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Author/s:

Northam, EA;Lin, A;Finch, S;Werther, GA;Cameron, FJ

Title:

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Date:

2010-07-01

Citation:

Northam, E. A., Lin, A., Finch, S., Werther, G. A. & Cameron, F. J. (2010). Psychosocial well-being and functional outcomes in youth with type 1 diabetes 12 years after disease onset. *Diabetes Care*, 33 (7), pp.1430-1437. <https://doi.org/10.2337/dc09-2232>.

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Psychosocial Well-Being and Functional Outcomes in Youth With Type 1 Diabetes 12 years After Disease Onset

ELISABETH A. NORTHAM, PHD^{1,2,3}
ASHLEIGH LIN, BSC³
SUE FINCH, PHD⁴

GEORGE A. WERTHER, MD^{3,5}
FERGUS J. CAMERON, MD^{3,5}

OBJECTIVE — Type 1 diabetes in youth and community controls were compared on functional outcomes. Relationships were examined between psychosocial variables at diagnosis and functional outcome 12 years later.

RESEARCH DESIGN AND METHODS — Participants were subjects with type 1 diabetes ($n = 110$, mean age 20.7 years, SD 4.3) and control subjects ($n = 76$, mean age 20.8 years, SD 4.0). The measures used included the Youth Self-Report and Young Adult Self-Report and a semi-structured interview of functional outcomes. Type 1 diabetes participants also provided information about current diabetes care and metabolic control from diagnosis.

RESULTS — Type 1 diabetes participants and control subjects reported similar levels of current well-being but for the youth with type 1 diabetes, the mental health referral rates over the previous 12 years were higher by 19% and school completion rates were lower by 17%. Over one-third of clinical participants were not currently receiving specialist care and this group had higher mental health service usage in the past (61 vs. 33%) and lower current psychosocial well-being. Within the type 1 diabetes group, behavior problems, high activity, and low family cohesion at diagnosis predicted lower current well-being, but were not associated with metabolic control history. Poorer metabolic control was associated with higher mental health service usage.

CONCLUSIONS — Type 1 diabetes participants report similar levels of current psychosocial well-being compared with control subjects, but higher levels of psychiatric morbidity since diagnosis and lower school completion rates. Psychiatric morbidity was associated with poor metabolic control and failure to transition to tertiary adult diabetes care.

Diabetes Care 33:1430–1437, 2010

The focus on prevention, early detection, and treatment of diabetes-related complications that followed the Diabetes Control and Complications Trial (DCCT) (1) has been paralleled by increased interest in promoting health-related quality of life and minimizing psychosocial morbidity in youth with type 1 diabetes. Epidemiological studies suggest that psychological difficulties are increased in children and adolescents with diabetes, as they are in youth with other chronic medical conditions (2). Mood

disorders are the most frequently reported diagnosis in youth with type 1 diabetes, but anxiety, conduct problems, and eating disorder rates are also elevated (3,4). Less clear is the trajectory of these problems into adulthood with conflicting evidence as to whether psychological difficulties persist into early adulthood or tend to diminish as reported in community samples (5). Psychiatric morbidity was high in the sample of young adults studied by Hislop et al. (6) with one-third reporting elevated levels of maladjust-

ment. Similar disorder rates were reported by Bryden et al. (7) in their sample of young adults with type 1 diabetes, while Grey et al. (8) found that depression in adolescence was associated with ongoing mood disorders in early adulthood. These findings suggest continuity of problems. In contrast, emotional and behavioral problem scores were not elevated in adolescents with type 1 diabetes in a controlled study conducted over three years (9) while a ten-year follow-up of a young adult cohort, aged 19–26 years, also found psychiatric morbidity to be similar to that of control subjects (10).

Psychological maladjustment in individuals with type 1 diabetes is particularly concerning because it is associated with poor metabolic control (4,11), which in turn increases the risk of diabetes-related complications (1). It is possible that neurohormonal changes associated with stress and mental illness affect endocrine pathways directly influencing metabolic control. It is more generally assumed, however, that psychiatric symptoms adversely affect metabolic control indirectly by disrupting the behaviors necessary for diabetes-related self-care (12). Better documentation of the risk factors for psychological difficulties and the associated problems with metabolic control is critical if intervention and clinical support are to be appropriately targeted.

This study documents the psychosocial well-being and functional and health outcomes of youth with type 1 diabetes studied prospectively from diagnosis. Immediately after diabetes onset, these children exhibited mild symptoms of psychological distress, which was largely resolved one year after diagnosis (13). Ten years after diabetes onset, 37% of an adolescent subset of the original cohort met the criteria for a DSM-IV psychiatric diagnosis (14), a morbidity two to three times higher than community levels (15). In addition, adolescents with a psychiatric diagnosis and those with a history of poor metabolic control had exhibited more behavior problems at diagnosis. The current report documents psychiatric morbidity and functional status in the original cohort 12 years after diagnosis with type 1

From the ¹Department of Psychology, Royal Children's Hospital, Melbourne, Australia; the ²Department of Psychology, The University of Melbourne, Melbourne, Australia; the ³Murdoch Children's Research Institute, Melbourne, Australia; the ⁴Statistical Consulting Centre, The University of Melbourne, Melbourne, Australia; and the ⁵Department of Endocrinology and Diabetes, Royal Children's Hospital, Melbourne, Australia.

