Fear of Hypoglycemia: Quantification, Validation, and Utilization

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Hypoglycemia can lead to various aversive symptomatic, affective, cognitive, physiological, and social consequences, which in turn can lead to the development of possible phobic avoidance behaviors associated with hypoglycemia. On the other hand, some patients may inappropriately deny or disregard warning signs of hypoglycemia. This study presents preliminary reliability and validity data on a psychometric instrument designed to quantify this fear: the hypoglycemic fear survey. The instrument was found to have internal consistency and test-retest stability, to covary with elevated glycosylated hemoglobin, and to be sensitive to a behavioral treatment program designed to increase awareness of hypoglycemia. *Diabetes Care* 10:617–21, 1987

Diabetic patients are typically taught that the symptoms of hypoglycemia (e.g., sweating, faintness, trembling, and pounding heart) may signal coma and possibly death if immediate action is not taken (1). Recently, it was found that negative moods are frequently associated with low blood glucose (L.G.-F. and D. J.C., unpublished observations). In addition to these unpleasant physical symptoms, negative moods, and threat of death, hypoglycemia can lead to socially and occupationally compromising situations secondary to associated cognitive motor dysfunctions (2,3). Consequently, hypoglycemia can be an unpleasant endogenous state with immediate aversive consequences. In some individuals, personal or vicarious experiences with hypoglycemia may even lead to a phobic avoidance reaction to low blood glucose.

Surwit et al. (4) speculated that the aversive nature of hypoglycemia may motivate diabetic patients to maintain elevated blood glucose. Weiner and Skipper (5) found that fear of hypoglycemia was a significant psychological barrier to diabetic adherence. This is of significant contemporary concern in light of the typical therapeutic objective of tight control, where patients are encouraged to maintain a blood glucose level that is more vulnerable to slipping into a hypoglycemic range (6). Handelsman and Turtle (7) speculated that "the absence of any mild hypoglycemia is a strong pointer to poor glycemic control." This has been confirmed by Dunn (8), who found reported frequency of hypoglycemic episodes had an inverted-U relationship with metabolic control. Continuous subcutaneous insulin infusion (CSII) may produce more fear of hypoglycemia, because preliminary data suggest that CSII is associated with increased episodes of hypoglycemia, which may be less detectable by these patients (6,9). In addition, clinical experience suggests that individuals significantly intimidated by hypoglycemia are not good CSII candidates.

Consequently, excessive fear of hypoglycemia may have clinical significance as a cause of poor adherence; i.e., patients may avoid hypoglycemia by keeping an elevated blood glucose, or they may overtreat early signs of hypoglycemia. If such fears contribute to an individual's poor adherence and subsequent poor control, specific therapeutic interventions may be indicated. Such an intervention may be systematic desensitization, a common form of behavior therapy designed to treat phobias and reduce avoidance behaviors. The target avoidance behaviors in this instance would be those that lead to elevated blood glucose.

Although excessive fear of hypoglycemia may interfere with self-management, a general indifference toward hypoglycemia may also jeopardize physical well-being. This may be more of a problem for patients who do not hormonally counterregulate (10). Hypoglycemia is a greater threat for such patients, because they lack the endogenous mechanisms to detect and reverse this potentially life-threatening situation. More fear of hypoglycemia is understandable for these patients, and motivation to maintain elevated blood glucose is not only appropriate but potentially lifesaving. If a patient

who does not counterregulate has a total disregard for hypoglycemia, a therapeutic objective may be to increase his/her conditioned emotional response to hypoglycemia.

Consequently, a methodology to quantify fear of hypoglycemia may be quite useful, much like the quantification of metabolic control through glycosylated hemoglobin (HbA_1). With such quantification a normal range of hypoglycemic fear could be defined, thereby defining abnormally elevated or suppressed fear. This may add to a better understanding of some patients in poor control as well as point to specific treatment interventions. The objectives of this study were to develop an objective means to quantify fear of hypoglycemia and to begin reliability and validation testing of such an instrument.

INSTRUMENT DEVELOPMENT

Procedure

Initial items were solicited from three sources. First, diabetes health-care providers were interviewed to solicit their impressions of patients' concerns over hypoglycemia. Second, 20 insulin-requiring diabetic patients were interviewed for possible items. This was an open-ended interview that asked, "What bothers you about hypoglycemia? What do you do to avoid or cope with hypoglycemia?" Third, and subsequently, the investigators developed two clusters of items that might tap patients' behavioral avoidance of hypoglycemia and their affective fear of hypoglycemia. A series of 34 items was generated and placed in Likert form, where subjects rated each item from 1 ("never") to 5 ("very often").

