article

Maternal understanding of infant diabetes risk: Differential effects of maternal anxiety and depression

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Purpose: This study describes maternal understanding of infant risk associated with newborn genetic screening for type 1 diabetes. **Methods:** Mothers of at-risk infants (n = 195), identified through the Prospective Assessment of Newborns for Diabetes Autoimmunity study, were notified of risk status by standardized script. Mothers participated in structured telephone interviews 1 and 3.5 months after notification that assessed understanding of infant risk and psychologic response to the news. **Results:** Most mothers (78.5%) were accurate in their understanding of infant risk at the initial interview, with a slight decline at the follow-up interview (73%). There was a significant increase in underestimation of risk from the initial (12%) to the follow-up interview (19%) (χ^2 (1) = 6.0, P = .01). Mothers with less education, those from ethnic minority backgrounds, and those who were not married tended to be less accurate. Further, mothers who experienced more anxiety and fewer depressive symptoms in response to the news were more likely to be accurate. Likewise, underestimation of risk was associated with fewer anxiety and more depressive symptoms. **Conclusion:** This study highlights the complex picture of factors promoting maternal understanding of infant diabetes risk in a sample of mothers whose newborns had been identified as at increased risk for type 1 diabetes. ***Genet Med*** **2006:8(10):665–670.**

The autoimmune destruction of insulin-producing beta cells that causes type 1 diabetes (T1D) is a process influenced by genetic and environmental factors.[1,2] However, the nature of this gene–environment interaction is not well understood and the subject of considerable scientific inquiry.[3–5] As part of this effort, newborn genetic screening for T1D risk is now being conducted worldwide.[6–9] These screening programs will provide a wealth of scientific information relevant to the natural history and pathogenesis of this disease. At the same time, genetic screening, in the absence of known methods to prevent T1D, raises ethical and psychosocial concerns.[10,11]

The Prospective Assessment of Newborns for Diabetes Autoimmunity (PANDA) study is a newborn screening program that jointly aims to identify genetic risk for T1D[9] and evaluate the ethical and psychologic implications of at-risk status.[12] In the PANDA study, the child's human leukocyte antigen (HLA)-DQB1 allele status and family history of diabetes are evaluated to determine risk status[13]; those at risk are followed prospectively. Mothers of at-risk infants are contacted by telephone, notified of risk status, and provided information about the infant's risk status with a standardized script. Mothers then take part in phone interviews to determine understanding of infant diabetes risk,[13] the psychologic impact of the news,[14–16] and prevention efforts.[17] The scant available research literature from PANDA and other screening programs suggests that mothers of infants and children screened for genetic risk may experience some initial anxiety, but that seems to dissipate over time.[14,18,19] There seems to be little evidence of an increase in depressive symptoms associated with genetic testing in this population, although few studies have been conducted.[15]

Even when considerable time and effort are dedicated to the explanation of risk information, a significant portion of mothers do not fully understand the child's risk or the purpose of the screening.[13,20] Mothers with less education and those from ethnic minority groups tend to have greater difficulty accurately recalling the risk information presented. Further, maternal risk perception accuracy seems to decline over time, primarily because of an increase in the number of mothers who underestimate their child's T1D risk. Mothers who report lower levels of anxiety in response to the news of the child's increased T1D risk are more likely to underestimate the child's risk over time.[16] This complex picture of sociodemographic characteristics and psychologic factors promoting accuracy and underestimation has to be further delineated to ensure effective communication of risk to all participants. Indeed, accurate knowledge of

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Submitted for publication April 14, 2006.

Accepted for publication June 14, 2006.

DOI: 10.1097/01.gim.0000237794.24543.4d

information presented about risk in the context of screening for T1D, as well as other diseases, has an impact on decision-making in genetic risk studies[21] and efforts to prevent disease onset.[17]

In this study, we aimed to elucidate this complex picture of factors promoting maternal understanding of infant diabetes risk in a sample of mothers whose newborns had been identified as at increased risk for T1D through the PANDA study. We tested the effects of the passage of time, maternal sociodemographic characteristics (ethnic minority status, education), and child characteristics (family history of diabetes) on maternal risk perception accuracy. Finally, we examined the association of maternal affective response to risk notification (anxiety and depressive symptoms) on maternal risk perception accuracy.

