Maternal Anxiety Associated With Newborn Genetic Screening for Type 1 Diabetes

SUZANNE BENNETT JOHNSON, PHD[1]
AMY E. BAUGHCUM, MS[2]
STACY K. CARMICHAEL, BS[2]
JIN-XIONG SHE, MD[3]
DESMOND A. SCHATZ, MD[4]

OBJECTIVE — To describe maternal anxiety associated with newborn genetic screening for type 1 diabetes during the first year after risk notification.

RESEARCH DESIGN AND METHODS — Mothers of at-risk infants (n = 435), identified through newborn genetic screening as part of the Prospective Assessment of Newborn for Diabetes Autoimmunity (PANDA) study, were administered a short form of the State Trait Anxiety Inventory (STAI) during telephone interviews ~3.5 weeks, 4 months, and 1 year after risk notification. Statistical analyses were conducted to examine predictors of maternal anxiety at each interview as well as changes in anxiety over time.

RESULTS — For the total sample, initial state STAI scores were not elevated and declined further over time. However, Hispanic mothers, those with low levels of education, those who overestimated the child's risk for diabetes, and mothers of infants in the highest risk group exhibited significantly elevated initial state STAI scores. At 4 months, higher state STAI scores were associated with higher initial state STAI scores, single parent status, having an infant with a first-degree relative with diabetes, and overestimation of the child's actual risk. Initial and 4-month STAI scores remained predictive of STAI scores at 1 year. In addition, single mothers and mothers of female children reported higher STAI state scores 1 year after risk notification.

CONCLUSIONS — For most mothers, newborn genetic screening to identify infants at increased risk for type 1 diabetes is not associated with significantly elevated maternal anxiety; anxiety further dissipates over time. However, anxiety levels vary considerably as a function of maternal ethnic status, education, marital status, maternal estimation of infant risk, and sex of the child and may be significantly elevated in some women.

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Individuals at risk for type 1 diabetes can now be identified years before disease onset. Early studies used islet cell antibody (ICA) testing in relatives of diabetic patients to identify those relatives at increased risk. The presence of ICA indicates underlying destruction of pancreatic β-cells in this autoimmune-mediated disease. Individuals who are ICA$^+$ are clearly at increased risk for type 1 diabetes even though the rapidity of β-cell destruction varies considerably, with some individuals never developing the disease (1). More recent research has identified specific genes located on the short arm of chromosome 6, the HLA region, that confer susceptibility to type 1 diabetes. Genetic screening studies (2) are underway with newborns in the U.S. and Europe to identify infants at risk prior to the development of autoimmunity and clinical diabetes.

Newborn screening programs are complicated by the imprecise markers of disease risk and the absence of any known effective method to prevent the disease in the identified at-risk child. Concerns about the psychosocial impact of such studies have been raised, although there are little empirical data addressing this issue (3,4). Studies of ICA$^+$ children and adults have documented increased anxiety immediately after risk notification, which dissipated over time. Parents of ICA$^+$ children appeared to be particularly affected, and certain coping styles were associated with greater maintenance of anxiety in ICA$^+$ children and their mothers (4–8). In one of the few studies to examine parental stress in newborns screened for diabetes risk, Yu et al. (9) obtained a measure of parenting stress 5–7 weeks after the baby's birth and 4–5 months after risk notification in a sample of 23 mothers with infants at increased risk for diabetes and 65 mothers whose infants were not at increased risk. Although the mothers of the at-risk infants reported greater stress than that of mothers of the low-risk infants, the difference was not statistically significant. Because parenting stress was not assessed immediately after risk notification, the absence of elevated stress 4–5 months postnotification is consistent with the decline in anxiety previously reported (4–8) in ICA$^+$ populations.

The current study represents a large-scale longitudinal investigation of the impact of newborn genetic risk screening for type 1 diabetes on maternal anxiety levels during the year following risk notification. All participants were mothers of infants at increased risk for diabetes. In a

From the [1]Department of Medical Humanities and Social Sciences, College of Medicine, Florida State University, Tallahassee, Florida; the [2]Department of Clinical and Health Psychology, College of Health Professions, University of Florida, Gainesville, Florida; the [3]Center for Biotechnology and Genomic Medicine, Medical College of Georgia, Augusta, Georgia; and the [4]Department of Pediatrics, College of Medicine, University of Florida, Gainesville, Florida.