Corresponding author: Ashleigh Lin, ashlin@unimelb.edu.au.

Received 7 December 2009 and accepted 13 March 2010. Published ahead of print at <http://care.diabetesjournals.org> on 31 March 2010. DOI: 10.2337/dc09-2232.

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diabetes. We asked the following questions:

1. Twelve years after disease onset, does the psychosocial status and functional well-being of youth with type 1 diabetes differ from that of healthy community control subjects?
2. Are psychosocial, functional, and health outcomes 12 years after disease onset associated with child behavior and temperament at diagnosis; family functioning at diagnosis; or history of metabolic control?

RESEARCH DESIGN AND METHODS

Consecutive admissions (aged 1–14 years) to the Royal Children's Hospital (RCH), Melbourne, Australia, with newly diagnosed type 1 diabetes between 1990 and 1992 ($n = 133$), together with age- and sex-stratified healthy control subjects ($n = 126$), were recruited into a longitudinal study to examine disease impact on functional outcome. Recruitment strategy was previously fully described (13,14). Twelve years later, all participants who could be located (125 with type 1 diabetes and 93 control subjects [94 and 74%, respectively]) using the study database, RCH and adult diabetes clinics, private endocrinologists, and the Health Insurance Commission, were invited to participate in a follow-up. Of those located, 110 participants with type 1 diabetes and 76 control subjects (rates of 88 and 82%, respectively) agreed to participate in the current study.

Participants were interviewed and completed a standardized measure of psychosocial well-being as part of a comprehensive evaluation that also included neuroimaging and neuropsychological assessments. Central nervous system outcomes were separately reported (16). The study was approved by the Human Ethics Research Committee of the Victorian Government Department of Human Services.

Baseline psychosocial measures

Child behavior. The Child Behavior Check List (CBCL) (17) is a 118-item questionnaire completed by the primary caregiver that provides scores for Internalizing (depression, anxiety, somatic concerns), Externalizing (aggression, hyperactivity, conduct problems) and Total problems (also includes social, thought, and attention problems not categorized into either the Internalizing or External-

izing broadband scales). Scores are expressed as standardized T scores ($\bar{X} = 50$, $SD = 10$), with higher scores indicating greater pathology. The two broadband scales and Total behavior problem score have excellent internal consistency ($\alpha = 0.89$ – 0.96) and test-retest reliability ($r = 0.89$ – 0.93).

Child temperament. The Emotionality, Activity, and Sociability Temperament Scale (EAS) (18) is a 20-item mother-rated measure of child temperament that provides scores for emotionality, activity, sociability, and shyness. The EAS is scored on a five-point response scale with higher scores indicating greater expression of the trait. Internal consistency across EAS scales ranges from 0.75 to 0.83, and test-retest reliabilities range from 0.57 to 0.80.

Family functioning. The Family Adaptability and Cohesion Evaluation Scales (FACES-III) (19) are a mother-rated 20-item measure that evaluates family functioning on cohesion and adaptability. Responses are rated on a five-point scale with higher scores reflecting more functional family relationships. The Adaptability and Cohesion scales have internal consistencies of 0.62 and 0.72, and test-retest reliabilities of 0.80 and 0.83, respectively.

Socio-economic status. The Daniel Scale of Occupational Prestige (20) was used to rate the occupational status of the principal earner on a six-point scale (1 = high, 6 = low).

Baseline measures were administered to type 1 diabetes participants during a home visit conducted three to four weeks after initial diagnosis and to control subjects at the time of recruitment. Child temperament and family functioning measures were administered to type 1 diabetes participants only.

Follow-up measures

Psychosocial well-being. The Youth Self-Report (YSR) (21) and Young Adult Self-Report (YASR) (22) are self-report measures for youth aged 11–18 (112 items) and 19–30 years (110 items), respectively, which provide scores for Internalizing (anxiety, withdrawal, somatic concerns), Externalizing (aggression and delinquency), and Total (also includes social, thought, and attention problems) problems. Scores are expressed as standardized T scores ($\bar{X} = 50$, $SD = 10$) and are comparable across the YSR/YASR. Higher scores indicate greater psychopa-

thology. YASR and YSR scales have excellent internal consistency ($\alpha = 0.71$ – 0.96) and test-retest reliability ($r = 0.80$ – 0.92).

Functional outcome. A semi-structured interview was conducted to obtain information about referral rates for mental health services over the previous 12 years as an indicator of overall psychological morbidity since diabetes onset. Information about school history and current study/work participation was also recorded. Type 1 diabetes participants reported their current diabetes medical care (i.e., hospital clinic, private endocrinologist, local medical officer, or other).

Biomedical measures

Participants were asked to report any episode of hypoglycemia associated with seizure activity or loss of consciousness since diagnosis. These reports were corroborated through the scrutiny of the medical records. The sample was dichotomized into those who reported no seizure activity and those with a history of ≥ 1 seizure/coma associated with hypoglycemia. All A1C measurements from diagnosis were obtained for each patient (range 4–57, median 37) from hospital and clinic databases. A1C was assessed at RCH using the BioRad (Hercules, CA) affinity column chromatography method prior to 1994 and using a Bayer (Calabria, Barcelona, Spain) DCA 2000 immunoagglutination method from 1994 to 2004. The methods used in adult clinics included Primus Boronate Affinity (Primus Diagnostics) and Bayer DCA 2000. All methods are referenced to the National Glycohemoglobin Standardization Program. In line with the DCCT finding that a mean A1C of $\geq 9\%$ was associated with an increased risk of diabetic complications (1), the percentage of total time from diagnosis that A1C was $\geq 9.0\%$ was calculated for each participant with type 1 diabetes to measure lifetime glycemic exposure.

