



Published in final edited form as:

J Pain Symptom Manage. 2011 April ; 41(4): 715–727. doi:10.1016/j.jpainsymman.2010.06.018.

The Diabetes Symptom Self-Care Inventory: Development and Psychometric Testing with Mexican Americans

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Abstract

Context—Type 2 diabetes is prevalent throughout the world. In previous studies of Mexican Americans with type 2 diabetes, 95-97% of those sampled reported having symptoms they believe were caused by diabetes and most self-treated their symptoms. To more accurately capture Mexican Americans' symptom prevalence and their self-treatments, the Diabetes Symptom Self-Care Instrument (DSSCI) was adapted from the Diabetes Self-Care Instrument.

Objectives—This paper describes the modification process used to perfect the DSSCI for use in improving self-care among people with Type 2 diabetes.

Methods—This instrumentation study used qualitative and quantitative methods. The study was completed in four phases that used focus groups, cognitive interviews, and survey administration. Four convenience samples were drawn from community-based Mexican American adults, aged 25-75, with type 2 diabetes in an urban area and a rural location in Texas.

Results—Phase I: Seven focus groups (n=45) generated data for revising items. Phase II: Cognitive interviews with 16 participants were used to evaluate four revisions of the questionnaire. Phase III: Surveys were administered to 81 participants. Total number of symptoms on the DSSCI correlated with scores on the Centers for Epidemiological Studies-Depression scale ($r=.65$, $p < .001$), Illness Perception Questionnaire-Revised Diabetes symptom subscale ($r=.57$, $p < .001$), and Audit of Diabetes-Dependent Quality of Life scale ($r= -.42$, $p < .001$). Minor revisions followed. Phase IV: Test-retest stability was demonstrated ($n = 44$).

Conclusion—The DSSCI is a culturally-relevant, sound measure of Mexican Americans' diabetes symptoms and the actions they take to address them.

Keywords

instrument development; type 2 diabetes; Mexican Americans; symptoms; self-care

Approximately 23.6 million people in the United States and 220 million worldwide have diabetes.^{1,2} Among them, 90-95% have type 2 diabetes, a disease that requires ongoing professional care and effective self-management to avoid devastating complications such as blindness, amputation, and renal failure.¹ In the U.S., Hispanics are the largest and fastest growing minority group. Mexican Americans, the largest Hispanic subgroup, are nearly two times as likely than non-Hispanic Whites to develop type 2 diabetes^{1,3} and are less likely than non-Hispanic Whites to have health insurance or access to medical care.⁴ Although self-management is important for all patients with diabetes, under such adverse circumstances, Mexican Americans' prognoses are even more dependent on their ability to be aware of their symptoms, to monitor those symptoms and to treat them properly.

Diabetes is associated with well-documented symptoms such as polyuria, polydipsia, polyphagia, and weight loss, as well as several non-specific symptoms including headache and fatigue.⁵ Symptoms are usually discussed in the context of diagnosing diabetes.^{6,7} However, long after the initial diagnosis, people with diabetes often have symptoms in response to hyper- and hypoglycemia, side effects of medication, and concurrent medical conditions.^{8,9}

Most people take some form of action in response to diabetes symptoms. However, too many act without knowing the symptoms' physiologic cause thus inviting potentially damaging consequences.^{8,9} Therefore, patients and their caregivers need an effective tool to identify symptoms, assess the perceived seriousness of those symptoms, and evaluate responses taken to alleviate symptoms. The purposes of this paper are to describe the processes used to develop, revise, and test the Diabetes Symptom Self-Care Inventory (DSSCI), a tool designed to measure Mexican Americans' symptom experience, and to report evidence for the revised questionnaire's reliability and validity.

Background

Other instruments to measure symptoms

There are several well-known surveys of general symptoms associated with both quality of life and functional status; but there are few instruments that measure symptoms specific to diabetes. Of the diabetes-specific questionnaires, the Diabetes Symptom Checklist¹⁰ (DSC) measures the prevalence and severity of 34 symptoms in the following categories: hyperglycemia, hypoglycemia, psychological-fatigue, psychological-cognition, cardiovascular, neuropathic-pain, neuropathic-sensory, and vision. The DSC asks respondents to identify symptoms experienced in the previous four weeks then rate symptom frequency and their perceived discomfort on a 4-point scale. The DSC does not allow respondents to report perceptions of other symptoms or convey their beliefs that any of their symptoms have more than one cause.

Another measure of diabetes symptoms is found in the Illness Perception Questionnaire-Revised (IPQ-R). The IPQ-R is composed of three sections. In the identity section, the respondent is presented with 14 general symptoms and asked to identify which symptoms they had ever experienced, and of those, which are attributed to the illness; but the IPQ-R does not indicate how the respondents relate their symptoms to their illness. The other two sections assess perceptions about the illness timeline, control, consequences, coherence, emotional dimensions, and causes.^{11,12} Although there is a diabetes-specific version, it does not include the most common diabetes-specific symptoms (increased thirst, urination, and hunger). Neither the DSC nor the IPQ-R provides a means of identifying symptom treatments used or an appraisal of the treatments' effectiveness.