Address correspondence and reprint requests to Suzanne Bennett Johnson, PhD, Department of Medical Humanities and Social Sciences, Florida State University, College of Medicine, Tallahassee, Florida 32306-4300. E-mail: suzanne.johnson@med.fsu.edu.

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Abbreviations: ICA, islet cell antibody; PANDA, Prospective Assessment of Newborn Diabetes Autoimmunity; STAI, State Trait Anxiety Inventory.

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

previous report (10), we described these mothers' understanding of their infant's diabetes risk ~3.5 weeks and 4 months after risk notification. Accuracy of mothers' recall of infant risk declined over time, with an increasing number of mothers underestimating the infant's risk. Accuracy of mothers' infant risk estimates was associated with a number of factors, including maternal education, ethnic minority status, family history of diabetes, infant risk, time since risk notification, and maternal anxiety about the baby's risk. In the current study, we examined maternal anxiety ~3.5 weeks, 4 months, and 1 year after risk notification and identified factors associated with mothers' initial anxiety in response to risk notification and any decline in maternal anxiety over time.

RESEARCH DESIGN AND METHODS

Prospective assessment of newborns for diabetes autoimmunity

Participants were recruited from the Prospective Assessment of Newborns for Diabetes Autoimmunity study (PANDA), a program funded by the National Institutes of Health and the Juvenile Diabetes Foundation that uses genetic testing to identify newborns at risk for type 1 diabetes (11). Mothers were contacted at the time of their child's birth and were asked for permission to screen the newborn for the presence of the high-risk HLA-DQB1 alleles using blood spots on filter paper (obtained by heel stick at the time of state-mandated screening for newborn metabolic diseases). Mothers were told they would be recontacted only if their child was at increased risk for type 1 diabetes. Informed consent was obtained. If a baby carried a high-risk gene, the baby's siblings were offered participation in PANDA. Also, in a few cases, mothers of newborn babies and of infants with a sibling with type 1 diabetes requested infant testing. If the baby tested positive for a high-risk HLA gene, the baby was followed in PANDA.

Infants who were tested were assigned to one of six risk categories depending on the child's HLA-DQB1 allele status and family history of type 1 diabetes (10). Mothers in the low, very-low, and protected risk categories were not recontacted. Mothers in the moderate, high-risk, and extremely high-risk groups were sent letters asking mothers to call for their infant's test results. If mothers did not call, efforts were made to contact the mothers by telephone. Once telephone contact was made, mothers were provided their infant's risk status using a standardized script that provided both a risk category and a numerical risk estimate: moderate, 2% risk; high, 5–10% risk; or extremely high, 20–25% risk. Mothers were also told that their infant's increased risk for diabetes did not mean that the baby would definitely develop diabetes. Their questions were answered, and mothers were asked permission for our research team to contact them for a telephone interview.

Over 90% of the mothers contacted ($n = 435$) agreed to be interviewed. The demographic characteristics of the study participants are shown in Table 1. This sample of mothers was largely Caucasian, well educated, and married. Most infants (74%) had a family history of diabetes, and 14% had a first-degree relative with the disease. Most infants (60%) were in the moderate-risk category, 35% were in the high-risk group, and 5% were in the extremely high–risk category.

Table 1—*Demographic characteristics of study participants* (n = *435*)

Maternal characteristics	
Age at time of first interview (years)	29.3 ± 5.6
Race	
White	348 (80.0)
Hispanic	38 (8.8)
African American	26 (6.0)
Asian	10 (2.3)
Other	11 (2.5)
Marital status	
Married	325 (75.4)
Never married	72 (21.3)
Divorced	9 (2.1)
Separated	5 (1.1)
Education	
Some high school	30 (7.0)
High school/GED	90 (20.9)
Some college/trade school	158 (36.7)
College degree	111 (25.8)
Some graduate school	10 (2.3)
Graduate school degree	32 (7.4)
Child characteristics	
Age at time of first interview (months)	7.4 ± 5.1
Infant risk classification	
Moderate (2%)	261 (60.0)
High (5–10%)	151 (34.7)
Extremely high (20–25%)	23 (5.3)
Sex (male)	216 (50.7)
Only child	161 (37.4)
Number of children in household	2.1 ± 1.2
Family history of diabetes*	
No family history	112 (25.7)
First-degree relative	62 (14.3)
Greater than or equal to second-degree relative	302 (69.4)

Data are means ± SD or *n* (%). *$n > 435$ because an infant could have a first-degree relative and other greater than or equal to second-degree relatives. GED, general equivalency diploma.

