

Assessing hyperglycemia avoidance in people with Type 1 diabetes



Harsimran Singh^{*1}, Linda Gonder-Frederick¹, Karen Schmidt², Derek Ford²,
Karen A Vajda¹, Jeffrey Hawley¹ & Daniel J Cox¹

Practice points

- Optimizing diabetes care involves maintaining the recommended metabolic levels while avoiding both hypoglycemia and hyperglycemia as much as possible.
- Fear of hypoglycemia is a well-established concern for people with diabetes using the insulin treatment. Clinical experience also supports that a few diabetes patients express extreme concern and avoidance behaviors linked to high blood glucose (BG) levels. Unfortunately however, the latter has not received adequate attention in the published literature.
- Patients with excessive concerns surrounding high BG levels could be a clinical challenge as they may attempt to keep BG lower than is clinically recommended for them, thereby increasing their risk for hypoglycemia.
- The Hyperglycemia Avoidance Scale (HAS) is a reliable and valid measure to help quantify the extent and impact of high BG-related concerns in a structured way. The measure includes 22 items overall, which are distributed across four subscales (immediate action, worry, low-BG preference and avoid extremes).
- Among other relevant findings, study data showed that the HAS subscales were predictive of future episodes of severe hypoglycemia and driving mishaps. Higher HbA_{1c} values were also significantly related to the HAS.
- The HAS can be used as part of routine clinic consultations to help healthcare professionals better understand BG management in their patients and offer opportunities for intervention if they find any extreme or abnormal concerns surrounding high BG levels.

SUMMARY: Aims: People with anxieties related to high blood glucose may engage in avoidance behaviors that increase their risk of hypoglycemia. Conversely, reduced concern about hyperglycemia could impair diabetes control. We developed the Hyperglycemia Avoidance Scale (HAS) to assess the extent of potentially problematic avoidant attitudes and behaviors in people with Type 1 diabetes (T1D). **Materials & methods:** The HAS was administered to 501 people with T1D (mean age: 43 years). Data analysis included Exploratory Factor Analysis (EFA) using polychoric correlations and Item Response Theory. Relationships between the HAS and other diabetes-related measures were examined. **Results:** The EFA supported a 22-item, four-factor solution with excellent item reliability for all factors. HAS factors were found to be predictive of prospective S Hand prospective driving mishaps. Higher HbA_{1c} values were also significantly related to the HAS. Pump users reported significantly greater avoidance of hyperglycemia than their counterparts. **Conclusion:** The HAS reliably quantifies affective and behavioral aspects of hyperglycemia avoidance. Future studies are encouraged to determine the usefulness of the scale with other more diverse populations with diabetes.

¹Department of Psychiatry & Neurobehavioral Sciences, University of Virginia Health System, Charlottesville, VA, USA

²Department of Psychology, University of Virginia, Charlottesville, VA, USA

*Author for correspondence: Tel.: +1 434 982 1022; hs9dc@virginia.edu

KEYWORDS

- anxiety • avoidance
- diabetes complications
- driving mishaps
- high blood glucose
- hyperglycemia
- hypoglycemia • quality of life • severe hypoglycemia
- Type 1 diabetes

Despite recent clinical and technological advancements, optimal diabetes care remains a delicate balancing act of maintaining adequate metabolic control while avoiding both hypoglycemia and hyperglycemia, especially for patients using insulin [1–6]. Fear of hypoglycemia (FoH) is a well-established concern in people with diabetes using insulin [7–11]. Some level of concern or fear of hypoglycemia is medically justified and adaptive, given the potentially dangerous consequences of severe episodes. However, a few patients, including those who have experienced episodes of severe hypoglycemia (SH), may consider its clinical and psychosocial effects more dangerous and imminent than the consequences of maintaining higher than recommended blood glucose (BG) levels [10]. Likewise, clinical experience and evidence supports that some patients may develop extreme concern and avoidance behaviors related to high BG levels, reflecting extreme fear of hyperglycemia, which can adversely affect diabetes management and control [12].