The previously mentioned tools were developed for and tested with predominantly Caucasian samples with type 1 diabetes. However, type 2 diabetes has a different etiology and onset and Mexican Americans often have different cultural perspectives that can influence their symptom perception, expression, and treatment.^{13,14}

Development of the DSCI and the DSSCI

In the early 1990s, Brown and colleagues began testing diabetes self-management interventions designed for Mexican Americans living along Texas' border with Mexico. To describe their sample's symptoms and better understand their symptom self-care habits, Brown and Upchurch⁸ developed the Diabetes Self-Care Instrument (DSCI). For the first version of the DSCI Brown and Upchurch derived a list of 20 diabetes-related symptoms, extracted from the literature and their clinical experience. Respondents were asked to

specify which of the symptoms they experienced in the previous month and report whether each was serious. Respondents next identified whether they used professional care, self-care, or both to treat the symptom and named the type of self-care response they used (prescription medication, over-the-counter medication, blood or urine testing, lifestyle change, herbal remedy, or other).

The symptoms were written in English and translated into Spanish by native speakers from south Texas. The items were then reviewed by bilingual community workers and health care professionals from the target population (S. A. Brown, personal communication, May 12, 2008).

To score the DSCI, each field was treated as a dichotomous variable: either the participant had the symptom or not, the symptom was serious or not, each type of symptom response was used or not. Frequencies and percentages were calculated for each variable. Symptoms were summed to obtain the total number of symptoms reported.⁸

The first use of the DSCI yielded useful descriptive data about the prevalence of type 2 diabetes-related symptoms among a sample of 63 Mexican Americans in south Texas and enumerated the broad categories of their symptom responses. For instance, all but one subject reported at least one symptom in the prior month. Most DSCI respondents reported the majority of their symptoms were not serious and they used a variety of self-care strategies. Few sought professional care.⁸ The DSCI data were used to evaluate differences in average glucose level, as measured by glycosylated hemoglobin (A1c), for those reporting specific symptoms. A1c is an indication of the amount of glucose bound to hemoglobin molecules over their lifespan, about 120 days. Hemoglobin molecules are normally 4-6% glycosylated but people with uncontrolled diabetes may have levels as high as 20%. Higher A1c levels were seen in those who reported having dizziness or chest pain on the DSCI.⁸ Despite the usefulness of the data obtained, the field tests showed that several participants did not understand the symptoms as defined; for example, some participants had difficulty with the concept of “excessive thirst” in relation to the south Texas heat. Another limitation was that the DSCI did not indicate which self-care strategies were effective.

Therefore, for a subsequent study, the DSCI was revised to clarify operational definitions for some symptoms, to record specific symptom responses, and to add the respondent's perception of the response's efficacy.⁹ The tool was renamed the Diabetes Symptom Self-Care Inventory (DSSCI) because it listed both symptoms and a broader variety of responses. In an effort to limit the symptom list to the most essential and to offset the anticipated burden to the respondents, the list of symptoms was reduced from 20 in the DSCI to only 10 in the DSSCI, including a blank so that participants could fill in their “other” symptoms.

Tested with a sample of 87 Mexican Americans with type 2 diabetes in central Texas, the DSSCI produced useful data on the prevalence of diabetes symptoms (97% reported at least one symptom), allowed participants to identify multiple responses and specific strategies to treat symptoms, and to indicate the effectiveness of their responses (most were perceived to be somewhat or very effective). Patients' reports of higher numbers of symptoms are associated with their lower quality of life and higher A1c levels, a sign of poorer diabetes control.¹⁵ A1c values were significantly higher in those reporting blurry vision or excessive hunger.

One shortcoming of the DSSCI was that it did not allow respondents to specify their self-care activities beyond broad categories. For instance, respondents could state they addressed symptoms using “lifestyle choices” but could not specify what changes they made, e. g., whether they ate or drank something to relieve symptoms, engaged in physical activity or rested. There was also evidence that the instrument did not capture all the symptoms that

Mexican Americans associated with their diabetes because participants listed many symptoms under the “other” category. Furthermore, many respondents indicated they “did nothing” in response to or “ignored” the symptom, which could be perceived as symptom management strategies in themselves. Therefore, the study reported in this paper was planned to revise the DSSCI again to produce a better measurement of Mexican Americans’ diabetes symptoms and their actions in response to those symptoms.

The specific aims of this study were to 1) gather qualitative data to serve as a basis for revisions to the DSSCI; 2) revise the DSSCI to a) ensure that the symptom list fully reflects Mexican American perspectives, b) elicit beliefs about symptom causes and importance, c) identify all self-care responses used and ratings of their effectiveness, and d) provide culturally meaningful and sensitive response choices; and 3) estimate reliability and validity of the revised DSSCI.