Procedure

Three structured telephone interviews were administered to the participants 3.5 ± 4.96 weeks, 4.0 ± 1.96 months, and 12.5 ± 2.45 months after risk notification. Mothers had the option to decline an interview at any point throughout the study. Only 34 mothers declined. However, a number of mothers were lost to follow-up due to moves or unlisted or disconnected phones, resulting in a final sample of 435 mothers with initial 3.5-week interviews, 344 with 4-month interviews, and 269 with 1-year interviews.

A 10-item short form of the state component of the State Trait Anxiety Inventory (STAI) (12) was used to assess mothers' anxiety levels at each of the interviews. The state component of the STAI is a reliable, well-validated measure of acute situational anxiety and has been previously used to measure anxiety in children and adults at risk for diabetes (6–8). The 10-item short form was derived by examining the items that most highly correlated with the full 20-item scale score for this population. The short form was highly reliable (3.5 weeks, $\alpha = 0.93$; 4 months, $\alpha = 0.92$; and 1 year, $\alpha = 0.90$). Because there was a high correlation between scores on the 10-item short form and the 20-item full form ($r = 0.97$), a regression equation was used to convert the short-form scores into full-scale scores compatible with STAI norms: predicted STAI score = (1.69 × short-form STAI) + 3.91.

The structured interviews also provided mothers with all six risk categories and asked mothers to select the category most similar to her child's risk. The mother's selection was compared with the child's actual risk category and coded as accurate, an underestimation, an overestimation, or "don't know." Mothers were

Table 2—*Maternal initial STAI scores compared with those of parents of ICA$^+$ children, pregnant women, and working women*

Mothers of genetically at-risk infants		Comparison groups	
Total sample[A,B]	37.0 ± 13.5 (433)	A) Parents of ICA$^+$ children*	55.4 ± 14.4 (33)
Hispanic[A,C,D]	44.0 ± 15.05 (38)	B) Pregnant women undergoing amneiocentesis†	44.9 ± 11.0 (100)
Non-Hispanic[A,B]	36.2 ± 13.1 (393)	C) Pregnant women‡	37.6 ± 11.0 (200)
High school or less[A,B,C,D]	41.5 ± 13.0 (119)	D) Working women§	36.2 ± 11.0 (210)
Some college[A,B]	36.2 ± 13.1 (310)		
Risk			
Extremely high[A,C,D]	42.7 ± 11.1 (23)		
High to moderate[A,B]	36.6 ± 13.5 (410)		
Overestimated[A,D]	45.7 ± 15.8 (16)		
Did not overestimate[A,B]	36.6 ± 13.3 (417)		

Data are means ± SD (*n*). Capitalized superscript indicates the comparison group that is significantly different from the study sample ($P < 0.05$); only mothers who completed all items on the STAI short form were included in the analysis. *From Johnson and Tercyak (7); †Tercyak et al. (13); ‡Marteau and Bekker (14); and §Speilberger (12).

then asked if they believed that their child would develop diabetes in the near future, with the following response options provided: "child will develop diabetes in the near future," "child will eventually develop diabetes, but a long time from now," "unsure what will happen," and "child will not ever develop diabetes." Demographic information was also collected, including maternal age, education, ethnicity, and marital status; number of children in the family; infant age and sex; whether the infant was an only child; and the infant's family history of diabetes.

Statistical analysis

Welch's *T* tests were used to compare maternal STAI scores with those previously obtained from parents of ICA$^+$ children (7), pregnant women undergoing amniocentesis (13), pregnant women (14), and working women (12).

