Effect of Adults' Self-Regulation of Diabetes on Quality-of-Life Outcomes

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OBJECTIVE — To examine the relationships among cognitive representations of diabetes, diabetes-specific health behaviors, and quality of life using Leventhal and Diefenbach's self-regulation model of illness (Leventhal H, Diefenbach M: The active side of illness cognition. In *Mental Representation in Health and Illness.* Skelton JA, Croyle RT, Eds. New York, Springer-Verlag, 1991, p. 247–272).

RESEARCH DESIGN AND METHODS — This research involved secondary analysis of a mailed survey completed by 296 adults (ages 20–90 years). Structural equation modeling was conducted to investigate relationships among cognitive representations, diabetes-specific health behaviors, and quality of life. Model differences by diabetes type were also investigated.

RESULTS — Findings indicated that certain cognitive representation constructs were related to increased diabetes-specific health behaviors, decreased sense of burden, and positive quality-of-life outcomes. Individuals' levels of understanding of diabetes and their perceptions of control over diabetes were the most significant predictors of outcomes. However, diabetes-specific health behaviors were related to an increased sense of burden that was negatively associated with quality of life. Multigroup analyses indicated that this self-regulatory model provided a good fit for individuals with type 1 diabetes, those with type 2 diabetes who take insulin, and those with type 2 diabetes who do not take insulin.

CONCLUSIONS — These findings advance what is known about cognitive representations of illness and the self-regulation of diabetes as well as the relationships between cognitive representations of illness, quality of life, and behavioral factors. In particular, results from this study suggest the need for further study to address ways of reducing the burden of diabetes associated with health behaviors and decreased quality of life.

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T he overriding goals of diabetes self-management education are to empower individuals to avoid the short-term risks and long-term complications associated with the disease as well as to maintain/improve quality of life (1–3). However, the diabetes-specific health behaviors that compose up to 99% of disease treatment (4) are difficult to maintain over time (5,6). This may be because individuals often make health care decisions on the basis of regimen difficulty and current symptoms rather than long-term benefits of behavior (7). Although much of the focus of diabetes education and intervention efforts concern health behavior change, research indicates that some aspects of diabetes-specific health behaviors (e.g., diet) may have a negligible (8–10), rather than a positive (11,12) impact on quality of life. These findings suggest a need to better understand factors underlying both quality

of life and the performance of diabetes-specific health behaviors.

The purpose of the present study was to investigate underlying cognitive predictors of diabetes-specific health behaviors and quality of life in a heterogeneous sample of people with diabetes. Specifically, the relationships among cognitive representations of diabetes, diabetes-specific health behaviors, and quality of life were investigated using a theoretical model informed by the process of illness self-regulation (Fig. 1).

Cognitive representation of illness can be defined as the psychological parameters in which an individual conceptualizes his or her illness. Leventhal and Diefenbach (13) suggest 5 basic components in the cognitive representation of illness: disease identity (understanding of the disease in terms of symptoms and labels), consequences (the perceived physical, psychological, social, and economic impact of the disease), timeline (time of onset, expected duration, and possibility of recurrence), cause (environmental, behavioral, and genetic factors), and controllability (possibility of cure or slowing of progression). Support for the utility of these components in predicting illness outcomes has been documented (14–16). Overall, cognitive representation of illness allows the individual to organize illness information and to guide monitoring of symptoms, actions, and consequences (i.e., to know what to expect or look for when experiencing illness) (17).

Although Leventhal and Diefenbach's (13) model of illness self-regulation has been extensively cited in the health literature, applications to diabetes have been few. In studies by Hampson and colleagues (11,18), "Consequences" and "Timeline" constructs were combined to form a single construct ("Seriousness") that was predictive of a variety of self-management behaviors. Likewise, Glasgow et al. (19) found that "Control" (termed "Treatment Effectiveness") also predicted self-management behaviors (e.g., diet, exercise, and self-monitoring of blood glucose).

