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Changes in Diabetes Distress Related to Participation in an Internet-Based Diabetes Care Management Program and Glycemic Control

Stephanie J. Fonda, Ph.D.,[1,2] Graham T. McMahon, M.B., B.C.H.,[2,3] Helen E. Gomes, M.S., A.P.R.N.,[3] Sara Hickson, M.P.H.,[3] and Paul R. Conlin, M.D.[2,3]

Abstract

Background:

This article investigated how changes in diabetes distress relate to receiving care management through an Internet-based care management (IBCM) program for diabetes and level of participation in this program. Further, it examined the relationship between diabetes distress and changes in glycemic control.

Methods:

We enrolled patients of the Veterans Affairs Boston Healthcare System with diabetes who had hemoglobin A1c (HbA1c) levels of ≥9.0%. Subjects were randomized to usual care (n = 52) or IBCM (n = 52) for 1 year. We measured diabetes distress at baseline and quarterly thereafter using the Problem Areas in Diabetes (PAID) questionnaire. Glycemic control was determined by baseline and quarterly HbA1c. For subjects randomized to IBCM, we measured participation by observing frequency and consistency of their usage of the IBCM patient portal over 12 months. Linear mixed models were used to analyze THE data.

Results:

PAID scores declined over time for both treatment groups. Among subjects randomized to IBCM, the decline in PAID scores over time was significant for sustained users of the IBCM patient portal but not for nonusers. Moreover, subjects whose usage of the patient portal was sustained throughout the study had lower PAID scores at baseline. With respect to changes in glycemic control, HbA1c reduced individual differences in PAID scores by 44%; a lower baseline HbA1c was associated with lower baseline PAID scores, and over time, the decrease in HbA1c was associated with further decreases in the PAID score.

Conclusions:

Participation in IBCM varies by initial diabetes distress, with people with less distress participating more. For people who participate, IBCM further mitigates diabetes distress. There is also a relationship between achievements in glycemic control and subsequent lowering of diabetes distress. Future research should identify how to maximize fit between patient needs and the provisions of IBCM, with the aim of increasing patient engagement in the active management of their health using this care modality. A key to maximizing fit might be first addressing metabolic control aggressively and then using IBCM for sustainment of health.

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Author Affiliations: [1]Joslin Diabetes Center, Boston, Massachusetts; [2]Harvard Medical School, Boston, Massachusetts; and [3]Medical Service of the Veterans Affairs Boston Healthcare System, Boston, Massachusetts

Abbreviations: (HbA1c) hemoglobin A1c, (IBCM) Internet-based care management, (IDEATel) Informatics for Diabetes and Education Telemedicine, (PAID) Problem Areas in Diabetes, (PCP) primary care physician, (VA) Veterans Affairs

Keywords: diabetes distress, disease management, Internet, PAID scale, patient care management, psychosocial

Corresponding Author: Stephanie J. Fonda, Ph.D., Walter Reed Army Medical Center, Department of Medicine/Endocrinology, 6900 Georgia Avenue NW, Bldg 2, Room 7D, Washington, DC 20307; email address *fondasj@gmail.com*

Introduction

Diabetes frequently coexists with mood problems, such as major depression, depressive symptoms, anxiety, and diabetes distress.[1–6] The biopsychosocial model[7,8] posits that mood problems are associated with glycemic control, particularly hemoglobin A1c (HbA1c). A meta-analysis of 24 studies[9] found support for this position with respect to depression/depressive symptoms and glycemic control. Less has been documented regarding diabetes-specific distress and glycemic control, although existing research suggests a similar relationship.[10,11] It is further hypothesized that mood problems relate, either as a barrier or as a consequence, to the ability to achieve and maintain an appropriate self-care regimen among people with diabetes.[12–17]

A systematic review of the literature indicates that disease and care management can improve some problems associated with diabetes, especially when combined with educational interventions, decision support, and reminders.[18] Recently, diabetes research has addressed whether the benefits of disease and case management can be realized effectively through the use of care management tools employing information technology. Much of this work shows that an Internet-based mode of delivery results in improvements in diabetes individual-level biomedical outcomes and quality of care.[19–21] For example, an Internet-based care management program for elderly people with diabetes, called the Informatics for Diabetes and Education Telemedicine (IDEATel) project, favorably affected subjects' glycemic control, blood pressure, and lipids irrespective of whether subjects were also depressed.[22] However, IDEATel was not associated with an improvement in depression and diabetes distress.[23] With the notable exception of research on the IDEATel project, there has been a paucity of studies addressing the efficacy of Internet-based care management for the mitigation of disease-related distress among people with diabetes.

