Health Literacy and Pregnancy Preparedness in Pregestational Diabetes

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OBJECTIVE — We investigated the association between functional health literacy and markers of pregnancy preparedness in women with pregestational diabetes.

RESEARCH DESIGN AND METHODS — English- and Spanish-speaking pregnant women with pregestational diabetes were recruited. Women completed the Test of Functional Health Literacy in Adults (TOFHLA) short form and a questionnaire. A TOFHLA score of ≤30 was defined as low functional health literacy.

RESULTS — Of 74 women participating in the study, 16 (22%) were classified as having low functional health literacy. Compared with women with adequate health literacy, those with low health literacy were significantly more likely to have an unplanned pregnancy (P = 0.02) and significantly less likely to have either discussed pregnancy ahead of time with an endocrinologist or obstetrician (P = 0.01) or taken folic acid (P = 0.001).

CONCLUSIONS — The results of this study suggest that low functional health literacy among women with pregestational diabetes is associated with several factors that may adversely impact birth outcomes.

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pproximately 19,000 pregnancies in the U.S. occur annually in women with pregestational diabetes. Although this represents a small proportion of total births, pregnancies in women with diabetes are important because of the potential for adverse outcomes, including spontaneous abortions, stillbirths, congenital anomalies, and the requirement for neonatal intensive care (1). The risk of these outcomes may be minimized with preconceptional planning. Specifically, periconceptional folic acid supplementation and good glycemic control before pregnancy have been shown to reduce these risks to a level only slightly higher than that of the baseline population (2–11).

Many women with diabetes unfortunately fail to receive preconceptional counseling or to achieve good glucose control before pregnancy. Health care providers have attempted to determine the barriers to ideal diabetes care. Diabetes is a chronic disease that can be very confusing and frustrating for patients. Many patients may not understand their disease, the information their health care providers give them, or the importance of tight glucose control. Studies in nonpregnant diabetic subjects have confirmed the relationship between low socioeconomic status, low literacy, and poorer glycemic control with a higher risk of complications (12-15). Two studies (16,17) specifically evaluating functional health

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Abbreviations: TOFHLA, Test of Functional Health Literacy in Adults.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

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literacy in nonpregnant diabetic patients found very high rates of inadequate and marginal health literacy at 50 to 75%.

Functional health literacy has not been studied in pregnant women with diabetes. We therefore performed a pilot study evaluating the association between low functional health literacy in women with pregestational diabetes and markers for adverse pregnancy outcome.

RESEARCH DESIGN AND

METHODS — Pregnant patients with pregestational diabetes, class B or higher, either type 1 or type 2, were prospectively recruited from three sites: two university-based clinics and one community-based high-risk obstetric ambulatory care clinic within the Chicago area. Women were approached at any point during their pregnancy once they had established prenatal care. Women were excluded if they did not speak either English or Spanish. The institutional review boards of all three sites approved the study, and recruitment occurred between May 2000 and November 2001.

We utilized a cross-sectional study design with birth-outcome data in a convenience sample of women recruited as they presented for a regularly scheduled prenatal appointment. Each participant completed the Test of Functional Health Literacy in Adults (TOFHLA) short form and a demographic and medical questionnaire (18). The TOFHLA is a validated measure of functional health literacy available in English and Spanish versions (19). The short form consists of 36 reading comprehension items. Each correct item is given 1 point, with a maximum score of 36 points. In our study, a score of ≤30 comprised the low functional literacy group. The test is in the form of two different reading passages where every fifth to seventh word is omitted and must be selected from a list of four possible choices. The reading level is at or below a 10th grade level, and the passages are written with regard to medical situations, i.e., instruction for having a radiologic study and Medicaid patient rights and responsibilities. The TOFHLA is a

timed test, and subjects have 7 min to complete the reading passages.

The additional questionnaire included basic socioeconomic questions such as level of education, work outside the home, and car or phone ownership. Other questions included were with regard to overall health, diabetes control, and whether the pregnancy was planned. The questionnaire took ~5 min to complete and was available in English or Spanish.