Concerns about high BG levels may result from various factors including: diabetes education (e.g., people may know that high BG levels should be avoided but do not fully understand why BG rises and how to manage it), unpleasant symptoms related to high BG levels (e.g., tiredness, low energy and irritability), and/or worries about developing long-term diabetes complications [13,14]. Patients with excessive concern for high BG levels may engage in more extreme behaviors to avoid hyperglycemia, including targeting BG levels that are clinically low or unsafe for them, potentially increasing their risk of frequent hypoglycemic episodes and their negative sequelae; for example, impaired awareness of hypoglycemia, increased driving-related risks. These patients may pose a significant challenge to healthcare professionals as they may be so focused on avoiding high BG levels that they either ignore or underestimate the dangers related to frequent hypoglycemia episodes, sometimes believing these to be necessary for good BG control [13].

Unfortunately, the potentially damaging impact of fear and atypical avoidance of hyperglycemia on patients' diabetes management and quality of life has not received much research attention. In part, this may be because people with diabetes are generally inundated with information about the association between high BG levels and development of complications,

which they could perceive as a 'point of no return' in terms of disease progression. The consequences of high BG levels are very well established. However, sensitizing patients to the complications related to high BG levels without balancing it with how they can avoid hyperglycemia can push people to accept hypoglycemia as a viable option to avoiding high BG levels. To date, only a handful of published reports have recognized the existence and impact of fear of hyperglycemia in the diabetes population [12–16]. Understanding patients' concerns and subsequent behaviors related to high BG is crucial, given how these factors could affect not only their day-to-day adjustment with diabetes but may also predict their success at using new technologies such as continuous glucose monitoring, which provides them with more control over BG levels [12,16]. To the best of our knowledge, there are no reliable and valid published measures that quantify the extent and impact of hyperglycemia-related concern in a structured way.

To quantify the degree of hyperglycemia avoidance in people with Type 1 diabetes (T1D), we developed the Hyperglycemia Avoidance Scale (HAS) with help from an expert panel including physicians (n = 3), psychologists (n = 5), diabetes healthcare professionals (n = 2) and semi-structured interviews conducted with T1D patients. The expert panel developed the first draft of items highlighting avoidance of high BG levels based on their experiences with their patients. These draft items were then reviewed by ten people with T1D who offered their feedback on the draft items and made recommendations for changes where necessary. After development of the first draft of the questionnaire, it was administered to T1D individuals who were participating in a larger Diabetes and Driving Study (DDST) designed to investigate factors affecting driving safety in these patients [17]. The purpose of the present study was to conduct psychometric evaluation of the HAS and highlight its clinical and research application in the diabetes community. Various hypotheses were tested, including establishing whether HAS is a reliable and valid measure of hyperglycemia avoidance. We hypothesized that frequent episodes of SH would be associated with higher scores on the HAS, in that participants high in hyperglycemia avoidance would have higher risk for hypoglycemia.

Research design & methods

• Study population & design

Overall, 515 people with T1D recruited from three sites in the USA (University of Virginia [VA, UA], Joslin Diabetes Center [MA, USA] and the International Diabetes Center [MN, USA]) consented to participate in the DDST. Participants were recruited through newspaper, diabetes media and radio advertisements. The Institutional Review Boards at each of these three sites approved the study protocol (IRB numbers: 10244 [VA, UA], CHS# 02-45 [MA, USA] and 1699-02C [MN, USA]). Of all 515 consenting individuals, 501 completed the entire study (Virginia = 121, Massachusetts = 165, Minnesota = 166) (**Table 1**). Fourteen patients did not complete the study and it is likely that this was due to their personal reasons and not so much study related, as the overall retention rate of the study was quite good. All participants satisfied the inclusion criteria in that they had had a formal clinical diagnosis of T1D for at least 1 year, measured their BG more than twice every day, had been driving more than 5000 miles per year, and had no severe visual and cognitive limitations.

All participants first attended a screening visit to sign an IRB-approved consent form. They were also assessed for hypothesized diabetes-specific and more general risk factors (self-report) that could affect their driving safety. Diabetes-related risk factors included symptoms of neuropathy, history of SH, hypoglycemia unawareness, fear of hypoglycemia, and avoidance of hyperglycemia (using the HAS). For prospective data collection, participants were provided with data-recording sheets to keep note of any hypoglycemia-related driving mishaps, among other variables. For the following 12 months, participants were contacted monthly to check if they had had any driving mishaps. This manuscript will focus exclusively on the results from the HAS in relation to other key variables from this study. Other results from the parent driving study have been published previously [17].