We previously documented substantial drops in HbA1c, blood pressure, and lipids among subjects treated through an Internet-based care management (IBCM) program for people with diabetes.[24] Within this same cohort of patients, the analyses reported here addressed three aims: (1) to examine whether changes in diabetes distress relate to receiving diabetes care management through an IBCM program; (2) among subjects who receive IBCM, to test whether changes in diabetes distress relate to usage of its patient portal; and (3) to determine whether changes in diabetes distress relate to changes in glycemic control.

Subjects, Materials, and Methods

Subjects

This prospective, randomized clinical trial was conducted at the Department of Veterans Affairs (VA) Boston Healthcare System. The institutional review board of the VA Boston Healthcare System reviewed and approved the study protocol. All subjects provided informed consent.

Study subjects had poorly controlled diabetes, as indicated by an HbA1c level ≥9.0% at screening.From this pool of potential subjects meeting, the study enrolled 104. The recruitment flow has been described previously.[24]

Protocol

All subjects attended a half-day self-management education session for instruction in diabetes core-content areas as recommended by the American Diabetes Association.[25] We then randomized subjects to IBCM (n = 52) or usual care (n = 52). Subjects in the IBCM group received a notebook computer, a glucose meter, a blood pressure monitor, training in the use of all study devices, complementary toll-free dial-up Internet service, and access to the secure IBCM program used for this study (MyCare Team, developed at Georgetown University). They were encouraged to perform home blood pressure monitoring at least three times weekly; recommendations for home glucose testing were individualized for each patient. The Web site (a) accepted electronic transmissions from blood pressure and glucose monitoring devices and displayed these data in graphic and tabular form for the participant and care manager to review in patient and provider portals, (b) allowed subjects to send and receive secure messages to and from the care manager, and (c) contained Web-enabled diabetes educational modules and links to other Web-based diabetes resources.

Subjects interacted with the study's advanced practice nurse, who was certified as a diabetes educator, through the internal messaging system of the IBCM and occasionally through telephone contact. Contact generally was initiated by the subjects. If a subject did not initiate contact for 2 weeks, the study coordinator attempted to contact him/her and encourage usage of the IBCM

portal. The advanced practice nurse also initiated contact if the subject uploaded home monitoring data or if new laboratory data were entered into the subject's electronic medical record. S/he would review these data and, using treatment algorithms for glucose and hypertension management, provide care recommendations to the primary care physician (PCP) and subjects.

Subjects in the usual care group continued to be cared for by their PCPs in the VA Boston Healthcare System. The VA has a series of performance measures and other benchmarks that PCPs are required to attend to, especially pertaining to diabetes care. Examples of these performance measures are whether patients are getting recommended examinations and lab tests at the recommended intervals and whether patients are achieving HbA1c and lipid goals. As a result, usual care in the VA Boston Healthcare System tends to be good, and PCPs typically give more attention to people with higher HbA1c values.

We collected outcome data from all subjects at baseline and at 3, 6, 9, and 12 months after enrollment. For subjects in the usual care group, visits for data collection were the only times they had contact with study staff other than the half-day diabetes education session. Log-ins to the IBCM were recorded automatically as they occurred.

Measures

For the assessment of diabetes distress, we used the Problem Areas in Diabetes (PAID) scale. The PAID scale comprises 20 items summed to provide a total score of diabetes distress. The scale asks about feelings of guilt, anxiety, worry, loneliness, and burnout around diabetes, feelings about diabetes care providers, and level of comfort with social situations, among other things. It has high internal reliability (>0.90), moderate to strong correlations with a range of theoretically related measures, and is responsive to changes in brief psychosocial and educational interventions.[26,27] Welch and colleagues[28] showed medium effect sizes for the PAID scale across different psychosocial, educational, and medical interventions for diabetes. Each item is coded to indicate the severity of a problem (0, not a problem, to 4, serious problem). We summed the 20 items and multiplied by 1.25 to yield a final score between 0 and 100.