Hierarchical linear regression models were used to examine predictors of STAI scores for each of the three interviews. This approach requires variables to be grouped in conceptually meaningful blocks and entered into the model in an a priori order. In this case, more general variables were entered earlier (e.g., maternal demographic characteristics), and variables expected to be more closely related to the mother's STAI scores (e.g., maternal understanding of infant risk) were entered later. When predicting STAI scores at 3.5 weeks, the first variable entered was time elapsed (in months) between at-risk notification and the interview. Next, maternal demographic variables were entered: maternal education level (0 = high school education or less, 1 = at least some college), maternal ethnicity (African American, Hispanic, and Asian/Other, all coded 1 = yes and 0 = no), marital status (1 = married, 0 = single, separated, widowed, or divorced), and maternal age (in years) at the time of the interview. The third block entered contained infant demographic variables: infant sex (1 = male, 2 = female); infant age (in months) at the time of the first interview; whether child was first born (1 = yes, 0 = no); number of children in the family; and family history of diabetes (first-degree relative or greater than or equal to second-degree relative, both coded 1 = yes, 0 = no). The fourth block of variables entered contained infant risk status (high and extremely high risk, both coded as 1 = yes, 0 = no). The final block entered included variables related to maternal understanding of the child's risk. Two variables were entered: the mother's estimate of when the child will develop diabetes (0 = never, 1 = unsure, 2 = much later, 3 = soon) and maternal accuracy of the child's actual risk (accurate, underestimation, overestimation, each coded 1 = yes, 0 = no). Throughout the hierarchical regression, when each block was added to the model, only variables that were significant at $P < 0.10$ were retained. When predicting 4-month STAI scores, initial 3.5-week STAI scores were entered first, followed by the hierarchical entry of variables in the blocks described above. Similarly, when predicting 1-year STAI scores, 3.5-week and 4-month STAI scores were entered first, followed by the same hierarchical entry of variables in blocks as outlined above.

Change in STAI scores over time was examined using a repeated-measures ANOVA. Between-subjects variables included those variables that proved to be significant predictors of 3.5-week STAI scores in the hierarchical regression analysis described previously: maternal education (dichotomized as "high school or less" or "at least some college"), Hispanic ethnicity (dichotomized as "yes" or "no"), infant's risk status (dichotomized as "extremely high" versus "not extremely high"), and risk overestimation (dichotomized as "yes" or "no"). The within-subjects variable was time of interview (3.5 weeks, 4 months, and 1 year). Only those mothers who completed all three interviews were included.

RESULTS

Initial maternal anxiety compared with parents of ICA$^+$ children, pregnant women, and working women

Table 2 depicts mothers' initial STAI scores compared with those obtained from parents of ICA$^+$ children, pregnant women undergoing amniocentesis, as well as normative samples of pregnant women and working women. For the total sample, mothers' STAI scores at the initial 3.5-week interview were comparable with comparison samples of pregnant women and working women and were significantly lower than STAI scores of parents of ICA$^+$ children [$Tw(37) = -7.11$, $P < 0.001$] and of pregnant women undergoing amniocentesis [$Tw(186) = -6.19$, $P < 0.001$].

Predictors of maternal anxiety

Predictors of anxiety at 3.5 weeks. The best predictors of initial STAI scores were maternal ethnic minority status and edu-

Table 3—*Predictors of maternal anxiety: final regression models predicting STAI scores at 4-week, 4-month, and 1-year interviews*

Dependent variable	β	*t*	*P*	Adjusted R^2
Initial anxiety (n = 429)				0.08
Hispanic	0.14	3.08	0.002	
Maternal education	−0.20	−4.36	0.001	
Extremely high risk	0.11	2.36	0.019	
Risk overestimation	0.11	2.24	0.026	
4-Month follow-up (n = 341)				0.46
Initial anxiety	0.60	13.16	0.001	
Time elapsed since notification	−0.10	−2.38	0.018	
Maternal marital status	−0.13	−3.29	0.001	
First-degree relative with diabetes	0.16	3.98	0.001	
Risk overestimation	0.09	2.25	0.025	
1-Year follow-up (n = 267)				0.38
Anxiety at 4-month follow-up	0.50	7.46	0.001	
Initial anxiety	0.14	2.13	0.034	
Maternal marital status	−0.12	−2.25	0.025	
Infant's sex	0.12	2.40	0.017	

The categorical variables Hispanic, extremely high risk, risk overestimation, and first-degree relative with diabetes were coded as "1" for yes and "0" for no. Marital status was coded as 1 for "married" and 0 for "not married." Maternal education was coded as 1 for "at least some college" and 0 for "high school education or less." Infant's sex was coded as 1 for "male" and 2 for "female."

