Article

# A longitudinal study of the stress of poor glucose control and diabetes distress

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#### Abstract

Poor glucose control can be viewed as a stressor, possibly promulgating diabetes distress. We examined the relationship between perceived blood glucose control and diabetes distress over time using a partially controlled cross-lagged path analysis model. After controlling for demographics, control at 6 months was directly related to change in distress at 12 months. Subsequently, distress at 12 months was directly related to change in control at 18 months. Both 6-month control and distress had significant indirect effects on 18-month control and distress. This demonstrates the nuanced bi-directional relationship between the stress of poor perceived control and diabetes distress.

#### **Keywords**

American Indian, community-based participatory research, glucose control, stress process, type 2 diabetes

#### Introduction

Diabetes is the seventh leading cause of death in the United States and affects approximately 8.8 percent of the population (Blackwell and Villarroel, 2018; Xu et al., 2018). In 2017, the estimated economic cost of diabetes was US\$327 billion (American Diabetes Association (ADA), 2018). For many American Indian communities, diabetes is an even bigger issue given disparities in diabetes prevalence and outcomes compared with the general US population. American Indians and Alaska Natives have an age-adjusted prevalence of 16.6 percent, double the national average (Blackwell and Villarroel, 2018). American Indians also experience more diabetes complications and a higher rate of death from these complications (O'Connell et al., 2010; Xu et al., 2018). These statistics highlight the importance of understanding and improving diabetes-related outcomes among American Indians.

Individuals with diabetes have unique stressors surrounding the diagnosis, bodily effects, and daily management of diabetes. Previous

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research has shown that difficulties managing and controlling diabetes can be characterized as stressors (Elm et al., 2019). Specifically, a person feeling as though their diabetes was not under control, or more specifically that their blood glucose was not where they hoped it would be, is a stressor. The stress process model (Pearlin, 1989; Pearlin et al., 1981) explains how stressor exposure leads to negative health outcomes. A foundational premise of the model is that differential exposure to psychosocial stressors is a root cause of health inequities. Based upon this empirical research and the stress process model, the stress of perceived poor blood glucose control would be expected to negatively impact diabetes-related outcomes.

One such negative outcome is diabetes distress. Diabetes distress is an emotional distress related to the frustration, tension, fatigue, overwhelm, and experience of "burnout" from dealing with diabetes (Aikens, 2012; Gonzalez et al., 2011; Fisher et al., 2010, 2012). Diabetes distress has been linked to poor blood glucose control using objective markers like hemoglobin A1c and to poorer self-management of diabetes such as healthy eating, physical activity, medication adherence, and foot care (Aikens, 2012; Fisher et al., 2007, 2008, 2010; Gonzalez et al., 2016). Based on these findings, diabetes distress would be expected to negatively impact perceived blood glucose control, indirectly through its relationship with selfmanagement behaviors and directly through its relationship with actual blood glucose levels.

These prior research findings lead to a "chicken or the egg" type of question: Does the stress of perceived poor blood glucose control negatively impact distress or does diabetes distress lead to worse perceived control? The purpose of this study was to examine the directional nature of the longitudinal association between diabetes distress and perceived glucose control.

## Methods

The Maawaji *idi-oog mino-ayaawin* (Gathering for Health) study is a community-based participatory research partnership between five American

Indian tribes in the Northern Midwest and researchers at the University of Minnesota. This mixed methods study included a qualitative strand followed by a longitudinal quantitative strand. The overall aims of the Gathering for Health study were to investigate sources of stress among American Indians with type 2 diabetes, culturally appropriate ways to measure stress among American Indians, and the relationship between stressors, supports, mental health, diabetes self-management, and diabetes outcomes. Tribal councils in each of the partnering communities provided tribal resolutions in support of this project prior to application for funding, and the Indian Health Service clinics partnering in this research provided letters of support for the project. Both the University of Minnesota and the Indian Health Service National Institutional Review Boards (IRBs) reviewed and approved the study procedures, IRB study number 1206S16361 and protocol N13-BE-07, respectively. Each community had a community research council to guide the research and serve as active partners in research from start to finish. The methods for this study are described elsewhere (see: Elm et al., 2019; Ratner et al., 2017; Walls et al., 2017).

