THE BEHAVIOURAL, PSYCHOLOGICAL AND SOCIAL CHARACTERISTICS OF NEWFOUNDLAND CHILDREN WITH BLEEDING DISORDERS

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by

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ABSTRACT

THE BEHAVIOURAL, PSYCHOLOGICAL AND SOCIAL CHARACTERISTICS OF NEWFOUNDLAND CHILDREN WITH HEMOPHILIA

This study tested the hypotheses that children with hemophilia differ from other children behaviourally, psychologically and socially, and that differences within the population of children with hemophilia are related to factors within the home, to factors within the child, and to the medical treatment.

The total population of children under seventeen years of age, diagnosed as having hemophilia, and living in Newfoundland, Canada, was assessed, and compared with a sample of children with spina bifida, and a sample of children without chronic physical handicap which were also assessed.

The assessment for each child consisted of:

1. Standardized psychiatric interview with the child. This incorporated tests of selected neurological features.

2. Intelligence and reading achievement testing for the school-age children.

3. Standardized parental assessment interview.

4. Questionnaire completed by teachers.

5. Interviews with physicians involved in the child's treatment.

6. Review of medical records.

The three groups of children were compared for rates of psychiatric disorder, as determined by the parental and child interviews, and the teachers' questionnaire. Comparison of the three groups was also carried out for all individual items from the parental and child interviews, and the teachers' questionnaire. The results of these comparisons were questionable due to difficulties obtaining adequately large control groups. Those difficulties were examined in detail.

The rates of psychiatric disorder, the intelligence and achievement scores did not differ for the three groups of children studied. Children without chronic physical handicap had a significantly higher range of peer contacts than those of the other two groups. The children with hemophilia were hospitalized more frequently than the children in the other groups. Physicians and parents attempted more activity restrictions for children with hemophilia than for the other two groups, but the activity of the three groups did not differ.

Within the population of children with hemophilia, comparisons of all individual items were made between the group with psychiatric disorder, and the group without

psychiatric disorder. The two groups of children with hemophilia did not differ in intelligence, reading achievement scores or any individual item of recent behaviour and emotional state. The families of the two groups of children differed in several respects. Limited information provided by physicians and hospital records precluded complete statistical analysis of medical care data.

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CHAPTER I

INTRODUCTION AND REVIEW OF LITERATURE

A method of generally acknowledged validity for the measurement of adjustment of children to chronic physical handicap does not exist. The presence of psychiatric disorder indicates that satisfactory adjustment has not been achieved, but the absence of psychiatric disorder does not necessarily mean that adjustment is good. One prerequisite for the formulation of valid methods for measuring adjustment of children to chronic physical handicap is accurate comparative information about the behavioural, psychological and social characteristics of children with various chronic physical handicaps, and children without chronic physical handicaps. Another prerequisite is comparative information about those children with chronic physical handicap who have psychiatric disorder, and those with chronic physical handicap who do not have psychiatric disorder.

A. Theory of the Relationship of Chronic Physical Handicap to Psychological, Social and Behavioural Characteristics

1. The nature of the relationship

Rutter, Tizard and Whitmore (1970) stated that the

relationship between somatic state and psychic function was two-way.

> "Somatic disease may have emotional and behavioural consequences, what may be termed 'somatopsychic' effects, and, conversely, emotional and psychological disturbances may influence a person's physical state, so called 'psychosomatic' effects."

2. The psychosomatic relationship

The psychosomatic relationship was viewed as "the relationship between the mental and emotional characteristics of a person and his predisposition toward certain types of organic disfunction" by Wright (1960), however, Rutter, Tizard and Whitmore (1970) defined this relationship so that it included the possibility of emotional states influencing the course of physical disorders other than those which had been traditionally set apart as "psychosomatic diseases."

3. The somatopsychic relationship

Rutter, Tizard and Whitmore (1970) divided somatopsychic relationships into direct and indirect relationships. The direct somatopsychic relationship involved alteration or impairment of brain function by organic states or processes, resulting in the observed psychological phenomena. The mental retardation associated with cretinism, or some of the behaviour of a child with a high fever were examples of direct somatopsychic relationships.

The indirect somatopsychic relationship referred to

the influence of somatic disorder on behaviour and emotions via many aspects of the physical condition, including the individual's own reactions to his body, the reactions of others (particularly parents) to the condition, the special problems imposed by the condition, limitation of activity, hospitalization, treatment procedures and many more. Wright (1960) placed research which investigated the ways in which the person with a disability coped with its social and personal connotations, and investigations of the social-psychological conditions that hampered or facilitated adjustment in the domain of somatopsychic or somatopsychological relations.

4. Implications

Pless, Roghmann and Haggerty (1972) noted that the outlined formulation of the relationship between somatic state and psychological function emphasized the complex multi-causal system of which behaviour is a product. The formulation assigned less importance to simple direct effects between physical handicap and psychological difficulties than to interaction effects of variables in the production of behavioural and psychological phenomena.

Binks (1964) suggested that, as a result, grounds existed for questionning the view, implicit in many of the beliefs about persons with physical handicap, that particular types of psychological functioning were invariably related to particular physical states.

Wright (1960) stated that many of the variables which interacted to produce behavioural and psychological phenomena in individuals who had physical handicaps were the same as those for individuals without physical handicap. Actually, many of the psychological experiences which appeared to be peculiar to persons with physical handicap were not so. For example "the psychological significance of the deprivation (of sensory loss) has to do in large measure with such matters as the threat of social isolation, the struggle for independence ..., and so on - experiences with which many, if not all, human beings are conversant."

Rutter, Tizard and Whitmore (1970) noted, however, that some difficulties which were faced by individuals with physical handicaps were not present for individuals without physical handicap, and certainly, as Wright stated, some psychological situations, although common to much of humanity, occurred with such intensity for many persons with physical handicap that these persons were forced to cope with them directly.

