Personal Models of Diabetes in Relation to Self-Care, Well-Being, and Glycemic Control

A prospective study in adolescence

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OBJECTIVE — Personal models of diabetes have been shown to be proximal determinants of self-care behavior in adults with diabetes, both cross-sectionally and prospectively. This study set out to test the predictive utility of this approach in adolescents with diabetes.

RESEARCH DESIGN AND METHODS — Participants were recruited from four regional hospitals in southern England (n = 54). They completed questionnaires assessing diabetes self-care, well-being, and personal models of diabetes (perceived impact, perceived seriousness, and short- and long-term treatment effectiveness) at baseline and 1-year follow-up. GHb assays performed as part of the patients’ usual diabetes care were used to assess glycemic control.

RESULTS — After controlling for baseline anxiety, change in perceived impact of diabetes prospectively predicted adolescents’ anxiety (β = 0.21; t = 2.65; P < 0.01). After controlling for baseline dietary self-care, change in perceived effectiveness of the diabetes treatment regimen to control diabetes predicted dietary self-care (β = 0.39; t = 3.28; P < 0.0005). Poorer dietary self-care and being female were predictive of poorer glycemic control (r² = 0.29; F = 2.74; P < 0.005).

CONCLUSIONS — This study provides further support for the role of personal models of illness in determining responses to illness. As adolescents take responsibility for the management of their diabetes, parents, clinicians, educators, and interventionists should consider these adolescents’ beliefs about their diabetes and its treatment as key factors influencing self-care, emotional well-being, and glycemic control.


Since publication of the Diabetes Control and Complications Trial (DCCT) results (1), it has been widely accepted that improving metabolic control must be a fundamental priority in type 1 diabetes care. However, the question remains as to whether the success of the DCCT in improving patients’ metabolic control was attributable primarily to the intensive insulin management, the intensive psychosocial support provided by the DCCT care teams, or a combination of both strategies. There is as yet no research to provide definitive answers to this question. However, the ability of one diabetes care team to achieve a mean HbA1c of 6.6 ± 1.2% in an unselected sample of 144 children and adolescents using primarily two injections a day (2) suggests that intensive insulin regimens are not the only key to improving control in diabetic adolescents. Furthermore, when intensive insulin regimens are used, the concurrent problems of increased episodes of hypoglycemia and weight gain exist.

Within this context, psychosocial research that attempts to predict and improve diabetes self-care is becoming increasingly important. Psychosocial research on adolescents with diabetes has tended to focus predominantly on the effects of family on diabetes outcome (3–5). However, there has been little consideration of the mechanisms by which the family environment influences self-care, well-being, and metabolic control (3–6). One model that has been put forward is that the family environment may influence the development of illness beliefs (7,8). Therefore, this study set out to test the utility of illness beliefs, conceptualized as personal models of diabetes, in predicting self-care, well-being, and subsequent glycemic control in diabetic adolescents (9,10).

An individual’s personal model of diabetes is hypothesized to be a proximal determinant of both the emotional and behavioral response to the illness. Personal models are an extension of schema theory from cognitive social psychology (11, 12). Thus, unlike other social cognition models, personal models are grounded in a general theory of cognition that accounts for the merging of incoming information with past experience. Like other cognitive schema, personal model beliefs will change in response to experience, especially during adolescence, when young people are learning to take responsibility for their own diabetes management; they differ in that personal models are patient-rather than researcher-generated. Personal models research is concerned with identifying those variables that patients themselves believe to be central to their experience of an illness and its management. Personal models include the representation of emotional response to disease and treatment, a variable that is lacking in
many other health belief models, by assessing the emotional consequences of diabetes (e.g., worry, fear, and ruminating).

There are five components to the personal model or representation of an illness: identity, cause, consequences, timeline, and control/cure (13,14). In diabetic adults, control/cure beliefs are conceptualized as beliefs about the effectiveness of treatment and have been found to be prospectively predictive of dietary and exercise self-management (10,15). In a sample of over 2,000 participants, beliefs about treatment effectiveness proved to be a better predictor of self-management than perceived barriers to adherence (16). Cross-sectional studies of adolescents have also supported an association between treatment effectiveness beliefs and self-care behavior (17,18). Moreover, treatment effectiveness beliefs in diabetes care can be split into two dimensions: the effectiveness of the regimen to control diabetes on a day-to-day basis and to prevent the long-term complications of diabetes. In adolescents, perceived effectiveness of treatment to control diabetes in the short term, but not perceived effectiveness of treatment to prevent long-term complications, has been associated with dietary self-care (7,19).

