Maternal Efforts to Prevent Type 1 Diabetes in At-Risk Children

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OBJECTIVE — The aim of this study was to assess maternal diabetes prevention efforts aimed at children identified as at risk through newborn genetic screening.

RESEARCH DESIGN AND METHODS — A total of 192 mothers of children identified as at risk for type 1 diabetes through newborn genetic screening were administered a structured interview 3.6 ± 0.8 years after risk notification. The interview assessed possible diabetes prevention behaviors across six domains: health surveillance, diet, physical activity, illness prevention, medications, and stress reduction. A mother's cognitive (diabetes risk perception and perceived control), affective (anxiety), and coping responses to the child's at-risk status were assessed.

RESULTS — A total of 67% of mothers reported one or more diabetes prevention behaviors. Monitoring behaviors (e.g., watching for signs of diabetes and checking blood glucose) were the most common, reported in 59%, followed by modifications in the child's diet in 34% and physical activity in 14%. Potentially harmful prevention behaviors (e.g., limiting contact with other children, delaying immunizations, and giving medications including insulin) were rare. Mothers who engaged in diabetes prevention behaviors reported higher diabetes risk perception, greater anxiety, and more use of certain coping styles. Infants of these mothers were more likely to have a first-degree relative with diabetes.

CONCLUSIONS — In the absence of known methods of preventing type 1 diabetes, most mothers of at-risk children report diabetes prevention behaviors. Such behaviors must be more carefully assessed to ensure accurate interpretation of data obtained from natural history studies and prevention trials.

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Newborn genetic screening studies are under way in the U.S. and Europe to identify infants at risk for diabetes (1–4). Early identification may reduce the severity of onset and clinical course for children in whom the disease develops (1). However, the imprecise markers of disease risk (the disease does not develop in all at-risk children) and the absence of an effective prevention strategy complicate newborn screening programs. Natural history studies of the prediabetic period are needed to fully understand the disease process, which is believed to result from genetic-environmental-immune interactions.

Unfortunately, unanswered questions remain regarding the psychosocial impact of genetic screening studies in general (5), and additional concerns have been raised when children are the target of screening (6,7). Studies examining maternal anxiety after notification that a child is at increased risk for type 1 diabetes have documented elevated anxiety immediately after risk notification that decreases over time (8–12). These studies suggest that newborn screening does not have long-term detrimental effects on parental adjustment, as measured by maternal anxiety.

However, few studies have addressed behavior changes that may result from knowing one's child is genetically predisposed to a condition for which there is currently no effective prevention strategy. In the absence of definitive recommendations from the health care community, mothers of at-risk newborns may initiate their own actions to prevent type 1 diabetes in their children. This study assessed maternal reports of spontaneous efforts to prevent type 1 diabetes in at-risk children The study also attempted to identify the cognitive (diabetes risk perception and perceived control), affective (anxiety), coping (e.g., information seeking), and sociodemographic characteristics of mothers who engaged in diabetes prevention efforts. Based on the previous literature, we expected that mothers who reported diabetes prevention behaviors would score higher on measures of diabetes risk perception, perceived control over diabetes onset, maternal anxiety, information seeking, and active coping.

RESEARCH DESIGN AND METHODS

— Participants were recruited from the Prospective Assessment of Newborns for Diabetes Autoimmunity (PANDA) study, a program funded by the National Institutes of Health and Juvenile Diabetes Foundation that uses genetic testing to identify newborns at risk for type 1 diabetes (2). Permission was granted by mothers to screen their infants for high-risk HLA-DQB1 alleles using

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Abbreviations: PANDA, Prospective Assessment of Newborns for Diabetes Autoimmunity; WCC-R, Ways of Coping Checklist–Revised.