All of this indicated that "when one views physical disability as a physical fact, any psychological cause - effect relationships are not immediately perceived because of necessity but require psychosomatic and somatopsychological theory and investigation to establish them."

B. Characteristics of Children Who Have Chronic Physical Handicap

1. Behavioural and psychological characteristics

a. Psychiatric disorder and adjustment to chronic physical handicap.

(i) Children with chronic physical handicap. Rutter, Tizard and Whitmore (1970) carried out an epidemiological survey of the education, health and behaviour of the total population of nine and ten year old children on the Isle of Wight. The survey included psychiatric assessment of children with chronic physical disorder. Standardized questionnaires and interviews of proven reliability and validity were used. Most of the children with chronic physical disorder showed no psychiatric disorder. However, the rate of psychiatric disorder for the group of children with chronic physical handicaps (excluding those with involvement of the brain) was 10.4 per cent, as compared with a rate in the general population under consideration of 6.6 per cent. In groups of children with asthma and miscellaneous disorders (all chronic physical disorders except asthma, eczema, and brain disorders above the brain stem) the rate of psychiatric disorder was up to twice that in the general population.

Specific types of psychiatric disorder were not associated with physical handicap. Antisocial disorders and neurotic disorders were equally common in the group of

children with chronic physical handicap, as was so for the general population. The rates of both antisocial disorder and neurotic disorder for the children with chronic physical handicap were raised above the rates in the general population.

Pless and Roghmann (1971) described the National Survey of Health and Development as comprised of a representative sample of children born in England, Scotland, and Wales during the first week of March, 1946. Parents, teachers and children completed behavioural symptom questionnaires. Pless analysed the data with the aim of comparing the prevalence and nature of psychosocial problems for children who had a chronic physical illness and for healthy children. Pless and Roghmann used, apparently interchangeably with the term psychosocial problems, the terms social and psychological malfunctioning, psychosocial handicaps, behavioural and psychological maladjustment, behavioural pathology, social and psychological disturbance, and psychological or social difficulties. Definitions of these terms were not supplied. The results were presented in terms of abnormal behavioural symptoms identified by the behavioural symptom questionnaires. The presence of two or more abnormal behavioural symptoms appeared to have been the criterion of psychological maladjustment, without discussion of the validity of this.

At age fifteen, twenty-five per cent of the children with chronic physical disorders had two or more abnormal

behavioural symptoms as compared with seventeen per cent in the healthy population. The extent to which the three information sources contributed to the findings was not identified. Teachers' ratings were reported to have identified the same degree of increased risk, but findings from the teachers' questionnaires apparently did not use the criterion of more than two behavioural symptoms. Data presented from teachers' questionnaires consisted of ratings of nervousness and/or aggressiveness. Methods used for those ratings were not presented.

Pless, Roghmann and Haggerty (1972) reported the results of the Rochester Child Health Survey. The study assessed two hundred nine school-aged children with symptoms of chronic physical illnesses and a control group of healthy children, matched for age, sex, socioeconomic status and race. Mental health of the children was assessed by parent descriptions of behaviour based on a standardized symptom checklist, children's self reports on a written inventory to assess self esteem, teachers' descriptions of behaviour and unidentified other school reports. These measures were incorporated into a mental health-adjustment index. At all ages more children with chronic physical illness were reported to score poorly. Whether or not the poor scores were those of the overall index or of the individual measures was not specified.

Discussion of reliability and validity of the measures was not presented.

Pless and Roghmann (1971) further analysed the results of the Rochester Child Health Survey. Identification of the object of this analysis was hindered by apparently interchangeable use of the terms social and psychological malfunctioning, psychosocial handicaps, behavioural and psychological maladjustment, behavioural pathology, social and psychological disturbances, and social or psychological difficulties. The terms were not defined. The presence of two or more behavioural symptoms appeared to have been the criterion of maladjustment. For the group of children aged six to ten, twenty-three per cent of those with chronic physical illness and sixteen per cent of those who were healthy had two or more abnormal behavioural symptoms. For the group aged eleven to fifteen, thirty per cent of those with chronic physical handicap, and thirteen per cent of those who were healthy had two or more abnormal behavioural symptoms.

Research on the relationship between psychiatric disorder and chronic physical handicap indicated that the rate of psychiatric disorder for children with chronic physical handicap was higher than that for children without chronic physical handicap. No association was found between chronic physical handicap and particular types of psychiatric disorder.

Most of the studies described lacked definition in operational terms of their aims. This resulted in assumptions that a variety of different measures were indices of adjustment, without systematic examination of whether or not that was so. An indication of the underlying lack of clarity was the interchangeable use of a variety of undefined terms.

(ii) Children with hemophilia. Bronks' (1968) follow-up study of one hundred thirty-five children and adults with hemophilia included enquiries about psychiatric treatment. Of the group, 6.7 per cent had attended psychiatrists. Only 4.5 per cent of the total group had actually received treatment. The study did not use control groups, hence comparative data was not available.