This scale was initially administered to 12 patients and diabetes health-care providers. Redundant items (interitem correlation >.80) were deleted or rewritten, leaving 29 items. These items were clustered into two subscales: behavior or avoidance items and worry or affect items. The revised version was then administered to 35 naive insulin-requiring diabetic patients.

Results

Internal consistency. Cronbach's α was .87. All 29 items were positively correlated with the total scale, and each item contributed significantly to α.

Factor analysis. The scale was image-factor analyzed, with varimax rotation. One major factor emerged, incorporating 10 of the items. Factor 1 had an eigenvalue of 7.4, which accounted for 44% of the response variance.

INITIAL RELIABILITY AND VALIDATION TESTING

On the basis of these preliminary results, 7 items were rewritten to avoid duplication in meaning or to clarify the concepts revealed in the factor analysis. The final scale consisted of 10 behavior or avoidance items (items 1–10) and 17 worry or affect items (items 11–27). The overall reading level was 4th–5th grade, as determined by the Edward Fry scale. Appendix 1 displays the hypoglycemic fear survey (HFS).

Procedure

To optimize generalization of the findings, the HFS was administered to 158 insulin-dependent diabetes mellitus (IDDM) patients from four divergent settings: 38 from Kaiser Permanente in San Diego, CA (health-maintenance organization), 32 from the International Diabetes Center in Minneapolis, MN (private), 16 from the Lewis Gale Clinic in Salem, VA (private), and 70 from the University of Virginia Medical Center. Ages ranged from 15 to 80 yr (mean ± SD = 38.1 ± 16.7), with an educational range from 4th grade to graduate school (13.5 ± 2.8). Duration of diabetes ranged from 1 to 48 yr (12 ± 8.6). Age of diagnosis demonstrated a bimodal distribution separating at age 35, with 108 subjects diagnosed before age 35 (young diagnosis) and 48 after age 35 (old diagnosis). HbA_1 was measured in 152 of these subjects within 24 h of completing the HFS.

Results

Normative data. The overall HFS mean and mode were 64 ± 17. The respective means ± SD for young- and old-diagnosis subjects were 66 ± 15 and 61 ± 21 for total score, 28 ± 5 and 25 ± 8 for the behavior subscale, and 38 ± 12 and 37 ± 16 for the worry subscale. There were no significant differences of HFS scores across the data samples. Duration of diabetes also was unrelated to total score (r = .09, NS). Consequently, young- and old-diagnosis data were pooled for subsequent analysis.

Internal consistency. The correlation between the behavior and worry subscales was +.48 ($P < .001$). For the entire scale, Cronbach's α was .90, suggesting a high level of reliability for the scale. The behavior subscale had an α of .60, and the worry subscale had an α of .89. The tests of internal consistency were rerun on the subsamples separately: old-diagnosis subjects' α values were .87, .60, and .90, and young-diagnosis subjects' α values were .90, .70, and .92, respectively. There were no negative item-to–total scale correlations in the aforementioned analyses.

Factor analysis. Similar to our pilot study, analysis revealed one primary factor that loaded exclusively on the worry subscale: items 11–15, 18, and 24–27. This factor had an eigenvalue of 6.6 and accounted for 40% of the response variance. This factor could be labeled *inability to anticipate both the occurrence and treatment of a hypoglycemic event.*

Validation. Construct validity of the HFS was tested by *1*) covariation with HbA_1 and *2*) evaluation of the sensitivity of the HFS to the effect of a behavioral treatment program designed to increase awareness of hypoglycemia.

Because the HbA_1 values were analyzed at different laboratories,* they were z-transformed and categorized into clin-

*The HbA_1 means ± SD for the California, Minnesota, and Virginia samples, respectively, were 11.40 ± 2.87, 11.10 ± 2.53, and 10.72 ± 3.94%.

APPENDIX 1
Hypoglycemic Fear Survey

This survey is intended to find out more about how low blood sugar makes people feel and behave. Please answer the following questions as frankly as possible.

I. General Information:

Name: _____ Phone No.: (Home) _____ (Work) _____

Address: _____ Date of Birth: _____

_____ Date of 1st diagnosis of Diabetes: _____

II. Behavior. Below is a list of things people with diabetes sometimes do in order to avoid low blood sugar. Read each item carefully. Circle *one* of the numbers to the right that best describes what you do during your daily routine to avoid low blood sugar.