Data analysis

Descriptive statistical analyses, correlations and group comparisons were performed using SPSS (version 19). Pearson correlations were computed between HbA_{1c} data and each of the HAS factors. The dimensional structure of the HAS was examined with Exploratory Factor Analysis (EFA) in Mplus [18] using mean- and

variance-adjusted weighted least squares estimation on the polychoric correlations of categorical responses (i.e., rating scale of 0–4) [18]. Typical statistical software packages have EFA procedures that assume continuous data and therefore use Pearson correlations for analysis. The number of factors needed to represent the structure of the HAS was determined using the Kaiser–Guttman criterion of considering factors that have an Eigenvalue greater than 1.0 and by considering factor interpretability. Model fit was further assessed by the Root Mean Square Error of Approximation (RMSEA) statistic, where an RMSEA <0.08 is considered acceptable [19]. Using these considerations, a four-factor solution (HAS-1, HAS-2, HAS-3 and HAS-4) was accepted as showing both good model fit (RMSEA = 0.065; 95% CI: 0.059–0.071) and interpretability (**Table 2**). Interpretation of the factor loadings was conducted following a Promax (oblique) rotation of the original factor solution. The scale items were developed to sample various aspects of anxiety surrounding high BG levels; therefore, some relationships between items was expected. Employing the Promax rotation allowed the factors to be correlated without forcing any relationships. The correlations among the four factors in this analysis ranged from 0.01 to 0.44.

Item Response Theory (IRT) methods were used to assess the rating scale of HAS items. HAS subscales were analyzed using the Rasch Partial Credit Model (PCM) [20] in Winsteps (version 3.68.0) [21]. Several statistics from PCM results assess item fitness. These include:

- Infit and Outfit statistics which indicate the degree of conformity between responses to an item and persons' measured trait levels, in this case, 'avoiding hyperglycemia';
- Point-measure correlations (which are similar to item-total correlations, ranging from -1 to 1) involving the item score with the PCM trait estimate (relatively high values are desirable). Items with low values should be examined further, and negative values indicate problematic items and/or sample concerns. Although some guidelines are given in the literature (e.g., 0.30 to 0.70 [22]), point-measure correlations depend on the variance of the sample and should be examined in context of other fit statistics);
- Separation index, which indicate the number of statistically distinct trait levels as measured by the scale, with high values desirable; for

Table 1. Characteristics of the study population at baseline.

Characteristic	Value
N	501
Sex (% female)	52.40
Age (years)	42.64 ± 12.63
Duration of diabetes (years)	25.13 ± 12.78
Ethnicity:	
Non-Hispanic white	485 (97.60)
African-American	7 (1.40)
Hispanic, other	5 (1)
Education [†] :	
<12 years	10 (2.00)
12 years	48 (9.70)
13–15 years	108 (21.90)
16 years	161 (32.60)
>16 years	167 (33.80)
Marital status [‡] :	
Single	121 (24.2)
Married	292 (58.5)
Cohabiting	25 (5.0)
Divorced	55 (11.0)
Widowed	6 (1.2)
Pump user	258 (52)
Total insulin units/day	41.26 ± 19.55
Insulin injections/day [‡]	2.05 ± 1.94
HbA _{1c}	7.8 ± 0.8

Data are n, mean ± standard deviation (range) or n (%).
[†]Cases may not add up to the total because of nonresponders.
[‡]Information on the type of insulin used was not collected.

example, a separation of ‘2’ indicates that two trait levels are distinct; a separation of ‘3’ indicates three levels, and so on. Separation is computed as the square root of the ratio of reliability to 1-reliability. Hence, a test with 0.95 reliability has a separation index of 4.35, indicating approximately 4 statistically distinct trait levels.

Item and person reliability for the HAS was assessed separately for the four factors using reliability statistics in Winsteps. Rasch item reliability gives a value indicating the predictability of items difficult to endorse actually being difficult items, and items easier to endorse actually being easier items [21]. In the context of this study, the concept of item difficulty indicates its location on the trait scale, reflecting the tendency for persons to endorse positively worded items with an ‘always’ response. Items with few strongly endorsed responses indicate high difficulty or location, and items with many strongly endorsed responses indicate low difficulty or location. High item reliability is desirable, and

it is associated with a large item difficulty or location range and/or a large sample of persons, and is uninfluenced by the number of items in the scale.

Results

• Exploratory factor analysis & item analysis

The initial item development phase of the HAS scale generated 24 items (Table 2). Each item has a five-point Likert scale response option ranging from 0 (never) to 4 (always) with a middle point of 2 (sometimes).

