

Mother-Daughter Interaction and Adherence to Diabetes Regimens

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This study explores the relationship of mother-daughter interaction to adherence to treatment plans among diabetic adolescents. Fifty mother-daughter dyads discussed conflict issues and feelings, problems, and concerns related to diabetes. Discussions were analyzed using the Hill Interaction Matrix and modified Beavers-Timberlawn Family Evaluation Scales. Interview questionnaires provided information on adherence, feelings, problems and concerns, parental supervision, adjustment, and family life. The less adherent the adolescent, the more emotionally charged the interaction, the more directly confrontive mother and daughter were, and the less efficient they were at negotiating issues. The adolescent's statements about herself confirmed observations that poor adherers, more than good adherers, had difficulty discussing feelings, problems, and concerns with their mothers ($r = -0.51$, $P \leq 0.001$). Poor adherers reported believing less strongly that adherence would delay/avoid complications ($r = 0.51$, $P \leq 0.001$), became more anxious about seeing a disabled diabetic person ($r = -0.29$, $P \leq 0.29$), and worried more about future health ($r = -0.27$, $P = \text{NS}$). No relationships were found between adherence and adolescent-physician rapport. Many adolescents were not engaging in good self-care behaviors, were quite concerned about future health, perceived mothers to be very concerned, hesitated telling peers about their illness, and did not share deeper illness-related concerns with their closest nondiabetic friends. *DIABETES CARE* 1985; 8:146-51.

Research on adherence to medical regimens among adolescents is sparse.¹ Daily regimens for insulin-dependent diabetic individuals are complex and demanding. The nature of insulin-dependent diabetes and its treatment requires that a great deal of responsibility for health maintenance and monitoring be assumed by diabetic adolescents and their families.² Since diabetes impinges on many aspects of daily living, the relationship between parents and diabetic adolescents is potentially quite complex and vulnerable to conflict and the development of maladaptive interaction patterns.³ The mother-child relationship may well be the most strained, as it is typically the mother who is most closely involved with practical management considerations, and in monitoring the adolescent's activities.²

There is some evidence that family interaction, conflict, and parental monitoring and response to the youngster's handling of the diabetes regimen influence adherence behaviors.⁴⁻⁸ The manner in which discussions of diabetes-related problems and concerns are handled within the family also

appears to have implications for adherence and adjustment. Observation and interview data suggest much noncommunication and underlying tension around illness-related issues in families of chronically ill youngsters.⁹

RESEARCH QUESTIONS

The primary research questions posed were: (1) Is there a relationship between mother-daughter interaction around conflict issues and the adolescent's adherence to her medical treatment plan? (2) Is there a relationship between mother-daughter interaction in discussions of feelings, problems, and concerns about diabetes and the adolescent's adherence to her treatment plan?

There was also interest in gaining information concerning the relationship of adherence to: (1) the adolescent's feelings, problems, and concerns about diabetes, (2) perceptions of the physician(s) primarily involved in her diabetes care, (3) parental supervision and involvement with the regimen, and (4) overall adjustment and family life.

DELIMITATIONS AND CONSIDERATIONS REGARDING THE RESEARCH DESIGN

The researchers were aware of some of the limitations of the design at the outset, and became aware of others in the course of the research. A major premise was that information gained in this exploratory study would provide direction for future research, wherein modifications would be made.

One limitation was that the study focused on mothers and daughters, rather than on the whole family unit. A second issue concerned the assessment of adherence. Only limited research has been done on adherence to complex regimens, and each adherence measure has its sources of error.¹⁰ Third, diabetes in some youngsters is easier to control than in others⁴ and lapses in adherence may, therefore, be less of a problem with some adolescents. Physiologic differences were not controlled for in the present study. Fourth, the study was cross-sectional rather than longitudinal. Longitudinal studies are necessary for ultimately drawing conclusions about the relationship of family interaction to adherence, as well as for understanding changes in adherence over time.

RESEARCH DESIGN AND METHODOLOGY

Participants and setting. Participants were 50 type I diabetic adolescent girls between the ages of 12 and 17 yr and their mothers. Age at diagnosis ranged from <1 yr to 14 yr old; length of time since diagnosis was 1–15 yr. Although the girls varied with respect to cognitive abilities, none were in classes for the retarded, emotionally disturbed, or health impaired. No youngster on an insulin infusion pump was included.

