The Family and Disease Management in Hispanic and European-American Patients With Type 2 Diabetes

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OBJECTIVE — To determine the relationship between the characteristics of families involved in disease management and the self-care practices of Hispanic and European-American (EA) patients with type 2 diabetes.

RESEARCH DESIGN AND METHODS — A total of 74 Hispanic patients and 113 EA patients with type 2 diabetes recruited from managed care settings were assessed on three domains of family life (family structure/organization, family world view, and family emotion management [four scales]) and five areas of disease management (biological, general health and function status, emotional tone, quality of life, and behavioral [seven scales]). Analyses assessed the independent associations of patient sex, family, and sex by family interactions with disease management.

RESULTS — Both sex and the three domains of family life were related to disease management, but the results varied by ethnic group. For EA patients, sex, family world view, and family emotion management were related to disease management (scores for Family Coherence were negatively associated with HbA1c level and depression, and poor scores for Conflict Resolution were linked with high depression); for Hispanic patients, sex and family structure/organization were related to disease management (high scores for Organized Cohesiveness were associated with good diet and exercise, and high scores for Family Sex-Role Tradionalism were related to high quality of life). No significant interactions with sex occurred.

CONCLUSIONS — Characteristics of the family setting in which disease management takes place are significantly linked to patient self-care behavior, and these linkages vary by patient ethnicity. A family’s multiple independent dimensions provide multiple targets for intervention, and differences in family norms, structures, and emotion management should be considered to ensure that interventions are compatible with the setting of disease management.

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An essential finding of the Diabetes Control and Complications Trial (DCCT) (1) and the U.K. Prospective Diabetes Study (2) is the importance of self-care behavior as part of an integrated program to maintain good blood glucose control over time (3). Some authors have suggested frameworks for identifying and organizing factors that are known to affect self-care practices for use in clinical intervention programs for patients with type 2 diabetes (4,5). These frameworks suggest that four groups of factors probably account for most of the variability in self-care behavior in patients with diabetes over time: characteristics of the patient, the patient’s family, the practitioner and health system, and the community/work setting (6).

Of these four factors, characteristics of the patient’s family, which is the primary social context of disease management, is the least explored. Several reasons exist for devoting more attention to the family regarding the clinical management of type 2 diabetes. First, most disease management behavior evolves through, is sanctioned by, or takes place within the family or home setting. Second, the family embodies the patient’s most powerful and influential web of intimate personal relationships and has an enormous supportive or deleterious effect on patient behavior, health, and well-being (7). Third, what is often interpreted as exclusive patient self-care behavior is often the result of combinations of patient and spouse behavior or of spouse behavior alone (8,9). Food preparation, exercise monitoring, and health monitoring, for example, are often undertaken by family members other than the patient. Fourth, considerable data suggest that stress frequently undermines tight glucose control over time (10), and family stress and marital satisfaction play a powerful role in this regard (11,12). Fifth, the family’s system of health-related beliefs, which is supported by culture and ethnicity, is the basis for how patients and family members recognize, understand, respond to, and manage chronic disease over time, even though some self-care behavior may take place in other social settings such as work (13,14). In these ways, the family creates a shared social reality that defines and describes chronic disease and its management and that incorporates the overt or covert involvement of the patient and all members of the family system (15). These conditions identify the family as unique and
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distinguish it from other social relationships that provide social support (16,17).

Although there are many studies of the family and type 1 diabetes, primarily with children and adolescents, there is a notable absence of research on the influence of the family on disease management for adult patients with type 2 diabetes (18). Identifying the linkages between specific aspects of the family and specific areas of disease management is crucial in designing interventions that enhance self-care practices and improve patient health and well-being because, in part, the outcomes of clinical interventions affect and are affected by the family. In this article, we examine the relationship between three areas of family life and five areas of disease management for Hispanic and European-American (EA) patients with type 2 diabetes. Below, we briefly summarize the current literature on family influences on disease management.