This study uses data from the longitudinal, quantitative phase of the study. Staff at each of the five participating community clinics generated a random sample of patients who were diagnosed with type 2 diabetes within the past 5 years, were 18 years or older, and self-identified as American Indian. Sampled individuals were recruited to participate in the study via the mail and contacted via telephone by a community-based interviewer. Consenting participants completed a computer-assisted personal interview (CAPI) with community-based interviewers in a location of the participants choosing. CAPIs were conducted at baseline (Wave 1), 6 months (Wave 2), 12 months (Wave 3), and 18 months (Wave 4). The CAPI included a battery of scales (at all waves) and a diagnostic interview (Waves 1 and 4). Of the 194 participants who completed the baseline interview, 166 participated at Wave 2, 163 participated at Wave 3, and 163 participated at Wave 4.

#### Measures

The measure of perceived blood glucose control was from the Personal Diabetes Questionnaire (Stetson et al., 2011). This single-item indicator asks participants, "How satisfied are you with your overall blood glucose control," with response options of "I have excellent control" (5), "I have pretty good control" (4), "I have good control" (3), "I have a few problems" (2), "I have poor control" (1), and "I have very poor control" (0). Responses to this single-item indicator are positively correlated with A1c (Stetson et al., 2011). Due to a skip pattern error in the CAPI, most participants did not answer this question at Wave 1. Thus, we use perceived blood glucose control at Waves 2 through 4 in our analyses.

The two-item Diabetes Distress Screener (DDS-2) was used as a measure of diabetesrelated emotional distress (Fisher et al., 2008). This screener was derived from the 17-item Diabetes Distress Scale (Polonsky et al., 2005). A positive screen on the DDS-2 is negatively associated with self-management behaviors and disease control, and the two items have an alpha coefficient of .73 (Fisher et al., 2008). The DDS-2 asks participants to rate how bothersome, from "not at all bothersome (1)" to "very bothersome (6)," the degree to which they have been distressed or bothered in the past month by the two statements (Fisher et al., 2008). A mean score of the two items from the DDS-2 are computed, with individuals scoring 3 or higher considered a screen positive for diabetes distress (Fisher et al., 2008). Although diabetes distress was asked at all four waves of the study, we include Waves 2-4 to be consistent with perceived blood glucose control.

Because diabetes distress and depression/ depressive symptoms are related (Burns et al., 2015; Fisher et al., 2014; Gonzalez et al., 2016), we controlled for depressive symptoms in multivariable analyses. Depressive symptoms were measured using the Patient Health Questionnaire (PHQ)-9 (Kroenke et al., 2001) at all four waves. The PHQ-9 assesses the frequency depressive symptoms in the past 2 weeks, using response categories "Not at all" (0), "Several days" (1), "More than half the days" (2), and "Almost every day" (3). The nine items are summed to create a continuous measure of depressive symptoms from 0 to 27. Previous validity evidence has been established for the PHQ-9; a Cronbach's alpha of .89, test–retest reliability of .84 and is related to depressive severity (Kroenke et al., 2001). To control for contemporaneous depressive symptoms, we specifically used PHQ-9 scores from Wave 2.

In addition, several demographic variables were gathered from participants including *gender* (1=male and 0=female), *age* (in years), *household income*, and *time since being diagnosed* with diabetes (in months). Per capita household income was computed from the reported household income, divided by the number of people living in the home.

