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ABSTRACT

To investigate vulnerability to psychological and emotional stress among chronically ill children, a battery of personality tests was selectively administered to 144 children (5- to 19-years-old) afflicted with one of the following conditions: diabetes, asthma, cystic fibrosis, or hearing impairment. Analyses centered on comparisons of norms developed for each scale with overall sample scores and scores broken down by age, sex, and type of illness. While some differences from normal children were noted (such as the hearing impaired Ss deviated from established norms in terms of lowered self-concept and that adolescents tended toward introversion), results consistently demonstrated Ss' functional strengths and coping abilities rather than their deviance from the norm. (LH)

Chronically Ill Children: A Psychologically and Emotionally Deviant Population?

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Chronically Ill Children: A Psychologically and Emotionally Deviant Population?

While it is currently in vogue for mental health professionals to talk about the social and emotional concomitants of physical illness on children and their families, these topics have received little experimental attention. Chronic physical illness can lead to adaptational handicaps for the child and his family (Diller, 1972; Bakwin and Bakwin, 1972). "Handicap" then can refer to the set of problems the child may develop in coping with the demands of reality, all of which are secondary to the physical illness process. Difficulties at home, at school, while in the hospital, or while interacting with peers can be explained on the basis of the handicapping nature of the illness. Consequently, such children are "at risk", vulnerable (Green, 1965) to stress and psychopathology, especially in the absence of environmental support. Similar claims have been advanced about the deleterious effects of a physically handicapped child on overall family functioning and family integration (Farber, 1959). From this perspective, all the family members, including the siblings, can be adversely affected by the presence of a physically handicapped child in the family.

Thus far, the available literature has focused mainly on defining the emotional problems the illness may lead to. Bakwin and Bakwin (1972) outline three common types: 1) the illness may interfere with the normal activity of the child and thereby lead to increased frustration; 2) it may make the

child feel different from his peers with detrimental effects on self-concept; 3) the illness may foster inappropriate parental attitudes and behaviors, ranging from overprotection to rejection. The child seems most affected in increased difficulties in growing towards independence, a problem often compounded by parental difficulty in letting go. The illness may become a rationale for failure or a tool for enlisting sympathy or tyranizing parents, teachers, and siblings. Mattson (1972) pointed out that when the family insists on self-responsibility by the child and when the child is allowed to communicate openly about the illness, the potential for the development of problem behaviors is significantly reduced. Yet, the parents often lack the skills or the energy (Gayton and Friedman, 1973) to provide such learning opportunities for their children.

One may catalogue each childhood illness category to derive the specific psychosocial implications postulated for each. Gayton and Friedman (1973) concluded from their review of the literature that Cystic Fibrosis results in profound social and emotional consequences for the child and his family. They pointed out that the frequent hospitalizations and progressive deterioration of the child lead to added stresses which the family has difficulty managing. Gayton, Friedman, Tavormina, and Tucker (in preparation) interviewed the families of 45 CF patients to determine the specific problems each faced in coping with the illness. Mothers, fathers, patients, and well-siblings were interviewed and given a battery of psy-

chosocial tests. Preliminary data indicate a number of problem areas, especially in the increased tension the day-to-day living which this disease engenders.

Researchers from Loughlin and Mosenthal in 1944 to Knowles in 1971 have concluded that a considerable number of diabetic children have behavioral or personality problems. These problems result from the need for constant attention and special diets, preoccupation with urine examinations and injections, and the knowledge that the child is different from his peers. Since diabetics have no visible physical disability they have no ready way to explain any inabilities to keep up in activities to doubting peers. Swift, Seidman, and Stein (1967) found support for their hypothesis that diabetic children show more social maladjustment than non-diabetic controls as judged by clinical evaluations and psychological test results. Some consequences of the self-doubt and low self-concept that typified the children in this study were reflected in the range of pathological behaviors they developed: from extreme aggressiveness with a "devil may care" attitude to shyness and isolation from peers. In addition to these social and emotional consequences, the child must learn proper ways to manage his disease or else face severe physical repercussions such as insulin shock.

