Brief Report: Parent Perceptions of Hypoglycemic Symptoms of Youth With Diabetes; Disease Disclosure Minimizes Risk of Negative Evaluations

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Objective Based on a theoretical model, this study explored the effects that the disclosure of diabetes has on parental perceptions of a hypothetical child experiencing hypoglycemia.

Methods Parents (N = 610) first read vignettes that varied in a 2 × 2 design (Male vs. Female Character × Preventative Disclosure of Illness vs. Nondisclosure) and then answered several questions regarding the hypothetical child, resulting in four subscales that were validated using confirmatory factor analysis. Results Disclosure of diabetes significantly increased perceptions of a medical problem, decreased suspicions of drug use, and presented a lower risk of parental restrictions on future contact with their child. Conclusions Individuals who disclose their diabetes may prevent negative social consequences and restrictions on social contact. Those who choose not to disclose may risk having a hypoglycemic event perceived as a drug or alcohol problem, which may ultimately interfere with appropriate medical intervention in a hypoglycemic event.

Key words diabetes; preventative disclosure; hypoglycemia; parental perceptions.

Current intensive insulin treatments for type 1 diabetes mellitus (T1DM) may significantly hinder the development and the progression of serious medical complications such as diabetic retinopathy, neuropathy, and nephropathy (Diabetes Control and Complications Trial [DCCT] Research Group, 1993). However, intensive insulin treatments have been associated with a one-and-a-half- to three-times increase in severe hypoglycemic events that require the help of another individual (Boland, Grey, Oesterle, Fredrickson, & Tamborlane, 1999). On average, those with T1DM suffer two episodes of symptomatic hypoglycemia per week and one severe hypoglycemic event per year (DCCT Research Group, 1993).

The symptoms of hypoglycemia are often idiosyncratic and vary across and within individuals (Johnson, Perwien, & Silverstein, 2000). Symptoms of hypoglycemia include irritability, dizziness, pale skin, sweating, poor coordination, slurred speech, unconsciousness, and convulsions. In the early stages of hypoglycemia, the preferred intervention is to give fast-acting carbohydrates. If unconsciousness and convulsions occur, the individual experiencing hypoglycemia is dependent on others to intervene on their behalf.

Despite the increased risks associated with nondisclosure, evidence suggests that many of those with T1DM struggle with the decision to disclose their illness to others (Olsen & Sutton, 1998). For many of those with a chronic illness, the process of disclosure may be associated with risks, fears, and anxiety (Olsen & Sutton, 1998) and can vary considerably according to type of illness and associated stigma and rejection (Greene, 2000). Although T1DM has been found to be one of the most “acceptable” chronic illnesses (Royal & Roberts,
facets of this medical condition and treatment (syringes, symptoms of hypoglycemia, etc.) may put individuals at an increased risk for stigmatization and social disruptions related to socially unacceptable conditions, such as drug abuse.

Recently, a preliminary theoretical framework has been proposed that details the relationship between stigma and disclosure for those with a chronic illness (Joachim & Acorn, 2000). According to this theoretical model, those with a chronic illness have two options in terms of managing stigma and information about their illness: nondisclosure and preventative disclosure.

**Nondisclosure.** Those who choose nondisclosure may attempt to “pass for normal” by using a variety of strategies, such as concealing their symptoms, blaming their symptoms on factors unrelated to diabetes, and failing to engage in self-care behaviors (Kyngas & Hentinen, 1995). Joachim and Acorn (2000) hypothesized two outcomes from this strategy that can each result in distress: becoming part of the group and being caught in a lie. Attempts to pass for normal can lead to stress, as the individual is in constant fear of being revealed and experiencing stigma (Thomas, 1997; Tröster, 1997). In addition to distress, individuals who successfully pass for normal may potentially limit their contacts to avoid disclosure and stigma (Schneider & Conrad, 1980).

**Preventative disclosure.** Preventative disclosure is an attempt to counteract possible stigma by selectively using concealment and disclosure (Joachim & Acorn, 2000; Tröster, 1997). This strategy includes informing others of the illness, educating others about courses of action for complications, and nondisclosure (Joachim & Acorn, 2000). Individuals who use this strategy believe that it is possible to change the beliefs of others through disclosing information about the illness. Those opting to disclose preventatively can choose to inform only those who may witness symptoms of the illness and who will not to disclose when symptoms occur or are detected.

