From Research to Practice / Barriers to Diabetes Care

Psychosocial Barriers to Diabetes Self-Management and Quality of Life

This article discusses psychosocial barriers to diabetes self-management and quality of life. Although the boundaries between psychosocial and other types of barriers are permeable and at times diffuse, to organize the wealth of information that is available and make sense of it, psychosocial barriers will be discussed in this article, whereas external (systems), internal symptom, and cultural barriers are addressed in companion articles on pages 23, 28, and 13, respectively.

We begin by defining what we mean by psychosocial barriers. Webster's dictionary defines a barrier as “something immaterial that impedes or separates.”¹ In our case, we are concerned with psychological and interpersonal factors that impede diabetes management or diabetes-related quality of life.

Before summarizing the literature on psychosocial barriers, it is necessary to review two decisions made in defining our scope of work. The first was inclusionary and involves considering low levels of psychosocial supports as barriers. For example, although high levels of self-efficacy and social support are generally facilitative of self-management, low levels of these factors can be considered as barriers. In this way of thinking, much of the assistance provided by diabetes educators is to help patients move along the continuum of key psychosocial resources and supports from lower to higher levels.

Second, we have separated proximal barriers arising from low levels of social support from more distal sources of support. For example, we will consider here support from family and significant others, but not support from health care team members, coworkers, or the community in general. This was challenging, since many of the assessment instruments and studies reviewed blend these different types of barriers. Considered from the perspective of an increasingly broad series of concentric rings of influence, the barriers discussed in this paper (see Figure 1) lie in the second level. They are more “external” than internal barriers such as symptoms and biological factors, but more proximal than both systems barriers, such as the organization of medical care, and community/cultural influences.

Priority areas. To reduce the number of studies available on every type of psychological barrier and disturbance imaginable, we have focused on three psychological constructs and two social/interpersonal factors that are both theoretically important and have been applied successfully in other areas of behavioral medicine. The psychological factors are (low levels of) self-efficacy, personal illness models and health beliefs, and depression. The social factors are stress and (low levels of) support from close friends and family.

The remainder of this article is organized into three sections:

1. A brief review of key diabetes studies on psychosocial barriers, including both assessment instruments and interventions designed to identify and cope with psychosocial barriers;
2. Data from a new scale that we have developed that blends the

In Brief

Diabetes self-management can be difficult and frustrating for both patients and practitioners. Information is needed about which barriers present the greatest obstacles for which types of patients, and from this, practical, cost-effective interventions need to be developed. This article reviews existing research on psychosocial and interpersonal barriers to diabetes self-management and quality of life. It also presents new data on a self-efficacy-based barriers instrument and makes recommendations for future research.
concepts of self-efficacy and external barriers, to illustrate some of the issues in this area of research; and,
3. Discussion of the strengths and weaknesses of current research on psychosocial barriers and recommendations for future research, focusing on steps that will expedite the translation from research to practice.

REVIEW OF RECENT LITERATURE
Two databases, National Library of Medicine PubMed and Online Computer Library Center First Search, were consulted combining the search terms diabetes and barriers with the terms self-management, self-efficacy, motivation, empowerment, psychosocial, personal models, problem solving, interventions, stress, depression, and social support. We considered both assessment and intervention studies that addressed barriers published from 1992 to 2000. Additional references on the topic that were cited in journal articles from these searches were also included.

Classification Schema for Studies
The classification schema recommended by Greenwald and Cullen was used to organize studies into five stages of research. In this schema, Phase 1 studies identify and evaluate the relative importance of barriers to diabetes self-management. In Phase 1, data are collected through interviews, focus groups, and cross-sectional and prospective evaluations. This information is prerequisite to developing hypotheses and behavioral targets for interventions. Phase 2 studies are designed to develop and test evaluation tools and methods. The validity and reliability of instruments are assessed. These types of studies are prerequisite to testing the efficacy of interventions. Phase 3 studies use ideal scientific conditions to test the efficacy of interventions designed to reduce barriers and improve diabetes self-management. Building from the results of all previous types of research, Phase 4 studies use large, representative samples to test the effectiveness of interventions when applied in clinical settings. Phase 5 studies evaluate the dissemination of barriers-based intervention protocols. Phase 5 studies were not identified and therefore are not discussed further.