The psychosocial concomitants of the psychophysiologic disorder of asthma have been well described in the literature (Werry, 1972; Purcell, Weiss, and Hahn, 1972). In fact, Werry concluded that asthmatic children seen in hospitals and clinics

showed evidence of increased psychopathology and abnormal parenting much to the same degree as that seen in other physically handicapped children. Similarly, the hearing impaired child suffers from a lack of socialization skills, has difficulty forming interpersonal relationships, and is often isolated from other children (Bakwin and Bakwin, 1972). Rainer, Altshuler, and Kallman (1963) added that interventions are extremely difficult with hearing impaired children, because of their postulated severe pathology, conceptual immaturity, poor motivation, and lack of communication skills.

The list of such studies across handicapping conditions seems endless (for a good overview of other conditions, see Diller, 1972). These results with their focus of pathology have created a set, bias, or stereotype of the handicapped child and his family as a deviant or at least deficient subset of the population.

From the hypotheses that abound in the literature, one can get the impression that physically ill children show social maladjustment, low self-concept, increased anxiety and immaturity, and social isolation much more frequently than any normative group of children. Yet, since most of the studies in the current literature were based on assumptions, clinical impressions, subjective evaluations, or abbreviated projective techniques, the findings should be considered tentative and largely speculative. It is critical to determine how these children and their families score on more standardized, systematic measurement instruments, before conclusions about psy-

chopathology can be made reliably. The present study was geared to test this notion by evaluating the "deviance" of a group of physically handicapped children when compared to the standardization norms on a battery of personality measures.

Method

Subjects

In the overall project, 144 families with a diabetic, asthmatic, cystic fibrotic, or hearing impaired child participated. One hundred sixty families were initially contacted, but permission was secured from 144. Children's ages ranged from five to 19 with an average age of 12. A wide range of severity of illness was represented, as determined by reports from the family physician. A wide range of family income level also was represented; $200 to $4000 per month, with an average of $1200. Twelve percent of the sample was black, the others were white.

Procedure

Each family was contacted initially by letter with a phone followup to explain the project and to secure permission for participation. If permission was granted, a home visit was made by a two person assessment team to administer the measures. Within the larger study, both parents (if available) were interviewed and tested as was the target child. Interviews were administered to children over the age of nine, and all children over the age of five received the testing battery. Finally, a segment of the interaction between the child and his/her parents was tape recorded for subsequent analysis.

The present study will report only on the results for the testing battery taken by the child.

Instruments

A battery of measures was chosen in an attempt to sample areas of personality functioning previously cited as important in physically handicapped children. However, criteria for selection included ease of administration and demonstrated validity and reliability for each instrument:

1) The Piers-Harris Self-Concept Scale (Piers and Harris, 1967) provides a total self-concept score rated by the subject. Factor analysis of the scale has resulted in six sub-factors, each of which can be scored separately, but for which there are as yet no standardization norms. These factors include self attitudes on behavior, intellectual and school status, physical appearance and attributes, anxiety, popularity, and happiness and satisfaction.

2) The Nowicki-Strickland Locus of Control Scale for Children (Nowicki and Strickland, 1973) measures the relative internal-external attribution of control as rated by children and adolescents. One total score is derived from the 40 yes-no questions. Higher scores represent more external locus of control.

3) The Junior Eysenck Personality Inventory (Eysenck, 1966) represents a revised version of the adult scale, specifically worded for children. It taps the dimensions of social desireability (lie scale), stability-instability (neuroticism),

and sociability (introversion-extroversion scale).

4) The Missouri Children's Picture Series (Sines, Pauker, and Sines, 1971) is a non-verbal personality test for children. Each child must sort 238 picture-cards into categories of "fun" and "not-fun". Based on the child's responses, eight scales are coded: conformity, masculinity-femininity, maturity, aggression, inhibition, activity level, sleep disturbance, and somatization. Children between the ages of five and 14 received this instrument.

5) The Psychological Screening Inventory (Lanyon, 1970) is a personality measure for adolescents and was administered to those over 14 in the present study. It taps areas of alienation, social non-conformity, discomfort (anxiety), expressiveness, and defensiveness.