In general, the following family characteristics have demonstrated consistently negative relationships with chronic disease outcomes: low family cohesion, high family conflict, too rigid or too permeable generation boundaries, low levels of family organization, hostile family affiliative tone, low marital satisfaction, criticalness, lack of clear communication, and low spouse involvement (4,16,18–23).

A limited number of studies have addressed how family relationships affect the management of type 2 diabetes. For example, patient-perceived barriers to diet and medication have been related to ratings of low marital satisfaction (24), and other research has found that non-disease-related marital problems often are acted out through the medium of diabetes (25). Patterns of spouse overinvolvement versus indifference regarding disease management also have been described (26,27). Likewise, Peyrot et al. (27) showed that a positive correlation exists between spouses on level of knowledge about diabetes and that a discrepancy in level of diabetes knowledge between spouses is related to low marital satisfaction. The researchers emphasized the need for “interpersonal congruence” between spouses regarding diabetes so that friction between spouses regarding disease management is kept to a minimum.

Several factors have been identified that influence the ways in which characteristics of family relationships affect self-care practices. The most important of these factors are non–disease-related stress (28), patient sex (29), and patient ethnicity and culture (30–33). The family–disease management relationship also is influenced by patient education, social class, and acculturation. Thus, programs that incorporate aspects of the patient’s family in the design and implementation of intervention programs need to address these contextual issues as well.

Several approaches have been undertaken to organize the immense complexity of the family into a practical framework for family assessment (34,35). Fisher et al. (36) identified four domains of family life that demonstrated documented links with various health outcomes (36). First, family structure/organization addresses the architecture of the family by assessing aspects of family orderliness and patterns of roles, rules, and boundaries among members and between the family and the external world (37). Second, family world view addresses the beliefs, values, and sentiments of the family, such as the belief in fate and the degree of optimism. Related to history and culture, family world view considers the family’s fundamental beliefs about the world and the family’s place in it. Third, family emotion management considers how the family manages and expresses feelings regarding conflict, closeness, affection, and loss (38). Fourth, family problem solving addresses the processes and outcomes of family problem resolution, such as those associated with managing a chronic disease (39). A major strength of the four-domain family approach is that it provides a realistic model of family variability within a single framework, a framework that has already been applied to several other chronic diseases (40,41).

In the present study, we sought to extend the findings on family and disease management to type 2 diabetes by identifying those characteristics of family relationships that display significant linkages with specific aspects of disease management, taking into consideration two major additional factors, patient sex and ethnicity.

RESEARCH DESIGN AND METHODS

Subjects

Patients who met the following criteria were identified from billing and clinical databases from 11 health facilities: a diagnosis of type 2 diabetes, time since diagnosis between 1 and 9 years, patient age between 25 and 62 years, no evidence of major diabetes complications (e.g., proliferative retinopathy, cerebrovascular accident or myocardial infarction within the past 12 months, renal insufficiency, amputations), the patient and consenting spouse or partner had been cohabiting for a minimum of 3 years, and the patient and spouse/partner identified themselves as either Hispanic (from Mexico or Central America) or EA.

After receiving an introductory letter, patients were screened for inclusion criteria by a telephone interview, and a home visit for eligible patients and spouses was scheduled to introduce the project and to review informed consent. The project included a 1.5-h home visit, completion of questionnaires in the home (45 min), and a 2.5-h office visit for both the patient and the spouse/partner.

Screening identified 262 eligible patients, of whom 187 agreed to participate (71% acceptance rate). The final sample consisted of 113 EA patients and 76 Hispanic patients and their spouse/partners (Table 1). Most patients who refused to participate ended the telephone interview before screening was completed. Most stated lack of time as the primary reason for refusal.

