

Development and validation of the self-management Barriers and Supports Evaluation for working-aged adults with type 1 diabetes mellitus

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ABSTRACT

Introduction To optimize type 1 diabetes mellitus self-management, experts recommend a person-centered approach, in which care is tailored to meet people's needs and preferences. Existing tools for tailoring type 1 diabetes mellitus education and support are limited by narrow focus, lack of strong association with meaningful outcomes like A1c, or having been developed before widespread use of modern diabetes technology. To facilitate comprehensive, effective tailoring for today's working-aged adults with type 1 diabetes mellitus, we developed and validated the Barriers and Supports Evaluation (BASES).

Research design and methods Participants 25–64 years of age with type 1 diabetes mellitus were recruited from clinics and a population-based registry. Content analysis of semistructured interviews (n=33) yielded a pool of 136 items, further refined to 70 candidate items on a 5-point Likert scale through cognitive interviewing and piloting. To develop and validate the tool, factor analyses were applied to responses to candidate items (n=392). Additional survey data included demographics and the Diabetes-Specific Quality of Life (QOL) Scale-Revised. To evaluate concurrent validity, hemoglobin A1c (HbA1c) values and QOL scores were regressed on domain scores.

Results Factor analyses yielded 5 domains encompassing 30 items: Learning Opportunities, Costs and Insurance, Family and Friends, Coping and Behavioral Skills, and Diabetes Provider Interactions. Models exhibited good to adequate fit (Comparative Fit Index >0.88 and Root Mean Squared Error of Approximation <0.06). All domains demonstrated significant associations with HbA1c and QOL in the expected direction, except Family and Friends. Coping and Behavioral Skills had the strongest associations with both HbA1c and QOL.

Conclusions The BASES is a valid, comprehensive, person-centered tool that can tailor diabetes support and education to individuals' needs in a modern practice environment, improving effectiveness and uptake of services. Clinicians could use the tool to uncover patient-specific barriers that limit success in achieving HbA1c goals and optimal QOL.

INTRODUCTION

Diabetes self-management is crucial for achieving good blood glucose control and

Significance of this study

What is already known about this subject?

- Tailoring self-management supports for people with type 1 diabetes mellitus is recommended.
- Current practice relies on tools that are out of date, narrow in scope, or not strongly associated with better outcomes.

What are the new findings?

- Using a patient-centered approach, we created a brief, multiple-choice tool.
- A tool can quickly determine which self-management challenges are a priority for a given person with type 1 diabetes mellitus.

How might these results change the focus of research or clinical practice?

- Barriers and Supports Evaluation tool can be used in clinical practice to quickly tailor the focus of education and supports for self-management to those that are valued by the person living with diabetes and are likely impacting meaningful outcomes such as A1c and quality of life.

preventing diabetes-related complications. Diabetes self-management includes behaviors such as physical activity, monitoring of blood glucose, healthy eating, and psychosocial adaptation to living with diabetes.¹ Although successful self-management can reduce the risk of diabetes complications by 30%–75%,² about 70% of US adults with type 1 diabetes mellitus have suboptimal blood glucose control.³ Over the lifespan and as people experience more diabetes-related complications, their health-related quality of life (QOL) may be negatively impacted.^{4 5} Although many socioeconomic factors associated with poorer type 1 diabetes mellitus outcomes are not modifiable (eg, race/ethnicity or educational attainment),^{3 6} interventions to address disparities in outcomes could focus on the specific

challenges through which such factors act to impede self-management. Efforts to enhance adults' type 1 diabetes mellitus self-management is of crucial importance because developing lasting positive self-management behaviors takes time and the impact of poor self-management aggregates over the years of living with type 1 diabetes mellitus.

To optimize diabetes self-management, the American Diabetes Association (ADA) Standards of Medical Care recommend a person-centered approach, in which individuals' specific needs are addressed in partnership with their care team.⁷ Tailoring resources to self-management challenges is crucially important,⁸ but currently available tools have limitations. Specifically, some recommended tools narrowly focus on physical activity or device use.^{9,10} Others demonstrate limited association with outcomes such as hemoglobin A1c (HbA1c)^{11,12} or were developed over 25 years ago and may not reflect the experiences of people with type 1 diabetes mellitus today.^{11,13} Without appropriate tailoring, uptake of interventions is limited. For example, even in the optimized setting of a clinical trial, as many as half of potential recipients either decline or drop out when offered untailed self-management interventions.¹⁴