Methods and results

Overall study

Design—A descriptive design was used in this instrumentation study. The study was conducted in four phases (Table 1). In Phase I Mexican Americans’ perceptions of diabetes symptoms, their beliefs about their symptoms’ seriousness, and their opinions about symptom responses were elicited in focus groups. The data from Phase I were used to modify the DSSCI symptoms and response choices. In Phase II, the revised DSSCI was evaluated for understandability and clarity using cognitive interviews. Feedback from the interviews served as the basis for further revisions. In Phase III, the DSSCI was administered along with four other questionnaires to assess construct validity. In Phase IV a subsequently revised version of the DSSCI was administered on two occasions one to two days apart to evaluate test-retest reliability. The methods and results for each phase are described later in this paper.

Setting—The study was set in two locations in Texas: a city in the central part of the state and a mostly rural area over 300 miles to the southwest. Austin, the state capital, is an urban area with almost 600,000 people; 32% are Hispanic, mostly Mexican American;¹⁶ 8% of them have diabetes.¹⁷ Starr County is a poor, less populated area situated on Texas’ border with Mexico. Participants lived in or near Rio Grande City, where 95.9% of the 11,923 residents is Mexican American.¹⁸ Diabetes is highly prevalent in Starr County; an early epidemiologic study reported that 50% of the adult population either had diabetes or was a first degree relative of someone with diabetes.¹⁹

Sampling—The population measured was adult Mexican Americans with type 2 diabetes. Separate convenience samples were used in all four phases. Each of the total of 186 participants self-identified as: 1) Mexican Americans with type 2 diabetes, 2) aged 25-75, and 3) Spanish- or English-speaking or bilingual. Participants in Austin were recruited using flyers placed in public areas such as in clinics, laundromats, libraries, and grocery stores. An invitation to join the study was also posted on an e-mail listserv for Hispanic women in Central Texas. In Starr County participants were recruited from a registry of over 700 people with type 2 diabetes and at a health fair. A university IRB approved the study protocol. Written informed consent was obtained from participants in each phase of the study.

Phases I and II: qualitative studies

Phase I Design and methods—In Phase I seven focus groups were convened to explore Mexican Americans’ diabetes symptom experiences. Because focus groups have proven to be an effective information gathering method to use with Hispanics,^{20,21} five groups (n=30)

were convened in Starr County and two in Austin (n=15). Groups were typically composed of 5-7 participants. Four groups were conducted in English, two in Spanish, and one in a combination of English and Spanish. Groups included men and women because participants preferred to be grouped with spouses rather than be interviewed in same-sex groups. Participants received a \$25 gift card after the discussion, which usually lasted about one hour. The moderator, a bilingual, Spanish-speaking nurse from south Texas, was assisted by the author who is also from the region and speaks Spanish.

Participants were asked about the sensations they associated with diabetes; what made their symptoms troublesome; and what they did when they had particular symptoms. All discussions were tape-recorded and the author took notes. A bilingual speaker native to the region transcribed the recordings verbatim and translated the Spanish transcripts. The author, the moderator, and three nurse graduate students who had expertise in diabetes coded transcripts and field notes. They identified themes, made comparisons across groups, discerned patterns in responses, and noted how the participants experienced and treated symptoms.

Phase I results—Most Phase I participants were female, aged 52 years, married, with 11 years of education. They had diabetes on average for 6 years (Table 2). During the focus groups participants reported a variety of physical and emotional symptoms and responses, methods of monitoring diabetes, and their impressions of symptom seriousness. Their comments about specific vocabulary prompted changes in the terms used. For example, when referring to dizziness or lightheadedness, Spanish-speaking focus group participants preferred the word *desfallecimiento*, meaning ‘on the point of passing out’ instead of the widely used word *borracho*, which literally means ‘drunken’. Participants’ symptoms were added to the DSSCI symptom list (e.g. memory loss, feeling susceptible to cold, and hair loss). Participants’ descriptions of strategies used to monitor their diabetes status and treat symptoms were included as new items (e.g. a comment about relying on feedback from family members became the item, “Do you know how your diabetes is doing because someone else tells you they think your sugar or diabetes is too high or too low?” with a yes/no response choice).

Analysis of the responses contributed to the generation of over 100 new items, the modification of existing items, and a change in the formatting of the questionnaire. New items included the following: the addition of symptoms that were reported during focus groups (e.g., loss of interest in sexual relations, loss of energy, irritability, and skin discolorations); a measure of how people gauged their diabetes control (options included glucose testing, feelings, input from others, and health care providers); the relative number of symptoms currently experienced; respondents’ perceptions about the cause of symptoms (high glucose, low glucose, both, something else, don’t know); perceptions about intensity and bother of the symptoms; confidence to relieve symptoms; eleven specific strategies for responding to symptoms; and items about which strategies worked best or did not work. This version of the DSSCI asked respondents to report which of 38 symptoms they experienced and asked 23 questions about symptom responses for up to 5 symptoms.