Previous research regarding illness self-regulation has tended to focus on bivariate associations between theoretical constructs
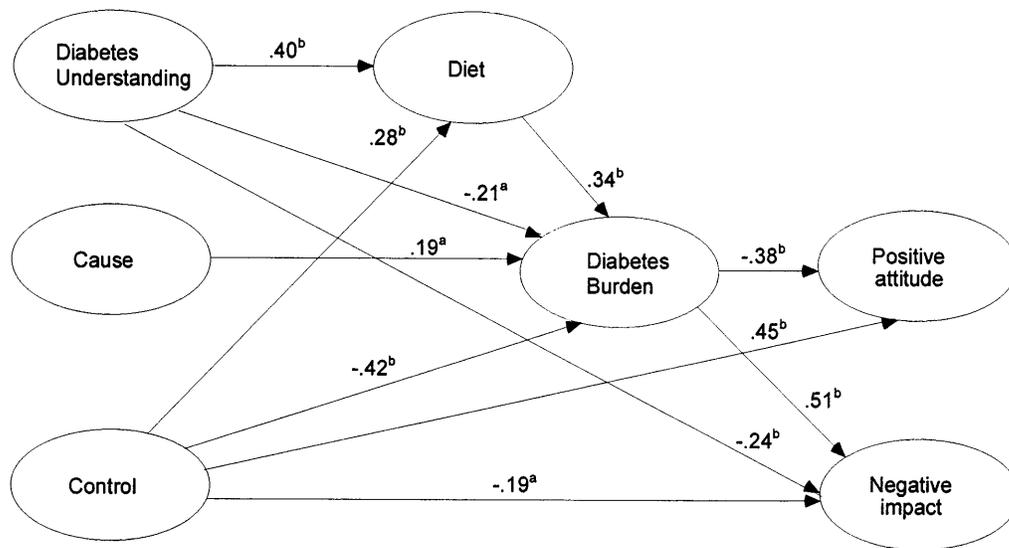
Figure 1—*Fit statistics and standardized parameter estimates for the final trimmed self-regulatory model. The model also included controls for age, sex, ethnicity, and type of diabetes, which are not shown in this figure. Loadings for the measurement model are shown in Table 1. [a]P , 0.05; [b]P , 0.001. Multiple r^2 for dependent variables were: $r^2_{Diet} = 0.31$, $r^2_{Burden} = 0.36$, $r^2_{Positive\ attitude} = 0.50$, and $r^2_{Negative\ impact} = 0.50$.*

and health outcomes. In the literature review for this article, no published studies were found that investigated the simultaneous relationships among cognitive representations, self-management behaviors, and quality of life in diabetes using a single theoretical model. This is a particularly important area of inquiry, given that diabetes health behaviors and perceptions of quality of life are salient but possibly conflicting outcomes in diabetes self-management. The present study addresses this gap in the scientific literature by investigating the extent to which individuals' cognitive representations of diabetes are associated with better health behavior and quality-of-life outcomes.

RESEARCH DESIGN AND

METHODS — This study involves secondary analysis of data collected to assess the reliability and validity of the Diabetes Care Profile (DCP), a comprehensive 234-item questionnaire measuring individuals' attitudes, beliefs, self-management behaviors, and quality-of-life concerns with regard to diabetes. Development of the DCP is described in detail elsewhere (20). Measures of cognitive representation factors in this study were theoretically derived, and they were tested using confirmatory factor analysis. "Diabetes Understanding" differs to some extent from Leventhal's description of this construct by reflecting disease symptoms or labels. Because research indicates that diabetes symptoms can be idiosyncratic (21), we chose instead to focus on individ-

uals' perceived understanding of common aspects of a diabetes treatment regimen. Three items were used to measure this construct. "Consequences" is representative of individuals' perceptions of possible complications associated with diabetes and was measured by 4 items. "Cause" represents attributions of hyperglycemic episodes to specific behaviors or feelings; this construct was measured by 4 items. "Control" represents individuals' perceptions of control over diabetes and is measured by 4 items.

Quality-of-life constructs for the self-regulatory model of diabetes management were measured by 3 previously validated DCP scales: Diabetes Burden, Positive Attitude Toward Life, and Negative Psychological Impact of Diabetes. Scale reliabilities (i.e., Cronbach's α) from previous studies ranged from 0.75 to 0.90 (20,22). Diet and exercise were measured with regard to frequency of these activities. Questionnaire items, their assigned factors and loadings, and Cronbach's α for each scale are presented in Table 1.

Recruitment of participants was conducted through 2 sources. A form letter requesting individuals' participation in the study was first mailed with a return postcard to 300 individuals on the Michigan Diabetes Research and Training Center newsletter list. The same materials were then sent to a random sample of 1,200 adults >20 years of age with diabetes who had received care at the University of Michigan Medical Center within an 18-month period (1989–1991).