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

Table 1—*Sample characteristics*

n	192
Mothers	
Age at notification (years)	30.5 ± 5.4
Race	
White	162 (85)
African American	6 (3)
Hispanic	13 (6)
Asian/other	10 (5)
Education	
High school or less	45 (23)
Some college/trade school	62 (32)
College degree or beyond	85 (44)
Marital status (married)	164 (85)
Annual family income*	
$0–20,000	21 (11.9)
$20,000–40,000	44 (23.0)
$40,000–60,000	32 (16.7)
$60,000–80,000	28 (14.6)
$80,000–100,000	18 (9.4)
>$100,000	15 (7.8)
Number of children	2.1 ± 1.1
Children	
Infant risk classification	
Moderate (2% risk)	108 (56)
High (5–10% risk)	71 (37)
Extremely high (20–25% risk)	13 (7)
Age at notification (months)	7.9 ± 6.2
Age at time of current study (years)	4.3 ± 0.9
Sex (male)	97 (51)
Only child (yes)	62 (33)
Family history	
No family history	50 (26)
Second-degree relative	82 (43)
First-degree relative	37 (19)

Data are *n* (%) or means ± SD. *A total of 31 participants (16.1%) declined to report income.

blood spots on filter paper obtained by heel stick. Mothers were told they would be contacted only if the child was at increased risk for type 1 diabetes.

Infants tested were assigned to one of six risk categories (protected to extremely high risk) depending on the child's HLA-DQB1 allele status and family history of type 1 diabetes. Mothers of infants in the increased risk categories were provided this information by telephone using a standardized script. If they agreed (90% did so), mothers were contacted by telephone ~4 weeks, 4 months, and 12 months later to assess maternal affective (e.g., anxiety) and cognitive responses (e.g., diabetes risk perception) as well as efforts to cope with the news (12,13).

Mothers who completed the initial 4-week postnotification telephone interview and at least one of the subsequent (4- and 12-month) interviews were eligible for the current study. Of 368 eligible mothers, 204 (55%) were contacted by telephone. Of these, 192 (94%) agreed to be interviewed, 10 (5%) declined, and 2 (1%) were ineligible because the child had developed diabetes. The study was conducted 3.6 ± 0.8 years after mothers were initially notified of the child's increased risk of type 1 diabetes. The study was approved by the University of Florida's Institutional Review Board.

Sample characteristics are shown in Table 1. Most mothers were white, married, and well educated; 15 had type 1 diabetes. At-risk children were ~4 years of age at the time of the study; most were at moderate risk and had a relative with diabetes.

With the use of data from the initial 4-week telephone interview (obtained ~4 years previously), current study participants ($n = 192$) were compared with those who could not be contacted ($n = 164$) or those who declined the request for an additional interview ($n = 10$). Current study participants were more likely to be married ($P < 0.001$), older at the time of notification ($P < 0.01$), better educated ($P < 0.01$), and had a higher annual family income ($P < 0.001$). Participating versus nonparticipating mothers did not differ in ethnicity, and their children did not differ in genetic risk, sex, or family history of diabetes. However, children of participating mothers (62%) were more likely to have had their blood tested for autoantibodies as part of the PANDA follow-up study protocol than the children of nonparticipating mothers (49%) ($P < 0.05$).

Participants were contacted by telephone and asked if they would agree to participate in an additional interview. A structured interview was collected and detailed information was obtained on *1*) maternal efforts to prevent diabetes in the child, *2*) maternal diabetes risk perception, *3*) maternal perceived control over diabetes onset, *4*) maternal anxiety about the child's increased risk, and *5*) maternal information seeking specific to diabetes.

Outcome variable: maternal efforts to prevent type 1 diabetes

The structured interview assessed possible diabetes prevention behaviors across six domains: *1*) health surveillance, *2*) diet, *3*) physical activity, *4*) illness prevention, *5*) medications (i.e., medicines, vitamins, or supplements), and *6*) stress reduction. The interview began with a simple "yes/no" question assessing whether the mother made any attempts to prevent diabetes in the child. This question was followed by open-ended questions to solicit spontaneous recall about each of the six domains (e.g., Have you done anything different with your son's physical activity patterns to prevent him from developing diabetes?). If a mother answered "yes" to any of these open-ended questions, she was asked for details. Finally, mothers were read a list of possible behaviors derived from the literature (14–16) and asked if they recognized any behavior as something they used to prevent diabetes in their child (Table 2).

