.]*

⓪ no diabetic identification readily available *[skip to #15]*
① carries billfold identification card **only** *[complete #14a]*
② wears necklace, bracelet or charm *[complete #14a]*

14a. How often in the past 7 days have you [worn your necklace / worn your bracelet / carried your ID card]? Would you say almost never, less than half the time, half the time, more than half the time, or almost always?

⓪ Never/Almost never
① Less than half the time
② Half the time
③ More than half the time
④ Always/Almost always

☐ (88) does not wear/carry identification

DIET

Next, I'll be asking about your eating habits.

15. What kind of system do you use to decide what and how much to eat? That is, do you count carbs, use carb choices or exchanges, eat a similar amount at each meal, or something else? *[Mark highest applicable response and use for subsequent questions.]*

① No specific eating pattern for type or amount of food – eats when hungry *[skip to #16]*
② Eats about the same amount at each meal but doesn't use exchanges or count carbs *[skip to #16]*
③ Uses exchanges *[complete #15a-e]*
④ Uses carb choices *[complete #15a-e]*
⑤ Counts carbs *[complete #15a-e]*

☐ (77) don't know *[skip to #16]*

Now, think about the last 5 meals that you ate. This means meals like breakfast, lunch, and dinner, but not snacks.

15a. For how many of those meals did you [count carbs / use carb choices / use exchanges]?
⓪ None *[skip to #16]*
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (88) does not use system

15b. For how many of those meals did you go by what you already know, without reading labels, measuring, or using a guidebook to figure out the [carb count / carb choices / exchanges]?
⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (88) does not use system

15c. For how many of those meals did you read labels or use a guidebook to figure out the [carb count / carb choices / exchanges]?
⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (88) does not use system

15d. For how many of those meals did you measure your food to figure out the [carb count / carb choices / exchanges]?
⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (88) does not use system

15e. For how many of those meals did you guess the [carb count / carb choices / exchanges]?

⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (88) does not use system

[Skip #16 if uses insulin pump or lantus/glargine.]

16. It is not always possible for people to eat at the same time every day. Sometimes you might "delay" eating or not eat when you should. **This does not include times when your blood sugar is too high and you need to wait before eating** but includes, for example, if you were supposed to eat at 12:00 noon and you didn't eat until 12:30 or 1:00. In the past 7 days, how many meals did you delay by 30 minutes or more?

⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals
⑥ Six meals
⑦ Seven meals
⑧ Eight meals
⑨ Nine meals
⑩ Ten or more meals

☐ (88) uses pump or lantus/glargine

17. Sometimes people skip eating a meal entirely. This might be when you skip lunch, for example, **but not when your blood sugar is too high or when you're sick**. In the last 7 days, how many meals did you skip?

⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals
⑥ Six meals
⑦ Seven meals
⑧ Eight meals
⑨ Nine meals
⑩ Ten or more meals

[If respondent indicates skipping one or more meals in the past 7 days, preface this question with "Including that/those meal(s)…"]

18. How many meals in the last 4 weeks did you skip?

⓪ None *[skip to #19]*
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals
⑥ Six meals
⑦ Seven meals
⑧ Eight meals
⑨ Nine meals
⑩ Ten or more meals

18a. *[If has skipped one or more meals]* For how many of those meals did you adjust or skip your [insulin/bolus]?

⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals
⑥ Six meals
⑦ Seven meals
⑧ Eight meals
⑨ Nine meals
⑩ Ten or more meals

☐ (77) don't know
☐ (88) has not skipped

18b. *[If made an adjustment one or more times]* What change did you make?
① took less insulin/no insulin *[includes bolusing less or not bolusing]*
② took more insulin *[includes bolusing more]*
③ other ________________________________

☐ (88) no adjustments

19. Sometimes people eat a different amount of food than usual. In the past 7 days, how many times did you eat **more** food than usual?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

20. Think about the last 5 times that you ate more food than usual. How many of those times did you make any changes in your insulin because of eating more food?