Agle and Mattsson (undated) reported a psychiatric study of more than fifty "bleeders", over half of whom were children. They concluded "that a number of conditions (psychiatric syndromes) appear related to the disease itself." No comparative data was supplied. Agle and Mattsson suggested that risk-taking behaviour was one psychiatric complication of the physical condition described by many of the adolescents in the group. Criteria by which behaviour was classified as "risk-taking" were not discussed, nor was any indication given of the number of individuals covered by the term "many". Five individuals in the group were found to follow a pattern of passive dependency. Passive dependency was said to involve being incapable of

self-care, and relying heavily on others to fulfil emotional needs. Specific criteria by which these individuals were identified were not provided. Discussion of the rationale for considering the two previous patterns of behaviour as psychiatric syndromes was not included. Agle and Mattsson did indicate that some individuals in their group were considered to be well-adjusted, but they did not indicate the number of individuals in this group. The criteria for inclusion in this group apparently included appropriate use of cognitive function, motor activity and expression of emotions. Specific criteria appeared to include seeing a relationship between activity and bleeding by the age of four or five years and consequently being cautious in their play, beginning to report bleeding by the age of four or five, and playing a greater role in their own management and treatment by the age of seven or eight years. These children were found to ventilate freely such feelings as anger and sadness during bleeding episodes, but not by actions such as temper tantrums. However, it was unclear whether these items were the criteria by which the group was identified, or characteristics identified after the group had been selected by other means.

Mattsson and Gross (1966 a, 1966 b) presented a two year study of thirty-five hemophilic boys and their parents. The study used psychiatric interviews and observations. Further information about these instruments

was not provided. The results and discussion were very similar to those of Agle and Mattsson. Five boys were identified as showing risk-taking behaviour, and three as showing passive dependency. Twenty-seven boys were found to have shown satisfactory adaptation to their illness for at least the previous two years.

Katz (1963, 1970) examined the psychosocial problems of one thousand fifty-five adults with hemophilia living in the United States, and explored the relationships between childhood experience and adult patterns of social adaptation. The total group completed one hundred-item questionnaires, and two groups of twenty individuals each were interviewed in detail. The small groups were selected as representatives of comparatively good and poor social adaptation. Criteria by which the small groups were selected were not identified, and the assessment techniques were not described. Risk-taking behaviour was identified as a common psychological reaction found in the hemophiliac. Another type of reaction identified was passivity, but individuals showing this reaction were said to constitute a minority. Data were not provided to support these claims. In fact, it was unclear if these remarks referred to the results of that particular study, or to a concensus of the findings of several studies. Risk-taking and passive phenomena were described in a fashion similar to that of Agle and Mattsson, which has already been described.

Gentil (1971) based statements about children with hemophilia on his experience as pediatrician with consultant responsibility for one hundred boys living in a boarding school for patients with hemophilia. He stated that many of the children presented emotional disturbances. The disturbances were said to consist of total passiveness, total opposition, or oscillation between these two reactions. The information was not quantified.

Research on psychiatric disorder in children with hemophilia has primarily used concepts of risk-taking and passive behaviour. The terms have not been defined, and several studies have not supplied data to support conclusions. None of the studies used control groups, hence comparative data were non-existent. In spite of this, the findings were said to indicate relationships between the identified behavioural constellations and the physical condition itself.

b. Individual items of behaviour and emotional state.

(i) Children with chronic physical handicap. Rutter, Tizard and Whitmore's (1970) study on the Isle of Wight used interviews and questionnaires of proven reliability and validity. The results of the parental questionnaires showed that 71.4 per cent of the group of children with miscellaneous chronic physical disorders (except asthma, eczema and brain disorders above the brain stem) had frequent headaches. In the general population, parental questionnaires identified 48.1 per cent of the children as having frequent headaches.

Parents also identified 31.5 per cent of the group with miscellaneous physical disorder as being miserable compared to 12 per cent of the general population. Teachers' questionnaires identified 19.5 per cent of the children with chronic physical disorder as fussy and overparticular, compared to 9 per cent so identified in the general population. No significant differences from the general population were found for the group of children with chronic physical disorders in relation to any of the items of antisocial behaviour on either parents' or teachers' questionnaires.

Pless and Roghmann (1971) analysed data from the National Survey of Health and Development, and the Rochester Child Health Study. They found that, compared with healthy children, chronically ill children were more frequently truant from school, more often troublesome in school, and more often socially isolated. They were more likely than the healthy children to be described by their teachers as having poor attitudes toward their work. Information about the significance of these differences was not provided.

Findlay, Smith, Graves, and Linton's (1969) study of ten families with children who had chronic disease involved contact with the families by senior medical students. The students reported finding greater than normal dependence on their mothers by children with physical handicaps. The methods of assessment in this study were

not identified, dependence was not defined in behavioural terms, and comparative data were not provided.

Allen and Pearson (1928) presented case studies of twelve individuals with various physical disabilities. They concluded that the behaviour of some individuals involved a desire to be the centre of attention, inability to face difficult situations, a feeling of shame or uneasiness, or a desire to compensate by attempting to grow up quickly actually or in fantasy. All of these items were felt to result from a feeling of inferiority. It was also concluded that some children showed increased dependence and infantilism. No consideration was given the extent to which such items were present in the population of individuals without physical handicap. Also, it was unclear exactly what items of behaviour were being considered, since most of the items listed were feeling states, not behaviour. No indication was given that the difficulties of assessing feeling states reliably and validly were considered.

Research into individual behavioural and emotional characteristics of children with chronic physical handicap provided contradictory findings. In particular, antisocial items were found to be related to chronic physical handicap by one study, and not to be related by another.

(ii) Children with hemophilia. Agle and Mattsson's (undated) psychiatric study of over fifty "bleeders", which delineated behaviour patterns of risk-taking and passive dependency, also reported individual items of behaviour and

emotional state. Nine of the sixteen adults in the group reported having had feelings of difference from or inferiority to others, and fears of their own aggressive activity. Comparative data were not available, and methods of obtaining the information were not described. Difficulties in processing retrospective accounts of feeling states were not discussed.