Based on prior research and Social Cognitive Theory, we hypothesized that a limited set of self-management barriers and supports, with clinically important impact on glycemic control and QOL, can be identified for adults with type 1 diabetes mellitus. Social Cognitive Theory posits that three key constructs—cognitive factors, socio-environmental factors and behavioral factors—influence self-management behaviors and ultimately outcomes such as glycemic control or QOL.¹⁵ With regard to cognitive factors, prior research suggests adults face challenges with acquiring the knowledge or understanding required for their diabetes self-care.^{16,17} Similarly, adults with type 1 diabetes mellitus also face self-management challenges related to socioenvironmental factors such as employment,¹⁸ insurance,¹⁹ and discrimination,²⁰ as well as the influence of interactions with family and peers.^{21,22} Lastly, behavioral factors influence self-management. For example, healthcare interactions can serve to support effective self-management^{17,23–25} as can opportunities to develop skills and coping strategies, such as being able to recognize hypoglycemia,^{9,17} or needing to address stressors, mental health needs, or the development of diabetes-related complications.^{26,27}

The objective of this study was to create a validated tool that healthcare systems and providers could use to quickly and comprehensively understand the factors influencing a working-aged adult's diabetes self-management. To achieve this objective, we sought to: (1) generate an item pool to reflect potential influences on adults' type 1 diabetes mellitus self-management, (2) develop and validate a survey to assess adults' type 1 diabetes mellitus self-management barriers and supports, and (3) use regression techniques to evaluate how well the new tool predicts important outcomes such as glycemic control and QOL.

SUBJECTS, MATERIALS AND METHODS

Participants

Participants for concept elicitation interviews were recruited from two sources to achieve maximum variation sampling. Participants from the Wisconsin Diabetes Registry Study (WDRS), a population-based registry of people diagnosed with type 1 diabetes mellitus from 1987 to 1992, were recruited via email or postal mail. Participants from the Diabetes Care Center at the University of North Carolina (UNC) were recruited at clinic visits after a care team member ascertained their willingness to learn about the research. For survey data collection, we also recruited participants from the Carolina Data Warehouse for Health by email. Eligibility required a diagnosis of type 1 diabetes mellitus for at least 1 year and age between 25 and 64 years. We excluded non-English speaking families due to lack of valid survey measures in these populations.

Development of item pool

To comprehensively identify factors experienced as influencing self-management and to create a pool of candidate items, we conducted concept elicitation interviews with 33 participants between July and December 2018. Trained interviewers conducted interviews at the two recruitment sites, or at a place convenient to the participant (eg, a private room at a public library). Participants received \$50 as remuneration.

The interviews used a semistructured guide, informed by a literature review of factors influencing diabetes self-management and a conceptual framework based on social-cognitive theory. The interview began with two open-ended questions about participants' daily self-management behaviors and which of these behaviors they considered most important for taking care of their diabetes. The interviewer then followed up with probes related to domains of the Social Cognitive Theory, including questions about the potential influence of cognitive factors (eg, areas where more information was desired), socioenvironmental influences (eg, diabetes-related challenges at work or the impact of social relationships on self-management), or behavioral factors (eg, disruption of routines or the role of their diabetes provider) on self-management. The semistructured format of the interviews allowed participants to engage in a conversational manner, focusing the conversation in areas that were important to them. The full interview guide is available as an online supplemental file. The elicitation interviews were audio-recorded and fully transcribed.

Two trained members of the research team with qualitative research experience (HK and EDC) analyzed interview transcripts line by line, identifying factors influencing diabetes management. One-sentence descriptions of each factor were created, using participants' specific wording and phrasing to make items relevant, easy to understand, and easy to answer. In a second step, factors with similar themes were grouped together and then



rewritten as questions. During this step, draft items were also mapped into hypothesized domains of the Social Cognitive Theory framework. All draft items were written with a reference period of 1 month. When possible, the items used common response dimensions, such as ‘how often,’ ‘how easy,’ or ‘to what extent.’ This process generated an initial pool of 136 candidate items. Items that had semantic overlap with other items challenging to respond to with the common 5-point response categories, or had complex wording (eg, double-barreled questions) were eliminated, leaving 107 candidate items.

To ensure that candidate items were easy to comprehend and interpreted in the intended way, trained research staff tested all 107 items through cognitive interviewing.²⁸ Interviewees were 13 demographically diverse participants, including participants with lower educational attainment. All candidate items were tested in at least two cognitive interviews. Each interview lasted for approximately 45 min (range: 33–73 min) and encompassed 30–35 candidate items. For each item, participants were asked to read the item aloud and then mark their answer on their survey. The interviewer then probed the participant, starting with ‘Tell me more about why you answered ...’ and ending with ‘How easy or difficult was it for you to answer this question?’ Depending on the item content or wording, interviewers asked additional probes (eg, ‘When you read, ‘my healthcare provider,’ who were you thinking of?’). Based on the interview transcripts and notes, members of the research team rated items as ‘works as written,’ ‘potentially problematic,’ or ‘definitely problematic.’ Problematic items were revised when possible and tested again.