Phase 1 Studies
Our search identified 22 Phase 1 barriers studies, each exploring psychosocial predictors of diabetes self-management. Only one study used a prospective, rather than cross-sectional design. Very few attempted to control for moderators such as social desirability of instruments, body mass index, diabetic complications, and so forth. The vast majority of studies used HbA1c as the primary indicator of how well subjects adhered to diabetes guidelines, although several included both HbA1c and measures of self-management behaviors. Finally, a large percentage of these studies were conducted with difficult-to-reach, low-income, and minority populations. While the attempt to reach low-income and minority populations represents important progress, unfortunately, response rates were often low, ranging from 30 to 70%, when reported at all.

The majority of Phase 1 studies were designed around well-established psychosocial constructs including the Health Belief Model, Locus of Control, Self-Efficacy, and Social Support. (See Table 1.) In these studies, low positive correlations were often found between psychosocial predictors and markers of self-management. The low correlation coefficients suggest that these global constructs may not be useful predictors of self-management behaviors and that investigators should look for other mediating factors when designing interventions. However, before coming to this conclusion, it is important to consider that the measurement of self-management behaviors and the measurement of psychosocial barriers are both challenging. Low correlation coefficients may result from measurement error rather than lack of construct significance.

Comparing two indicators of self-management behavior illustrates one difficulty with measurement in barriers research. In much of the literature reviewed, two dependent variables were used, usually HbA1c and self-reported behaviors. The correlations between these two variables were surprisingly low in each of the studies that looked at both. Moreover, in one study, the correlation between self-management and HbA1c disappeared completely when the analyses were restricted to subjects with significant complications. This finding highlights the possibility that, for many individuals, physiological processes and medications may cause the relationship between HbA1c and self-management behaviors to be tenuous or insignificant. An important note made by several researchers examining HbA1c was that often patients were not aware of the marker’s significance. Several authors suggested that personalized feedback on HbA1c levels may be a useful tool that clinicians could use to educate patients and help them avoid complications.

In a series of studies, Hampson and colleagues have developed and tested Personal Models of Diabetes (e.g., beliefs about the consequences of having diabetes and about the effectiveness of treatment) as predictors of
self-care behaviors. Building from other models, Personal Models may represent a significant advancement because they have been shown, through prospective designs, to predict HbA1c levels and self-management after controlling for other factors. Personal Models theory is an extension of Self-Schema theory. It identifies those variables that patients themselves believe to be central to their experience of illness and its management. Findings suggest that Personal Models may mediate the association between social support and behaviors. Hampson’s work and other findings underscore the importance of internal locus of control with respect to cause of disease and the importance of patients believing in the efficacy of their treatment regimen.

Cox and colleagues have highlighted the psychosocial implications of insulin-induced hypoglycemia