#### Analysis

We used SPSS Version 25 (Statistics Package for the Social Sciences) for data recoding and descriptive statistics, and MPLUS Version 7.2 (Muthén and Muthén, 1998-2014) for all path analyses. First descriptive statistics were calculated for all study variables. Next, we determined bivariate relationships between diabetes distress, perceived blood glucose control, and control variables. To address the main objective of this study, we utilized autoregressive cross-lagged path analysis to determine the longitudinal relationship between perceived blood glucose control and diabetes distress (Figure 1). The path model contains autoregressive paths for diabetes distress between waves (e.g.  $DDS_{W2}$  to  $DDS_{W3}$ ), autoregressive paths for perceived blood glucose control between waves (e.g. BG<sub>w2</sub> to BG<sub>w3</sub>), crosslagged paths between diabetes distress and subsequent perceived blood glucose control (e.g.  $DDS_{W2}$  to  $BG_{W3}$ ), cross-lagged paths between perceived blood glucose control and diabetes distress (e.g.  $BG_{W2}$  to  $DDS_{W3}$ ), and correlations between diabetes distress and perceived blood glucose control within each wave (e.g.  $DDS_{W2}$  with  $BG_{W2}$ ). This model allowed

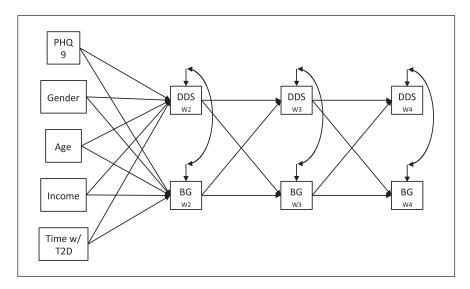


Figure 1. Autoregressive cross-lagged path model of perceived blood glucose control and diabetes distress.

us to test the direction of the relationships among the focal variables (cross-lagged paths) while controlling for their prior levels (autoregressive paths) and the cross-sectional associations between them (within-wave correlations). We also examined the indirect associations between Waves 2 and 4 for diabetes distress and perceived control. Both diabetes distress and perceived control at Wave 2 were regressed on the control variables.

We tested a series of nested path models with various parameter constraints imposed (Figure 1). If the chi-square test comparing the constrained and unconstrained models was not significant, the constrained model was selected because it was statistically equivalent to the unconstrained model and more parsimonious (Table 1). Models were tested in the following order (if the test was not significant, the constraints were imposed in subsequent models): (1) fully unconstrained model, (2) constraining the cross-sectional correlations between diabetes distress and perceived blood glucose control, (3) constraining the autoregressive paths for diabetes distress, (4) constraining the autoregressive paths for perceived blood glucose control, (5) constraining the cross-lagged paths from

diabetes distress to perceived blood glucose control, and (6) constraining the cross-lagged paths from perceived blood glucose control to diabetes distress. Only one set of constraints, the cross-sectional correlations, resulted in a significant chi-square test; the correlations were unconstrained in all subsequent models.

Because Wave 2 was the first wave in which all participants answered the perceived blood glucose control question, we restricted the analytic sample to the 166 participants interviewed at Wave 2. This reduced the sample from the baseline sample of 194. Compared with those interviewed at Wave 2, those who did not participate had significantly fewer depressive symptoms (3.07 vs 5.65, p < .01), lower levels of diabetes distress (2.09 vs 2.64, p < .05), and more months since their diabetes diagnosis (25.19 vs 16.86, p < .05) at their baseline interview. In addition, the original sample contained a larger proportion of males than the Wave 2 sample (43.8% vs 39.2%, p < .01). There were no differences in age, income, or baseline perceived blood glucose control. Six additional cases were removed from the analysis because of missing information on the baseline control variables, resulting in a final sample size of

	Log Likelihood (LL) unconstrained	Log Likelihood (LL) constrained	−2∆ Log Likelihood (LL)	$\Delta df$	Þ
I. Unconstrained model	36.75				
2. Cross-sectional correlations	36.75	46.60	19.69	2	.00
3. DDS autoregressive paths	36.75	37.03	0.55	Ι	.46
4. BG autoregressive paths <sup>a</sup>	37.03	38.55	3.04	Ι	.08
5. DDS to BG cross-lagged paths <sup>a</sup>	38.55	38.56	0.02	Ι	.89
6. BG to DDS cross-lagged paths <sup>a</sup>	38.56	38.66	0.10	Ι	.75

**Table I.** Model comparisons (n = 160).

BG: perceived blood glucose control; DDS: Diabetes Distress Screener.