⓪ None *[skip to #21]*
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) Did not eat more than usual

20a. *[If made any changes]* What change did you make?
① took less insulin *[includes bolusing less or not bolusing]*
② took more insulin *[includes bolusing more]*
③ other ___________________________________

☐ (88) no changes

21. In the past 7 days, how many times did you eat **less** food than usual?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

22. Think about the last 5 times that you ate less food than usual. How many of those times did you make any changes in your insulin because of eating less food?
⓪ None *[skip to #23]*
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) Did not eat less food than usual

22a. *[If made any changes]* What change did you make?
① took less insulin *[includes bolusing less or not bolusing]*
② took more insulin *[includes bolusing more]*
③ other ___________________________________

☐ (88) no changes

23. In the past 7 days, how many times have you eaten fatty foods, like chips, cookies, pizza, french fries, hot dogs, etc. (more than a bite or two)?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

24. In the past 7 days, how many times have you eaten sweets, like cookies, cakes, ice cream, or candy more than your meal plan allows or your doctor or dietician recommends?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

☐ (88) no recommendation *[skip to 26]*

25. Think about the last 5 times you ate more sweets than your meal plan allows or your doctor or dietician recommends. How many of these times did you
[If uses insulin shots] take extra insulin?
[If uses insulin pump] bolus more?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) Has never eaten sweets above and beyond allotted carbs

BLOOD GLUCOSE CHECKING

Next, I'll be asking about your habits when it comes to checking your blood sugar. Try to be as honest and accurate as you can about your blood sugar checks.

26. In the past 7 days, how often have you checked your blood sugar?
[If child gives a total per week, prompt to ensure correct number per day.]

⓪ less than once a day
① 1 time a day
② 2 times a day
③ 3 times a day
④ 4 times a day
⑤ 5 times a day
⑥ 6 or more times a day

☐ (88) has not checked blood sugar in the past 7 days

27. How often has your doctor suggested that you check your blood sugar? *[if range given, report lowest value]*

⓪ less than once a day
① 1 time a day
② 2 times a day
③ 3 times a day
④ 4 times a day
⑤ 5 times a day
⑥ 6 or more times a day

☐ (77) don't know
☐ (88) no suggestion given

28. Think about the last 5 times that your blood sugar results were over 200. How many of those times did you adjust your insulin dose, diet, or exercise because of your blood sugar being high?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know

29. Think about the last 5 times your blood sugar was over 300. How many of those times did you test your urine for ketones?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) blood sugar was not over 300 for at least 5 times

30. How often do you test for ketones when you are sick? This includes colds, flus and any kind of infection or virus. Would you say almost never, less than half the time, half the time, more than half the time, or almost always?

⓪ Never/Almost never
① Less than half the time
② Half the time
③ More than half the time
④ Always/Almost always

INSULIN

Next, I have some questions about how you usually take your insulin.

31. Everyone's doctor tells them when to take their insulin. This may be at a certain time of day or when they eat. Sometimes people delay [taking their insulin / an insulin bolus], like if they forget and take it a little later. In the last 7 days how often have you delayed taking your insulin by more than 30 minutes?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

[If respondent indicates delaying one or more times, preface this question with "Including that/those delay(s)…"]
32. How many times in the last 4 weeks have you delayed [an insulin shot / a bolus] more than 30 minutes?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

33. Sometimes people wait to [take their insulin / bolus] until right after they eat. In the last 7 days how often have you waited until after you ate to [take your insulin / bolus]?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

[If respondent indicates waiting one or more times, preface this question with "Including that/those times(s)…"]
34. How many times in the last 4 weeks have you waited until after you ate to [take your insulin / bolus]?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

Sometimes people take more or less insulin than their doctor has told them to take.

35. In the last 7 days, how often have you
[If uses insulin shots] taken **more** than the prescribed amount of insulin; that is, even more than your sliding scale allows for?
[If uses insulin pump] bolused **more** insulin than you should have bolused?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

[If respondent indicates one or more times, preface this question with "Including that/those time(s)…"]
36. How many times in the last 4 weeks have you
[If uses insulin shots] taken **more** than the prescribed amount of insulin?
[If uses insulin pump] bolused **more** insulin than you should have bolused?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

37. In the last 7 days, how often have you
[If uses insulin shots] taken less than the prescribed amount of insulin; that is, even less than your sliding scale allows for?
[If uses insulin pump] bolused **less** insulin than you should have bolused?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

[If respondent indicates one or more times, preface this question with "Including that/those time(s)…"]
38. How many times in the last 4 weeks have you
[If uses insulin shots] taken **less** than the prescribed amount of insulin?
[If uses insulin pump] bolused **less** insulin than you should have bolused?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

39. In the last 7 days, how often have you missed [an insulin shot/ a bolus], like if you forgot or were too busy?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

[If respondent indicates missing an insulin shot or bolus in the last 7 days, preface this question with "Including that/those time(s)…"]
40. How many times in the last 4 weeks have you [missed an insulin shot / missed a bolus].