Patients continued to receive standard prenatal care and management of their diabetes. Medical records were reviewed after the postpartum visit for additional information on pregnancy and delivery. Care providers were unaware of the results of the TOFHLA, which was not scored until after all data on the pregnancy were collected. Differences in clinical factors between the low and adequate functional literacy subgroups were assessed by Student's t test or Mann-Whitney test for continuous variables and Fisher's exact test or χ^2 test for dichotomous variables. A P value of < 0.05 was considered significant, and all tests were two sided.

Our primary outcomes were related to pregnancy preparedness, and we based our sample size calculation on the rates of planned pregnancy. In the U.S., only 50% of women plan their pregnancy (20). We hypothesized that women with low functional health literacy would be even less likely to have a planned pregnancy as compared with women with adequate literacy. Based on $\alpha = 0.05$ and $\beta = 0.70$, we were powered to detect a 50% difference in pregnancy planning between groups. This study was not funded, and the goal was to collect pilot data; therefore, it was slightly underpowered with $\beta = 0.70.$

RESULTS — Seventy-four women with pregestational diabetes completed the TOFHLA and general questionnaire. Participants were categorized into low (≤30) and adequate (>30) functional health literacy based on TOFHLA scores. Sixteen subjects (22%) were classified as having low functional health literacy. Women with low functional health literacy had a mean score of 23 \pm 6 on the TOFHLA compared with 35 \pm 1 (P < 0.001) for women with adequate literacy. There were 39 (67%) women with type 1 diabetes in the adequate functional health

Table 1—Maternal demographic and socioeconomic characteristics by functional health literacy status

	Total	Low	Adequate	P*
n	74	16	58	
Maternal age (years)	31 ± 6	29 ± 7	31 ± 6	NS
Maternal prepregnancy weight (kg)	72.9 ± 19.1	78.4 ± 20.3	71.4 ± 17.1	NS
Race				
Caucasian	41 (55)	0	41 (70)	0.001
African American	14 (19)	5 (31)	9 (16)	
Hispanic	17 (23)	9 (56)	8 (14)	
Other	2 (3)	2 (13)	0	
Duration of diabetes	12 ± 9	6 ± 5	14 ± 9	0.001
Retinopathy	12 (16)	1 (6)	11 (19)	NS
Nephropathy	8 (11)	0	8 (14)	NS
Hypertension	15 (20)	3 (19)	13 (22)	NS
Multiparous	45 (61)	13 (81)	33 (57)	NS
Completed high school	59 (80)	7 (44)	52 (90)	0.001
Work outside the home	41 (55)	3 (19)	38 (66)	0.001
Do not own a car	21 (28)	10 (63)	11 (19)	0.001
Do not own a phone	8 (11)	5 (31)	3 (5)	NS

Data are means \pm SD or n (%). *Statistical difference between women with low and adequate health literacy.

literacy category and 8 (50%) in the low functional health literacy group (P =0.33). Maternal demographic and socioeconomic characteristics by functional health literacy status are shown in Table 1. Women with adequate health literacy presented for prenatal care earlier than women in the low literacy group (8.3 ± 3) vs. 12.8 ± 7.8 weeks of gestation, respectively, P = 0.04), but there was no difference in the gestational age of the two groups for when the women completed the TOFHLA and questionnaire (22.4 ± 9.1 vs. 21.9 \pm 10.2 weeks of gestation, P = 0.86). Women with adequate health literacy were more likely of Caucasian race and had a longer average duration of diabetes. As anticipated, fewer women in the low literacy group had a high school education. The low literacy group also had a higher rate of markers indicating

lower socioeconomic status, such as not owning a car.

We found significant differences between the low and adequate literacy groups for different factors related to pregnancy preparedness, as is shown in Table 2. Women with low functional health literacy were significantly more likely to have an unplanned pregnancy. They were less likely to have discussed becoming pregnant with the doctor who managed their diabetes or with an obstetrician. Compared with women with adequate functional health literacy, they were less likely to have taken folic acid before pregnancy or during the first trimester.

