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## Original Article

# Parent responses to participation in genetic screening for diabetes risk

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Abstract: Screening for type 1 diabetes (T1DM) risk in newborns has little negative emotional impact on mothers. In this study, the impact on the mother and the father was evaluated both in the general population and in families with diabetes. All parents with a newborn in Skåne, Sweden, were invited to a screening for T1DM risk in their children (the Diabetes Prediction in Skåne (DiPiS)). Blood was obtained at delivery from the mother and the child. When the child was 2 months old, parents gave written consent and filled out questionnaires, but were not informed about the genetic risk. Of the 10 538 invited families, 6831 (64.8%) consented and 806 (7.7%) declined participation. Five questions addressing both parents were filled out by 6676 (63.4%) mothers and 6099 (57.8%) fathers. In 146/6676 (2.2%) families, one family member had diabetes (D-families). Participation in DiPiS did not affect most parents and the majority was satisfied with the information. The majority of parents (28.9%) were reassured and only 1.1% (140/12 670) reported increased worries because of participation, compared to 2.8% of the mothers in D-families. Parents in D-families more often ascribed diabetes risk to their child as well as the risk being higher. Mothers and fathers differed in their answers on four of the five study questions, with mothers being more satisfied with the information, reporting more knowledge of diabetes, estimating lower risk of their child to get diabetes, but reporting more worries of possible future chronic disease in the child. Parents with lower education, being born abroad, or being younger who reported worries of chronic disease in the child were also reassured by participation in the study. These results confirm that screening for T1DM risk in newborns does not create worries in most parents, but stress that fathers differ from mothers in opinions and reactions, that parents' reactions are affected by diabetes in the family, and that demographic factors might be important for the parents' reports.

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Type 1 diabetes mellitus (T1DM) is associated with the histocompatibility complex (HLA) and the presence of antibodies against autoantigens of insulin-producing cells. HLA has a well-defined risk of T1DM detectable in both case-control and linkage analysis of affected sibpairs (1, 2). The risk in the general population for a newborn to develop T1DM before 18 yr of age varies from country to country, ranging between 1/200 and 1/500. In first-degree relatives, the risk of the disease is increased by a factor of VIII (3). Refined methods of HLA typing combined with prospective autoantibody analyses have improved the prediction of T1DM (4). While patients with T1DM or parents of diabetic children might have a clear interest in screening their offspring for diabetes, only 15% of children with new onset of T1DM have a first-degree relative with the disease (5). Even though T1DM is one of the most common chronic illnesses in children, in most parts of the world, the prevalence of the disease in children is not more than 0.15–0.2% (6). It has, therefore, been questioned whether it is ethical to screen children in the general population (7). Objections to

screening for high-risk HLA include its low predictive value and the lack of treatment or intervention that can prevent or delay the disease (7, 8).

Informing parents about a child's increased risk of developing T1DM might trigger psychological reactions of worries and anxiety, with possible serious consequences for the life of the family. Most studies on psychological reactions to an increased T1DM risk have been performed with first-degree relatives of patients with diabetes (9–12). Information about the presence of antibodies in a close relative showed an immediate but transient increase in anxiety (12–14). By contrast, a population-based screening study of newborns showed no difference in anxiety between parents who were informed that their child was at an increased risk and parents who were told that the child had a lower risk of developing diabetes (15, 16). More mothers than fathers expressed worry about diabetes risk. High anxiety in the parents was more strongly related to life events than to the information of possible risk of diabetes (16).

Two population-based screening studies for T1DM in newborns showed that 1.5% of the mothers expressed an increased anxiety (17–19). These mothers were more likely to be in an unstable social situation. Increased anxiety was reported by 2.5% of mothers with diabetes in the family (19). On the other hand, more than half of the mothers felt calmer/more reassured because of their participation, whereas the remaining mothers were not affected at all (18).

To date, emotional reactions to screening for T1DM in newborns has focused primarily on mothers, even though fathers' reactions to such projects are important to investigate. Screening studies are prospective investigations with possible recurring sampling of blood from the children and will require major efforts from parents to remain in the study. Having a positive attitude regarding the study and minimizing anxiety in each parent may be important to enrolling and crucial to retention. This effort might be facilitated by actively involving both parents. In addition, a less worried parent could support a more worried spouse. As most studies have investigated parental reactions in families with existing diabetes, the aim of the present study was to find out whether mothers and fathers with or without diabetes in the family react in the same way.