In 70% of the families the natural father of the focal adolescent was living in the home; in five families there was a stepfather or mother's boyfriend present. The study group consisted of 17 white Protestant families, 15 white Catholic families, 8 white Jewish families, 3 Hispanic Catholic families, and 7 black families of various religious backgrounds. Family incomes ranged from \$7000 (plus public assistance) to over \$60,000, with the median income being \$24,500.

Lists of potential participants were obtained from pediatric endocrinologists affiliated with New York-area teaching hospitals (The Brookdale Hospital Medical Center, Long Island Jewish-Hillside Medical Center, and North Shore University Hospital). Over 75% of the mother-daughter pairs that were approached agreed to participate. Interviews were conducted within the home.

Procedure. Participants were told that the information they gave was strictly confidential unless clinical evidence suggested that the adolescent's life was in danger. Separate interviews were conducted with mothers and adolescents using structured and semistructured questionnaires. Data were gathered on medical adherence behaviors, parental involvement with the regimen, health beliefs and concerns about diabetes, perceptions of physicians, and adjustment and family life.

An interview was conducted with the adolescent to identify conflict issues between adolescent and mother.¹¹ The general areas of questioning included responsibility, autonomy, social life, school achievement, and response to frustration. The

three most salient issues were selected for discussion. Mothers and daughters were then brought together to discuss these issues for 5 min each, with the aim of presenting their respective points of view and moving toward a mutually satisfactory solution. Discussions were timed and tape recorded. The interviewer left the room during these discussions; her return after 5 min signaled the end of a particular discussion. After the third discussion, mother and daughter were instructed to spend the next 5 min discussing their feelings, problems, and concerns about diabetes together.

Assessment of adherence. The assessment of adherence to complex medical treatment plans is in an early stage of development.¹⁰ In assessing adherence to diabetes regimens, it is necessary to assess multiple behaviors.^{12,13} Patient interviews continue to be the most common method used to assess adherence.¹ In this study, information about the adolescent's health care behaviors was obtained in separate interviews with mothers and adolescents, employing Likert-type questionnaires.¹⁴ The physician most closely involved with the adolescent's diabetes care completed a similar questionnaire. The questionnaires focused on the adolescent's behaviors with regard to: (1) eating well-balanced meals, (2) limiting sweets, (3) adhering to recommendations regarding starches, (4) eating the appropriate number of calories on a consistent basis, (5) skipping meals, (6) eating on a regular schedule, (7) injecting insulin and scheduling, (8) testing blood and urine, (9) recording blood and urine test results, (10) exercising, and (11) carrying sweets in case of a reaction.

Recordings were made of what mothers and daughters reported. The interview procedure permitted the asking of questions to clarify unclear or contradictory statements. The information obtained was independently rated by the interviewer and a nurse with extensive experience with diabetic adolescents. Interrater reliabilities across these 11 behaviors ranged from 0.84 to 0.97, with a mean correlation of 0.92. Correlations of adolescents' and mothers' responses ranged from 0.67 to 0.88, with a mean correlation of 0.79. Ratings based on mothers' and adolescents' reports across the 11 areas were combined, yielding a linear composite score, the "overall adherence rating." This composite score was used as the adherence variable. Mothers' reports about their daughters' adherence were more favorable than were the daughters' reports about themselves (Student's $t = 7.0$, $P \leq 0.001$). The physicians' ratings correlated 0.70 with the overall adherence rating.

Interaction scoring systems. The Hill Interaction Matrix (HIM)¹⁵ and a modified version of the Beavers-Timberlawn Family Evaluation Scales¹⁶ were used to assess mother-daughter interaction. Both were used to rate discussions of conflict issues; the HIM was used to rate discussions of feelings, problems, and concerns about diabetes. The HIM is a statement-by-statement rating method, whereas the Beavers-Timberlawn yields more global ratings.

On the HIM, statements are classified along two basic dimensions, Content Style and Work Style (Figure 1).