For the characterization of participation in the IBCM program's patient portal among subjects in the treatment group, we studied and summarized each subject's log-in history to reveal common patterns of usage. These patterns included nonuse (n = 16), early cessation (n = 9), sustained but irregular use (n = 13), and sustained, consistent use (n = 14). Nonuse applied to subjects who logged in only during the month following study enrollment. Early cessation referred to the pattern of subjects who generally logged into the patient portal on a monthly basis during the first 3 to 6 months of the study, but not afterward. Sustained, irregular use described the pattern of subjects who logged into the patient portal at least 1 day during most of the 12 months of the study with the exception of 1 to 3 nonconsecutive months. Sustained, consistent use referred to the usage of subjects who logged into the patient portal at least 1 day during each month following enrollment; most of these logged in multiple days per month.

The study used a time-varying measure of HbA1c, namely HbA1c level as quantified by laboratory assay at baseline and at 3, 6, 9, and 12 months. By time-varying, we mean that the value for each subject's HbA1c measure can differ at each measurement occasion. To facilitate interpretation of the statistical analyses of HbA1c effects, we recentered time-varying HbA1c around a substantively meaningful constant, namely 7.0%.[29]

Statistical Analyses

The analyses tested for group differences in baseline characteristics using t-tests for continuous variables and χ^2 tests for categorical variables. The analyses also examined pairwise correlations of subjects' baseline characteristics with their PAID scores and their HbA1c levels. Using linear mixed models for longitudinal data, the analyses characterized subjects' changes in PAID scores to establish an unconditional growth or baseline model. Again using linear mixed models, we next tested the associations of (1) treatment group, (2) usage of the technology (among recipients of IBCM), and (3) changes in HbA1c with changes in PAID scores. We checked the validity of the findings by adding subjects' baseline characteristics to the linear mixed models; only baseline characteristics found to be significant in pairwise correlation analyses were added. We performed all analyses using in SAS version 9.1 software (SAS Institute, Cary, NC).

Results

At baseline, the mean age of the subjects was 61 years and the sample was predominantly male (99%), non-Hispanic white (77%), currently married (61%), and had attended some college or more (67.3%) (**Table 1**). The average duration of diabetes was 12.5 years, with only four subjects having been diagnosed within 1 year of

enrollment in the study and none having been diagnosed for less than 3 months. About 49% of the subjects were taking oral medications but not insulin, and 51% were taking insulin. The subjects' average HbA1c level at baseline was 9.9%. The average PAID score was 25.1. Data showed that a person with approximately this score could have reported "minor" to "somewhat serious problems" for over two-thirds of the items covered by the PAID questionnaire. The treatment groups were not statistically different at baseline with respect to social-demographics, health characteristics, and PAID scores.

In correlation analyses, age and duration of diabetes were significantly related to PAID score and HbA1c. Older age was associated with lower PAID scores, and longer duration of diabetes was associated with higher PAID scores. Because new diagnosis of diabetes has a potentially confounding effect, we examined the HbA1c and PAID scores for the four subjects diagnosed within a year of study enrollment and found that they varied.

Change in Diabetes Distress

Table 2 presents the results of characterizing all subjects' PAID scores over time prior to adding independent variables. Subjects varied in their PAID scores (intercept for random variance = 233.1; $p < 0.0001$), but not necessarily in the rates and direction of change in scores (slope for random variance = 0.8; $p = 0.2$). The average initial PAID score was 23.4 ($p < 0.0001$), which decreased by 1.9 points per quarter ($p < 0.0001$).

Table 1.
Means/Percentages for Subjects' Baseline Characteristics

Variable	Total (n = 104)	IBCM group (n = 52)	Usual care group (n = 52)	P value
Age (years; mean ± SD[a])	60.9 ± 10.3	61.7 ± 10.1	60.0 ± 10.5	0.42
Gender (%)				
Male	99.0	100.0	98.1	0.32
Female	1.0	0.0	1.9	
Race/ethnicity (%)				
Hispanic	5.8	3.9	7.7	0.59
Non-Hispanic white	76.7	74.5	78.9	
Non-Hispanic black	13.6	17.7	9.6	
Other	3.9	3.9	3.9	
Marital status (%)				
Single	11.1	8.2	14.0	0.83
Married/partnered	60.6	63.3	58.0	
Separated/divorced	22.2	22.5	22.0	
Widowed	6.1	6.1	6.0	
Educational attainment (%)				
< High school graduate	12.5	17.3	7.7	0.29
High school graduate	20.2	21.2	19.2	
Some college or above	67.3	61.5	73.1	
Years since diagnosis of diabetes (mean ± SD)	12.5 ± 7.8	12.5 ± 7.6	12.5 ± 8.1	0.99
Diabetes medication (%)				
None reported	1.0	0.0	1.9	0.61
Oral medication only	48.5	49.0	48.1	
Insulin	50.5	51.0	50.0	
HbA1c (mean ± SD)	9.9 ± 0.9	10.0 ± 0.9	9.9 ± 0.8	0.25
PAID scores (diabetes distress; mean ± SD)	25.1 ± 18.9	23.5 ± 17.9	26.8 ± 19.8	0.38