## Materials and methods

The Diabetes Prediction in Skåne (DiPiS) project is a prospective, longitudinal study for the prediction of T1DM in all newborns in the southern part of Sweden (Skåne) (20). Based on data from the Swedish Bureau of Statistics and the National Diabetes Registry in Sweden, more than 12 000 infants are born every year in Skåne, of which 80–100 children are expected to develop T1DM before 18 yr of age. The overall hypothesis is that events during pregnancy, life stress, or both, or events in the child might trigger the development of autoantibodies and contribute to T1DM in children with an increased genetic risk of the disease. The study was approved by the Ethics Committee at Lund University, Lund, Sweden.

All expecting parents are informed at the Maternity Health Care Clinics (MVC) by means of video, posters, and brochures about DiPiS. They are also encouraged to visit DiPiS' home page (www.dipis.info) for more information about diabetes and the project. There are five maternity clinics where mothers can deliver their babies. Usually parents choose the clinic geographically closest to them. At delivery and after oral consent from the mother, a blood sample is taken from her and blood is also collected from the child's umbilical cord. The child's HLA is determined by using dried blood spots (21). On acceptance of the dried blood spots, information is given about the child's sex, if it is a twin, and if the mother has diabetes, together with the mother's name and Swedish 'personal number'.

When the child is 2 months old and has been entered into the population registry, the parents are invited by letter to participate with their child in the DiPiS project. If the parents agree to do so, they give their written consent and fill out two questionnaires. In the psychosocial questionnaire, the mother is asked about her pregnancy, delivery, and the child's first months of life. In addition, the questionnaire also contains five identical questions to be answered by both mother and father. Three of the questions were constructed for the study (questions 1–3), and two (questions 4–5) were obtained from a questionnaire used earlier. The possibility to include these types of questions was limited; therefore, the scope of the questions was rather narrow, but was felt to meet our goal of obtaining both parents' views on issues that could be relevant to respective parents' participation in the study. The questions addressed each parent's satisfaction with the information and parental knowledge about diabetes before enrollment, as well as concerns about the child's risk of diabetes. We assumed that responses to these questions might influence the parents' report both on more general worries about the disease in the child and on more specific worries about participating in a screening study. The parents also reported their own educational background and whether or not they were born in Sweden (for the complete questions, see Tables 1 and 2).

In the hereditary questionnaire, the parents reported on diabetes in the family. They also gave their written consent to participate in DiPiS. If the questionnaires were not returned after a month, a reminder was mailed. Even if parents did not want to participate in the study, they were requested to

Table 1. Characteristics of the entire study group, including participants (completed the psychosocial questionnaire) and non-participants

| | Study group | Participants [n (%)] | Non-participants [n (%)] | Participants vs. non-participants [OR (95% CI)*] | p-value |
|---|---|---|---|---|---|
| Children | 10 696 | 6765 (100) | 3931 (100) | | |
| Premature: gestational age of <37 weeks | 580 | 347 (5.1) | 233 (5.9) | 0.79 (0.67–0.94) | 0.007 |
| Boys | 5415 | 3536 (52.3) | 1879 (47.8) | 1.06 (0.98–1.15) | Non-significant |
| Families | 10 538 | 6676 (100) | 3862 (100) | | |
| First born | Not known | 3288 | Not known | Not applicable | Not applicable |
| Twin pairs | 154 | 85 (1.3) | 69 (1.8) | 0.73 (0.53–1.00) | 0.049 |
| Triplets | 2 | 2 | 0 | | |
| Diabetes in the family | Not known | 146 (2.2) | Not known | Not applicable | Not applicable |
| Single mothers | Not known | 181 (2.7) | Not known | Not applicable | Not applicable |
| Child born in smaller city | 2543 | 1762 (26.4) | 781 (20.2) | 1.41 (1.29–1.56) | <0.001 |
| Mothers | 10 538 | 6676 (100) | 3862 (100) | | |
| Mothers' age: mean (SD) | 30.2 (5.0) | 30.5 (4.6) | 29.7 (5.5) | | <0.001 |
| Mothers' education:† | Not known | | Not known | Not applicable | Not applicable |
| Primary school | | 389 (5.8) | | | |
| High school | | 3466 (51.9) | | | |
| University | | 2777 (41.6) | | | |
| Mother born abroad | Not known | 673 (10.1) | Not known | Not applicable | Not applicable |
| Diabetes (T1DM, T2DM) | 62 | 46 (0.7) | 16 (0.4) | 1.67 (0.95–2.91) | Non-significant |
| Gestational diabetes | 213 | 144 (2.2) | 69 (1.8) | 1.21 (0.90–1.61) | Non-significant |
| Fathers | 10 538 | 6099 (91.4) | 4439 | | |
| Fathers' age: mean (SD) | Not known | 33.0 (5.7) | Not known | Not applicable | Not applicable |
| Fathers' education:† | Not known | | Not known | Not applicable | Not applicable |
| Primary school | | 662 (9.9) | | | |
| High school | | 3686 (55.2) | | | |
| University | | 2262 (33.9) | | | |
| Father born abroad | Not known | 755 (11.3) | Not known | Not applicable | Not applicable |