### Table 1. Number of Studies Reporting Different Types of Information

<table>
<thead>
<tr>
<th>Type of research</th>
<th>Number of studies identified</th>
<th>Psychosocial Barriers (number looking at each barrier)</th>
<th>Self-care Regimen Area (number addressing each area)</th>
<th>Study Population (number using each type)</th>
<th>Design Used (% each type)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1 (studies designed to evaluate the relative importance of certain barriers)</td>
<td>22</td>
<td>Alternative therapies, 1 Anxiety, 1 Attitudes, 4 Depression, 2 Empowerment, 2 Fear of hypoglycemia, 1 Health beliefs, 5 Interview responses, 6 Knowledge, 2 Locus of control, 7 Motivation, 2 Outcome expectancies, 2 Personal Models, 3 Problem solving, 1 Self-efficacy, 1 Self-esteem, 3 Social support, 6 Stress, 3</td>
<td>Multiple (diet, exercise, glucose monitoring, taking medications), 16</td>
<td>Convenient sample, 6</td>
<td>Cross-sectional, 13</td>
</tr>
<tr>
<td>Phase 2 (studies designed to measure the validity, reliability, and utility of assessment instruments)</td>
<td>7</td>
<td>Anxiety, 1 Attitudes, 1 Depression, 1 Coping, 1 Emotional distress, 1 Health beliefs, 1 Locus of control, 1 Personal Models, 1 Self-efficacy, 4 Social support, 2</td>
<td>Multiple, 4 Glycemic control (HbA1c), 4 Other, 3</td>
<td>Convenien sample, 5 Low-income &amp; minority, 1 YOUTH, 2</td>
<td>Intervention change scores, 2 Correlation with other measures of self-care, 4 Test-retest reliability, 2 Cluster analyses, 1 Prospective predictive validity, 2</td>
</tr>
<tr>
<td>Phase 3 (studies that used ideal experimental conditions to test interventions designed to reduce psychosocial barriers)</td>
<td>3</td>
<td>Attitudes, 2 Empowerment, 1 Knowledge, 3 Personal Models, 1 Problem solving, 1 Self-efficacy, 1 Social support, 2 Stress, 1</td>
<td>Multiple, 3 Quality of life, 1 HbA1c, 4</td>
<td>Convenient sample, 3 Low-income &amp; minority, 1 YOUTH, 1</td>
<td>Randomized control trial, 3 Quasi-experimental, 2</td>
</tr>
<tr>
<td>Phase 4 (studies that used typical clinical conditions to test interventions designed to reduce psychosocial barriers)</td>
<td>1</td>
<td>Self-efficacy</td>
<td>Multiple, 1</td>
<td>Convenient sample, 1</td>
<td>Pre-post test, 1</td>
</tr>
</tbody>
</table>
among type 1 diabetes patients. These findings are particularly relevant because intensive insulin therapy is becoming more common. These studies suggest that fear of severe hypoglycemia may be a barrier to tight metabolic control for some type 1 patients. The significance of the barrier is related to the number of past hypoglycemic episodes and a patient’s ability to detect and respond to hypoglycemic symptoms. The series of studies by Cox and colleagues also suggests that hypoglycemic episodes may adversely influence family relationships. These authors recommend that clinicians assess this barrier in their type 1 diabetes patients and, when appropriate, provide hypoglycemic awareness training.

While only one article was identified that examined whether the use of alternative therapies could be considered a barrier to conventional self-management of diabetes, the findings were important. In interviews of 43 elderly, low-income, Hispanic diabetes patients, Hunt et al. observed that the use of herbs and prayer in the treatment of diabetes was not a barrier. Rather, those who used alternative treatments also used conventional treatments, and those who did not use conventional treatments did not use alternative therapies either.

Six Phase 1 studies were identified that examined the relationship between social support barriers and self-management. Most studies reported moderate positive correlations between levels of social support and markers of self-care (most often Hba1c). Most of the studies were cross-sectional in nature, and rarely was the strength of the relationship tested by determining whether significant relationships remained after controlling for other predictors. Boehm et al. observed that it may be possible to get too much social support. In this study, subjects reporting that they received more social support than desired (using the Diabetes Care Profile) were less likely to work with a nurse to improve health behaviors using contingency contracting. The authors speculate that patients feared being nagged or harassed about their behaviors. Other authors noted that reliance on family and friends can be risky because family and friends may have limited information about diabetes regimens and may be unable to accurately evaluate the extent of the patient’s adherence.

Moreover, if health care recommendations are not consistent with values and beliefs, family or friends can subvert self-management. Finally, it was noted that family members can be supportive of a patient following a special diet for diabetes but often times are not interested in following such a diet themselves. Preparing two types of meals may not be feasible for most families.

Several authors noted that assessment instruments may be useful for identifying patients for whom low levels of social support is an important barrier. A well-validated, practical instrument would help practitioners and patients identify possible social support problems, including too much social support.

Phase 2 Studies
Seven studies were identified that primarily focused on development and validation of barriers-related assessment instruments. A majority of these studies focused on psychometric characteristics, especially internal consistency, and presented cross-sectional validity data, often using Hba1c as the criterion. Progress has been made in this area, and, in particular, useful instruments have been developed to measure self-efficacy and empowerment. In our opinion, however, the majority of the literature has focused too much on internal consistency reliability and not enough on prospective predictive validity, sensitivity to change as a result of intervention, or on the development of instruments that are broadly applicable and feasible to use in applied settings.

Important exceptions to these generalizations are the work of Polonsky and colleagues on the Problem Areas in Diabetes (PAID) scale, as well as that of Hampson and colleagues on Personal Models of Diabetes and of Cox and colleagues on fear of hypoglycemia, which were discussed above. The PAID is a diabetes-specific distress instrument that has respondents rate the degree to which each of 20 common situations is currently problematic for them. This scale assesses diabetes-specific overall emotional distress, interpersonal distress, regimen-related distress, and physician-related distress. A recent 28-item revision of the PAID produces subscales on these four dimensions as well as an overall score. The original PAID has good construct and criterion validity and has been shown to be responsive to psychosocial intervention.

