Changing Patterns of Self-Management in Youth with Type I Diabetes

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Self-management of type I diabetes is key to good physical and psychosocial outcomes of the disease, yet little is known about how youth and their parents share responsibility for illness management. This study describes the division of labor between youth and their parents, self-management conflict, and three patterns of self-management in youth across four developmental stages: preadolescence, early adolescence, mid-adolescence, and late adolescence. Twenty-two youth (8–19 years) with type I diabetes and one of their parents were interviewed using semistructured interviews. Data were analyzed using qualitative content analysis. Results indicated that parents of preadolescents (8–11 years) performed much of their children’s diabetes care. Dyads reported some conflicts, particularly over food, amount of bolus, and blood glucose testing. The dyads demonstrated a self-management pattern that we identified as parent-dominant. Most early adolescents (11–15 years) performed much of their own daily care, but parents actively participated in their self-management and oversaw it. The majority of dyads reported conflict over food and blood glucose testing. Most early adolescents demonstrated a transitional self-management pattern whereby they managed their own daily care, with varying amounts of parental oversight. In mid-adolescence (15–17 years), youth managed nearly all of their diabetes care; however, some dyads reported that parental oversight of illness care was still considerable. Exercise was conflictual for the majority of these dyads. Over half of the youth and, by late adolescence (17–19 years), all youth demonstrated a pattern of adolescent-dominant self-management. In adolescent-dominant self-management, youth independently managed their diabetes. Half of the dyads reported that there were sometimes conflicts over food and blood glucose testing. Understanding the nature of sharing self-management responsibilities, the nature of conflict in carrying out such responsibilities, and the pattern of self-management may help nurses provide more targeted assistance to youth with diabetes and to their parents.

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ONE IN EVERY 400–500 children and adolescents in the United States has type I diabetes (American Diabetes Association, 2004). The incidence of type I diabetes is rising, especially in children under 5 years (Juvenile Diabetes Research Foundation, 2004). In type I diabetes, the pancreas produces little or no insulin due to the destruction of insulin-producing β cells, leading to abnormalities in carbohydrate, protein, and fat metabolism (Boland & Grey, 2000). The goal of diabetes treatment is to keep blood glucose levels within normal range because both hypoglycemia and hyperglycemia carry short-term and long-term health risks and potential complications (Boland & Grey, 2000). Low glycosylated hemoglobin (HbA1c) levels have been shown to delay the onset and to slow the progression of diabetes complications in adolescents (Diabetes Control and Complications Trial Group, 1994). Thus, intensive management using multiple daily insulin injections or an insulin pump is currently the standard of care for children over 7 years (American Diabetes Association, 2003).

Youth with type I diabetes and their parents face a daunting task: to control blood glucose levels on a daily basis by monitoring and regulating diet, exercise, and insulin dosage and administration. Little is known, however, about how youth with type I diabetes, or other chronic diseases for that
matter, and their parents share illness management responsibilities (Buford, 2004). Schilling, Grey, and Knafl (2002a) clarified the concept of self-management of type I diabetes in youth and defined it as: “an active, daily, and flexible process in which youth and their parents share responsibility and decision making for achieving disease control, health, and well-being through a wide range of illness-related activities” (p. 92). They identified three essential attributes of the concept: process, activities, and goals. The purpose of this study was to explicate activities in the self-management of type I diabetes in youth by: (1) describing the division of labor in illness management between parents and youth, including the nature of the conflict between them, and (2) describing the state of the transfer of management responsibility from parents to youth.

**BACKGROUND**

Self-management of type I diabetes in youth must be understood in relation to the developmental stages of children and adolescents. The advancement of fine motor, communication, and reasoning skills makes it possible for children in late childhood to understand the basics of the disease and its treatment, to physically manipulate treatment paraphernalia (syringes and pumps), and to communicate with family and others about the disease (Savinetti-Rose, 1994). However, children and preadolescents have neither the cognitive ability nor the emotional maturity to consistently plan ahead and to make decisions about regimen adjustment (Golden, 1999).

Because the abilities, concerns, and needs of youth change during adolescence, it is helpful to view this developmental period in stages. Hamburg (1998) differentiated the key issues and capabilities of adolescents in early adolescence (11- to 15-year-olds), mid-adolescence (15- to 17-year-olds), and late adolescence (beginning at 17 years). Early adolescence is a critical transition in which youth face the challenges of both puberty and peer conformity (Hamburg, 1998). Thought processes are primarily concrete and present-oriented (Hamburg, 1998), making it difficult for these youth to imagine hypothetical situations. The quieter and less stressful stage of mid-adolescence demonstrates a greater array of cognitive abilities and makes it possible for youth to think abstractly and to plan ahead (Hamburg, 1998). However, in emotional and social situations, adolescent thinking is often less mature. Hamburg stated that the senior year in high school marks a transition into adulthood and the stage of late adolescence when adult-level reasoning skills are attained. During this stage, adolescents become increasingly autonomous and progress toward consolidating their personal identities.