*Below 1.0 less likely to participate; above 1.0 more likely to participate.
†Mothers have higher education than fathers ($p < 0.001$).

check for non-participation, sign, and return the questionnaire.

Parents who agreed to participate in the study at the 2-month invitation are contacted again when the child is 2 yr of age, provided that their child has any genetic risk of developing TIDM. At 2 yr, a blood sample is taken from the child and parents fill out another questionnaire. The child and the parents are then followed annually in the same manner, as at 2 yr. Contrary to other studies, the parents, in our study, are not informed about their child's possible risk of T1DM until the 3-yr follow-up. The Ethics Committee decided to use this approach of not informing the parents. However, parents who contacted us about their child's results were given the requested information. So far, few parents have done so. The present report covers our first year of study from September 2000 until December 2001 and includes the four start-up months, when blood samples were not yet obtained from all five maternity clinics. The aim of the study was to describe parent responses to genetic screening for diabetes risk in a population-based study in south Sweden. The secondary aim was to examine the differences between responses of the mother and the father to participation.

## Statistical methods

$\chi^2$-tests tested for associations between two categorical variables. Logistic regression examined whether clinical measurements obtained at birth were predictors of participation in the psychosocial questionnaire. Continuous variables were expressed as mean ± SD and two-sample *t*-tests tested for differences between independent groups. For a comparison between the mothers' and fathers' answers, differences in the scores were summarized as mean (95% CI), and the paired *t*-test tested for significance. The relationship between parent worries (dependent variable) and potential predictors of worries (independent variables) was analyzed by using multiple linear regression analysis.

Statistical analysis was performed by using S-PLUS 6.1 software (Insightful Corp., Seattle, WA, USA) and p-values of less than 0.05 were regarded as statistically significant.

## Results

During the study period (September 2000 until December 2001), there were approximately 14 100 deliveries with blood obtained from 10 856 (77%) newborns and their mothers, including 154 pairs of twins (2.8%) and

Table 2. Number of answers from mothers and fathers to the study questions in D-families and ND-families with the distribution of scores