Phase II design and methods—In Phase II, the new items and format of the DSSCI were evaluated using cognitive interviews, a procedure to explore participants’ mental processes as they react to questionnaires and to identify problems in item comprehension, memory retrieval, and decision processes.²² In one-on-one tape-recorded interviews (n= 16), participants talked about their perceived meanings of the items on the questionnaire and how they derived their answers. Interviews lasted about one hour and participants received a \$25 gift card. The author and a graduate research assistant reviewed field notes and audiotapes from the interviews to identify items or instructions that participants misunderstood or had

difficulty in answering and to evaluate ease of administration and the quality of information gathered. Four iterations of the DSSCI were evaluated with cognitive interviews.

Phase II results—Phase II participants' demographic characteristics are summarized in Table 2. Most were women (75%) from Starr County (75%), Spanish-speaking (62.5%), and aged 54 years with an average of 11 years of education. The cognitive interviews led to refinements in item wording, response options, item ordering, and page layout.²³ The final outcome of Phase II was Version 2005 of the DSSCI.

Version 2005 of the DSSCI, used in Phase III, was composed of 47 items asked of all participants. They included five items to determine participants' usual ways of monitoring diabetes status (blood glucose meter, feelings, recent eating and activity, feedback from family or friends, or other methods); one item to assess the relative number of symptoms experienced in the previous two weeks; one open-ended item asking respondents to report symptoms experienced in the previous two weeks; a list of 38 symptoms to which respondents indicated any they had experienced in the previous two weeks; one item asking respondents to rank their most important symptoms (based on frequency, intensity, duration, worry, or bother); and one item to address the perceived cause of their most important symptoms (high or low glucose level or both, side effects of medication, complications of diabetes, other conditions, or unknown). If respondents indicated a symptom was important to them and attributed the symptom to diabetes, its side effects, or to an unknown etiology, those respondents were asked 18 additional questions about the symptom's frequency, the respondent's confidence in treating the symptom, the particular actions taken (e.g., glucose monitoring, food or drink intake, avoidance of particular foods or beverages, physical activity, rest, application of self-treatment to a part of the body, mental approaches such as prayer or self-talk, medication use, or general diabetes care) and to rate the effectiveness of treatments used. The set of 18 symptom response questions were asked for each important symptom the participant identified. To score the DSSCI the total number of symptoms was summed; each of the other items was examined descriptively. There is no total score obtained for all the items on the DSSCI because they compose an index of single items and subscales each relating to the diabetes symptom experience.

Phases III and IV: quantitative instrument testing

Phase III design and methods—A descriptive correlational design was used to evaluate construct validity of the DSSCI (Version 2005).

Sample—A convenience sample of 81 Mexican Americans with type 2 diabetes (41 in Austin and 40 in Rio Grande City) was selected. Power analysis using NQuery Advisor® Version 6.01²⁴ recommended a sample of 38 to detect an expected moderate correlation of .40 between the total number of symptoms reported on the DSSCI with scores on a quality of life scale¹⁵ with alpha set at .05 and power at .80.

Procedures—Surveys were administered in community settings (e.g. the participant's home, public library, local church, community center, or health fairs) in the participant's preferred speaking language, either Spanish or English. Participants were interviewed in one-on-one sessions during which the questionnaire was read aloud (respondents were given a copy of the survey to read along if they chose) and the participants' responses were noted. This method of formatting and administering surveys has worked well in several studies with participants with low reading abilities or vision impairments as well as with bilingual participants accustomed to speaking a mixture of English and Spanish.^{8,9,25} Each participant received a gift card to a regional grocery store.

Phase III instruments—The following instruments were administered during Phase III: a demographics form, the DSSCI Version 2005, the Centers for Epidemiological Studies Depression scale (CES-D), IPQ-R, and the Audit of Diabetes Dependent Quality of Life scale (ADDQoL); each is described below. Spanish language versions of CES-D, IPQ-R, and ADDQoL were obtained from the literature or from the instrument developers. To make certain they would be understood by respondents in this region, the surveys were subjected to translation and back-translation by native, bilingual Mexican Spanish speakers. Spanish versions were revised until the author and translators were satisfied that the wordings were appropriate to the regional vernacular and linguistically and conceptually equivalent to English versions.^{26,27}

The participants' age, sex, education, marital status, length of time with diabetes, diabetes treatment, past diabetes education, and concurrent conditions were documented with a form created for this study. In addition, the Short Acculturation Scale for Hispanics,^{27,28} composed of 4-items related to language choice and proficiency with a 5-point response choice, was used to describe the participants. Items scores were summed and averaged to yield an interval level value. Scores from 1.0 to 2.9 indicated someone was less acculturated; scores of 3.0 and above meant they were more acculturated. The scale showed high internal consistency reliability ($\alpha = .92$); validity was demonstrated by high correlations with familial generation in the United States, time in the United States, and participants' self-evaluation of acculturation.²⁷