Predictor variables

Sociodemographics. Information collected included date of birth (mother and

Table 2—*Prevalence of mothers' reported efforts to prevent diabetes in the child by question format (open-ended recall or recognizing behaviors from a list)*

	Recall	Recognition
Health surveillance	30 (16)	114 (59)
Watched for signs	7 (4)	97 (51)
Tested child's blood glucose level at doctor's office		36 (19)
Tested child's blood glucose level at home	15 (8)	27 (14)
Attended more frequent pediatrician visits	1 (1)	3 (2)
Continued in blood draws for PANDA*	8 (4)	102 (53)
Tested for ketones†	*1 (1)*	
Child seen by specialist	*1 (1)*	
Diet	49 (26)	65 (34)
Fed child less sweet foods	37 (19)	38 (20)
Fed child less soda		30 (16)
Fed child less juice	3	23 (12)
Fed more diet and sugar-free drinks		12 (6)
Increased duration of breast feeding		8 (4)
Fed child more often		5 (3)
Delayed introduction of cow's milk	1 (1)	5 (3)
Tried to get child to lose weight	2 (1)	4 (2)
Fed child less to eat	1 (1)	3 (2)
Fed child more juice		2 (1)
Fed more to eat		1 (1)
Fed child less often		1 (1)
Tried to get child to gain weight		0 (0)
Changed timing of introduction to solid foods		0 (0)
Avoided cow's milk altogether		0 (0)
Decreased child's carbohydrate intake	5 (3)	
Fed child more water	*1 (1)*	
Fed child more protein	*1 (1)*	
Fed child more vegetables	*1 (1)*	
Physical activity	13 (7)	26 (14)
Child exercised more often	13 (7)	19 (10)
Encouraged child to be active every day	1 (1)	17 (9)
Encouraged child to rest more during exercise		3 (2)
Encouraged child to exercise less often		1 (1)
Illness prevention	8 (4)	18 (9)
Worked harder to protect child from germs	2 (1)	15 (8)
Limited child's exposure to other kids	1 (1)	8 (4)
Kept child out of daycare	1 (1)	5 (3)
Had child wash hands more often		2 (1)
Avoided child exposure to chemicals (i.e., pollution, food additives)		2 (1)
Delayed immunizations for child		2 (1)
Avoided child's exposure to smoke		1 (1)
Increased child's exposure to other children to boost immunity		0 (0)
Protected child from becoming cold	*1 (1)*	
Avoided child's exposure to known allergens	*2 (1)*	
Prevented ear infections in child	*1 (1)*	
Medications, vitamins, supplements	0 (0)	6 (3)
Administered vitamins to child		6 (3)
Administered diabetes medications to child		1 (1)
Administered insulin to child at home		1 (1)
Administered nicotinamide		0 (0)
Used herbal supplements		0 (0)
Stress reduction	1 (1)	5 (3)
Had child rest more often		3 (2)
Actively lowered child's stress level	1	2 (1)
Actively distracted child's focus during stressful situations		1 (1)
Avoided distressing situations for child		1 (1)
Other/miscellaneous	2 (1)	
Prayer	*2 (1)*	

Data are *n* (%). *Item not included in health surveillance score; †italicized items are those spontaneously reported and not provided on the behavioral recognition list.

child), maternal education, marital status, family income, ethnicity (mother and child), whether the child was an only child, and if not, the number of children in the household and the number of the child's first-, second-, and third-degree relatives with diabetes.