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

[If uses insulin pump]
41. In the last 7 days, how often have you not gotten your basal insulin because your pump was not working or not inserted? This does not include times when you took the pump off for sports, exercise, showering, or bathing.

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (88) uses insulin shots

[If uses insulin pump]
[If respondent indicates not getting basal insulin in the last 7 days, preface this question with "Including that/those time(s)…"]
42. How many times in the last 4 weeks have you not gotten your basal insulin because your pump was not working or not inserted? Again, this does not include times when you took the pump off for sports, exercise, showering, or bathing.

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (88) uses insulin shots

PARENT ASSESSMENTS

PARENT-YOUTH DISTRIBUTION OF RESPONSIBILITY FOR DIABETES MANAGEMENT TASKS

Below are different tasks that relate to diabetes management. For each of the tasks, we would like to know whose job it is in your family to see that it is done. The answers range from the job is totally your child's to the job is totally yours. The middle response is that you and your child share the job of seeing that it is done. For a task that is nobody's job in your family, place a mark at "it's no one's job".

	It's all my child's job	*It's mostly my child's job*	*My child and I share*	*It's mostly my job*	*It's all my job*	*It's no one's job*
1. Remembering or deciding when to check blood sugar.	①	②	③	④	⑤	⓪
2. Doing blood sugar checks.	①	②	③	④	⑤	⓪
3. Recording results of blood sugar checks.	①	②	③	④	⑤	⓪
4. Noticing the early signs of an insulin reaction.	①	②	③	④	⑤	⓪
5. Carrying some form of sugar to take for insulin reactions.	①	②	③	④	⑤	⓪
6. Treating insulin reactions.	①	②	③	④	⑤	⓪
7. Remembering or deciding when to do urine ketone tests.	①	②	③	④	⑤	⓪
8. Doing urine ketone tests.	①	②	③	④	⑤	⓪
9. Recording urine ketone test results.	①	②	③	④	⑤	⓪
10. Remembering or deciding when to inject insulin.	①	②	③	④	⑤	⓪
11. Deciding how much insulin to inject.	①	②	③	④	⑤	⓪
12. Adjusting insulin according to how high or low the blood sugar is.	①	②	③	④	⑤	⓪
13. Drawing insulin into the syringe.	①	②	③	④	⑤	⓪
14. Choosing and rotating injection sites.	①	②	③	④	⑤	⓪
15. Injecting insulin.	①	②	③	④	⑤	⓪
16. Deciding what time to eat when at home.	①	②	③	④	⑤	⓪
17. Deciding what time to eat when away from home.	①	②	③	④	⑤	⓪
18. Deciding what and how much to eat at home.	①	②	③	④	⑤	⓪
19. Deciding what and how much to eat away from home.	①	②	③	④	⑤	⓪

	It's all my child's job	It's mostly my child's job	My child and I share	It's mostly my job	It's all my job	It's no one's job
20. Adjusting how much to eat according to how high or low the blood sugar is.	①	②	③	④	⑤	⓪
21. Counting carbs.	①	②	③	④	⑤	⓪
22. Adjusting insulin according to how much is eaten.	①	②	③	④	⑤	⓪
23. Deciding when to exercise.	①	②	③	④	⑤	⓪
24. Deciding what kind and how much exercise to do.	①	②	③	④	⑤	⓪
25. Adjusting insulin based on exercise or activity level.	①	②	③	④	⑤	⓪
26. Adjusting eating based on exercise or activity level.	①	②	③	④	⑤	⓪
27. Adjusting amount of exercise if blood sugar is unusually high or low.	①	②	③	④	⑤	⓪
28. Calling the doctor in case of severe symptoms that you cannot correct.	①	②	③	④	⑤	⓪
29. Making sure that there is enough supplies for checking urine ketone.	①	②	③	④	⑤	⓪
30. Making sure that there is enough insulin.	①	②	③	④	⑤	⓪
31. Making sure that there is enough supplies for testing blood sugar.	①	②	③	④	⑤	⓪
32. Checking expiration dates on diabetes supplies.	①	②	③	④	⑤	⓪
33. Telling teachers, coaches, or other adults how to treat low blood sugar.	①	②	③	④	⑤	⓪
34. Telling friends about diabetes.	①	②	③	④	⑤	⓪
35. Remembering day of clinic appointment.	①	②	③	④	⑤	⓪
36. Talking to the doctor about diabetes regimen during clinic visit.	①	②	③	④	⑤	⓪
37. Remembering to wear bracelet or necklace as diabetes identification.	①	②	③	④	⑤	⓪
38. Remembering to bring diabetes equipment when going out.	①	②	③	④	⑤	⓪
39. Testing blood sugar every 3-4 hours when having the flu or another illness.	①	②	③	④	⑤	⓪
40. Remembering to take extra liquids when having the flu or another illness.	①	②	③	④	⑤	⓪