Results

Analyses centered on comparisons of the overall sample scores and scores broken down by age, sex, and type of illness with the norms developed for each scale. In light of the large number of tests performed, an alpha-level of .01 was used in testing for significance.

Table 1 presents the results across the Piers-Harris Scale. The mean score for the entire sample was significantly

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Insert Table 1 here

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higher than the standardization norms. In terms of illness

categories, all followed this pattern with the exception of the hearing impaired children who scored significantly below both the scale norms and the rest of the sample. There were no overall sex differences on the scale, but boys reported significantly less problems with physical appearance and attributes and tended ($p < .05$) to report more behavior problems than girls. There were no clear-cut age trends, but the 11 to 13 year old group showed a tendency to report fewer self-concept problems.

On all three scales of the Eysenck Inventory (Table 2),

Insert Table 2 here

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sample scores closely approximated scale norms. Similarly, no overall differences between scale norms and sample scores were found on the Locus of Control Scale (Table 3). Boys tended ($p < .05$) towards less social desireability (lowered lie scale scores) and more instability (higher neuroticism) than girls. The hearing impaired children recorded significantly higher

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Insert Table 3 here

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neuroticism scores and significantly more external locus of control than did their counterparts. The younger children (5-10) recorded higher neuroticism scores and the older (14-19) recorded higher lie and lowered extraversion scores,

while the 11 to 13 year olds consistently scored closest to the scale norms.

Sample children recorded significantly higher scores on two (aggression and activity level) of the 8 scales of the Missouri Children's Picture Series (Table 4) than the standardization norms. There were no clear-cut sex differences, but the girls recorded less maturity ($p < .05$) than the boys on this scale. Again, the hearing impaired children stood out

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Insert Table 4 here

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as less conforming and more aggressive than the others, while the cystic fibrotic children appeared ($p < .05$) somewhat more dependent and less mature than the other groups. No significant age differences were found, with the exception of a trend ($p \leq .05$) for the younger children to appear less conforming.

The adolescents reported significantly more alienation on the Psychological Screening Inventory (Table 5) than did the standardization sample, especially the diabetics and the

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Insert Table 5 here

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hearing impaired. Overall scoring patterns on the other scales conformed to the published norms. Girls were significantly more expressive than boys, and the asthmatic adolescents appeared more defensive, but no other significant patterns could be detected.

Discussion

The overall patterning of scores closely approximated scale norms across instruments. The "typical" child in the study performed much like a "normal" child and the scoring distributions also followed normative patterns with respect to variance. Even though there were some clear cut exceptions, the normalcy rather than the deviance of this sample was demonstrated across measures. In short, the children's functional strengths noticeably outweighed their weaknesses.

While there were few differences among scoring patterns for the asthmatic, diabetic, and cystic fibrotic youngsters, the hearing impaired group stood out as different and more closely fit the hypothesis of the vulnerable child. On a number of scales, the hearing impaired children deviated from the established norms, most noticeably in terms of lowered self-concept and more pronounced instability. Nevertheless, before using a pathological label for such children, one must consider that they had the most difficult time completing the verbally oriented measures and that their families fell in the lowest socioeconomic categories in the present sample, both of which could have affected their scoring patterns.

For the other groups, some findings conformed to stereotyped expectancies. The diabetics were alienated and somewhat rebellious, and the asthmatics were more defensive. The cystic fibrotic youngsters were more dependent, less mature, and voiced more problems with intellectual and school status and

their physical appearance. Yet, the validity of these stereotypes must be questioned seriously and necessarily counterbalanced by consideration of the overriding strengths in functioning demonstrated across scales. Clearly, one has the choice to focus on the strengths these youngsters demonstrated or to ignore the coping skills and dwell on the areas of weakness.

In line with other results, the boys had more problems than the girls. Boys were more unstable, restless, and moody and less verbally expressive. They also made less socially desireable responses than the girls. However, the girls (especially ages 11 to 13) were less mature than the boys, a puzzling finding in light of the other results. Whatever the case, sex differences in the development of physically handicapped children warrant further experimental attention.

