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The Psychological Study of Chronically Ill and Disabled Children: Are Healthy Siblings Appropriate Controls?[1]

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This study examined the appropriateness of siblings as controls in the psychological assessment of children with chronic illness or disability. Findings from 304 cases and 360 randomly selected controls were compared to findings from a subset of 206 case-sibling pairs. Cases were children 6 to 18 years of age with cystic fibrosis, cerebral palsy, myelodysplasia, and multiple handicaps, selected from specialty clinics in two teaching hospitals in the Cleveland area. Results from both data sets were in agreement on major findings indicating that children with cystic fibrosis are not at increased risk for psychopathology, whereas children in the remaining three diagnostic groups show a substantial excess in Mentation Problems and Isolation. The comparisons with matched siblings underestimated pathology in the disabled children in Regressive-Anxiety and aggressive behavior.

Numerous studies have shown that physical illness and disability in childhood might have profound impact on the psychological adjustment of the affected children. Few, however, have employed standardized assessment instruments or control groups. Moreover, in some studies in which control groups were used, the appropriateness of the controls, and hence the validity of the comparisons, was open to question (see reviews by Gayton & Friedman, 1973; Pless & Pinkerton, 1975).

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An appealing strategy followed by some researchers involves the use of physically unimpaired siblings as controls, either alone or in conjunction with a second control group (Demb & Ruess, 1967; Gayton, Friedman, Tavormina, & Tucker, 1977; Klein & Simmons, 1979). There are clear advantages in this approach: Important genetic as well as environmental influences are held constant, thus enabling the researcher to measure the impact of physical disability on the psychological status of the child, uninfluenced by interrelated but irrelevant factors. Such design advantages have not yet been appropriately exploited, however. Previous studies in which siblings were used included, when present, all siblings or all those in a particular age bracket, and formed samples in which some cases had no siblings at all, whereas other cases had more than one sibling each. Comparisons were made between affected children and siblings if they were two independent samples, each constituting a set of independent observations. In reality, the two samples are neither independent nor correlated. Since they are not independent, it should be apparent that the use of a difference-of-means test, or other models that assume independence, is unjustified. On the other hand, since there is not a one-to-one correspondence between cases and controls, the test of the mean of the pair-by-pair differences is also unjustified. (The proper approach entails selecting case-sibling pairs and testing the significance of the difference between means for correlated samples.) The failure to comply with the assumptions that underline statistical models probably has not influenced materially the results of most of these studies. In one instance, however, findings about school dropout of patients and siblings were an artifact of the differences between the number of cases (one) and siblings (ranging from zero to several) that each family contributed to the sample and the associations among family size, social class, and school dropout (Demb & Ruess, 1967).

There is an obvious limitation to the case-sibling design. All only-children or children with siblings below or above the designated age range are necessarily excluded. Consequently, to the extent that the subset of disabled children with eligible siblings has unique psychological attributes, inferences about the general population of chronically ill children might be biased. Clearly, the level of disparity between those with siblings and those without must be considered. Although there is evidence in the literature that ordinal position is a factor in psychological adjustment, it is generally acknowledged that such a factor is confounded with other family variables (Schooler, 1972), variables that would be controlled in a case-sibling study. Moreover, since the distinction here is not between a child with siblings and an only child, but rather between a child with siblings and an only child or a child with siblings outside a designated age bracket, any birth-order effect can

be assumed to be attenuated. It might, however, be the case that birth order, even in this relatively indeterminate sense, has a unique effect on children with chronic physical illness. Direct empirical evidence on this question is not available.

The use of siblings as controls might be questioned also on the ground that they might be at increased risk for psychological disturbance (Breslau, Weitzman, & Messenger, 1981). Thus, for example, in one report in which sick children were compared to siblings, negative findings (i.e., no difference between patients and siblings) were attributed to the possibility that the psychological status of siblings might be adversely affected by their brother's or sister's illness (Klein & Simmons, 1979).

In this paper we examined empirically the appropriateness of siblings as controls. The following questions were addressed: (1) Is a subset of disabled children 6 to 18 years old who have one or more siblings in this age range a biased sample of the entire study cohort (i.e., including those without siblings)? (2) Are inferences about disabled children drawn from comparisons with siblings different from inferences drawn from comparisons with a randomly selected sample of the general population of children?