| Questions and answer options (scores within parenthesis) | ND-families | | | D-families | | | p-value* |
|---|---|---|---|---|---|---|---|
| | Mothers | Fathers | All | Mothers | Fathers | All | |
| 1. How do you see the information you have been given about DiPiS? | 6388 | 5799 | 12187 | 145 | 131 | 279 | |
| | % | % | % | % | % | % | |
| Very satisfying (1) | 18.8 | 9.0 | 14.2 | 24.1 | 11.5 | 18.1 | |
| Satisfying (2) | 74.7 | 78.4 | 76.4 | 66.9 | 74.8 | 70.7 | 0.03 |
| Unsatisfying (3) | 5.7 | 8.5 | 7.5 | 8.3 | 13.0 | 10.5 | |
| Very unsatisfying (4) | 0.8 | 3.0 | 1.9 | 0.7 | 0.8 | 0.7 | |
| Mean score (S.D) | 1.89 (0.51) | 2.07 (0.55) | 1.97 (0.54) | 1.86 (0.58) | 2.03 (0.53) | 1.94 (0.56) | |
| 2. Did you know about diabetes before joining DiPiS? | 6499 | 5948 | 12447 | 146 | 133 | 279 | |
| | % | % | % | % | % | % | |
| No, not at all (1) | 5.3 | 9.0 | 7.1 | 2.1 | 1.5 | 1.8 | |
| Yes, a bit (2) | 59.3 | 68.7 | 63.8 | 11.6 | 11.4 | 11.5 | $<0.001$ |
| Yes, a lot (3) | 35.4 | 22.3 | 29.1 | 86.3 | 87.1 | 86.7 | |
| Mean score (SD) | 2.30 (0.56) | 2.13 (0.54) | 2.22 (0.56) | 2.84 (0.42) | 2.86 (0.39) | 2.85 (0.41) | |
| 3. Do you think that there is a risk of your newborn child to get diabetes in the future? | 6501 | 5937 | 12438 | 146 | 133 | 279 | |
| | % | % | % | % | % | % | |
| No, no risk (1) | 29.5 | 25.7 | 27.7 | 5.5 | 9.0 | 7.2 | |
| Don't know (2) | 37.1 | 33.1 | 35.2 | 12.3 | 15.8 | 14.0 | $<0.001$ |
| Yes, a small risk (3) | 32.4 | 40.1 | 36.1 | 65.8 | 60.9 | 63.4 | |
| Yes, a great risk (4) | 1.0 | 1.1 | 1.0 | 16.4 | 14.3 | 15.4 | |
| Mean score (SD) | 2.05 (0.81) | 2.16 (0.82) | 2.10 (0.82) | 2.93 (0.71) | 2.80 (0.79) | 2.87 (0.75) | |
| 4. How do you feel about the possibility that your child in the future might get a chronic or serious disease? | 6489 | 5912 | 12401 | 145 | 132 | 277 | |
| | % | % | % | % | % | % | |
| Very calm or calm (1 or 2) | 28.9 | 34.9 | 31.7 | 18.6 | 38.6 | 28.2 | |
| Neither calm nor worried (3) | 41.6 | 41.8 | 41.7 | 39.4 | 35.7 | 37.5 | 0.012 |
| Worried or very worried (4 or 5) | 29.5 | 23.3 | 26.6 | 42.0 | 25.7 | 34.3 | |
| Mean score (SD) | 3.02 (1.04) | 2.82 (1.08) | 2.92 (1.07) | 3.37 (1.05) | 2.83 (1.07) | 3.12 (1.09) | |
| 5. How do you feel now when you know that your child is part of DiPiS? | 6466 | 5920 | 12386 | 144 | 133 | 277 | |
| | % | % | % | % | % | % | |
| More reassured or reassured (1 or 2) | 28.8 | 29.2 | 28.9 | 31.2 | 32.3 | 31.8 | |
| Neither reassured or worried (3) | 70.2 | 69.6 | 70.0 | 66.0 | 66.9 | 66.4 | not significant |
| Worried or much more worried (4 or 5) | 1.0 | 1.2 | 1.1 | 2.8 | 0.8 | 1.8 | |
| Mean score (SD) | 2.64 (0.66) | 2.64 (0.67) | 2.64 (0.66) | 2.64 (0.67) | 2.53 (0.78) | 2.59 (0.72) | |

*Test between ND-families and D-families.
DiPiS, Diabetes Prediction in Skåne.

two triplets. After four start-up months, mother/child samples were received from about 85% of all deliveries. A total of 162 (1.5%) children/families were excluded, because they had moved out of the area, the child was deceased, or could not be traced in the population registry. Consequently, 10 538 families were invited to participate. The frequency of parents responding was 72.5% (7637), of which 7.7% (806) declined to participate. A total of 64.8% (6831) of the families gave written consent to participation, but 155 of the psychosocial questionnaires were missing. Therefore, in this study, there are 6676 participating families (Table 1).