In the present study, focus was on the Work Style dimension. The Work Style dimension is comprised of four types

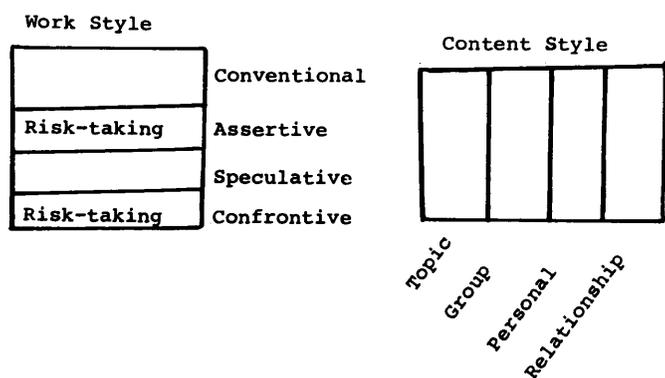


FIG. 1. Hill Interaction Matrix: Work and Content Styles.

or "styles" of behavior: Conventional (everyday social conversation), Assertive (counterdependent or negativistic statements that assert independence or deny the possibility of the problem being worked out between mother and daughter), Speculative (asking questions with the apparent aim of gaining understanding, and offering tentative solutions), and Confrontive (honest feelings and intellectual reactions of one person to another, attending to discrepancies and distortions documented with quotations from the topic person herself). Assertive and Confrontive Styles are regarded as Risk-taking Styles because the person is expressing thoughts and feelings in a rather direct way rather than dealing with an issue in a controlled or tentative manner.

The Beavers-Timberlawn Family Evaluation Scales consist of 13 nine-point Likert-type scales. Nine of these were selected and modified for use in the present study. Mother and daughter were rated separately on empathy (sensitivity to, and understanding of, the other's feelings), expressiveness (the extent to which there is open expression of thoughts and feelings), clarity (clearness of expression of thoughts and feelings), permeability (openness and receptivity to what the other person is saying), and responsibility (the degree to which the person takes responsibility for her actions). Mother and daughter were rated as a unit on closeness (the extent to which they seemed close while maintaining distinct boundaries), goal-directed negotiation (efficiency in negotiation and problem solving), mood and tone (degree of positive mood and feeling tone), and conflict (the degree of seemingly unresolvable conflict).

RESULTS AND DISCUSSION

While the sample size in this study is large compared with the number of families or parent-child dyads in most observational studies of interaction, it is relatively small, statistically speaking. The supplementary questionnaires on feelings, problems, and concerns about diabetes, perceptions of physicians, and family life and adolescent adjustment need to be refined and normed; at present they do not have status as psychometric instruments. Therefore, results must be inter-

preted with caution. As age showed a relationship to adherence ($r = -0.36$, $P \leq 0.01$), the analyses are partial correlations, controlling age.

Mother-Daughter Interaction Findings

Findings were in the direction of poor adherers and their mothers judging their disagreements as being bigger or more salient issues. These relationships, however, were weak and not statistically significant ($r = -0.22$, $P = \text{NS}$; $r = -0.19$, $P = \text{NS}$, respectively).

In discussions of conflict issues, poorly adherent adolescents and their mothers were distinguished on the HIM by being higher on Risk-taking ($r = -0.36$, $P \leq 0.05$; $r = -0.41$, $P \leq 0.005$, respectively). Mothers of poor adherers were higher on the Confrontive component of Risk ($r = -0.41$, $P \leq 0.005$). Poorly adherent girls were higher on the Assertive component, but this difference was not statistically significant ($r = -0.26$, $P = \text{NS}$). In contrast, good adherers and their mothers were higher on the Speculative style ($r = +0.29$, $P \leq 0.05$; $r = +0.31$, $P \leq 0.05$, respectively).

Similar patterns were found in discussions of feelings, problems, and concerns about diabetes. Poor adherers were high on Risk-taking and both of its components, the Assertive and Confrontive styles ($r = -0.45$, $P \leq 0.005$; $r = -0.31$, $P \leq 0.05$; $r = -0.32$, $P \leq 0.05$, respectively). Good adherers were higher on the Speculative style ($r = +0.38$, $P \leq 0.01$). Mothers of poor adherers were higher on Confrontive style and Risk, while mothers of good adherers were higher on Speculative style ($r = -0.50$, $P \leq 0.001$; $r = -0.49$, $P \leq 0.001$; $r = +0.39$, $P \leq 0.01$, respectively).