We pilot tested 95 survey items with 27 participants and culled items that were highly correlated, had low variability in responses, or were duplicative, while ensuring each Social Cognitive Theory domain was sufficiently represented. The final survey for administration contained 70 items reflecting potential diabetes self-management barriers and supports, with response options on a 5-point scale. Positively worded items were reverse-scored.

Survey data collection

From October of 2019 to June of 2020, consented participants were asked to complete the 70 items, as well as items reflecting QOL, demographics, and disease or regimen factors. Participants could complete the survey electronically via Qualtrics or on paper.

QOL was assessed with 57 items from the validated Diabetes-Specific Quality of Life Scale-Revised (DSQOLS-R), with all responses on a 6-point Likert scale (6=very strongly agree to 1=do not agree at all).²⁹ To reduce survey burden, we did not administer the goals and wishes for diabetes treatment and satisfaction scales. Mean score is calculated and transformed to a 100% scale, with higher scores indicating better QOL. All six subscales of the DSQOLS-R used in our study have shown very good to excellent internal consistency ($\alpha=0.85-0.94$).²⁹

Other measures

Surveys also included items about demographic characteristics and factors related to participants’ disease or diabetes regimen that are known or hypothesized to be associated with glycemic control or self-management. Demographics included age (continuous) and gender, race/ethnicity (white, non-Hispanic vs all other), and education (standard categories). Disease and regimen factors included years since diagnosis, technology use (eg, insulin pump or continuous glucose monitor), health status (excellent or good vs all others), and diabetes-related comorbidities (eg, kidney disease or neuropathy), collapsed to having any such comorbidity (yes/no).

HbA1c

HbA1c values were obtained from the participant’s healthcare provider. For participants recruited through WDRS, the medical record with the most recent HbA1c was requested. For participants recruited through UNC, HbA1c was abstracted from the electronic health record. Only HbA1c values obtained within 45 days before or after survey completion were included in the analysis. The values were considered continuous for modeling purposes.

Quantitative analyses

We used means with SDs and proportions to describe participants. To develop and validate the tool, analyses were conducted using the recommended practice of creating the tool using one sample, and confirming the measure using a second independent sample.³⁰

First, we drew a random subsample ($n=200$; factor analysis sample) from our overall quantitative sample ($n=392$). We used iterative exploratory factor analysis (EFA) on responses to all 70 potential items to statistically extrapolate a factor structure, using maximum likelihood estimation and oblique rotation in Mplus V.7.4.³¹ Visual inspection of scree plots and lower Bayesian Information Criteria in competing EFAs were used to determine the number of factors to retain.³² Items that loaded <0.3 on all factors or had strong shared variance (indicating high correlation) within a factor were eliminated. Model fit was assessed using accepted values for the Comparative Fit Index (CFI >0.90) and the Root Mean Squared Error of Approximation (RMSEA <0.08).³³

Second, to evaluate construct validity, we conducted a confirmatory factor analysis and evaluated model fit on a second random subset of participants ($n=192$; confirmatory sample). Items that cross-loaded on multiple factors in the EFA were retained but forced to load on the ‘highest’ factor and shared item variance was accounted for at the factor level, not the item level.^{30 31} In addition, we examined tau equivalence of the resulting factors across the entire sample ($n=392$) to evaluate the appropriateness of unity weighting for constructing factor scores. The tau-equivalent measurement model constrains equal loadings for all items within a factor, essentially

calculating final domain scores by averaging item scores within each factor.³⁴ This model is then compared with the congeneric, or least restrictive model, estimating free factor loadings and item variances to ensure that scale reliability is maintained with the simpler scoring.

Finally, to examine concurrent validity, we conducted regression analyses relating the average score on each domain to participants' HbA1c values (n=254 with an HbA1c within 45 days of the survey) and QOL (n=387 with completed DSQOLS-R items) using SAS V.9.4. Beta estimates and 95% CIs represent the increase in HbA1c or QOL associated with a 1-unit increase in domain score. Significance was established as p<0.05 (two tailed) for all analyses.

