

Contextual Assessment of Problematic Situations Identified by Insulin Pump Using Adolescents and Their Parents

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For youth with type 1 diabetes mellitus (T1DM) using insulin pumps, maintaining metabolic control through appropriate self-care is a complex biopsychosocial process reciprocally influenced by individual, familial, social, and technological variables. Adolescents ($n = 20$) with T1DM using insulin pumps and their parents ($n = 34$) were interviewed to determine (a) the most frequent and difficult situations faced by adolescents and their parents, (b) how the frequency and difficulty of these situations vary as a function of the respondent, the nature (content) of the problem, and the systemic context(s) in which problems occur, and (c) the relationship between the average difficulty rating and the youth's

metabolic control. The most frequently reported problematic situations were T1DM self-care. For youth these problems were predominantly related to social and peer contexts; parents identified problems primarily related to the family context. Implications and additional analyses are reported.

Keywords: insulin pump, continuous subcutaneous insulin infusion, type-1 diabetes, adolescent, family, social-ecological

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Type 1 diabetes mellitus (T1DM) is a metabolic disorder affecting the body's capacity to produce insulin, a hormone that allows blood glucose to be used for energy. The landmark Diabetes Control and Complications Trial has shown that intensive treatment of T1DM aimed at keeping blood glucose near normal (nondiabetic) levels delays the onset and slows the progression of diabetes complications (Diabetes Control and Complications Trial [DCCT], 1993). Although intensively treated adolescents showed significant improvements in metabolic control as measured by hemoglobin A_{1c} (HbA_{1c}) compared with conventionally treated peers, they did not attain the normoglycemia that their adult counterparts

attained on similar protocols (DCCT, 1994). For both adolescents and adults, maintaining metabolic control and the associated self-care, however, is a complex biopsychosocial process reciprocally influenced by multiple individual, familial, and social variables (see Gonder-Frederick, Cox, & Ritterband, 2002; Wysocki, Greco, & Buckloh, 2003, for extensive reviews).

Kazak and colleagues' social-ecological model of children with pediatric illness is a helpful framework to understand the complexities of how this multifactorial process interacts with the multiple settings and contexts in which the child actively functions (Kazak, Rourke, & Crump, 2003; Kazak, Segal-Andrews, & Johnson, 1995). These contexts can include, for example, the immediate family (e.g., parents and siblings), the medical team, peers, schools, neighborhoods, and hospitals; as well as contexts that indirectly influence the child, such as technology, culture, and parental social networks. Based upon the earlier work of Bronfenbrenner (1979), the social-ecological model of pediatric chronic illness emphasizes the transactional nature context, individual development, coping, and adaptation.

The transactional influence of interpersonal relationships, developmental processes, and T1DM self-management is apparent during adolescence. Physiological, psychological, and attitudinal changes are among the developmental factors that contribute to or detract from managing the difficult tasks of maintaining optimal metabolic control during adolescence (Boland, Ahern, & Grey, 1998; Cerreto & Travis, 1984; Daneman & Frank, 1992; Rapaport & Sills, 1994). Adolescents have been found to have more problems maintaining adherence than younger children, even though they possess greater diabetes knowledge (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Thomas, Peterson, & Goldstein, 1997). Adolescents may be aware of future health complications from poor adherence but may have more difficulty

maintaining their regimen because they are apprehensive about being singled out by their peers (Susman-Stillman, Hyson, Anderson, & Collins, 1997). Youth have been found to adhere poorly to dietary regimens when among friends (Delamater, Smith, Kurtz, & White, 1988) and to not engage in self-care around others in an attempt to appear similar to their peers without diabetes (Kyngäs & Hentinen, 1995). Difficulties with diabetes management may arise from the attitudes or expectations held by peers, the attitudes or expectations held by youth with T1DM about peers, and the interaction of these phenomena across social contexts (Hains, Berlin, Davies, Parton, & Alemzadeh, *in press*). In a study by Jacobson et al. (1986), approximately one third of youth with newly diagnosed diabetes believed that if their friends knew of their diabetes they would be liked less. Despite these expectations, it has been found that peers, compared with family members, provide more companionship and diabetes-related emotional support to youth with T1DM (La Greca et al., 1995).