Some age specific differences were also intriguing. The adolescents were more alienated, made more socially desireable responses, and were less sociable than the other children. On the other hand, the youngest children (aged 5 to 10) were less stable and less conforming than the other groups. Such results may suggest a developmental progression for handicapped children in which they learn to deal with the fact that they differ from other children. The instability, high aggression and activity level, and reduced conformity may represent ways in which the younger children attempt to cope with beginning perceptions of their illness. The adolescent introversion may reflect the fact that they have become more

aware of their condition and its effects. Nevertheless, their differences in functioning do not translate into pathology, especially in light of their overriding strengths across other areas tapped by the present study. Realistically, these children are "different," and these results illustrated some of their attempts to come to grips with that reality.

Consequently, in contrast to the present literature and the prevailing attitudes about physically handicapped children, these results consistently demonstrated the strengths and coping abilities of this sample of children. Clearly, exceptions and differences were noted, but to focus on the "deviance" obscures the fact that most of these children are adapting successfully in spite of their handicaps. Indeed, physical handicap or physical illness may be a convenient culprit variable or scapegoated explanation for behaviors evidenced by children referred for problems, who also happen to have a handicapping condition. But, when one evaluates the entire sample of such children, the strengths rather than the weaknesses stand out most clearly.

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Table 1: Piers Harris Results Across Sex, Illness, and Age Variables

		Total Self-concept		Behavior		Intellectual and School Status		Physical Appearance and Attributes		Anxiety		Popularity		Happiness and Satisfaction	
	N	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD
Published Norms:		51.8*	13.9	(N O		N O R M S		A V A I L A B L E)							
for Entire Sample	134	58.0	12.1	3.4**	3.4	5.0	3.8	4.6	2.9	3.9	2.9	3.4	2.7	1.8	2.0
by Sex:															
Male	70	58.4	11.3	3.9	3.5	4.5	3.6	3.9	2.6	3.5	2.8	3.4	2.7	1.7	2.0
Female	64	57.5	13.0	2.8	3.2	5.5	4.0	5.3	3.1	4.2	3.1	3.4	2.8	1.9	2.1
Illness:															
Asthma	19	61.0	9.2	2.7	2.5	4.0	3.1	3.6	2.1	3.2	2.3	3.1	2.4	1.1	1.3
C.F.	26	58.1	11.0	2.9	3.4	5.8	4.2	5.1	2.9	3.7	2.9	3.6	2.6	1.4	1.6
Diabetes	75	59.3	12.9	3.1	3.3	4.3	3.4	4.7	3.1	3.7	3.0	2.8	2.6	1.6	1.9
Hearing	14	46.9	7.1	6.5	3.5	8.4	3.8	4.5	2.9	6.7	1.9	6.7	2.5	4.2	2.5
by Age:															
5-10 years	40	56.9	11.5	3.9	3.5	5.1	3.5	4.0	2.4	4.1	2.4	4.1	2.3	1.5	1.7
11-13 years	58	60.0	11.9	3.0	3.7	4.6	3.8	4.7	3.0	3.3	2.9	2.9	2.6	1.5	1.9
14-19 years	36	56.1	12.9	3.5	2.7	5.4	4.1	5.2	3.2	4.6	3.3	3.4	3.3	2.6	2.3

* higher total score is more appropriate

** higher scores on the 5 subscales indicate more [illegible]

Table 2: Junior Eysenck Personality Inventory Results Across Illness, Sex, and Age, Expressed as Standardized Z Scores

			Lie		Neuroticism		Extroversion	
		N	$\bar{X}$ Z	SD	$\bar{X}$ Z	SD	$\bar{X}$ Z	SD
Norms			0	1.0	0	1.0	0	1.0
Entire Sample		129	-.01	1.22	.21	1.25	.02	1.05
by Sex:	Male	67	-.20	1.06	.40	1.16	.14	.99
	Female	62	.21	1.35	.00	1.33	-.10	1.10
by Illness:	Asthma	19	-.11	1.72	.22	1.07	.32	.95
	C.F.	27	.06	1.00	-.30	1.11	.16	.82
	Diabetes	74	-.07	1.18	.30	1.32	-.04	1.11
	Hearing	9	.56	.91	.95	1.08	-.48	1.20
by Age:	5-10 years	37	-.35	1.14	.71	1.04	.18	1.03
	11-13 years	56	-.19	1.08	.05	1.23	.09	.97
	14-19 years	36	.63	1.31	.09	1.37	-.24	.16