Pregnancy outcomes by functional health literacy status are shown in Table 3. There was no difference in the mean initial glycosylated hemoglobin value between the two groups $(8.2 \pm 2.4 \text{ vs. } 7.5 \pm$

Table 2—Pregnancy preparedness by functional health literacy status

	Total	Low	Adequate	P^*
n	74	16	58	
Planned pregnancy	39 (53)	4 (25)	35 (60)	0.02
Prepregnancy talk with diabetes MD	35 (47)	3 (19)	32 (55)	0.01
Prepregnancy talk with obstetric MD	27 (36)	2 (13)	25 (43)	0.01
Took folic acid	53 (72)	5 (31)	48 (83)	0.001
Gestational age on initial visit (weeks)	9.7 ± 5.2	8.3 ± 3	12.8 ± 7.8	0.04
Initial HbA _{1c} (mg/dl)	7.6 ± 2.0	8.2 ± 2.4	7.5 ± 1.8	NS
Third trimester HbA _{1c} (mg/dl)	6.4 ± 1.0	7.1 ± 1.8	6.5 ± 1.2	NS

Data are means \pm SD or n (%). *Statistical difference between women with low and adequate health literacy.

Table 3—Pregnancy outcomes by functional health literacy status

	Total	Low	Adequate	P^*
n	74	16	58	
Hospitalized during pregnancy	32 (43)	11 (69)	21 (36)	0.03
Gestational age at delivery (weeks)	37 ± 2	38 ± 2	37 ± 4	NS
5-min Apgar	9 ± 1	9 ± 1	8 ± 1	NS
Vaginal delivery	45 (61)	7 (48)	34 (62)	NS
Shoulder dystocia	5 (7)	3 (20)	2 (4)	NS
Birth weight (g)	$3,493 \pm 789$	$3,854 \pm 747$	$3,395 \pm 777$	< 0.05
Birth weight >4,000 g	21 (28)	10 (63)	11 (19)	0.001
Neonatal intensive care unit admission	25 (34)	19 (33)	6 (38)	NS

Data are means \pm SD or n (%). *Statistical difference between women with low and adequate health literacy.

1.8, P = 0.28), but overall patients who had a repeat value in the pregnancy demonstrated improvement in their glucose control. The greater likelihood of hospitalization during the pregnancy in the low literacy group was largely attributable to the need for improving metabolic control. There was no difference in gestational age at delivery, but birth weight was significantly higher in the low functional health literacy group. Women with low functional health literacy were also more likely to have a neonate that weighed >4,000 g compared with women with adequate health literacy. Other birth outcomes were similar between the two groups.

CONCLUSIONS— Functional health literacy has not been previously studied in pregnant women with diabetes. In our pilot study, nearly one-fourth of women presenting for prenatal care with pregestational diabetes qualified as having low functional health literacy. Our study had inadequate power to assess meaningful differences in birth outcomes. It is concerning, however, that low functional literacy was found to be associated with several factors known to negatively impact outcomes in pregnancies complicated by diabetes. Although our study had small numbers, we did find significant differences in our primary outcome, planned pregnancy, and in other issues of pregnancy preparedness. Women with low functional health literacy were less likely to plan their pregnancy, take folic acid, or talk to a physician before their pregnancy and presented for prenatal care at a later gestational age.

We felt it was important to include Hispanic patients in this pilot study because of the relatively high rate of diabetes in this growing segment of the U.S. population. However, our relatively small sample size (only seven subjects were Spanish speaking) prevented the assessment of potential confounding influences on the association found between low health literacy and lack of pregnancy preparedness. For example, our low literacy group was more likely to have markers of lower socioeconomic status, such as not owning a car. It is plausible that there is interaction between low health literacy and other socioeconomic factors, which pose barriers to medical care.

A recent study by Schillinger et al. (21) evaluated physician communication with patients with low functional health literacy. Patients whose recall or comprehension was assessed by their physicians had significantly lower HbA_{1c} levels than those who did not. This novel study suggests that physicians may improve patients' health by employing communication techniques. If a larger investigation confirms the associations found in our pilot study, intervention trials are warranted to assess whether such strategies are effective in ensuring that women with diabetes have the opportunity to prepare for pregnancy regardless of their level of functional health literacy.