The family literature suggests that, in general, there is an increase in family conflict during the adolescent years (Collins, 1990; Eccles et al., 1993). Eccles and Midgley (1989) proposed that families experience the most disruption when there is a mismatch between adolescents' increasing need for autonomy and control and the opportunities for autonomy and control provided by the familial environment. Developmentally adaptive and responsive family environments are important for adolescents with T1DM, as a variety of important outcomes have been linked to family variables. Families exhibiting high cohesion and low conflict (Dumont et al., 1995), developmentally appropriate self-care responsibility or autonomy (Anderson et al., 1990; La Greca, Follansbee, & Skyler, 1990; Wysocki et al., 1996), greater problem solving, and less family stress (White, Kolman, Wexler, Polin, & Winter, 1984)

have more favorable diabetes-related outcomes.

In addition to the transactional influences of peers and family, scientific and technological advances also directly and indirectly influence outcomes for youth with T1DM. One such technological advancement is continuous subcutaneous insulin infusion (CSII, or insulin pump therapy). CSII may be a treatment alternative particularly well suited for the challenges experienced by adolescents with T1DM. CSII leads to greater lifestyle flexibility by allowing minute insulin changes that can accommodate variations in metabolic demands, daily schedules, mealtimes, and activity levels. CSII has been found to significantly reduce the incidence of severe hypoglycemic events compared with other intensive treatments (Bode, Steed, & Davidson, 1994; Boland, Grey, Oesterle, Fredrickson, & Tamborlane, 1999) without detriment to psychosocial functioning (Boland et al., 1999; DCCT, 1996; Kaufman, Halvorson, Fisher, & Pitukcheewanont, 1999). Results of a recent meta analysis show that CSII is associated with improved glycemic control compared with traditional insulin therapies (conventional therapy and multiple daily injections) and does not appear to be associated with significant adverse medical outcomes (Weissberg-Benchell, Antisdel-Lomaglio, & Seshadri, 2003).

Balancing the medical benefits of CSII with adolescents, potential disadvantages and complications of CSII with adolescents include potential weight gain (Boland et al., 1999), hyperglycemia or diabetic ketoacidosis due to dislodgement of catheters (Farkas-Hirsch & Hirsch, 1994), site infections, pump malfunctions, and hypoglycemia (Weissberg-Benchell et al., 2003). In light of the comparatively large body of literature on medical outcomes of CSII, there is a relative lack of research exploring the potential psychosocial impact of this technologically advanced therapy on individuals and families (Weissberg-Benchell et al., 2003). Additionally, there are no published

assessment measures to specifically address the behavioral and psychological demands of insulin pump use and associated coping strategies.

THE PRESENT STUDY

Insulin pump therapy and T1DM serve as an excellent example of the complex transactions among chronic illness management, technological advances, and individual, social, and family variables (Mengel, Connis, Gordon, & Taylor, 1988). Therefore, the overall purpose of this project was to integrate a family-systems and social-ecological framework (Bronfenbrenner, 1979; Kazak et al., 2003) with Goldfried and D'Zurilla's (1969) behavior-analytic model of measurement development to identify (a) the most frequent and difficult situations faced by adolescents using insulin pumps and their parents, (b) how the frequency and difficulty of these situations vary as a function of the respondent (adolescent, mother, or father), the nature (content) of the problem, and the context in which problems occur, and (c) the extent to which the relationships between average difficulty rating and the youth's metabolic control varies by the respondent (adolescent, mother, or father). A multisource qualitative assessment should facilitate the identification and interpretation of rich descriptive data about the complex transactional effects of the family members, health management behaviors, and health outcomes across multiple contexts (Kazak et al., 1995; Quittner, 2000).

METHOD

Participants

Participants were 20 youth using insulin pumps (mean age = 14.04 years, SD = 2.84 years), their mothers (n = 19), and/or their fathers (n = 15; mean parent age = 44.09 years, SD = 5.62 years). The adolescent sample was 80% (n = 16) female and 95% (n = 19) White, with one adopted Latina participant. All parents identified

themselves as White. The mean years of parent education was 15.97 ($SD = 2.44$ years). This sample represented 32.8% of the youth population using insulin pumps in the Diabetes Center of Children's Hospital of Wisconsin at the time of the study. There were no significant differences between participating and nonparticipating youth using insulin pumps in terms of HbA_{1c} , $F(1, 59) = .53, p = .49$ (participants: $M = 8.27, SD = 1.04$; nonparticipants: $M = 8.07, SD = 1.07$), age, $F(1, 59) = 1.58, p = .21$ (nonparticipants: $M = 14.78, SD = 1.71$), or gender, $\chi^2(1, N = 61) = .917, p = .34$ (participants: 20% male; nonparticipants: 31.7% male). The mean duration of insulin pump use for the sample was 18.44 months ($SD = 12.33$ months, range = 4.27 to 52 months).