Several benefits of preventative disclosures have been proposed. This strategy may prevent others from forming negative impressions regarding one’s illness. Berlin, Sass, Davies, and Hains (2002) demonstrated in an analogue study that preventative disclosure helped observers avoid misconstruing normal self-care behaviors of T1DM as symptoms of an eating disorder. Schneider and Conrad (1980) suggested that a preventative disclosure might also reduce the extent to which complications of chronic illness are attributed to other stigmatized conditions. Most important, the educational component of preventative disclosures can ensure that others know what to do if a complication of the illness occurs (Tröster, 1997).

To date, little research exists regarding the impact of disclosure on others’ perceptions of individuals with T1DM. Given the paucity of disclosure studies using pediatric samples, this study had two related goals. The first goal was to utilize an analogue design to explore how a simplified preventative disclosure of T1DM influenced attributions made about an individual who exhibited symptoms of hypoglycemia. Given the control needed to formulate functional hypotheses, an analogue design allowed us to eliminate and reduce variables that would otherwise contaminate our assessment within pediatric samples and their environments (Hintze, Stoner, & Bull, 2000). Further, given the possible negative effects of disclosure (i.e., stigmatization), some preliminary evidence for the positive effects of disclosure seemed warranted before proceeding to pediatric samples. The second goal was to develop a brief questionnaire with sufficient psychometric properties to test hypotheses related Joachim and Acorn’s theory of disclosure (2000) as it related to those with T1DM.

Based on previous disclosure literature (Berlin et al., 2002; Joachim & Acorn, 2000; Schneider & Conrad, 1980; Tröster, 1997), the current investigation hypothesized that a preventative disclosure of diabetes would significantly reduce restrictions on social contact as well as suspicions of drug use and that it would significantly increase ratings of a medical problem and of worry related to the vignette character’s behaviors. Owing to limited research in this area, no specific hypotheses were made regarding the outcome of parental status (mothers vs. fathers). Although vignette-character gender differences were examined and hypothesized based on previous literature, no effect of this manipulation was found; thus, these results are not included here, for purpose of brevity.

**Methods**

**Participants**

Data were collected from 610 parents who at the time of the study had at least one child between 10 and 14 years of age (M = 12.92, SD = 6.9). This age range was selected given that past research has indicated that 92% of youth have experimented with alcohol at least once, often by age 12 (Irwin, 1993). Middle-aged parents (M = 36.3, SD = 8.25; 57% mothers) who received at least some high school education (M = 14.61, SD = 2.34) participated in this study. Participant ethnicity was as follows: 80.5% Caucasian, 9.6% African American, 4.0% Latino,
2.3% Asian, 2.1% mixed/biracial, 1% other, and 0.5% Native American. The majority of participants were married (70.0%), with others being single (14.3%), divorced (10.7%), separated (3.9%), and widowed (0.8%). The mean number of children per participant was 2.38 (SD = 2.28).

**Procedures**

Participants were selected based on a snowball sampling technique (Coleman, 1958), in which 60 students from a psychology course, blind to the study’s hypotheses, identified 10 or more individuals that were willing to participate in the study. Questionnaires were randomly distributed, and each took approximately 30 min to complete, with the location varying for the participants’ convenience. The vignettes differed according to a 2 × 2 design (Male vs. Female Character × Preventative Disclosure vs. Nondisclosure of Diabetes) and were based on behavioral symptoms associated with hypoglycemia, which overlapped with symptoms of drug use and alcohol intoxication.

**Measurement Construction**

Given the absence of available measures to address our specific research hypotheses, 32 items were written to tap four distinct constructs: restrictions on social contact, suspicions of drug use, level of worry related to presented behaviors, and medical problem or difficulty. Factor scores were computed by summing the responses and then dividing them by the number of items to represent a mean rating via the study’s 5-point scale. As a result, scores ranged from 1 (strongly disagree) to 5 (strongly agree).

**Item Parcels**

Item parcels, which are the sum of homogeneous items, were based on the item content, in addition to taking the Pearson correlation between the two items into account for item classification. Schallow (2000) delineated several benefits from this method yet proposed that the method used to combine items may have limited impact on model-fit statistics. For a review of the advantages, disadvantages, and procedures of item parcels, see Baladals and Finny (2001). The use of item parcels in this study condensed the number of items from 24 to 12. Eight items were left unused because of their lack of unidimensionality within the four constructs or because of their poor item-level statistics.