A few items were identified as problematic during the EFA (Table 2). Items 2 and 4 did not load reasonably (loadings <0.30) [23] on any of the four factors, and were therefore dropped from the scale and any further analysis. Items 16, 18, 21 and 23 crossloaded on two of the four factors and were finally assigned to individual factors based on their loading strength and item statistics (infit and outfit measures, point measure correlation). For example, Item 16 loaded on both HAS-2 (0.59) and HAS-3 (0.36), but it was finally included as part of HAS-2 (infit

Table 2. Exploratory factor analysis results: mean scores and factor loadings on the four factors.

Item	Item wording	Scores (mean ± SD)	F1 [†]	F2 [‡]	F3 [§]	F4 [¶]
	How often do you...:					
1	try to lower your blood sugar as soon as it is higher than 200 mg/dl?	2.96 ± 1.11	0.68	0.10	0.13	0.01
12	test your blood sugar more often when you think it is too high?	2.91 ± 1.03	0.58	0.16	-0.02	0.18
6	keep your blood sugar in a normal range?	2.89 ± 0.73	0.50	-0.25	0.06	0.05
7	increase your next insulin dose as soon as you know your blood sugar is high?	3.02 ± 1.04	0.47	0.15	0.13	-0.16
10	eat differently after you know your blood sugar is high?	2.65 ± 1.10	0.31	0.05	0.09	0.29
19	worry about losing your health due to your diabetes?	2.23 ± 1.17	0.18	0.94	-0.18	-0.12
14	worry about heart disease, kidney disease, blindness and other complications?	2.20 ± 1.06	0.28	0.84	-0.15	-0.07
15	consider high blood sugars to be a serious problem for you?	1.90 ± 1.05	-0.09	0.59	-0.03	0.13
16	feel upset when your blood sugars are too high?	2.36 ± 1.08	0.24	0.59	0.36	-0.08
24	worry about your doctor's reaction when your blood sugars are too high?	1.07 ± 1.10	-0.29	0.52	0.12	0.04
20	worry about not recognizing/realizing that your blood sugar is too high?	1.41 ± 1.08	0.07	0.47	0.13	0.20
22	feel bothered about need to urinate frequently or at inconvenient times?	1.23 ± 1.14	-0.25	0.38	0.06	0.14
23	worry about not knowing how to lower your blood sugar when it is high?	0.53 ± 0.76	-0.34	0.33	0.11	0.29
13	prefer to keep your blood sugar too low rather than risk being too high?	1.11 ± 1.10	0.12	-0.15	0.75	0.07
17	feel comfortable being hypoglycemic sometimes if that is what it takes to control your blood sugar?	1.08 ± 1.06	-0.06	-0.12	0.58	0.03
3	choose to take a little more insulin rather than risk taking too little?	1.78 ± 1.05	0.06	0.10	0.53	-0.16
21	feel mad at yourself when your blood sugars are too high?	1.94 ± 1.21	0.12	0.51	0.45	-0.04
11	avoid situations/activities that might cause you stress and raise your blood sugar?	0.99 ± 1.04	-0.02	-0.11	0.07	0.67
9	avoid restaurants/social events that tempt you to eat foods that raise your blood sugar?	0.81 ± 0.96	-0.09	-0.09	0.14	0.65
5	check your urine for ketones when your blood sugar is high?	0.98 ± 1.14	0.17	-0.03	-0.20	0.54
18	worry about going into DKA?	0.74 ± 0.91	0.03	0.37	-0.16	0.52
8	exercise to lower your blood sugar?	1.92 ± 1.04	0.19	0.02	0.03	0.36
2 [#]	<i>skip snacks your doctor recommends so your blood sugar won't be too high?</i>	1.16 ± 1.15	-0.002	0.27	0.13	0.10
4 [#]	<i>treat your low blood sugar with as little food as possible so you won't be too high later?</i>	1.38 ± 1.05	0.10	-0.04	0.22	0.15

Factor loadings in bold represent those items that were finally included in that particular factor.
[†]F1 (HAS-1): immediate action.
[‡]F2 (HAS-2): worry.
[§]F3 (HAS-3): low-BG preference.
[¶]F4 (HAS-4): avoid extremes.
[#]Items 2 and 4 were removed from the scale after their psychometric evaluation.
DKA: Diabetic ketoacidosis; F: Factor; HAS: Hyperglycemia Avoidance Scale; SD: Standard deviation.

and outfit statistics were within acceptable limits [0.6–1.5]) and the point-measure correlations were above 0.5 (desirable values = 0.3 and above). Employing a similar methodology, item 18 was included under HAS-4, item 21 under HAS-3, and item 23 was included as part of HAS-2 (see **Table 2**).