Measures

Structured Interview. A structured interview adapted from Quittner (1998) was utilized to collect data for the Situational Analysis Phase of Goldfried and D'Zurilla's (1969) model of measurement development. Each interview began with an open-ended question to elicit problem situations that have occurred since the initiation of insulin pump use. This was followed by probes in specific functional domains that were both developmentally appropriate (e.g., social activities and dating for adolescents) and documented in the literature as problematic for chronically ill children (e.g., coping with demands imposed by medical treatment). A domain refers to a related set of tasks and behaviors that are important for developmental progress (e.g., peer relationships), as well as for managing the disease (e.g., following up on recommendations from the care team). This methodology has been successfully used to assess stresses and problems encountered in pediatric populations such as cystic fibrosis (DiGirolamo et al., 1997; Quittner, 2000).

Both open-ended and domain-specific probes were used to obtain sufficient detail to establish the context of the situation, for example "who was there," "what were you

thinking or feeling," "when did it take place," and "where did it happen." More complex response sequences were elicited by asking the respondent what they did next and how the other people involved responded. Once an adequate description of the problem was obtained, respondents were asked to rate the difficulty of the problem (how distressing), using a 5-point scale ranging from 1 (*not at all difficult*) to 5 (*extremely difficult*). These interviews were audiotaped and transcribed.

Metabolic Control. Metabolic control of the sample was measured by the most recent percentage of HbA_{1c} . All samples were collected via a DCA2000 system (Bayer, Tarrytown, NY) with the nondiabetic reference range between 4.5% and 5.7%. HbA_{1c} levels reflect the average level of blood glucose over a 2- to 3-month period.

Procedures

Participants were approached about this study by members of the diabetes treatment team either in the clinic or by a letter mailed to their parents. If they agreed to have their name and phone number released, an appointment was scheduled for a home visit (or appointment at a neutral site if they preferred). Seventy-five percent ($n = 15$) of the visits were scheduled in the participants' homes. The remaining 25% ($n = 5$) of the visits were completed at the University of Wisconsin-Milwaukee Psychology Clinic. During each visit, the principal investigator reviewed the purpose and procedures of the study and then formally obtained informed consent from the parent and assent from the youth. The interviewers then located themselves throughout the home (or clinic) in a manner that maximized privacy of the family members and allowed for the best audio recording of the interviews. Each participant received a \$15 gift certificate for completing the study.

The interviewers were graduate or senior undergraduate students in psychology or a health-related field and received 20

hours of training in interview skills, research ethics, and the specific data collection procedures of this protocol. They performed two practice interviews with volunteers and observed one actual project interview before performing their first project interview, which was observed live by an experienced interviewer.

RESULTS

Problem Elicitation Phase–Content Analysis

The 20 youth reported 180 problematic situations, with a mean of 9.0 situations per participant ($SD = 3.26$, range = 5 to 16). The 17 mothers reported 159 problematic situations, with a mean of 9.4 situations per participant ($SD = 4.06$, range = 4 to 19). The 15 fathers reported 103 problematic situations, with a mean of 7.5 situations per participant ($SD = 3.44$, range = 2 to 14). Due to technical difficulties and/or inaudible tapes, transcripts were unavailable for two mothers (and the corresponding frequencies/difficulty ratings) and two fathers, resulting in some discrepancies in sample sizes and frequencies. To organize these situations into reliable domains for later analyses, a series of steps was completed.

Step 1: Creation of Situation Descriptors. The principal investigator independently read the entire set of transcribed interviews and summarized each situation into a descriptive sentence that succinctly detailed its various facets (e.g., “Hypoglycemia at school,” “Pump failure on a school trip,” and “Having to eat so many glucose tablets/drinking so much juice when low”).

Step 2: Content and Context Domain Development. To guide the process of developing and labeling content domains, a recent meta-analysis of the impact of CSII therapy was used (Weissberg-Benchell et al., 2003). In addition to the domains suggested by the meta-analysis, nondiabetes and complex content domains were included in this study. Context domains were

based on the social–ecological model outlined by Kazak et al. (2003). Operational definitions of the content and context domains (see Table 1) were developed by the authors to facilitate coding of the situations into the appropriate domains.