Phase 3 and Phase 4 Studies
Compared to the number of Phase 1 studies identified, only a handful of Phase 3 barriers-based intervention efficacy studies were found. All five Phase 3 intervention studies identified reported significant treatment-related improvements. However, the effect sizes of interventions were not large, and most of the interventions would need significant modification before they would appeal to a wide range of either health care practices or patient populations or would likely be maintained after research funding was terminated.

Interventions were often time-consuming for both patients and practitioners. Excluding the two interventions specifically designed for follow-up or to be brief, the number of hours invested by subjects participating in a diabetes management intervention was considerable. This time investment, combined with transportation needs, restricts participation to highly motivated individuals who are able to travel repeatedly to intervention sites during usual work hours.

The intervention studies do add important information to our understanding of how to reduce psychosocial barriers. Of interest are prospective findings suggesting that care must be taken in developing interventions to enhance social support. In this study of adolescent type 1 patients, initial improvements in the likelihood of socially skillful responses later deteriorated, suggesting that assertiveness training may not have been sufficient and, in the long run, may have led to behavioral inhibition and reduced social support.

Only one Phase 4 effectiveness intervention to reduce psychosocial barriers was identified. In this study, self-efficacy for self-management behaviors was assessed in 115 insulin-requiring patients before and after 12 home nursing visits. The intervention was shown to enhance self-efficacy for self-management, particularly among those patients with low self-efficacy at the beginning of the intervention. Whether self-efficacy improvement brought about by home care nurses translates into improved self-management behaviors, improved patient health, and reduced health care costs are important topics for future investigation.
ILLUSTRATIVE BARRIERS INSTRUMENT AND DATA

To illustrate several of the conceptual, assessment, and analytic issues involved, this section presents data on a new barriers instrument from our research group. Earlier work by our group on the Barriers to Self-Care questionnaire is briefly reviewed to provide a context for discussion of the new instrument, called Challenges to Illness Management Scale (CIMS), and recent findings.

The original barriers scale was developed for use with type 1 diabetes and consisted of 15 items, including at least 3 items from each of 4 regimen areas: diet, exercise, glucose testing, and insulin administration.22 It was modified in 1989 to be applicable to people with type 2 diabetes and to older adults.23,24

The second version of the Barriers to Self-Care scale was evaluated in one prospective assessment study and one intervention study of 127 and 78 type 2 diabetes patients, respectively.23,24 There was consistency across studies in the reported frequency of barriers to different regimen components, with barriers to dietary self-care occurring most frequently, followed by exercise barriers. The psychometric characteristics of the instrument included high Chronbach’s alphas for the overall scale (0.84–0.86) and also indicated that the Barriers scores were moderately stable over 6 months. The Barriers scores were related to concurr-ently collected self-report measures of dietary and exercise self-management, with the regimen-specific Barriers scales being the best predictors of these respective behaviors. Barriers to self-care have tended to be unrelated to HbA1c, given that some people who encounter barriers will overcome them, and others will not. Analyses to predict 6-month self-management behaviors from baseline Barriers scores indicated that, in general, the overall Barriers score was the best pre-dictor of both self-reported and more objective measures of dietary and exercise performance.

To create the CIMS, the Barriers to Self-Care instrument was expanded to include an individual’s disease management challenges across several different settings, ranging from more proximal factors, such as personal challenges and obstacles from family and friends, to more distal factors, including health care team, worksite, organizational, and community barri-

ers. Barriers to engaging in the self-management tasks of lowering dietary fat intake, engaging in physical activity, and taking medication were retained; barriers to engaging in stress-management activities were added.