	Never	Rarely	Sometimes	Often	Very often
1. Eat large snacks at bedtime	1	2	3	4	5
2. Avoid being alone when my sugar is likely to be low	1	2	3	4	5
3. If test urine, spill a little sugar to be on the safe side. If test blood glucose, run a little high to be on the safe side	1	2	3	4	5
4. Keep my sugar higher when I will be alone for a while	1	2	3	4	5
5. Eat something as soon as I feel the first sign of low blood sugar	1	2	3	4	5
6. Reduce my medication (insulin/pills) when I think my sugar is too low	1	2	3	4	5
7. Keep my blood sugar higher when I plan to be in a long meeting or at a party	1	2	3	4	5
8. Carry fast-acting sugar with me	1	2	3	4	5
9. Avoid a lot of exercise when I think my sugar is low	1	2	3	4	5
10. Check my sugar often when I plan to be in a long meeting or go out to a party	1	2	3	4	5

III. Worry. Below is a list of concerns people with diabetes sometimes have. Please read each item carefully (do not skip any). Circle *one* of the numbers to the right that best describes how often you worry about each item because of low blood sugar.

	Never	Rarely	Sometimes	Often	Very often
11. Not recognizing/realizing I am having a reaction	1	2	3	4	5
12. Not having food, fruit, or juice with me	1	2	3	4	5
13. Feeling dizzy or passing out in public	1	2	3	4	5
14. Having a reaction while asleep	1	2	3	4	5
15. Embarrassing myself or my friends/family in a social situation	1	2	3	4	5
16. Having a reaction while alone	1	2	3	4	5
17. Appearing stupid or drunk	1	2	3	4	5
18. Losing control	1	2	3	4	5
19. No one being around to help me during a reaction	1	2	3	4	5
20. Having a reaction while driving	1	2	3	4	5
21. Making a mistake or having an accident at work	1	2	3	4	5
22. Getting a bad evaluation at work because of something that happens when my sugar is low	1	2	3	4	5
23. Having seizures or convulsions	1	2	3	4	5
24. Difficulty thinking clearly when responsible for others (children, elderly, etc.)	1	2	3	4	5
25. Developing long-term complications from frequent low blood sugar	1	2	3	4	5
26. Feeling lightheaded or faint	1	2	3	4	5
27. Having an insulin reaction	1	2	3	4	5

TABLE 1
Discriminant analysis of hypoglycemic fear survey items in predicting low, average, and high HbA_1

Items	Function 1	Function 2
1	+.63	+.24
4	−.62	+.09
5	−.46	−.14
7	−.12	−.44
8	−.32	−.16
9	+.16	+.35
11	+.42	+.11
15	+.07	−.68
16	+.68	−.36
18	−.26	+.48
19	−.94	+.21
21	−.07	+.41
22	+.16	+.55
24	+.51	+.00
26	+.28	−.49

Values are standardized canonical discrimination coefficients.

ically meaningful categories: average (±1SD around the mean), high (>1SD above the mean), or low (<1SD below the mean). It was predicted that responses on the HFS would identify individuals with high HbA_1 values. All 27 items were entered into a stepwise discriminant analysis. The linear combination of items maximally discriminating the three levels of HbA_1 are in Table 1.

The resulting Wilk's λ was .57 ($F = 2.95$, df = 30, $P < .001$). This analysis was able to correctly classify 70.3% of the HbA_1 cases, with six behavior items and nine worry items. As can be seen in Table 2, this discriminant function was not likely to categorize a subject with low or average HbA_1 as being high (0.7% chance of a false-positive error), nor was it likely to identify a subject in the high-HbA_1 group as being low (5.8% false-negative error).

The second validation effort involved providing 16 of the University of Virginia subjects with a group treatment program designed to improve their ability to detect hypoglycemia (D.J.C., W.R. Carter, L.G.-F., W.L. Clarke, and S. Pohl, unpublished observations). It was predicted that improving the ability to anticipate hypoglycemic episodes would lead to a lowering of the HFS score. After a 6-wk treatment program, these subjects were able to increase their awareness of hypoglycemia, and their HFS scores dropped significantly, from 66 ± 16.1 to 55 ± 14.8 ($P < .05$).

TABLE 2
Discriminant function classifications of low, average, and high HbA_1

	Predicted groups		
	Low	Average	High
Actual groups			
Low	30 (60)	20 (40)	0 (0)
Average	14 (16.5)	70 (82.4)	1 (1.2)
High	1 (5.9)	9 (52.9)	7 (41.2)

Absolute values (n) given with percentages in parentheses.

Test-retest reliability. To evaluate the stability of the scale over time, two test-retest reliability studies were performed with two subject samples different from the original validation sample. The first study involved 22 IDDM subjects at the University of Virginia, participating in an independent study. These individuals completed the HFS during their initial introductory session and again just before entering the primary experimental manipulation. Their mean age was 32.4 yr, and their mean history of diabetes was 7.8 yr. Their average intertrial interval was 3 mo. The test-retest reliability for the HFS was .68 ($P < .018$), and reliability was .68 ($P < .009$) for the behavior subscale and .64 ($P < .013$) for the worry subscale.