MATERIALS AND METHODS

Procedure

Mothers were recruited from three Florida cities (Gainesville, Pensacola, and Orlando) as part of the PANDA study. The study protocol was approved by the University of Florida Health Science Center Review Board. Shortly after the child's birth, mothers provided informed consent; blood samples obtained for state-mandated newborn metabolic screening were used. Mothers were told they would be re-contacted only if their child was at increased risk for T1D. HLA DRB1 and DQB1 alleles were measured in the author's (J-XS) laboratory with modified Luminex (microbead) assays.[9] On the basis of the child's HLA allele status and family history of diabetes, infants were assigned to one of six risk categories: protected, very low, low, moderate, high, and extremely high.[13] Mothers of children in the protected, very low, and low categories were not recontacted. Mothers of infants in the moderate, high, and extremely high risk categories were contacted by telephone and given both a label describing the child's risk category and a numeric estimate: moderate risk (2/100 babies), high risk (5 to 10/100 babies), and extremely high risk (20 to 25/100 babies). Mothers were told that the infant's increased risk did not mean the child would definitely develop diabetes. Phone calls were made at various times during the day depending on the availability of the mother. Questions were answered, and each mother was asked permission to be contacted by our research team for a follow-up telephone interview.

A structured telephone interview was conducted 1 month (27.5 ± 18.4 days) after risk notification. Mothers were recontacted approximately 2.5 months later (106.4 ± 28.7 days after risk notification). The initial and follow-up interviews included questions aimed at determining maternal understanding of infant risk, present sociodemographic characteristics of the family, and responses of anxiety and depressive symptoms to infant risk. In the current study, 212 mothers were contacted and 195 mothers (92%) agreed to the telephone interview. Table 1 displays the demographic characteristics of the sample; most mothers were white, married, and college-educated, and had newborns in the moderate-risk category. At the time of notification, the mean child age was approximately 10 months (305.8 ± 162.8 days). Only 13 mothers declined the second interview, although we were unable to reach 38 mothers, resulting in a second interview sample of 144 (73.8%). Mothers who did not complete the second interview were less educated in comparison with mothers who completed both interviews (χ^2 (1) = 4.24, P = .04). There were no differences across other sociodemographic characteristics or levels of maternal anxiety and depressive symptoms.

Table 1
Participant characteristics

Maternal characteristics	Number/mean ± SD	%
Maternal age at risk notification (y)	28.2 ± 6.0	
Maternal ethnicity		
Caucasian	159	81.5
African-American	28	14.4
Hispanic-American	15	2.6
Asian-American	2	1.0
Did not report	1	0.5
Marital status		
Married	140	71.8
Never married	48	24.6
Divorced/separated	7	3.6
Maternal education		
Some high school	27	13.9
Graduated high school	45	23.1
Some college	61	31.3
Graduated college	42	21.5
Some graduate school	2	1.0
Completed graduate school	18	9.2
Child characteristics		
Child age at risk notification (d)	305.8 ± 162.8	
Risk status		
Moderate	138	70.8
High	50	25.6
Extremely high	7	3.6
Family history of diabetes		
No family history	57	29.2
First-degree relative with type 1 diabetes	18	9.2
≥Second-degree relative	120	61.5

MEASURES

Maternal risk perception accuracy

During the initial interview and the follow-up interview, mothers were asked to recall the risk status of the infant. Moth-

ers were asked, "Do you remember a specific category or any numbers you were told about?" If a mother was unable to recall the child's at-risk status spontaneously, she was given descriptions of the risk categories, using both labels and numbers, and asked whether she recognized the category that described her child's risk. A mother's risk perception was coded as *accurate* if she was able to identify the child's risk category by label or numeric risk either spontaneously or on the recognition task. Mothers who were not accurate were categorized as either providing an *underestimation* of the infant's risk (i.e., reported a lower level of risk than the child's actual risk), an *overestimation* of the infant's risk (i.e., reported a higher level of risk than the child's actual risk they were told), or not knowing the child's risk if they were unable to select a risk category.

Predictors of maternal risk perception accuracy

Maternal and child characteristics

Maternal characteristics tested for association with maternal risk perception accuracy included: age (years), ethnicity (1 = African-, Hispanic-, or Asian-American and 0 = white), education level (1 = some high school to 6 = completed graduate school), and marital status (1 = not married, separated, divorced, and 0 = married). Child variables included age at the time of risk notification (days), risk status (1 = high and extremely high risk, 0 = moderate risk), first-degree relative with diabetes (1 = yes, 0 = no), and ≥ second-degree relative with diabetes (1 = yes, 0 = no).