Total sample size was determined using simulation studies³⁵ suggesting that with 400 participants, we would have adequate sample to develop the models and confirm

these models on two (n=200) independent samples of participants. Specifically, we would have power of 0.96 to elucidate five factors with a sample size of 100. In addition, factor analytic techniques typically suggest 5–10 observations for each item being considered for inclusion to ensure validity of estimation and model fit assessment methods.³⁶ With an anticipated final tool consisting of 20–30 items, n=392 would be sufficient.

RESULTS

Participant characteristics

Table 1 provides participant characteristics for our three samples: (1) the overall sample (n=392), (2) the sample used to construct the measure (n=200) and (3) the independent, confirmatory sample (n=192). On average, participants were about 43 years of age and had lived with

Table 1 Participant characteristics by analysis sample*

Characteristics	Overall (n=392) % (n)	EFA (n=200) % (n)	CFA (n=192) % (n)
Age, years (mean (SD))	42.5 (10.1)	42.4 (9.6)	42.7 (10.6)
Years since diagnosis (mean (SD))	27.0 (10.5)	26.2 (10.5)	27.9 (10.5)
Female	61 (241)	66 (132)	57 (109)
Married	65 (253)	65 (130)	64 (123)
Non-Hispanic/Latino white	81 (319)	80 (160)	83 (159)
Education			
High school graduate or less	6 (24)	8 (15)	5 (9)
Some college/technical college	29 (114)	27 (53)	32 (61)
Bachelor's degree	37 (146)	38 (76)	36 (70)
Graduate or professional degree	27 (107)	28 (55)	27 (52)
Household income			
\$50 000 or less	31 (121)	30 (59)	32 (62)
\$50 001–\$100 000	29 (112)	30 (60)	27 (52)
\$100 001 or more	39 (151)	39 (78)	38 (73)
At least one diabetes-related comorbidity	25 (99)	22 (44)	29 (55)
Technology use			
Pump and CGM	35 (139)	36 (72)	35 (67)
Closed loop system	23 (89)	21 (42)	24 (47)
CGM only	13 (49)	15 (30)	10 (19)
Pump only	11 (44)	12 (24)	10 (20)
No technology use	18 (70)	16 (31)	20 (39)
Outcome measures			
A1c (mean (SD))†			
IFCC (%)	7.7 (1.4)	7.6 (1.5)	7.7 (1.4)
NGSP (mmol/mol)	60.3 (15.6)	59.9 (16.3)	60.7 (14.9)
Diabetes-Specific Quality of Life Scale (mean (SD))	61.5 (21.0)	61.4 (20.0)	61.5 (22.1)

*Values may not add to 100% due to rounding or non-response.

†n=254 with an A1c value within 45 days of survey completion.

CFA, confirmatory factor analysis; CGM, continuous glucose monitor; EFA, exploratory factor analysis; IFCC, International Federation of Clinical Chemistry and Laboratory Medicine.

diabetes over half of their lives. Our samples had slightly more female participants than male, and about two-thirds of participants were married. Most were non-Hispanic, white; about one-quarter had at least one diabetes-related comorbidity. Participants' education and income varied widely. The vast majority used some type of technology to manage their diabetes. Mean HbA1c was about 7.7% (61 mmol/mol). Average diabetes-specific QOL was about 61.5 points.

Identifying self-management barrier and support domains

The EFA suggested a five-factor solution (eigenvalues 8.5, 3.5, 2.3, 2.2, 1.6): (1) Learning Opportunities, (2) Costs and Insurance, (3) Family and Friends, (4) Coping and Behavioral Skills, and (5) Diabetes Provider Interactions. Items and factor loadings are shown in [table 2](#). The Learning Opportunities domain items reflect interest in learning more about self-management, including recognizing patterns in blood sugars. The items in the Costs and Insurance domain represent the degree to which diabetes-related costs and insurance make self-management harder or worrisome. The items within the Family and Friends domain reflect whether the people closest in the environment of the adult with type 1 diabetes mellitus are knowledgeable, supportive, and helpful with self-management. The Coping and Behavioral Skills domain includes items that reflect the idea of behavioral self-efficacy and coping with diabetes management, even in the face of stressors such as limited time or fatigue. The Diabetes Provider Interactions domain reflects access to the provider, feeling heard, and obtaining useful, up-to-date advice.

Construct validity

Fit indices for the EFA sample indicate good model fit (CFI=0.900 and RMSEA=0.057; [table 3](#)). For the independent, confirmatory sample, adequate model fit was demonstrated (CFI=0.883; RMSEA=0.063).