METHOD

Subjects

Families of children with cystic fibrosis, cerebral palsy, myelodysplasia, and multiple physical handicaps were selected from four pediatric specialty clinics in two teaching hospitals in Cleveland, Ohio, whose case loads provide relatively representative samples of area children in these diagnostic categories. Families of patients 3 to 18 years of age, who resided in the Cleveland area, were asked to participate in the study. From 460 eligible families, 369 (80%) complete interviews were obtained. In families with patients 6 years of age and older, data were obtained on the psychological functioning of the child. Of the 304 patients in this age range, there were 65 children with cystic fibrosis, 98 with cerebral palsy, 63 with myelodysplasia, and 78 with multiple physical handicaps.

Procedure

For a comparison group (controls), a multiple-stage probability sample was designed to represent all Cleveland area families with one or

more children 3 to 18 years old.[3] From 530 eligible families, 456 (86%) complete interviews were obtained. In each "control" family, a randomly selected child between the ages of 3 and 18 years, the age range of the disabled children, was defined as the index child. Psychological functioning was measured on 360 children who were 6 to 18 years old. In *all* study families, those with disabled children and "controls," in which there were normal siblings 6 to 18 years old, psychological measurements were also obtained of a randomly selected sibling in this age group. Data were gathered from mothers in home interviews using a structured questionnaire.

Psychological functioning of index children and siblings was measured by the Psychiatric Screening Inventory, developed by Langner, Gersten, McCarthy, Eisenberg, Greene, Herson, and Jameson (1976). The measure is based on mothers' answers to 35 items and comprises seven subscales, each with 5 items, measuring seven areas of child behavior: Self-Destructive Tendencies, Mentation Problems. Conflict with Parents, Regressive-Anxiety, Fighting, Delinquency, and Isolation. The sum of the 35 items provides a composite measure of psychological disorder and a cutoff point of 6 distinguishes between severe psychological impairment and moderate or no impairment (Langner, Gersten, Greene, Eisenberg, Herson, & McCarthy, 1974; Langner et al., 1976).

The construction of Langner's Screening Inventory was based on a factor analysis of a large pool of items. The seven subscales, which measure the derived factors, cover the major domains of child behavior commonly reported in studies using factor-analytic methods as well as a priori formulations. The measure is not without its limitations, however. Chiefly, these stem from its reliance on mothers' reports. Since a mother's report is dependent on her knowledge and perception of the child, ratings based on it are open to criticisms of bias. To guard against bias, Langner and his associates avoided questions that asked the mother to judge the child's behavior. Instead, questions about specific behaviors, which left less room for distortion, were used. A recent review of research in this field concluded that mothers provide a more complete picture of their children's behavior than do teachers or other observers (Achenbach, 1978).

[3]The random selection of controls avoids the problems that plague studies using matched controls, in which known and unknown confoundings remain unmatched. Further, our sampling scheme produced a representative sample of the general (normative) population, rather than an idiosyncratic sample of indeterminate generalizability, as might be the case when controls are matched. When a random sample is used, "matching" is accomplished statistically in the analysis.

RESULTS

Children with disabilities and controls were nearly evenly distributed across sex and age categories. The samples were also similar with respect to sibship size, age and sex of eligible sibling, age of youngest child in the family, and mother's age and marital status. Controls had somewhat higher income and higher level of maternal education. Means of family income for disabled and control groups were $16,000 and $21,000, respectively ($p < .01$), and means of mother's years of schooling for the respective samples were 12 and 12.5 ($p < .01$).

Of the 304 families with disabled children 6 to 18 years of age, 206 contained also at least 1 physically unimpaired sibling in this age bracket, thus providing 206 matched "case-sibling" pairs. The question of whether the 206 "cases" in this subset are a biased subsample of the 304 disabled children was examined by comparing them to the 98 children for whom eligible siblings were unavailable. Table I shows the comparisons of the two groups on the total inventory and the seven subscales. As can be seen, with the exception of Regressive-Anxiety, on which those without siblings scored significantly higher than those with siblings, the two groups were undistinguishable on all behavioral domains and on the total inventory (Table I). Data on the rate of severe psychological impairment are consistent with these results. The proportion of those classified as psychiatrically severely impaired (scoring 6 and above on the total inventory) was almost identical in the two groups, 27% and 28% in those with and without siblings, respectively. These data do not support the notion that disabled children