cation, the infant's risk status, and whether the mother overestimated the infant's risk (Tables 2 and 3). Elevated STAI scores were exhibited by mothers who were Hispanic, had a high school education or less, had infants who were classified as extremely high risk, and overestimated their child's risk. Mothers in these subgroups generally experienced anxiety comparable with pregnant woman undergoing amniocentesis and significantly more anxiety than the pregnant and working women comparison groups. However, their anxiety remained lower than that of parents of ICA^+ children (Table 2).

Predictors of anxiety at 4 months. The best predictors of 4-month STAI scores were the initial STAI scores, time elapsed since risk notification, maternal marital status, family history of diabetes, and whether the mother overestimated her child's actual risk (Table 3). As expected, mothers who reported higher STAI scores at the initial interview tended to report higher STAI scores at the 4-month interview. The longer the time since risk notification, the lower the mother's STAI score. Mothers who were not married reported greater anxiety (STAI = 34.5 ± 13.3, n = 70) than mothers who were married (29.9 ± 10.2, n = 271). Mothers who had infants with a first-degree relative with diabetes experienced more anxiety (35.4 ± 11.0, n = 57) than mothers of infants without a first-degree relative with diabetes (29.9 ± 10.8, n = 285). Mothers who overestimated their child's actual risk had significantly higher STAI scores (33.7 ± 13.8, n = 47) than mothers who did not (30.4 ± 10.5, n = 295).

Predictors of anxiety at 1 year. The best predictors of 1-year STAI scores were 3.5-week and 4-month STAI scores, maternal marital status, and sex of the child (Table 3). Mothers who were more anxious at the previous interviews were also more anxious at the 1-year interview. Unmarried mothers had higher STAI scores (31.7 ± 13.0, n = 48) than mothers who were married (30.0 ± 9.0, n = 213). Mothers of female infants reported higher STAI scores (29.2 ± 10.3, n = 127) than mothers of male infants (27.2 ± 8.7, n = 126).

Change in anxiety over time

As expected, STAI scores declined significantly over time, from a mean of 37.0 ± 13.5 at 3.5 weeks to a mean of 30.9 ± 11.0 at 4 months and a mean of 28.1 ± 9.5 at 1 year (Table 4). The main effects for infant risk status and maternal risk overestimation also approached significance. Across all three interviews, mothers of extremely high–risk infants and those who initially overestimated the infant's actual risk tended to have higher STAI scores. There was also a significant interaction between education and time. Compared with more educated mothers, those with a high school education or less had significantly higher STAI scores at the initial 3.5-week interview, but reported a steeper decline in STAI scores at the 4-month and 1-year interviews.

Comparison of mothers who completed one versus two or more interviews

Over 80% (n = 351) of the sample completed two or three interviews. These mothers were compared with mothers who completed only one interview (n =

Table 4—*Change in maternal anxiety over time: repeated-measures ANOVA results*

Variable	df	MS	*F*	*P*
Between-subject variables				
Hispanic	1	135.81	0.52	0.47
Maternal education	1	30.84	0.12	0.73
Extremely high risk	1	876.70	3.38	0.07
Risk overestimation	1	935.18	3.61	0.06
Error	243	259.27	—	—
Within-subject variables				
Time	2	1146.91	20.97	0.001
Time × Hispanic	2	14.64	0.27	0.77
Time × maternal education	2	312.16	5.71	0.004
Time × extremely high risk	2	97.61	1.79	0.17
Error (time)	486	54.69	—	—

n = 262. The categorical variables Hispanic, extremely high risk, and risk overestimation were dichotomized as yes or no. Maternal education was dichotomized as "at least some college" or "highschool education or less." df, degrees of freedom; MS, mean squares.

84) on the demographic variables listed in Table 1. Compared with mothers we interviewed only once, mothers who completed multiple interviews were more likely to be married ($\chi^2 = 11.96$, $P < 0.001$), Caucasian ($\chi^2 = 4.25$, $P < 0.039$), and have some college education ($\chi^2 = 6.76$, $P < 0.009$). Mothers whose infant had a first-degree relative with diabetes were also more likely to complete two or more interviews ($\chi^2 = 5.87$, $P < 0.015$). However, there was no significant difference in initial STAI scores between mothers who completed one (34.8 ± 13.0) versus multiple interviews (37.5 ± 13.5).