PARENT-ADOLESCENT COMMUNICATION

Please tell us how much you agree or disagree with the following statements.

	strongly disagree	*moderately disagree*	*neither disagree nor agree*	*moderately agree*	*strongly agree*
1. I can discuss my beliefs with my child without feeling restrained or embarrassed.	①	②	③	④	⑤
2. Sometimes I have trouble believing everything my child tells me.	①	②	③	④	⑤
3. My child is always a good listener.	①	②	③	④	⑤
4. I am sometimes afraid to ask my child for what I want.	①	②	③	④	⑤
5. My child has a tendency to say things to me which would be better left unsaid.	①	②	③	④	⑤
6. My child can tell how I am feeling without asking.	①	②	③	④	⑤
7. I am very satisfied with how my child and I talk together.	①	②	③	④	⑤
8. If I were in trouble, I could tell my child.	①	②	③	④	⑤
9. I openly show affection to my child.	①	②	③	④	⑤
10. When we are having a problem, I often give my child the silent treatment.	①	②	③	④	⑤
11. I am careful about what I say to my child.	①	②	③	④	⑤
12. When talking with my child, I have a tendency to say things that would be better left unsaid.	①	②	③	④	⑤
13. When I ask questions, I get honest answers from my child.	①	②	③	④	⑤
14. My child tries to understand my point of view.	①	②	③	④	⑤
15. There are topics I avoid discussing with my child.	①	②	③	④	⑤
16. I find it easy to discuss problems with my child.	①	②	③	④	⑤
17. It is very easy for me to express all my true feelings to my child.	①	②	③	④	⑤
18. My child nags or bothers me.	①	②	③	④	⑤
19. My child insults me when he is angry with me.	①	②	③	④	⑤
20. I don't think I can tell my child how I really feel about some things.	①	②	③	④	⑤

HOME CHAOS

These are statements about families. Indicate which of these are true for your family and which are false. If you feel the statement is both true and false, please indicate which best represents your feelings about your family.

	True	*False*
1. There is very little commotion in our home.	①	②
2. We can usually find things when we need them.	①	②
3. We almost always seem to be rushed.	①	②
4. We are usually able to stay on top of things.	①	②
5. No matter how hard we try, we always seem to be running late.	①	②
6. It's a real zoo in our home.	①	②
7. At home we can talk to each other without being interrupted.	①	②
8. There is often a fuss going on at our home.	①	②
9. No matter what our family plans, it usually doesn't seem to work out.	①	②
10. You can't hear yourself think in our home.	①	②
11. I often get drawn into other people's arguments at home.	①	②
12. Our home is a good place to relax.	①	②
13. The telephone takes up a lot of our time at home.	①	②
14. The atmosphere in our home is calm.	①	②
15. First thing in the day, we have a regular routine at home.	①	②

DIABETES SELF-MANAGEMENT PROFILE
PARENT VERSION

[For all questions, unless otherwise instructed, read the question and let the parent answer. Then read response that most closely matches what he/she said and see if [he/she] agrees with that answer.]

What we're trying to learn in this interview is what you and your child do to take care of [his/her] diabetes. Kids often have a hard time doing everything that their doctor told them to do for their diabetes. Your answers won't be shared with your child or your doctor, so you don't have to say what you think **I want** you to say. Just try to be completely honest with me about what your child does in taking care of [his/her] diabetes. Some of the questions ask about how often [she/he] does certain diabetes management tasks. For these questions, we want to know how often the tasks are done, regardless of who does them. So if you do them instead of your child, then you can answer that they are done just the same as you would if your child did them.

1. First, please tell me about how your child takes [his/her] insulin? Does [he/she] take insulin shots or does [he/she] use an insulin pump?

[If shots] Does [he/she] use Lantus/Glargine?