Content of the highest loading items in each of the four HAS factors was examined to enable labeling of the four subscales. Factor 1 (HAS-1, five items) includes items describing immediate actions that patients could take in order to lower their BG levels and was labeled 'Immediate action', Factor 2 (HAS-2, eight items) was labeled 'Worry', as it includes items that relate to high BG-related worry and concerns. Factor 3 (HAS-3, four items) was labeled 'Low BG preference' and included items indicating a tendency to prefer low glucose levels over high. Factor 4 (HAS-4, five items) included items describing actions and concerns related to very high BG levels and was therefore, labeled 'Avoid extremes'. The mean summed scores for the four subscales were 14.43 (SD: 3.09; range: 0–20; possible maximum score: 20), 12.95 (SD: 5.48; range: 0–30; possible maximum score: 32), 5.90 (SD: 3.05; range: 0–15; possible maximum score: 16), and 5.39 (SD: 3.16; range: 0–17; possible maximum score: 20), respectively.

Item & person reliability

Item reliability (true item variance divided by observed item variance) for all four factors was excellent and ranged between 0.92 and 1.00. The person reliability statistic estimates the degree to which the scale differentiates people on the items assessed and is the Rasch equivalent of Cronbach's alpha, although the Rasch estimate slightly underestimates reliability, and Cronbach's alpha overestimates it [21]. Person reliability for the four factors was as follows: HAS-1 = 0.54, HAS-2 = 0.79, HAS-3 = 0.61 and HAS-4 = 0.54. Person reliability for HAS-2 and HAS-3 was acceptable but low for HAS-1 (immediate action) and HAS-4 (avoid extremes). This indicated that our sample had a narrow spread on items for HAS-1 and HAS-4. In other words, the majority of participants scored higher on the HAS-1 factor (i.e., took immediate action to lower BG when it was high) and scored lower on HAS-4 (i.e., were less likely to take steps to avoid situations that could lead to high BG levels). Overall, based on item and person reliability estimates, all items were retained.

• Validity & relationship between HAS subscales & other study variables

Negative binomial regression was used to evaluate the ability of the four HAS factors to predict the number of SH episodes and total number of prospective hypoglycemia-related driving mishaps. Two separate regression models were specified and tested ($\alpha = 0.05$). In the first model, the total number of SH episodes reported by participants over the subsequent 12-month follow-up period was the outcome variable (1.02 ± 3.11) and the participants' scores on each of the four HAS factors were included as predictors. Only HAS-3 (low BG preference) was found to be predictive of prospective SH ($p = 0.002$). A summary of this model and a subsequently described model is presented in **Table 3**. Examination of the estimated incidence rate ratio (IRR) for HAS-3 suggests that a 1-point increase in score on this factor would result in a 14% increase in the incident rate of episodes of SH. Generally, if the IRR >1 , then an increase in value of the predictor variable is associated with an increase in the number of outcome events, that is, episodes of SH. Conversely, an IRR <1 indicates that an increase in the value of the predictor variable is associated with a decrease in the number of outcome events.

Using the total number of prospectively reported hypoglycemia-related driving mishaps as outcome variable (1.65 ± 3.18), a second negative binomial regression model was specified with the scores on each of the HAS factors included as predictors. As shown in **Table 3**, this model indicated that HAS-2 (worry) is predictive of prospectively reported mishaps ($p = 0.02$).

Significant relationships were also identified between HbA_{1c} values and two HAS subscales, in that poorer glycemic control (higher HbA_{1c} values) was negatively associated with a likelihood to take some immediate action to lower BG (HAS-1; $r = -0.22$; $p < 0.001$) and positively associated with worry about high BG levels (HAS-2; $r = 0.16$; $p < 0.001$). Participants who were using an insulin pump reported significantly greater mean avoidance of hyperglycemia than their counterparts on two subscales (HAS-1, 15.37 vs 13.49, $p < 0.001$; and HAS-4, 5.93 vs 4.85, $p < 0.001$). As expected, all four HAS subscales were significantly correlated with the Hypoglycemia Fear Survey (worry subscale; HAS-1: $r = 0.11$, $p < 0.01$; HAS-2: $r = 0.51$, $p < 0.001$; HAS-3: $r = 0.31$, $p < 0.001$; and HAS-4: $r = 0.25$, $p < 0.001$), indicating that those reporting greater concern about and avoidance of high BG levels were also more worried about hypoglycemia.