[a] Standard deviation

Change in Diabetes Distress by Treatment Group

Likewise, **Figure 1** shows that PAID scores improved overall (see also **Table 2**: –2.3; $p < 0.0001$). The initial PAID scores and rate of change in scores did not differ by treatment group per se (–3.1; $p = 0.3$). The *t*-tests underscored that the mean decline in PAID scores between baseline and 12 months was similarly significant in the treatment group.

Change in Diabetes Distress by Usage of the IBCM Program

Among subjects in the group that received IBCM, the usage groupings and their interactions with time accounted for an 11.9% reduction in individual differences in mean PAID scores (**Table 2**). The rate of decline in PAID scores did not differ for the usage groups; however,

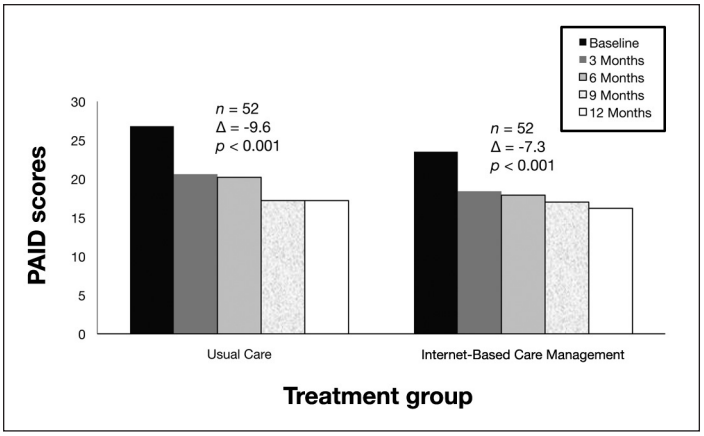

Figure 1. Mean PAID scores (diabetes distress) for the usual care and IBCM groups, over time. A Δ denotes change in mean PAID scores between baseline and 12 months, with negative values showing declining scores. The *p* values are for paired *t*-tests.

Table 2.
Results for Longitudinal Models Analyzing Changes in PAID Scores (Diabetes Distress)[a]

	Time only ($n = 104$)	Treatment group ($n = 104$)	Time only, IBCM group only ($n = 52$)	Usage of the IBCM program ($n = 52$)	Change in HbA1c ($n = 104$)
	Estimate (SE)	Estimate (SE)	Estimate (SE)	Estimate (SE)	Estimate (SE)
Random variance					
Intercept	233.1 (36.3)***	231.6 (35.8)***	219.2 (45.9)***	193.2 (42.1)***	129.6 (13.0)***
Slope	0.8 (1.0)	0.9 (0.9)	2.7 (1.3)*	1.5 (1.3)	3804.4 (274.9)***
Residual	69.0 (6.4)***	68.3 (6.2)***	61.5 (7.4)***	64.3 (8.0)***	47.7 (3.5)***
Fixed effects					
Intercept	23.4 (1.6)***	24.9 (2.3)***	21.8 (2.2)***	28.0 (3.8)***	18.3 (1.8)***
Time	–1.9 (0.3)***	–2.3 (0.4)***	–1.6 (0.4)***	–0.8 (0.7)	-0.3 (6.1)
Treatment		–3.1 (3.2)	—	—	—
Treatment × time		0.7 (0.5)	—	—	—
Early cessation				–5.9 (6.3)	—
Sustained, irregular				–6.5 (5.6)	—
Sustained, regular				–13.2 (5.6)*	—
Early cessation × time				–1.0 (1.2)	—
Sustained, irregular × time				–1.7 (1.1)+	—
Sustained, regular × time				–1.0 (1.0)	—
HbA1c					2.0 (0.6)***
HbA1c × time					-0.7 (0.3)*
Goodness of fit					
Raw likelihood (–2 LL)	3990.4	3987.5	1981.9	1976.9	4472.8
Akaike information criterion	3994.4	3995.5	1985.9	1992.9	4480.8
Bayesian information criterion	3999.7	4006.0	1989.8	2008.5	4491.4