Thus, a pervasive style of mother-daughter interaction was identified (not specific to the manner in which diabetes-related issues were handled) that was associated with adherence problems. On the HIM it was found that poorly adherent girls more often made counterdependent or negativistic statements that asserted their independence and denied the possibility of the issue being worked out between their mothers and themselves. They more frequently made statements concerning their uniqueness or the uniqueness of their difficulties, and put on a facade of ignoring their mothers, or responded to them with arguments, heckling, or needling. Mothers of poor adherers, in turn, challenged their daughters with examples of misbehaviors and pointed out discrepancies in their daughters' accounts of their problems. While the intention of these mothers may well have been to bring about a behavior change, their approach typically resulted in an escalation of the conflict or by the adolescent withdrawing. Thus, the manner in which discussions were handled was not conducive to opening up about deeper concerns, or for formulating realistic plans to modify behaviors. In contrast, good adherers and their mothers were more likely to ask questions with the apparent goal of gaining understanding and proposing tentative solutions to problems.

When discussions of disagreements were evaluated using the modified Beavers-Timberlawn Family Evaluation Scales,

good adherers and their mothers were judged to be lower on seemingly unresolvable conflict, more efficient in negotiation and problem solving, more positive in mood, and more optimally close (r 's ranged from $+0.34$ [$P \leq 0.05$] to $+0.37$ [$P \leq 0.01$]). They were also rated as more empathic and open to what the other was saying (r 's ranged from $+0.35$ [$P \leq 0.05$] to $+0.42$ [$P \leq 0.005$]). Good adherers were thought to communicate with greater expressiveness and clarity ($r = +0.36$, $P \leq 0.05$; $r = +0.35$, $P \leq 0.05$, respectively).

Questionnaire Data

Health care behaviors. Despite instructions to do blood and/or urine testing three times a day at a minimum, only slightly over 40% were testing two or more times a day. Less than 25% were recording results this often. Although instructed to always carry sweets in case of an insulin reaction, over 40% reported not carrying sweets with them more than 25% of the time. More than 40% were judged to be quite sedentary as they got no more than $1\frac{1}{2}$ h of exercise a week (other than what they had to do at school in gym class).

If these findings are at all representative of what adolescent girls with diabetes do, it raises serious questions about the adequacy of their self-care.

Adherence, demographic variables, and parental supervision/involvement. Neither age of onset, nor duration, nor birth order, nor the number of children in the family was related to adherence (r 's ranged from $+0.01$ to $+0.18$). While income was in the direction of being positively related to adherence, the relationship was not statistically significant ($r = +0.24$, $P = \text{NS}$). The educational levels of both mother and father, however, were related to the girl's adherence ($r = +0.29$, $P \leq 0.05$; $r = +0.36$, $P \leq 0.01$, respectively). It may be that the type of supervision provided in better educated families or better understanding of the disease and the treatment plan could partially account for this latter finding.

Younger girls were more adherent than older girls. The mothers' involvement with concrete tasks and in supervising the regimen appeared to be an important factor contributing to this finding. Mothers of younger girls were perceived as providing more assistance with injections and blood and urine testing, and more actively supervising the diet and other aspects of the treatment plan (r 's ranged from -0.31 [$P \leq 0.05$] to $+0.52$ [$P \leq 0.001$]). Discussions indicated that adherence became more of a problem as the girls grew older, as they had less structured school schedules and spent more time away from home. Changes toward better adherence were noted, however, among some 16- and 17-yr-olds. The psychosocial data suggested that while the girls' maturing and working out relationship problems contributed to improved adherence, the mothers of these girls placed considerable and appropriate emphasis on good overall health care behaviors.

The forms of social support provided by families included: (1) limiting the amount of concentrated sweets kept in the house, (2) having siblings bring home something the diabetic child could have when they got snacks for themselves, (3) attempting to get all family members to have a healthy diet

and preparing well-balanced meals, (4) providing gentle "reminders" not to take another handful of potato chips, and (5) praising good adherence. Social supports may be an important factor influencing adherence. Future investigations need to explore social supports in a more thorough and systematic manner.

Adherence, health beliefs, and feelings, problems, and concerns. Poor more than good adherers reported believing less strongly that adherence would result in delaying or avoiding diabetes-related complications (e.g., blindness, neuropathy, kidney disease) ($r = +0.51$, $P \leq 0.001$). They reported, however, that they became more anxious about seeing an older disabled diabetic person than did good adherers ($r = -0.29$, $P \leq 0.05$). There was also a nonsignificant trend in the direction of poor adherers worrying more about their future health ($r = -0.27$, $P = \text{NS}$). Poor adherers also reported having considerably more difficulty talking with their mothers about their feelings, problems, and concerns about diabetes than did good adherers ($r = -0.51$, $P \leq 0.001$). The latter finding is in accord with observations of mothers and daughters interacting with each other around diabetes-related issues in the present study.