Appropriateness of unity weighting

The CFI and RMSEA suggest the tau-equivalent model, which permits simple calculation of factor scores as averages of domain items, fits the data adequately. Model comparisons using the likelihood ratio test indicate that the congeneric model, in which factor loadings and item variances are freely estimated, does fit the data significantly better ([table 3](#)).

Concurrent validity: relating barriers and supports to diabetes-related health outcomes

Concurrent validity was demonstrated through consistent, significant associations between the mean domain scores and HbA1c or QOL ([table 4](#)). All but one regression was significant and in the expected direction. Notably, the Family and Friends domain showed no significant association with HbA1c but was related to QOL. The largest associations between HbA1c and domain scores were seen for Coping and Behavioral Skills, where, on average, a 1-unit increase in average domain score was associated

with HbA1c values that were 0.63% points (6.9 mmol/mol) higher. Learning Opportunities and Coping and Behavioral Skills were the two domains most highly associated with QOL, with a 1-point increase in the domain score associated with QOL that was, on average, about 18 points lower.

DISCUSSION

Our new 30-item survey is a valid tool for identifying self-management barriers and supports among working-aged adults with type 1 diabetes mellitus. Our findings suggest that five barrier or support domains exist: (1) Learning Opportunities, (2) Costs and Insurance, (3) Family and Friends, (4) Coping and Behavioral Skills, and (5) Diabetes Provider Interactions. Healthcare systems and clinics could use the tool in clinical care to address self-management in a patient-centered manner, where the patient's input is incorporated into selecting resources and referrals.

Our findings support the tool's content, construct, and concurrent validity. The domains identified from our participants with type 1 diabetes mellitus correspond to the three factors expected from Social Cognitive Theory. Specifically, we found domains consistent with cognitive processes (eg, Learning Opportunities), as well as socio-environmental factors (eg, Costs and Insurance or Family and Friends) and behavioral influences (eg, Coping and Behavioral Skills or Diabetes Provider Interactions that support self-management behaviors). Model fit indices suggest good to adequate fit of the model to the data, even when constraining the factor loadings to be equal, which allows easy scoring in the clinical setting. Further, the scores for each domain within our tool are consistently and significantly associated in the expected manner with important outcomes of type 1 diabetes mellitus self-management, as measured by HbA1c and QOL.

In 2017, the Association of Diabetes Care & Education Specialists (ADCES) published national standards for diabetes self-management education and support,³⁷ resulting in the creation of certified or recognized programs through ADCES and the ADA.^{38 39} A key component of these programs is the need to tailor the education and self-management support to people's needs.³⁷ Currently, a variety of assessment tools have been suggested to facilitate such tailoring. Some of these, such as Barriers to Physical Activities in Diabetes or Barriers to Device Use and Reasoning for Discontinuing Devices, have a narrower focus than our Barriers and Supports Evaluation (BASES) tool.^{9 10} One early measure of barriers to self-management, the Barriers to Self-Care Scale, demonstrated high internal consistency, but scale scores did not show a significant association with HbA1c.¹² Another comprehensive and widely used measure is the 20-item Problem Areas in Diabetes (PAID) measure from 1995, intended as a measure of diabetes-related distress.¹¹ While there is some overlap in item content between BASES and the PAID, no items related to

Table 2 Unstandardized and standardized factor loadings for items from confirmatory factor analysis (n=192)