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References

- 1. Engelgau MM, Herman WH, Smith PJ, German RR, Aubert RE: The epidemiology of diabetes and pregnancy in the U.S., 1988. *Diabetes Care* 18:1029–1033, 1995
- 2. Pregnancy outcomes in the Diabetes Con-

- trol and Complications Trial. *Am J Obstet Gynecol* 174:1343–1353, 1996
- Kitzmiller JL, Gavin L, Gin G, Javonovic-Peterson L, Main B, Zigrang W: Preconception care of diabetes: glycemic control prevents congenital anomalies. *JAMA* 264:731–736, 1991
- 4. American Academy of Pediatrics Committee on Genetics: Folic acid for the prevention of neural tube defects. *Pediatrics* 104: 325–327, 1999
- Kitzmiller JK, Buchanan T, Kjos S, Combs C, Ratner R: Preconception care of diabetes, congenital malformations, and spontaneous abortions. *Diabetes Care* 19:514–533, 1996
- Delgado-Rodriquez M, Gomez-Olmedo M, Bueno-Cavanillas A, Galvez-Vargas R: Unplanned pregnancy as a major determinant in inadequate use of prenatal care. Prev Med 26:834–838, 1997
- 7. Dunne FP, Brydon P, Smith T, Essex M, Nicholson H, Dunn J: Pre-conception diabetes care in insulin-dependent diabetes mellitus. *QJM* 92:175–176, 1999
- Herman WH, Janz NK, Becker MP, Charron-Prochownik D: Diabetes and pregnancy: preconception care, pregnancy outcomes, resource utilization and costs. *J Reprod Med* 44:33–38, 1999
- Nielson GL, Sorensen HT, Nielson PH, Sabroe S, Olsen J: Glycosylated hemoglobin as a predictor of adverse fetal outcome in type 1 diabetic pregnancies. *Acta Dia*betol 34:217–222, 1997
- Casson IF, Clarke CA, Howard CV, Mc-Kendrick O, Pennycook S, Pharoah PO, Platt MJ, Stanisstreet M, van Velszen D, Walkinshaw S: Outcomes of pregnancy in insulin dependent diabetic women: results of a five year population cohort study. BMJ 315:275–278, 1997
- Elixhauser A, Weschler JM, Kitzmiller JL, Marks JS, Bennert HW Jr, Coustan DR, Gabbe SG, Herman WH, Kaufmann RC, Ogata ES, Sepe SJ: Cost-benefit analysis of preconception care for women with established diabetes mellitus. *Diabetes Care* 16:1146–1157, 1993
- 12. Larsson D, Lager I, Nisson PM: Socioeconomic characteristics and quality of life in diabetes mellitus: relation to metabolic control. *Scand J Public Health* 27:101–105, 1999
- 13. Hawthorne K, Tomlinson S: Pakistani Moslems with type 2 diabetes mellitus: effects of sex, literacy skills, known diabetic complications and place of care on diabetic knowledge, reported self-monitoring management and glycemic control. *Diabet Med* 16:591–597, 1999
- 14. Van der Meer JB, Mackenbach JP: The care and course of diabetes: differences according to level of education. *Health Policy* 46:127–141, 1999
- 15. Overland JE, Hoskins PL, McGill MJ, Yue

Health literacy in diabetic pregnancy

- DK: Low literacy: a problem in diabetes education. *Diabet Med* 10:847–850, 1993
- Williams MV, Baker DW, Parker RM, Nurss JR: Relationship of functional health literacy to patients' knowledge of their chronic disease: a study of patients with hypertension and diabetes. *Arch Intern Med* 158:166–172, 1998
- 17. Nurss JR, El-Kebbi IM, Gallina D, Zeimer D, Musey V, Lewis S, Liao Q, Phillips L: Diabetes in urban African-Americans:
- functional health literacy of municipal hospital outpatients with diabetes. *Diabetes Educ* 23:563–568, 1997
- 18. Parker RM, Baker DW, Wialliams MV, Nurss JR: The test of functional health literacy in adults (TOFHLA): a new instrument for measuring patients' literacy skills. *J Gen Intern Med* 10:537–541, 1995
- 19. Williams MV, Parker RM, Baker RW, Parikh NS, Pitkin K, Coates WC, Nurss JR: Inadequate functional health literacy
- among patients at two public hospitals. *JAMA* 274:1677–1682, 1995
- Henshaw S: Unintended pregnancy in the United States. Fam Plann Perspect 30:24– 29, 1998
- 21. Schillinger D, Piette J, Grumbach K, Wand F, Wilson C, Daher C, Leong-Grotz K, Castro C, Bindman A: Physician communication with diabetic patients who have low health literacy. *Arch Intern Med* 163:83–90, 2002