Measures of the family

Three of the four original family domains described by Fisher et al. (36) (those with the most direct links to disease management) were included in the current research: family structure/organization, family world view, and family emotion management. Scales representing each family domain were selected as exemplars, and no attempt was made to assess each domain comprehensively in a single study. All scales referred to appraisals of the patient’s current family (not the family of origin), which included the patient, his or her spouse/partner, and any offspring. Extended family members were included in the definition of “family” only if they were residing within the same household. All scales were translated into Spanish by one translator and were back-translated into English by a second translator. Differences were reconciled into a final Spanish translation (31). Items were then reviewed by focus groups of Hispanic patients or their spouse/partners, and final English and Spanish protocols were prepared. Hispanic patients elected to use either the Spanish or English versions.
Family structure/organization

This family domain was assessed by using two self-report scales. Organized Cohesiveness is a 13-item scale developed by Fisher et al. (37) (α = 0.76) to assess the degree of interpersonal closeness and orderliness in the family. Originally developed as separate scales, these two dimensions continually demonstrated high intercorrelations in several studies (r > 0.70) and were therefore combined in subsequent research (42). Family Sex-Role Traditionalism is a 13-item scale developed by Felton et al. (43) (α = 0.79) to assess support for traditional sex roles within the family, such as a woman’s involvement in work outside the home.

Family world view

Family Coherence is a 13-item scale developed by Ransom et al. (44) (α = 0.84) to assess the family’s belief that the world is “comprehensible, meaningful, and manageable,” based on the work of Antonovsky (45).

Family emotion management

Because disagreements about diabetes and its management can be a major stressor for patients and spouses, we elected to focus the assessment of this domain on the effectiveness of conflict management (27). One self-report scale from the Multidimensional Assessment of Intercparental Conflict (46) was included with items modified to refer exclusively to conflict regarding diabetes management. Conflict Resolution is a modification of a five-item scale (α = 0.75) that assesses the degree to which the respondent believes that conflicts with his or her spouse/partner regarding diabetes are not effectively resolved. High scores reflect unresolved conflict.

Measures of disease management

Based on the work of Glasgow (5), we defined disease management broadly to include five general areas, which were each assessed by one or two scales.

1. Biological: This area was assessed by HbA1c and BMI levels.
2. General health: The General Health subscale of the Medical Outcome Study 36-Item Short-Form Health Survey (SF-36) (47) includes five items (α = 0.78) that are each rated on a five-point scale. This subscale assesses self-appraised general health.
3. Diabetes quality of life: The Satisfaction subscale of the Diabetes Quality of Life (DQOL) developed by the DCCT (47a) includes 15 items (α = 0.84) that are each rated on a five-point scale. This subscale assesses satisfaction with various components of diabetes care, including current treatment, sleep, and disease burden.
4. Emotional tone: The Center for Epidemiological Studies—Depression (CESD) (48) is a measure of depression during the past 4 weeks. It contains 20 items (α = 0.83).
5. Behavioral: Measures of exercise and diet were included. 24-Hour Activity (ACT24) is an index of physical activity during a 24-h period. The patient indicates how many hours he or she spends at five levels of energy expenditure from rest to heavy activity during a typical day. Each level is then weighted by relative oxygen consumption and is then summed for the entire 24-h period (49). Diet Observations assesses the degree to which the patient observed each of five American Diabetes Association dietary recommendations (50) by using a 3-day food record: less than recommended number of 1) calories and 2) carbohydrates per day, 3) saturated fat intake <10% of calories per day, 4) total fat intake <30% of calories, and 5) consumption of at least 20 g fiber/day. One point is added to the patient’s score for each criterion achieved (range = 0–5).