Statistical analyses

SPSS version 15 (SPSS, Chicago, IL) was used for all analyses. We used ANCOVA to examine group (type 1 diabetes, control) differences on YSR/YASR Total, Internalizing, and Externalizing T scores, controlling for sex and socio-economic status (SES). χ^2 analyses were used to investigate group differences on categorical variables, e.g., mental health referral, school completion, and study/work participation rates. Analyses of school completion rates and specialist diabetes care

were limited to participants no longer attending school or receiving pediatric diabetes care.

Regression analyses were used to predict outcomes within the diabetes group using binary logistic regression for categorical outcomes (school completion, study/work participation, specialist diabetes care, school completion, history of seizures) and multiple linear regression if the outcome was continuous (YSR/YASR scores, percentage of time A1C $\geq 9\%$). Sex was included as a predictor in all regression models. To predict functional outcome from YSR/YASR scores, Internalizing and Externalizing scores were entered in a separate models from the Total scores to overcome the problem of multicollinearity. When using baseline variables to predict outcome (metabolic control history, YSR/YASR scores, functional outcome), CBCL Internalizing and Externalizing scores were included separately from CBCL Total problem scores for the same reason. SES at baseline was included when child behavior (CBCL) or parent functioning measures (FACES) were entered as predictors. To predict outcome from illness-related variables, the models included the percentage of time A1C $\geq 9\%$, history of seizures, and age of onset (early or later onset).

RESULTS — The samples consisted of participants with type 1 diabetes ($n = 110$, 54 males, 56 females) and control participants ($n = 76$, 37 males, 39 females). At assessment, mean age was 20.7 years (SD 4.3) and mean SES was 4.3 (SD 1.1) for participants with type 1 diabetes. Mean age for control subjects was 20.8 years (SD 4.0) and SES was 4.1 (SD 1.2). Group differences on sex ratio, age, and SES at baseline and 12-year follow-up were small. SES for both groups was comparable with the Australian population mean of 4.1 (SD 1.1) (20). SES did not differ between type 1 diabetes participants or control subjects who were assessed at 12 years and those who were recruited initially but could not be located or declined to take part in the current study. Of the individuals with type 1 diabetes, 41 had early onset (≤ 5 years) diabetes, and 47 reported at least one episode of severe hypoglycemia resulting in seizure or coma. Mean time since diagnosis that A1C was $\geq 9\%$ was 42.9% (SD 26.6), and the most recent mean A1C was 9.1% (SD 1.7).

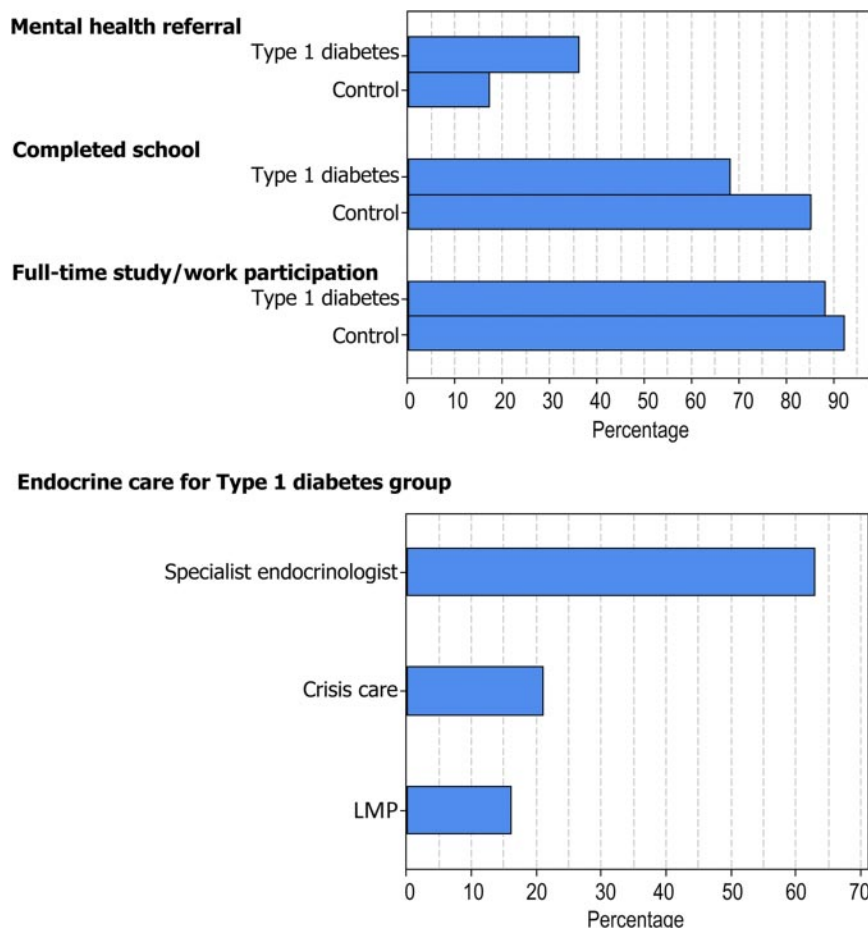


Figure 1—Functional outcomes for subjects with type 1 diabetes and control subjects. LMP, local medical practitioner. A high-quality color representation of this figure is available in the online issue.