Table 3. Summary of three negative binomial regression models predicting the number of severe hypoglycemic episodes or driving mishaps prospectively and retrospectively.

Model	Predictor	IRRexp (coefficient)	SE	z	p-value
SH episodes					
Prospective	Constant	0.42	0.28	-3.10	0.002
	HAS-3 [†]	1.14	0.04	-3.10	0.002
Driving mishaps					
Prospective	Constant	1.01	0.22	0.04	0.97
	HAS-2 [‡]	1.04	0.02	2.38	0.02

[†]HAS-3: Low-BG preference.
[‡]HAS-2: Worry.
HAS: Hyperglycemia Avoidance Scale; IRR: Incidence rate ratio; SE: Standard error; SH: Severe hypoglycemia; z: Test statistic.

Discussion

We have described the development of a new instrument to quantify the extent of hyperglycemia avoidance in people with T1D and have provided preliminary data to support this scale as a reliable and a valid measure. Factor analysis of the HAS produced four subscales. Although person reliability indices were low for two of the four subscales (HAS-1 and HAS-4), item reliability indices were excellent for all the four HAS subscales. Therefore, all four subscale item sets were retained. Several findings supported the construct validity of the HAS. The 'worry' subscale of the Hypoglycemia Fear Survey was significantly correlated with all HAS subscales, but most strongly related to the worry subscale, indicating that some T1D patients may have general underlying anxiety regarding extreme BG levels (both high and low). Previous studies have found a relationship between fear of hypoglycemia and trait anxiety [10], which may also be associated with fear of hyperglycemia. In addition, it could be that some patients who avoid high BG levels and aim to keep BG levels low are aware that they are at increased risk of a hypoglycemia episode if they are not extremely careful. This may add to their general anxiety about extreme BG levels. Future studies could examine the relationship between general anxiety measures and the HAS scale. It could be that people with diabetes who have extreme anxieties relating to both high and low BG levels are generally more anxious overall.

In support of the construct validity of the HAS measures, HAS-3 (low BG preference) significantly predicted prospective episodes of SH. Therefore, people with diabetes who preferred to keep their BG levels on the lower end were, as expected, more likely to experience episodes of SH in the future. A general underlying worry about high BG levels (HAS-2) was a significant indicator of prospective hypoglycemia-related

driving mishaps. This emphasizes that people with a general fear or concern about being in poor control may be motivated to maintain lower BG levels, which can have adverse effects on their daily activities including driving. Relationships between the HAS subscales and HbA_{1c} values indicated that participants reporting poorer glycemic control were less likely to take quick action to lower their BG levels (HAS-1) but were more likely to worry about their high BG levels (HAS-2). This may indicate that worry about hyperglycemia, as measured by the HAS, may for some individuals reflect a reality-based concern about their poor BG control and risk for complications. Similarly, fear of hypoglycemia, as measured by the Hypoglycemia Fear Survey, can be associated with an individual's history or risk of episodes of SH [11]. Frequent daily BG monitoring is often recommended for people using insulin pumps, who also have more flexibility in insulin dosing. Therefore, pump users are more likely to be aware of when their BG is high and this information may subsequently encourage them to take steps to lower it. Based on this, it was not surprising to find that participants using pumps were more likely to take immediate action to lower their BG when high (HAS-1) and indicated greater motivation to avoid high BG levels (HAS-4) compared with the pump non-users.

The study sample was recruited by advertising across various mediums including print and radio. It is therefore difficult to estimate the number of people approached for participation to assess how many potential participants declined the study. Our specific study sample included mainly white, non-Hispanic people with diabetes who were relatively well educated. These factors limit generalization of results to other populations with diabetes including minorities, less-educated patients and those whose diabetes diagnosis is more recent than the current sample. We encourage further

research to evaluate the suitability of this measure for people with diabetes from other diverse groups, people with Type 2 diabetes and adolescents with diabetes. Furthermore, we do not yet have longitudinal data to determine test–retest reliability of the HAS, or its sensitivity to clinical interventions. As part of our future research endeavors, we will aim to collect these data to understand the instrument’s usefulness in detecting change in patients over time.