Table 1—Characteristics of the sample

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Statistic</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hispanic</td>
<td>EA</td>
<td></td>
</tr>
<tr>
<td>n (male/female)</td>
<td>74 (48/26)</td>
<td>113 (67/46)</td>
<td>χ² = 0.48</td>
</tr>
<tr>
<td>Age (years)</td>
<td>48.41 ± 8.91</td>
<td>51.69 ± 7.68</td>
<td>t = 2.71</td>
</tr>
<tr>
<td>Income†</td>
<td>4.25 ± 1.61</td>
<td>6.98 ± 1.63</td>
<td>t = 11.10</td>
</tr>
<tr>
<td>Education</td>
<td>3.13 ± 2.05</td>
<td>5.82 ± 1.34</td>
<td>t = 10.99</td>
</tr>
<tr>
<td>Years married</td>
<td>21.84 ± 10.40</td>
<td>24.34 ± 11.00</td>
<td>t = 1.57</td>
</tr>
<tr>
<td>Children (n)</td>
<td>3.42 ± 2.09</td>
<td>2.16 ± 1.44</td>
<td>t = 4.93</td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td>4.16 ± 2.31</td>
<td>4.31 ± 2.39</td>
<td>t = 0.46</td>
</tr>
<tr>
<td>Medication (diet and exercise/oral medication/insulin)</td>
<td>12/56/6</td>
<td>19/67/27</td>
<td>χ² = 8.70</td>
</tr>
<tr>
<td>HbA1c (%)</td>
<td>8.96 ± 2.12</td>
<td>8.18 ± 1.59</td>
<td>t = 2.92</td>
</tr>
<tr>
<td>Microalbumin (%)</td>
<td>41.96 ± 93.21</td>
<td>34.45 ± 95.18</td>
<td>t = 0.54</td>
</tr>
<tr>
<td>Waist-to-hip ratio</td>
<td>0.93 ± 0.06</td>
<td>0.95 ± 0.09</td>
<td>t = 1.06</td>
</tr>
</tbody>
</table>

Data are n or means ± SD. *Income values are as follows: 1 = <$5,000, 2 = $6,000–10,000, 3 = $11,000–20,000, 4 = $21,000–30,000, 5 = $31,000–40,000, 6 = $41,000–50,000, 7 = $51,000–75,000, 8 = $76,000–100,000, 9 = >$100,000. †Education was categorized by level of education completed: 1 = <grade 6, 2 = grades 7–9, 3 = grades 10 and 11, 4 = high school diploma, 5 = some college education, 6 = 4-year college degree, 7 = some graduate-level education, and 8 = postgraduate degree.

Data analysis

Because the disease management scales were moderately intercorrelated, the general multivariate likelihood criterion and its associated F statistic (51) were used to assess the independent relationship of each of four sets of independent variables (patient sex, family structure/organization, family world view, and family emotion management) with the block of seven dependent disease management scales. If a multivariate test was significant at P < 0.10, given the initial evaluation of these data, we examined the univariate tests to determine where the significant linkages with the disease management scales occurred.

The analyses were conducted separately for Hispanic patients and EA patients. Ethnic differences involve a host of contextual effects that are not easily reduced to a set of variables that can be controlled in a single multivariate analysis (31,52). The two ethnic groups differed in several significant respects (Table 1), and a test for homogeneity of the variance/covariance matrices of the family scales in the two ethnic groups indicated a lack of equality ($χ^2 = 35.26$, df = 10, P = 0.0001). This result suggested that the pattern of intercorrelations among the four family scales was significantly different between the two ethnic groups.

Because we were interested in patient sex as a factor that may influence the family-disease management relationship, we also examined the multivariate test of four
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Table 2—Multivariate analyses of the effects of patient sex and family on disease management