Browne, Mally and Kane's (1960) three-year study of twenty-eight children with hemophilia and their families included parental interviews, psychiatric interviews or play sessions and Rorschach testing with the children. "Most of the children were outwardly docile and passive; however, they would rebel in subtle ways against the restrictions placed upon them." Factors considered in reaching this conclusion were not identified. It was reported that Rorschach protocols revealed underlying active and aggressive urges, a constant preoccupation with muscular action giving rise to immediate anxiety. The major psychological problem of children with hemophilia, as identified by Rorschach testing was conflict about activity. Constriction of fantasy life and affective responsiveness, and much concern about internal organs were also revealed. The Rorschach protocols were apparently compared with those of the subjects in a normative study, but comparative findings were not specifically discussed.

Olch (1971 a) in a study of forty-five hemophiliacs between the ages of two and twenty-one years also administered Rorschach tests. Findings included the youngest boys having equal numbers of active and passive movement responses, the eight to twelve year old group showing mainly passive responses, and the younger adolescents having more active percepts. Another finding was that affect was inhibited for all of the groups, although anxiety was marked in the youngest group. Comparisons with normative expectations were provided, and the findings appeared to indicate those areas in which the group of children with hemophilia differed from normative data.

A finding of a second part of the study by Olch (1971 b) indicated that scores for the group of individuals with hemophilia on Wechsler Performance Subtests requiring some appreciation of social situations (Picture Arrangement) were consistently low.

Kos-Robes and Zapotoczky (1971) conducted a preliminary study of the psychological behaviour of hemophilic children and youths using a standardized psychiatric exploration, projective and intelligence tests. Three main points on which the psychological pattern of these persons seemed to be based were identified. These were (i) a deep-seated fear for their lives expressed as fear of new situations, or as fear of a vigorous male role (involving inability to detach from mother or deficient identification with father), (ii) searching for conscious and unconscious chances for compensation, and (iii) bragging about the

disease (a special attempt to compensate). The translation of the summary of this research did not provide further details of the study or its subjects.

Research on individual characteristics of behaviour and emotional state for children with hemophilia has emphasized activity and responses to it. Results have been inconsistant, but trends towards fear of, or conflict about activity were evident. The studies provided no systematic examination of the extent to which the findings differed from those for other groups of children.

c. Intelligence

(i) Children with chronic physical handicap. A finding of the study by Rutter, Tizard, and Whitmore (1970) on the Isle of Wight was that the intelligence of the total group of children with physical disorders which did not involve the brain was closely similar to that of a control group. However, when the children with asthma and eczema were excluded, it was found that the verbal and performance intelligence quotients of children with other types of physical disorder were slightly depressed below those in the general population. This was a very small difference and was felt to have a possible relationship to the effects of missed schooling.

(ii) Children with hemophilia. Olch (1971 b) found that, on the whole, forty-five individuals with hemophilia who

were given the separate Wechsler Performance and Verbal Scales functioned in the high average range of intelligence. She (1971 a) noted that the mean score was 109.33 but scores ranged from sixty-one to one hundred fifty-two.

Weise (in Malikin, 1971) administered intelligence tests to a random sample of hemophiliacs consisting of one hundred nineteen individuals. Forty-six children achieved a mean intelligence quotient of one hundred twenty-one on the Wechsler Intelligence Scale for Children, seventeen children achieved a mean of one hundred sixteen on a Stanford-Binet, and fifty-four older individuals achieved a mean of one hundred seventeen on a Wechsler Adult Intelligence Scale. Twenty-one per cent of the sample were reported to be intellectually highly superior, as compared to two per cent of the total population.

Kos-Robes and Zapotoczky (1971) in their preliminary study of children and youths with hemophilia, reported results of intelligence tests - Hawie and Hawik, All persons with hemophilia who were tested had intelligence quotients above one hundred five. As noted previously, translation of the study summary did not provide details of the sample or its number.

Grunfeld's (1971) study of Norwegian hemophiliacs found that, as a group, they scored better on intelligence tests than the general population. The tests used were not identified, and data supporting the finding were not provided.

Gentil (1971) stated that intelligence testing was carried out for the children with educational problems at the boarding school for hemophilic patients in which he held the responsibility as consultant pediatrician. Intelligence quotients around eighty were found for less than ten per cent of the children. The scores were more often around average. The tests used were not identified.

The information available provides some evidence that children with hemophilia, as a group, appear to have higher intelligence quotients than population norms. However, none of the studies used control groups, and comparisons were made with test standards only.

d. Achievement

(i) Children with chronic physical handicap. Rutter, Tizard and Whitmore's (1970) study on the Isle of Wight used the Wide Range Achievement Test to measure achievement. Children with chronic physical handicaps were, as a group, at a level nine months below their chronological age in relation to reading accuracy, and the children with miscellaneous physical disorders (except asthma, eczema and brain disorders above the brain stem) had the greatest difficulties. Two-fifths of that group were at least twenty-four months backward in relation to their chronological age.

In that study, reading retardation was defined as an attainment on either reading accuracy or reading comprehension which was twenty-eight months or more below the level

predicted on the basis of each child's age and short WISC IQ. Fourteen per cent of the group of children with chronic physical handicap (excluding disorders of the brain) had reading retardation as compared with 5.4 per cent of children in the general population under study. The children who had specific reading retardation and chronic physical handicap had significantly higher absence rates from school than had the children who had chronic physical handicap but did not have reading retardation. The absences had been repeated and short, rather than one prolonged absence.

Pless and Roghmann (1971) analysed data from the National Survey of Health and Development to derive average aggregate scores on tests of achievement. The scores for children with chronic physical illness were significantly below those of healthy children.

The information available indicated academic delay for children with chronic physical handicaps.

(ii) Children with hemophilia. Olch (1971 b) used the Wide Range Achievement Test to assess thirty-seven students who had hemophilia. Eleven students had reading deficits up to 3.4 grades. The mean and range of deficits were not provided.