Group (type 1 diabetes/control subjects) differences in current psychiatric status and functional outcome

There were only very small group differences on the problem scores of the YSR/YASR: Internalizing problems [type 1 diabetes $\bar{X} = 47.03$, control subjects $\bar{X} = 48.18$, 95% CI for difference = -2.09 – 4.38 , $F(1,167) = 0.06$, $P = 0.8$]; Externalizing problems [type 1 diabetes $\bar{X} = 49.75$, control subjects $\bar{X} = 50.26$, 95% CI for difference = -2.59 – 3.60 , $F(1,167) = 0.13$, $P = 0.7$]; or Total problems [type 1 diabetes $\bar{X} = 48.70$, control subjects $\bar{X} = 49.54$, 95% CI for difference = -2.46 – 4.15 , $F(1,167) = 0.08$, $P = 0.8$]. Mental health referral, school completion, and study/work participation rates are shown in Figure 1. Youth with type 1 diabetes were more likely than control subjects to have had contact with mental health services [37 vs. 18%, $\chi^2(1) = 8.30$, $P = 0.004$, $n = 181$]. Youth with type 1 diabetes who had reached

school-leaving age were less likely to have completed Year 12, which is the final pre-tertiary year of education in Australia, than control subjects [68 vs. 85%, $\chi^2(1) = 5.02$, $P = 0.025$, $n = 131$]. Group differences in the percentage currently in full-time study/work were small [89% with type 1 diabetes vs. 92% of control subjects, $\chi^2(1) = 0.50$, $P = 0.5$, $n = 185$].

Within the type 1 diabetes group, regression models were used to predict functional outcomes from current psychosocial status (YSR/YASR scores). Mental health referral was associated with current total problems (odds ratio [ORs] 1.06 [95% CI 1.02–1.11], $P = 0.007$). Reduced study/work participation rates were associated with higher current Internalizing (1.09 [1.0–1.18], $P = 0.039$) and Total (1.07 [1.01–1.13], $P = 0.023$) problems. School completion was not strongly associated with current psychosocial status. Of the youth no longer attending RCH for medical care ($n = 75$), 47 (63%) reported attendance at a hospi-

tal diabetes clinic or private endocrinologist; 11 (15%) reported receiving diabetes care from their local medical practitioner; and 17 (23%) reported crisis-driven attendance only at either a local medical practitioner or hospital emergency clinic. Local medical practitioner/crisis-only diabetes care was associated with higher current Externalizing (1.11 [1.03–1.19], $P = 0.008$) and Total (1.07 [1.02–1.12], $P = 0.01$) problems. Sixty-one percent of youth accessing crisis-only diabetes care had a history of referral for mental health services at some time since diagnosis compared with 33% of those receiving regular medical care ($\chi^2(1) = 4.72$, $P = 0.03$, $n = 93$). The percentage time in poor metabolic control did not differ between those receiving tertiary diabetes care ($\bar{X}$ 39.96%, SD 28.15) and those accessing local medical officer/crisis-only care ($\bar{X}$ 46.11%, SD 20.84), $t(68.23) = -1.22$, $P = 0.23$.

Associations between baseline variables and psychosocial, functional, and health outcome

Regression models predicting current psychosocial and functional outcomes from baseline variables are presented in Table 1.

CBCL Total problem scores at baseline predicted 15–20% of the variance in Internalizing, Externalizing, and Total YSR/YASR scores 12 years after diabetes onset. Baseline CBCL Internalizing and Externalizing problem scores predicted 12–17% of variance in Internalizing, Externalizing, and Total problem scores at follow-up. The CBCL Externalizing score was a better predictor than the CBCL Internalizing score. Activity was the best of the EAS predictors but, in general, child temperament variables at diagnosis were not as powerful predictors of YSR/YASR scores (2–7% of variance) as CBCL measures. FACES predicted up to 10% of the variance in Internalizing, Externalizing, and Total problem scores at follow-up, primarily reflecting the association between lower Cohesion scores at baseline and lower levels of current psychosocial well-being.

Elevated CBCL Total problem scores at diagnosis were associated with higher mental health referral rates (Table 1). Other baseline CBCL, EAS, and FACES scores were not strong predictors of mental health referral, school completion, current study/work participation rates, or current diabetes care. Lower SES at base-

line was strongly associated with lower school completion rates. CBCL, EAS, and FACES scores at baseline were poor predictors of metabolic control since diagnosis, accounting for ~2–6% of variance in the percentage of time A1C, was $\geq 9\%$.