Over the past two decades, themes in relation to developmental stage and diabetes self-management in youth have emerged from the literature. First, as children grow older, they assume more responsibility for diabetes-related tasks, and parents are likely to remain involved, to varying degrees, in some diabetes tasks in mid-adolescence (15–17 years) and beyond (Ingersoll, Orr, Herrold, & Golden, 1986). Furthermore, Wysocki et al. (1996), studying children from 5 to 17 years, have shown that children are more likely, as they grow older, to assume levels of self-care responsibility that are excessive relative to psychological maturity, resulting in decreased adherence to diabetes regimen tasks. Additionally, there is conflicting evidence as to whether the frequency of diabetes mismanagement behaviors changes over the stages of adolescence (Hanna & Guthrie, 1999; Weissberg-Benchell et al., 1995). Finally, although youth assume more responsibility for performing regimen tasks as they mature, their adherence to the regimen decreases over the course of adolescence (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Jacobson et al., 1987; LaGreca, Follansbee, & Skyler, 1990).

In spite of the importance of evaluating the diabetes self-management of youth within the context of developmental stages (LaGreca et al., 1990), minimal research has been framed in this manner. Additionally, there has been no research on how youth with insulin pumps and their parents share diabetes self-management responsibilities. Furthermore, researchers have not addressed diabetes-related conflict between parents and youth across the stages of adolescence. Anderson (2004) recently reviewed studies on family conflict and its effects on adherence to diabetes treatment and on metabolic control in youth. Her review indicated that greater family conflict correlated with less adherence to diabetes treatment and with poorer glycemic control for youth.

Grounded on the cited conceptualization of self-management (Schilling et al., 2002a), this study was designed to address the literature gap on differences in self-management across developmental stages and to answer the following three
questions: (a) What is the division of labor between youth and their parents in the performance of activities in the self-management of diabetes? (b) What conflicts do youth and their parents report around the performance of these activities? (c) What are the perspectives of youth and their parents on the degree of independence shown by youth in their self-management of diabetes?

**METHODS**

**Design**

The method used in this study was qualitative description (Sandelowski, 2000). To accomplish this description, qualitative content analysis of interviews with youth and their parents was conducted.

**Sample**

After obtaining Institutional Review Board approval, a purposive sample of 22 youth with type I diabetes (from 8 to 19 years) and one of their parents was enrolled in the study. The sample was derived from a population of youth enrolled in two studies being conducted by one of the investigators (M.G.). Participants responded to flyers and a poster left at the clinic, and to phone calls inviting participation after referral from the clinic staff. Thirteen female and nine male youth were interviewed; their mean age was 14.5 years ($SD = 3.1$). The duration of illness ranged from 2 to 16.5 years. All but one child were Caucasian. The majority of youth ($n = 17$) were on insulin pumps. Mothers ($n = 17$) were more frequently interviewed than fathers ($n = 5$). No demographic data on parents were collected.

**Procedure**

After youth and their parents had agreed to participate in the study, separate interview times were set up at their convenience. Most participants ($n = 43$) chose to be interviewed in their own homes and, sequentially, in the same block of time ($n = 40$). Before the interviews, parents signed written consent, and youth gave either written assent or consent, depending on age.

**Data Collection**

Youth and one of their parents were interviewed separately using semistructured interviews. Both child and parent interviews contained questions relating to who was doing what to manage the child’s diabetes, areas of conflict in illness management, circumstances surrounding consultations with health care professionals, and management goals. Interview questions and probes were developed based on the literature and on our theoretical concept analysis of self-management of type I diabetes in youth (Schilling et al., 2002a). Coding categories were developed from the interview guide.

**Data Analysis**

Interviews were audiotaped and transcribed verbatim. All transcriptions were checked against original audiotapes for accuracy and were corrected before entry into the qualitative software program Atlas ti (Muhr, 1997). A coding system was developed by two of the investigators (L.S. and K.K.) based on interview questions. Thirty-four a priori common codes were used to accomplish the content analysis of both child and parent interviews. The codes were related to six broad areas of self-management: the activities of self-management, parent–youth sharing of diabetes responsibilities, relationships with health care providers, conflicts regarding diabetes management, transfer of responsibilities from parent to youth, and diabetes goals. In addition, four codes were specific to parental interview content (motivation for helping child, spouse and diabetes, altering ways to help, and deciding to alter child’s level of responsibility), and one was specific to child interview content (reaction to parental help). A codebook, which defined each code and its application criteria, was developed before interview coding. Subsequently, the investigators independently coded six interviews, meeting after each coding to resolve differences and to further clarify definitions of codes and their application criteria. Following the final clarification of the coding scheme and its application, one author (L.S.) completed the coding for all interviews ($N = 44$). For this analysis, only codes related to the activities of self-management were analyzed. Interview themes were identified through a process of constant comparison (comparing across interview comments to identify crosscutting themes).

**RESULTS**

Interview data on the activities of self-management were organized to reflect three main themes that emerged: (a) division of labor in the perfor-
mance of activities; (b) nature of conflict in six activities of self-management: diet, testing, insulin dosing, exercise, and treatment of hypoglycemia and hyperglycemia; and (c) degree of transfer of responsibility for the performance of activities from parent to child. To place the findings in a developmental context, we stratified our analysis of each of these main themes by the developmental stages of adolescence, as defined by Hamburg (1998): (a) preadolescence, children between 8 and 11 years (n = 4 dyads); (b) early adolescence, youth between 11 and 15 years (n = 9 dyads); (c) mid-adolescence, youth between 15 and 17 years (n = 5 dyads); and (d) late adolescence, youth 17 years and older (n = 4 dyads). Table 1 summarizes the results relating to the three themes (division of labor, conflict, and degree of transfer of responsibility) across the developmental stages of adolescence. In analyzing the state of the transfer, we identified three patterns of self-management of type I diabetes in youths. Table 2 presents study participants by stage of adolescence and pattern of self-management. In all cases, we combined child and parental interview data to give the most complete picture of each dyad’s self-management of type I diabetes.