From these 1,500 mailings, 576 individuals (38%) responded and were mailed the DCP questionnaire. The number of surveys returned was 428 (74%), with 362 being complete. Individuals with no prior exposure to diabetes education ($n = 59$) were not asked to complete certain portions of the questionnaire relevant to the present study; data from these respondents were not included in analyses. Similarly, data from individuals who could not be classified according to diabetes type ($n= 7$) were not included in analyses for this study. Therefore, the final number of respondents included in the present study is 296.

RESULTS

Sample characteristics
The age range of respondents was 20–90, with a mean age of 52 years (median 53). There was a relatively equal distribution by age-group: young adults 20–44 years ($n = 106$) composed 36% of the sample, middle-aged adults 45–64 years ($n = 114$) were 39% of the sample, and older adults 65–90 years ($n = 76$) were 26% of the sample. Respondents were also evenly split according to diabetes classification: those with type 1 diabetes ($n = 106$) made up 36% of the sample, those with type 2 diabetes who use insulin ($n = 98$) were 33% of sample, and those with type 2 diabetes who do not use insulin ($n = 92$) were 31% of the sample. The majority of the final sample was female (62%), married (61%), white

(89%), and living at home (89%). Most respondents (71%) reported living with 1–3 other people in their household. Only 23% of respondents had not completed high school, and 47% had completed ≥1 year of college.

The sample is representative of the general population with diabetes in many respects; however, there are several noticeable differences (23). Individuals with type 1 diabetes in the present sample were older, more likely to be female, more highly educated, and less likely to be employed or seeking employment than people with type 1 diabetes in the general population. Individuals with type 2 diabetes in the present sample were younger, more likely to be white, and more highly educated than people with type 2 diabetes in the general population.

Structural equation modeling of diabetes self-management

Confirmatory factor analysis using Lisrel 8.1.2 (24) was conducted to assess the theoretically derived measurement model of cognitive representations in this sample. The fit of the measurement model was acceptable (χ^2 [84 df, $n = 296$] = 186.45, GFI = 0.92, CFI = 0.96, NNFI = 0.95, RMSEA = 0.06). Structural equation modeling was used to describe relationships among factors in models for diet and exercise behavior. For the context of each diabetes-specific health behavior, a series of nested models was estimated to determine the most parsimonious and best-fitting model. In the preliminary or "full" model, the relationships among all constructs were estimated. Nonsignificant factor loadings for the full model were then removed to arrive at a final "trimmed" model consistent with the self-regulatory conceptual model. Fit statistics and standardized parameter estimates for the model involving dietary behavior are presented in Fig. 1. (Results for exercise behavior paralleled those for diet, but results were generally weaker or nonsignificant. This possibly reflects lowered validity and/or reliability of the single-item measure for exercise.)

With regard to the direct effects illustrated in Fig. 1, specific cognitive representation constructs were associated with increased frequency of diet and improved perceptions of quality of life. Specifically, increased perceptions of control and understanding of diabetes were associated with better adherence to diet, less interference with social and personal functioning

Table 1—*Constructs used in the diabetes self-regulation model*

	Factor loading	Cronbach's α
Cognitive representations		
Diabetes understanding	—	0.81
How do you rate your understanding of…*		
Diet and blood sugar control	0.92	—
Exercise	0.73	—
Use of insulin/pills	0.66	—
Consequences	—	0.91
Taking the best possible care of diabetes will delay or prevent…†		
Eye problems	0.91	—
Kidney problems	0.96	—
Foot problems	0.95	—
Heart disease	0.87	—
Cause	—	0.78
During the past year, how often have you had changes in your blood glucose (too high) because you…‡		
Ate the wrong types of food	0.86	—
Ate too much food	0.85	—
Had less physical activity than usual	0.53	—
Were feeling stressed	0.46	—
Control	—	0.72
I am able to…§		
Keep my blood sugar in good control	0.57	—
Keep my weight under control	0.58	—
Do the things I need to do for diabetes	0.84	—
Handle my feelings about diabetes	0.57	—
Health behaviors		
Diet	—	0.86
How often do you …‖		
Follow a meal plan or diet?		
Follow the schedule for your meals or snacks?		
(Or the person who cooks your food) use exchange lists to plan meals?		
Exercise		
How often do you exercise?¶		
Quality of life		
Interference with social and personal functioning (burden)	—	0.90
My diabetes and its treatment keep me from…(sample of 13 items)§		
Keeping a schedule I like (e.g., eating or sleeping late)		
Meeting school, work, household, and other responsibilities		
Going out or traveling as much as I want		
Positive attitude toward life§	—	0.77
I feel satisfied with my life.		
I can do just about anything I set out to do.		
Diabetes doesn't affect my life at all.		
I am pretty well off, all things considered.		
Things are going very well for me right now.		
Negative psychological impact of diabetes§	—	0.71
I am afraid of my diabetes.		
I find it hard to believe that I really have diabetes.		
I feel unhappy and depressed because of my diabetes.		
I feel I'm not as good as others because of my diabetes.		
I find it hard to do all the things I have to do for my diabetes.		