Two versions of the new instrument were constructed. One, the CIMS/Difficulty version, asked the respondent to indicate for each barrier, using a scale from 1 to 5, how difficult it was over the past 3 months to overcome that obstacle in trying to reach their self-management goals. The second, the CIMS/Confidence version, asked respondents to indicate, on a scale from 0 to 10, how confident they were that, over the next 3 months, they could follow their self-management activities when faced with each obstacle. This section reports on the use of the CIMS in two recent studies, focusing only on the psychosocial barriers aspects of the scale.25

One study was a randomized clinical intervention trial,25 and one26 was a prospective observational study. The observational study included a convenience sample, whereas the intervention study drew a representative sample of participants from lists of primary care patients. The intervention study targeted dietary change, was delivered one-on-one by dietitians and research staff, included 40 physicians from 12 medical practices, and was conducted in a hospital wellness center setting.

Statistical Analyses

The statistical software package SPSS for Windows, version 9.0, was used for all analyses. The characteristics and normative data for each study sample are expressed in means ± SD or percentages. Pearson correlation coefficients were computed to evaluate the magnitude of association between baseline and post-test (test-retest), of the CIMS/Difficulty version (at 6 months) and CIMS/Confidence version (at 12 months) for the intervention study. Pearson correlation coefficients were also computed to assess relationships of regimen area subscales (i.e., diet, exercise, stress management, medication taking) and the Overall Challenges scores to criterion variables (validity coefficients). Alpha reliability coefficients were used to assess relationships among items within a scale.

Results

All participants had type 2 diabetes for at least 1 year (average durations of 6.3 and 8.5 years) (Table 2). The mean ages of the two samples were 59 and 62 years, and there were slightly more women than men.

The mean levels and standard deviations for both the CIMS/Difficulty version and the CIMS/Confidence version are presented in Table 2 (higher values indicate more obstacles to self-care and more confidence on all scales). These means show consistency across studies, with patients typically reporting higher levels of dietary, exercise, and stress-management barriers and lower levels of medication-taking barriers. The internal consistency of the scales, assessed by alpha reliability coefficients, was very acceptable (mean = 0.90).

Test-retest correlations over 4 months were examined for the observational study and over a 6-month period for the control group only in the intervention study. All were significant, although the magnitude of these correlations tended to be moderate (mean r = 0.6; range of r = 0.43 [for medication taking in the intervention study] to 0.80 [for the Overall Challenges scores in the observational study]).

Correlations among the CIMS scales measuring different regimen behaviors within each study (not shown in Table 2 but available from the authors) ranged from 0.20 to 0.81, with an average correlation of 0.50.

Correlations were calculated to evaluate relationships between the CIMS subscales and participant characteristics within each study (i.e., age, insulin status, gender, number of co-morbid conditions, diabetes duration, smoking status, ethnicity, income, living alone). Overall, there were few significant correlations. Only one trend emerged across both studies: older people had fewer barriers on most scales, and this correlation was modest (mean r = 0.32). Social desirability was assessed in the observational study26 and did not significantly correlate with any of the CIMS subscales.

Table 3 shows the correlations between Overall Challenges score as well as the dietary, exercise, and stress-management subscales, with criterion variables. For the intervention study, two versions of the CIMS instrument were administered.
Therefore, both 6-month (using difficulty ratings) and 12-month (using confidence ratings) concurrent validity coefficients are reported. Prospective validity coefficients are also presented using 6-month CIMS scales to predict 12-month behavioral outcomes. For dietary comparisons, criterion measures were derived from the Kristal Food Habits Questionnaires,27 the Summary of Diabetes Self-Care Diet subscale28 and the Block Fat Screener.29 For exercise, comparisons were with the Summary of Diabetes Self-Care Exercise subscale28 and the Physical Activity Scale for the Elderly (PASE).30 For stress management, comparisons were with the Lifestyle Appraisal Questionnaire.31 In addition to these criterion variables, for the Overall Challenges score, comparisons were also made with the Illness Intrusiveness Scale,32,33 a measure of quality of life. These correlations were all significant.

For the observational study, these same criterion measures were used, except that the Perceived Stress Scale34 was used to validate the stress-management scale; and to further validate the Overall Challenges score, we also used the Center for Epidemiological Studies-Depression (CES-D) scale.

Concurrent validity coefficients were of moderate magnitude, and all in the expected direction. As would be expected given their strong interrelationship (even over the 6-month interval), concurrent validity correlations for CIMS/Difficulty version and CIMS/Confidence version ratings were generally similar. Stress- and exercise-dependent variables appeared to be predicted better than dietary indices. Prospective analyses were more mixed. Although significant relationships were reported in all self-management areas in the Glasgow and Toobert (2000) intervention study,25 only stress management was predicted prospectively by CIMS/Difficulty ratings in the observational study or with an impressive magnitude. More definitive prospective data are not yet available for the confidence ratings.