	Unstandardized* (SE)	Standardized†
Learning Opportunities		
To what extent did you understand why your blood sugar changed the way it did?	1.00 (0.00)	0.53
How easy has it been for you to recognize patterns in your blood sugar?	1.64 (0.29)	0.73
How easy has it been for you to recognize when your blood sugar is too low?	1.05 (0.23)	0.43
To what extent did you feel you needed to learn more about taking care of your diabetes?	0.75 (0.21)	0.33
How often did you have difficulty knowing how much insulin to take?	0.73 (0.17)	0.45
Costs and Insurance		
To what extent did cost or insurance issues make it hard to take the best care of your diabetes?	1.00 (0.00)	0.91
To what extent did you have to accept not using the best tools and supplies for your diabetes because of insurance or cost issues?	0.93 (0.06)	0.85
To what extent did your insurance make taking care of your diabetes a bigger hassle than it should be?	0.77 (0.06)	0.74
How often did you have trouble paying for the things you need to take care of your diabetes?	0.76 (0.06)	0.78
To what extent have you been worried or troubled by the financial burden that diabetes puts on your family?	0.80 (0.06)	0.77
Family and Friends		
To what extent did the people who are most important to you do all they can to help you to take care of your diabetes?	1.00 (0.00)	0.70
To what extent did the people who are most important to you encourage you to take care of your diabetes?	0.92 (0.11)	0.67
To what extent did the people who are most important to you know what to do to help with your diabetes?	1.03 (0.11)	0.81
To what extent did the people who are most important to you understand how much you need to do to take care of your diabetes?	1.15 (0.12)	0.86
Coping and Behavioral Skills		
How often did you feel that there was too much going on in your life to take good care of your diabetes?	1.00 (0.00)	0.82
How often have you put off doing what is needed to take care of your diabetes?	0.75 (0.07)	0.72
How often have you been too tired to take care of your diabetes?	0.88 (0.07)	0.77
How often did you feel you just didn't want to deal with your diabetes?	1.00 (0.09)	0.76
How often did you make choices that aren't good for your diabetes to make things easier for others at social gatherings?	0.59 (0.07)	0.58
How often did you find yourself just guessing what your blood sugar is, instead of actually checking it?	0.55 (0.08)	0.52
How easy has it been for you to accept that you have to take care of your diabetes?	0.60 (0.08)	0.55
How easy has it been for you to find time to take care of your diabetes while at work?	0.62 (0.09)	0.52
How often did stress make it harder to take care of your diabetes?	0.89 (0.08)	0.72
How often did you let your sugars run high to avoid going low?	0.51 (0.06)	0.56

Continued

Table 2 Continued

	Unstandardized* (SE)	Standardized†
How often were other mental health issues a bigger priority for you than taking care of your diabetes?	0.64 (0.07)	0.65
To what extent has being out of your routine made it harder to take care of your diabetes?	0.56 (0.08)	0.47
Diabetes Provider Interactions		
To what extent did you feel your healthcare providers are up to date on the latest ways of taking care of diabetes?	1.00 (0.00)	0.77
To what extent did you feel your healthcare providers are willing to listen to you?	1.07 (0.11)	0.78
To what extent did you feel that your healthcare providers' advice is useful in taking care of your diabetes?	1.20 (0.12)	0.74
How easy was it for you to see or reach your healthcare providers?	1.05 (0.12)	0.71

*Unstandardized factor loadings are on the original item scales, reflecting the extent to which the domain covaries with the item.

†Standardized factor loadings reflect the extent to which the domain is correlated with the item.

Cost and Insurance are represented in the PAID, perhaps reflecting the growth in new and costly technologies for managing type 1 diabetes mellitus as well as rising insulin costs, especially in the USA. Our tool was developed from the experiences of today's adults with type 1 diabetes, offering a current, patient-centered and comprehensive view of the influences of self-management. Given the tool's brevity, this tailoring could occur quickly and efficiently, perhaps through the patient portal in electronic health records.

Use of the tool has several potential benefits for healthcare delivery systems and for accredited or recognized diabetes self-management and education programs. These entities likely already have in place resources and providers to address several of the barriers and supports reflected in the tool. For example, if the tool identified a person with 'Learning Opportunities,' multidisciplinary diabetes clinics and accredited programs typically have diabetes educators available to assist people in learning more about managing their diabetes. In addition, regularly scheduled use of the tool would provide the data needed to inform decisions about the types of self-management support and education that would be most beneficial to the populations served. These data could be

instrumental in planning budgets and making staffing decisions. Lastly, results may also illuminate areas where new resources may need to be developed or specifically integrated into existing programs. For example, it is unclear how programs or healthcare systems might best address barriers related to interactions with the diabetes provider. Possible solutions could involve understanding more deeply what the person may need or simply suggesting the patient work with another provider. Similarly, while ADCES national standards include topics related to cost and insurance and pharmacists can help with lower cost insulin and supply alternatives,^{40,41} implementation of consistent, evidence-based approaches is likely needed.

As with all observational research, limitations must be considered. Although our work relies on data from two institutions, our participants' characteristics are similar with regard to demographics and disease factors to that of a nationally representative sample of adults of similar age with type 1 diabetes mellitus.⁴² The self-reported nature of our data could, through social desirability bias, lead to under-reporting of self-management barriers and ultimately underestimating the challenges experienced by adults with type 1 diabetes mellitus. As all models of

Table 3 Model fit indices from factor analyses

	EFA (n=200)	CFA (n=192)	Congeneric model (n=392)	Tau equivalent model (n=392)
H ₀ loglikelihood (number parameters)	n/a*	n/a*	-15 449.48 (100)	-15 560.02 (75)
BIC	n/a*	n/a*	31 496.08	31 567.88
CFI	0.90	0.88	0.93	0.89
RMSEA (90% CI)	0.06 (0.05 to 0.07)	0.06 (0.06 to 0.07)	0.05 (0.04 to 0.05)	0.05 (0.05 to 0.06)

*BIC and H₀ are not provided as these models are not directly comparable.