**Confirmatory Factor Analysis**

Confirmatory factor analysis (CFA) using a maximum-likelihood estimation method in LISREL 8.51 (Joreskog & Sörbom, 1996a) was employed to evaluate the four-factor measurement model developed by the authors. A covariance matrix produced by PRELIS 2 (Joreskog & Sörbom, 1996b) was analyzed using LISREL 8.51 (Joreskog & Sörbom, 1996a). For the purposes of latent variable scaling and statistical identification, the first construct loading for each latent variable was set to 1.00. The statistics employed to evaluate model fit were the chi-square normed fit index (NFI), non-normed fit index (NNFI), comparative fit index (CFI), and root mean square error of approximation (RMSEA).

**CFA Model Evaluation and Reliability Analyses**

CFA analyses indicated that the proposed model adequately fit the data according to the aforementioned standards, \( \chi^2 (48, N = 581) = 296.837, p < .05, \) NFI = .93, NNFI = .92, CFI = .94, RMSEA = 0.099 (90% confidence interval [CI] = .089—.109). Given the relatively high ratio of chi-square to degrees of freedom, the modification indexes were evaluated to determine if any parameters significantly improved the CFA model fit. Modification indexes indicated that the theta–epsilon parameter between Parcel 2 and 3 on the first factor would significantly improve the CFA model fit, \( \chi^2 (1) = 123.992, p < .05, \) and was therefore added based on statistical justification. The modified CFA model suggests a good model fit, \( \chi^2 (47, N = 581) = 196.73, p < .05, \) NFI = .95, NNFI = .95, CFI = .96, RMSEA = 0.073 (90% CI = .063–.085) and provides support for the utility and factor structure of this measurement model.

Reliability analyses conducted on the Restrictions on Social Contact, Drug Suspicions, Worry, and Medical Problem factors resulted in acceptable Cronbach’s alpha coefficients of .78, .86, .76, and .75, respectively. Corrected item–total coefficients ranged from .51 to .57 (M = .53; SD = .03) for the Restrictions on Social Contact factor, .45 to .82 (M = .71; SD = .17) for the Drug Suspicions factor, .36 to .56 (M = .47; SD = .08) for the Worry factor, and .40 to .57 (M = .51; SD = .07) for the Medical Problem factor.

Standardized structure coefficients (lambda–chi)—which all ranged from .409 to .943 (M = .719, SD = .18)—Cronbach’s alpha coefficients, corrected item–total correlations, and interitem coefficients provided strong evidence for content and construct validity while illustrating that the constructs of interest were sufficiently captured.

**Analysis Plan**

To test the four dependent variables or constructs of interest (Restrictions on Social Contact, Drug Suspicions, Worry, and Medical Problem), two 2 × 2
(Disclosure Status × Parent Gender) multivariate analyses of variance (MANOVA) were conducted using the data from the 580 complete surveys. Because the Restrictions on Social Contact and Drug Suspicions factors were moderately correlated (r = .35) and the Worry and Medical Problem factors were correlated (r = .56), these pairs were entered as the dependent variables in the two MANOVAs. To produce a more parsimonious explanation of the data and to eliminate nonsignificant parameters, a backward elimination procedure was conducted on the MANOVAs. As a result, interaction terms were removed.

Results

Outcomes from the two aforementioned MANOVAs did not retain any significant interactions beyond the .05 level; consequently, the MANOVAs evaluated consisted of only main effects. For the dependent variables on the two MANOVAs, multivariate omnibus results were as follows: Restrictions on Social Contact, F(2, 579) = 11.18, p < .0001, R² = .04, Drug Suspicions, F(2, 579) = 13.51, p < .0001, R² = .05, Worry, F(3, 579) = 9.35, p < .0001, R² = .05, and Medical Problem, F(2, 579) = 15.95, p < .0001, R² = .05.

Follow-up analyses from the first 2 × 2 (Disclosure Status × Parent Gender) MANOVA revealed significant differences on the disclosure variable for Restrictions on Social Contact, F(1, 579) = 20.28, p < .0001, d = −.380, and Drug Suspicions, F(1, 579) = 31.46, p < .0001, d = −.468. In both cases, when disclosure occurred, parents reported fewer restrictions on social contact (M = 2.08, SD = .61) and fewer drug-related concerns (M = 2.91, SD = .83) compared to when there was no disclosure (M = 2.31, SD = .63; M = 3.29, SD = .81, respectively). Parent gender did not significantly affect the Restrictions on Social Contact or the Drug Suspicions scores (effect sizes, d = .13 and d = .02, respectively).