Table I. Comparisons of Disabled Children With and Without Eligible Siblings on the Psychiatric Impairment Inventory

	With siblings ($N = 206$)		Without siblings ($N = 98$)		
	$\bar{x}$	*SD*	$\bar{x}$	*SD*	p^a
Self-destructive tendencies	.15	(.46)	.24	(.58)	n.s.
Mentation problems	1.38	(1.42)	1.24	(1.40)	n.s.
Conflict with parents	.49	(.79)	.42	(.71)	n.s.
Regressive-anxiety	.60	(.73)	.81	(.82)	< .05
Fighting	.48	(.71)	.45	(.79)	n.s.
Delinquency	.19	(.45)	.22	(.55)	n.s.
Isolation	.58	(.87)	.61	(.97)	n.s.
Total inventory	3.88	(3.21)	3.96	(3.55)	n.s.

[a] For a two-tailed t test for independent samples.

Table II. Comparisons of Disabled Children and Siblings (Matched Pairs) on the Psychiatric Inventory ($N = 206$)

	Disabled children		Siblings		
	$\bar{x}$	*SD*	$\bar{x}$	*SD*	p^a
Self-destructive tendencies	.15	(.46)	.21	(.65)	n.s.
Mentation problems	1.38	(1.42)	.56	(1.00)	$< .005$
Conflict with parents	.49	(.79)	.44	(.94)	n.s.
Regressive-anxiety	.60	(.73)	.55	(.71)	n.s.
Fighting	.48	(.71)	.64	(.91)	$< .05$
Delinquency	.19	(.45)	.33	(.67)	$< .05$
Isolation	.58	(.87)	.19	(.60)	$< .005$
Total score	3.88	(3.21)	2.93	(3.64)	$< .005$

[a] For a two-tailed t test for correlated samples.

with siblings constitute a biased subset of the total sample of disabled children in our study. The exclusion of disabled children who do not have an eligible sibling in a "case-sibling" design does not constitute an important limitation, according to these results.

The question of whether inferences about disabled children drawn from comparisons with siblings are different from those drawn from comparisons with randomly selected controls was examined next. In Table II appear the matched-pairs comparisons of disabled children and healthy siblings on the total inventory and the seven subscales. Disabled children differed significantly from their siblings on the total inventory and on four of the seven subscales. The differences in Mentation Problems and Isolation were particularly marked. It is in these two behavioral domains that the disabled children manifested considerable excess in psychopathology compared to their healthy siblings.[4] On Fighting and Delinquency, two scales tapping interpersonal aggression, rash behavior, and conduct problems at school disabled children scored significantly lower, indicating less aggressive behavior than their siblings. Finally, as can be seen in Table II, in three areas, Self-Destructive Tendencies, Conflict with Parents, and

[4] We examined the possibility that the mean difference between disabled children and siblings in Mentation Problems was associated with the presence of mental retardation in some of the disabled children. Although we have not measured IQ levels, we have used information from clinics' records to classify the disabled children into three categories of mental retardation: severe, moderate, or none. As expected, mean scores on Mentation Problems varied directly with level of retardation. However, the mean Mentation Problems score of 137 disabled children with *no* mental retardation was still significantly higher than that of their siblings, .99 and .45, respectively ($p < .005$).

Table III. Comparisons of Children with Cystic Fibrosis and Siblings (Matched Pairs on the Psychiatric Inventory ($N = 42$)

	Disabled children		Siblings		
	$\bar{x}$	*SD*	$\bar{x}$	*SD*	p^a
Self-destructive tendencies	.12	(.39)	.09	(.37)	n.s.
Mentation problems	.69	(1.07)	.43	(.80)	n.s.
Conflict with parents	.50	(.80)	.57	(.86)	n.s.
Regressive-anxiety	.64	(.76)	.59	(.73)	n.s.
Fighting	.59	(.77)	.62	(.76)	n.s.
Delinquency	.21	(.52)	.26	(.54)	n.s.
Isolation	.14	(.52)	.21	(.90)	n.s.
Total inventory	2.90	(2.95)	2.79	(2.82)	n.s.

[a] For a two-tailed t test for correlated samples.