① Insulin pump *[complete #1a]*

② Insulin shots with Lantus/Glargine *[complete #1c]*

③ Neither pump nor Lantus/Glargine *[complete #1b and #1c]*

1a. [If pump] *How long has [he/she] used an insulin pump?*

_____ year(s) _____ month(s) *[proceed to question 2]*

☐ (77) don't know
☐ (88) injects insulin

1b. *[If neither pump nor Lantus/Glargine]* Which types of insulin does [he/she] take?

Types of insulin:____

☐ (77) don't know
☐ (88) uses insulin pump

1c. *[If insulin shots]* How many insulin shots has your doctor recommended your child take on a typical day?

Shots per day: _______

☐ (77) don't know
☐ (88) uses insulin pump or no recommendation

<u>Interviewer</u>: Note for future questions if using pump vs. injections and if using Lantus/Glargine

2. It is not possible to have the same blood sugar results every day. Most families with a child having diabetes are happy with blood sugars that fall within in a certain range most of the time. We would like to know which range of blood sugar results you would be most happy with for your child **in the next three months**. Please tell me the upper limit and lower limit of blood sugar you would be happy with. Think about the range that you consider good for **your child**, not an absolute best.

Upper limit _________mg/dl

Lower limit _________mg/dl.

☐ (77) don't know

EXERCISE

In this part of the interview, I'll be asking about your child's exercise habits.

3. What kinds of exercise or physical activity does your child get throughout the year?

____

____

☐ (77) don't know

4. On how many of the past 7 days did your child exercise or participate in physical activity for at least **20 minutes** that made [him/her] sweat and breathe hard, such as basketball, soccer, running, swimming laps, fast bicycling, fast dancing or similar aerobic activities?

⓪ None
① One day
② Two days
③ Three days
④ Four days
⑤ Five days
⑥ Six days
⑦ Seven days

☐ (77) don't know

5. On how many of the past 7 days did [he/she] participate in physical activity for at least **30 minutes** that did not make [him/her] sweat and breathe hard, such as fast walking, slow bicycling, skating, or pushing a lawn mower?

⓪ None
① One day
② Two days
③ Three days
④ Four days
⑤ Five days
⑥ Six days
⑦ Seven days

☐ (77) don't know

6. On the days that [he/she] **exercises less than usual**, does [he/she] ever make any changes to [his/her] diabetes care routine (like changing the amount [he/she] eats or the amount of insulin [he/she] takes)?

⓪ No *[skip to #7]*
① Yes *[complete #6a & #6b]*

☐ (77) don't know

6a. What does [he/she] do? *[Mark all that apply.]*
① Take **less** insulin
② Take **more** insulin
③ Eat **less**
④ Eat **more**
⑤ Other (specify)

____

☐ (77) don't know
☐ (88) no change or never exercises less

6b. Think of the last 5 times that your child got less exercise than usual. Out of the last 5 times [he/she] exercised less than usual, how many times did [he/she] make that change?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) no change or never exercises less

7. On the days that your child **exercises more than usual**, does [he/she] ever make any changes to [his/her] diabetes care routine (like changing the amount [he/she] eats or the amount of insulin [he/she] takes)?

⓪ No *[skip to #8]*
① Yes *[complete #7a & #7b]*

☐ (77) don't know

7a. What does [he/she] do? *[Mark all that apply.]*

① Take **less** insulin
② Take **more** insulin
③ Eat **less**
④ Eat **more**
⑤ Other (specify)

____

☐ (77) don't know
☐ (88) no change or never exercises less

7b. Think of the last 5 times that your child got more exercise than usual. Out of the last 5 times [he/she] exercised more than usual, how many times did [he/she] make that change?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) no change or never exercises less

[If uses insulin pump]

8. Does your child ever take off [his/her] pump or decrease [his/her] basal rate during exercise?

⓪ No
① Yes

☐ (77) don't know
☐ (88) N/A uses insulin shots

HYPOGLYCEMIA

Next, I have some questions about low blood sugar.

