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Parental Estimation of Their Child's Increased Type 1 Diabetes Risk During the First 2 Years of Participation in an International Observational Study: Results From the TEDDY study

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Abstract

This study assessed mothers' and fathers' perception of their child's risk of getting type 1 diabetes (T1D) during the first 2 years of their participation in The Environmental Determinants of Diabetes in the Young (TEDDY) study. TEDDY parents were informed of their child's increased genetic risk for T1D at study inception. Parent perception of the child's risk was assessed at 3, 6, 15, and 27 months of age. In families with no history of T1D, underestimation of the child's T1D risk was common in mothers (>38%) and more so in fathers (>50%). The analyses indicated that parental education, country of residence, family history of T1D, household crowding, ethnic minority status, and beliefs that the child's T1D risk can be reduced were factors associated with parental risk perception accuracy. Even when given extensive information about their child's T1D risk, parents often fail to accurately grasp the information provided. This is particularly true for fathers, families from low socioeconomic backgrounds, and those with no family history of T1D. It is important to develop improved tools for risk communication tailored to individual family needs.

Keywords

risk perception, screening, children, type 1 diabetes, informed consent

Type 1 diabetes (T1D) is one of the most common chronic diseases in childhood, and its incidence is rapidly increasing worldwide (D.I.A.M.O.N.D. Project Group, 2006; Patterson et al., 2009; SEARCH for Diabetes in Youth Study Group et al., 2006). T1D is a serious chronic disease that occurs following the autoimmune destruction of insulin-producing cells in the pancreas. Currently, T1D cannot be prevented or cured, but must be treated with daily administration of exogenous insulin throughout the life of the patient. If not well managed, T1D can lead to serious long-term complications such as eye, kidney, and nerve disease (American Diabetes Association, 2015a, 2015b). This is in contrast to type 2 diabetes, a much more common condition accounting for 90% to 95% of all diabetes cases, in which lifestyle factors, such as diet and physical activity, are known to contribute to the development of the disease. T1D is usually diagnosed in underweight or normal weight children, whereas type 2 diabetes (T2D) is typically diagnosed in individuals who are overweight. Individuals with T2D are often treated with lifestyle changes and oral medications, although some may also be prescribed insulin as their condition progresses (American Diabetes Association, 2015a, 2015b).

Past research has elucidated the Human leukocyte antigen (HLA) genotypes that predispose individuals to T1D. However, the concordance rate for monozygotic twin is only 30% to 50%, suggesting that environmental factors also play a role in the pathogenesis of T1D (Pociot et al., 2010). Therefore, it is hypothesized that a combination of an individual's genetic predisposition and environmental factors (e.g., viruses, microbiomal factors, stress, etc.) likely contributes to the development of T1D (Eringsmark & Lernmark, 2013). However, to identify the environmental factors that contribute to the development of T1D, large-scale screening studies follow infants at genetic risk for T1D for many years and collect relevant

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data through biologic samples and questionnaires (TEDDY Study Group, 2007).

However, there are a number of ethical and psychological issues surrounding newborn genetic screening for T1D (Ross, 2003; Roth, 2001; Stolt, Helgesson, Liss, Svensson, & Ludvigsson, 2005, Swartling & Helgesson, 2008). Testing children for T1D risk could increase distress in parents, which in turn could negatively affect the child. The published literature suggests that while parents (mostly mothers) often initially report distress when informed of their child's increased risk, this distress dissipates over time (Carmichael et al., 2003; Hummel, Ziegler, & Roth, 2004; Johnson, Baughcum, Carmichael, She, & Schatz, 2004; Johnson, Baughcum, et al., 2007; Johnson, Riley, Hansen, & Nurick, 1990; Johnson & Tercyak, 1995; Kerruish et al., 2007; Simonen et al., 2006). This literature also suggests that many parents engage in one or more behaviors in an effort to prevent the disease, the most common being increased monitoring behaviors and dietary changes (Baughcum et al., 2005; Hendrieckx, De Smer, Kristoffersen, & Bradley, 2002; Heshka, Palleschi, Howley, Wilson, & Wells, 2008; Smith et al., 2014).