Step 3: Content and Context Domain Ratings and Reliability. Two raters (doctoral students in pediatric psychology with professional and personal experience with diabetes) independently coded all 395 situations into the appropriate content and context domains. Preliminary interrater reliability was excellent (Sattler, 2002) with the following reliabilities: Cohen’s kappa for content = .79 and Cohen’s kappa for context = .76. After correcting for typographical errors that occurred during the coding process and briefly discussing conceptual disagreements pertaining to the coding of situations, interrater reliability was improved (Cohen’s kappa for content = .83 and Cohen’s kappa for context = .92). Of the 395 situations, there was disagreement in terms of content coding for 16% ($n = 64$) of the situations, and in terms of context coding there was also disagreement for 16% ($n = 63$) of the situations. Of these 127 situations, 18 lacked agreement in terms of both content and context. Situations without agreement were resolved via additional discussion with a third rater (a pediatric psychologist with extensive experience in diabetes and in utilizing behavior–analytic methodology). This discussion included eliciting the rationale used for coding each situation and reaching consensus for final coding. The complete list of situations by content and context can be obtained from the corresponding author.

Frequency and Difficulty of Problematic Situations

Given the interdependent nature of the family data collected for this study, a key statistical assumption of analysis of variance (independence of observations) is violated, which potentially has serious consequences (Kenny & Judd, 1986). Therefore, a standardized mean difference (Cohen’s d) score

Table 1
Content and Context Domain Definitions

	Description
Content domain	
1. Hypoglycemia	Situations related to experiencing, treating, or dealing with low blood glucose/insulin reactions ($<\approx 70$ mg/dL)
2. Diabetic ketoacidosis (DKA)/hyperglycemia	Situations related to experiencing, treating, or dealing with high blood glucose ($>\approx 300$ mg/dL); DKA
3. Technological difficulties/pump malfunctions	Situations in which the insulin pump malfunctions or does not work as expected (mechanical, electrical problems, etc.); mastery issues; initial adjustment, placement issues
4. Site problems/infections	Situations related to discomfort/irritation with the infusion set, infections, the site coming off, problems putting the infusion site in; potentially leading to hyperglycemia
5. Self-management	Includes carbohydrate counting, meal planning; administration/adjustment of insulin; diet issues; checking/testing blood sugar; and other diabetes-related treatment tasks; excludes behaviors related to hyperglycemia and hypoglycemia
6. Non-diabetes	Situations not directly related to diabetes
7. Complex	Situations involving more than one domain
Context domain	
1. Family functioning	Environments involving parents, siblings, significant others, extended family, etc.
2. Social/peer functioning	Environments involving nonfamily members (peers, school personnel, coaches, etc.)
3. Patient-provider relationships	Environments involving medical staff; clinic or hospital visits; trainings, etc.
4. Indirect contexts	Environments that indirectly affect the child, including parents' social networks, employers, colleagues, the workplace, insurance, etc.
5. Multiple contexts	Environments meeting multiple contextual descriptors, or problems that could occur across multiple environments

was calculated on the comparisons of interest, with the caveat that these were nonindependent observations and that only youth and parents who reported at least one problematic situation in each of the content or context domains provided difficulty ratings. Thus, the descriptive statistics (frequencies, means, and standard deviations) for each content and context domain are based on different subsamples of youth and parents.

To determine the most frequent and difficult problems encountered by adolescents using insulin pumps and their parents, descriptive statistics were computed using domain and context codes as well as difficulty ratings from each situation. The

mean difficulty ratings and frequencies across content and context domains can be found in Figures 1 and 2, respectively. The descriptive statistics from the difficulty ratings and matrices of frequencies by content and context for youth, mothers, and fathers are available from the corresponding author.