Diabetes risk perception. A composite score of diabetes risk perception was derived from three measures. First, mothers were asked to identify the child's level of diabetes risk from a list of risk categories. Responses were classified as "accurate" (scored 2), "overestimate" (scored 3), "underestimate" (scored 0), or "unknown" (scored 1) based on the mother's response and the child's actual risk (13). Second, mothers rated the child's level of risk compared with other children using a 5-point scale (1 = much lower to 5 = much higher) (15). Third, mothers described their beliefs about the child's likelihood of developing type 1 diabetes (child will develop type 1 diabetes: soon = 3; a long time from now = 2; unsure = 1; never = 0) (17). The three variables were transformed into *z*-scores (due to different scaling) and a mean *z*-score was calculated ($\alpha = 0.61$; sample mean $z = 0 \pm 0.74$).

Perceived control. Using a 5-point scale (1 = strongly disagree to 5 = strongly agree), two questions assessed maternal beliefs about whether type 1 diabetes can be prevented (15,18). The mean response served as a composite measure of perceived control ($\alpha = 0.66$, sample mean = 2.79 ± 0.99).

Anxiety. A composite maternal anxiety score was derived from two measures. First, mothers completed the 10-item short form of the state component of the State Trait Anxiety Inventory (STAI) (19) used in all previous interviews (12,14). Second, mothers used a 5-point scale (0 = never to 4 = very often) to describe how often they worried the child would develop type 1 diabetes (15). The two measures were transformed into *z*-scores (due to different scaling), and a mean *z*-score was calculated ($\alpha = 0.80$; sample mean $z = 0 \pm 0.91$).

Information seeking. Each mother was asked whether she had obtained diabetes-related information from a physician, family members/friends, the Internet, written diabetes materials, and diabetes-related television shows. The total number of information sources reported served as the information-seeking score

Table 3—*Final logistic regression model predicting maternal efforts to prevent diabetes in the child

Predictor variable	β	SE	Odds ratio	Wald statistic
First-degree relative†	2.96	1.15	19.34	6.66‡
Actual risk§	−0.65	0.44	0.52	2.16
Perceived risk composite	0.73	0.34	2.08	4.67¶
Anxiety composite	0.73	0.32	2.07	5.14¶
Information seeking	0.69	0.24	1.99	8.02‡
Wishful thinking	2.47	1.01	11.79	5.91¶

*Maternal efforts to prevent diabetes are coded as "At least one reported prevention behavior = 1" and "No reported prevention behaviors = 0"; †coded as "Yes = 1" and "No = 0"; ‡$P < 0.01$; §coded as "Extremely high risk = 1," "High risk = 1," and "Moderate risk = 0"; ¶$P < 0.05$.

(sample mean = 0.99 ± 1.04). Most mothers (60%) reported seeking information from at least one source. Of these, 55% received information from written materials, 40% talked to a physician, 27% talked to a family member/friend, 23% obtained information from television, and 19% obtained information from the Internet.

Coping. How mothers coped with the news of their child's at-risk status had been previously assessed at the 4-month and 1-year postnotification PANDA interviews using the Ways of Coping Checklist-Revised (WCC-R) (20). Data from the 4-month interview (or 1-year interview if the 4-month interview was unavailable) were used to derive five scale scores: problem-focused coping (α = 0.81; mean ± SD = 0.48 ± 0.24), seeking social support (0.73; 0.54 ± 0.31), wishful thinking (0.70; 0.25 ± 0.23), self-blame (0.53; 0.03 ± 0.13), and avoidance (0.36; 0.13 ± 0.11) (21).

Statistical analyses

Because of the non-normal distribution of maternal reports of diabetes prevention behaviors, the outcome measure was examined dichotomously, comparing mothers who reported engaging in at least one prevention behavior with mothers who reported none. Hierarchical logistic regressions were used to predict to the two groups.