9. How can you tell when your child has an insulin reaction or when [his/her] blood sugar is too low?
[For symptoms the parent does not directly observe but the youth reports him/her, insert: "child reports…"]

____

____

☐ (77) don't know

10. What does your child usually do when [he/she] has a low blood sugar?

____

____

☐ (77) don't know

11. Does [he/she] eat or drink something **right away**?
⓪ No *[skip to #12]*
① Sometimes *[complete #11a-11e]*
② Yes *[complete #11a-11e]*

☐ (77) don't know

11a. What does [he/she] eat or drink? *[If drinks soda, probe for regular or diet soda.]*
____

____

☐ (77) don't know
☐ (88) does not eat or drink

11b. How much does [he/she] eat or drink?
____

____

☐ (77) don't know
☐ (88) does not eat or drink

11c. How many grams of carbs is that?
① 15 grams of carbs
② variable carbs based on blood glucose reading
③ unknown carbs *[consistent amount of food, but number of carbs unknown]*
④ variable carbs *[eating whatever is available]*
⑤ other _________________

☐ (77) don't know
☐ (88) does not eat or drink

11d. Does your child check [his/her] blood sugar after [he/she] eats or drinks?
① Rarely/Never *[skip to #12]*
② Sometimes *[complete #11e]*
③ Always/Almost always *[complete #11e]*

☐ (77) don't know
☐ (88) does not eat or drink

11e. How soon after eating or drinking does this check occur?

① less than 10 minutes
② 10-20 minutes
③ 21-30 minutes
④ more than 30 minutes

☐ (77) don't know
☐ (88) does not eat or drink/does not check blood sugar

12. How often in the past 7 days has your child had something available to eat or drink in case [his/her] blood sugar got too low? Would you say almost never, less than half the time, half the time, more than half the time, or almost always?

⓪ Never/Almost never
① Less than half the time
② Half the time
③ More than half the time
④ Always/Almost always

☐ (77) don't know

13. Sometimes people get so hungry after a low blood sugar that they eat too much and end up with a high blood sugar. Think about the last five times your child had a low blood sugar. How many of those times did [he/she] eat so much that [his/her] blood sugar went high?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know

14. Does your child ever wear or carry anything that identifies [him/her] as having diabetes, like a card or bracelet? *[Mark highest applicable response and use for subsequent questions.]*

⓪ no diabetic identification readily available *[skip to #15]*
① carries billfold identification card **only** *[complete #14a]*
② wears necklace, bracelet or charm *[complete #14a]*

☐ (77) don't know

14a. How often in the past 7 days has [he/she] worn [his/her] necklace / worn [his/her] bracelet / carried [his/her] ID card? Would you say almost never, less than half the time, half the time, more than half the time, or almost always?

⓪ Never/Almost never
① Less than half the time
② Half the time
③ More than half the time
④ Always/Almost always

☐ (77) don't know
☐ (88) child does not wear/carry identification

DIET

Next, I'll be asking about your child's eating habits.

15. What kind of system does your child use to decide what and how much to eat? That is, does [he/she] count carbs, use carb choices or exchanges, eat a similar amount at each meal, or something else? *[Mark highest applicable response and use for subsequent questions.]*

① No specific eating pattern for type or amount of food – eats when hungry *[skip to #16]*
② Eats about the same amount at each meal but doesn't use exchanges or count carbs *[skip to #16]*
③ Uses exchanges *[complete #15a-e]*
④ Uses carb choices *[complete #15a-e]*
⑤ Counts carbs *[complete #15a-e]*

☐ (77) don't know

Now, think about the last 5 meals that [he/she] ate. This means meals like breakfast, lunch, and dinner, but not snacks.

15a. For how many of those meals did [he/she] count carbs / use carb choices / use exchanges?

⓪ None *[skip to #16]*
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (77) don't know
☐ (88) does not use system

15b. For how many of those meals did [he/she] go by what [he/she] already knows, without reading labels, measuring, or using a guidebook to figure out the [carb count / carb choices / exchanges]?
⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (77) don't know
☐ (88) does not use system

15c. For how many of those meals did [he/she] read labels or use a guidebook to figure out the [carb count / carb choices / exchanges]?
⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (77) don't know
☐ (88) does not use system

15d. For how many of those meals did [he/she] measure [his/her] food to figure out the [carb count / carb choices / exchanges]?
⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (77) don't know
☐ (88) does not use system

15e. For how many of those meals did [he/she] guess the [carb count / carb choices / exchanges]?
⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals

☐ (77) don't know
☐ (88) does not use system

[Skip #16 if uses insulin pump or lantus/glargine.]

16. It is not always possible for people to eat at the same time every day. Sometimes your child might "delay" eating or not eat when [he/she] should. This does not include times when [his/her] blood sugar is too high and [he/she] needs to wait before eating_but includes, for example, if [he/she] was supposed to eat at 12:00 noon and [he/she] didn't eat until 12:30 or 1:00. In the past 7 days, how many meals did your child delay by 30 minutes or more?