Associations between illness variables and current psychosocial and functional outcome

Metabolic control variables (percent of time A1C $\geq 9\%$, history of seizures, early or later onset of illness) and sex were entered into regression analyses to identify their relationship to YSR/YASR scores and functional outcome (supplemental Table 2, available at <http://care.diabetesjournals.org/cgi/content/full/dc09-2232/DC1>). A history of hypoglycemic seizures was associated with higher Externalizing and Total problems on the YSR/YASR, explaining 4 and 6% of the variance, respectively. Poorer metabolic control (i.e., higher percent of time with A1C levels $\geq 9\%$) was associated with higher rates of mental health referral since diagnosis and lower rates of study/work participation, but was not associated with school completion or type of diabetes care. Males were less likely than females to be currently receiving specialist diabetes care (51 vs. 72%), but over time since diagnosis females spent a higher average percentage of time than males in poor metabolic control ($\bar{X}$ 48 vs. 38%, $t(108) = 2.06$, $P = 0.042$).

CONCLUSIONS — Youth with type 1 diabetes reported similar levels of current psychosocial well-being compared with healthy control subjects. Referrals for mental health services over the previous 12 years however were 19% higher and school completion rates were 17% lower in youth with type 1 diabetes, suggesting higher rates of overall psychological morbidity over the 12 years since diagnosis. Within the diabetic group, there were associations between higher mental health referral rates since diagnosis and lower study/work participation rates and current levels of psychosocial well-being. Over one-third of the youth no longer attending RCH had failed to make the transition to specialist diabetes care and, of these, the majority had been referred for mental health services in the past and also had higher levels of current psychosocial maladjustment.

Taking a longitudinal perspective, behavior problems at diagnosis predicted

higher mental health referral rates over the ensuing 12 years and greater current psychosocial difficulties. Higher child activity levels and lower levels of family cohesion at baseline were also associated with lower current levels of psychosocial well-being. A history of hypoglycemic seizures was related to current psychosocial maladjustment, but not to functional outcomes. Those with a history of poorer metabolic control were more likely to have been referred for mental health services at some point since diagnosis and less likely to be in full-time study or work.

The findings that youth with type 1 diabetes reported similar levels of psychological symptoms to those described by the healthy community control subjects on the YSR/YASR contrasts with evidence of higher levels of psychopathology in youth with diabetes in a number of previous reports (3,4,6,7,8), but is similar to that found in several other longitudinal studies (9,10). Sampling and methodological differences may contribute to inconsistent findings. Studies reporting elevated psychopathology tended to lack normative controls (3,4,6,7,8), assess participants cross-sectionally (4,6), and/or focus on a single disorder, usually depression (4,8). They also tended to study younger samples (3,4,8) and rely, at least in part, on parent reports. It is possible that as youth with type 1 diabetes move through adolescence, they achieve a degree of physiological and psychological equilibrium as the hormonal perturbations of puberty recede, their sense of personal identity consolidates, and they develop a greater sense of control and acceptance of their illness. This might then be reflected in similar levels of self-reported psychosocial well-being to that of their healthy peers.

However it is also possible that with greater maturity, the desire of youth with a chronic illness to portray themselves in a positive light, to identify with healthy peers, and to minimize differences and difficulties may increase. That is, youth with type 1 diabetes may deny or minimize problems that really exist. This phenomenon, sometimes referred to as response shift (23), may be particularly strong when respondents are aware that comparison will be made with healthy peers as was the case in two previous studies (9,10) reporting similar levels of psychosocial well-being. Psychosocial maladjustment has been higher in our cohort at previous assessment points. For example, 10 years after diagnosis, over

Table 1—Baseline predictors of psychosocial, functional, and health outcome for type 1 diabetes group: outcomes