Kerr (1971) reported the results of a survey of the patients of a hemophilia clinic, who represented nearly all known adult hemophiliacs and three-quarters of affected

children in New South Wales, Australia. Kerr stated that poor educational performance was found, but he did not provide details of assessment methods used, or the nature or extent of the poor performance. The study did not use a control group.

Grunfeld (1971) reported on achievement of individuals in Norway who had hemophilia. He stated that the final examination marks of children with hemophilia in the seven to nine year elementary and compulsory education were a little above average. No data supporting the claim were provided.

Britten, Spooner, Dormandy and Biggs (1966) examined school absenteeism for two hundred eighty children with hemophilia who attended regular school. One hundred nineteen of the children missed more than one quarter of school time. Twenty of these missed more than half of school time. Comparative data were not provided.

Stuart, Davies, Cumming, Girdwood, and Darg (1966) studied a group of individuals with hemophilia, in which three of the five school-aged children attended regular school. They missed an average of seventy-nine days per year. Total number of days in the school year was not provided.

Lazerson (1972), in the process of assessing a home transfusion programme for children with hemophilia, examined their school attendance records. Prior to the start of the

programme, the children missed an average of 70.6 days per year from a total of one hundred seventy-seven days. The expected absenteeism in the normal population was five to seven days per child per year.

Olch (1971 b) assessed not only absenteeism from school for children with hemophilia, but also examined the relationship between poor attendance and low achievement. One third of a group of boys with hemophilia missed one quarter of each school year, but no relationship was found between poor attendance and low achievement on the Wide Range Achievement Test reading, spelling or arithmetic.

Most studies indicated academic delay for children with hemophilia. Absenteeism from school appeared to be prominent for children with hemophilia, but examination of the relationship between absenteeism and achievement has produced contradictory results.

2. Social characteristics

a. Maternal characteristics

(i) Children with chronic physical handicap. Allen and Pearson's (1928) presentation of case studies of twelve patients with physical handicaps found that the mothers of five children had shown overprotective attitudes, usually inconsistent and accompanied or followed by real or apparent rejection, during the early lives of these children. Overprotection and rejection were not defined

in operational terms, and the study was not comparative. Assessment techniques which were used were not described.

(ii) Children with hemophilia. Browne, Mally and Kane (1960) interviewed twenty-six mothers of children with hemophilia and found that "as a group, the mothers were depressed, anxious women who tearfully discussed their hemophilic children. They all felt resentment or fear about having been punished .... All but three tried to explain away the genetic factor by attempting to account for the bleeding in other ways." The anxiety of the mothers increased with the increasing mastery of locomotion by the child and increasing peer contact. All felt guilt. The type of interview used was not identified, and complete data supporting the conclusions were not provided.

In their psychiatric study of over fifty "bleeders", Agle and Mattsson (undated) stated that mothers of well-adjusted children with hemophilia had mastered conflicting emotions and coped successfully with initial grief, guilt and anger. "Nine of the sixteen adult patients in the group reported extremes of overprotection in their upbringing and" all of these nine said their mothers were "the most active parent in this respect." Methods of assessing the mothers were not specified, "overprotection" was not defined, and this was not a comparative study.

The two year study by Mattsson and Gross (1966 a, 1966 b) of thirty-five hemophilic boys and their parents stated that the mothers of eight poorly adapted hemophiliacs

were worried, over-anxious and overprotective. The study was reported to have used psychiatric interviews and observations, but these were not described. Maternal characteristics mentioned were not defined in operational terms.

Behar and Spencer (1969) assessed the psychosocial adjustment of twenty-six males with hemophilia by using the Social Maturity Index of the California Personality Inventory. They found that the group rated as having high social maturity consistently rated their mothers as less dominating and overprotecting than the group rated as having low social maturity. However, each group rated the ideal mother as further in the direction in which they had rated their own mothers. Behar and Spencer pointed out that the results were not necessarily an indication that over-protectiveness led to lower social maturity, but might have indicated that the less socially mature perceived their mothers as overprotective. Thus the results of this study showed that using children's descriptions of their parents, as has been done by other studies, may not be a valid method of determining parental characteristics.

Studies of the mothers of children with hemophilia identified them as being worried, anxious and overprotective. Methodological difficulties limited the acceptability of the findings. Characteristics were not given operational definitions, and the studies did not use control groups.

b. Paternal characteristics

(i) Children with hemophilia. Browne, Mally and Kane's (1960) study of twenty-eight children with hemophilia included interviews with fathers. Fourteen fathers were interviewed. Some of these men were reported to be aloof and remote, and they attempted to deny the existence of the problem. Most, however, were anxious. The group wished their sons to be active and masculine, but feared the harm of activity. Some were afraid to play with their sons, but many believed their children capable of doing more than was permitted. Most ridiculed the mothers' methods, but were made very anxious and upset by the children's injuries, then feeling that the mother was not doing her best. Substantiation of the conclusions was not provided.

Agle and Mattsson's (undated) study of over fifty "bleeders" found that fathers of well-adjusted children with hemophilia accepted mutual responsibility for the children's care, and participated in physical activities with their sons. Some of the boys with hemophilia who showed poor adjustment came from fatherless homes. Assessment techniques were not described.

Mattsson and Gross's (1966 a, 1966 b) two year study of thirty-five hemophilic boys and their parents stated that fathers of the twenty-seven well-adapted patients took an active role in caring for their sons.

The fathers of three of the poorly-adjusted "bleeders" had been absent for several years due to divorce, and the fathers of the other five poorly-adjusted children had left initiative and decisions regarding the children to their wives. Again, assessment techniques were not described.