**Division of Labor in the Performance of Activities**

**Preadolescence (n = 4)**

Preadolescents were on insulin pumps and participated in their diabetes management, but they relied heavily on direct parental participation in and oversight of their diabetes care. All children reported that their parents reminded them to check their blood glucose, and three of four children said that their parents checked their blood glucose levels while they slept. One preadolescent routinely performed his own blood glucose monitoring (BGM). These preadolescents reported that they performed most of their own bolusing (dialing up the amount of insulin to be delivered through their insulin pumps), but were still learning how to count carbohydrates and to calculate correction boluses for existing blood glucose levels. Children usually told their parents if their blood glucose levels were too “low” or too “high,” and parents

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Division of Labor</th>
<th>Conflict</th>
<th>Transfer of Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preadolescence</td>
<td>Parents perform much of diabetes care, oversee bolusing and insulin dosing, are involved in BGM, and are most often responsible for treating “highs” and “lows.”</td>
<td>There are varying levels of conflict, but they are generally low-level.</td>
<td>Parents take active steps to transfer diabetes management responsibilities to the child, but self-management is parent-dominant.</td>
</tr>
<tr>
<td>(8–11 years; n = 4)</td>
<td>Early adolescence (11–15 years; n = 9)</td>
<td>Adolescents give own injections, boluses, and perform daytime BGM. Some parents do nighttime BGM. Over these years, adolescents assume responsibility for food choices. Some adolescents bolus independently and change their own infusion sites. Adolescents consult with parents. Most adolescents treat “lows,” but most do not treat “highs” independently. Parents “pinch-hit” when adolescents are tired, sick, or need a break.</td>
<td>All dyads report diabetes-related conflicts. The majority of adolescents and parents report conflict over food and BGM.</td>
</tr>
<tr>
<td>Mid-adolescence (15–17 years; n = 5)</td>
<td>Adolescents manage most of their daily care, including independent insulin dose adjustment. Most treat “lows” and “highs” independently. Parents accompany adolescents to the clinic. Most parents order/stock diabetic supplies.</td>
<td>Exercise is conflictual for the majority. There is conflict over food and BGM in two of five dyads.</td>
<td>Some adolescents demonstrate adolescent-dominant self-management, and others demonstrate transitional self-management.</td>
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<tr>
<td>Late adolescence (17–19 years; n = 4)</td>
<td>There is independent self-management of diabetes. Parents continue to remind the children (testing, eating “right,” and foot care).</td>
<td>There is little conflict for most.</td>
<td>Self-management is adolescent-dominant.</td>
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</tbody>
</table>
most often took the responsibility for treating these “highs” and “lows.”

Parents reported that they changed infusion sites, filled pump reservoirs, kept track of blood glucose results, and actively oversaw their children’s bolusing. They instructed their children on counting carbohydrates and calculating boluses, what to do in different situations, what to do when not feeling well, healthy eating, and adjusting basal rates on the pump. Parents also reported that they reminded their children to check blood glucose levels and to bolus, and then checked to make sure they did. In this age group, parents contacted the clinic if there were how-to-manage questions, and parents communicated with school nurses about boluses children took in school.

**Early Adolescence (n = 9)**

With the exception of the youngest adolescent in this group, the majority of early adolescents reported administering their own insulin injections (n = 2) or administering their own insulin boluses (n = 6). All adolescents reported that they performed their own daytime BGM, with varying amounts of parental reminders. However, four parents reported that they either routinely or sporadically tested their children during the night. Parents of the 11- and 12-year-olds, with one exception, reported that they oversaw their children’s food intake. By the age of 13 years, children reported (and parents concurred) that they were making many of their own food choices.

Of the six children on insulin pumps, all but two reported managing the routine counting of carbohydrates and bolusing independently; half reported changing their own infusion sites. Two less independent adolescents reported that they either routinely reviewed the amount of bolus with a parent or they relied on a parent to guide the bolus amount. The parent of the latter adolescent said that counting carbohydrates and calculating boluses “are a shared thing, but it’s more on my end. I want to make sure I’m hearing what she’s putting in.” Four more independent insulin pump users reported that they consulted parents for a variety of reasons: if they were “high” or “low” and could not determine why, if they were uncertain about what to do, and to seek advice about the number of carbohydrates in a particular food or meal.

Youth in early adolescence reported that they usually told someone (parent, teacher, or friend) if their blood glucose numbers were “high” or “low.” All but the youngest adolescents in this group reported that they initiated action to treat their “lows,” unless the degree of hypoglycemia required someone to help them. Only one of the oldest adolescents in this group reported that she routinely treated “highs” by herself. The others, although they might initiate measures to lower their blood glucose (such as drinking water or diet soda and increasing or decreasing exercise) reported that they usually checked with a parent before altering their insulin doses.