CONCLUSIONS

Overall, mothers informed that their infants are at increased risk for type 1 diabetes did not report elevated levels of state anxiety 3.5 weeks after risk notification. Their state anxiety scores dissipated further by 4 months and remained low at 1 year. These findings are consistent with previous reports (4–9) documenting a decline in anxiety in parents of at-risk children 4–5 months after risk notification. However, all mothers did not respond to the news of the infant's at-risk status in similar ways. Hispanic mothers, those with infants who were classified as extremely high risk, and mothers who overestimated their child's risk experienced anxiety comparable with that of pregnant woman undergoing amniocentesis and significantly more anxiety than that of pregnant or working women comparison groups. However, their anxiety was significantly lower than that of parents of ICA^+ children (7). This is understandable because the risk of diabetes onset in ICA^+ children is considerably higher than the risk of diabetes in our highest risk group. It is estimated that 45% of ICA^+ individuals will go on to develop type 1 diabetes (15), a risk that is more than twice as high as the extremely high–risk category in this study. Findings from the current investigation offer further support for the impact of actual and perceived risk on maternal anxiety. Mothers of infants in the highest risk group and mothers who overestimated their infant's risk reported significantly greater initial anxiety and tended to remain more anxious across all three interviews.

Future studies need to assess whether the increased initial anxiety exhibited by Hispanic mothers is specific to at-risk notification or is a function of greater background anxiety and stress in this population. In a previous report (10), we noted that Hispanic mothers and mothers with a high school education or less were also less accurate when reporting their child's actual risk. In the current study, mothers with a high school education or less were not only less accurate about their child's actual diabetes risk but reported significantly greater initial anxiety, although this anxiety declined over time.

We also examined factors that were associated with the decrease in anxiety over time because there was considerable variability in the extent and rate of this decline. Mothers who reported higher initial levels of anxiety tended to remain more anxious at both the 4-month and 1-year interviews. At 4 months, mothers whose infants had a first-degree diabetic relative and those who overestimated their child's risk tended to remain more anxious. Mothers of infants with a first-degree diabetic relative are well aware of the serious nature of diabetes, which may increase their anxiety about their infant's increased risk for the disease. Certainly mothers who overestimate their child's actual risk are likely to worry more about the actual onset of diabetes in their child.

Mothers who were single reported greater anxiety at both the 4-month and 1-year interviews. Perhaps the social support offered by a spouse helps dissipate any anxiety associated with learning that one's infant is at risk for a serious disease. At 1 year, mothers of girls reported greater anxiety than mothers of boys. The actual difference in STAI scores was small, and the reliability of this finding remains to be seen. One might speculate that mothers of girls might harbor greater concern for their daughter's ability to marry and have children if she should develop diabetes.

Although 90% of children who develop type 1 diabetes have no family history of the disease (16), our sample predominantly consisted of infants with diabetic relatives; only 25% of the sample had no family history of diabetes. Consequently, caution should be exercised in applying findings reported here to families of at-risk children with no family members with the disease. We also found that mothers who remained in the study beyond the initial interview were more likely to be married, Caucasian, better educated, and have experience with diabetes in the infant's immediate family than mothers who dropped out after the initial interview. Although study completers and dropouts did not differ in initial anxiety scores, the greater loss of mothers from the follow-up interviews who were single, were less educated, were ethnic minorities, and with no immediate diabetic family members restricted the power of the study to detect effects related to these factors.

Nevertheless, our findings suggest that most mothers do not experience significant levels of anxiety in response to newborn genetic screening programs when children at risk for diabetes are identified. However, certain subgroups of women (i.e., those who are Hispanic, are poorly educated, have infants at extremely high risk, and who overestimate the child's risk) do experience considerable initial anxiety in response to newborn screening programs of this type. This anxiety appears to dissipate over time, attesting to maternal resiliency in the face of genetic information that a child is at risk for diabetes. Nevertheless, mothers differ in initial levels of maternal anxiety as well as the speed and extent to which their anxiety declines. Demographic factors, such as maternal ethnicity, education, and marital status, appear to be related to maternal understanding of diabetes risk (10) and anxiety in response to risk notification. Greater consideration of these factors may help us better support families who are asked to participate in longitudinal natural-history studies or diabetes prevention trials.