The CES-D is a 20-item rating scale that measures the frequency of depression symptoms on a 4-point scale. The responses are summed to yield a total score (range = 0-60). Scores greater than 16 identify persons at risk for depression.²⁹ High estimates of the CES-D's reliability ($\alpha = .80-.88$) and validity have been documented with Mexican and Mexican American English and Spanish speakers.³⁰⁻³²

Only data from the IPQ-R, Diabetes Version³³ identity section (with reported $\alpha = .75$) were analyzed. Respondents were presented with 14 general symptoms and asked to identify which symptoms had been experienced and which of those they attributed to diabetes.¹¹⁻¹² Evidence for the IPQ-R's validity with people with diabetes includes significant correlations with the CES-D, Well-Being Questionnaire, Medical Outcomes Survey Short Form-36 (a measure of functional status and life quality), and the World Health Organization's Quality of Life scale.³⁴

The ADDQoL measures patients' perceptions of the impact of diabetes on their quality of life. It uses a 7-point Likert scale to measure global quality of life (2 items) and the impact of diabetes on various domains of life quality (13 items). Participants were asked to rate on a 4-point scale how important each domain is to them, ranging from very important to not important at all. The total score was obtained by multiplying each of the 13 domain scores by its corresponding importance score and summing the products. The 13 domains are internally consistent ($\alpha = .86$). Evidence for validity was seen with lower scores among patients using insulin and patients with more complications.³⁵

Phase III data analysis—Data were coded and entered into SPSS. Items were reverse coded, if indicated, and data accuracy verified. Frequencies and distributions were analyzed to identify outliers, skewness, and floor or ceiling effects. Descriptive statistics including frequencies, means, standard deviations, ranges, and bivariate calculations were calculated. Pearson correlations between the total number of symptoms on the DSSCI with scores on the CES-D and the IPQ-R diabetes symptom identity subscale were used to assess convergent validity. Pearson correlations between the total number of symptoms on the DSSCI with the ADDQoL subscales were used to assess divergent validity. The total

number of symptoms tallied from the DSSCI was expected to correlate positively with the total number of symptoms on the IPQ-R and the CES-D. A negative correlation was expected between the total number of symptoms and ADDQoL scores.

Phase III results—Characteristics of the 81 participants are shown in Table 2. On average, participants were similar to participants in earlier phases. They were female (65%), married (73%), about 54 years of age, fairly acculturated, had been diagnosed with diabetes for 8.5 years, took diabetes pills (69%), and had at least one co-morbid condition (75%). Most interviews were conducted in English (70%).

Administration of the DSSCI Version 2005 took approximately 15-20 minutes depending on the number of important symptoms reported. Respondents reported on average 14 symptoms (SD = 9, range 0-37). The list of 38 symptoms was internally consistent ($\alpha = .92$). The IPQ-R diabetes illness identification subscale, the CES-D, and the ADDQoL were also internally consistent with this sample: $\alpha = .81$, $.87$, and $.95$, respectively.

Higher total numbers of symptoms reported on the DSSCI positively correlated with scores on the IPQ-R identity subscale ($r = 0.57$, $p < .001$). The mean score of the CES-D was 12.5 (SD = 11.3), well below the cutoff score for depression. Higher total numbers of symptoms reported on the DSSCI positively correlated with CES-D scores ($r = 0.65$, $p < .001$). The mean quality of life score was -3.02 , near the middle of the possible range of scores (from -7.95 to $+3.00$, SD = 2.21). Reporting more symptoms correlated with worse overall quality of life ($r = -0.42$, $p < .001$).

Instrument revision—After Phase III, minor modifications were made to the DSSCI, resulting in Version 2006. The modifications included: 1) reducing the time period in which respondents' symptoms were experienced from two weeks to one week after test administrators reported that participants had difficulty recalling symptoms experienced in the longer time period; 2) eliminating three symptoms from the checklist because of conceptual overlap with other symptoms (e.g. loss of energy and sleepiness were deleted but tiredness was retained); 3) adding symptoms that were frequently reported via the "other" category (e.g. upset stomach or nausea and memory loss were commonly cited under "other") resulting in a list of 39 symptoms and room to write one "other"; and 4) eliminating the yes/no dichotomous choice response scale for the symptom list in favor of a four-point scale modeled after the CES-D scale in which 1 = never or rarely, 2 = sometimes, 3 = occasionally or often, and 4 = mostly or constantly, which captures the frequency of symptom occurrence. Version 2006 of the DSSCI was tested in Phase IV.

Phase IV design—The DSSCI (Version 2006) was administered to a new sample ($n=44$) recruited from Starr County on two occasions one to two days apart. The re-test period was selected to capture the transient nature of many diabetes symptoms but was long enough so that participants would not likely remember their responses to the first test administration.³⁶ The procedures for data collection and data management were the same as those used in Phase III.