BIC, Bayesian Information Criteria; CFA, confirmatory factor analysis; CFI, Comparative Fit Index; EFA, exploratory factor analysis; RMSEA, Root Mean Square Error of Approximation.

Table 4 Unstandardized betas* and 95% CIs for association of each domain score with HbA1c† and QOL

Domain	HbA1c		QOL	
	Beta	95% CI	Beta	95% CI
Learning Opportunities	0.35	0.09 to 0.62	-17.59	-20.43 to -14.76
Costs and Insurance	0.27	0.12 to 0.42	-8.36	-9.94 to -6.79
Family and Friends	0.10	-0.06 to 0.27	-3.43	-5.49 to -1.37
Coping and Behavioral Skills	0.63	0.39 to 0.87	-18.96	-21.16 to -16.75
Diabetes Provider Interactions	0.39	0.17 to 0.61	-6.26	-8.71 to -3.80

*Betas reflect a unit change in outcome variable for each 1-unit increase in domain score.

†International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) units.

HbA1c, hemoglobin A1c; QOL, quality of life.

health behavior have intrinsic strengths and weaknesses, other models could also be considered for conceptualizing the types of self-management influences experienced by adults with type 1 diabetes mellitus. While our results address many aspects of validity, future work could examine additional aspects such as the variability in scores over time and how changes in scores are related to fluctuations in glycemic control or other outcomes. In addition, given the large number of factors that can potentially influence self-management, our tool may represent only the first step in comprehensively characterizing self-management barriers and supports. However, we did begin our tool development from a comprehensive item pool arising from qualitative analysis of the current lived experience of a diverse sample of working-aged adults with type 1 diabetes mellitus.

In summary, the BASES tool is a promising brief survey to assess barriers and supports for self-management as faced by working-aged adults with diabetes. Identifying these factors can facilitate tailoring of self-management resources to meet individuals' needs, potentially resulting in greater effectiveness and efficiency in achieving improved glycemic control or QOL. Future work will further examine variability in the domain scores over time and how its use in clinical settings can influence outcomes.

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QUALITATIVE PATIENT INTERVIEW GUIDE

Question order 1

Introduction and “consent”: Thank so much for participating in our study! When we first contacted you by mail, we sent you a little info sheet about the study. But that’s been a while ago. So let me quickly go through the basics before we start with the interview.

The study we’re doing is about how people take care of their diabetes and what makes that more difficult or easy. So we’ll be talking to people like you and get your take on that. I’ll be asking you a lot of questions, and there are no right or wrong answers. We really value what you have to tell us because you’re the real expert on what it means to take care of diabetes day after day.

If that’s okay with you, I’ll record the interview. We’ll then later have someone type out what you said so that we can be sure that we got everything right. I want to stress that whatever you tell us is strictly confidential. Only the researchers who are part of this project will see what you say. We won’t share anything with your doctors, your family, or anyone else. And if there are any questions that you’re not comfortable answering, just let us know. The interview should take us about an hour. Does that work for you? Do you have to be anywhere after this?

As a thank you for your time we can offer you a \$50 Amazon gift cards for participating. [Reassess by situation: phone, in person]. We will email you those Amazon gift cards in the next week or so if that’s okay. I have your current email address listed as (X), is that correct?

Do you have any questions?

Okay, great, then I’ll turn on the recorder now.

Introduction and Open Questions [do not read]

Just to get started, can you tell me a little bit about yourself? When were you diagnosed with diabetes?

If participant doesn’t know how to respond: Things like: Where do you live? How old are you? What do you do for a living?

Let’s talk about the basics on how you take care of your diabetes.

1. If you think of a typical day, what do you do to take care of your diabetes?
 - a. Is there anything else you’d do on a typical day?
 - b. Can you say more about ...
2. And what do you think are the most important things you do to take care of your diabetes?

So we’ve talked about a typical day. Let’s think back to the past month.

3. What difficulties have you experienced with taking care of your diabetes?
4. If you think back even farther, have you had any other difficulties with taking care of your diabetes?
 - a. So is that something you no longer experience now? Can you say more why this is no longer an issue?
5. Are there times when taking care of your diabetes is harder for you? Tell me about those.

In the survey that you sent us, you mentioned that you’re using a .../not using a ... Is that right?

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6. When did you first get that? Was it something you asked for or that your doctor suggested?
7. How has having a ... affected how you take care of your diabetes?