Parents helped these early adolescents by overseeing their diabetes activities; reminding when necessary; performing administrative duties (e.g., ordering supplies; making clinic appointments and accompanying their children to the clinic, but not necessarily into the examination room; and troubleshooting, as necessary, at school); educating them about diabetes and encouraging them to be more independent and responsible; and “pinch-hitting” when needed. Both parents and youth described “pinch hitting,” which included parents testing their children during the night, giving injections or testing blood glucose levels when the adolescents needed a break, telling their children how much to bolus if they were stressed or sick, or bolusing and/or setting up the pump for the adolescents as needed. “Pinch hitting” involved parents performing some activity of self-management to, as one parent said, “give [the] child a ‘break’ or take the responsibility off [the child] and

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**Table 2. Stage of Adolescence and Age of Youth Participants, by Pattern of Self-Management**

<table>
<thead>
<tr>
<th>Stage of Adolescence</th>
<th>Age</th>
<th>Pattern of Self-Management</th>
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</thead>
<tbody>
<tr>
<td>Preadolescence</td>
<td>8 years 8 months</td>
<td>Parent-dominant</td>
</tr>
<tr>
<td></td>
<td>9 years 3 months</td>
<td>Parent-dominant</td>
</tr>
<tr>
<td></td>
<td>9 years 9 months</td>
<td>Parent-dominant</td>
</tr>
<tr>
<td></td>
<td>10 years 10 months</td>
<td>Parent-dominant</td>
</tr>
<tr>
<td>Early adolescence</td>
<td>11 years 5 months</td>
<td>Parent-dominant</td>
</tr>
<tr>
<td></td>
<td>11 years 7 months</td>
<td>Transitional</td>
</tr>
<tr>
<td></td>
<td>12 years 7 months</td>
<td>Transitional</td>
</tr>
<tr>
<td></td>
<td>12 years 8 months</td>
<td>Transitional</td>
</tr>
<tr>
<td></td>
<td>13 years 1 month</td>
<td>Transitional</td>
</tr>
<tr>
<td></td>
<td>13 years 6 months</td>
<td>Transitional</td>
</tr>
<tr>
<td></td>
<td>14 years 7 months</td>
<td>Transitional</td>
</tr>
<tr>
<td></td>
<td>14 years 11 months</td>
<td>Transitional</td>
</tr>
<tr>
<td>Mid-adolescence</td>
<td>15 years 5 months</td>
<td>Transitional</td>
</tr>
<tr>
<td></td>
<td>15 years 6 months</td>
<td>Adolescent-dominant</td>
</tr>
<tr>
<td></td>
<td>16 years 5 months</td>
<td>Adolescent-dominant</td>
</tr>
<tr>
<td></td>
<td>16 years 8 months</td>
<td>Adolescent-dominant</td>
</tr>
<tr>
<td></td>
<td>16 years 11 months</td>
<td>Transitional</td>
</tr>
<tr>
<td>Late adolescence</td>
<td>17 years 3 months</td>
<td>Adolescent-dominant</td>
</tr>
<tr>
<td></td>
<td>18 years 2 months</td>
<td>Adolescent-dominant</td>
</tr>
<tr>
<td></td>
<td>18 years 7 months</td>
<td>Adolescent-dominant</td>
</tr>
<tr>
<td></td>
<td>19 years 1 month</td>
<td>Adolescent-dominant</td>
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</tbody>
</table>
let [the child] feel like a kid.” Five of nine parents reported doing this.

**Mid-adolescence (n = 5)**

Youth in mid-adolescence reported that they managed most or nearly all of their diabetes care. Those on insulin pumps (n = 3) reported that they were totally in charge of their pumps, including putting in their own infusion sites, and parents reported that they did not know how to operate the pumps or certain aspects of the pumps (e.g., changing basal rates). One adolescent reported that he relied on his mother to count carbohydrates for him when she was around, but the other two adolescents said that they did not consult their parents for this or for bolus amounts. All three adolescents reported that they made changes in their basal rates by themselves. The adolescents (n = 2) on injections said that they gave and adjusted their own insulin doses. One of these adolescents reported that she shared her plan for dosing with her mother, if present. Most parents reported that they did not know the specifics of their children’s insulin dosing. Two adolescents reported that they had e-mailed providers with specific questions about their treatment, and these same adolescents also described how they evaluated advice from their caregivers, sticking with the advice if it worked and discarding or altering it if it did not. One adolescent said:

> I think they [what health care professionals say I should do] stick in my head. Sometimes I don’t always do them, but I think for the first 2 weeks after I’ve been there and they’ve suggested something, I’ll do it. And then it kind of goes back to my normal routine. It’s still in the back of my head; I just don’t do it sometimes . . . and sometimes it’s just not for me. Cause I know, like they’ll suggest having something else for breakfast or something, but I know that just wouldn’t work.

All mid-adolescents reported treating their “lows” unless they were physically unable. Most also treated their own “highs,” not necessarily telling anyone that they were high. One adolescent reported telling parents if they were around, and one adolescent consulted with her mother if she is “too high.”