Phase IV data analysis—Internal consistency of the symptom list was assessed with Cronbach's alpha. Test-retest reliability was assessed using Cohen's kappas for all dichotomously measured items and intraclass correlation coefficients (ICC) to measure agreement for the continuously measured symptoms.³⁷ The ICCs were calculated using one-way ANOVAs ($ICC_{1,1}$) assuming that there were no systematic differences between survey administrations. The coefficients for single measures were reported because the usual anticipated usage is for one administration per time period.^{37,38} Kappa and ICC measure

absolute agreement between values, not only consistency in measurements and thus constitute a stricter evaluation of test-retest reliability.³⁷

Phase IV results—Characteristics of the Phase IV sample are described in Table 2. The predominantly female, married sample was less educated ($t = 4.975$, $df = 121$, $p < .001$), more likely to speak Spanish (chi square = 26.934, $df = 1$, $p < .001$), and reported more symptoms ($t = -4.116$, $df = 124$, $p < .001$) than the Phase III sample. Most of the 44 respondents reported they used a blood glucose meter (80%) to monitor their diabetes status. They also relied on how they were feeling (68.9%) and their eating and activity behaviors from the previous day (68.9%) to gauge their diabetes status. The most commonly reported symptoms were tiredness (68.9%), dry mouth and a burning sensation (66.7% each), blurry vision, sadness, and weakness (64.4% each), urinating more than usual, intense thirstiness, nervousness, sweating, and memory loss (62.2% each). Most people identified at least one important symptom (defined by worry, frequency, bother, or intensity). The most frequently noted important symptoms were blurry vision (28.9%), numbness or tingling in an extremity (20.0%), sadness (13.3%), and weakness (13.3%). For those symptoms they believed were related to their diabetes, respondents provided information about relative frequency, their confidence in managing the symptom, how they managed the symptom, and each treatment's effectiveness.

The revised symptom list, this time using the 4-point response option, was internally consistent ($\alpha = .90$). Test-retest stability of the symptom list was assessed using consistency and agreement. The number of symptoms reported at time 1 and time 2 was consistent ($r = 0.87$, $p = .012$). The means for most symptoms were consistent across time (Table 3). Paired t-tests for only two symptoms: burning sensation in feet and hair loss, showed statistically significant differences in symptom frequency ratings. However, those differences were not clinically meaningful (burning sensation 2.48 ± 1.3 at time 1 and 2.16 ± 1.2 at time 2 and hair loss 1.68 ± 1.1 at time 1 and 1.41 ± 0.8 at time 2). ICC estimates for agreement between each symptom ranged from 0.90 to .14 (Table 3). For the item measuring the amount of symptoms relative to the previous week, ICC = 0.47. The items measuring respondents' ways of glucose level awareness (glucose meter, sensations, habits, feedback from family or friends, and other) achieved moderate kappas of 0.28-0.67.

Discussion

The DSSCI is a tool to document symptom prevalence, experience, and symptom responses in Mexican American adults with type 2 diabetes. Their symptoms are elusive, subjective, transient sensations that may or may not be attributable to diabetes. The DSSCI captures quantifiable descriptive data about patients' symptoms; it measures methods used to monitor diabetes, the prevalence of symptoms related to diabetes as well as their frequency. Respondents were asked to name the four most important of their symptoms based on intensity, severity, worry, bother, or discomfort. For each of their important symptoms respondents were asked about the symptom frequency in relation to the previous week, their confidence in managing the symptom, their habit of glucose testing in response to the symptom, and about specific actions taken for the symptom and those actions' effectiveness.

The DSSCI is a somewhat unusual instrument because it is a decision tree rather than a scale (similar in format and content to the Self-Care Diary by Nail and colleagues³⁹ that produced descriptive data about chemotherapy patients' side effects and self-care strategies to manage them). All respondents answer the DSSCI's first 48 items, including the list of 38 symptoms. The remaining items refer to attitudes and actions taken for specific symptoms. Therefore, the number of respondents identifying a particular symptom as important is much smaller than the overall sample. The responses of those who identified a particular symptom as

important can be compared to others who found that symptom important but not necessarily to those who found other symptoms important. As a result, it was not appropriate to use Cronbach's coefficient alpha to evaluate the internal consistency of the entire instrument. Future testing of the DSSCI with much larger samples would be necessary to have adequate respondents for each of the items before the factor structure of the DSSCI could be evaluated.

The value of the DSSCI is its ability to identify and record what patients are feeling and doing about their symptoms. When health care providers know what patients are experiencing, they can tailor patient education and health care treatments. For research purposes, the tool is useful for the descriptive data it generates. For instance, in this study the total number of symptoms experienced was correlated with depression and with low quality of life. In previous research¹⁵ the total number of symptoms experienced was correlated with higher (worse) A1c levels. Future studies with larger samples would allow identification of symptoms that appear in clusters and their correlates.