The second 2 × 2 (Disclosure Status × Parent Gender) MANOVA revealed significant differences between mothers and fathers on the Worry factor, F (1, 579) = 25.76, p < .0001, d = .427, and the Medical Problem factor, F (1, 579) = 10.25, p = .0014, d = .280. In both cases, mothers worried more about the vignette character (M = 4.06, SD = .52) and reported more concern for medical problems (M = 3.53, SD = .58) than did fathers (M = 3.83, SD = .57; M = 3.36, SD = .59, respectively). A statistically significant difference was also found on the Medical Problem factor in relation to disclosure, F (1, 579) = 20.37, p < .0001, d = .385, with vignette characters who disclosed their diabetes receiving greater concern for medical troubles (M = 3.56, SD = .60 vs. M = 3.34, SD = .56). Disclosure, however, did not significantly affect how worried respondents were concerning the symptoms presented in the vignette (d = .092).

Discussion

Results confirmed the hypothesis that a preventive disclosure would significantly reduce restrictions on social contact and the extent to which symptoms of hypoglycemia were attributed to other socially disreputable conditions (i.e., underage drug and alcohol use). Support was also obtained for the hypothesis that a preventative disclosure of T1DM would increase attributions of a medical problem. No significant differences were found in levels of worry between the disclosure conditions, suggesting that a hypoglycemic event with behaviors associated with drug and alcohol use is equally alarming to parents regardless of diabetes disclosure.

In support of Joachim and Acorn’s theoretical framework (2000), our data suggest that those with T1DM who choose to disclose the illness may prevent negative social consequences and restrictions on social contact based on inaccurate perceptions. These findings also suggest that those who choose not to disclose may risk having their hypoglycemia perceived as a drug or alcohol problem, potentially interfering with appropriate medical intervention in a hypoglycemic event. Although the mean scores indicate that parents disagree with limiting social contact based on one vignette, one may speculate that over repeated situations parents may subsequently limit social contacts with a person whom they misperceive as using drugs or alcohol. This is particularly concerning in that studies have linked social interaction and social support to treatment adherence (Thomas, 1997) and metabolic control (La Greca & Thompson, 1998). There appear to be multiple benefits to preventatively disclosing pediatric T1DM, such as preventing misperceptions of eating disorders (Berlin et al., 2002) and drug or alcohol problems (as demonstrated here) and enhancing the ability of peers to provide emotional support to those with T1DM (Thomas, 1997). Health care professionals are encouraged to consider these results when working with families of those with T1DM.

Given the relative absence of measures designed specifically to assess disclosure and other variables related to Joachim and Acorn’s framework (2000), the measures used to evaluate these variables must be developed and validated. Consequently, the second goal of this study was to establish this measure’s psychometric properties by ascertaining its reliability and validity. The
measure evaluated suggests promise, as the factor structure and reliability coefficients provide evidence for the psychometric properties of this measure as well as good preliminary support for the content, construct, and criterion validity.

Several limitations and areas for future research should be discussed. Because the symptoms of hypoglycemia vary significantly within and across individuals, the single vignettes used in this study reflect only one of the many possible presentations of symptoms. Additionally, information regarding behaviors obtained in analogue studies may fail to correlate with actual behaviors (Hintze et al., 2000). Consequently, future studies should explore the effects of disclosure using clinical samples while assessing other variables that may mediate or moderate disclosure.

One possible moderating variable that was not measured or controlled for in this study was knowledge or education about diabetes. It is likely that if parents are educated about diabetes and to the symptoms of hypoglycemia, their responses may be quite different from those of parents with scant knowledge. It is important to note, however, that even under the supervision of an adult who is purportedly knowledgeable about T1DM (e.g., a parent of a youth with diabetes), appropriate responses are not always ensured (Johnson et al., 2000). Future investigations should explore whether preventative disclosures (including an educational component) influence appropriate interventions.

The results of this paper emphasize the importance of preventive disclosure. These findings were consistent regardless of parental status or vignette character gender. This methodology provides a novel procedure to understand societal perceptions of chronic illness and a strategy to ameliorate negative and inaccurate perceptions.

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References


**Note**

1 Due to space limitations, several elements of this study were not included but can be obtained from the corresponding author or from the following URL: http://www.uwm.edu/~hobart/disclosure.html. These elements include vignette copies, factor items, various means and standard deviations, analyses conducted to ensure item parcel integrity, the covariance matrix used, rational for reported model-fit statistics, and CFA figure with parameter estimates.