Studies of characteristics of fathers of children with hemophilia indicated a relationship between the involvement of the fathers and the adjustment of the children. However, the studies did not use control groups or operational definitions.

c. Family life and relationships

(i) Children with chronic physical handicap. Rutter, Tizard and Whitmore (1970) attempted to ascertain the impact of a child's handicap on the family in terms of disorganization of routine, impaired social relations and dissatisfaction with services. Of the group of families who had children with physical disorders other than asthma and brain disfunction, seventy per cent had problems of disorganization. The greatest proportion of the problems were related to difficulties or inconvenience in taking the child to a hospital or clinic. Seventy-three per cent of the families had problems of dissatisfaction with services (primarily in relation to medical and school problems). Only twenty per cent of the families had problems of disturbed family relations.

Pless, Roghmann and Haggerty (1972) examined relationships between physical health, family functioning and mental health. Assessment of the quality of family life was dichotomized by measures of high and low family functioning. Findings indicated that children with chronic physical handicap in families with low functioning scores had a greater risk of receiving low scores on a self-esteem inventory than those in families with high functioning scores. This was also true for children without chronic physical handicap. The same trend was evident for measures of behaviour symptoms and teacher behaviour rating.

(ii) Children with hemophilia. Katz (1963, 1970) stated that his research on one thousand fifty-five adults with hemophilia indicated that "the specific parental pattern of permissiveness and protectiveness is the most important variable that influences the degree of self-direction and independence that the adult hemophiliac develops." Specific supporting information was not included.

Research which investigated interrelationships between the presence of hemophilia, specific aspects of family history, life and relationships, and specific behavioural and social characteristics was rare, and results inconclusive.

d. Medical aspects

(i) Hospitalization. Hospitalization is one factor in the lives of children with chronic physical handicap which has

received little research attention specifically related to its significance for these children. However, current research does indicate that hospitalization may have long-term consequences for children who do not necessarily have chronic physical handicaps. The review of literature which follows is a sampling of that research.

Prugh, Staub, Sands, Kirschbaum and Lenihan (1953) assessed two groups of fifty children between the ages of two and twelve years, admitted to hospital for varying reasons and varying periods of time. The groups were matched as closely as possible for age, sex, diagnosis, and other factors. The members of one group were the recipients of special supportive practices, such as a play programme, psychological preparation for diagnostic and therapeutic procedures and daily visiting by parents. Forty-four per cent of that group, and fifty-eight per cent of the other group exhibited disturbing reactions three months after discharge from hospital. Nearly half of the children who showed such disturbance were under four years of age. Other factors which seemed to be related to persistent disturbance were unsatisfying relationships with parents, severe stress during hospitalization, and difficulty adapting to ward milieu in hospital.

Schaffer and Callender (1959) studied infants, aged three to fifty-one weeks, with all types of medical and surgical conditions. Post-hospital reactions for those

under approximately seven months of age were brief (maximum of four days) and consisted mainly of extreme preoccupation with the environment. The older infants, however, showed a pattern of which overdependence on the mother was the main characteristic. These disturbances lasted up to eighty days. It was also pointed out that the effect of the separation on the mother's future capacities in her relationship with the child had not been considered.

Stacey, Dearden, Pill and Robinson (1970) studied children hospitalized for tonsillectomy and adenoidectomy. Four-fifths of them showed an increase in disturbance of behaviour during the first week after discharge. The number was reduced by half two months later, but most of the children who were disturbed after that period continued to manifest disturbance six months after discharge from hospital. The children who were found to be most vulnerable were (1) those whose mothers expressed high or low, rather than moderate, anxiety, (2) those who had had low experience of normal untraumatic separation, (3) boys who had experienced a permissive parental regime (4) boys in the youngest group (four years to four years two months), and (5) those rated behaviourally inhibited, verbally inhibited and overtly aggressive before hospitalization.

Vaughan (1957) studied children admitted to hospital for five days for the correction of strabismus. One finding was that some of the children only mildly disturbed in hospital became severely disturbed on returning

home. Some of the most disturbed children in the ward were least so at home. A possible explanation given for this was that "disturbed" behaviour on the ward involved beneficial expression of anxiety.

That the hospital experiences described produced long-term undesirable results for some children was clear, but the hospital experiences of children with chronic physical handicap may involve recurrent, frequent and/or long-term hospitalizations, some beginning with emergency admissions. As well, visits to emergency departments, hospital clinics and doctors' offices may be frequent, with various regimes prescribed by physicians for interim periods at home. The effects of such a situation on the affected children have not been systematically explored.

(ii) Compliance, general studies. Becker, Drachman, and Kirscht (1972) studied a random sample of one hundred twenty-five cases drawn from a population of children being treated for otitis media. Mothers who complied with medical regimes were more concerned than non-compliant mothers about the child's health in general, as well as the present illness. The compliant mothers felt that illness was a substantial threat to their children, but had confidence in the ability of physicians and medication.

Francis, Korsch and Morris (1969) studied the content of eight hundred initial patient visits concerning a new illness to pediatricians. Postvisit and follow-up interviews with the mothers were conducted. Perception by

the mothers, not the physicians, of the seriousness of the illness influenced the degree of compliance. Complex regimes were related to low compliance.

Research on the compliance of patients with prescribed medical regimes indicated that mothers' assessments of the severity of children's illness predicted most compliance measures, such that an assessment of greater severity by the mother (not the doctor) was related to greater compliance. Complex regimes decreased compliance, particularly when change was recommended in such personal habits as activity level.

(iii) Compliance, children with hemophilia. Compliance with medical regimes per se of children who have hemophilia and their families has not been investigated. However, for children with hemophilia, prescribed medical regimes may include advice about activity level. Review of literature which has examined aspects of activity level for children with hemophilia follows.

Browne, Mally and Kane's (1960) study of twenty-eight children with hemophilia identified a number of ways in which mothers attempted to restrict the activity of their children who had hemophilia. They were reported to supply the children with such items as books, television, music or quiet games, and also chose playmates for their children - younger, smaller, passive children, preferably quiet little girls. They constantly supervised play and

discouraged after school play. No figures were supplied to support these conclusions, and comparison with the mothers of other children was not made.

