

Brief Report: Parent's Health Literacy among High-Risk Adolescents with Insulin Dependent Diabetes

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Objective To describe the health literacy of parents of high-risk adolescents with insulin dependent diabetes and to examine the relation of parent's health literacy with treatment adherence. **Methods** Participants were 93 adolescents in poor metabolic control diagnosed with insulin dependent diabetes and their primary caregivers. **Results** All parents had adequate health literacy as defined by the S-TOFHLA. Better parent reading comprehension scores were significantly related to family structure, race, and treatment regimen. Reading comprehension in turn significantly predicted adherence for adolescents on an intensive insulin regimen but not for those on conventional regimens. **Conclusions** Parents with low health literacy may struggle to help their children adhere to the increasingly complex diabetes regimens being used at present. Such families may benefit from more intensive diabetes education or different approaches to teaching diabetes management skills.

Key words health literacy; parents; adolescents; diabetes; high-risk.

Health literacy has been recognized as a national health challenge with over one-third of Americans having compromised ability to read, understand, and apply health information (Kutner, Greenberg, Jin, & Paulsen, 2006). This is particularly problematic because inadequate health literacy has been shown to relate to less access to care, illness exacerbation, and complications, higher rates of hospitalization and emergency care, and poorer treatment adherence (e.g., Davis & Wolf, 2004). To date, most efforts to understand and improve health literacy have focused on adult patients, with little attention paid to the health literacy of parents of children with chronic conditions (Betz, Ruccione, Meeske, Smith, & Chang, 2008).

A need for adequate health literacy may be especially important for parents of children with type 1 diabetes. The management of type 1 diabetes is a complex balance between many factors, including an insulin, diet, and exercise regimen. It is critical for caregivers of children with diabetes to develop accurate diabetes knowledge and skills, including the ability to give injections, monitor blood glucose (BG), manage the child's diet and exercise, and manage acute problems like hypoglycemia. Furthermore, the advent of intensive insulin regimens requires families

to make even more management decisions to maintain in-range BG levels, including those that accommodate the unpredictable exercise and eating habits of children. The knowledge and skills of the parent may be a more important predictor of adherence and glycemic control than those of the child (Wysocki et al., 2009). There is almost no research on the health literacy of parents of urban minority children, a group that is at higher risk for both literacy problems (Kutner et al., 2006) and poorer health outcomes (Kirk et al., 2006).

The goal of the current study was to describe the health literacy of parents of high-risk adolescents with insulin dependent diabetes and to examine the relation of parent's health literacy with treatment adherence.

Methods

Participants

The sample consisted of 93 adolescents and their primary caregivers who were participating in a clinical trial investigating the effectiveness of a home-based psychotherapy for improving regimen adherence in youth with diabetes in chronically poor metabolic control. Data used in the

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present analyses were drawn from the participant's baseline data collection prior to study randomization. Adolescents were aged between 10 and 17 years ($M = 14.2$, $SD = 2.2$), had a diagnosis of type 1 (82%) or type 2 (18%) diabetes for at least a year that required management with insulin, had a current hemoglobin A1c (HbA1c) of $\geq 8\%$ and a mean HbA1c of $\geq 8\%$ during the year before study entry (Mean HbA1c = 11.5, $SD = 2.5$), and resided in a home setting. The average length of time since diabetes diagnosis was 4.5 years ($SD = 2.8$). Children with moderate or severe mental impairment and/or psychosis were excluded. In total, 57% of adolescents were females.

The average age of parents in the study was 41.1 years ($SD = 8.3$) and 89% were females. The average annual family income was \$38,000 ($SD = \$29,700$) and 38% of households had both parents staying at home (including biological and non-biological parents). In total, 83% of adolescents and parents were African-American, 70% adolescents were on an intensive insulin treatment regimen (basal-bolus insulin therapy administered by injection or use of an insulin pump), and 30% were on a conventional regimen (2–3 injections of mixed short- and intermediate-acting insulin/day). Adolescents on the conventional regimen were significantly older than those on an intensive regimen, $t(91) = 2.47$, $p < .05$.

Ninety percent of eligible families agreed to participate. Reasons given for non-participation included concerns over time commitment, HIPAA authorization, and psychological counseling. The research was approved by the Human Investigation Committee of the university affiliated with the hospital where the adolescents were seen for medical care. All participants provided informed consent and assent to participate.