[a] Results are maximum likelihood estimates fitted using SAS PROC MIXED. SE, standard error; LL, log likelihood. HbA1c was recentered using the constant 7.0%. Reference for usage patterns was nonuse group.
+$p < 0.10$, *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

post hoc paired *t*-tests of mean baseline and 12-month PAID scores for each usage group showed that the decline in distress for the groups that used the IBCM patient portal consistently were statistically significant, whereas it was not significant for the nonuse group.

Although the focus of the analyses was change in diabetes distress over time, results also showed that sustained users of the patient portal tended to have less diabetes distress at baseline (**Figure 2**). Initial PAID scores of subjects who were sustained, regular users of the patient portal were 14.7 points lower than those for subjects who did not use the patient portal ($p = 0.006$). A similar trend was suggested for the sustained, irregular users of the patient portal, whose initial scores were 9.3 points lower than nonusers. This finding approached statistical significance ($p = 0.09$).

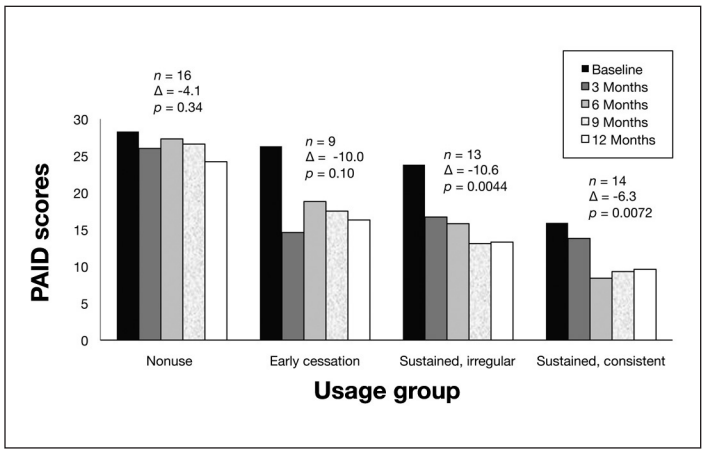

Figure 2. Mean PAID scores (diabetes distress) for the IBCM usage groups, over time. A Δ denotes change in mean PAID scores between baseline and 12 months, with negative values showing declining scores. The *p* values are for paired *t*-tests.

Change in Diabetes Distress by Change in HbA1c

Time-varying HbA1c was significantly related to PAID scores. The addition of HbA1c to the analyses reduced individual differences in PAID scores by 44.4%. Each 0.1% drop in HbA1c over time was associated with a 0.7 drop in PAID score per measurement occasion ($p = 0.03$) (**Table 2**). Thus, a participant who experienced a decline in HbA1c of 0.8% over the 12 months could experience a cumulative decline in PAID score of 5.4. HbA1c was also associated with baseline PAID scores. For each 0.1% increase in HbA1c, subjects' baseline PAID scores were higher by 2.0 ($p = 0.0003$) on average. Changes in glycemic control did not eliminate the effects of using the IBCM patient portal among subjects in the treatment group.

Also, the contribution of age and duration of diabetes did not change our conclusions about the relationships of treatment group, usage patterns, and change in HbA1c to diabetes distress.

Discussion

This study investigated whether changes in diabetes distress were associated with participation in a 12-month IBCM program and with changes in glycemic control. We hypothesized that subjects who received IBCM and used this care modality would have greater improvements in diabetes distress. The hypothesis was informed by previous studies showing that this mode of care improved diabetes-related physical outcomes.[19–21] A plausible counterhypothesis is that people with poorly controlled diabetes who receive IBCM would experience worse diabetes distress as they are coached to pay more attention to their diabetes and make changes in their self-care regimen. Some previous research showing that the intensity of diabetes self-care and treatment is linked to poor mood and psychosocial outcomes supports this counterhypothesis.[33] Our second hypothesis was that improved glycemic control would correlate with reductions in diabetes distress over time. This hypothesis was informed by the strong, documented linkage between glycemic control and other measures of mood, particularly depression/depressive symptoms.