⓪ None	⑥ Six meals
① One meal	⑦ Seven meals
② Two meals	⑧ Eight meals
③ Three meals	⑨ Nine meals
④ Four meals	⑩ Ten or more meals
⑤ Five meals	

☐ (77) don't know
☐ (88) uses pump or lantus/glargine

17. Sometimes people skip eating a meal entirely. This might be when [he/she] skipped lunch, for example, but not when [his/her] sugar is too high or when [he/she] is sick. In the last 7 days, how many meals did your child skip?

⓪ None	⑥ Six meals
① One meal	⑦ Seven meals
② Two meals	⑧ Eight meals
③ Three meals	⑨ Nine meals
④ Four meals	⑩ Ten or more meals
⑤ Five meals	

☐ (77) don't know

[If respondent indicates skipping one or more meals in the past 7 days, preface this question with "Including that/those meal(s)…"]

18. How many meals in the last 4 weeks did [he/she] skip?

⓪ None *[skip to #19]*	⑥ Six meals
① One meal	⑦ Seven meals
② Two meals	⑧ Eight meals
③ Three meals	⑨ Nine meals
④ Four meals	⑩ Ten or more meals
⑤ Five meals	

☐ (77) don't know

18a. *[If has skipped one or more meals]* For how many of those meals did your child adjust or skip [his/her] [insulin/bolus]?

⓪ None
① One meal
② Two meals
③ Three meals
④ Four meals
⑤ Five meals
⑥ Six meals
⑦ Seven meals
⑧ Eight meals
⑨ Nine meals
⑩ Ten or more meals

☐ (77) don't know
☐ (88) has not skipped

18b. *[If made an adjustment one or more times]* What change did [he/she] make?
① took less insulin/no insulin *[includes bolusing less or not bolusing]*
② took more insulin *[includes bolusing more]*
③ other ______________________________

☐ (77) don't know
☐ (88) no adjustments

19. Sometimes people eat a different amount of food than usual. In the past 7 days, how many times did your child eat **more** food than usual?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

☐ (77) don't know

20. Think about the last 5 times that your child ate more food than usual. How many of those times did [he/she] make any changes in [his/her] insulin because of eating more food? This includes any adjustments your child made based on [his/her] insulin-to-carbohydrate ratio.

⓪ None *[skip to #21]*
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) Did not eat more than usual

20a. *[If made any changes]* What change did [he/she] make?
① took less insulin *[includes bolusing less or not bolusing]*
② took more insulin *[includes bolusing more]*
③ other ________________________________

☐ (77) don't know
☐ (88) no changes

21. In the past 7 days, how many times did your child eat **less** food than usual?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

☐ **(77) don't know**

22. Think about the last 5 times that your child ate less food than usual. How many of those times did [he/she] make any changes in [his/her] insulin because of eating less food?

⓪ None *[skip to #23]*
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) Did not eat less food than usual

22a. *[If made any changes]* What change did [he/she] make?
① took less insulin *[includes bolusing less or not bolusing]*
② took more insulin *[includes bolusing more]*
③ other ________________________________

☐ (77) don't know
☐ (88) no changes

23. In the past 7 days, how many times has your child eaten fatty foods, like chips, cookies, pizza, french fries, hot dogs, etc. (more than a bite or two)?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

☐ (77) don't know

24. In the past 7 days, how many times has your child eaten sweets, like cookies, cakes, ice cream, or candy more than [his/her] meal plan allows or [his/her] doctor or dietician recommends?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times
⑥ Six times
⑦ Seven times
⑧ Eight times
⑨ Nine times
⑩ Ten or more times

☐ (77) don't know
☐ (88) no recommendation *[skip to 26]*

25. Think about the last 5 times your child ate more sweets than [his/her] meal plan allows or [his/her] doctor or dietician recommends. How many of these times did [he/she]
[If uses insulin shots] take extra insulin?
[If uses insulin pump] bolus more?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) Has never eaten sweets above and beyond allotted carbs

BLOOD GLUCOSE CHECKING

Next, I'll be asking about your child's habits when it comes to checking [his/her] blood sugar. Try to be as honest and accurate as you can about your child's blood sugar checks.

26. In the past 7 days, how often has your child checked [his/her] blood sugar?
[If parent gives a total per week, prompt to ensure correct number per day.]