Meyers, Adams, Dardick, Reinisch, von Reyn, Renna and McIntyre (1972) interviewed all of the hemophiliacs in New Hampshire and Vermont, and the parents of those under sixteen years of age. They found that the structuring of play activities was an especially difficult problem for parents of children with hemophilia. Many recurrent conflicts occurred between parent and child about sports activities such as bicycling, hunting and mountaineering. This was predominantly among the group with severe clotting factor deficiencies. The study had the same methodological weaknesses found in the study by Browne, Mally and Kane (1960).

Olch's (1971 b) study of forty-five hemophiliacs used parental questionnaires. These indicated that hobbies such as model building, and such activities as reading, watching television and listening to radio ranked high in importance for children with hemophilia during recovery from bleeding episodes. Data supporting the findings were not provided.

Research by Katz (1970) found that, in a group of individuals with hemophilia, solitary activities predominated over group activities. Forty-five per cent of the group were in the solitary end of a five-point ordinal scale for social interaction, while twenty-five per cent were in the

group end of the scale. However, the solitary activities were not necessarily sedentary. Only twenty-two per cent of the study group confined themselves to sedentary activities. Comparisons with other groups were not made.

Investigation of the activity level of children with hemophilia indicated that parents attempted to control the participation in activities of their children who had hemophilia. This seemed to have been a source of conflict. Contradictory findings exist about the actual participation of individuals with hemophilia.

(iv) Causes of bleeding episodes. Browne, Mally and Kane's (1960) study of twenty-eight children with hemophilia found that trauma was not the important factor in bleeding. The majority of bleeding episodes were spontaneous. Falls, bumps, strains accounted for a minority of bleeding episodes and numerous episodes of severe trauma without subsequent bleeding were reported. Long-term laboratory studies showed no variation of the blood level of antihemophilic factor, but in keeping with the evidence about trauma, all patients reported easier and more frequent bleeding at some times than at others, without correlation to trauma. Reports indicated seasonal variation, easier bleeding at times of inactivity, and at special occasions (e.g. Christmas). Records of greater frequency of hospitalization at Christmas appeared to substantiate the patients' reports. The common factor in these occasions was anticipation of increased

activity or independence, and the result of the bleeding was usually prevention of the increase.

Mattsson and Gross (1966 a, 1966 b) assessed thirty-five boys with hemophilia over a period of two years. Most had cycles of bleeding and freedom from bleeding. Spontaneous bleeding was observed for eight of the group before special events which would involve enthusiasm and excitement. For three individuals, greater independence and activity preceded or coincided with decreased bleeding episodes.

Agle and Mattsson (undated) also reported that at least half of their study group described multiple episodes of apparently spontaneous bleeding following emotional situations or the anticipation of them. The emotions seemed to be fear or anger. Agle and Mattsson noted that ten patients described improved clinical state after changing from fearful passivity to more aggressive independence. Laboratory data did not support the view that the improved clinical state preceded the behaviour change. Again, it was noted that severe trauma had little effect at some times, while minor trauma sometimes produced marked reactions during periods of frustration or despondency. This was viewed as evidence against unnoticed trauma as the actual cause of apparently spontaneous bleeding. Agle and Mattsson also reported that observations of the Cardeza Institute suggested more frequent and severe bleeding with dental surgery in

tense, frightened hemophiliacs than in those in a more relaxed state.

Salk, Hilgartner and Granich (1972) asked parents of forty-two patients with hemophilia about the bleeding episodes of their children. The parents of eighty-three per cent of the children reported spontaneous bleeding for their children. They reported seasonal variation and emotional states (anger and excitement) to be related to the bleeding episodes. Most of the patients themselves could not describe a regular pattern to their bleeding episodes, but all except one could isolate factors which were related to frequent bleeding. The most frequent factors were again season and emotional factors.

Bronks and Blackburn's (1968) study involved asking one hundred thirty-five individuals with hemophilia about effects on bleeding of worry and anxiety. Their results were less definitive than the other studies in that 42.2 per cent of the group did not know if bleeding was affected. Positive responses were given by 27.4 per cent of the group and negative responses by 30.4 per cent. The younger group (under fourteen years) had significantly more negative or unknown responses.

Garlinghouse and Sharp (1968) found that of three hundred seven bleeding episodes reported during a thirteen month period for eighteen children with hemophilia, only sixty-four were directly attributed by the mothers to

traumatic incidents. The authors then examined the relationship between the number of bleeding episodes, the self-concept of the child, and familial stress, excluding bleeding episodes. Self-concept was assessed by the Colvin Silhouette Test of Self-Concept and Interpersonal Relations. Familial stress was assessed by the Schedule of Recent Experience Questionnaire. The findings revealed that when stress was low, a high self-concept was associated with fewer bleeding episodes and a low self-concept with more bleeding. When stress was high, bleeding was high regardless of self-concept.

Poinsard (1957), who investigated twenty-five individuals with hemophilia, attributed emotional patterns of either passivity or aggression to all of the group, and looked for a relationship between such adjustment and severity of hemophilia based on the history rather than laboratory assessment. He found no correlation.

Egeberg (1963) used laboratory experiments to obtain results which provided a possible explanation for some of the observations of the previous studies. He examined the effects of exercise and adrenalin infusion upon blood level of antihemophilic A factor and bleeding time in individuals with von Willebrand's disease, severe hemophilia A and without bleeding disorders. He found that short and long-term exercise and adrenalin infusion increased antihemophilic A factor and shortened bleeding time in normal individuals. For individuals with moderate von Willebrand's disease,

adrenalin infusion increased the antihemophilic A factor blood level, but did not markedly decrease bleeding time. With severe von Willebrand's disease, short-term exercise did not affect either the antihemophilic A factor level or bleeding time. In the individuals with severe classical hemophilia, adrenalin infusions did not induce measurable antihemophilic A factor activity, but did shorten the bleeding time.