Table 3: Nowicki-Strickland Locus of Control Scale Results Across Illness, Sex, and Age, Expressed as Standardized Z Scores

		N	$\bar{X}$ Z	SD
Norms			0	1.0
for Entire Sample		128	.21	1.26
by Sex:	Male	68	.11	.96
	Female	60	.32	1.53
by Illness:	Asthma	19	.16	1.16
	C.F.	26	-.02	1.20
	Diabetes	74	.19	1.31
	Hearing	9	1.05	1.04
by Age:	5-10 years	39	.20	.95
	11-13 years	54	.20	1.50
	14-19 years	35	.23	1.20

Table 4: Missouri Children's Picture Series Results Across Age, Sex, and Illness Variables

		Conformity		Masculinity & Femininity		Maturity		Aggression		Inhibition		Activity Level		Sleep Disturbance		Somatization	
	N	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD
Norms		50	10	50	10	50	10	50	10	50	10	50	10	50	10	50	10
Entire Sample	86	48.2	12.7	46.8	11.7	47.6	10.4	54.6	10.4	50.5	11.2	54.2	8.7	48.4	10.4	52.6	10.3
by Sex:																	
Male	49	47.0	14.2	46.5	11.5	49.5	10.4	53.3	10.7	51.5	11.6	54.1	9.0	49.3	10.7	51.7	10.7
Female	37	49.9	10.2	47.2	12.2	45.1	9.9	56.5	9.9	49.2	10.7	54.3	8.5	47.4	9.9	53.7	9.7
by Illness:																	
Asthma	15	48.0	16.1	51.1	10.9	49.6	8.8	52.5	11.0	50.3	9.0	52.8	7.6	47.1	9.5	48.7	8.4
C. F.	14	51.9	12.1	41.4	12.1	44.9	8.5	55.1	11.2	47.9	10.4	54.1	7.4	48.9	9.0	53.4	7.6
Diabetes	48	49.2	11.6	47.3	11.1	48.4	10.6	54.3	10.2	51.7	11.4	54.0	9.5	48.8	11.4	52.8	11.3
Hearing	9	38.0	8.6	45.3	15.2	44.1	12.6	59.3	10.0	48.3	15.3	57.0	8.6	48.0	8.8	56.9	10.2
Age 5-10 years	40	45.4	13.9	49.3	11.0	50.4	8.9	52.3	9.9	50.9	11.8	54.1	8.0	50.1	10.9	51.0	9.5
11-13 years	46	50.7	11.1	44.7	12.1	45.1	11.0	56.6	10.6	50.2	10.8	54.2	9.4	47.0	9.8	54.0	10.8

Table 5: Psychological Screening Inventory Results Across Sex and Illness Variables

	N	Alienation		Social Nonconformity		Discomfort		Expression		Defensiveness	
		$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD
Norms		50	10	50	10	50	10	50	10	50	10
for Entire Sample	34	57.7	12.3	51.7	9.1	52.2	9.9	49.7	7.9	49.6	8.1
By Sex: Male	17	58.9	13.2	51.2	9.1	54.0	9.1	46.1	4.3	49.5	5.9
Female	17	56.4	11.5	52.1	9.4	50.4	10.6	53.4	9.1	49.7	10.0
by Illness:											
Asthma	3	51.0	8.5	54.3	4.6	55.7	6.0	53.7	4.6	58.7	6.4
C. F.	9	50.1	10.5	49.3	7.0	44.7	9.4	49.1	7.6	51.3	5.1
Diabetes	18	59.4	11.6	51.7	11.0	54.4	9.0	49.6	9.3	47.2	7.8
Hearing	4	71.5	8.2	55.0	6.7	56.5	11.2	48.5	4.1	49.5	12.4