Diabetes distress, as measured by PAID scores, declined over time for both treatment groups. In contrast to the counterhypothesis, PAID scores did not increase for the IBCM group despite their increased attention to their condition. Looking at usage patterns among recipients of the IBCM, we found that distress declined for all usage groups, but this decline was significant for sustained users of the IBCM patient portal and not for nonusers. Results also showed a significant relationship between changes in diabetes distress and glycemic control. HbA1c and its interaction with time accounted for a substantial percentage of variability in PAID scores (44.4%).

There are several explanations for the finding that the decline in distress was similar for both treatment groups, before investigating these changes by usage of the patient portal. First, several studies of psychosocial outcomes (which did not include diabetes-specific distress) and Internet-based programs of different types have found that both treatment and usual care groups had favorable responses.[31–33] This pattern for usual care or control groups is consistent with the familiar concept of "attention bias."[34] Second, as noted earlier,

usual care in the VA Boston Healthcare System tends to be good because there are numerous diabetes-related performance measures that VA PCPs attend to with their diabetes patients and PCPs also tend to give extra attention to patients with poor glycemic control, such as those recruited for this study. Third, as documented previously,[24] mean HbA1c declined significantly for this cohort, including the usual care group, but subjects who received IBCM had significantly greater improvements in HbA1c than subjects who received usual care. The most sustained and regular users of the IBCM patient portal had the greatest improvement. Given the strong association between HbA1c and PAID scores reported here and the prior finding that HbA1c improved for both treatment groups—albeit unequally—it makes sense that both treatment groups felt better over time. However, we would expect the treatment group and/or greater users of the IBCM patient portal to improve comparatively more. Delving into the usage patterns, therefore, revealed subject differences in diabetes distress that were missed by looking at treatment allocation alone.

With respect to quantity of usage of the IBCM patient portal, a common problem with Internet-based tools is that many patients do not "engage" with them or do so for only short periods of time. Eysenbach[35] refers to this as *nonusage attrition*. Eysenbach states that relatively high rates of nonusage attrition (relative to drug trials, for example) are a distinct feature of eHealth and self-help interventions. In this study, 52% of the subjects used the IBCM patient portal with at least some regularity for the full 12 months of the study. This usage rate is high compared to studies cited by Eysenbach as well as other, shorter interventions.[36]

What contributed to usage among subjects in the IBCM group? We observed that subjects whose usage of the patient portal was sustained throughout the study had lower baseline PAID scores than nonusers. Lower baseline HbA1c was also associated with lower baseline PAID scores. This and the aforementioned finding that distress declined significantly for certain groups highlight the often complex, reciprocal relationship between how people feel and what they do; i.e., lower distress means people can participate more and/or adopt lifestyle changes to better their glycemic control, and participating more and/or achieving better glycemic control mitigates distress.

Because of the study design, we cannot definitely ascribe causation, but we believe subjects felt better because their HbA1c levels dropped (rather than vice versa). The IBCM program targeted metabolic control rather than mood, and the advanced practice nurse who worked with subjects was a diabetes specialist, not a mental health specialist. Also, although diabetes distress and HbA1c were gathered together at each measurement occasion (at baseline and at 3, 6, 9, and 12 months), the two measures are not perfectly contemporaneous. To illustrate, the 3-month HbA1c indicated what had occurred with the subjects' blood glucose during the 30–60 days before month 3, whereas the 3-month PAID score indicated what the subjects felt at the time the questionnaire was administered. Thus, the time-varying PAID scores in our statistical models are subsequent to antecedent changes in glycemic control. The temporal order of the measures implies causation.

The results have several implications for future research and clinical practice. Based on the observation that people who had lower diabetes distress from the outset tended to be the same people who used the technology and felt better, it is important to recognize that certain patient characteristics may better *match* patients with the Internet-based approach to care management. The concept of matching patients' needs and abilities with the provisions of a care management mode is consistent with theories of person–environment fit.[37–39] A better match could increase the likelihood of engagement with IBCM and, ultimately, of a favorable clinical response. Future research can address the relative contribution of diabetes distress compared with that of other individual-level factors known to relate to patients' usage/nonusage of medical care interventions so that busy clinicians can evaluate their patients accordingly before initiating IBCM. Another implication is that aggressively pursuing metabolic control among people who are poorly controlled can yield psychosocial benefits, irrespective of how it is approached (through an IBCM program or other means). Once these psychosocial benefits are realized, patients may then be in a better position to engage in the active management of their health using this or other tools that "fit" them, and sustain achievements.

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