The HAS shows promising psychometric properties and indicates useful clinical implications. Healthcare professionals could keep track of patients’ HAS scores over time to check for any abnormal anxieties surrounding high BG levels (e.g., patient scoring 3 or 4 on the majority of items). Some anxiety for high BG is almost expected in people with diabetes given the general focus of clinicians and diabetes care experts on avoiding complications related to hyperglycemia. However, using HAS could allow healthcare professionals to intervene and help patients who indicate extreme avoidance of high BG levels. Efforts could be made to better understand what drives these patients’ extreme fear for hyperglycemia followed by steps to help patients normalize their anxieties and concerns. HAS-3 (low BG preference) significantly predicted prospective episodes of SH. Therefore, in a clinic setting, patients who score high on the HAS-3 subscale could be educated on the risks of SH and the need to keep BG levels within a normal range. Further studies would need to be conducted to obtain normative data on HAS scores across different patient populations that can potentially be used to guide clinical interpretations. However, current findings demonstrate four subscales that could have important clinical implications.

To the best of our knowledge, the HAS is the only measure that evaluates both affective and behavioral aspects of hyperglycemia avoidance in people with T1D. The only instrument assessing a related construct [24] measures negative emotional responses to BG monitoring when reading results are high.

Conclusion & future perspective

Some adaptive fear and anxiety about high BG levels is certainly normal in diabetes, and some concern and/or fear of high BG is almost necessary to motivate diabetes patients to try to keep BG levels within a clinically desirable range. However, our data suggest that it could be beneficial to identify patients with extreme levels of

anxiety and behaviors to avoid high BG. Excessive avoidance can potentially impair diabetes management and adjustment in Type 1 patients by increasing their risk for hypoglycemia. Concerns over hyperglycemia may even be expressed as an inverted-U function, where less than adequate concerns may contribute to elevated BG levels while excessive fear could lead to dangerously low BG levels. Future studies could explore whether patients with moderate fear of high BG levels manage their diabetes better (both clinically and psychologically) compared with patients with little or very high fear of hyperglycemia. It would also be useful to examine relationships between the HAS and other measures that evaluate trait anxiety. It could be that general anxiety measures assessing trait anxiety overlap with the HAS to some extent, indicating that patients who have excessive worries and concerns surrounding high BG levels also show high anxiety more generally. However, given that the HAS includes items that are specific to high BG levels, it is expected to highlight opportunities for intervention more appropriately.

The development and use of the HAS is another step forward to better understand the complex interplay of patients’ beliefs and behaviors that influence the management of their BG levels. Using the HAS together with measures assessing fear of hypoglycemia, such as the HFS-II [11], may help in identifying psychological and behavioral factors contributing to poor diabetes control.

Author contributions

H Singh researched data, wrote/edited the manuscript, contributed to discussion. L Gonder-Frederick reviewed data analysis, reviewed/edited the manuscript, contributed to discussion. K Schmidt researched data, reviewed/edited the manuscript, contributed to discussion. D Ford researched data, reviewed/edited the manuscript. KA Vajda researched data. J Hawley researched data, reviewed/edited the manuscript. D Cox reviewed data analysis, reviewed/edited the manuscript, contributed to discussion.

Financial & competing interests disclosure

This research was supported by NIH grant R01DK28288. The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

No writing assistance was utilized in the production of this manuscript.