Across respondents, the content domain with the most frequently reported difficulties was self-management. When context was considered, mothers and fathers reported difficulties with self-management most often within a family context or within multiple contexts, whereas youth reported more frequent self-management

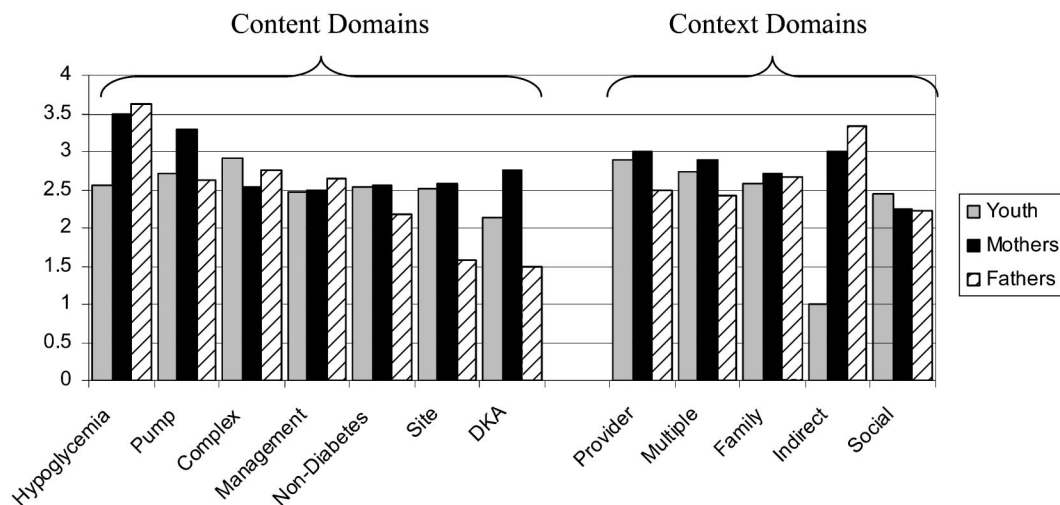


Figure 1. Mean difficulty ratings across content and context. DKA = diabetic ketoacidosis.

difficulties in a peer context. Comparing the difficulty ratings by context and participant revealed a narrow range of scores, whereas greater variability in difficulty ratings emerged by examining the interaction of participant by content. For youth, the two highest content ratings were the relatively infrequently reported nondiabetes and complex situations. For mothers and fathers, on average, the most difficult situations occurred in the content domain

of hypoglycemia, followed by pump malfunctions for mothers and complex situations for fathers.

To explore the degree to which mean difficulty ratings vary as a function of content and context, the standardized difference (d) between the highest and lowest mean difficulty ratings (within content and context) were computed. Across contexts, these d values were all <1 ($d = 0.39, 0.78$, and 0.81 for youth, mothers, and fathers,

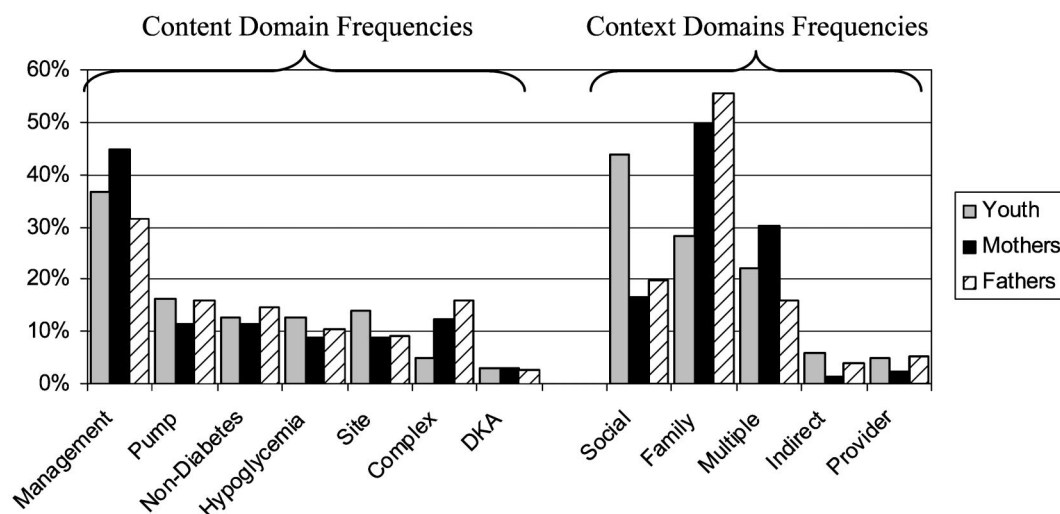


Figure 2. Frequencies of problematic situations by content and context. DKA = diabetic ketoacidosis.

respectively), suggesting a relative homogeneity of difficulty scores across context domains compared with the largest d values for content ($d = 1.59, 0.98$, and 2.36 for youth, mothers, and fathers, respectively). Thus, there appears to be more systematic variability in difficulty ratings related to the type of problem (content) than the setting of the problem (context).