Procedure

Data Collection

All measures were collected by a trained research assistant in the participants' homes. Both the youth and the primary caregiver completed questionnaires. Families were provided with \$50 to compensate them for participating.

Measures

Health Literacy

The Test of Functional Health Literacy in Adults (S-TOFHLA; Baker, Williams, Parker, Gazmararian, & Nurss, 1999) has two parts: reading comprehension and numeracy. The reading comprehension scale is comprised of two passages with 36 items. Two points are given for each correct reading item, resulting in a possible score of 72. The numeracy scale is comprised of four items.

Seven points are given for each correctly answered numeracy item, resulting in a possible score of 28. The S-TOFHLA has been shown to have good reliability and validity (Baker et al., 1999).

Illness Management

The Diabetes Management Scale (DMS; Frey, Ellis, Naar-King, & Greger, 2004) is a 20-item questionnaire designed to measure a broad range of diabetes management behaviors, such as insulin management, dietary management, BG monitoring, and symptom response with adequate reliability and validity. Respondents are asked "What percent of the time do you take your insulin?" and answers are scored on a 0–100% scale. Items are summed to obtain a total score reflecting overall management behavior. The DMS was developed prior to the widespread use of basal-bolus insulin regimens. Therefore, a subset of dietary items in the DMS, such as those that ask about adherence to a prescribed meal plan, were not appropriate for adolescents on intensive insulin regimens and these items were not used, resulting in a 10-item measure for those participants. Parent and adolescent report on the DMS was collected.

As an objective measure, frequency of BG checking was obtained directly from the adolescent's BG meter, and an average daily checking frequency was calculated.

Metabolic Control

Metabolic control was calculated using HbA1c, a retrospective measure of average BG during the past 2–3 months. Values were obtained using the FDA approved Accubase A1c test kit. The test uses a capillary tube blood collection method instead of venipuncture and is therefore suitable for home-based data collection. High performance liquid chromatography (HPLC) is used to analyze the blood sample (reference range 4.3–5.5%).

Data Analysis

Statistical analyses were performed using SPSS 15.0. Univariate frequency distributions and means with standard deviations were used to describe categorical and continuous variables, respectively. Bivariate correlations were calculated to determine the associations among health literacy, illness management, and metabolic control. Hierarchical multiple regression was used to examine the predictive value of health literacy on adherence.

Results

Descriptive Statistics for Parent's Health Literacy

The proportion of parents answering numeracy and reading comprehension items correctly on the S-TOFHLA are

Table 1. Proportion of Participants Answering Numeracy and Reading Comprehension Items Correctly on the S-TOFHLA

	Correct (%)
Numeracy items	
Take medication every 6 hr	83
Normal blood sugar	84
Appointment slip	88
Take medication on empty stomach	80
Numeracy items completed correctly	(%)
0	0
1	5
2	11
3	28
4	56
Number correct on reading items ^a	
A—Preparation for an upper GI	
0–11	0
12–14	5
15–16	95
B—Medication rights and responsibilities	
0–10	0
11–15	3
16–18	28
19–20	69

^aA is written at a fourth grade reading level; B is written at a 10th grade level.

presented in Table 1. Out of a possible score of 28 on the numeracy scale, the sample mean number correct was 24.7 ($SD = 4.6$; range = 10.5–28). Out of a possible score of 72 on the reading comprehension scale, the sample mean number correct was 68.9 ($SD = 3.6$; range = 56–72). All parents' scores reflected adequate health literacy (≥ 67 points out of 100). The numeracy and reading comprehension scales were significantly negatively skewed. For further analysis both scales were transformed using a reflected square root transformation to improve normalcy. Higher scores represent better health literacy.

Bivariate correlations were calculated between demographic characteristics and the reading comprehension and numeracy subscales. There was a significant relation between reading comprehension and one versus two-parent family, $r_{pb}(91) = .29$, $p < .01$. Parents in a two-parent family scored better on reading comprehension. There was a significant relation between reading comprehension and child's race, $r_{pb}(91) = .23$, $p < .05$. Parents of White children scored better than parents of minority children. Parent's race was marginally related to reading comprehension in the same direction ($p = .056$). Parents of adolescents on an intensive regimen scored better on reading comprehension than parents with adolescents on a conventional regimen, $r_{pb}(91) = .24$, $p < .05$. Health

literacy was not significantly related to child or parent age, gender, family income, or diabetes type.