Communicating risk information is often difficult as the child's increased risk does not guarantee the child will necessarily get the disease. Simply asking families whether they understand the information provided is insufficient; individuals often state they understand information, when in fact their understanding is inaccurate (Stolt et al.,). Studies suggest that individuals who are very familiar with T1D, because they live with someone who has it, understand the risk information better than individuals with no immediate family members living with the disease (Carmichael et al., 2003; Johnson & Tercyak, 1995).

Accurate understanding of risk information is important for informed participant decision making in research studies. Previous studies have shown that T1D risk perception accuracy is associated with increased anxiety or worry, efforts to prevent the disease, and study retention (Baughcum et al., 2005; Hendrieckx et al., 2002; Hood, Johnson, Baughcum, She, & Schatz, 2006; Lernmark et al., 2012; Smith et al., 2014), whereas underestimation of risk has been associated with study dropout (Johnson et al., 2011). However, our current understanding of parental risk perception accuracy is limited due to the fact that most studies have focused on relatively small samples of mothers familiar with T1D over a relatively short period of time.

The Environmental Determinants of Diabetes in the Young (TEDDY) study provides a unique opportunity to study factors associated with both mothers' and fathers' risk perception accuracy over time in a large multinational study of parents from the general population with no immediate family history of T1D as well as parents whose at-risk child has a first-degree relative with T1D. All TEDDY children are at increased genetic risk for T1D, and all TEDDY parents were informed of this increased risk at the time they joined TEDDY. We report here mothers' and fathers' risk perception accuracy during their first 2 years of TEDDY participation and factors associated with risk perception accuracy.

Method

The TEDDY Study

TEDDY is a prospective multinational cohort study supported by the National Institutes of Health investigating the environmental determinants of T1D in 8,676 genetically at-risk children identified at birth. Most TEDDY children (89%) come from the general population with no immediate family history of T1D; the remaining TEDDY children are families where the children have a first-degree relative with T1D. Three centers are located in the United States (Colorado, Florida/Georgia, Washington), and three centers are located in Europe (Finland, Germany, Sweden). TEDDY children are seen every 3 months for the first 4 years and biannually thereafter. Data collected at each study visit include biological samples (e.g., blood, nasal swabs), diet records, and a wide range of demographic and psychological measures (TEDDY Study Group, 2007). The relevant Institutional Review Board at each TEDDY site approved the TEDDY study and protocol.

Study Population

Parent questionnaire data available as of April 30, 2013, were obtained from 3- (mothers only), 6-, 15-, and 27-month study visits. On this date, all TEDDY participants were 36 months or older. Excluded from analysis were children whose last TEDDY visit was prior to 27 months of age (n = 2,090), children who were determined to be HLA ineligible (n = 39), and children who became antibody positive at or before the 27-month study visit (n = 447). Selected for analysis were the questionnaire responses of 5,953 families (5,769 mothers and 5,247 fathers) who completed at least one questionnaire at the 6- or 27-month study visits (excluding 118 families). Most were families from the general population (89%; n = 5,293), with the remaining 660 families (11%) having a known family history of T1D.

Risk Communication Protocol in TEDDY

After genetically screening the infant at birth, eligible families were contacted by phone (between 6 and 12 weeks after the test) and informed about their child's increased T1D genetic risk and eligibility for the TEDDY study. During the call, the parent was given a numerical estimate of the child's risk in a standardized manner; this information was subsequently reiterated in a letter sent to the parent's home.

The numerical risk given varied by country, based on country-specific epidemiological data, and whether the child belonged to the general population or had a close relative with T1D. For example, a mother from the general population in the United States and Germany was informed that out of 100 children with her child's genetic risk, approximately three children would develop T1D. In Sweden and Finland, where there is higher incidence of T1D, general population mothers were informed that out of 100 children with their child's genetic risk, approximately seven children would develop T1D. A mother of a U.S. or German child with a known family history of T1D was informed that out of 100 children with her child's genetic risk, 14 would develop T1D. The numerical estimate about the TEDDY child's risk for T1D was followed by comparing information about risk for T1D in children without their child's genetic risk: one out of 300 would develop T1D.