Predictor variables were entered in successive blocks according to hypothesized relationships from prior literature. Time elapsed between maternal notification of the child's increased risk and the study interview was entered first. Maternal demographic variables were entered next: maternal education (1 = ≥some college, 0 = ≤high school); ethnicity (white: 1 = yes; 0 = no); marital status (1 = yes; 0 = no); number of children, and age at time of risk notification. The third block consisted of child demographic variables: sex (1 = male, 2 = female); only child status (1 = yes, 0 = no); age at the time of interview; family history of diabetes (first-degree diabetic relative, 1 = yes, 0 = no; second-degree or other relative, 1 = yes, 0 = no). Actual risk was entered next (0 = moderate, 1 = high, 2 = extremely high). Maternal cognitive (diabetes risk perception and perceived control), affective (anxiety), and coping variables (information seeking and WCC-R coping scales) were tested in separate models. A final predictive model was developed by including all significant predictors identified in previous models; only those remaining significant ($P < 0.05$) in the final model were retained.

RESULTS

Maternal efforts to prevent type 1 diabetes

When mothers were asked whether they had made any attempt to prevent type 1 diabetes, 36% answered yes. However, when mothers were read a list of possible diabetes prevention behaviors, 67% endorsed at least one (mean ± SD = 2.00 ± 2.53) (Table 2). Of these, 30% reported two to three behaviors, 24% reported four to six behaviors, and 8% reported more than six behaviors (2.98 ± 2.57). The most frequently endorsed prevention behavior was watching for signs of type 1 diabetes (51%). Testing the child's blood glucose, reducing consumption of sweets, and encouraging the child to exercise were also commonly reported. Behaviors that might indicate heightened maternal concern over illness (e.g., keeping the child out of daycare or limiting exposure to other children) or unwarranted use of medications, vitamins, or supplements were rarely endorsed.

Characteristics of mothers who reported efforts to prevent type 1 diabetes

Maternal sociodemographic characteristics failed to predict efforts to prevent type 1 diabetes. Family history was the only significant sociodemographic predictor; mothers whose children had a first-degree relative with diabetes were 19 times more likely to report prevention efforts than mothers of children without first-degree relatives with diabetes (Table 3).

Maternal cognitive, affective, and coping responses were all significant predictors. Controlling for the child's actual risk, mothers with higher diabetes risk perception were more likely to report prevention efforts. Mothers who were more anxious about the child's diabetes risk were also more likely to report diabetes prevention behaviors (Table 3). How mothers coped with the news of the child's increased risk, measured years before the current study data were collected, also predicted the mothers' diabetes prevention efforts. Mothers who used active coping strategies (problem-focused coping and seeking social support) at the time of risk notification were more likely to report efforts to prevent type 1 diabetes years later. Mothers with high information-seeking scores obtained during the current study were also more likely to report prevention behaviors.

Two findings were unexpected. First, perceived control over diabetes onset did not predict type 1 diabetes prevention efforts. Second, a passive coping strategy (wishful thinking) proved to be a strong predictor. When all of the significant WCC-R scales (problem-focused coping, seeking social support, and wishful thinking) were included in the same model, only wishful thinking remained significant (Table 3). The more active coping strategies (problem-focused coping and seeking social support) were related to information seeking ($r = 0.32$ and 0.28, respectively), explaining no additional variance. In contrast, wishful thinking seems to measure a very different coping strategy, explaining variance above and beyond that offered by maternal diabetes risk perception, anxiety, and information seeking.

CONCLUSIONS — Across all six behavior domains (health surveillance, diet, physical activity, illness prevention, medications, and stress reduction), asking mothers to recognize a possible prevention behavior yielded a greater rate of endorsement (67%) than asking mothers to spontaneously recall prevention behaviors (37%). This is consistent with the literature documenting greater ease of accessing events from memory presented by recognition compared with recall tasks.