We've already talked a bit about how you've taken care of your diabetes in the past. Let me ask you specifically:

8. Were there times in your life when taking care of your diabetes was easier or harder than it is right now?
 - a. Can you say more about that?
 - b. What was it that made it easier or harder?
9. Have you had any major changes or events happen in your life?
 - a. *If participant has difficulty answering:* For example, having a child, changing jobs, or moving in with a partner?
10. Have any of those affected how you take care of your diabetes?
 - a. Can you tell me how they have changed things for your diabetes?
 - b. *If participant mentions event but doesn't say whether or not it had effect on diabetes:* You mentioned ... Is that something that has had an effect on how you take care of your diabetes?

I want to ask you about work. You said that you work as ...

11. What issues with your diabetes do you encounter at work?
12. Are there things about your work are helpful to taking care of your diabetes?
13. Have you worked in a different job before? Or a different position at your current job? Can you tell me if changes in your job situation have had an effect on how you take care of your diabetes?

I'd like to talk about health care and health issues now.

14. Can you tell me about the health care you are getting for your diabetes?
15. How has your doctor (or the care you receive) affected how you take care of your diabetes?
 - a. Is there anything about your doctors or health care in general that make taking care of your diabetes harder?
 - b. And are there things about your doctors that have made taking care of your diabetes easier?
16. Do you have any health issues other than diabetes? On the survey we sent you, you said you had ...
17. Does this affect how you take care of your diabetes? If yes: How so?
18. Can you tell me about any financial or insurance issues related to your diabetes care that you have encountered?
 - a. *If participant seems hesitant:* I know that sometimes people are uncomfortable talking about these issues, and that's okay. Whatever you say is strictly confidential.

Let's switch gears a bit. Let's talk about things you know or have learned about taking care of your diabetes.

19. When you think back, were there any pieces of information or skills you've learned that help you take care of your diabetes?
20. Is there anything you wished you'd learned sooner?
21. And is there anything you'd like to learn *now* about taking care of your diabetes?

I want to specifically ask about a couple of things. Let me start with food and food choices

22. Do you have any difficulties in taking care of your diabetes related to eating and food choices?

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23. Is there anything about eating and food choices that is helpful to taking care of your diabetes?
24. And when it comes to food choices, is there anything that you feel you'd need to know, or certain skills that would be helpful?
25. Has carb counting ever been a part of how you take care of your diabetes?
 - a. Again, with carb counting, is there anything you'd need to know, or skills that would be helpful?
26. Another thing is physical activity. Has physical activity ever been a part of how you take care of your diabetes?
 - a. *If participant seems to have difficulty with term "physical activity"*: Things like exercise, or also just taking the stairs instead of the elevator, or walking to the grocery store.
 - b. Do you think it could be helpful to you?
 - c. What are some of the things that make it hard for you to get physical activity?
27. Do you ever experience low blood sugars? How does that influence how you take care of your diabetes? Is that something that has changed over the course of your life?

Let's talk about something else now. We'd like to know more about how others influence how you take care of your diabetes. Or how diabetes impacts your social relationships. And that's can be in a good way or a bad way.

28. Are there people in your life who have an influence on how you take care of your diabetes?
 - a. What do they do? What kind of influence do they have?
29. Other people may sometimes make it harder to take care your diabetes. Is that something that you have experienced? Can you tell me more about that?
30. Who do you talk to about taking care of your diabetes? I mean other than to your doctors and health care providers?
31. Can you tell me how your diabetes affects your social relationships?
 - a. *If participant has difficulty answering*: Things like friendships, or romantic relationships.
 - b. What about family relationships?

Sometimes other people may have opinions on how you should take care of your diabetes.

32. Are there any people in your life who try to tell you how to take care of your diabetes? What kinds of things are they telling you to do?
33. Do you know anyone else who has type 1 diabetes? Is the way you take care of your diabetes the same or different from others? How so?
34. Do you ever feel judged by others about your diabetes or how you care for your diabetes?
 - a. Tell me about an example when that happened.

Okay, we're almost done. Just three more questions.

35. How do you motivate yourself to take care of your diabetes, day after day?
36. Are there any things about you as a person that make taking care of your diabetes easier or harder?
37. And finally, how much do you feel like you're in charge of your diabetes?

Alright, that's it! Thanks so much. Just to be sure,

38. Is there anything else about your diabetes that I haven't asked about? Would you like to mention anything else?

Interviewer comments

Overall impressions (e.g., tone, sophistication)
Non-verbal (e.g., comfort level, body language)