There were some national variances in risk communication: Sweden and Finland (but no other country) did not make any distinction between whether the child came from the general population or had a first-degree relative when informing the parents but instead gave the same numerical risk value (7/100). However, in Finland, the risk information was complemented with a brochure containing more detailed risk estimates.

Upon request, parents of children with a family history of T1D were given more detailed risk estimates based on whether the family member with T1D was a mother, father, or sibling. All families were told that the purpose of TEDDY was to identify the environmental trigger(s) of T1D in genetically at-risk children, and if environmental trigger(s) were identified, this information could be used in the future to develop methods of preventing the disease. If families asked whether there was anything they could do to prevent T1D in their child, they were told that no means of prevention are currently available, and that they should encourage the development of healthy habits in the child.

At each TEDDY visit, blood was drawn for T1D autoantibodies. At all sites, results were sent home by mail except for Sweden where test results were provided at the next study visit. Even when the child tested negative for T1D autoantibodies, the parents were told that the child's risk for T1D had not changed, and the child remained at increased risk for T1D (reiterating the risk estimates).

Measures

Risk perception accuracy. Risk perception accuracy was assessed by the following item at the 3- (mothers only), 6-, 15-, and 27-month study visits: Compared with other children, do you think of your child's risk for developing diabetes is (mark only one answer)—much lower, somewhat lower, about the same, somewhat higher, or much higher? Parents answering "much lower," "somewhat lower," or "about the same" were classified as inaccurate, whereas parents answering "somewhat higher" or "much higher" were classified as accurate.

Sociodemographic and maternal lifestyle measures. Child sociodemographic variables included the child's gender (male, female), only child status (yes/no), ethnic minority status (yes/no) (U.S. definition: TEDDY child's mother's first language is not English or she was not born in the United States or the child is a member of an ethnic minority group; European definition: TEDDY child's mother's first language or country of birth is other than the TEDDY country in which the child resides), and first degree relative (FDR) status (yes/no).

Parent sociodemographic variables included mother's age at birth (years), parent's education (basic primary education, some trade school or college, graduated college), marital status (married or living together, single parent), country of residence (the United States, Finland, Germany, and Sweden), and household crowding (number of persons living in the household divided by the number of rooms in the house). As the crowding distribution was skewed, it was rescored to normalize the distribution (1 = 0.00-0.49, 2 = 0.50-0.59, 3 = 0.60-0.75, 4 = 0.76-1.00, 5 ≥ 1.00).

Maternal lifestyle behaviors included whether the mother smoked during pregnancy (yes/no) or after having given birth (measured at 9 months; yes/no), whether the mother worked during pregnancy (yes/no) or after birth (measured at 9 months; yes/no), and whether the mother drank alcohol during pregnancy (yes/no).

Parental belief that T1D risk can be reduced. At the 6-, 15- and 27-month study visits, parents were asked whether they believed they could do something to reduce their child's risk for developing T1D. Parents were asked to agree or disagree to three statements on a 5-point Likert-type scale (1 = *strongly agree* to 5 = *strongly disagree*): (1) "I can do something to reduce my child's risk of developing diabetes," (2) "Medical professionals can do something to reduce my child's risk for developing diabetes," and (3) "It is up to chance or fate whether my child develops diabetes." Responses to Statements 1 and 2 were reversed scored and then summed with the response to Statement 3 so that higher scores indicated greater belief that risk of T1D could be reduced. This three-item scale score exhibited high internal consistency (Cronbach's α coefficient of .821 for mothers and .793 for fathers).

Statistical Analyses

The percentage of mothers and fathers with accurate risk perception at 3, 6, 15, and 27 months was calculated. McNemar's test was used to test for differences between mothers and fathers and also within parent across time.