The perceived consequences dimension of the personal model is similar to two constructs in the health belief model: perceived severity of diabetes and perceived susceptibility to complications of diabetes (20). Perceived consequences beliefs are also similar to the perceived impact of diabetes. Research on these comparable beliefs has failed to generate consistent correlations to either self-care or glycemic control (18–25). However, perceived consequences of diabetes may be more important in determining an individual’s emotional response to diabetes. In adults, the perceived threat of diabetes, a combination of perceived severity and perceived susceptibility to complications, was predictive of depression (26,27). In adolescents, perceived impact and perceived severity of diabetes were both associated with emotional well-being, with greater impact and severity predicting poorer well-being (7,19,21,22).

If personal models are proximal determinants of individuals’ behavioral and emotional responses to illness, then they may serve to mediate the association between demographic variables and outcome measures. Although studies have demonstrated that personal model beliefs are associated with demographics and that demographics are associated with self-care, they have not tested whether personal model beliefs mediate the association between demographics and self-care (10,16). Using the health belief model, the perceived threat of diabetes was found to partially mediate the association between demographics and depression (26). Similar results have been reported in a cross-sectional study of adolescents, with perceived impact of diabetes mediating the association between gender and emotional well-being and between socioeconomic status and dietary self-care (19). These studies suggest that personal models may partially mediate the associations among demographics, well-being, and self-care, an issue that clearly warrants further examination.

Reviewers have been critical of the continued use of cross-sectional studies (4,5). This study reports the 1-year follow-up data from a prospective study that was designed to examine whether personal models of diabetes have any utility in predicting self-care, well-being, and glycemic control during adolescence.

RESEARCH DESIGN AND METHODS

Table 1—Table summarizing demographics of sample completing follow-up

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Girls</th>
<th>Boys</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>25 (46)</td>
<td>29 (54)</td>
</tr>
<tr>
<td>Age (at recruitment)</td>
<td>14.4 ± 1.8</td>
<td>14.6 ± 1.9</td>
</tr>
<tr>
<td>Duration of diabetes (at recruitment)</td>
<td>5.0 ± 4.5</td>
<td>4.8 ± 3.0</td>
</tr>
<tr>
<td>Insulin regimen (two injections)</td>
<td>23 (92)</td>
<td>25 (86)</td>
</tr>
<tr>
<td>Parental occupation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td>5 (20)</td>
<td>8 (28)</td>
</tr>
<tr>
<td>Intermediate</td>
<td>10 (40)</td>
<td>10 (34)</td>
</tr>
<tr>
<td>Skilled nonmanual</td>
<td>4 (16)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Skilled manual</td>
<td>4 (16)</td>
<td>7 (22)</td>
</tr>
<tr>
<td>Semiskilled/unskilled</td>
<td>2 (8)</td>
<td>2 (8)</td>
</tr>
</tbody>
</table>

Data are n (%) or means ± SD. Classification of parental occupation was taken from the Classification of Occupations and Directory of Occupational Titles: I: Introduction, Structure and Index. London, HMSO, 1980.

Procedure

All eligible participants were sent a letter introducing the project to them before their scheduled outpatient appointment. At their appointment, they were given further details about the project. Those individuals who agreed to participate and parents of all those under age 16 years then completed an informed consent form. At that time, demographic details were taken. After ensuring they understood all the instructions in the questionnaire booklet, the adolescents were then asked to complete the booklet unaided in
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t heir own time and return it in the stamped, addressed envelope provided.

The second follow-up questionnaire booklet was sent to participants 12 months after recruitment (6-month follow-up data is reported elsewhere) (7), and participants were asked to complete and return it in the envelope provided. If the questionnaire was not returned within 3 weeks of posting, a reminder letter was sent. On receipt of the questionnaire, results of GHb assays performed as part of the patients’ normal care over the follow-up interval were obtained from medical records.

**Measures**

Gender, age, duration of illness, and parental occupation were obtained from the participants and parents at recruitment. The baseline and follow-up questionnaires contained three brief measures assessing well-being, self-care, and personal models of diabetes.

The Well-Being Questionnaire (28) is a validated 22-item instrument containing no somatic items that was developed specifically for use with diabetic individuals. It produces four subscales that assess depression, anxiety, positive well-being, and perceived energy over the previous 7 days. Pilot interviews indicated that some of the youngest participants would not understand items from the perceived energy and positive well-being scales, so only the data on the depression and anxiety scales are reported here. Baseline data indicated that the internal consistency (assessed by coefficient $\alpha$) was adequate for depression ($\alpha = 0.63$) and anxiety ($0.78$) and that the two scales were correlated ($r = 0.62; n = 70; P < 0.001$) (19).

