Parents of adolescents with type 1 diabetes are involved in a challenging transition: the transfer of primary responsibility for diabetes management from themselves to their children. During this transitional period, experts advocate for continuing parental involvement in adolescents’ diabetes management to achieve better metabolic control. However, “miscarried helping” by parents can be detrimental to parent-adolescent relationships and adolescents’ development of competence, ultimately affecting diabetes management. Greater knowledge of the ways in which parents are involved (performing tasks, making decisions, providing support, and communicating) would be beneficial to health care professionals providing guidance to parents of adolescents with diabetes. Thus, the purpose of this preliminary study was to examine parents’ perceptions of specific ways they are involved in the management of their adolescents’ type 1 diabetes.

Literature Review
Research on parental involvement in diabetes management has focused on parents’ performance of diabetes tasks, which decreases during their children’s adolescence. This is congruent with literature documenting that adolescents seek autonomy and their parents decrease their authority. However, research has focused only on performance and has not examined decision making, which, like performance, is considered an important aspect of behavioral autonomy. Additional information is needed regarding parental involvement in adolescents’ diabetes management decision making.

Parental involvement in performance of diabetes management has had a positive impact on diabetes outcomes for young adolescents. Parental involvement has been associated with better diabetes management among 10- to 15-year-olds and better metabolic control among 12- to 16-year-olds. Further, when families experienced an intervention to enhance parental involvement, adolescents (10–15 years of age) achieved better metabolic control. However, there is a paucity of research on parental involvement among older adolescents with diabetes.

Providing support to adolescents is one way that parents can be involved while still promoting their adolescents’ development of diabetes management competence and responsibility. Parental support is important because adolescents report that parents provide more support for diabetes management tasks than do friends. Although parental support is important, the relationship of diabetes-specific parental support and adolescents’ diabetes management and metabolic control is not clear. The conflicting findings may result from a failure to examine developmental changes in support, especially with the peak in parent-adolescent relationship difficulties during middle adolescence.

Communication is another way parents can be involved in their adolescents’ diabetes management. However, families of adolescents with diabetes have been found to talk less overall and to ask fewer questions than comparison families without chronic illness. Lack of communication can lead to problems with communication. In fact, parent-adolescent conflict has been associated with diabetes management difficulties and poor metabolic control, whereas resolution of family conflict has been associated with better metabolic control. These findings are congruent with research literature on adolescents in which positive parent-adolescent communication has been linked with positive outcomes and negative communication with negative outcomes.

To summarize, then, examination of specific parental involvement variables (performance, decision making, communication, and support) would provide valuable information to health care professionals providing guidance to parents of adolescents with type 1 diabetes. More information is needed about possible changes in parental involvement from the early to middle to late adolescent periods. Both communication amount and agreement need to be assessed because families of adolescents communicate less, and conflict affects diabetes management and metabolic control. Finally, it would be beneficial to know if these parental involvement variables are related to one another as well as to metabolic control. The literature on adolescents supports a relationship between parent-adolescent communication and adolescents’ decision making and independence.

Research Questions
The specific research questions for our study were:

1. What is the difference in parental involvement in diabetes management (performance, decision making, communication, and support) as reported by parents of early-, middle-, and late-stage adolescents with type 1 diabetes?
2. What is the relationship among various aspects of parental involve-
A1C of 8.7% (SD = 1.5) and a mean hemoglobin level of 6.4% (SD = 1.2). The adolescents had a mean age of 14.76 years (SD = 1.9). Participating parents had a mean age of 40.3 years (SD = 5.0), 77% were mothers, 90% were Caucasian, and 71% had education beyond the high school level. The adolescents of these parents had a mean hemoglobin A1C of 8.7% (SD = 1.5) and a mean age of 14.76 years (SD = 1.9).

**Measures**

*Parental Involvement in Performance of Diabetes Management Checklist.* This checklist was adapted from the Diabetes Family Responsibility Questionnaire, with additional items included to be more inclusive of diabetes management activities. The checklist included 34 items related to daily diabetes management (e.g., glucose monitoring, insulin administration, food choices, exercise, and dental hygiene) and nondaily diabetes management (e.g., obtaining monitoring supplies, making and keeping appointments, discussing health concerns with health care providers, paying for health expenses, watching weight, performing foot care, and discussing diabetes with adults and friends).

