Psychological Impact of Islet Cell Antibody Screening for IDDM on Children, Adults, and Their Family Members

SUZANNE BENNETT JOHNSON, PHD
KENNETH P. TERCYAK, JR, BA

OBJECTIVE — To describe the psychological impact of positive islet cell antibody (ICA) screening results in children and adults, as well as their parents and spouses.

RESEARCH DESIGN AND METHODS — The psychological impact of ICA screening results was assessed subsequent to subjects' being informed of ICA-positive (ICA^+) status and was re-evaluated 4 months later. Impact was measured using the state subscale of the State-Trait Anxiety Inventory (STAI) for adults or the State-Trait Anxiety Inventory for Children (STAIC), as well as structured interviews. A total of 34 ICA^+ children, 34 ICA^+ adults, 33 parents, and 25 spouses were evaluated.

RESULTS — At initial notification of ICA^+ status, clinically and statistically significant anxiety was observed in ICA^+ children and adults and their family members ($P < 0.001$). Parents of ICA^+ children were more anxious than spouses of ICA^+ adults ($P < 0.05$). Child and parent anxiety were significantly correlated ($P < 0.05$); more-anxious children lived with more-anxious parents. No significant association was found between ICA^+ adults' initial anxiety and their spouses' anxiety. For ICA^+ participants and their family members, anxiety dissipated to normal levels in 4 months ($P < 0.02$). ICA^+ children were less likely than parents to believe they would ever develop insulin-dependent diabetes mellitus (IDDM). Nevertheless, 52% of ICA^+ children and 24% of ICA^+ adults endorsed lifestyle or behavior changes as a result of their ICA^+ status. Behavior change was associated with greater initial anxiety in both children and adults ($P < 0.05$ for both).

CONCLUSIONS — These data suggest that notification of ICA^+ status has both emotional and behavioral impact. Initial notification of ICA^+ status is associated with considerable anxiety in both ICA^+ individuals and their family members. In most cases, this initial anxiety appears to dissipate to normal levels over time. However, many ICA^+ individuals report initiating lifestyle or health behavior changes in an effort to delay or prevent IDDM onset.

From the Center for Pediatric Psychology Research (S.B.J.) and the Department of Clinical and Health Psychology (K.P.T.), University of Florida, Gainesville, Florida.

Address correspondence and reprint requests to Suzanne Bennett Johnson, PhD, Center for Pediatric Psychology Research, University of Florida Health Science Center, P.O. Box 100165, Gainesville, FL 32610-0165.

Received for publication 22 December 1994 and accepted in revised form 29 June 1995.

ICA, islet cell antibody; ICA^+, ICA-positive; IDDM, insulin-dependent diabetes mellitus; IVGTT, intravenous glucose tolerance test; STAI, State-Trait Anxiety Inventory; STAIC, State-Trait Anxiety Inventory for Children.

Islet cell antibody (ICA) screening assays have been used to identify individuals at risk for developing insulin-dependent diabetes mellitus (IDDM) before full-blown disease onset has occurred (1,2). Since ICA-positive (ICA^+) individuals must be informed of their at-risk status and monitored over long periods of time, concerns have been raised about the psychological impact of ICA screening on at-risk individuals and their family members (3). Further, the psychological impact of at-risk status may influence participation rates or participant behavior in IDDM prevention trials. We previously published data addressing the psychological impact of ICA screening in an initial sample of 18 ICA^+ children, 6 ICA^+ adults, and 22 family members (4). The purpose of the present study is to assess the psychological impact of ICA screening on a larger sample of ICA^+ individuals and their family members.

RESEARCH DESIGN AND METHODS

— A screening program identified ICA^+ individuals (1), who were telephoned about study participation. For ICA^+ children >8 years of age (study procedures were not appropriate for younger children), parental consent was obtained first and then the project was discussed with the child. Participants were informed that ICA^+ status indicated increased risk for IDDM, but no participant was ever told that he/she would definitely develop diabetes. Of those approached, ~80% agreed to participate. Reasons for refusal included parental belief that the child was too young, physical discomfort associated with the intravenous glucose tolerance tests (IVGTTs) to be conducted subsequent to ICA^+ notification, and long distance between the ICA^+ individual's home and the site for the IVGTT.

Participants were asked to describe their personal reactions to the news of their own (or a loved one's) ICA^+ status using the state subscale of the State-Trait Anxiety Inventory (STAI) (5) or the State-

Table 1—*Initial and follow-up anxiety scores*

	ICA$^+$ participants		Family members	
	Children	Adults	Parents	Spouses
Initial	41.9 ± 9.4 (34)*	44.7 ± 12.7 (34)*	55.4 ± 14.4 (33)*	46.2 ± 11.0 (23)*
4-month follow-up	32.1 ± 6.6 (21)†	34.1 ± 11.2 (25)†	38.7 ± 8.7 (21)†	40.4 ± 11.0 (17)†
Normative sample	30.9 ± 8.2 (1554)	35.8 ± 9.7 (484)	35.8 ± 9.7 (484)	35.8 ± 9.7 (484)

Data are means ± SD (*n*). Normative sample means adapted from Spielberger et al. (5,6). Adults were administered the state subscale of the STAI and children the state subscale of the STAIC. *Significant difference from the normative sample. †Significant decline in scores over time.