References

Papers of special note have been highlighted as:
• of interest

- 1 The DCCT Group. Hypoglycemia in the diabetes control and complications trial. *Diabetes* 46, 271–286 (1997).
- 2 UK Prospective Diabetes Study (UKPDS) Group. Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with Type 2 diabetes (UKPDS 33). *Lancet* 352, 837–853 (2005).
- 3 UK Hypoglycaemia Study Group. Risk of hypoglycaemia in Types 1 and 2 diabetes: effects of treatment modalities and their duration. *Diabetologia* 50, 1140–1147 (2007).
- 4 Bode BW, Schwartz S, Stubbs HA, Block JE. Glycemic characteristics in continuously monitored patients with Type 1 and Type 2 diabetes: normative values. *Diabetes Care* 28, 2361–2366 (2005).
- 5 Cryer PE. Hypoglycaemia: the limiting factor in the glycaemic management of Type I and Type II diabetes. *Diabetologia* 45, 937–948 (2002).
- 6 Kitabchi AE, Umpierrez GE, Miles JM, Fisher JN. Hyperglycemic crisis in adult patients with diabetes. *Diabetes Care* 32, 1335–1343 (2009).
- 7 Cox DJ, Irvine A, Gonder-Frederick L, Nowacek G, Butterfield J. Fear of hypoglycemia: quantification, validation, and utilization. *Diabetes Care* 10, 617–621 (1987).
- 8 Gonder-Frederick LA, Vajda KA, Schmidt KM *et al.* Examining the Behavior Subscale of the Hypoglycemia Fear Survey using aggregated data from five countries. *Diabetic Med.* 30(5), 603–609 (2013).
- **This article may help readers better appreciate the problem of hyperglycemia avoidance in people with Type 1 diabetes.**
- 9 Green L, Feher M, Catalan J. Fears and phobias in people with diabetes. *Diabetes Metab. Res. Rev.* 16, 287–293 (2000).
- **Good article for information on diabetes-related fears and phobias in people with diabetes.**
- 10 Wild D, Maltzahn RV, Brohan E, Christensen T, Clauson P, Gonder-Frederick LA. Critical review of the literature on fear of hypoglycemia in diabetes: implications for diabetes management and patient education. *Patient Educ. Couns.* 68, 10–15 (2007).
- 11 Gonder-Frederick LA, Schmidt KM, Vajda KA *et al.* Psychometric properties of the Hypoglycemia Fear Survey-II for adults with Type 1 diabetes. *Diabetes Care* 34(4), 801–806 (2011).
- 12 Ritholz M. Is continuous glucose monitoring for everyone? Consideration of psychosocial factors. *Diabetes Spectrum.* 21, 287–289 (2008).
- **Discusses concerns and avoidance behaviors in people with diabetes that are linked to high blood glucose (BG) levels.**
- 13 Ritholz M. Working with challenging patients in diabetes treatment. In: *Contemporary Diabetes: Educating Your Patient with Diabetes (1st Edition)*. Weinger K, Carver CA (Eds). Humana Press, NY, USA, 197–212 (2009).
- **Presents a good overview of the factors related to high BG levels that can be concerning to people with diabetes and may lead to anxieties/fears associated with high BG readings.**
- 14 Shiu AT, Wong RY. Fears and worries associated with hypoglycaemia and diabetes complications: perceptions and experience of Hong Kong Chinese clients. *J. Adv. Nurs.* 39, 155–163 (2002).
- 15 Ramchandani N, Canteley-Kiser JM, Alter CA *et al.* Self-reported factors that affect glycemic control in college students with Type 1 diabetes. *Diabetes Educ.* 26, 656–666 (2000).
- 16 Evert A, Trence D, Catton S, Huynh P. Continuous glucose monitoring technology for personal use: an educational program that educates and supports the patient. *Diabetes Educ.* 35, 565–580 (2009).
- 17 Cox DJ, Ford D, Gonder-Frederick LA *et al.* Driving mishaps among individuals with Type 1 diabetes mellitus: a prospective study. *Diabetes Care* 32(12), 2177–2180 (2009).
- 18 Muthén LK, Muthén BO. *MplusUser's Guide (5th Edition)*. Muthén & Muthén, CA, USA (2007).
- 19 Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct. Equ. Modeling* 6, 1–55 (2004).
- 20 Masters GN. A Rasch model for partial credit scoring. *Psychometrika* 47, 149–174 (1982).
- 21 Linacre JM. WINSTEPS Rasch Measurement Computer Program (Version 3.68.0). IL, USA, 21 (2009). www.winsteps.com
- 22 Allen MJ, Yen WM. *Introduction to Measurement Theory*. Waveland Press, Inc., IL, USA (1979).
- 23 Kline P. *An Easy Guide to Factor Analysis*. Routledge, London, UK, 52–53 (2002).
- 24 Hood KK, Butler DA, Volkening LK, Anderson BJ, Laffel LMB. The Blood Glucose Monitoring Communication Questionnaire: an instrument to measure affect specific to blood glucose monitoring. *Diabetes Care* 27, 2610–2615 (2004).
- **Describes an instrument to assess negative emotional responses to high BG readings.**