Anxiety symptoms in response to risk notification

A six-item short version of the State-Trait Anxiety Inventory (STAI)[22] was administered to mothers to determine anxiety symptoms in response to risk notification. Mothers were asked to respond to each STAI item while thinking specifically about the newborn's risk for T1D. The six items were selected by analyzing a previous sample of 435 PANDA mothers; a high correlation existed between this six-item short version and the full-scale state STAI ($r = 0.95$). To permit comparison with prior studies using the full-scale STAI, a regression equation was calculated to convert the six-item total score to a full-scale score (total score = 2.80 [six-item total score] + 6.89). In the current study, the six-item STAI demonstrated excellent internal consistency (first interview, $\alpha = 0.88$; second interview, $\alpha = 0.91$).

Depressive symptoms in response to risk notification

The 20-item Center for Epidemiologic Studies-Depression Scale (CES-D)[23] was used to assess depressive symptoms in response to risk notification. Mothers were asked to respond to each CES-D item while thinking specifically about the newborn's risk for T1D. The CES-D was included in both the first and second interviews. The measure demonstrated excellent internal consistency (first interview, $\alpha = 0.92$; second interview, $\alpha = 0.90$).

Statistical analysis

Statistical analyses were performed with Statistical Analysis System version 8.02 for Windows (SAS Institute, Cary, NC). The McNemar test was used for comparison of risk perception accuracy over the two interviews. Logistic regression was used to identify predictors of accuracy and underestimation at the initial and follow-up interviews. Variables were entered into the model in a predetermined order: time since risk notification, maternal characteristics, child characteristics, and maternal anxiety and depressive symptoms in response to risk notification. In the follow-up regression models, initial accuracy or underestimation was the first variable entered, followed by time since risk notification, mother and child demographic variables, and maternal anxiety and depressive symptoms in response to risk notification. Variables that failed to exhibit any predictive power ($P > .10$) were dropped from further consideration.

RESULTS

Maternal understanding of infant risk

Of the 195 mothers who participated in the initial interview, most mothers (153; 78.5%) were accurate in their recall of the infant's risk. There were 23 mothers (11.8%) who underestimated the infant's risk and only two mothers (1.0%) who overestimated the risk. A small percentage of mothers (17/195, 8.7%) did not know the child's risk status.

At the follow-up interview, there was a small, nonsignificant decline in accuracy; 72.9% mothers were accurate. However, there was a significant increase in the percentage (19.4%) of mothers who underestimated the infant's risk (28/144 mothers) (χ^2 (1) = 6.0, $P = .01$). Four mothers (2.8%) overestimated the risk, and seven mothers (4.9%) did not know the risk status of the infant (Table 2).

Predictors of maternal risk perception accuracy

The results for all logistic regression analyses are presented in Table 3. The first logistic model identified predictors of mothers who were accurate versus inaccurate on the initial interview. The model was significant (χ^2 (4) = 13.25, $P = .01$), and two predictors were identified: time since notification ($P = .03$) and maternal education ($P = .02$). Mothers were more likely to have an accurate understanding of infant risk when less time had passed since risk notification and when they had a higher level of education (Table 4).

Table 2
Risk perception accuracy rates for mothers who completed both interviews (n = 144)

	Initial interview		Follow-up interview	
Risk perception accuracy category	N	%	N	%
Accurate	111	77.1	104	72.2
Underestimate	19	13.2	33	22.9
Overestimate	2	1.4	2	1.4
Did not know	12	8.3	5	3.5

Table 3
Results from logistic regression analyses

Variable	B	SEB	Wald χ^2	*P*
Initial accuracy (n = 195)				
Time since notification	−0.02	0.01	4.55	.033
Maternal education[a]	0.40	0.17	5.71	.017
Follow-up accuracy (n = 144)				
Initial accuracy	2.12	0.50	17.77	<.0001
Time since notification	−0.02	0.01	5.72	.017
Ethnic minority status[b]	−0.67	0.29	5.22	.022
Depression at follow-up	−0.06	0.03	3.48	.062
Anxiety at follow-up	0.04	0.02	2.76	.097
Initial underestimation (n = 195)				
Time since notification	0.03	0.01	7.10	.008
Initial anxiety	−0.05	0.03	3.11	.078
Follow-up underestimation (n = 144)				
Initial underestimation	1.90	0.65	8.53	.004
Time since notification	0.02	0.01	4.86	.028
Non-married marital status	0.52	0.27	3.60	.058
Depression at follow-up	0.07	0.03	4.57	.033
Anxiety at follow-up	−0.05	0.03	3.51	.061

SEB, standard error value for the constant b.
[a]Maternal education coded 1 = some high school to 6 = completed graduate school.
[b]Ethnic minority status coded 1 for African-, Hispanic-, or Asian-American and 0 for white.