The Summary of Diabetes Self-Care Schedule (29) is a validated 12-item self-report instrument that assesses four areas of diabetes self-management (diet, exercise, blood glucose monitoring, and injecting) over the previous 7 days, and it has been used previously with adolescents (18,20). The scales were scored by combining the scores for items contributing to the diet, exercise, and insulin injection scales. For the blood glucose testing scales, the item responses were converted into a common metric (as the items used different response options) and then combined. For all scales, higher scores reflected better or more frequent self-care. Baseline data indicated internal consistency (assessed by coefficient $\alpha$) was adequate for diet ($\alpha = 0.64$), exercise (0.83), and blood glucose testing (0.80) but poor for insulin injecting (0.41) (19).

The Personal Models of Diabetes Questionnaire, developed from interview studies with adults (10,15) and revised for use with adolescents (30), is a brief, eight-item self-report instrument. It measures four constructs: effectiveness of treatment to control diabetes, effectiveness of treatment to prevent complications, perceived seriousness of diabetes, and perceived impact of diabetes. Each item has a five-point Likert scale response option (ranging from 1 = not at all serious/important/likely to help to 5 = extremely serious/important/likely to help).

The instrument has four items on which patients evaluate their beliefs about the effectiveness of their treatment regimen, two of which assess the belief that self-management will control their diabetes (internal consistency, $r = 0.54$ [Spearman’s rho correlation coefficient]) and two items assessing beliefs that self-management can prevent the complications of diabetes (internal consistency, $r = 0.48$ [Spearman’s $p$]). The remaining four items relate to the consequences of diabetes, two of which assess the patient’s feeling of seriousness and worry concerning diabetes complications (internal consistency, $r = 0.60$ [Spearman’s $p$]) and two of which assess the impact of diabetes on the patient’s daily life (internal consistency, $r = 0.68$ [Spearman’s $p$]). Combining the two items for each scale generated the four summary scores.

Glycemic control was assessed using GHb assays. All assays up to 1 month before baseline and 1 month after follow-up were recorded, resulting in a range of three to six assays per participant. Therefore, the first and last assays only were used for analysis in this study. Because hospitals used different assaying procedures, the results were standardized. Reference range data were used to calculate the mean and standard deviation for each hospital, and these statistics were used to convert assays into $z$ scores.

**RESULTS** — Compared with those who did not complete follow-up, the final sample was not significantly different based on age, duration of diabetes, baseline glycemic control, socioeconomic status, gender, baseline measure of anxiety, blood glucose testing, exercise, perceived impact of diabetes, treatment effectiveness to control diabetes, and treatment effectiveness to prevent complications. However, adolescents who did not complete follow-up reported statistically significant higher depression scores ($5.5 \pm 3.1$ vs. $4.3 \pm 2.1; t = 2.13; df = 72; P < 0.05$), had poorer dietary ($10.6 \pm 3.9$ vs. $12.6 \pm 3.0; t = -2.83; df = 72; P < 0.001$) and injecting self-care ($5.0 \pm 1.2$ vs. $5.4 \pm 0.9; t = -2.35; df = 72; $P < 0.05$) scores, and perceived their diabetes to be more serious ($6.9 \pm 1.8$ vs. $5.4 \pm 1.8; t = 2.23; df = 72; $P < 0.05$) at baseline.

To test for gender differences and changes over follow-up, a series of two-by-two analyses of variance were undertaken (with time as a within-subjects factor and gender as a between-subjects factor). These analyses indicated that there was a significant increase in depression ($F = 5.44; df = 1; P < 0.05$) and a significant reduction in the frequency of exercise ($F = 5.31; df = 1; P < 0.01$) and

| Table 2—Outcome measures for boys and girls at 1-year follow-up |
|-----------------|-----------------|-----------------|-----------------|
|                 | Baseline | Follow-up |                 | Baseline | Follow-up |
| Depression      | 3.9 ± 1.0 | 4.2 ± 2.3 |                 | 4.8 ± 2.2 | 5.2 ± 2.4 |
| Anxiety         | 3.6 ± 2.5 | 3.9 ± 2.3 |                 | 6.6 ± 3.5 | 6.9 ± 3.4 |
| Diet            | 12.1 ± 3.1 | 11.4 ± 3.6 |                 | 13.3 ± 2.7 | 12.9 ± 2.8 |
| Exercise        | 12.1 ± 5.0 | 11.4 ± 5.2 |                 | 9.8 ± 5.0  | 9.4 ± 5.1  |
| Blood glucose   | 7.3 ± 3.6  | 6.9 ± 3.7  |                 | 7.5 ± 3.9  | 7.3 ± 3.7  |
| Insulin injections | 5.3 ± 0.9 | 5.3 ± 0.9 |                 | 5.4 ± 1.0  | 5.3 ± 1.1  |
| Perceived impact | 4.1 ± 1.9 | 4.2 ± 2.2 |                 | 5.3 ± 2.1  | 5.3 ± 1.6  |
| Perceived seriousness | 5.0 ± 1.6 | 6.0 ± 1.7 |                 | 6.1 ± 2.0  | 7.2 ± 1.7  |
| Effectiveness to control | 7.6 ± 1.5 | 7.7 ± 1.5 |                 | 7.9 ± 1.2  | 7.9 ± 1.5  |
| Effectiveness to prevent | 7.6 ± 1.5 | 7.6 ± 1.5 |                 | 8.0 ± 1.2  | 8.1 ± 1.8  |