Table 1. Mothers and Fathers Risk Perception Accuracy at 3 (Mothers Only) 6, 15, and 27 Months by GP/FDR Status.

				Inaccurate estimation of risk				Accurate estimate of risk		
		Age		Much lower	Somewhat lower	About the same	Inaccurate estimation	Somewhat higher	Much higher	Accurate estimation
Parent	FDR/GP	Study visit month	*n*	%	%	%	% (total)	%	%	% (total)
Mothers	GP	3	5,248	3.0	5.5	31.2	38.7	57.3	3.0	61.3
		6	5,130	3.0	5.5	31.2	39.7	57.3	3.0	60.3
		15	4,896	3.1	4.8	32.7	40.5	56.9	2.6	59.5
		27	4,852	2.5	4.6	32.8	40.0	57.1	3.0	60.0
	FDR	3	655	0.0	0.9	10.4	11.3	67.1	20.0	88.7
		6	639	0.5	0.6	11.7	12.8	67.1	20.0	87.2
		15	601	0.8	0.5	14.3	15.6	70.4	14.0	84.4
		27	549	0.5	0.5	12.8	13.8	71.8	14.4	86.2
Fathers	GP	6	4,659	4.4	7.0	41.9	53.2	44.2	2.6	46.8
		15	4,414	3.8	6.2	42.8	52.8	45.0	2.3	47.2
		27	4,134	3.3	6.2	42.3	51.8	46.2	2.0	48.2
	FDR	6	588	1.0	2.2	21.8	25.0	58.8	16.2	75.0
		15	553	1.3	2.4	23.9	27.5	59.7	12.8	72.5
		27	489	0.6	2.2	23.1	26.0	63.2	10.8	74.0

Note. FDR = TEDDY child has a first-degree relative with T1D. GP = TEDDY child has no first-degree relative with T1D. TEDDY = The Environmental Determinants of Diabetes in the Young; T1D = type 1 diabetes. GP; general population.FDR; first degree relative

Chi-square was used to test for differences between families from the general population and families with a history of T1D. Logistic regression was used to identify factors independently associated with having an accurate versus inaccurate risk perception. Separate regression models were fitted for mothers and fathers at 6 and 27 months using sociodemographic variables, maternal lifestyle behaviors, and parent belief that the child's T1D risk can be reduced. Factors with p values less than .05 were considered statistically significant and retained. Statistical analyses were conducted using SAS (Version 9.4).

Results

Table 1 provides the risk perception accuracy data for mothers and fathers by T1D family history status and across time by study visit. Most parents who underestimated their child's risk believed that their child's T1D risk was "about the same" as another child; few parents selected responses indicating that they believed their child's risk to be lower than a comparison child. At 6 months, the majority of general population mothers (61.3%) had accurate risk perceptions, whereas the majority of general population fathers (53.2%) had inaccurate risk perceptions ($\chi^2 = 241.9$, $p < .0001$). There was no significant change in risk perception accuracy for mothers or fathers from the general population across time. Mothers where the child had a family history of T1D were far more likely to have accurate risk perceptions (89% at 3 months and 86% at 27 months) than mothers from the general population (61% at 3 months and 60% at 27 months; $\chi^2 = 188.1$, $p < .0001$), and their risk perception accuracy did not change across time. Mothers where the child had a family history of T1D were also more likely to hold accurate risk perceptions compared with fathers with the same background ($\chi^2 = 37.3$, $p < .0001$). In addition, fathers where the child had a family history of T1D were more likely to have accurate risk perceptions than fathers from the general population ($\chi^2 = 166.4$, $p < .0001$). The majority of both mothers and fathers where the child had a family history of T1D held accurate risk perceptions.