Each of the four phases in this study used a separate sample, yielding a total number of 186 participants. The samples were drawn from two areas in Texas, one more rural and with fewer socioeconomic resources, the other more urban with more resources. Although the proportion of the samples from each area varied across the four phases of the study, the combined samples are representative of the heterogeneous population. Future studies are needed to examine the instrument's applicability to other Hispanic subgroups and also to non-Hispanic groups.

The revision process produced a version of the DSSCI that demonstrates its content validity, construct validity, and temporal stability. The developers based their original survey (DSCI) on a review of the literature and their clinical experience. Nurses who were experts in diabetes self-management and Mexican American culture and patients with diabetes provided input to the revisions. These processes support the DSSCI's content validity.⁴⁰ Construct validity was supported by significant correlations in the expected directions between the number of symptoms experienced and scores on the CES-D depression scale, the identity subscale of the IPQ-R, and the ADDQoL. That the DSSCI yielded meaningful descriptive data is also evidence that it is a valid measure of diabetes symptoms and experience.⁴⁰ After Phase III, response options for the symptom items were changed from a dichotomous choice to a four-point scale to measure frequency of symptoms and the context for the symptoms to be recalled was decreased from two weeks to one. While these changes in format are not likely to affect the evidence for construct validity, validation analyses should be repeated on the altered version.

With regard to stability, ICC and kappa values showed fair to moderate stability over a short 1-2 day retest period.⁴¹ The kappa coefficients and ICCs are lower than ideal for several reasons. First, although respondents were asked to recall their symptoms experienced over the prior week, symptoms are often transient and may not last more than a few minutes. Therefore, retesting after even a brief passage of time might not capture the identical symptoms. Second, a symptom felt continuously may become a background sensation and therefore less likely to be identified or even noticed. Third, symptoms that are not perceived as serious may be ignored, consciously or unconsciously, until further questioning prompts reporting. Fourth, testing may have alerted participants that reporting more symptoms might lead to answering more questions causing some respondents to report fewer symptoms in order to complete the process sooner. Fifth, kappa and ICC estimates may be more stable with a larger sample size. Both kappa and ICC coefficients are sensitive to outliers. Kappa is based on expected proportions of responses and even small changes of one or two persons per cell in a contingency table can result in low kappa coefficients.³⁶ Finally, intraclass

correlation coefficients are reduced when the range of possible responses is narrow.⁴² There are four response options for the symptom list; a wider range of response choices may increase ICC estimates.

As a result of the revisions, analyses indicate the DSSCI (Version 2006) shows promise as a culturally meaningful, reliable, and valid measure of symptoms and symptoms self-management strategies. Copies of the instrument and scoring instructions are available from the author. The DSSCI can be of immediate clinical use for the improvement of Mexican American patients' comfort and quality of life. It may also be of use in research studies to describe symptom prevalence and management strategies, examine correlates of diabetes control, quality of life, and complications, and measure changes in response to intervention.

Acknowledgments

This project was supported by a pilot grant from The Center for Health Promotion and Disease Prevention Research in Underserved Populations, #P30 NR005051, from the National Institute of Nursing Research (NINR), National Institutes of Health (NIH). The content of this paper is solely the responsibility of the author and does not necessarily represent the official views of the NINR or the NIH. The funding source had no involvement in the conduct of the study or the preparation of the article.

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Table 1

Overview of Phases in DSSCI Revisions

Phase	Year	Design and Method	Sample	Impact on DSSCI	Evidence for Reliability and Validity
I	2004	Qualitative: Focus groups	N=45 in 7 groups	Discussants' words and phrases used to write items, choose aspects to address	Input from professional- and lay-experts in development stage support content validity.
II	2005	Qualitative: Cognitive interviews	N = 16	Items reworded and reformatted for clarity	Instructions, items, and response choices acceptable.
III	2005	Quantitative: Descriptive correlational with five surveys	N = 81	Evidence accumulated for construct validity.	Correlations of symptom list with scores on depression scale, symptom identity, and quality of life support construct validity.
IV	2006	Quantitative: Survey test-retest	N = 44	Minor revisions to format and items evaluated over two administrations.	Symptom list's internal consistency and whole scale's stability support reliability. Generation of useful data supports construct validity.