The discrepancy between mothers' spontaneous recall (16%) and recognition (59%) of diabetes prevention behaviors was largest in the health surveillance domain. Mothers may have viewed these behaviors primarily as efforts to monitor onset of diabetes rather than true prevention behaviors. The other domains—diet, physical activity, illness prevention, medications, and stress reduction—may better reflect maternal efforts to prevent type 1 diabetes; many mothers (40%) reported these behaviors. Most common were changes in the child's diet and physical activity, with particular emphasis on reducing sweets and increasing exercise. Mothers may have been influenced by the considerable media attention on diet and exercise as a means of preventing type 2 diabetes (22) and may have attempted to apply this to the prevention of type 1 diabetes.

Reports of limiting the child's contact with other children, delaying immunizations, limiting exercise, or giving diabetes medications, including insulin, were rare. These results suggest that newborn genetic screening for type 1 diabetes risk does not lead to widespread maladaptive behaviors that might endanger the child.

Mothers whose child had a first-degree relative with diabetes were far more likely to report prevention behaviors. Most relatives had type 1 diabetes, and in nearly half of families, the relative was the mother herself. Mothers living with the disease and understanding its severity may be more inclined to take actions to prevent it in their offspring.

Mothers who perceived the child to be at greater risk were more likely to report prevention efforts. These findings are consistent with literature suggesting that increased perceived risk is associated with increased adoption of disease prevention behaviors (23,24). In our study, actual risk was not a significant predictor, suggesting that in predicting behavior, how mothers viewed the child's risk may be more important than the risk itself.

Consistent with previous reports (10,15), mothers who reported greater diabetes-specific worry and anxiety were more likely to report engaging in prevention behaviors. Studies with other populations have also documented a link between a person's affective response to a health threat and the person's adoption of health-protective behaviors (25).

How the mother coped with the news of her child's increased risk, assessed years before the current study's interview, was also predictive of prevention efforts. Mothers who previously reported using active coping strategies (problem-focused coping and seeking social support) and who reported seeking information about diabetes were more likely to report prevention efforts.

An unexpected finding was the strong association between the wishful thinking coping style and efforts to prevent diabetes. Wishful thinking, often considered a passive coping strategy, may also reflect an individual's sense of optimism. Optimistic mothers may have high scores on wishful thinking because they believe the child will not get the disease. At the same time, they may be willing to engage in diabetes prevention efforts because they are optimistic that their prevention efforts will be successful.

This study represents an important first step in understanding the impact of newborn genetic screening on parental care-taking behavior. Diabetes prevention behaviors are worthy of study in their own right but also have significant implications for natural history studies and prevention trials. Environmental triggers are presumed important to onset of diabetes in at-risk children. However, the critical environmental triggers have yet to be identified. Unless carefully monitored, such spontaneous prevention behaviors could threaten the validity of any natural history or prevention study.

Any study's findings must be viewed within the context of its limitations. Compared with PANDA mothers we were unable to reach, this study's mothers were better educated, were older, were more likely to be married, had higher income, and were more likely to have brought the baby in for at least one PANDA follow-up blood test. Compared with the general population, study mothers may have been more likely to engage in diabetes prevention behaviors. However, because these same mothers are also more likely to agree to participate in research, their spontaneous prevention efforts need close monitoring to ensure accurate interpretation of natural history and prevention study findings.

Future studies need to evaluate the validity of maternal type 1 diabetes prevention reports. For example, some mothers reported giving their children fewer sweets, but whether their children actually ate fewer sweets than children of mothers who reported no efforts in change sweet consumption remains to be seen. Similarly, mothers whose children had first-degree relatives with diabetes were more likely to report engaging in diabetes prevention behaviors. What is unknown is whether all mothers of children who have first-degree relatives with diabetes engage in similar behaviors or whether the process of at-risk identification through newborn genetic screening played an important role in triggering increased diabetes prevention efforts. Studies attempting to document true behavioral differences in parenting of at-risk children will require comparison groups and more sophisticated behavioral assessment strategies. However, the findings reported here suggest that the expense and time demands of such studies are clearly warranted.

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