In conclusion, these analyses suggest that the CIMS has reasonable psychometric properties. It appears that the Overall Challenges scores had better psychometric properties than subscale scores, especially on the CIMS/Confidence version, while the regimen-specific subscales were generally better predictors of their respective criterion variables. A potential advantage of the CIMS is that it can

### Table 2. Sample Characteristics, Reliability Estimates, Normative Data, and Test-Retest Results for Challenges Scales

<table>
<thead>
<tr>
<th>Study</th>
<th>Reliability estimates</th>
<th>M eans and standard deviations for Challenges Scales</th>
<th>Test-retest</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Scale</td>
<td>Items (n)</td>
<td>Coefficient alpha (%)</td>
</tr>
<tr>
<td>Glasgow &amp; Toobert, 2000</td>
<td>CIMS/Difficulty Version (1-5)</td>
<td>Diet 14</td>
<td>0.92</td>
</tr>
<tr>
<td></td>
<td>CIMS/Confidence Version (0-10)</td>
<td>Diet 14</td>
<td>0.97</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exercise 11</td>
<td>0.97</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stress M gt.</td>
<td>9.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M eds 5</td>
<td>0.85</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Overall Score 47</td>
<td>0.98</td>
</tr>
<tr>
<td>Glasgow et al., 2000</td>
<td>CIMS/Difficulty Version</td>
<td>Diet 14</td>
<td>0.91</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Exercise 11</td>
<td>0.92</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stress M gt.</td>
<td>5.80</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M eds 5</td>
<td>0.84</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Overall Score 47</td>
<td>0.95</td>
</tr>
</tbody>
</table>

Average values are mean percentages ± SD unless otherwise specified.

*Test-retest* for the first study compares the Difficulty version versus the Confidence version of the scale, so the signs for these correlations have been reversed.

† P < 0.001

** Socioeconomic status

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Average values are mean percentages ± SD unless otherwise specified.
be used with patients having multiple chronic illnesses or to compare barriers across different disease groups.

**DISCUSSION**

We have reviewed a number of different concepts, instruments, and approaches related to psychosocial barriers to diabetes self-management and quality of life. The complexity of this area can be overwhelming, and we still have much to learn, as discussed below. Nevertheless, in this section we attempt to summarize the key conceptual issues, research findings, and lessons learned by the studies conducted to date.

The first conceptual issue is to clarify what is a barrier and what is an outcome. For example, depending on the specific research question being addressed, depression can be either a barrier/independent variable or an outcome/dependent variable. In this article, we have defined (psychosocial) barriers as psychological and interpersonal factors that impede diabetes self-management and quality of life. In this conceptualization, depression would be a barrier, due to its demonstrated inverse relationship to self-management and quality of life.

The underlying assumption in this conceptualization is that psychosocial barriers influence other longer-term outcomes, such as glycemic control, cardiovascular status, and eventual development of diabetes complications indirectly via their influence on self-management and/or quality of life. Brown and Hedges have found empirical support for this assumption, but at least some psychosocial barriers, such as stress and possibly depression and social support, may also have direct as well as indirect effects on metabolic outcomes.

As shown in Table 1, the vast majority of studies in this area have been Phase 1 or hypothesis-generating studies. Some concepts have been translated into useful assessment instruments (Phase 2 research), but few barriers concepts have yet been translated into effective or practical interventions. Although it may seem intuitively obvious that interventions...
to modify demonstrated barriers would prove beneficial, this is not necessarily the case. Some barriers may prove resistant to change, and alteration of others may not produce improved outcomes—especially if such an intervention is not related to patient values and goals. Clearly, more barriers-based intervention research is needed.

The Phase 1 psychosocial barriers studies have done a good job of including different ethnic and cultural groups and have identified both common and unique barriers to self-management across different groups. However, later-phase studies generally have yet to apply these findings or to include diverse or representative patient samples.

Based on the research to date, the general psychosocial barriers that seem most strongly and consistently related to low levels of self-management and diabetes-related quality of life are low self-efficacy and low levels of family social support. There are also emerging literatures, including multiple prospective studies, studying the impact of both depression and Personal Models of Diabetes on diabetes outcomes. Finally, two more specific measures of barriers, fear of hypoglycemia and diabetes-related distress, appear to be clinically useful.