Data are means ± SD.
blood glucose testing (F = 6.92; df = 1; P < 0.01). There were also a number of gender differences, which are summarized in Table 2. Girls reported higher levels of depression (F = 7.69; df = 1; P < 0.01) and anxiety (F = 15.73; df = 1; P < 0.0001) and that their diabetes was more serious (F = 7.13; df = 1; P < 0.01) and had a greater impact on their life (F = 4.95; df = 1; P < 0.05). Over the 1-year follow-up period, there was a significant decline in glycemic control (F = 5.62; df = 1; P < 0.05), equating to a mean increase of ~1% in GHb. Girls showed poorer glycemic control (F = 718.26; df = 1; P < 0.001).

Age, duration of diabetes, and socioeconomic status were not associated with depression, anxiety, exercise, blood glucose monitoring, injection behavior, or any of the personal models constructs. However, participants from lower socioeconomic groups had poorer diets (r = −0.25 [Spearman’s ρ]; P = 0.05) and poorer glycemic control (r = 0.44 [Kendall’s τ]; P < 0.001).

As a first step in testing the proposed model, changes in personal model beliefs (baseline minus 12-month follow-up) were correlated with changes in self-care and well-being. Because of the number of tests conducted, the probability for a result to be taken as significant was reduced to 0.01. Change in perceived impact was significantly correlated with change in anxiety (r = 0.37; P < 0.01) but not with change in depression. Change in the perceived effectiveness of treatment to control diabetes was correlated significantly with change in dietary self-care (r = 0.42; P < 0.005) but not with any other self-care measure.

To test the prospective utility of treatment effectiveness and perceived impact to predict follow-up anxiety and dietary self-care behavior, two multiple regressions were undertaken, with anxiety and dietary self-care at follow-up as the dependent measures. On step 1, demographic variables (gender for anxiety, and socioeconomic status for diet) and baseline levels of the outcome measure were entered. On step 2, the relevant change score, perceived impact, or effectiveness to control was entered.

Baseline anxiety accounted for 62% of the variance in follow-up anxiety (β = 0.83; t = 10.41; P < 0.0001). Change in perceived impact added significantly to the prediction of follow-up anxiety (β = −0.21; t = −2.65; P < 0.01), so that an increase in the perceived impact of diabetes was predictive of greater anxiety, accounting for a further 6% of the variance (r² = 0.68; F = 48.87; P < 0.0001). Gender did not enter the regression to predict follow-up anxiety, which suggested that perceived impact of diabetes mediates the association between gender and anxiety.

For dietary self-care, baseline behavior and demographics accounted for 22% of the variance in follow-up dietary self-care (β = 0.51; t = 4.28; P < 0.001). Change in perceived effectiveness of treatment to control diabetes added significantly to the prediction of follow-up dietary self-care (β = −0.39; t = −3.28; P < 0.005), so that changes to greater belief in the effectiveness of treatment predicted better self-care, accounting for a further 17% of the variance (r² = 0.39; F = 13.92; P < 0.0001). Socioeconomic status did not enter the regression to predict follow-up dietary self-care, suggesting that the perceived impact of diabetes mediates the association between socioeconomic status and dietary self-care.

Using the mean of the baseline and follow-up assessments, bivariate correlations indicated that dietary self-care (r = −0.29; P < 0.05) and anxiety (r = −0.26; P = 0.05) were significantly associated with glycemic control. Therefore, along with gender and socioeconomic status, diet and anxiety were entered together into a stepwise multiple regression. This indicated that gender (β = −0.45; t = −3.00; P < 0.005) and dietary self-care (β = −0.41; t = 2.70; P < 0.01) were significant predictors of glycemic control, so that girls had poorer control, and better self-care was predictive of better control, accounting for 29% of the variance in mean GHb assays (F = 7.24; P < 0.005). Anxiety was no longer predictive of glycemic control once dietary self-care was entered into the regression. However, because anxiety was associated with dietary self-care (r = 0.23; P < 0.01), this suggested that dietary self-care may partially mediate the association between anxiety and glycemic control (31).