Outcomes	Internalizing problems at follow-up (regression coefficient)			Externalizing problems at follow-up (regression coefficient)			Total problems at follow-up (regression coefficient)		
	Estimate	95% CI	P	Estimate	95% CI	P	Estimate	95% CI	P
Explanatory variables									
CBCL Total problems	0.33	0.13–0.53	0.002	0.40	0.19–0.60	<0.001	0.45	0.24–0.66	<0.001
Gender	2.77	–1.55 to 7.10	0.2	–0.87	–5.26 to 3.52	0.7	1.21	–3.32 to 5.74	0.6
SES	1.44	–0.44 to 3.31	0.1	0.19	–1.71 to 2.09	0.8	0.82	–1.14 to 2.78	0.4
Overall model	$F(3, 75) = 6.2, P = 0.001, R^2 = 16.6$			$F(3, 75) = 5.5, P = 0.002, R^2 = 14.8$			$F(3, 75) = 7.5, P = <0.001, R^2 = 20.0$		
CBCL Internalizing	0.13	–0.12 to 0.38	0.3	–0.05	–0.30 to 0.19	0.7	0.04	–0.22 to 0.30	0.8
CBCL Externalizing	0.21	–0.04 to 0.46	0.1	0.48	0.23–0.73	<0.001	0.42	0.16–0.69	0.002
Gender	2.29	–2.24 to 6.82	0.3	–2.31	–6.74 to 2.11	0.3	0.02	–4.69 to 4.73	>0.9
SES	1.49	–0.44 to 3.42	0.1	0.05	–1.84 to 1.94	>0.9	0.78	–1.23 to 2.79	0.4
Overall model	$F(4, 74) = 3.8, P = 0.008, R^2 = 12.4$			$F(4, 74) = 5.0, P = 0.001, R^2 = 16.9$			$F(4, 74) = 5.0, P = 0.001, R^2 = 16.9$		
EAS shyness	0.72	–1.23 to 2.66	0.5	–0.40	–2.12 to 1.33	0.7	0.04	–1.90 to 1.97	>0.9
EAS emotionality	0.04	–0.82 to 0.90	>0.9	0.78	0.02–1.55	0.05	0.50	–0.36 to 1.36	0.3
EAS sociability	–0.14	–1.57 to 1.28	0.8	–0.37	–1.63 to 0.89	0.6	–0.22	–1.63 to 1.20	0.8
EAS activity	1.26	–0.10 to 2.62	0.07	1.55	0.35–2.76	0.01	1.66	0.31–3.02	0.02
Gender	4.74	0.29–9.19	0.04	0.55	–3.41 to 4.51	0.8	3.44	–1.00 to 7.87	0.1
Overall model	$F(5, 92) = 1.4, P = 0.2, R^2 = 2.2$			$F(5, 92) = 2.4, P = 0.05, R^2 = 6.5$			$F(5, 92) = 1.9, P = 0.1, R^2 = 4.3$		
FACES cohesion	–1.57	–2.70 to –0.44	0.007	–0.66	–1.75 to 0.44	0.2	–1.36	–2.54 to –0.19	0.02
FACES adaptability	0.00	–1.19 to 1.19	>0.9	–0.32	–1.47 to 0.83	0.6	0.18	–1.06 to 1.41	0.8
Gender	3.01	–1.20 to 7.22	0.2	–0.83	–4.92 to 3.25	0.7	1.37	–3.01 to 5.76	0.5
SES	0.83	–1.09 to 2.74	0.4	0.05	–1.81 to 1.91	>0.9	0.68	–1.31 to 2.68	0.5
Overall model	$F(4, 91) = 3.5, P = 0.01, R^2 = 9.6$			$F(4, 91) = 0.6, P = 0.7, R^2 = -1.6$			$F(4, 91) = 2.0, P = 0.1, R^2 = 4.1$		
Outcomes at follow-up									
Explanatory variables									
CBCL Total problems	1.05	1.00–1.09	0.05	1.00	0.95–1.05	>0.9	1.05	0.98–1.11	0.2
Gender	1.35	0.54–3.42	0.5	0.48	0.16–1.44	0.2	0.91	0.26–3.19	0.9
SES	1.01	0.68–1.50	>0.9	2.02	1.20–3.39	0.008	1.15	0.67–1.99	0.6
Overall model	$\chi^2 = 4.9, df = 3, P = 0.2$			$\chi^2 = 10.1, df = 3, P = 0.02$			$\chi^2 = 2.9, df = 3, P = 0.4$		
CBCL Internalizing	1.02	0.96–1.07	0.6	0.98	0.92–1.04	0.5	1.02	0.95–1.09	0.7
CBCL Externalizing	1.03	0.98–1.09	0.2	1.02	0.96–1.08	0.6	1.03	0.96–1.10	0.5
Gender	1.24	0.48–3.21	0.7	0.44	0.14–1.38	0.2	0.87	0.24–3.18	0.8
SES	1.00	0.67–1.50	>0.9	1.98	1.17–3.34	0.01	1.17	0.67–2.02	0.6
Overall model	$\chi^2 = 4.4, df = 4, P = 0.4$			$\chi^2 = 10.7, df = 4, P = 0.03$			$\chi^2 = 2.1, df = 4, P = 0.7$		
EAS shyness	0.93	0.64–1.35	0.7	0.81	0.47–1.41	0.5	1.17	0.68–1.98	0.6
EAS emotionality	1.04	0.89–1.23	0.6	0.94	0.77–1.16	0.6	1.05	0.82–1.34	0.7
EAS sociability	0.78	0.59–1.04	0.09	0.93	0.64–1.35	0.7	1.03	0.69–1.54	0.9
EAS activity	1.16	0.88–1.53	0.3	1.38	0.93–2.04	0.1	0.83	0.57–1.21	0.3
Gender	1.05	0.45–2.45	>0.9	0.51	0.17–1.51	0.2	0.84	0.24–2.89	0.8
Overall model	$\chi^2 = 3.4, df = 5, P = 0.6$			$\chi^2 = 6.7, df = 5, P = 0.2$			$\chi^2 = 1.4, df = 5, P = >0.9$		
FACES cohesion	0.88	0.70–1.11	0.3	0.90	0.66–1.25	0.5	0.94	0.70–1.25	0.7
FACES adaptability	1.25	0.97–1.60	0.08	0.86	0.62–1.18	0.4	0.83	0.59–1.18	0.3
Specialist diabetes care (OR)									
Estimate	1.04	0.99–1.09	0.1	1.04	0.95–1.06	>0.9	1.00	0.95–1.06	>0.9
95% CI	0.47	0.17–1.29	0.1	0.47	0.17–1.29	0.1	1.04	0.99–1.11	0.1
P	0.99	0.65–1.51	>0.9	0.99	0.65–1.51	>0.9	0.95	0.62–1.47	0.8
Estimate	1.04	0.95–1.06	>0.9	1.04	0.95–1.06	>0.9	1.04	0.95–1.06	>0.9
95% CI	0.47	0.17–1.29	0.1	0.47	0.17–1.29	0.1	1.04	0.99–1.11	0.1
P	0.99	0.65–1.51	>0.9	0.99	0.65–1.51	>0.9	0.95	0.62–1.47	0.8

(continued)