<sup>a</sup>Tested paths in previous model are constrained in this model.

160. We used full information maximum likelihood estimation, which is robust to non-normally distributed variables (Asparouhov and Muthén, 2005; Muthén and Muthén, 1998–2014) and to account for missing data at Waves 3 and 4.

#### Results

Descriptive statistics of study variables are detailed in Table 2. Perceived blood glucose control decreased slightly between Waves 2 and 3, but diabetes distress stayed fairly stable. The percentage of participants reporting poor blood glucose control (i.e. very poor control, poor control, or a few problems) was 27.9 percent at Wave 2, 35.9 percent at Wave 3, and 35.8 percent at Wave 4. Using the cutoff score for the DDS-2, 37.6, 38.6, and 39.2 percent of participants met criteria for a positive diabetes distress screen at Waves 2–4, respectively. At Wave 2, using a cutoff score of 10 or more, 20.1 percent of the sample met criteria for depressive symptoms.

Table 2 also shows the bivariate statistics between study variables. Perceived blood glucose control and diabetes distress were significantly and negatively correlated with each other at each wave and across waves, although the magnitude of the correlations were stronger at more proximal observations. For example, the correlation was stronger between BG<sub>W2</sub> and DDS<sub>W2</sub> (r=-.44, p < .001), but weaker between DDS<sub>W2</sub> and BG<sub>W4</sub> (r=-.19, p < .05). PHQ-9 was negatively associated with perceived control and positively associated with diabetes distress at all three waves. Gender was only correlated with diabetes distress and PHQ-9. Age was positively associated with perceived control at all three waves and negatively associated with diabetes distress only at Wave 2. Time with diabetes diagnosis was uncorrelated with perceived control and diabetes distress.

The standardized results of the path analysis are shown in Figure 2. For the control variables, only depressive symptoms was positively and significantly associated with diabetes distress  $(\theta = .22, p < .01)$  at Wave 2. Age  $(\theta = -.18, \theta = .01)$ p < .05) and male gender ( $\beta = -.18$ , p < .05) were negatively associated with diabetes distress, and age was positively associated with perceived blood glucose control ( $\theta$ =.22, p < .01). Both diabetes distress and perceived control had considerable stability over time, as indicated by the moderately strong, statistically significant autoregressive coefficients. All cross-lagged path coefficients were statistically significant, suggesting that the longitudinal relationships between diabetes distress and perceived control were reciprocal in nature. Diabetes distress was negatively associated with perceived control at the following wave, and perceived control was negatively associated with subsequent diabetes distress. We used the Wald test in MPLUS to determine whether the cross-lagged coefficients were statistically different from each other and found no difference. This suggests the magnitudes of the effects of perceived blood glucose control on diabetes

	_	2	e	4	5	6	7	8	6	0	=
L. BG <sub>W2</sub>	00 <sup>.</sup> I										
2. BG <sub>W3</sub>	0.45***	1.00									
3. BG <sub>W4</sub>	0.34***	0.46***	00 <sup>.</sup> I								
4. DDS <sub>W2</sub>	-0.44***	-0.30***	-0.19*	00 <sup>.</sup> I							
5. DDS <sub>W3</sub>	-0.34***	-0.58***	-0.43***	0.45***	I.00						
6. DDS <sub>W4</sub>	-0.36***	-0.43***	-0.45***	0.40***	0.59***	00 <sup>.</sup> I					
7. PHQ-9	-0.17*	-0.24**	-0.19*	0.28***	0.34***	0.19*	00 <sup>.</sup> I				
8. Gender (male = I)	0.13	0.05	-0.03	-0.18*	-0.15	-0.12	-0.20*	1.00			
9. Age	0.25**	0.17*	0.20*	-0.21**	-0.11	-0.03	-0.08	-0.03	00 <sup>.</sup> I		
10. Per capita income	0.16*	0.17*	0.07	-0.16*	-0.14	-0.09	-0.12	-0.02	0.21**	1.00	
II. Time with diabetes	-0.14	-0.02	-0.12	0.07	0.12	-0.01	0.02	-0.02	-0.02	0.00	00 <sup>.</sup> I
Mean	3.14	2.95	2.93	2.42	2.54	2.48	4.66	0.39	46.91	9.83	16.86
Standard deviation	1.22	I.35	I. I8	1.32	I.46	1.34	4.84	0.49	16.11	8.90	15.02
Range	05	0-5	0-5	9-1	9-1	9-1	0-25	I−0	24-77	0.16-37.5	960
Cronbach's alpha				0.71	0.84	0.78	0.85				