The more sophisticated thinking of these mid-adolescents was revealed in their ability to evaluate their own performance. For example, one adolescent reported, “I’ve come to the conclusion that I can’t expect myself to be perfect and there’s no way I can sit down and test my blood sugar every 20 minutes.” Adolescents in this group also described their ability to tell family and friends to “back off” when their advice or reminder was intrusive, and their experiences of trying, evaluating, and then “tweaking” the advice they receive from health care providers. One adolescent also demonstrated mature thinking in determining when she needed to tell someone she had diabetes and when she did not. When she realized she would be spending a lot of time with someone, she taught that person how to test her blood glucose, the signs of low blood glucose, and how to give glucagon. In her work situation, which involved working with younger children, she decided not to make her diabetes obvious to avoid children’s questions and to prevent her illness from infringing on what the children were supposed to be doing. She reasoned:

> If, like, say, I go to take a shot or something like that, I always try and go to the bathroom to do it so the kids aren’t like, oh my God, it’s a needle. But, you know, I don’t avoid telling them. I just, it’s easier not to have that there because, you know, then they’re asking tons of questions when they should be concentrating on . . . whatever they’re supposed to be doing.

All parents reminded their children to test their blood glucose levels, but only one parent said she constantly needed to remind her child to bolus, change the site, and take supplies when leaving the house. In terms of administrative duties, mothers reported that they called the clinic if a call was necessary; for most, this was infrequent. Many continued to take their children to the clinic (one adolescent drove herself), and all but one parent ordered and stocked diabetes supplies. “Pinch hitting” also occurred in this age group. Four of five parents reported that they helped their children at least occasionally by testing in the early morning or during the night, testing when the child was sick, or testing on weekend mornings to allow the child to sleep in. All parents reported that they remained alert for signs that their children were “high” or “low.”

Although all these parents described ways in which they supported their adolescents, two mothers, in particular, talked about being available to their children when they were needed. One mother described it like this:

> I will feel . . . sometimes a period of time can go by and I won’t have asked her, just like I’ve almost forgotten that she has diabetes. And it’s, oh, I haven’t asked her for a while, how are your glucose levels? And I think that usually definitely comes during a period of time where she is on a real healthy stretch. If she is not feeling healthy, she shows it in every way
within, you know, you can see it in her complexion, you can see it in her energy level, and so that’s when, that’s a period of time I’ll stay more tuned in.

Late Adolescence (n = 4)

The adolescents in this group (all insulin pump users) were self-managing their diabetes. These adolescents determined their own insulin doses, made corrections in doses, inserted their own infusion sites and performed pump maintenance, treated their own “highs” and “lows,” planned what they would eat, called or e-mailed providers when problems arose, and (most; three of four) adjusted their own basal rates. One adolescent had begun to order her own supplies, and another had begun to attend the clinic without a parent. Only one adolescent routinely shared blood glucose numbers with parents. One adolescent could have been speaking for all when she said, “I check, I fix, I correct, I change, I do whatever needs to be done.”

Parents of these late adolescents reported that they continued to remind their children to test before driving, to test in general, to eat the right things, and to take care of their feet. Adolescents responded in varying ways to these parental reminders. One said, “I don’t get angry, I don’t get upset. I just kind of brush them off. I just don’t take it. In general, my whole lifestyle is kind of independent.” Another shared:

When I was 13 or so, it [Mom asking if I’ve tested] got to me. I’m like, stop asking me. Because she’s like, you feel ok? I’m like, I’m fine. But now I know she’s looking out for me. [When Mom reminds me clinic is coming up or asks what my numbers are], I always say fine, but I make a mental note. Maybe I need to do some changes.

Although parents reported that they believed their children should be independently managing their diabetes and all were satisfied with the children’s level of self-management, all described worry about their children’s well-being and described how difficult it was to promote independence and not know the specifics of adolescents’ diabetes care. Two dyads reported that parents “pinch-hit” by setting up pump site changes (n = 1) or by testing the child so that she could sleep in (n = 1).

Nature of Conflict in Self-Management

Preadolescence

The children and their parents reported varying levels of conflict in their self-management of diabetes. Two of four dyads reported conflict over food, one dyad reported conflict over exercise, and one dyad reported conflict about the treatment of hypoglycemia. This dyad sometimes disagreed about what food should be eaten when the child was hypoglycemic. Two of the dyads said that they sometimes disagreed over the amount of a bolus. BGM was rarely conflictual for one dyad, not conflictual at all for another dyad, and somewhat conflictual for the other two dyads.

Early Adolescence

Seven of nine dyads reported conflict over food and testing. For three families, conflict over food was daily and considerable. There were disagreements over food choices, whether children should eat when their blood glucose levels were high, sneaking food, and what food should be eaten when the children were hypoglycemic and hyperglycemic. BGM was also an area of conflict for most (seven of nine) of these dyads. When asked about testing, one parent said:

Not when or how often, but did you do it. That’s the biggie. You know, because, oh, I forgot. Well you’ve been doing this for 9 years, how could you forget this. . . . But it’s just his age, too. . . . Sometimes we handle it by saying, ok, wait 20 minutes. . . . and he always will walk back in and just do it, you know. It gives him a little control.

For one of the adolescents, there was conflict over her refusal to write down her test results. Three parents wished their children would get more exercise, but only two adolescents whose parents described a conflict said that exercise was a source of conflict. One adolescent said, “Well, my [parent] is almost now constantly on my back about how I have to exercise and everything. It’s just really annoying.” For the other adolescent, one for whom exercising when “higher” made her go “higher,” conflict erupted when she was told to stop “running around” by her parents to prevent this from happening. There was relatively little conflict for these dyads over the treatment of hypoglycemia and hyperglycemia (three of nine) and insulin dosing (two of nine). Only two of the youth, both on pumps, reported that there were disagreements between them and their parents over how much insulin to give.