Outcomes at follow-up			Mental health referral (OR)			School completion (OR)			Full-time study/work (OR)			Specialist diabetes care (OR)		
Explanatory variables			Estimate	95% CI	P	Estimate	95% CI	P	Estimate	95% CI	P	Estimate	95% CI	P
Gender			1.21	0.51–2.85	0.7	0.27	0.08–0.94	0.04	0.93	0.27–3.23	>0.9	0.34	0.12–1.01	0.05
SES			1.15	0.78–1.69	0.5	1.93	1.07–3.50	0.03	1.12	0.62–2.03	0.7	1.10	0.68–1.77	0.7
Overall model			$\chi^2 = 4.3$, df = 4, $P = 0.4$			$\chi^2 = 15.4$, df = 4, $P = 0.004$			$\chi^2 = 2.4$, df = 4, $P = 0.7$			$\chi^2 = 5.0$, df = 4, $P = 0.3$		
Outcomes			Seizure at follow-up (OR)			Metabolic control at follow-up (regression coefficient)								
Explanatory variables			Estimate	95% CI	P	Estimate	95% CI	P						
CBCL Total problems			1.02	0.98–1.06	0.4	0.49	–0.05–1.03		0.49			–0.05–1.03		0.08
Gender			0.74	0.30–1.79	0.5	0.30–1.79			9.91			–1.68–21.49		0.09
SES			0.98	0.67–1.44	>0.9	0.67–1.44			0.27			–4.67–5.21		>0.9
Overall model			$\chi^2 = 1.3$, df = 3, $P = 0.7$									$F(3, 77) = 2.2$, $P = 0.09$, $R^2 = 4.3$		
CBCL Internalizing			0.96	0.91–1.01	0.1	0.91–1.01			0.20			–0.46–0.86		0.5
CBCL Externalizing			1.05	1.00–1.11	0.07	1.00–1.11			0.35			–0.34–1.04		0.3
Gender			0.62	0.25–1.58	0.3	0.25–1.58			9.12			–2.74–20.99		0.1
SES			0.97	0.66–1.42	0.9	0.66–1.42			0.23			–4.79–5.24		>0.9
Overall model			$\chi^2 = 4.4$, df = 4, $P = 0.4$									$F(4, 76) = 1.6$, $P = 0.2$, $R^2 = 2.7$		
EAS shyness			0.82	0.56–1.19	0.3	0.56–1.19			–2.04			–6.76–2.69		0.4
EAS emotionality			1.14	0.96–1.35	0.1	0.96–1.35			1.40			–0.70–3.51		0.2
EAS sociability			0.91	0.69–1.20	0.5	0.69–1.20			–0.29			–3.78–3.20		0.9
EAS activity			1.27	0.97–1.67	0.08	0.97–1.67			–2.25			–5.58–1.08		0.2
Gender			0.73	0.32–1.69	0.5	0.32–1.69			6.70			–4.01–17.41		0.2
Overall model			$\chi^2 = 7.2$, df = 5, $P = 0.2$									$F(5, 96) = 1.4$, $P = 0.2$, $R^2 = 1.8$		
FACES cohesion			1.00	0.80–1.24	>0.9	0.80–1.24			–0.07			–2.89–2.74		>0.9
FACES adaptability			0.83	0.65–1.05	0.1	0.65–1.05			2.71			–0.25–5.66		0.07
Gender			0.59	0.26–1.35	0.2	0.26–1.35			12.75			2.21–23.28		0.02
SES			0.87	0.60–1.27	0.5	0.60–1.27			4.86			0.07–9.65		0.05
Overall model			$\chi^2 = 4.0$, df = 4, $P = 0.4$									$F(4, 95) = 2.7$, $P = 0.04$, $R^2 = 6.3$		

R^2 value is the adjusted R^2 . Gender was coded as male = 0, female = 1. Hence in the logistic regression models, males are the baseline category. A higher score on this measure represents lower SES. For analysis, EAS scores were divided by 2, and FACES scores were divided by 3 to aid meaningful interpretation of estimates.

one-third of an adolescent subset of the original sample met DSM-IV criteria for a psychiatric disorder (14). Furthermore, higher mental health service referral rates, lower school completion rates, and poor transition to specialist diabetes care documented in the current assessment suggest there is a psychiatric morbidity associated with growing up with diabetes, even if one accepts at face value the current reports of psychosocial well-being.

The association between child variables at diagnosis and longer-term psychological and functional outcomes is a key finding of the study. Youth with behavior problems and high activity levels at diagnosis were more likely to have ongoing psychological difficulties and to have correspondingly increased rates of referral for mental health services. However in contrast to our findings at 10 years post-diagnosis (14), behavior problems at diagnosis were not directly associated with poor metabolic control history, although they did predict higher mental health referral rates, which in turn were associated with poor metabolic control. Lower family cohesion at baseline predicted higher levels of psychological symptoms in youth 12 years after diagnosis, consistent with previous findings (24) suggesting the importance of family support for youth growing up with a chronic illness. Family functioning measured at diabetes onset did not predict longer-term metabolic control histories in contrast to previous reports of such associations (e.g., 4). It is possible that as distance between assessment time points increases and measurement of variables becomes more distal, other factors attenuate direct relationships between family dysfunction and poor metabolic control.