Given that the content domain (hypoglycemia) with the highest difficulty rating for both parents was the least difficult for youth, d values were calculated to compare youth and parent difficulty ratings for situations involving hypoglycemia. Parents, when compared with youth, tended to rate situations involving hypoglycemia as being more difficult ($d = 1.46$ and 1.47 for mothers and fathers, respectively). Given the frequency of situations involving self-management reported by youth, mothers, and fathers, d values were computed to explore whether the difficulty ratings of self-management situations varied across source of report. There did not appear to be variability in terms of difficulty ratings ($d = 0.03$, youth vs. mothers; and $d = -0.11$, youth vs. fathers).

Relationship Between Difficulty and Metabolic Control (HbA_{1c})

Zero-order correlations between the overall mean difficulty ratings and metabolic control (HbA_{1c}) were computed. Based on Cohen's (1992) standards, there were small-sized relationships between parents' difficulty ratings and their youth's metabolic control ($r = .261$ and $r = .138$ for mothers and fathers, respectively) and a medium-sized relationship between the youth's difficulty ratings and their metabolic control ($r = .334$).

DISCUSSION

The overarching goal of the current project was to consider the interactions among multiple contexts and content, rather than focus exclusively on one content domain or context in which difficulties

arose for insulin pump-using adolescents and their parents. Overall, these findings suggest that families of adolescents using CSII experience a variety of problematic situations that occur across multiple contexts. These results are consistent with the large body of research demonstrating that diabetes-related outcomes are reciprocally influenced by multiple individual, familial, and social variables (Gonder-Frederick et al., 2002; Wysocki et al., 2003). In terms of content, the findings also mirror those of the 2003 meta-analysis conducted by Weissberg-Benchell et al., who found that pump malfunctions/technological difficulties, hypoglycemia, site problems/infections, and diabetic ketoacidosis/hyperglycemia were commonly reported problematic situations for families with adolescents using CSII. The current study also documents the fact that the rated difficulty of these situations differs by family member and context.

More specific to the objectives of this study is an examination of the most commonly reported frequent situations. Consistent across respondents, the content domain with the most frequently reported difficulties was self-management. A different picture of self-management emerged, however, when context was considered. Both mothers and fathers reported difficulties with self-management most often within a family context or within multiple contexts (e.g., the situation involved interactions between the family and other microsystems, creating a mesosystem as defined by Kazak et al. (2003), whereas youth reported more frequent self-management difficulties in a peer context.

A frequently reported example that illustrates well the interaction of self-management tasks, family, and social contexts was parental report of sleepovers (i.e., "allowing child to sleep over only if friend's parents can check blood at night or child's own parent can attend," "dealing with the logistics of child's nighttime blood sugar checks at sleepover and husband's associ-

ated anxiety,” and “parent allaying their anxiety by frequently calling to check up on the child while at a sleepover.” Other multiple context examples include interaction of family, self-management, and school (“parent’s partner had to educate teachers at school about diabetes” and “school staff concerned with child calling parent too frequently with self-care questions [e.g., when to correct or snack].” These findings underscore the importance of considering both the types of difficulties experienced by this population and the contexts and individuals that must be included in reaching and implementing an appropriate solution.

In considering the overall clustering of the most frequently reported situations, different patterns emerge for each family member. For youth, the modal interaction of content and context was self-management difficulties within a social context, whereas for mothers it was self-management within a family context. Fathers, on the other hand, reported two modal content domains (hypoglycemia and pump malfunctions), both occurring most frequently within a family context. That youth reported more difficulties in social contexts than did parents is probably not surprising, but it raises concerns that the situations most impacting youth self-care are occurring outside the awareness of parents. Parents, on the other hand, seem to be acutely aware of ongoing issues around diabetes management in the family context that youth apparently see as causing comparatively little difficulty. This may potentially impede family communication regarding diabetes management while the adolescent is on the developmental path to young adulthood. Furthermore, diabetes-related communication patterns, developmental trajectories, and intra- and interpersonal functioning appear to have reciprocal influence.