Mid-adolescence

Exercise was conflictual for three dyads. One of the adolescents for whom exercise was a source of conflict “all the time” admitted that he needed more
exercise, “I just don’t. But I’ve got to work on it. That’s the main problem with my life.” Food was a major conflict for one dyad and an occasional problem for another. For the minority of these adolescents and their parents, food choices (two of five) and the treatment of hypoglycemia and hyperglycemia (two of five) were conflictual. Conflict over insulin doses happened rarely for two dyads and never happened for the others. BGM was, or had been, conflictual for two dyads. For one dyad, the parent reported that there was “a constant battle” about testing. The parent added, “... he’s gotten to the stage now where, why bother? Unless he feels low or shaky ... and even at that point he would [rather] just go and grab a swig of apple juice than actually want to know what his number was.” For the other dyad who reported conflict over testing, the parent’s reminders for the adolescent to test, especially when the adolescent first got a driver’s license, became annoying, and the adolescent asked her mother to be less intrusive.

**Late Adolescence**

Two of four dyads reported that there was “sometimes” conflict over food (i.e., food choices, not eating enough, and not adequately keeping track of what was eaten) and BGM. Two adolescents in these dyads resented parental reminders to test because they believed that they were competent to assume this responsibility. One adolescent said:

> If we disagree about it [testing], I’ll just tell them no and that’s kind of the end of it because I do take responsibility for it. And I know that if I’m saying no to that particular time, it’s either because my blood sugar feels fine or I just checked or I’m about to check in like 20 more minutes, to wait and see how the dosage I just gave myself goes.

For one dyad, there was persistent conflict reported over food and testing. When asked if food was a source of conflict, this adolescent said, “A lot. Over when I eat or if I eat. It’s always something. It doesn’t get resolved. It’s a big problem.” This adolescent–parent dyad agreed that testing also remained a big problem.

**Degree of Transfer of Responsibility**

**Preadolescence**

All (n = 4) parents reported taking active steps to transfer responsibility to their children and expressed overall satisfaction with their children’s level of self-management. However, two parents reported specific areas of dissatisfaction with their children’s self-management. One parent wished the child would be more responsible for bolusing for meals. Another parent wished the child would test on his own more, would take care of his “highs” and “lows” more immediately, and would refrain from eating when he was “high.” One parent talked about the importance of developmental readiness in transferring diabetes care to the child:

> I remember, I know years ago, the idea, the thought, was that the earlier you potty-trained the child, the better. And it was kind of a shameful thing if you didn’t potty-train them early enough. With our children, it wasn’t until they turned 3 and they started being interested and we said fine, now it’s time ... and I think the same thing to some extent is true also with diabetes care. That we’ve really, to a large extent, waited until [the child is] ready. We gave hints; we gave opportunities. But it was more as [the child] was ready, then it was an easier transition.

All preadolescents demonstrated a pattern of self-management that we labeled parent-dominant. In parent-dominant self-management, parents did much of the hands-on care (e.g., BGM and giving injections). Parents reminded, checked, and called health care providers. Children might have been doing a limited amount of bolusing on their own, but parents most often closely supervised. For children on pumps, parents played a dominant role in counting carbohydrates. Parents actively taught their children how to do this and how to calculate insulin doses.

**Early Adolescence**

These early adolescents (n = 9) assumed considerable responsibility for their diabetes care. Only one dyad, with the youngest early adolescent, reported that the parent performed most of the child’s diabetes care (i.e., giving injections, telling the child when to test, and controlling the child’s food intake). Another young adolescent and her parent remained at a point where the parent was in charge of insulin dosing (although the child administered the insulin bolus) and carbohydrate counting. Although this parent preferred to oversee the bolusing, she reported that she encouraged her child to figure it out first and then reviewed it with her. A third young adolescent in this group reported that he verified with his mother, when she was present, the amount of boluses. The rest of the adolescents in this group (n = 6) performed most of their routine diabetes care, with varying degrees of parental oversight.
Except for the youngest early adolescent, all early adolescents demonstrated a pattern of self-management that we labeled transitional. In transitional self-management, parents continued to play a role in counting carbohydrates, sporadically or much of the time. Most parents knew when their children were “high” or “low” and were apt to be involved in insulin corrections, especially when their children were “high.” Parents no longer performed routine BGM, but some tested their children in the early morning, during the night, or to give their children a break. For the most part, it was the parents who adjusted basal rates on the insulin pumps, independently or through consultation with health care professionals. Parents called health care providers if necessary. Adolescents performed most, even all, activities of their daily care, but they did so with varying degrees of parental oversight. Oversight, which was reported by all nine dyads in this stage, included one or more of the following: watching what the children ate, checking insulin doses, reminding children to test or bolus, watching the store of supplies, testing during the night, giving advice if children did not know what to do, counting carbohydrates with the children, and checking pump settings. Parents actively promoted transfer of responsibility by educating, involving children in decision making, and explaining the consequences of decisions.