There was no difference between participating and non-participating families regarding the child's sex (Table 1). A smaller proportion of families with premature children (born before gestational week 37), compared to full-term ($p = 0.007$), and fewer families with twins ($p = 0.049$) were enrolled in the study. The mean age of participating mothers was significantly higher than that of non-participating mothers. A greater proportion of both younger (<25 yr) ($p > 0.001$) and older mothers (>40 yr) ($p < 0.001$) compared to mothers between 25 and 40 yr were non-participants (data not shown). Mothers who delivered in hospitals in smaller cities (Kristianstad and Ystad) were more likely to participate, compared to mothers from the larger cities (Lund, Malmö, and Helsingborg) (Table 1). A total of 46/62 (74%) mothers with diabetes participated. All but two of the participating mothers reported taking insulin. There was no evidence that mothers with diabetes were more likely to participate than mothers without diabetes (Table 1). A multiple regression analysis confirmed that families were more likely to participate if the children weren't premature or twins, the mother was between 25 and 40 yr old, and the baby was delivered in a hospital in a smaller city.

Questionnaire answers from 6676 mothers (63.4%) and 6099 fathers (57.9%) were analyzed (Table 1). Close to 95% (6329/6676) of the mothers reported, they were married or co-habitants and only 181 (2.7%) were single mothers. Mothers had significantly higher education than fathers ($p < 0.001$; Table 1). Ten percent of the mothers and 11% of the fathers were born in another country. In 146/6676 (2.2%) of the participating families, someone in the family had diabetes (46 mothers, 89 fathers, and 12 siblings). These families will be referred to as D-families (families with diabetes) as opposed to ND-families (families without diabetes).

The parents' answers to the study questions have been presented in Table 2. In some questionnaires, not all questions were answered and therefore the number of answers on individual questions may vary. Even though a clear majority of all parents were satisfied with the information about DiPiS (question 1), a larger proportion of parents in the D-families were dissatisfied ($p < 0.03$; Table 2). Not surprisingly, parents in the D-families reported more knowledge about diabetes (question 2) than parents in ND-families and were less likely to state that they did not know about diabetes at all ($p < 0.001$). Parents in D-families estimated the risk of their newborn to get diabetes to be significantly higher and were more likely to ascribe the risk to their child than parents in ND-families, who, to a larger extent, answered "no risk" or "don't know" (question 3; $p < 0.001$; Table 2). A comparatively large proportion of the mothers in D-families (42%) reported worries regarding the possibility that the child might get a chronic or serious disease in the future (question 4), compared to both fathers in D-families (25.7%), and all parents in ND-families (26.6%). Overall, most parents reported that they were not affected by participation in the DiPiS study (question 5). Instead of reporting increased worries, a larger proportion of parents stated that they were reassured by the participation. The total number of parents who reported increased worries by taking part in DiPiS was few and represented only 67/6610 (1.1%) mothers and 73/6053 (1.2%) fathers. Indeed, 24/6630 (0.4%) mothers and 33/6040 (0.5%) fathers reported that they had become very worried because of enrollment. In 15 families, both mother and father reported that they had become very worried. Only one parent among the very worried reported having diabetes in the family. Mothers in the D-families most frequently reported increased worries (2.8%). There was no difference between ND-families and D-families in the distribution of reported feelings of worry regarding participation in the DiPiS study (Table 2).

Comparing the mean scores for mothers and fathers where both parents answered the questions, results showed significant differences between mothers and fathers in four of the five questions (questions 1–4; Table 3). The results indicated that mothers were more satisfied with the information, reported more knowledge of diabetes, estimated lower risk of diabetes in the child, and reported more worries about possible chronic disease in the child, but did not differ from the fathers in their report on feelings regarding participation in the DiPiS study (Table 3).

In order to analyze what factors influenced the mothers' and fathers' reporting of worries on questions 4 and 5, a multiple regression analysis for each question was performed (Table 4a,b). Together with known characteristics of the participating parents, the answers to questions 1–3 were included as independent variables in the analysis. Results showed that there were several variables that independently contributed to an increased tendency by both the mother and the father to report worries in relation to a possible future chronic or serious disease in the child (question 4) (Table 4a). Having a lower education, being born outside of Sweden, being younger, reporting less knowledge of diabetes, and ascribing diabetes risk to the child were

Table 3. Comparison of scores for mothers and fathers in the families where both parents answered the questions.