At the follow-up interview, the logistic regression model was also significant (χ^2 (5) = 38.53, $P < .0001$), with five predictor variables identified: initial accuracy ($P < .0001$), time since notification ($P = .02$), ethnic minority status ($P = .02$), and depressive ($P = .06$) and anxiety ($P = .10$) symptoms in response to the news (Tables 3 and 4). As expected, mothers who were accurate at the initial interview were more likely to be accurate at the follow-up interview. Once again, a longer time interval between the interview and risk notification was associated with poorer risk perception accuracy. In addition, mothers from ethnic minority backgrounds were less likely to be accurate at follow-up. Finally, anxiety and depressive symptoms in response to infant risk were marginally significant, but predicted risk-perception accuracy in opposite ways. Mothers who endorsed a higher level of anxiety symptoms in response to the infant's at-risk status were more likely to be accurate, and mothers who endorsed more depressive symptoms were less likely to be accurate. Effect size calculations revealed a small effect for anxiety ($d = 0.18$) and a moderate effect for depression ($d = 0.34$).

Predictors of underestimation of infant risk

As noted, 23 of 195 mothers (11.8%) underestimated the infant's risk at the initial interview. A logistic regression analysis was conducted to determine the predictors of mothers who underestimated the child's risk versus those who did not. This model was significant (χ^2 (4) = 14.51, $P = .006$), with two predictor variables identified: time since notification ($P < .01$) and anxiety symptoms in response to infant risk ($P = .08$). When more time elapsed since notification, mothers were more likely to underestimate risk. Mothers were less likely to underestimate risk when they had higher levels of anxiety symptoms. Effect size calculations revealed a medium effect ($d = 0.56$) for anxiety symptoms between mothers who underestimated risk and those who did not. Table 4 depicts these differences across accuracy groups.

At the follow-up interview, a higher percentage of mothers (28/144, 19.4%) underestimated the infant's risk. The follow-up interview logistic model was significant,

Table 4
Significant predictor variables for the total sample and by risk perception group

Variable	Total sample	Accurate	Inaccurate	Underestimate[a]
Initial interview	N = 195	N = 153	N = 42	N = 23
Time since notification (d)	27.5 ± 18.4	25.8 ± 17.5	33.5 ± 20.4	39.9 ± 19.9
Maternal education (% college)	63%	66.7%	50%	52.2%
Initial anxiety (STAI state score)[b]	38.9 ± 11.5	39.1 ± 11.6	38.0 ± 11.5	33.8 ± 8.5
Follow-up interview	N = 144	N = 105	N = 39	N = 28
Time since notification (d)	106.4 ± 28.7	102.3 ± 27.1	117.4 ± 30.5	120.6 ± 32.3
Ethnic minority status (% minority)	16%	11.4%	28.2%	25%
Marital status (% married)	75%	79.1%	64.1%	57.1%
Depression symptoms at follow-up (CES-D score)[c]	4.9 ± 7.1	4.2 ± 6.9	6.7 ± 7.5	7.4 ± 7.9
Anxiety symptoms at follow-up (STAI state score)[b]	34.1 ± 11.2	34.6 ± 10.9	32.5 ± 12.0	31.1 ± 9.3

[a]"Underestimate" category was drawn from those mothers (n = 42) who were "inaccurate."
[b]STAI = State-Trait Anxiety Inventory; full-scale score converted from six-item short form. Normative sample of working adults, mean score = 35.7 ± 10.4.
[c]CES-D = Center for Epidemiologic Studies–Depression Scale. Normative sample of adults, mean score = 6.3 ± 8.7.

(χ^2 (5) = 33.66, $P < .0001$), with five predictor variables: initial underestimation ($P = .004$), time since notification ($P = .03$), marital status ($P = .06$), and depressive ($P = .03$) and anxiety ($P = .06$) symptoms in response to the infant's risk status (Tables 3 and 4). Initial underestimation of risk and more time since notification were associated with underestimation at follow-up. Further, mothers who were not married were also more likely to underestimate risk. Once again, anxiety and depression exhibited opposite effects. Mothers who endorsed higher levels of depressive symptoms were more likely to underestimate risk, and mothers who endorsed more anxiety symptoms were less likely to underestimate risk; both variables had moderate effect sizes ($d = 0.49$ for anxiety and $d = 0.43$ for depression symptoms).

DISCUSSION

In this study, mothers participated in newborn genetic screening and were later notified of the infant's increased T1D risk through a standardized script. Results indicated that 78.5% were initially accurate in their recall of infant risk, consistent with the 73.1% accuracy rate reported previously.[13] Although most mothers understood the risk information presented, a substantial minority did not. In this study and one prior study,[13] poorly educated mothers (≤high school) were more likely to have difficulties understanding this complex information. Additional attention needs to be given to developing communication strategies that will successfully reach this population.