<table>
<thead>
<tr>
<th>Effect</th>
<th>F</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>EA patients (n = 113)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main</td>
<td>2.32</td>
<td>0.0001</td>
</tr>
<tr>
<td>Sex</td>
<td>1.89</td>
<td>0.0800</td>
</tr>
<tr>
<td>Family</td>
<td>2.42</td>
<td>0.0001</td>
</tr>
<tr>
<td>Structure/organization</td>
<td>1.32</td>
<td>0.2000</td>
</tr>
<tr>
<td>World view</td>
<td>3.60</td>
<td>0.0020</td>
</tr>
<tr>
<td>Emotion management</td>
<td>2.36</td>
<td>0.0300</td>
</tr>
<tr>
<td>Hispanic patients (n = 74)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Main</td>
<td>2.47</td>
<td>0.0001</td>
</tr>
<tr>
<td>Sex</td>
<td>7.63</td>
<td>0.0001</td>
</tr>
<tr>
<td>Family</td>
<td>1.89</td>
<td>0.0060</td>
</tr>
<tr>
<td>Structure/organization</td>
<td>1.73</td>
<td>0.0600</td>
</tr>
<tr>
<td>World view</td>
<td>1.56</td>
<td>0.1600</td>
</tr>
<tr>
<td>Emotion management</td>
<td>1.26</td>
<td>0.2900</td>
</tr>
</tbody>
</table>

Results

Initial analyses

EA patients were better educated (t = 10.98, P < 0.001), had higher family incomes (t = 11.10, P < 0.001), and had lower HbA1c levels (t = 2.92, P = 0.004) than Hispanic patients (Table 1). No significant differences were found between ethnic groups regarding microalbumin, waist-to-hip ratio, or time since diagnosis. Intercorrelations among the seven disease management scales were moderate. For the family domain, high scores for Conflict Resolution were related to good diabetes quality of life (DQOL Satisfaction subscale). Significant differences between male and female patients in disease management also occurred. Hispanic male patients reported a lower BMI and were more physically active than Hispanic female patients (ACT24).

Table 3—Standardized regression coefficients for multivariate analyses of the effects of sex and family on disease management

| Dependent variable | EA patients (n = 113) | HbA1c | -0.07 | -0.05 | 0.01 | -0.20* | -0.15 | 0.04 | 0.440 |
|                   | BMI               | -0.14 | 0.01  | -0.13 | 0.02 | -0.02 | -0.15 | 0.04 | 0.420 |
|                   | SF-36 (General Health) | 0.14  | 0.15  | 0.19† | 0.34† | -0.14 | 0.23 | 0.001 |
|                   | DQOL (Satisfaction) | 0.14  | 0.07  | -0.02 | 0.33† | -0.32‡ | 0.38 | 0.001 |
|                   | Depression        | -0.09 | 0.12  | -0.12 | -0.38‡ | 0.14 | 0.11 | 0.030 |
|                   | ACT24             | 0.24† | 0.13  | 0.13  | 0.16  | 0.14 | 0.11 | 0.030 |
|                   | Diet observations | -0.11 | -0.09 | 0.12  | 0.16  | -0.12 | 0.04 | 0.460 |
|                   | Hispanic patients (n = 74) | HbA1c | -0.05 | -0.10 | 0.01 | 0.06 | -0.01 | 0.02 | 0.940 |
|                   | BMI               | -0.52‡ | -0.10 | -0.19 | 0.01 | 0.05 | 0.31 | 0.001 |
|                   | SF-36 (General Health) | 0.17  | -0.02 | 0.03  | -0.01 | -0.33‡ | 0.24 | 0.002 |
|                   | DQOL (Satisfaction) | -0.15 | 0.06  | -0.31† | 0.22 | -0.15 | 0.15 | 0.040 |
|                   | Depression        | 0.11  | -0.12 | -0.14 | -0.43‡ | 0.21† | 0.13 | 0.090 |
|                   | ACT24             | 0.26† | 0.31‡ | 0.14  | 0.06  | -0.02 | 0.18 | 0.020 |
|                   | Diet observations | -0.09 | -0.26‡ | 0.23* | 0.04 | -0.02 | 0.13 | 0.080 |

*P < 0.10; †P < 0.05; ‡P < 0.01.
Interaction effects with patient sex

The multivariate test for the conditional effect of sex on the family–disease management relationship failed to reach significance for both ethnic groups (EA patients: $F = 0.84, \text{df} = 28,400, P = 0.70$; Hispanic patients: $F = 1.02, \text{df} = 28,248, P = 0.44$). In addition, none of the separate univariate interaction effects reached significance.