**Methodological and Interpretive Issues**

Assessment of diabetes barriers presents a variety of methodological challenges. Foremost among these are decisions regarding how barriers questions will be phrased and what criterion variables will be used. Standard questionnaire development issues of potential response bias, ensuring an adequate range of responses, and investigating and/or controlling for potential social desirability and method variance issues apply. In addition, there are issues specific to barriers assessment that raise interpretive complexities.

One important issue concerns the type of ratings that respondents are asked to provide and the time frame of the questions (e.g., “over the past 6 months” vs. “currently” vs. “thinking ahead over the coming 3 months”). Many barriers questions have asked how difficult barriers items have been over a previous period of time. Having done this ourselves, we understand that this is intuitively appealing and seems straightforward. Interpretive difficulties arise, however, when attempting to differentiate self-reports of self-management behaviors (“How often did you do X?”) from this type of barriers assessment (“How difficult was barrier A in preventing you from doing X?”).

Many respondents likely have difficulty understanding the difference between these two questions. If they do make the distinction, it is likely that respondents will base their difficulty ratings on their self-management behavior outcomes. This is problematic and somewhat circular if barriers are to be considered as predictors of self-management. Methodologically cleaner ways to state barriers questions are a) to ask about the frequency of barrier occurrence (and to separate this from assessment of self-management behaviors), or b) to ask about confidence in overcoming barriers over a future interval (and to prospectively assess self-management).

This brings up the related issue of what should be used as criterion variables in studies of diabetes barriers. In our opinion, self-management—especially if it is possible to assess self-management via different modalities—and diabetes-related quality of life are the most direct and appropriate consequences of barriers. As discussed above, the most commonly used outcome in the literature has been HbA1c, however. This practice can create interpretive difficulties, especially when only cross-sectional analyses are conducted. In the most extreme (but not unusual) case, when barriers are assessed “at present” and HbA1c is collected concurrently (reflecting glycemic control over the past 6–8 weeks) it is impossible to determine directionality of effects. The most logical conclusion if a relationship is found in this type of study would be that poor glycemic control produced barriers, rather than vice versa, given the temporal parameters.

This is why prospective designs are a necessity in barriers research. Even if using a prospective design, it is strongly recommended that investigations also include measures of self-management and quality of life when using HbA1c as an outcome. This strategy then permits investigation of direct versus indirect effects of barriers. A final interpretive issue concerns whether one should expect barriers ratings to be stable or to change over time, specifically as a result of intervention. In our view, this depends on how barriers questions are worded. If questions are phrased concerning the frequency of experiencing different barriers, one would not necessarily expect intervention to impact the frequency of different barriers. On the other hand, if barriers questions are phrased as self-efficacy type questions, asking about confidence that one can overcome different barriers, it would be expected that such a measure would be responsive to intervention.

**Future Directions**

We conclude with three recommendations for future research.

1. **Move beyond correlational studies** to research designs that allow causal inferences. Either longitudinal designs that permit causal modeling or, preferably, intervention studies that tailor interventions based on reported barriers are needed to advance the field. Such designs will allow investigation of the extent to which changes in barriers versus other process factors are related to improvements in study outcomes.

2. **Identify similarities and differences in both individual barriers and in types of barriers across different ethnic and cultural groups and across different regimen behaviors.** Few direct comparisons have been made of psychosocial barriers across different groups. A recent exception to this conclusion is a cross-cultural study of the PAID instrument among Dutch and U.S. patients.

Given the well-established finding of low intercorrelations among different self-management behaviors, it is likely that different barriers may predict different self-management behaviors. Few studies have addressed this level of complexity.

3. **Develop practical assessment and intervention approaches that can be implemented in primary care or similar settings and are capable of reaching large and representative segments of the population.** There is still important basic research to be conducted regarding psychosocial diabetes barriers. However, more efforts need to be devoted to developing methods that can be integrated broadly into practice settings (as evidenced by the dearth of Phase 4 and Phase 5 studies). We need “translational research” to test...


22Glasgow RE, Anderson RM: In diabetes care, moving from compliance to adherence is not enough: something entirely different is needed. Diabetes Care 22:2090–2092, 1999


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