Table 2

Participant Characteristics in Frequency (Percent) or Mean (Standard Deviation)

Study Phase	I	II	III	IV
Sample size	45	16	81	44
Residents of Starr County	30 (66.7)	12 (75.0)	40 (49.4)	44 (100)
Female	32 (71.1)	12 (75.0)	53 (65.4)	33 (75.0)
Age in years	52.1 (11.4)	54.4 (10.1)	54.3 (13.2)	55.9 (12.7)
Married	34 (75.6)	8 (50.0)	59 (72.8)	30 (68.2)
Years education	11.4 (2.8)	10.9 (3.7)	11.7 (4.0)	7.7 (4.5)
Employed full time	22 (73.3)	7 (43.8)	33 (40.7)	12 (27.3)
Preferred speaking Spanish	9 (20.0)	10 (62.5)	24 (29.6)	35 (79.5)
Acculturation			3.0 (1.3)	
Time since DM diagnosis in years	7.2 (6.4)	10.3 (8.7)	8.5 (7.3)	11.3 (10.8)
Taking diabetes pills	33 (65.9)	9 (56.2)	56 (69.1)	31 (70.5)
Taking insulin (alone or with pills)	8 (17.8)	4 (25.0)	21 (26.3)	10 (22.7)
Have concurrent medical condition	29 (64.4)	12 (75.0)	61 (75.3)	39 (88.6)
Total number symptoms reported			12.3 (9.3)	18.4 (7.5)

Table 3

Phase IV Symptom, Mean (SD), Intraclass Correlation Coefficient, 95% CI (n = 44)

Symptom	Time 1 M (SD)	Time 2 M (SD)	ICC	95% CI
Vaginal dryness*	1.77 (1.3)	1.69 (1.2)	.90	.81-.95
Genital/Vaginal itching	1.48 (0.9)	1.52 (0.9)	.78	.64-.88
Constipation	2.11 (1.2)	2.11 (1.3)	.78	.63-.87
Dry mouth	2.34 (1.2)	2.32 (1.1)	.75	.59-.86
Burning sensation in feet	2.48 (1.3)	2.16 (1.2)	.74	.56-.85
Headache	1.88 (1.1)	2.12 (1.2)	.74	.56-.85
Hungrier than usual	1.70 (1.0)	1.82 (1.2)	.73	.56-.84
Trouble concentrating	1.70 (1.1)	1.79 (1.1)	.73	.55-.84
Cravings	1.84 (1.1)	1.75 (1.2)	.73	.55-.84
Sweating	2.39 (1.2)	2.2 (1.1)	.73	.55-.84
Intense thirstiness	2.34 (1.3)	2.27 (1.2)	.71	.53-.83
Anxious	2.00 (1.1)	1.91(1.1)	.70	.52-.83
Blurry vision	2.27 (1.1)	2.11 (1.0)	.70	.52-.82
Hair loss	1.68 (1.2)	1.41 (0.8)	.69	.50-.82
Loss of interest in sex	2.09 (1.4)	1.86 (1.2)	.69	.50-.82
Trembling	2.09 (1.1)	1.95 (1.0)	.67	.46-.80
Memory loss	2.07 (1.1)	2.02 (1.1)	.66	.46-.80
Weight loss	1.55 (1.1)	1.39 (0.8)	.66	.46-.80
Memory loss	2.07 (1.1)	2.02 (1.1)	.66	.46-.80
Dry skin	1.75 (1.1)	1.84 (1.2)	.66	.45-.80
Tiredness	2.44 (1.2)	2.33 (1.2)	.65	.44-.80
Problems sleeping	1.91 (1.2)	1.77 (1.1)	.65	.44-.79
Sensitive to light/noise	1.98 (1.2)	1.77 (1.1)	.65	.44-.79
Numbness or tingling of hands or feet	2.30 (1.3)	2.12 (1.2)	.60	.37-.76
Dizziness or lightheaded	1.98 (1.0)	1.84 (1.1)	.60	.37-.76
Sad	2.2 (1.1)	2.39 (1.1)	.59	.36-.75
Indigestion or nausea	1.75 (1.0)	1.52 (0.9)	.58	.35-.75
Urinating more than usual	2.36 (1.2)	2.18 (1.7)	.58	.34-.74
Flushing	1.84 (1.1)	1.73 (1.1)	.56	.32-.74
Weakness	2.34 (1.2)	2.14 (1.1)	.56	.32-.73
Easily angry	2.05 (1.1)	2.27 (1.0)	.48	.22-.68
Nervous	2.07 (1.0)	1.93 (1.1)	.45	.18-.66
Discolored skin	1.14 (0.5)	1.07 (0.3)	.43	.16-.64
Weight gain	1.43 (0.8)	1.27 (0.7)	.43	.16-.64
Irritability	2.26 (1.0)	2.26 (1.1)	.42	.14-.64
Physical discomfort during or problems performing sex	1.45 (1.0)	1.39 (0.9)	.38	.09-.60
Fidgety	2.18 (1.1)	1.95 (1.1)	.35	.07-.59

Symptom	Time 1 M (SD)	Time 2 M (SD)	ICC	95% CI
Susceptible to catching cold	1.36 (0.8)	1.27 (0.7)	.31	.02-.55
Itchy skin	1.67 (1.1)	1.44 (0.9)	.24	-.06-.50
Infection	1.27 (0.6)	1.23 (0.6)	.14	-.16-.42

Note: ICC = Intraclass Correlation Coefficient, CI = Confidence Interval

*
n = 34