Regressive-Anxiety, the mean scores of the disabled children were not significantly different from those of their healthy siblings. An analogous series of matched comparisons on the 222 pairs of index children and siblings from the randomly selected control group (in which the index children and the siblings were physically unimpaired) revealed no statistically significant differences on any of the seven subscales or on the total inventory. Clearly, the markedly different pictures displayed by the disabled children and their siblings must be regarded as evidence of the effect of physical disability. Whether or not these results provide an accurate assessment of these effects will be judged below on the basis of a comparison with another set of data. However, before these data are introduced, we present in Table III to VI comparisons of the disabled children and their healthy siblings according to diagnostic category.

In Table III appear the results for cystic fibrosis. Mean differences between children with cystic fibrosis and their healthy siblings are slight and statistically insignificant. This is the case for the total inventory as well as for all seven subscales. The negative findings on the impact of cystic fibrosis on psychological functioning are in accord with previous research, in which patients were assessed directly or via parents' or teachers' ratings (Drotar, Doershuk, Stern, Boat, Boyer, & Mathews, 1981; Gayon et al., 1977).

Results for cerebral palsy, presented in Table IV, replicated closely those for the total subset of disabled children and siblings, presented in Table II. A marked and statistically significant excess in psychopathology was observed in the areas of Mentation Problems and Isolation. Although in Fighting and Delinquency children with cerebral palsy scored lower than their healthy siblings, the difference reached statistical significance only in

Table IV. Comparisons of Children with Cerebral Palsy and Siblings (Matched Pairs) Psychiatric Inventory ($N = 68$)

	Disabled children		Siblings		
	$\bar{x}$	*SD*	$\bar{x}$	*SD*	p^a
Self-destructive tendencies	.15	(.50)	.26	(.80)	n.s.
Mentation problems	1.40	(1.44)	.54	(1.03)	< .0005
Conflict with parents	.50	(.82)	.47	(1.01)	n.s.
Regressive-anxiety	.60	(.76)	.63	(.77)	n.s.
Fighting	.50	(.76)	.78	(1.09)	n.s.
Delinquency	.13	(.38)	.41	(.76)	< .01
Isolation	.73	(.91)	.21	(.53)	< .0005
Total inventory	4.01	(3.25)	3.31	(4.30)	n.s.

[a] For a two-tailed t test for correlated samples.

the Delinquency comparison. Since the size of the cerebal palsy group is less than one-third as large as that of the total sample, a difference that would be statistically significant for the larger group is not so for the cerebral palsy group. The same explanation may account also for the negative result on the total inventory, although the mean difference here is smaller than that in the total sample comparison.

Table V presents the results for myelodysplasia, and, as can be seen, the pattern of markedly increased disorder in Mentation Problems and in Isolation characterized this group as well. In Fighting and Delinquency, children with myelodysplasia, like children with cerebral palsy, scored lower than their healthy siblings; the differences here reached statistical significance in both behavioral domains.

Table V. Comparisons of Children with Myelodysplasia and Siblings (Matched Pairs) on the Psychiatric Inventory ($N = 45$)

	Disabled children		Siblings		
	$\bar{x}$	*SD*	$\bar{x}$	*SD*	p^a
Self-destructive tendencies	.22	(.60)	.33	(.83)	n.s.
Mentation problems	1.69	(1.41)	.73	(1.03)	< .0005
Conflict with parents	.40	(.78)	.58	(1.21)	n.s.
Regressive-anxiety	.47	(.62)	.35	(.57)	n.s.
Fighting	.42	(.66)	.80	(1.01)	< .05
Delinquency	.11	(.32)	.31	(.73)	< .05
Isolation	.69	(.73)	.13	(.50)	< .0005
Total inventory	4.00	(3.05)	3.24	(4.22)	n.s.

[a] For a two-tailed t test for correlated samples.

Table VI. Comparisons of Children with Multiple Handicaps and Siblings (Matched Pairs) on the Psychiatric Inventory ($N = 51$)

	Disabled children		Siblings		
	$\bar{x}$	*SD*	$\bar{x}$	*SD*	p^a
Self-destructive tendencies	.12	(.32)	.14	(.40)	n.s.
Mentation problems	1.69	(1.49)	.57	(1.10)	< .0005
Conflict with parents	.59	(.78)	.20	(.53)	< .005
Regressive-anxiety	.67	(.77)	.59	(.70)	n.s.
Fighting	.41	(.64)	.37	(.60)	n.s.
Delinquency	.33	(.55)	.29	(.61)	n.s.
Isolation	.65	(1.05)	.21	(.46)	< .01
Total inventory	4.45	(3.43)	2.37	(2.63)	< .0005

[a] For a two-tailed t test for correlated samples.