Factor scores represent the mean of predictor items. Factor loading is the standardized solution from confirmatory factor analysis. Fit indexes for trimmed model: χ^2 (15 df, $n = 296$) = 25.76, GFI = 0.98, CFI = 0.98, NNFI = 0.95, RMSEA = 0.05. Item scoring: *1 = poor to 5 = excellent; †1 = strongly disagree to agree, 2 = strongly agree; ‡1 = never to 5 = often; §1 = strongly disagree to 5 = strongly agree; ‖1 = never to 5 = always; ¶1 = less than once a week to 5 = daily.

(Burden), and fewer negative feelings associated with the disease. Perceived control was also associated with a more positive attitude toward life in general. Attributing hyperglycemia to personal behaviors or feeling stressed (Cause) was associated with increased interference with social and personal functioning. Increased frequency of diet behavior was associated with greater interference with social and personal functioning.

Multigroup analyses comparing the model fit for the 3 groups (i.e., type 1 diabetic patients, type 2 diabetic patients taking insulin, and type 2 diabetic patients not taking insulin) indicated no significant model parameter differences among diabetes types for either the diet or exercise model.

It should be noted that although cognitive representation constructs had a salutatory direct association with the perception of diabetes burden, the total effects of these constructs were reduced with dietary adherence as an intervening variable (Fig. 1). Specifically, the total effect of diabetes understanding on perceived diabetes burden was weaker ($\beta = -0.07$, $P > 0.05$) than the direct effect of diabetes understanding on perceived diabetes burden ($\beta = -0.21$, $P < 0.05$). Likewise, the total effect of perceived control on diabetes burden ($\beta = -0.32$, $P < 0.001$) was reduced from the direct effect of perceived control on diabetes burden ($\beta = -0.42$, $P < 0.001$). These associations were explored further in tests for nonlinearity.

Tests for nonlinearity

Regression analyses were used to test for possible curvilinear relationships between self-management behaviors and perceived burden. Results indicated a marginally significant negative nonlinear association (i.e., inverted U-shaped relationship) between Diet and Burden ($\beta = -0.63$, $P = 0.05$). In other words, dietary adherence increased perceptions of diabetes burden only up to a point; the role of diet in increasing perceptions of diabetes burden was minimal at both lower and higher levels of dietary adherence.

Conversely, results indicated a positive nonlinear association (i.e., U-shaped relationship) between Exercise and Burden ($\beta = 0.60$, $P = 0.04$). Frequency of exercise was associated with decreased perceptions of diabetes burden; however, there appears to be a point beyond which increased frequency of exercise is associated with increased perceptions of burden.

CONCLUSIONS — Self-regulatory models of diabetes management suggest that more accurate and developed cognitive representations of diabetes are predictive of increased involvement in diabetes-specific health behaviors relevant to the self-management of the disease and improved quality of life. The purpose of the present study was to investigate cognitive representations predicting diabetes-specific health behaviors and quality of life in a heterogeneous sample of people with diabetes. Specifically, the relationships among cognitive representation, diabetes-specific health behaviors, and quality of life were investigated using a theoretical model informed by the process of illness self-regulation (13). Overall, our findings provide partial support for Leventhal's theory of illness self-regulation by indicating that certain cognitive representations of illness are associated with health behavior and perceived quality of life.