The second reliability trial involved 22 IDDM patients (13 women) from Cambridge, UK, participating in a drug trial. They completed the HFS twice before entering the actual drug trial, with a mean intertrial interval of 6 wk. Their mean age was 44.3 ± 7.9 yr, and their mean duration of diabetes was 25.7 ± 8.5 yr. The test-retest reliability was .89 ($P < .001$) for the total scale, .81 ($P < .001$) for the behavior subscale, and .85 ($P < .001$) for the worry subscale. The means and SD for the total, behavior, and worry scales at first test were 60.0 ± 13.8, 26.4 ± 4.5, and 33.4 ± 10.9, respectively, and for retest were 62.3 ± 7.9, 26.4 ± 5.2, and 35.6 ± 14.8, respectively.

DISCUSSION

The first essential aspect of a sound psychometric instrument is that it be reliable. The two test-retest reliability evaluations demonstrate the stability of the HFS. Although these two samples were small, the facts that they represent two different countries with different health-care systems and that both samples demonstrated significant reliability quotients enhance our confidence in the stability of the HFS. These reliability coefficients would be anticipated to be larger with smaller intertrial intervals. Reliability is further supported by the consistent high measures of internal consistency for the entire scale. The fact that the behavior subscale had a relatively lower α is to be expected, because adherence to some aspects of the diabetic regimen is unrelated to adherence to others (11). For example, the fact that a patient carries fast-acting glucose is no indication that he/she will perform self-monitoring of blood glucose more frequently.

Uncertainty typically increases fear in a threatening situation (12). Consequently, it was theorized that the more an individual was aware or could be made aware of hypoglycemia, the less the intimidation. Such awareness of hypoglycemia should lower fear because it both reduces uncertainty and provides the opportunity to take the necessary corrective action (consume carbohydrates) to prevent the negative effects of hypoglycemia. The experimental manipulation of hypoglycemic awareness provided such construct validation. This study is being replicated with both a larger sample and a control group.

The discriminant analysis suggests that the HFS may be

very useful in predicting poor metabolic control. It was able to identify 7 of 17 high-HbA_1 subjects (41%), although inappropriately classifying 1 of 135 low- or average-HbA_1 subjects. This 41% identification of high HbA_1 is quite robust considering all the other physiological and psychological variables that could contribute to poor metabolic control (13).

This suggests that the HFS may be able to identify individuals likely to maintain high blood glucose levels, which could lead to a better understanding of the reason for the poor metabolic control. It also points to a treatment focus. The challenge to clinical researchers will be to devise procedures that effectively reduce such fear. We have some indication that this might be accomplished (D.J.C., W.R. Carter, L.G.-F., W.L. Clarke, and S. Pohl, unpublished observations) by increasing patient awareness of their blood glucose fluctuations.

The fact that both the pilot and the secondary sample, representing divergent geographical and medical samples, yielded a similar single primary factor is persuasive. The centrality of this factor (inability to anticipate both the occurrence and treatment of hypoglycemia) is supported by the finding of the construct-validation study that increased ability in detecting hypoglycemia led to a lowering of HFS scores. Apparently, inability to anticipate hypoglycemic episodes is primary in fear of hypoglycemia.

However, this factor is not a complete picture of this fear, as evidenced by two facts. First, analysis indicated that this factor only accounted for 40% of the response variance, leaving many other items unaccounted for. Second, the discriminant analysis used many additional items beyond those that loaded on the primary factor, indicating that these additional items were necessary to predict high HbA_1 values. Consequently, the scale cannot be reduced to this single factor.

Before clinical reliance can be placed on the HFS, first, the discriminant analysis findings must be replicated with larger and differing samples. Second, the theoretical underpinnings of this scale must be further explored. This may involve determining whether there is a continuum of hypoglycemic fear ranging from *1*) high fear for IDDM patients who do not counterregulate to *2*) moderate fear for counterregulating IDDM patients to *3*) slight fear for patients on oral medications who would be less likely to be affected by hypoglycemic episodes to *4*) those whose treatment regimen is diet therapy alone and who should be the least concerned by hypoglycemia. Additionally, the reasons for elevated fear need to be investigated. These may include personal and/or vicarious experiences with hypoglycemia and the premorbid physiological and psychological subtrait on which such experiences are imposed. Finally, the overt behavioral consequences of inappropriate levels of hypoglycemic fear need to be investigated. Confirmation and exploration of these issues will be valuable in terms of any future clinical trials directed at reducing this fear and its subsequent avoidance behaviors and in further promoting better metabolic control.

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