Metabolic control in this cohort of youth with type 1 diabetes was less than optimal. Almost half of the sample had experienced a seizure or loss of consciousness associated with hypoglycemia and, as a group, they had spent a mean 42% of time since disease onset in poor metabolic control. Current mean A1C level exceeded that associated with the accelerated risk of diabetes complications in the DCCT (1). Over one-fifth of the cohort currently access medical treatment only in times of metabolic crisis and a further 15% receive diabetes care—albeit irregularly for some—from their local medical practitioner. These are similar figures to those reported by Pascaud et al. (25) in their study of youth over the first few years in the adult health care system.

Table 2—Illness variables and current psychosocial and functional outcomes for type 1 diabetes group

Outcomes	YSR/YASR Internalizing problems at follow-up (regression coefficient)				YSR/YASR Externalizing problems at follow-up (regression coefficient)				YSR/YASR Total problems at follow-up (regression coefficient)			
	Estimate	95% CI	P		Estimate	95% CI	P		Estimate	95% CI	P	
Explanatory variables												
Metabolic control	0.02	−0.06 to 0.10	0.7		0.05	−0.02 to 0.13	0.2		0.05	−0.04 to 0.13	0.3	
Seizure	3.94	−0.32 to 8.20	0.07		5.14	1.25–9.02	0.01		6.0	1.77–10.23	0.006	
Onset of diabetes	−3.56	−7.97 to 0.85	0.1		−0.19	−4.22 to 3.84	>0.9		−2.46	−6.85 to 1.92	0.3	
Gender	3.76	−0.53 to 8.05	0.09		−0.85	−4.76 to 3.07	0.7		1.92	−2.34 to 6.17	0.4	
Overall model	$F(4, 100) = 2.2$	$P = 0.07$	$R^2 = 4.6$	$F(4, 100) = 2.1$	$P = 0.09$	$R^2 = 4.0$	$F(4, 100) = 2.7$	$R^2 = 6.2$				
Mental health referral at follow-up (OR)												
	Estimate	95% CI	P		Estimate	95% CI	P		Estimate	95% CI	P	
Metabolic control	1.03	1.01–1.04	0.004		1.03	1.00–1.05	0.05					
Seizure	1.26	0.54–2.94	0.6		1.79	0.50–6.36	0.4					
Onset of diabetes	0.57	0.24–1.40	0.2		0.34	0.07–1.69	0.2					
Gender	0.96	0.41–2.26	>0.9		0.79	0.22–2.81	0.7					
Overall model	$\chi^2 = 11.9$	$df = 4$	0.02		$\chi^2 = 7.3$	$df = 4$	0.1					
Specialist diabetes care at follow-up (OR)												
	Estimate	95% CI	P		Estimate	95% CI	P		Estimate	95% CI	P	
Metabolic control	1.02	1.00–1.04	0.1		1.01	0.99–1.03	0.4					
Seizure	1.57	0.58–4.25	0.4		1.99	0.72–5.48	0.2					
Gender	0.33	0.12–0.93	0.04		0.40	0.14–1.12	0.08					
Overall model	$\chi^2 = 6.7$	$df = 3$	0.08		$\chi^2 = 5.0$	$df = 3$	0.2					

Categorical variables coded as: male = 0, female = 1 (gender); no history of seizure = 0, seizure history = 1 (seizure); later onset diabetes = 0, early onset diabetes = 1 (onset of diabetes); levels coded as 0 are the baseline. For specialist diabetes care and school completion, only participants older than school-leaving age and no longer in pediatric diabetes care were included in analysis ($n = 75$). Thus, onset of diabetes is not included in this analysis.

Together these findings raise serious questions about the efficacy of current transition procedures. Participants who had experienced one or more hypoglycemic seizure reported higher levels of current psychosocial maladjustment, as did the participants accessing suboptimal diabetes care. A history of poor metabolic control was associated with higher mental health referral rates over diabetes lifetime, which is consistent with previous findings (11,12) and with lower rates of study/work participation. These findings reinforce the interdependence of psychological and medical factors in influencing health outcomes.

This report describes psychosocial, functional, and health outcomes in a controlled study of youth with type 1 diabetes followed prospectively from diagnosis for 12 years. The findings highlight the fact that outcome should be considered as a multifaceted concept incorporating psychosocial well-being, successful mastery of life-stage developmental tasks such as school completion and study/work participation, as well as ongoing participation in specialist diabetes care and optimal metabolic control. Behavior problems evident at diagnosis should become a focus for clinical attention and early intervention given their association with ongoing mental health problems. Refinement of transition processes is also indicated if we are to ensure that youth who have benefited from tertiary-level diabetes care in childhood continue to receive such care as they enter adulthood.

Acknowledgments— This research was supported by the Juvenile Diabetes Foundation International (Grant 1-2003-135). E.A.N., A.L., S.F., and G.A.W. report no commercial sponsorships or industry-based research support in the past 12 months. F.J.C. has received research funding support, travel support, and honoraria from the following diabetes-related companies: Novo Nordisk, Eli Lilly, Aventis, Medtronic, Abbott/Medisense, and Animas. He belongs to the Hvideøre Study Group of Childhood Diabetes, which is supported by Novo Nordisk. No other potential conflicts of interest relevant to this article were reported.

This study was presented at the 35th annual meeting of International Society for Pediatric and Adolescent Diabetes, Ljubljana, Slovenia, 2–5 September 2009.

We acknowledge the contributions of Deb Boyce, SN, in locating and recruiting participants.

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