A physician researcher who works with diabetic adolescents reviewed the checklist items for thoroughness and appropriateness. Answers were coded as either “parent involved” (either parent handled the item or adolescent and parent both handled the item) or “not involved” (either adolescent handled the item or no one handled the item). Items were summed for total diabetes management performance scores, with higher scores indicating higher levels of involvement. The Kuder Richardson alpha was 0.81, which indicates that the checklist has good reliability.

*Parental Involvement in Decision Making for Diabetes Management Checklist.* This checklist included the same 34 items mentioned above, and, again, answers were coded as “parent involved” or “not involved,” and all responses were summed for a total score. Parents were asked who made the decisions rather than who performed the tasks. The Kuder-Richardson alpha reliability was 0.87.

*Communication Amount for and Agreement About Diabetes Management Checklists.* Two checklists (amount and agreement) were devised, using the same 34 items discussed above. First, parents were asked if they talked with their adolescent about each of the diabetes management tasks and were instructed to indicate “yes” or “no.” Then, parents were asked if they and their adolescents agreed about each task and were instructed to indicate “yes” or “no.” The positive responses were summed to obtain both amount of and agreement about communication scores. The Kuder-Richardson reliability was 0.84 for the Amount Checklist and 0.96 for the Agreement Checklist.

*Parental Support for Diabetes Management Checklist.* This checklist was devised, using the same 34 items mentioned above. Participants were asked if they tried to help their adolescents for each of the diabetes management tasks and were instructed to indicate “yes” or “no.” Again, the positive responses were summed to obtain a parental support score. The Kuder-Richardson alpha reliability was 0.89.

**Procedure**

Permission to carry out the study was obtained from the various institutional review boards and clinics involved. Parents were approached about their interest in participating when their adolescents had appointments for diabetes management. In some cases, data collectors explained the study and obtained informed consent forms, and then participants completed self-administered checklists while waiting for clinic appointments. In other cases, potential participants indicated their willingness to clinic staff to have data collectors contact them by telephone. Data collectors then explained the study, collected audiotaped informed consents, and administered the checklists to these participants by telephone.

**Results**

Descriptive statistics were computed for parental involvement in diabetes management (performance, decision making, communication, and support). Because the sample size was small, missing data values were imputed (determined by calculating averages for individual responses for other checklist items and substituting these averages for occasional missed items).

The means, standard deviations, and ranges for parental involvement in performance, decision making, communication, and support are delineated in Table 1. The means were greater than the midpoints of potential ranges for performance, decision making, communication, and support, indicating that there was a relatively

**Table 1. Means, Standard Deviations, and Ranges for Parental Involvement in Performance of, Decision Making for, Communication About, and Support of Diabetes Management**

<table>
<thead>
<tr>
<th>Category</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>Potential Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication Amount</td>
<td>22.8</td>
<td>10.0</td>
<td>1–34</td>
<td>0–34</td>
</tr>
<tr>
<td>Communication Agreement</td>
<td>29.5</td>
<td>7.5</td>
<td>8–34</td>
<td>0–34</td>
</tr>
<tr>
<td>Support</td>
<td>23.0</td>
<td>6.5</td>
<td>12–34</td>
<td>0–34</td>
</tr>
<tr>
<td>Performance</td>
<td>20.6</td>
<td>4.9</td>
<td>9–30</td>
<td>0–34</td>
</tr>
<tr>
<td>Decision Making</td>
<td>25.6</td>
<td>5.5</td>
<td>15–34</td>
<td>0–34</td>
</tr>
</tbody>
</table>
high degree of parental involvement in performance, decision making, communication, and support for diabetes management.

The mean for communication agreement (29.5) was considerably higher than the mean for communication amount (22.8); thus, differences between agreement and amount were further examined. Because there was great variability in communication amount and agreement as indicated by the standard deviations, the nonparametric Wilcoxon’s signed-rank test was performed to determine the difference in communication amount and agreement. There was a significant difference between diabetes management communication amount and communication agreement (Wilcoxon’s signed-rank = 2.872, P = 0.004).