**Mid-adolescence**

Three of five mid-adolescents and their parents reported that the adolescents were “independent” or “in charge” of their diabetes. One adolescent described her situation as follows:

> Well, [my parents] get me my pump supplies and they get me my insulin and basically everything I need to use it. But other than that, I do the rest. [Because] I reset the pump, I change my basal rates, I do boluses, I do pretty much everything.

In the other two dyads, the balance of responsibility for self-management had not entirely shifted to the adolescents, and they remained in a transitional pattern of shared management. In each of these dyads, the adolescents believed that they should be allowed to take on more responsibility. One adolescent said, “I wish they’d let me loose a little.” The other said she could do more because “I’m going to have to do it eventually with college and everything.” These two parents, however, believed that their children had not demonstrated to them that they could be consistently responsible for their diabetes care. The parent of one of these adolescents reported that her child was not testing at school; continued to ask her to count his carbohydrates; had to be reminded to bolus, change his pump site, and take his glucometer along when he left the house; refused to exercise; and ate the “wrong” foods. The parent of the other adolescent said her child ate too much food, still needed to be checked when calculating her insulin dose, and had to be reminded to take her insulin.

Thus, three of five mid-adolescents had progressed to a pattern of self-management that we labeled as adolescent-dominant, whereas two mid-adolescents remained in a transitional pattern of self-management. In adolescent-dominant self-management, adolescents regularly performed all the daily activities of self-management. The majority did not ask their parents for help or advice. Instead, they were likely to call or e-mail health care providers themselves. Parents continued to ask adolescents about their BGM numbers, and to remind, support, and encourage them. Most parents continued to test their adolescents when the adolescents wanted to sleep in or were sick. Most parents continued to make health care provider appointments for their children and to stock supplies, although their children independently managed the rest of their care.

**Late Adolescence**

For all four of these dyads, the responsibility for self-management had shifted to the adolescents. One parent described the shift this way:

> I do very little for her now. She prides herself on having the responsibility for and taking the responsibility for just about, really, everything. And she resents intrusions at this point, which we still make out of habit and concern. Because she wants it to be all her’s. Really, she even goes so far as to order her own supplies for herself and there’s very little that I’m doing with [her diabetes], the family’s doing.

Other parents described their adolescents’ self-management of diabetes as “totally independent,” “autonomous,” and “fully responsible.” For the adolescents, there was realization and acceptance of being in charge. This—along with an awareness of what it might be like for her parents to relinquish control—is reflected in this comment:

> I don’t know what my [parent] told you about how [she] contributes to my diabetes management, but [my parent] doesn’t. And I think they feel bad about that. I think that they kind of feel they’ve, you know, there’s something they had in their power and they controlled
how everything was. It’s a sense of security for them that they’ve lost.

All late adolescents demonstrated the adolescent-dominant pattern of self-management described above.

**DISCUSSION**

We have described the themes of division of labor in the performance of self-management activities, the nature of self-management conflict, and the pattern of self-management in four developmental stages. The three patterns of self-management of type I diabetes in youth, describing the degree of transfer of diabetes management responsibilities, emerged from the data and included parent-dominant, transitional, and adolescent-dominant self-management. A limitation of this study is its small sample size; thus, findings should be seen as exploratory.

Our data revealed that children and adolescents assumed more responsibility for the self-management of their diabetes as they got older, and this is consistent with what has been reported in the literature (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Drotar & Ievers, 1994; LaGreca et al., 1990). As is consistent with developmental theory (Crombrinck-Graham, 1991), available data (Anderson et al., 1990; Drotar & Ievers, 1994; Faulkner, 1996), and recommendations (Golden, 1999), preadolescents and their parents reported direct parental participation in the performance of the activities of self-management. They reported generally low levels of self-management conflict, and all four dyads demonstrated a parent-dominant pattern of self-management.

In the more stressful stage of early adolescence (Hamburg, 1998), youth in our sample took on more direct responsibility for the self-management of diabetes. Ingersoll et al. (1986) reported that approximately 44% of children with diabetes under 15 years self-adjusted their insulin, whereas most of the early adolescents in this study did so. All early adolescents and their parents reported diabetes-related conflicts; a majority of these dyads reported conflicts over food choices and BGM. Recently, Buford (2004), in her qualitative study of the transfer of asthma management responsibility to children, reported that conflicts occurred when children became more independent in their decision making regarding their illnesses. Our data support this finding in youth with type I diabetes. Given the fact that conflict is correlated with poorer performance of diabetes tasks and poorer metabolic control (Anderson, 2004), this is a cause for concern for youth in this developmental stage. All but the youngest adolescent in this group demonstrated a transitional pattern of self-management, wherein youth and their parents shared diabetes management responsibilities.

Our data suggest that there is greater variability in self-management at mid-adolescence than in other developmental stages. By mid-adolescence, some adolescents have moved beyond transitional self-management, but some have not. By late adolescence, all dyads reported an adolescent-dominant pattern of self-management. Although the adolescent was clearly in charge of diabetes care, parents continued to remind their children to perform various activities of self-management and to occasionally “pinch-hit.” This is consistent with existing literature indicating that parents are likely to help out with some diabetes tasks up to mid-adolescence and beyond (Drotar & Ievers, 1994; Ingersoll et al., 1986). Exercise presented as a source of conflict for the majority of mid-adolescents and their parents. Prior to this stage, exercise was identified as a conflict for only one preadolescent and parent, and one early adolescent and parent.