Table 2. Descriptive statistics and bivariate correlations.

BG: perceived blood glucose control; DDS: Diabetes Distress Screener; PHQ: Patient Health Questionnaire. \*p <.05. \*\*p <.01.

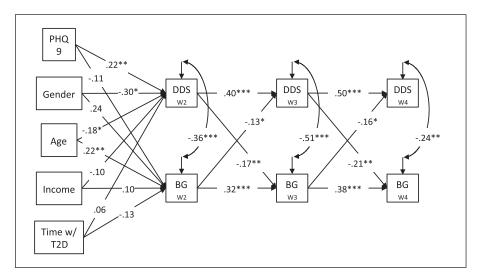


Figure 2. Standardized results (n = 160).

distress and of diabetes distress on perceived blood glucose control are similar in strength.

We also examined the indirect longitudinal relationship between  $DDS_{W2}$  and  $BG_{W4}$  (Table 3). The pathways through both diabetes distress and perceived blood glucose control at Wave 3 were significant and negative, suggesting that diabetes distress carries longer term consequences for perceived control via its more proximal associations with diabetes distress and glucose control. We repeated that test to assess whether  $BG_{W2}$  was associated with  $DDS_{W4}$ , finding similar results. Perceived control at Wave 2 has negative distal association with diabetes distress at Wave 4 through both perceived control and diabetes distress at Wave 3.

#### Discussion

This study provides insight into the reciprocal relationship between perceived blood glucose control and diabetes distress. It implicates the stress of perceiving poor glucose control as detrimental toward diabetes distress, consistent with the stress process model (Pearlin, 1989; Pearlin et al., 1981) and prior empirical work (Elm et al., 2019). At the same time, this work supports prior research linking diabetes distress to actual glucose control and behaviors (Aikens,

Table 3.	Decom	position	of	indirect	effects.
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	Indirect effect
$\overline{\text{DDS}_{W2} \rightarrow \text{BG}_{W4}}$	-0.15**
Indirect via DDS <sub>W3</sub>	-0.09***
Indirect via BG <sub>W3</sub>	-0.07***
BG <sub>W2</sub> →DDS <sub>W4</sub>	-0.12*
Indirect via BG <sub>W3</sub>	-0.07***
Indirect via DDS <sub>W3</sub>	-0.05*

BG: perceived blood glucose control; DDS: Diabetes Distress Screener. \*p < .05. \*\*p < .01.

\*\*\*\*p<.001.

2012; Fisher et al., 2007, 2008, 2010; Gonzalez et al., 2016). Indeed, these findings tell a more nuanced relationship than purely one preceding another, suggesting instead a bi-directional relationship whereby each influences the other over time. This more nuanced relationship represents a distinctly realistic appraisal of the complexities of living with a chronic disease.