Passage of time was associated with a decrease in risk perception accuracy, consistent with findings previously reported.[13] This decrease in risk-perception accuracy can be attributed primarily to a significant increase in underestimation of risk. Underestimation of risk was more likely among ethnic minority members and unmarried mothers. In a previous study, ethnic minority status was also associated with poorer risk perception accuracy.[13] This suggests there may be important cultural differences in our ability to successfully communicate risk information and in how individuals cope with that information. It is unclear why unmarried women in the present study were more likely to underestimate the child's risk over time. Perhaps the opportunity to share risk information with a spouse helps mitigate the tendency to minimize risk as time passes. Or perhaps there are other psychologic or socioeconomic factors associated with single parenthood that will ultimately explain this association. In a previous study, we found that mothers whose infants had no family history of diabetes were more likely to underestimate risk over time.[13] We were unable to replicate that finding in the current sample, probably because of a lack of power (in the previous study there were 110 infants with no history of diabetes compared with 57 in the current sample) and the addition of other significant effects (e.g., depressive symptoms).

Of particular interest was the association between maternal anxiety and depressive symptoms and risk perception accuracy and underestimation. In a previous study, we found anxiety to be marginally associated with risk underestimation.[13] In the current study, we included measures of both anxiety and depression. We not only replicated the previous anxiety effect but also elucidated the differential effects of each. Although anxiety and depression symptoms are frequently correlated, as was the case in the current study (initial interview, $r = 0.44$; follow-up interview, $r = 0.35$), they had opposite effects on maternal risk perception accuracy. Mothers who reported higher levels of anxiety were more likely to be accurate about the child's risk and were less likely to underestimate the child's risk initially or over time. In contrast, mothers who reported more depressive symptoms were less likely to have accurate risk perceptions and more likely to underestimate the child's risk. It is important to note that the participants' anxiety and depression scores were not excessively high. Their STAI scores of approximately 39 at the initial interview and 34 at the follow-up interview are consistent with previous reports and suggest some initial anxiety that dissipates over time.[14] The depressive symptoms scores were actually lower than reported in the CES-D normative sample.[23] This suggests that relatively normal levels of anxiety and depressive symptoms are associated with risk perception accuracy and a mother's likelihood of underestimating her child's risk over time.

Study limitations include the predominantly white, educated, and married sample, which may have limited our ability to detect important sociodemographic effects. Further, a disproportionate number of poorly educated mothers failed to complete the follow-up interview. Nevertheless, education, ethnicity, and marital status effects emerged as significant, suggesting that these are powerful predictors of risk perception accuracy. The small number of infants with no family history of diabetes limited our power to detect effects in this population. Because newborn genetic screening is now being performed in the general population,[6–9] it will be important to conduct future studies of this type with larger numbers of infants with no diabetes family history. Finally, there were so few infants in the extremely high-risk group, we could not assess the effects of study variables in this particular group. A previous study[13] suggested that mothers of extremely high-risk infants may have particular difficulty accurately recalling the child's diabetes risk. Only larger studies with substantial numbers of extremely high-risk infants will permit us to elucidate the specific needs of this vulnerable population.

In sum, this study replicates and expands previous findings on diabetes risk perception accuracy among mothers whose infants have been identified as at increased risk for T1D through newborn genetic screening. Findings from this study highlight the substantial proportion of mothers who do not fully understand the genetic risk information presented to them. Future studies are needed to test other methods of notification (e.g., additional written letters, notification through health care providers known to family) to determine which methods may be best for notifying these particular mothers. In addition, this study draws particular attention to the differential effects of maternal anxiety and depressive symptoms in response to infant risk and the need for careful inspection of

these maternal affective responses in future studies. With these findings in mind, future studies on the most effective ways of communicating at-risk information are needed to ensure informed decision-making and continued participation in these important studies.

ACKNOWLEDGMENTS

Dr. Hood is supported by a career development grant (K23 DK-073340). This study was made possible by generous funding from the American Diabetes Association and partial funding from the Children's Miracle Network of North Central Florida, University of Florida's Department of Pediatrics, and National Institutes of Health grant numbers P01-DK-39079, K04-HD-00686, CRCGRR00082, and R01-HD-37800. The Juvenile Diabetes Research Foundation International provided additional support. We thank the members of the PANDA research team for their hard work. We appreciate the willingness of all of the mothers to participate in this study and thank them for their time.

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