As Buford (2004) pointed out, relatively little is known about how parents and children with chronic illness share illness management responsibilities and how parents ultimately transfer these responsibilities to their children. Our cross-sectional qualitative study was not designed to describe the process of transfer, but our conceptualization of self-management (Schilling et al., 2002a), which served as the theoretical framework for this study, was broadened by the description of three self-management patterns in youth: parent-dominant, transitional, and adolescent-dominant. Although the activities of self-management were described in an earlier article (Schilling et al., 2002a), this study contributes to a broader understanding of the nature of how activities of diabetes self-management are shared between children and parents, and how this changes as children grow older.

Finally, this study found that, as children began to take over more responsibility for their diabetes care in early adolescence, parents reported the practice of “pinch hitting” (doing an activity of self-management for the child when the child
needed a break from the responsibility). Although this study did not attempt to quantify how frequently parents “pinch-hit” for their children, the practice of “pinch hitting” was reported not only in early adolescence but in mid-adolescence and late adolescence as well.

**IMPLICATIONS FOR NURSING PRACTICE**

Health care providers need to assess where families are in the process of self-management so that they can support, educate, and facilitate movement from parent-dominant to adolescent-dominant self-management appropriately. For example, many, if not all, parents of youth with parent-dominant self-management may benefit from health care providers’ recognition and support for the demanding role they play in the diabetes management of their children. In addition, it is possible that, by dividing the self-management process into phases for families, caregivers can help both parents and children understand the nature of their current self-management situation while preparing for the next stage. For example, if families are prepared for possible changes in conflict as the self-management pattern changes, it may be easier for them to accept conflict as normal and to see it as an opportunity to learn new ways to solve conflict—a useful endeavor for any family with adolescents. Although families with youth with type I diabetes in any developmental stage of adolescence may well need supportive care, it is possible that families with early adolescents in the transitional pattern of self-management may require even more support. In addition to a possible increase in self-management conflict during this time, early adolescence is the time of greatest parent–child conflict in general (Laursen, Coy, & Collins, 1998). An educational approach for caregivers that combines knowledge of adolescent development and the phases of self-management may result in specific suggestions for parents. For example, given the fact that the thinking of early adolescents is likely to be concrete and grounded in the present (Hamburg, 1998), it seems prudent that parents, while decreasing their own performance of self-management activities in this stage of adolescence, remain active in their oversight of diabetes management. Additionally, parents of adolescents who have moved into adolescent-dominant self-management may need support as they relinquish knowing everything about their adolescents’ diabetes management.

When health care providers evaluate where families are in the process of self-management it may result in specific suggestions for adolescents. Caregivers who are alert to developmental readiness and the ultimate goal of adolescent-dominant self-management, can suggest specific strategies to the adolescents themselves. For example, when adolescents in transitional self-management show readiness, they can be encouraged to contact providers directly, without going through their parents. Furthermore, as adolescents move to more adolescent-dominant self-management, it is possible that health care providers may play a significant role in supporting and educating adolescents for their more independent performance of diabetes activities.

**IMPLICATIONS FOR RESEARCH**

Many questions concerning the paths youth take toward the self-management of diabetes remain. More work remains to be done with regard to describing the process of self-management, including determination of how families recognize and act on signs that their children are able to assume more self-management responsibilities. Currently, no self-report instrument measuring all attributes of the concept exists (Schilling, Grey, & Knafl, 2002b); once such a measure has been developed, it would be useful to assess self-management in a large number of adolescents, both to document their self-management practices and to see if the developmental parameters for parent-dominant, transitional, and adolescent-dominant self-management hold.

Further investigation of parent–child conflict in the self-management of type I diabetes is also needed. How do the frequency and intensity of self-management conflict change over the stages of adolescence? How might parent–child self-management conflict influence the division of labor in carrying out the activities of self-management and the transfer of responsibilities for diabetes management from parent to child? Leonard, Skay, and Rheinberger (1998) suggested that parent–child conflict “can be a barrier to the successful parental transfer of diabetes management skills and responsibility to the child” (p. 231). If this is so—and it seems plausible that it is—it is important to understand when families are most vulnerable and, ultimately, what interventions may help to decrease conflict.

Further exploration of self-management in mid-adolescence is also necessary. During this stage of
adolescence, why do some dyads remain in a transitional pattern of self-management whereas others have moved on to the adolescent-dominant pattern? Over time, what happens to the dyads that present in a transitional pattern during mid-adolescence? Do they remain stuck in this pattern, or do they reach an adolescent-dominant pattern at a later date?

A variety of study designs and methodological approaches are needed to address these questions. Longitudinal—rather than cross-sectional—qualitative research would be useful in investigating how families recognize and act on signs of readiness in their children to assume more self-management responsibilities. From this approach, it would be possible to begin to investigate parental, family, and adolescent characteristics that promote or impede movement toward adolescent-dominant self-management. Qualitative research would also be helpful in enlarging our understanding of the goals of self-management: What self-management goals emerge for families? Do parents and adolescents share the same goals? What role, if any, do goals play in the movement from parent-dominant to adolescent-dominant self-management?

Much work remains to be done to adequately understand self-management both in youth with type I diabetes and, more broadly, in youth with other chronic illnesses. Qualitative and quantitative researchers alike can find areas of research that, when taken together, can enlarge and focus our understanding of the concept.

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