The present findings indicate potential areas for improvement in care of those with diabetes. Across several waves, a consistently high proportion of participants reported poor perceived blood glucose control and meeting criteria for diabetes distress. Interventions to manage or buffer the stress of low perceived blood glucose control have potential to reduce diabetes distress; possible strategies include fostering social support and disease-specific social support, bolstering diabetes self-management education, and improving self-efficacy toward diabetes management. Current disease management guidelines recommend screening for diabetes distress, especially for those with poor disease control or complications (ADA, 2019). Addressing diabetes distress using clinical interventions could help healthcare providers improve patient perceptions of glucose control and minimize the stress associated with diabetes management. Interventions where providers listen to patients and acknowledge the emotional burdens of managing disease may be more effective than those aimed at action and behavior change (Fisher et al., 2013).

Future research could expand upon this work. This study relied upon perceptions of glucose control as an indicator of stress; prior work has linked diabetes distress to objective markers like blood glucose level or hemoglobin A1c. It would be interesting to determine how perceptions of glucose control, objective markers of glucose control, and diabetes distress relate to one another over time. This would provide more context to fully elucidate the role of perceived glucose control as a stressor. Future work may also further develop, explore, and test interventions where providers acknowledge and discuss or attempt to transform negative perceptions of glucose control. This may lead to reduced diabetes distress and has potential to positively impact diabetes outcomes. Another important avenue for further study involves understanding mechanisms of influence, including ways in which blood glucose control impact subsequent diabetes distress. For instance, physiological stress response (e.g. hypothalamic-pituitary-adrenal axis (HPA) dysregulation) and/or cognitive processes (i.e. appraisal of personal diabetes management) may underlie linkages between perceived control, objective control, and diabetes distress. Finally, future work could determine what buffers (e.g. social support and self-efficacy) the negative impact of perceived

blood glucose control and diabetes distress on other diabetes-related outcomes.

#### Limitations

An important consideration in all research involves cultural frameworks of health and wellbeing. Indigenous cultural factors like identity, engagement in traditions, indigenous language use, and community connectedness have been associated with better mental health and diabetes outcomes (Brockie et al., 2018; Carlson et al., 2017; Dill et al., 2016; Oster et al., 2014). This prior work should be considered when interpreting the current results; additional work is needed to further elucidate cultural influences on perceptions of blood glucose control, diabetes distress, and other diabetes-related variables.

Another limitation to consider when interpreting the findings of this study is the measurement interval, survey design, and measures used. While we found a reciprocal relationship between perceived blood glucose control and diabetes distress, it is possible that the relationship is more dynamic than we can infer from the measurement interval used in this study (i.e. 6 months between each wave). In addition, there are many other stressors present in life (Elm et al., 2019) that may negatively impact perceptions and actual diabetes control, diabetes self-management behaviors, and diabetes distress. These other confounding stressors, and possible proliferations of stress, are not included in this study. There is, as one would expect in a CAPI research study, potential for recall bias and social desirability bias. Our measure of blood glucose control was based on participant perceptions of their own control. While previously shown to be related to A1c (Stetson et al., 2011), it is not an objective marker of glycemic control. The intent of this study was, rather, to understand how perceptions of control may act as a stressor. As previously mentioned, future research could also include A1c or blood glucose readings as objective markers as well.

There are two possible limitations to consider when evaluating the generalizability of the present findings. First, possible non-random study attrition may impact generalizability given the differences in those who dropped out after Wave 1 compared with those who stayed in the study. Second, this work represents individuals from only five American Indian tribes; given considerable diversity within and across American Indian communities and tribal groups and other racial and ethnic groups, it is unclear how these findings translate to other American Indian, Alaska Native, and non-indigenous communities.

## Conclusion

In this study, we operationalized perceived blood glucose control as a stressor. This is an important distinction for clinicians and researchers alike. Glucose control is typically viewed as a disease outcome, thus neglecting the impact on and meaning of poor glucose control to our patients. We found a negative bi-directional relationship between perceived blood glucose control and diabetes distress over time. This means that for some, poor glucose control could become a downward spiral, whereby poor perceptions of glucose control lead to diabetes distress, which subsequently leads to poorer perceptions of glucose control. Thus, it is imperative that clinicians work with patients to alleviate both the stress of poor glucose control and diabetes distress.

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