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References

1. Dorman JS, McCarthy BJ, O'Leary LA, Koehler AN: Risk factors for insulin-dependent diabetes. In *Diabetes in America*.

Harris MI, Bennett PH, Boyko EJ, Cowie CC, Dorman JS, Everhart JE, Herman WH, Martin DB, Palumbor PJ, Reiber GE, Stern MP, Eds. Bethesda, MD, National Institutes of Health, 1995, p. 165–173
2. Kupila A, Muona P, Simell T, Arvilommi P, Savolainen H, Hamalainen A, Korhonen S, Kimpimaki T, Sjoroos M, Honen J, Knip M, Simell O: Feasibility of genetic and immunological prediction of type 1 diabetes in a population-based birth cohort. *Diabetologia* 44:290–297, 2001
3. Ross LF: Minimizing risks: the ethics of predictive diabetes mellitus screening research in newborns. *Arch Pediatr Adolesc Med* 157:89–95, 2003
4. Roth R: Psychological and ethical aspects of prevention trials. *J Pediatr Endocrinol Metab* 14:669–674, 2001
5. Galatzer A, Green E, Ofan R, Benzaquen H, Yosefsberg Z, Weintrob N, Karp M, Vardi P: Psychological impact of islet cell antibody screening. *J Pediatr Endocrinol Metab* 14:675–679, 2001
6. Johnson SB, Riley W, Hansen C, Nurick M: The psychological impact of islet cell–antibody screening: preliminary results. *Diabetes Care* 13:93–97, 1990
7. Johnson SB, Tercyak KP: Psychological impact of islet cell antibody screening for IDDM on children, adults, and their family members. *Diabetes Care* 18:1370–1372, 1995
8. Johnson SB, Carmichael S: At-risk for diabetes: coping with the news. *J Clin Psychol Med Settings* 7:69–78, 2000
9. Yu MS, Norris JM, Mitchell CM, Butler-Simon N, Grosheck M, Follansbee D, Erlich H, Rewers M, Klingensmith G: Impact of maternal parenting stress of receipt of genetic information regarding risk of diabetes in newborn infants. *Am J Med Genet* 86:219–226, 1999
10. Carmichael SK, Johnson SB, Baughcum A, North K, Hopkins D, Dukes M, She JX, Schatz DA: Prospective Assessment in Newborns of Diabetes Autoimmunity (PANDA): maternal understanding of infant diabetes risk. *Genet Med* 5:1–7, 2003
11. Schatz D, Muir A, Fuller K, Atkinson M, Crockett S, Huang H, Winter W, Ellis T, Taylor K, Saites C, Dukes M, Fang Q, Clare-Salzer M, She J: Prospective Assessment in Newborns for Diabetes Autoimmunity (PANDA): a newborn screening program in the general population of Florida (Abstract). *Diabetes* 49 (Suppl. 1): A67, 2000
12. Spielberger C: *Manual for the State-Trait Anxiety Inventory STAI (Form Y)*. Palo Alto, CA, Consulting Psychologists Press, 1983
13. Tercyack K, Johnson SB, Roberts S, Cruz A: Psychological response to prenatal genetic counseling and amniocentesis. *Patient Educ Couns* 43:73–84, 2001
14. Marteau T, Bekker H: The development of a six-item short-form of the state scale of the Spielberger State-Trait Anxiety Inventory (STAI). *Br J Clin Psychol* 31:301–306, 1992
15. Schatz D, Krisher J, Horne G, Rilery W, Spillar R, Silverstein J, Winter W, Muir A, Derovanesian D, Shah S, Malone J, Maclaren N: Islet cell antibodies predict insulin-dependent diabetes in United States school age children as powerfully as unaffected relatives. *J Clin Invest* 93:2403–2407, 1994
16. Dahlquist G, Blom L, Holmgren G, Hogglof B, Larsson Y, Sterky G: The epidemiology of diabetes in Swedish children 0–14 years: a six year prospective study. *Diabetologia* 28:802–808, 1985