| Question* | All families where both parents answered (n = 6530) n | Mothers Mean (SD) | Fathers Mean (SD) | Difference† Mean (95% CI) | p-value |
|---|---|---|---|---|---|
| 1. How do you see the information you have been given about DiPiS? | 5839 | 1.88 (0.51) | 2.06 (0.55) | −0.18 (−0.20 to −0.17) | <0.0001 |
| 2. Did you know about diabetes before joining DiPiS? | 6056 | 2.32 (0.57) | 2.15 (0.55) | 0.18 (0.16–0.19) | <0.0001 |
| 3. Do you think that there is a risk of your newborn child to get diabetes in the future? | 6049 | 2.07 (0.82) | 2.18 (0.83) | −0.10 (−0.13 to −0.08) | <0.0001 |
| 4. How do you feel about the possibility that your child in the future might get a chronic or serious disease? | 6019 | 3.03 (1.04) | 2.82 (1.08) | 0.20 (0.17–0.23) | <0.0001 |
| 5. How do you feel now when you know that your child is part of DiPiS? | 6008 | 2.64 (0.66) | 2.64 (0.67) | −0.00 (−0.02–0.02) | Non-significant |

*The scores and the alternatives for answering the questions have been presented in Table 2.
†Mother's score minus father's score.
DiPiS, Diabetes Prediction in Skåne.

all factors that contributed to both the mothers' and the fathers' reports of being worried. Moreover, significant for the mothers' answers on more worries were (i) having diabetes in the family, (ii) being a single mother, and (iii) being dissatisfied with the information. The result of the multiple regression analysis of question 5 regarding the parents' answers to how they were affected by participating in DiPiS as the dependent variable (Table 4b) showed that several of the significant characteristics regarding question 4 also related to the parents' answers to question 5. However, several of the variables were significant in the other direction, i.e., parents answered that they were reassured by the participation. Mothers with lower education, born outside of Sweden, being younger, giving birth in a smaller city, and reporting less knowledge of diabetes were more likely to report that they were reassured by participation, whereas having a boy and being dissatisfied with the information predicted answers of increased worries (Table 4b). For fathers, lower education, being born outside of Sweden, and the child being born in a smaller city were the factors that contributed to a more reassured answer, but having a boy, diabetes in the family, reporting higher risk of diabetes in the child, and being dissatisfied with the information contributed to an answer of increased worries in the participating father.

## Discussion

In our study, we have confirmed that taking part in genetic screening does not create worries in the large majority of mothers and fathers from the general population. We also found that mothers and fathers differed in their responses to several of the study questions, and that having someone with diabetes in the family may influence the parents' opinions. Mothers in D-families more often report worries. Furthermore, our results indicate that while several demographic characteristics (education, country of birth, and age) might be important for the parents' likelihood of reporting worries, the same characteristics are also important for parents reporting reassurance by taking part in a study.

In contrast to most other screening studies, parents were not informed of the child's actual risk. Consequently, the findings may not apply to studies that provide risk information. Few parents reported problems

Table 4a. Multiple regression analyses of independent variables on mothers' and fathers' answers of question 4: How do you feel about the possibility that your child in the future might get a chronic or serious disease?

| Independent variable* | Direction of answers Mothers | p-value | Fathers | p-value |
|---|---|---|---|---|
| Diabetes in the family | More worried | 0.0092 | None | – |
| Single mother | More worried | 0.0046 | None | – |
| Lower education | More worried | 0.0058 | More worried | <0.0001 |
| Born outside of Sweden | More worried | <0.0001 | More worried | <0.0001 |
| Being younger | More worried | 0.0015 | More worried | 0.0001 |
| Dissatisfaction with information | More worried | <0.0001 | None | – |
| Less knowledge of diabetes | More worried | 0.0081 | More worried | 0.0003 |
| Child has higher risk of getting diabetes† | More worried | <0.0001 | More worried | <0.0001 |

*The following predictors were not significant for neither mother nor father: child's gestational age, child's sex, number of siblings in the family, and place of birth.
†"Don't know" answers are included in the group "yes, a small risk" and are consequently given a score of 2.