Trait Anxiety Inventory for Children (STAIC) (6). The STAI and STAIC were initially administered by telephone within 1 week after the participants first learned of their own or a loved one's ICA$^+$ status and then were readministered when the ICA$^+$ person went for the IVGTT, ~4 months after the initial telephone contact (mean = 3.6 ± 1.7 months). Previously published psychometric data indicate the STAI and STAIC to be reliable, valid, sensitive to changes in anxiety over time, and resistant to practice effects (7–11). Reliability estimates for the present study sample were excellent (coefficient $\alpha = 0.91$ and 0.92 for the STAI at initial and 4-month follow-up; coefficient $\alpha = 0.92$ and 0.90 for the STAIC at initial and 4-month follow-up). Structured interviews were conducted during the initial telephone contact and at the time of follow-up IVGTT testing in a subset of ICA$^+$ participants (25 children, 29 adults) and their family members (19 parents, 15 spouses) to further assess: *1*) feelings about ICA$^+$ status and study participation, 2) behavioral changes associated with ICA$^+$ status, and 3) thoughts and beliefs about the likelihood of developing diabetes.

RESULTS— The study sample consisted of 34 ICA$^+$ children (19 boys, 15 girls) 8–17 years of age (mean = 12.6), 34 ICA$^+$ adults (9 men, 25 women) 18–61 years of age (mean = 37.1), 33 parents of ICA$^+$ children (1 father, 32 mothers) 29–53 years of age (mean = 37.9), and 25 spouses of ICA$^+$ adults (17 husbands, 7 wives) 25–57 years of age (mean = 41.0).

Using the STAI/STAIC scores, the mean levels of anxiety at the initial and 4-month follow-up evaluations were compared with published norms using the Welch approximate *t* statistic, which controls for the experimentwise error rate when heterogeneous variances and unequal group sizes are both present (Table 1). Initially, both ICA$^+$ children and adults exhibited clinically significant anxiety [$t(24) = 6.78$, $P < 0.001$ for children; $t(25) = 4.02$, $P < 0.001$ for adults]. Clinically significant anxiety was also observed in parents [$t(24) = 7.67$, $P < 0.001$] and spouses [$t(17) = 4.43$, $P < 0.001$]. Analysis of variance was used to test the relationship of sex and family role (parent or spouse) to initial anxiety. While sex was unrelated to initial anxiety, parents were more anxious than spouses [$F(1,54) = 6.62$, $P < 0.05$]. ICA$^+$ children's initial anxiety was also significantly correlated with parents' anxiety [$r = 0.40$, $P < 0.05$]. However, there was no significant association between ICA$^+$ adults' anxiety and that of their spouses. Dependent *t* tests were used to examine change in anxiety over time. For all participants, initial anxiety dissipated over the 4-month follow-up [$t(21) = 4.78$, $P < 0.0001$ for ICA$^+$ children; $t(25) = 3.89$, $P < 0.0007$ for ICA$^+$ adults; $t(21) = 5.75$, $P < 0.0001$ for parents; $t(17) = 2.85$, $P < 0.012$ for spouses]. At follow-up, the amount of reported anxiety was not significantly different from levels exhibited by the normative sample.

In the structured interview, 96% of adult respondents indicated they were glad to have participated in the ICA screening study. A minority (10%) of ICA$^+$ children wished they had not participated, citing concerns about pain associated with blood draws. Initially, most ICA$^+$ participants were unsure whether they would ever develop IDDM, but in the 4-month follow-up, 41% of ICA$^+$ children and 40% of ICA$^+$ adults had formed the opinion that they would never develop the disease. Parents and spouses were also initially uncertain about whether their loved one would develop diabetes. At the 4-month follow-up, spouses remained uncertain. In contrast, 44% of parents believed their ICA$^+$ child would develop the disease, while only 6% of their children thought this would be the case.

When asked whether they had made any changes in response to notification of ICA$^+$ status, 52% of the ICA$^+$ children and 24% of the ICA$^+$ adults acknowledged changes in lifestyle or health behavior, the most common involving diet (decreased calories and sweets) and exercise (increased activity). Point biserial correlations were used to determine whether initial anxiety (measured by the STAI or STAIC) was associated with lifestyle or health behavior change. In both ICA$^+$ children ($r = 0.50$, $P < 0.05$) and ICA$^+$ adults ($r = 0.22$, $P < 0.05$), behavior change was associated with greater initial anxiety.