CONCLUSIONS — The findings indicate significant linkages between characteristics of the family and disease management that support a social ecological perspective of the management of chronic disease. The pattern of family–disease management linkages, however, differs by ethnic group: family world view and family emotion organization are linked to disease management for EA patients, and family structure/organization is linked to disease management for Hispanic patients. In general, disease management is best in families described as well organized, in families with clear traditional sex roles, in families that have an optimistic belief that life is understandable and manageable, and in families in which both spouses are able to resolve differences of opinion regarding diabetes care. Furthermore, differences in disease management occur by patient sex: male patients from both ethnic groups report more physical activity than female patients, and male Hispanic patients have a lower BMI than female Hispanic patients.

These findings have several implications for clinical care. First, interventions to improve diabetes management may need to be broadened to consider how changes in self-care practices and outcomes will affect and be affected by the family or home setting of care. For example, the effectiveness of programs to improve diabetes-related problem solving may be related to the beliefs, structures, emotional tone, and patterns of relationships that exist in the setting in which most disease management takes place (53). Likewise, patients in families that are in constant conflict will have considerable difficulty following diabetes management regimens.

Second, the multiple independent associations between domains of family life and disease management suggest that the family is not a unidimensional construct (e.g., the supportive vs. the nonsupportive family). The family's multiple dimensions provide multiple targets for intervention that are different in each ethnic group but can be tailored to the needs of individual patients and families, such as training in couple problem-solving and conflict resolution skills or help with family organization and orderliness regarding disease management.

Likewise, the data suggest that disease management also is not a unidimensional construct. Family linkages with disease management occur mainly within the quality of life and behavioral areas, with variation by ethnicity. This finding suggests the need to move beyond an exclusive focus on biological outcomes to assess the effectiveness of clinical interventions.

Third, the findings suggest that different family domains are associated with disease management in the two ethnic groups. The differences, however, may have as much to do with differences in sample size, social class, and life stress as they do with ethnicity per se. For example, the finding that family structure/organization is associated with disease management for Hispanic patients but not for EA patients may be related to the fact that Hispanic patients, who in our sample had a much lower socioeconomic status than EA patients, reported much higher levels of familial and extrafamilial stress than EA patients. High stress may increase the importance of family structure/organization as a stabilizing force regarding disease management. This speculation is supported by an exploratory analysis in which we repeated the family structure/organization and disease management analyses for EA patients by contrasting those EA patients who reported high levels of multiple stresses with those who reported low levels of multiple stresses. We reasoned that, if family structure/organization moderated the effects of multiple stresses on disease management, then highly stressed EA patients would have family structure/organization–disease management relationships similar to those of Hispanic patients. Similar to Hispanic patients, we found that highly stressed EA patients displayed far more linkages between family structure/organization and disease management than did EA patients with less stress.

The lack of uniform findings between the ethnic groups in the other family domains directs attention to differences between groups in social class and stress within the context of different cultural beliefs and practices. These factors provide additional points of reference for developing culturally relevant patient-specific interventions (54).

Several cautions need to be considered when reviewing these findings. For example, we included patients who were at a relatively early stage of the disease, we assessed a very complex set of relationships (the family) with a limited range of family scales, we included only two ethnic groups, and we assessed the patients only at one point in time. More comprehensive longitudinal research with patients and families with type 2 diabetes is needed.

These findings suggest that, like other chronic diseases, characteristics of family relationships are linked to disease management in type 2 diabetes. Further research to describe these relationships over time is necessary. Despite the added complexity, incorporating specific aspects of family organization, world view, emotion management, and problem solving into intervention programs, with or without other family members present, may help patients to better integrate disease management skills into their life context. Preliminary family assessment and intervention guidelines already have been proposed (4) that should highlight this process.

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