Table 4b. Multiple regression analyses of independent variables on mothers' and fathers' answers of question 5: How do you feel now when you know that your child is part of DiPiS?

| | Direction of answers | | | |
|---|---|---|---|---|
| Independent variable* | Mothers | p-value | Fathers | p-value |
| Having a boy | More worries | 0.008 | More worries | 0.007 |
| Diabetes in the family | None | – | More worries | 0.03 |
| Lower education | More reassured | <0.0001 | More reassured | <0.0001 |
| Born outside of Sweden | More reassured | <0.0001 | More reassured | 0.0067 |
| Being younger | More reassured | <0.0001 | More reassured | 0.0046 |
| Child born in smaller city | More reassured | 0.009 | More reassured | 0.0135 |
| Dissatisfaction with information | More worries | <0.0001 | More worries | <0.0001 |
| Less knowledge of diabetes | More reassured | <0.0001 | More reassured | 0.002 |
| Child has higher risk of getting diabetes† | None | – | More worries | 0.0002 |

*The following predictors were not significant for neither mother nor father: child's gestational age, number of siblings in the family, and mother being single.
†"Don't know" answers are included in the group "yes, a small risk".
DiPiS, Diabetes Prediction in Skåne.

participating in our study. However, particularly, mothers of children with diabetes in the family reported being worried that their children would develop serious disease in the future. The lack of feedback to the parents might partly explain the large proportion of parents participating, who reported that they were not at all affected by the participation. Despite this, about 1% of parents reported worries, which corresponds well with earlier findings (15–19). It has been reported that it is a little more common for mothers with diabetes to become worried by study participation (19). Our study indicates that mothers in D-families more often reported worries about possible future chronic disease in the child, but that fathers in D-families more often reported worries because of study participation. Without an appropriate comparison group, we cannot be certain that participating in DiPiS did not increase parental worries in ND-families. Studies of the general population may, therefore, require other comparison groups in order to determine possible differences in worries.

As enrollment in DiPiS has few incentives for parents, other than contributing to research and the possibility of learning about their child's risk of developing T1DM, the proportion of parents who accepted the invitation is satisfactory. It is possible that a larger proportion of parents who did not answer or did not want to participate reacted with more worries to the invitation than participating parents. Other reasons for declining participation might be reluctance to have blood drawn from their child at 2 yr of age, disliking completing questionnaires, and hesitation to give out personal information. Recurring discussions in the media on how blood samples and human tissue are used and handled in research might also have deterred parent participation. As a large majority of participating parents were satisfied with the information about DiPiS, it is unlikely that insufficient information was a major factor among non-participating parents.

The result that mothers with diabetes were not participating to a greater extent than healthy mothers was surprising. Could our observation of increased worries in mothers from the D-families indicate resistance to participation in these mothers? Two reasons for not enrolling might be a desire not to know their child's risk or awareness of the lack of preventive treatment.

It is important that expecting mothers and fathers are properly informed about the objectives of DiPiS. The majority of all parents were satisfied with the information they had received, but more fathers than mothers were dissatisfied. To be informed about DiPiS, the father needs to accompany the mother to the MVC or the mother needs to forward information to the father. The differences between mothers and fathers regarding knowledge of diabetes and the estimate of the child's risk of diabetes might be because of differences in information given to mothers and fathers. Results indicate that not being properly informed could increase the parents' reports on worries. We found that there are associations between the first three questions (satisfaction with information, knowledge of diabetes, and child's diabetes risk) and the two questions about worries. Parents are more likely to report more worries when they are dissatisfied with the information or when they think that the child has an increased risk of diabetes. On the other hand, parents who have less knowledge of diabetes and report worries for chronic disease in the child are reassured by study participation.

Socially more vulnerable parents (having lower education, being born in another country, or being younger) more often reported worries of chronic disease in the child (22–24), but our data indicate that study participation could be reassuring for these parents. In order not to increase worries and perhaps prevent dropout from the study, special attention needs to be paid to these parents by offering appropriate psychological support in connection with screening.

Moreover, to assure that parents are given good information seems to be an important factor for minimizing parents' reports on worries. Therefore, giving feedback to the parents regarding the child's risk of developing T1DM, according to the results of our analyses, should be an important part of the information provided. The fact that D-families are more likely to ascribe diabetes risk to their child and even a great risk suggests that early information about the risk should be considered. This might also be an important factor for reducing reports about worries in the D-family mothers.

It is concluded that screening for T1DM in newborns in the general population does not cause worries in most parents. Our data suggest that more information on diabetes and diabetes risk might lessen worries. The responses of both parents need to be considered, because there are differences in their reports. In addition, having someone with diabetes in the family influences the answers and needs to be considered when informing about the study. Attention should also be paid to families who are more socially vulnerable.

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