Table VI depicts the results for multiple handicaps, a miscellaneous category of congenital disorderes, all with physical stigmata including in most cases neurological deficits. Children in this category also scored higher than their siblings on Mentation Problems and Isolation. However, in contrast to children with cerebral palsy and myelodysplasia, children with multiple handicaps scored higher than their siblings on four other subscales. On Conflict with Parents the mean difference reached statistical significance. The pervasive excess in psychiatric disorder in this group was reflected in the high mean total inventory score, compared to children in other diagnostic categories. The mean difference between children with multiple handicaps and their healthy siblings on the total inventory was marked and statistically significant.

Several conclusions can be drawn from these data. Children with cerebral palsy, myelodysplasia, and multiple handicaps are at increased risk of psychiatric disorder in the areas of Mentation Problems and Isolation. In contrast, children with cystic fibrosis do not show increased disorder in any area measured by the screening inventory. The proportions of disabled children and siblings in each diagnostic group who fell in the range of severe psychiatric impairment are consistent with this general picture. The proportion of children with cystic fibrosis who were classified as psychologically severely impaired was similar to that of their siblings. In contrast, the rates of severe impairment in children with cerebral palsy, myelodysplasia, and multiple handicaps, which ranged between 24% and 37%, were markedly higher than among the matched healthy siblings, which ranged betweeen 10% and 17%.

A comparison of all 304 disabled children 6 to 18 years old, including those with no eligible siblings, and the randomly selected sample of the

Table VII. ANOVAs of the Psychiatric Inventory of Disabled Children in Four Diagnostic Groups and Randomly Selected Controls (Means, F statistic, Eta^2, Scheffé Tests)

		CF (65)	CP (98)	Myelo (63)	MH (78)	Controls (360)
Self-destructive tendencies	$\bar{x}$	.11	.17	.22	.20	.15
	SD	(.36)	(.56)	(.55)	(.52)	(.48)
			$F = .68$		Eta^2 = .00	
Mentation problems[c]	$\bar{x}$	.71	1.49	1.41	1.63	.55
	SD	(1.06)	(1.53)	(1.40)	(1.41)	(.93)
			$F = 26.03$[a]		Eta^2 = .13	
Conflict with parents[b]	$\bar{x}$	.43	.51	.38	.54	.26
	SD	(.77)	(.81)	(.73)	(.75)	(.61)
			$F = 4.71$[a]		Eta^2 = .02	
Regressive-anxiety[b]	$\bar{x}$	.58	.68	.59	.76	.42
	SD	(.68)	(.83)	(.66)	(.81)	(.61)
			$F = 5.90$[a]		Eta^2 = .02	
Fighting	$\bar{x}$	.52	.53	.38	.40	.42
	SD	(.73)	(.89)	(.61)	(.61)	(.71)
			$F = .80$		Eta^2 = .00	
Delinquency	$\bar{x}$	.15	.19	.11	.31	.18
	SD	(.44)	(.57)	(.32)	(.52)	(.55)
			$F = 1.47$		Eta^2 = .00	
Isolation[c]	$\bar{x}$	.12	.70	.60	.85	.20
	SD	(.45)	(.87)	(.71)	(1.17)	(.42)
			$F = 24.84$[a]		Eta^2 = .13	
Total score[c]	$\bar{x}$	2.63	4.28	3.70	4.68	2.18
	SD	(2.65)	(3.71)	(2.94)	(3.33)	(2.81)
			$F = 18.22$[a]		Eta^2 = .09	

[a] $p < .001$.
[b] Controls are significantly different from CP and MH (Scheffé tests).
[c] Controls are significantly different from CP, Myelo, and MH (Scheffé tests).

general population of children in the same group is presented in Table VII. Disabled children were classified into four diagnostic categories and a series of ANOVAs was performed on five groups—the four disabled groups and "controls." In addition to testing the statistical significance of the differences across the five groups, we also measured the degree of association between each psychological variable and the classification variable. Scheffé comparisons (Scheffé, 1959) were calculated when the ANOVAs yielded statistically significant results. As can be seen, on Mentation Problems and on Isolation, the differences across the five groups were most striking. The results are statistically significant and the degree of association, as measured by Eta^2, is the highest, .13 in each. Scheffé comparisons indicate that in each of these two areas controls scored significantly lower than children with cerebral palsy, myelodysplasia, and multiple handicaps, but not cystic fibrosis. The results on the total inventory were similar, but somewhat attenuated ($Eta^2 = .09$).