**Answers to Research Questions**

*What is the difference in parent involvement in diabetes management as reported by parents of early-, middle-, and late-stage adolescents with type 1 diabetes?* The means and standard deviations for parent involvement in diabetes management by stage of adolescence are delineated in Table 2. The means for parental involvement in performance of diabetes management decreased from early to middle to late adolescence. Means for parental involvement in communication, support, and decision making for diabetes management decreased from early to middle adolescence and then increased from middle to late adolescence.

Because there was great variability in standard deviations for parental involvement at the various stages of adolescence, a nonparametric Kruskal Wallis test was performed to determine if there were significant differences in parental involvement for different stages of adolescence. There were no significant differences in parental involvement in diabetes management during the different stages of adolescence (see Table 2).

*What is the relationship among various aspects of parental involvement in diabetes management and metabolic control as reported by parents of adolescents with type 1 diabetes?* Pearson correlations were performed to examine the relationships among these variables. Parental provision of support was significantly correlated with parental involvement in performance (R = 0.71, P = 0.000) and decision making for (R = 0.50, P = 0.004) diabetes management. Parental involvement in performance of diabetes management was significantly correlated with parental involvement in decision making for diabetes management (R = 0.65, P = 0.000) and was nearly significantly correlated with communication agreement for diabetes management (R = 0.35, P = 0.057).

There were no significant relationships between metabolic control and any of these aspects of parental involvement.

**Discussion and Clinical Implications**

Health care professionals can use parental performance, decision making, communication, and support as a guide to assess parental involvement in adolescents’ diabetes management. Because parental involvement in diabetes management is advocated,1 parents are to be commended when highly involved in performing, making decisions, communicating, and providing support related to adolescents’ diabetes management, as parents were in this study.

In assessing parental involvement, health care professionals must be cognizant of adolescent development. There was a decrease in parental involvement in decision making, support, and communication at middle adolescence, which is when disequilibrium in parent-adolescent relationships peaks.10 Although there were changes, the differences in parental involvement for the stages of adolescence were not statistically significant. This may be related to the study’s small sample size. Further study involving larger samples is needed.

Parental involvement in performance of diabetes management did not decrease in middle adolescence, as parental involvement in decision making, communication, and support did. Parental concerns for maintenance of metabolic control may override adolescents’ assertion of autonomy. Parents have concerns about adolescents’ failure to be responsible for diabetes management and its consequences.20 Further, parents may be more vigilant of metabolic control as with pubertal hormonal changes, there is greater insulin resistance.21

Health care professionals should explore parent-adolescent communication about diabetes management. Interestingly, parents reported greater communication agreement than communication amount. This could reflect true agreement, with parents and adolescents having reached the point at which the division of responsibilities for diabetes management is clear and handled as a matter of course. However, it could indicate that parents are assuming that they and their adolescents agree but are not recognizing their adolescent’s assertion of autonomy in becoming responsible for diabetes management.

Parental involvement in terms of performance as well as decision making, support, and communication may provide ways that parents can be involved yet facilitate adolescents’ development of competence in diabetes management responsibility. Parental control of diabetes management is counter to older adolescents’ development of competence for diabetes management. Controlling family

<table>
<thead>
<tr>
<th>Table 2. Differences in Parental Involvement (Performance, Decision Making, Communication, and Support) for Early, Middle, and Late Adolescence</th>
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<tbody>
<tr>
<td><strong>Communication Amount</strong></td>
</tr>
<tr>
<td>Communication Agreement</td>
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<tr>
<td>Support</td>
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<tr>
<td>Performance</td>
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<tr>
<td>Decision Making</td>
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<tr>
<td><strong>Communication Agreement</strong></td>
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</table>
members of adolescents with diabetes inhibit development of adolescents’ independence,22 which will be necessary by the time these adolescents leave their parents’ home to live on their own.

Further research is needed on the relationship of parental involvement with adolescents’ development of responsibility for diabetes management. Perhaps parental involvement in performance, decision making, support, and communication influence adolescents’ development of competence or responsibility for diabetes management, which then influences metabolic control. This could explain why parental involvement in performing, making decisions, communicating, and providing support for diabetes management was not related to metabolic control in this study. This result conflicts with other studies, in which high levels of parental performance of diabetes management were related to better metabolic control among young adolescents with type 1 diabetes.3,7

References


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