CONCLUSIONS— Data from this sample of ICA$^+$ children and adults suggest that notification of ICA$^+$ status induces clinically significant anxiety in ICA$^+$ individuals and their family mem-

bers. The ICA^+ children who were initially most anxious lived with parents who were also anxious. Initial high levels of anxiety were also predictive of behavior change in both ICA^+ children and adults; presumably more-anxious patients made an effort to prevent the onset of IDDM. Among family members, parents appeared to be particularly affected; their initial anxiety was significantly greater than that of spouses. Initial anxiety appeared to dissipate over time in both ICA^+ participants and family members. These findings are consistent with prior studies examining the psychological impact of IDDM diagnosis on children and their parents (12,13). However, there appeared to be some differences in beliefs about the ICA^+ individual's ultimate health status; while many ICA^+ children believed they would never develop diabetes, parents often held the contrasting view. Further, the association of initial anxiety with subsequent lifestyle and health behavior changes has implications for ongoing IDDM prevention trials. We have yet to determine the influence of psychological and behavioral sequelae of ICA^+ status notification on ICA^+ individuals' and their families' decision to participate in IDDM prevention protocols or, once entered into a prevention protocol, on their decision to engage in intervention strategies different from or in addition to those recommended by the investigators.

Acknowledgments— This study was supported by National Institutes of Health Grants PO1-DK-39079, KO4-HD-00686, and CRCG RR00082.

We are grateful to the ICA^+ individuals and their families who participated in this research. Special thanks to study interviewers: John-Paul Abner, Judy Clark, Cheryl Halpern, Laura Mee, Michael Nurick, Sherry Risch, and Lynn Tanner. Drs. Noel Maclaren, William Riley, Desmond Schatz, and Janet Silverstein, Rebecca Spillar, and the staff of the Clinical Research Center provided valuable consultation, advice, and assistance.

References

1. Riley WJ, Maclaren, NK, Krischer J, Spillar RP, Silverstein JH, Schatz, DA, Schwartz S, Malone J, Shah S, Vadheim C, Rotter JI: A prospective study of the development of diabetes in relatives of patients with insulin-dependent diabetes. *N Eng J Med* 323:1167–1172, 1990
2. Schatz D, Krischer J, Horne G, Riley W, Spillar R, Silverstein J, Winter W, Muir A, Derovanesian D, Shah S, Malone J, Maclaren N: Islet cell antibodies predict insulin-dependent diabetes in United States school age children as powerfully as in unaffected relatives. *J Clin Invest* 93:2403–2407, 1994
3. Vialettes B, Mattei-Zevaco C: Should screening for type I diabetes in children of insulin dependent parents be encouraged? *Diabetes & Metab* 18:115–117, 1992
4. Johnson SB, Riley WJ, Hansen CA, Nurick MA: Psychological impact of islet cell-antibody screening: preliminary results. *Diabetes Care* 13:93–97, 1990
5. Spielberger CD, Gorsuch RL, Lushene R: *Test Manual for the State-Trait Anxiety Inventory*. Palo Alto, CA, Consulting Psychologists, 1970
6. Spielberger CD: *Test Manual for the State-Trait Anxiety Inventory for Children*. Palo Alto, CA, Consulting Psychologists, 1973
7. Dreger RM, Brabham JL: Two clinical validation studies on the state form and types of reliability of the trait form of the State-Trait Anxiety Inventory. *Multivar Exp Clin Res* 8:195–209, 1987
8. Knight RG, Waal-Manning HJ, Spears GF: Some norms and reliability data for the State-Trait Anxiety Inventory and the Zung Self-Rating Depression Scale. *Br J Clin Psychol* 22:245–249, 1983
9. Rule WR, Traver MD: Test-reset reliabilities of State-Trait Anxiety Inventory in a stressful social analogue situation. *J Pers Assess* 47:276–277, 1983
10. Spielberger CD, Vagg PR: Psychometric properties of the STAI: a reply to Ramanaiah, Franzen, and Schill. *J Pers Assess* 48:95–97, 1984
11. Papay JP, Spielberger CD: Assessment of anxiety and achievement in kindergarten and first- and second-grade children. *J Abnorm Child Psychol* 14:279–286, 1986
12. Kovacs M, Finkelstein R, Feinberg TL, Crouse-Novak M, Paulauskas S, Pollock M: Initial psychologic responses of parents to the diagnosis of insulin-dependent diabetes mellitus in their children. *Diabetes Care* 8:568–575, 1985
13. Kovacs M, Feinberg TL, Paulauskas S, Finkelstein R, Pollock M, Crouse-Novak M: Initial coping responses and psychosocial characteristics of children with insulin-dependent diabetes mellitus. *J Pediatr* 106:827–834, 1985