Although these findings replicate the results of the siblings' comparisons, there are other findings in Table VII that do not. In comparison with the randomly selected controls, but not in comparison with their siblings, children with disabilities scores higher on Conflict with Parents and Regressive-Anxiety. For those with cerebral palsy and with multiple handicaps, the differences reached statistical significance. The associations with disability were, however, low; in both areas Eta^2 was .02. Further, in comparison with randomly selected controls, children with disabilities did not score significantly lower on Fighting or Delinquency, as they did in comparison with their siblings.

A series of analyses of covariance, testing differences across means of the five groups on the total inventory and the seven subscales with family income and mother's education as covariates, was also performed. Results replicated those in Table VII, with the exception that the adjusted mean difference between cystic fabrosis patients and controls on Regressive-Anxiety reached statistical significance ($p < .05$).

DISCUSSION

Our data indicates that the use of siblings as controls in a matched-pairs design does not introduce a selection bias attendant on the inevitable exclusion of disabled children with no eligible siblings (i.e., the only child, or the child with siblings outside the designated age range).

Results from comparisons with siblings and with randomly selected controls are in agreement on major findings. Both approaches reveal that (1) children with cystic fibrosis are not at increased risk for psychopathol-

ogy, and (2) children in the remaining three diagnostic categories under study, namely, cerebral palsy, myelodysplasia, and multiple handicaps, have excess pathology in the areas of Mentaton Problems and Isolation and greater risk of being severely impaired psychologically. There were, however, disparities between the two approaches. The case-sibling approach underestimated pathology in the disabled children in Regressive-Anxiety and in three areas of aggressive behavior. These additional psychological problems were, however, milder and less pervasive. In Conflict with Parents and Regressive-Anxiety, the two areas on which disabled children scored higher than random controls, but not differently from their siblings, effects were slight. (Eta^2 was .02 in each case.) Moreover, the excess in pathology was found to be statistically significant only for children with cerebral palsy and multiple handicaps, not with myelodysplasia. On Fighting and Delinquency, areas on which disabled children scored lower than siblings but the same as randomly selected controls, the discrepant findings do not amount to a detection of additional psychopathology.

The more favorable picture that emerges when disabled children are compared to their siblings, namely, that they are less aggressive and less regressed or anxious, is a picture biased by the fact that in these behavioral domains siblings show increased disorder, compared to the general population of children (Breslau et al., 1981; Breslau, 1982). Disabled children *and* their siblings have greater disorder than randomly selected controls in Conflict with Parents and Regressive-Anxiety. Apart from this shared psychopathology, siblings show somewhat more aggressive behavior outside the home, as measured by the Fighting and the Delinquency subscales.

The implications of the bias in the case-sibling comparison depend on the prognostic significance of the areas in which disorder in the disabled children might be obscured, namely, Regressive-Anxiety and Conflict with Parents. On the basis of previous research on children generally (Gould, Wunsch-Hitzig, & Dohrenwend, 1980), we might be inclined to emphasize the prognostic prominence of Conflict with Parents but view Regressive-Anxiety symptoms with less concern. Whether or not these general trends exist also among children with physical disability is yet unknown. The developmental course of disabled children and the distinction between psychological problems that they are likely to outgrow and those that forecast pathology later on are yet to be described.

Because of these uncertainties, it might be prudent to evaluate the psychological adjustment of disabled children by comparing them to children other than their own siblings. In recommending this more conservative approach, we also take into account the limitations of our measurement method for identifying the type and level of disturbance in the disabled

children as well as their siblings. Recent advances in psychiatric diagnosis should enable future research in this field to estimate the psychological impact of disability on affected children and their siblings with greater precision. Longitudinal studies are needed to inform us about continuity and change in the psychological concomitants of childhood illness and disability.

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