Separate multiple logistic regressions were fitted for mothers and fathers to identify the independent factors associated with accurate risk perception at 6 and 27 months. Table 2 provides the significant results for mothers. The results were essentially the same at 6 and 27 months. As expected, mothers where the child had a family history of T1D were more likely to hold accurate risk perceptions than general population mothers (87% vs. 60%). College-educated mothers were more likely to hold accurate risk perceptions compared with those with a primary school education (71% vs. 44%). Mothers from Finland (72%) and Germany (75%-77%) were also significantly more likely to hold accurate risk perceptions compared with mothers from the United States (61%-63%) and Sweden (55%-56%). Child ethnic minority status and household crowding were associated with poorer risk perception accuracy. Approximately 50% of mothers of ethnic minority children were accurate compared with 65% of mothers of nonminority children. Approximately 60% of

Table 2. Logistic Regression Results for Mothers' Risk Perception Accuracy at 6- and 27-Month Study Visits.

	6 months (n = 5,577)				27 months (n = 5,034)			
Factor	n (% accurate)	OR	95% CI	p value	n (% accurate)	OR	95% CI	p value
First-degree relative with T1D								
No	4,968 (60.1)	1.00	Ref.		4,509 (59.9)	1.00	Ref.	
Yes	609 (86.7)	4.17	[3.25, 5.37]	<.001	525 (86.5)	4.14	[3.17, 5.41]	<.001
Country of residence								
The United States	2,114 (62.9)	1.09	[0.94, 1.26]		1,957 (61.3)	0.91	[0.83, 1.14]	
Finland	1,258 (72.2)	1.75	[1.48, 2.07]		1,093 (72.1)	1.64	[1.38, 1.9]	
Germany	358 (74.6)	1.58	[1.19, 2.09]		272 (76.5)	1.69	[1.21, 2.31]	
Sweden	1,847 (54.7)	1.00	Ref.	<.001	1,712 (55.9)	1.00	Ref.	<.001
Child ethnic minority								
No	4,820 (64.9)	1.00	Ref.		4,363 (64.6)	1.00	Ref.	
Yes	757 (51.0)	0.70	[0.59, 0.83]	<.001	671 (49.9)	0.70	[0.58, 0.84]	<.001
Mothers' education								
Primary education	1,033 (44.5)	1.00	Ref.		919 (44.1)	1.00	Ref.	
Some college/trade school	1,338 (59.3)	1.47	[1.24, 1.76]		1,159 (57.1)	1.43	[1.17, 1.71]	
Finished college	3,206 (70.5)	2.52	[2.15, 2.94]	<.001	2,956 (70.6)	2.71	[2.30, 3.20]	<.001
Only child								
No	3,218 (63.5)	1.00	Ref.		2,876 (63.1)	1.00	Ref.	
Yes	2,359 (62.4)	0.87	[0.84, 0.94]	.02	2,158 (62.0)	0.87	[0.76, 0.98]	.03
Household crowding		0.89	[0.84, 0.94]	<.001		0.94	[0.91, 0.97]	<.001
Belief that T1D risk can be reduced		0.93	[0.91, 0.96]	<.001		0.92	[0.87, 0.98]	.01

Note. OR = odds ratio; CI = confidence interval; T1D = type 1 diabetes.

mothers from the most crowded household were accurate compared with 67% of those from the least crowded household. Only child status had a weak but significant effect and was associated with poorer risk perception accuracy. Strong beliefs that the child's T1D risk could be reduced were actually associated with poorer risk perception accuracy. For example, at 3 months, only 58% of mothers with scores in the highest quartile on this measure were accurate compared with 73% of those with scores in the lowest quartile. We found no significant associations between child gender, maternal age, marital status, or maternal lifestyle factors and risk perception accuracy.

Table 3 provides the results of the logistic regression for fathers at 6 and 27 months. In most respects, the results mimic the findings for mothers. The most important factors associated with risk perception accuracy for fathers were T1D family history status, country, and fathers' education ($p < .0001$). Greater household crowding was also associated with poorer risk perception accuracy ($p < .01$ at 6 months and $p < .0001$ at 27 months), and like mothers, fathers who held strong beliefs that their child's T1D risk could be reduced were more likely to hold inaccurate risk perceptions ($p < .0001$ at 27 months). The child's ethnic minority status and only child status were not significant predictors for fathers, in contrast to their significant effects for mothers. These findings were consistent across time.