⓪ less than once per day
① 1 time per day
② 2 times per day
③ 3 times per day
④ 4 times per day
⑤ 5 times per day
⑥ 6 or more times per day

☐ (77) don't know
☐ (88) child has not checked blood sugar in the past 7 days

27. How often has your doctor suggested that your child check [his/her] blood sugar? *[if range given, report lowest value]*

⓪ less than once per day
① 1 time per day
② 2 times per day
③ 3 times per day
④ 4 times per day
⑤ 5 times per day
⑥ 6 or more times per day

☐ (77) don't know
☐ (88) no suggestion given

28. Think about the last 5 times that your child's blood sugar results were over 200. How many of those times did your child adjust [his/her] insulin dose, diet, or exercise because of [his/her] blood sugar being high?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know

29. Think about the last 5 times your child's blood sugar was over 300. How many of those times did [he/she] test [his/her] urine for ketones?

⓪ None
① One time
② Two times
③ Three times
④ Four times
⑤ Five times

☐ (77) don't know
☐ (88) blood sugar was not over 300 for at least 5 times

30. How often does your child test for ketones when [he/she] is sick? This includes colds, flus and any kind of infection or virus. Would you say almost never, less than half the time, half the time, more than half the time, or almost always?

⓪ Never/Almost never
① Less than half the time
② Half the time
③ More than half the time
④ Always/Almost always

☐ (77) don't know

INSULIN

Next, I have some questions about how your child usually takes [his/her] insulin.

31. Everyone's doctor tells them when to take their insulin. This may be at a certain time of day or when they eat. Sometimes people delay [taking their insulin/ an insulin bolus], like if they forget and take it a little later. In the last 7 days, how often has your child delayed taking [his/her] insulin by more than 30 minutes?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

[If respondent indicates child delayed one or more times, preface this question with "Including that/those delay(s)…"]

32. How many times in the last 4 weeks has your child delayed [an insulin shot / a bolus] more than 30 minutes?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

33. Sometimes people wait to [take their insulin / bolus] until right after they eat. In the last 7 days how often has your child waited until after eating to [take insulin / bolus]?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

[If respondent indicates waiting one or more times, preface this question with "Including that/those times(s)…"]

34. How many times in the last 4 weeks has your child waited until after eating to [take insulin / bolus]?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

Sometimes people take more or less insulin than their doctor has told them to take.

35. In the last 7 days, how often has your child
[If uses insulin shots] taken **more** than the prescribed amount of insulin; that is, even more than [his/her] sliding scale allows for?
[If uses insulin pump] bolused **more** insulin than [he/she] should have bolused?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

[If respondent indicates one or more times, preface this question with "Including that/those time(s)…"]

36. How many times in the last 4 weeks has your child
[If uses insulin shots] taken **more** than the prescribed amount of insulin?
[If uses insulin pump] bolused **more** insulin than [he/she] should have bolused?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

37. In the last 7 days, how often has your child
[If uses insulin shots] taken less than the prescribed amount of insulin; that is, even less than [his/her] sliding scale allows for?
[If uses insulin pump] bolused **less** insulin than [he/she] should have bolused?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

[If respondent indicates one or more times, preface this question with "Including that/those time(s)…"]
38. How many times in the last 4 weeks has your child
[If uses insulin shots] taken **less** than the prescribed amount of insulin?
[If uses insulin pump] bolused **less** insulin than [he/she] should have bolused?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

39. In the last 7 days, how often has your child missed [an insulin shot/ a bolus], like if [he/she] forgot or was too busy?

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

[If respondent indicates missing an insulin shot or bolus in the last 7 days, preface this question with "Including that/those time(s)…"]
40. How many times in the last 4 weeks has [he/she] missed [an insulin shot /a bolus].

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

☐ (77) don't know

[If uses insulin pump]

41. In the last 7 days, how often has your child not gotten [his/her] basal insulin because [his/her] pump was not working or not inserted? This does not include the times the pump was taken off for sports, exercise, showering, or bathing.

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

- ☐ (77) don't know
- ☐ (88) uses insulin shots

[If uses insulin pump]

[If respondent indicates not getting basal insulin in the last 7 days, preface this question with "Including that/those time(s)…"]

42. How many times in the last 4 weeks has your child not gotten [his/her] basal insulin because [his/her] pump was not working or not inserted? Again, this does not include the times the pump was taken off for sports, exercise, showering, or bathing.

⓪ None	⑥ Six times
① One time	⑦ Seven times
② Two times	⑧ Eight times
③ Three times	⑨ Nine times
④ Four times	⑩ Ten or more times
⑤ Five times	

- ☐ (77) don't know
- ☐ (88) uses insulin shots