Parent's Health Literacy and Adolescent Adherence

Bivariate correlations between parent's health literacy, average number of BG tests per day, adolescent-reported and parent-reported adherence on the DMS, and HbA1c level showed the following: there was a marginal relationship between parent's reading comprehension and BG tests per day in the total sample, $r(91) = .20$, $p < .10$. Health literacy was not significantly related to DMS and HbA1c for the total sample. However, for adolescents on the intensive insulin regimen ($n = 65$), parent's health literacy correlated significantly with DMS adherence. Specifically, parent's reading comprehension was significantly related to parent- and adolescent-reported adherence on the DMS, $r(63) = .31$, $p < .01$ and $r(63) = .32$, $p < .01$, respectively. In the intensive regimen group, reading comprehension was not significantly related to BG testing frequency or HbA1c. Numeracy was not significantly related to study variables.

Hierarchical multiple regression analyses were conducted to determine if health literacy significantly predicted DMS adherence for the intensive treatment group after controlling for relevant demographic characteristics. Demographic characteristics were entered in step 1 and health literacy was entered in step 2. To obtain the most parsimonious model, only variables significantly correlated at $p < .20$ were included. Based on this criterion, years since diagnosis and reading comprehension were included as predictors of adolescent-reported DMS. The final model with both variables in the model was significant, $F(2, 62) = 4.42$, $p < .05$. However, only reading comprehension was a significant predictor of DMS adherence, $\beta = .30$, $p < .05$.

For the analysis of parent-reported DMS, years since diagnosis, parent's age, reading comprehension, and numeracy were included as predictors. The final model with all variables in the model was significant, $F(4, 60) = 3.24$, $p < .05$. Only reading comprehension was a significant predictor of DMS adherence, $\beta = .26$, $p < .05$.

Discussion

The goal of the current study was to examine the health literacy of parents of high-risk adolescents with insulin dependent diabetes. Results show that all parents in this sample had adequate health literacy according to the

S-TOFLA. The majority of parents answered all items correctly on both the numeracy and reading comprehension scale. The health literacy scores in this sample are better than health literacy scores found at the national level (Kutner et al., 2006). It is possible that the current sample of parents had better health literacy because they have been managing their children's diabetes for several years. The average length of time since diagnosis in this sample is >4 years. Furthermore, parents were recruited from a multidisciplinary clinic where diabetes educators, psychologists, and social workers are available to meet with families at no additional cost. Access to these services may also have resulted in improved health literacy for parents. Future studies should compare the health literacy of participants from multidisciplinary clinics to those from primary care settings to better understand the relation between clinic type and outcomes.

In the current sample, parent's reading comprehension health literacy was significantly related to adolescent- and parent-reported illness management for those youth on intensive insulin regimens. In conventional regimens where youth take a set insulin dose and follow a prescribed meal plan, ability to gain diabetes management skills through mastery of written material may be less crucial than in the case of complex intensive regimens where parents and youth make constant adjustments to insulin dose based upon carbohydrate intake and BG level. In addition, parents of adolescents on an intensive regimen had higher reading comprehension scores than did parents of adolescents on a conventional regimen. In the clinic from which youth were recruited, intensive insulin therapy is considered the standard of care and youth are moved to conventional therapy only if they "fail" intensive management through chronically high BG. Prospective, longitudinal studies are necessary to confirm that families where parents have lower health literacy may be at risk for being placed on outdated insulin regimens and that poorer adherence may be one reason why this occurs.

Limitations include the relatively small, intervention study sample of families, reducing generalizability. Second, the S-TOFHLA has been noted by the Institute of Medicine as an indicator of skills rather than a measure of the full range of skills needed for health literacy (IOM, 2004). Therefore, the description of health literacy in this study is limited by the degree to which the S-TOFHLA reflects this construct. Furthermore, the S-TOFHLA was based on responses from primary care setting patients; therefore normative data on chronic illness samples in multidisciplinary clinics is needed to appropriately define "adequate health literacy". Third, because this study was

cross-sectional we could not fully evaluate the relation of health literacy to regimen type.

Parents with lower health literacy may have less access to more effective intensive insulin regimens and they may struggle to help their children adhere when they do have such access. Such families may benefit from educational approaches used to address low health literacy in adults with diabetes (Schillinger et al., 2003). These results suggest that even among parents with "adequate health literacy", the level of parental health literacy is an important component of their child's illness management.

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