Discussion

To our knowledge, this is the largest study to date of risk perception accuracy in parents of infants genetically at risk for a serious disease (T1D). The study is unique in that it assessed risk perception accuracy: (a) of both mothers and fathers, (b) of parents from the general population as well as those with T1D immediate family members, (c) of parents living in four different countries, and (d) at multiple time points over a 2-year period.

In TEDDY, parents are fully informed of their child's increased genetic risk for T1D at study inception. Furthermore, children are regularly tested for T1D autoantibodies, and parents are informed of these test results. In cases of negative antibody test results, parents are told that the child's risk for T1D has not changed, and the child remains at increased risk for T1D. Despite these extensive and repeated efforts to inform parents of their child's increased risk, a large proportion of both mothers and fathers, particularly from the general population, underestimated their child's risk. Only 60% of mothers from the general population and less than half of general population fathers had accurate perceptions of their child's risk. In contrast, parents where the child had a family history of T1D had significantly more accurate risk perceptions. More than 80% of the mothers and more than 70% of the fathers had accurate risk perceptions. The high-risk perception accuracy rates found in mothers with a T1D immediate family

Table 3. Logistic Regression Results for Fathers' Risk Perception Accuracy at 6- and 27-Month Study Visits.

Study visit	6 months (n = 5,016)				27 months (n = 4,454)			
Factors	n (% accurate)	OR	95% CI	p value	n (% accurate)	OR	95% CI	p value
First-degree relative with T1D								
No	4,460 (47.0)	1.00	Ref.		3,984 (48.3)	1.00	Ref.	
Yes	556 (75.9)	3.28	[2.65, 4.05]	<.001	470 (73.8)	2.90	[2.31, 3.64]	<.001
Country residence								
The United States	1,827 (46.4)	0.65	[0.56, 0.76]		1,610 (46.5)	0.59	[0.50, .69]	
Finland	1,130 (53.5)	0.94	[0.80, 1.12]		1,003 (56.6)	1.01	[0.85, 1.21]	
Germany	342 (68.1)	1.37	[1.05, 1.80]		255 (65.9)	1.20	[0.89, 1.64]	
Sweden	1,717 (48.4)	1.00	Ref.	<.001	1,586 (49.6)	1.00	Ref.	<.001
Child ethnic minority								
No	4,390 (51.3)	1.00	Ref.		3,923 (52.3)	1.00	Ref.	
Yes	626 (42.5)	0.91	[0.76, 1.10]	.33	531 (41.6)	0.90	[0.73, 1.10]	.23
Father education								
Primary education	1,232 (35.4)	1.00	Ref.		1,061 (35.1)	1.00	Ref.	
Some college/trade school	1,272 (48.6)	1.65	1.38, 1.96]		1,121 (47.4)	1.61	[1.34, 1.95]	
Finished college	2,512 (58.2)	2.63	[2.25, 3.07]	<.001	2,272 (60.2)	2.94	[2.49, 3.47]	<.001
Household crowding		0.93	[0.88, 0.98]	<.01		0.90	[0.85, 0.96]	.001
Belief that T1D risk can be reduced		0.97	[0.95, 1.00]	.05		0.95	[0.92, 0.97]	<.001

Note. OR = odds ratio; CI = confidence interval; T1D = type 1 diabetes.

member are consistent with prior reports (Carmichael et al., 2003; Hood et al., 2006). These results are expected because parents from the general population do not have the experience and knowledge about T1D as well as its heritability so familiar to families living with an immediate family member with the disease.

Fathers, regardless of T1D family history, were consistently less accurate than mothers. TEDDY fathers did accompany the child to the study visits less often than mothers (e.g., 29% of TEDDY fathers came to the 6-month TEDDY visit compared with 98% of TEDDY mothers). However, TEDDY father attendance at TEDDY clinic visits was unrelated to risk perception accuracy; fathers who attended TEDDY clinic visits did not have more accurate risk perceptions than fathers who failed to attend. There is ample evidence that mothers are the primary caretakers of most children and make most of the health care decisions for their families (Matoff-Stepp, Applebaum, Pooler, & Kavanagh, 2014). Consequently, mothers may be more attentive to health-related information relevant to their children.