Conclusions — These results indicate that the more adolescents believe that their treatment regimen will control their diabetes, the better their subsequent dietary self-management will be. Better dietary self-care and gender were associated with better glycemic control of diabetes. The greater impact a young person perceives diabetes to have on his or her life, the more anxiety he or she subsequently experiences. The ability of changes in personal model beliefs to predict both anxiety and dietary-self care after controlling for baseline values provides further support for the importance of personal model beliefs in determining outcome of diabetes care.

The brief personal model assessments reported here were as predictive of dietary self-care and anxiety as were much lengthier interviews and questionnaires in other studies (10,15,16). Moreover, the ability to account prospectively for 17% of the variance in dietary treatment at follow-up is important, given that diet is frequently reported as the most difficult part of the diabetes treatment regimen (32). Anxiety is an index of an individual’s emotional well-being, which is as important as physiological indexes in successful diabetes management.

Differentiating between long- and short-term beliefs may also be important in understanding the conflicting results for threat expectancies in previous work on adolescents with diabetes (18,20,25). Whether predicting anxiety, depression, or dietary self-management in adolescents, it was the short-term effects of the illness and its treatment (perceived impact of diabetes and effectiveness of treatment to control diabetes) that were important (19). Neither beliefs about the seriousness nor beliefs about the prevention of complications, both of which are related to the long-term effects of diabetes, were predictive of self-management or well-being. This finding was consistent with research that has found an association between fear of hypoglycemia, another short-term threat expectancy, and poor diabetes control in adolescents (33). Previous research on threat expectancies has done little to distinguish between short-and long-term expectancies, which would appear to be an important distinction for this age group.

The lack of association between treatment effectiveness and the other self-care measures could be attributable to a number of factors. First, there was little variability in insulin injections and blood glucose testing. Next, many participants reported that they had not been encouraged to, or had not recalled being encouraged to, exercise as part of their treatment, which may account for the lack of predict-
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...tion in this area. Another problem was that the personal models measures referred to diabetes management in general rather than specific questions for each component, which may have greater utility.

In addition to these psychometric issues, it should be remembered that self-care will be influenced by a multitude of factors, of which personal models beliefs are but one component. For example, beliefs can predict behavior only when the individual has responsibility for the activities concerned. As this sample contained a significant proportion of young adolescents who were predominately on two injections a day, those adolescents were probably prompted or told by parents when to do self-care behaviors and so were not acting solely in response to their own beliefs.

The most obvious limitation of this study was the nature of the sample, which was exclusively Caucasian with a middle-class bias. Furthermore, 20% of the young people scheduled to attend the outpatient clinic did not attend during the recruitment period. The failure to include non-attendees is a recurring problem in this field of research and an area that clearly warrants investigation. Moreover, participants who dropped out of the study had poorer self-care and reported greater depressive symptomatology at baseline. However, this should be contrasted with the fact that 73% of the sample completed follow-up and that the final sample equated to 37% of the eligible population. The reliance on self-report measures is another weakness of the study. Although participants may have overreported their levels of self-care, it is noteworthy that 25% of the participants reported that they performed either none or only a few of the blood glucose tests recommended by their care team, which suggests that participants were responding fairly honestly.

Despite these limitations, this study confirms the importance of personal models of illness in determining adolescents’ responses to illness. Although any conclusion must be tentative because adolescents take responsibility for the management of their diabetes, parents, clinicians, educators, and interventionists should consider young people’s beliefs about their diabetes and its treatment as key factors influencing self-care, emotional well-being, and glycemic control. Clinicians need to understand young people’s beliefs about their diabetes, particularly regarding short-term control and the impact of diabetes, to inform and support the individual’s decisions about diabetes management. Despite the longitudinal design, reciprocal relationships cannot be ruled out. Changes in personal model beliefs may well be a function of an individual’s self-care and anxiety levels. Therefore, further work is warranted to determine whether 1) the distinction between short- and long-term beliefs are important for adolescents; 2) the predictive ability of personal model beliefs remains after controlling for the other constructs, such as family support, self-esteem, and perceived barriers that are closely related to self-care and well-being; and 3) personal model beliefs are determinants of self-care and well-being and not vice versa.

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References
21. Grey M, Boland EA, Davidson M, Yu C,