In structural models of diabetes self-regulation, certain cognitive representation constructs (in particular, understanding and perceived control of diabetes) were found to be significant predictors of engagement in diabetes-specific health behaviors and positive perceptions of quality of life. However, the total effects of cognitive representations in relieving the perceived burden of dealing with diabetes were reduced by the inclusion of dietary adherence in the model as an intervening variable.

Intuitively, it would seem that in addition to improving glycemic control and reducing diabetes-related complications, increased adherence to a treatment regimen would also be related to improved quality of life. In fact, improved quality of life is often cited as a benefit of adherence to treatment protocols (even when this relationship is not actually analyzed). However, some research indicates that engaging in self-management behaviors has a negligible effect on quality of life (8,10,25). Likewise, improved glycemic control associated with diabetes-specific health behaviors is not consistently related to quality of life (9,26). Findings in the present study suggest that dietary adherence may negatively affect quality of life by increasing the level of perceived diabetes-related burden. People with diabetes are often restricted in the amount, types, and timing of food consumption (e.g., meals at certain times, waiting for insulin effect before eating and between-meal snacks). These restrictions may negatively affect individuals' perceptions of life quality and interactions with others.

The presence of an additional negative curvilinear relationship between dietary behavior and perceived burden in this study also suggests that perceptions of burden may be less for those individuals reporting the least and greatest adherence to a dietary regimen. On the one hand, nonadherence could be associated with denial of disease impact and also with the fact that there actually may be less lifestyle burden for the person with diabetes who does not follow a dietary regimen. On the other hand, although self-reporting of greater adherence to diet could reflect deliberate misreporting, it could also reflect the successful incorporation of dietary regimen into one's lifestyle.

In analyses involving exercise behavior, the presence of a positive curvilinear relationship between exercise and perceived burden suggests that there may be an optimal level of exercise behavior beyond which the effects on quality of life become more negative. Beyond this optimal level, adherence to an exercise regimen may be perceived less as a pleasurable pursuit or goal-related activity and more as a task that must be performed on a continual basis to keep diabetes under control (27–29).

Limitations of this study are noted. First, although the directionality of effects in this study as hypothesized is in keeping with a model of illness self-regulation, the cross-sectional nature of the data does not allow causal inferences to be made. Therefore, this study provides only a static snapshot of model effects. Future research is needed to capture the dynamic interaction of the self-regulatory process. Also, there was a low representation of nonwhites among respondents with type 2 diabetes; in the general population, the disease is significantly more prevalent among nonwhites (30). This and other demographic differences between this sample and the general population with diabetes (e.g., sex, level of education, and employment status) affect the generalizability of these findings. Similarly, because the final models were determined partly by trimming, they may to some extent reflect idiosyncrasies of the particular sample. Finally, in this study, only brief measures of self-management behaviors were used, and only differences in disease type and treatment were analyzed. Further research is needed to investigate the nature of self-regulatory processes in more detail, with the inclusion of a wider variety of possible confounding factors (e.g., disease duration, severity, and glycemic control).

In summary, these results provide support for a conceptual model of illness self-regulation in which cognitive representations of diabetes are important predictors of health behaviors and quality of life. These findings are particularly important given that diabetes-specific health behaviors and quality of life are salient, yet at times conflicting, components of diabetes self-management.

Leventhal and Diefenbach's (13) model suggests that appraisal of disease self-management provides feedback that serves to update people's cognitive representations of disease and health behaviors. Therefore, people may be less likely to engage in health behaviors that are related to negative assessments of quality of life. This is likely to occur when health behaviors are complicated, difficult to maintain, or do not provide immediately evident results (7). For example, although adherence to diabetes-specific health behavior is predictive of increased glycemic control, the clinical benefits of diabetes self-management are often long term and unobservable to patients, and patients may see no relationship between glycemic control and quality of life (9). The fact that diabetes-specific health behaviors may be subjectively associated with no improvement in, or even decreased perceptions of, quality of life illustrates an inherent fallacy of interventions that are based on the assumption that increased diabetes-specific health behaviors will necessarily or automatically improve quality of life.

The current findings have implications for diabetes self-management interventions. These results suggest that developing and strengthening individuals' cognitive representations of diabetes cannot have the full desired positive effect on self-management behavior (and thereby on health) and quality of life unless the burden associated with self-management is reduced. With improved understanding of the self-regulatory process for diabetes, physicians and educators might more effectively individualize treatment regimens to improve self-management without increasing perceptions of burden.

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