In addition to examining the most frequently reported situations, another objective of the current study was to identify how the reported difficulty of these situa-

tions varied as a function of the respondent, content, and systemic context. Examination of the difficulty ratings by context and participant revealed a narrow range of scores without any one context standing out as being particularly difficult. A greater range of difficulty ratings was found by examining the interaction of participant by content. The two highest content difficulty ratings for youth were the relatively infrequently reported nondiabetes and complex situations (i.e., “mom not allowing child to a sleep over at a friend’s house because of the child’s earlier exercise and parental concern about hypo/hyperglycemia”). For mothers and fathers, on average, the most difficult situations occurred in the content domain of hypoglycemia, followed by pump malfunctions for mothers and complex situations for fathers. Of interest, the content domain with the highest difficulty rating for both mothers and fathers was the least difficult for youth. This example may reflect an issue of “defining” what is problematic, which may potentially impede efforts to improve adherence and self-management behaviors. This disparity may also reflect the complexity and difficulty of transitioning to more autonomous self-management for youth across the different types of self-care behaviors. The treatment of hypoglycemia, given its nature and progression, at times requires the assistance of others; whereas other types of behaviors, such as insulin administration and carbohydrate counting, do not typically require assistance of others. The rates at which progression toward autonomous self-care occur may vary as a result of the context and nature of the task. The extent to which conclusions can be reached about these observations is limited, in part, by the variable occurrences of problematic situations in particular contexts (i.e., content by context interactions).

The last objective was to determine the strength of the relationship between difficulty ratings and metabolic control. Although the sample size of this study lim-

ited the ability to detect statistically significant relationships there were small (mothers and fathers)- to medium (youth)-sized positive relationships between the youth's metabolic control and respondents' average difficulty ratings. In families in which everyone reports more difficulty dealing with the management problems they experience, the youth tends to have poorer glycemic control.

The identification of common problem areas obtained in this study points to potential preventive interventions and targets for anticipatory guidance. For example, difficulties with self-management in social contexts for youth can be targeted during clinic trainings or follow-up visits before or after initiation of CSII. The information obtained in this study can also be used to help inform families considering CSII about the variety of difficult situations that arise across contexts (e.g., the ones that tend to occur at school or with peers when the parent might not be as aware). Professionals involved in the care of families using CSII could provide instruction or education on how to deal with the variety of problems (across content and context) that could and do occur (with the emphasis that all family members are somehow involved in the preventative measures and ameliorative aspects of dealing with the problematic situation regardless of content or context).

Future workers should explore the perceptions of other family members about issues brought up by one, but not other, family members (e.g., how youth view family context problems seen by parents and how parents view the social context problems described by youth). Additional exploration and content analyses of the qualitative data gathered in this study could yield further rich, descriptive, and sequential accounts of problems experienced by families of youth using CSII as well as the contexts in which these problems occurred. For example, related to self-management, a response that is adaptive within the family

may in fact be ineffective or lead to potential difficulties in social contexts. These sequential accounts can also be used to develop a contextually specific measure based on Goldfried and D'Zurilla's (1969) model, similar to the one developed for parents and youth with cystic fibrosis by Quittner (1998). The current and growing body of research, however, suggests that our ability to develop both predictive models and effective interventions is greatly enhanced by attending to context (Coyne & Smith, 1991; Sandler, Reynolds, Kliever, & Ramerz, 1992; Quittner, 2000; Wolchik, West, Westover, & Sandler, 1993).

Several limitations to this study need to be acknowledged. The first limitation is the generalizability of the findings given the sample characteristics (i.e., a greater number of Caucasian and female participants). Although no significant demographic and disease differences were found between the study participants and nonparticipants, all patients using CSII in the diabetes clinic have already been deemed "well suited" and therefore constitute a biased sample compared with the general population of youth with T1DM. With this in mind, it is important to note that even though this sample was biased toward "better" coping, there were numerous difficulties identified. To help control for this bias in future studies a comparison group of other children and families with T1DM before use of a pump or multiple daily injections may be useful. Although not of critical importance to the qualitative aspects of this study, a second limitation is that the sample size essentially prevented the detection of any meaningful statistical relationships and comparisons.

This examination of difficulties encountered by family members of youth using CSII, integrating family-systems and social-ecological approaches, confirms the fact that adherence difficulties are experienced in specific social contexts that differ by family member. This situation certainly creates communication challenges during

problem-solving efforts by the family and/or professionals with the youth. In attempting to increase adherence and promote the development of autonomy, one must take into account the social contexts of the challenges for each family member and recognize that successful management will require appreciation of the multisystemic interactions among chronic illness, technology, and individual, social, and family variables.

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