The finding that poor adherers report believing less strongly that adherence will delay or avoid complications may suggest that these girls do not adhere because they do not believe adherence will make a difference. There is a considerable body of research, however, which suggests that attitudes follow behaviors rather than cause them.¹⁰ It may be that poor adherers rationalize their lack of adherence because they have difficulty complying. Interestingly, good adherers were more anxious than poor adherers when performing urine tests or getting these results ($r = +0.31$, $P \leq 0.05$). More adherent adolescents may be better able to channel their anxiety into good health care behaviors. The interactions observed between good adherers and their mothers, along with social supports for adherence, would help make this possible.

Adherence and thoughts and feelings about physicians. Most adolescents rated their physicians as honest, caring, careful, reliable, and friendly. There was an insufficient range of scores on some of these semantic differential-type items¹⁴ to expect a relationship with adherence. There were, however, adequate ranges on other physician questions and no relationships to adherence were found. There was no relationship between adherence and how much the adolescent liked the doctor, how free she felt talking with her doctor, whether her doctor gave her enough time, or whether she thought her doctor encouraged questions (r 's ranged from -0.11 to -0.01).

It may be that other questions or in-depth interviews may have revealed relationships of health care provider variables to adherence. It is possible, however, that since a visit to a pediatric endocrinologist typically occurs once in a few months, the influence of the physician is overridden by daily pressures toward nonadherence and interactions with family and peers.

General findings regarding feelings, problems, and concerns. Many of the girls expressed considerable concern about their present and future health. Approximately 50% were

moderately to very nervous about their urine test results and about going to the doctor for checkups. Almost 75% worried from a moderate extent to a great deal about their future health, and over 80% became moderately to very anxious about seeing an older disabled person with diabetes. Almost 90% believed that their mothers were quite worried about both their present and future health. Forty percent said they believed their lives would be a lot better if they weren't diabetic.

Although 90% said their friends did not treat them differently because they were diabetic, almost 50% said they would wait from a moderately long time to as long as possible before telling a girl they wanted to be friends with that they were diabetic. About 40% said they would wait a moderate to a very long time before telling a boy they liked as a boyfriend that they were diabetic. Only 15% viewed their mothers as going out of their way to encourage friendships with other diabetic adolescents.

The findings that a substantial proportion of these girls were quite concerned about their health, experienced their mothers as very concerned, and thought their lives would be a lot better if they weren't diabetic, suggest that diabetes has a pervasive and continuing psychosocial impact.

While a task group of the National Conference on Behavioral and Psychosocial Issues in Diabetes (1979)¹⁷ concluded that a friend with diabetes is one of the most effective sources of support, very few of these girls presently had even moderately intimate contact with another diabetic adolescent. The interviews also revealed that most were uncomfortable discussing their deeper feelings and concerns even with their close nondiabetic friends.

Implications and Recommendations

Identification of maladaptive mother-daughter interactions appears necessary when trying to understand and promote adherence among diabetic adolescents. It has been suggested that chronically ill youngsters and their families be assessed for adjustment and adaptive capacities early in the course of the illness, with periodic reassessments thereafter. Evidence for deteriorating or maladaptive family relationships needs to be followed by rapid interventions.¹⁸

Integrated, ongoing programs of education, monitoring, and support for young people and their families living with diabetes are needed. Those working with diabetic adolescents and their families would do well to trouble-shoot for adjustment and interactional problems, as well as deal specifically with adherence and diabetes-related problems and concerns. Health care providers may need to take a more active role in promoting self-help groups and support networks for diabetic adolescents and their families.

Further research needs to focus on refining the assessment of adherence, evaluating and controlling for metabolic factors when studying adherence, and assessing diabetic adolescents and their families over time with respect to adherence. The paradigm used in the present study should be expanded to include fathers and other family members. The development of a questionnaire like the feelings, problems, and concerns

questionnaire used in this study could be valuable as a screening device for health care professionals involved with diabetic adolescents and their families.

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