In TEDDY, we found risk perception accuracy to be highly stable across time, with no decline in risk perception over time previously reported by Carmichael and colleagues (2003) and Hood and colleagues (2006). When the TEDDY protocol was established, the investigators were well aware that risk perception accuracy could decline across time and in response established a protocol of repeated communication with parents about their child's risk, including sending letters home, and reiterating information provided on phone calls or at study visits. In this context, it is interesting to note that Sweden was the only TEDDY country that did not regularly send home risk information (giving the results orally at the next visit), and Swedish parents demonstrated the lowest percentages of parents with accurate risk perceptions among TEDDY countries.

In this study, we also found that ethnic minority status, whether one lived in more crowded households, and had less parental education were all factors associated with higher rates of inaccurate risk perception, confirming results published in earlier studies (Carmichael et al., 2003; Hood et al., 2006). These results once again confirm that risk information is difficult to successfully communicate. The results also suggest that risk communication protocols and effective strategies need to be developed for those who are less educated and from lower sociodemographic backgrounds.

The analyses showed that parental belief that a child's T1D risk could be reduced was associated with having a less accurate risk perception. While being accurate in risk perception accuracy and having a belief that risk can be changed are two different things—It may be that people who believe they can reduce risk may underestimate the child's risk more. Perhaps parents who believe the risk can be reduced view the risk information as less stable and more modifiable, taking the information less seriously and giving it less credence. Previous studies suggest that belief that one can control T1D onset may be linked to increased efforts to prevent the disease, even though no means of preventing T1D currently exist (Hendrieckx et al., 2002; Smith et al., 2014).

This study is limited by the inclusion of families who agreed to join the TEDDY study, with its demanding and intensive protocol. Consequently, our findings may not represent risk perception accuracy among families who declined study participation. Nevertheless, our findings suggest that risk information is challenging to present in ways that parents understand. This is particularly the case when parents are not well educated, come from lower sociodemographic backgrounds, and have no immediate family experience with T1D.

This study's results have important implications beyond the care of children with a genetic risk for T1D. Risk communication is a common component of many patient–provider, as well as investigator–participant, communications, and this study's findings highlight the difficulty of successfully communicating risk. Development of improved strategies for risk communication tailored to individual and family needs is warranted.

Best Practices

A large proportion of parents from the general population underestimate their child's increased genetic risk for T1D over an extended period of time (2 years), and fathers underestimate risk more often than mothers. Findings suggest the importance of viewing risk communication as a process, involving both study staff and the participating families. Not having an accurate risk perception may influence informed decision making, so researchers should take notice of situations where parents have formed and continue to have an incorrect understanding of risk. This is particularly important when families have no prior experience with the disease, are members of minority groups, have less education, or have a lower socioeconomic status.

These findings suggest the importance of developing tailored risk communication protocols and effective strategies designed for those who are less educated and from lower sociodemographic backgrounds.

Research Agenda

Different methods of communicating risk (oral, written, and visual) are important tools when informing parents of their child's risk status. These different methods should be used to tailor risk communication strategies for specific populations and test their effectiveness.

Educational Implications

These results are valuable for the staff involved in the TEDDY study and risk communication in general. Tailored information can be designed to help parents develop a correct understanding of their child's risk status and assist those families who hold inaccurate risk perceptions.

Appendix

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[1]Ancillary Studies, [2]Diet, [3]Genetics, [4]Human Subjects/ Publicity/Publications, [5]Immune Markers, [6]Infectious Agents, [7]Laboratory Implementation, [8]Maternal Studies, [9]Psychosocial, [10]Quality Assurance, [11]Steering, [12]Study Coordinators, [13]Celiac Disease, [14]Clinical Implementation, [15]Quality Assurance Subcommittee on Data Quality.

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