Research indicated that trauma was less important as a causal factor of bleeding episodes than emotional factors and activity level. A variety of emotional states appeared to be related to increased bleeding, while some evidence was found that increased activity was related to low bleeding rates.

C. Summary

1. Conclusions of the literature review

Theory of the relationship of chronic physical handicap to psychological, social and behavioural characteristics suggested a complex interaction. Emotional state may affect the course of physical disorders, and physical state may influence behaviour and emotions, directly and indirectly. Research is necessary to establish the nature and extent of the relationships.

Groups of children with various chronic physical

handicaps have been found to have higher rates of psychiatric disorder than other children. Investigations of individual items of behaviour and emotional state provided contradittory findings, particularly in relation to items of antisocial behaviour. Research dealing with the intelligence and academic achievement of children with chronic physical handicap indicated intelligence to have been similar to the general population, but academic delay to have been significantly greater, and related to repeated short absences from school.

A study of the families of children with chronic physical handicap concluded that mothers were overprotective and rejecting, but did not examine fathers. Other studies concluded that the child's handicap affected the organization of the family, and that family functioning influenced the mental health of children with and without physical handicap.

Studies of children with hemophilia used concepts of risk-taking and passive behaviour. These constellations were said to be related to the physical condition itself, and were considered by one study to be psychiatric conditions. Use of these concepts made comparison with other results difficult. Investigations of individual items of behaviour and emotional state dealt primarily with activity and responses to it. Trends toward fear of, and conflict over, activity were evident. Investigation of intelligence and academic achievement for groups of children with hemophilia has found that they attained higher intelligence scores than

test norms, but were academically delayed (however, no clear evidence for the latter conclusion was presented). High rates of absenteeism from school were found for children with hemophilia.

Studies of the families of children with hemophilia concluded that mothers, particularly mothers of poorly adjusted children, were anxious, guilty, and overprotective. A relationship was found between the extent of involvement of fathers with the children, and the adjustment of the children.

The medical experiences of children with chronic physical handicaps, including those with hemophilia, have not been systematically explored. Medical contacts of these children may be frequent and of various types. Research results have indicated post-hospital reactions of several months duration after single hospitalizations for some children without chronic physical handicap.

Medical personnel may include recommendations for home care as part of treatment plans for children with chronic physical handicap. General compliance studies have concluded that such factors as the nature of recommendations, and mothers' assessments of severity of the medical condition, influenced the degree of compliance. Recommendations of medical personnel regarding activities for children with hemophilia have not been examined, but research conclusions suggested that parents attempted to restrict activities of these children.

Research examination of the causes of bleeding in patients with hemophilia suggested that trauma was a less important factor than emotional state. There were suggestions that increased activity was related to decreased bleeding.

2. Hypotheses of this study

Although chronic physical handicap has been postulated to have effects upon behaviour and emotions, the specific nature of these effects has not been identified, beyond establishing that a higher rate of psychiatric disorder is found in groups of children with chronic physical handicaps than in other groups. The factors which mediate the relationship of chronic physical handicap to behaviour and emotional state have received little research attention.

Investigations of children with hemophilia have employed concepts which are different from those of investigations of groups with chronic physical handicap.

This study investigated the behavioural, psychological and social characteristics of children who have hemophilia. The hypotheses tested were (i) that children with hemophilia differ from other children behaviourally, psychologically, and socially, and (ii) that differences within the population of children with hemophilia are related to factors within the child, within the home, and to their medical treatment.

CHAPTER II

METHODOLOGY

A. Purpose and Scope of the Study

1. Strategy and subjects

The total population of children under seventeen years of age, diagnosed as having hemophilia and living in Newfoundland, Canada, was assessed. A sample of children with spina bifida, and a sample of children without chronic physical handicap were also assessed.

The assessment for each child consisted of standardized interviews with the child and with parents, interviews with physicians involved in the child's treatment, a questionnaire completed by the child's teacher, and a review of the child's medical records.

Comparison of the rates of psychiatric disorder for the three groups was made, as was comparison for each of the individual items in the parental and child interviews, and the teachers' questionnaires. Within the population of children with hemophilia, comparisons of all individual items were made between the group with psychiatric disorder, and the group without psychiatric disorder.

2. Location and services

The population of the island of Newfoundland is located mainly in coastal communities. All communities involved in the study were connected by road to the remainder of the island.

The Newfoundland Department of Health Annual Report (1971) indicated that Newfoundland was served by seventeen general hospitals and sixteen cottage hospitals at that time. Located in St. John's, on the south-east coast of the province, were a pediatric hospital, the Children's Rehabilitation Centre, and a coagulation laboratory. The Newfoundland Medical Directory (1973) and the Newfoundland Medical Care Commission Annual Report (1972-73) identified approximately five hundred and fifty medical practitioners in the province, of whom nineteen were pediatricians.

The province had a branch of the Canadian Red Cross Society and a provincial chapter of the Canadian Hemophilia Society.

B. The Subjects

1. The study group.

The study group consisted of the total population of children under the age of seventeen years on May 31, 1973, diagnosed as having hemophilia, and living in Newfoundland, Canada.

a. Sources of identification

A complete list of members of the study group did not exist. The members of the group were identified by approaching all of the major agencies in the province of Newfoundland which were likely to have had contact with them, and doctors in all areas of the province. The agencies approached were the Coagulation Laboratory of the St. John's General Hospital, the Newfoundland Red Cross, the Newfoundland chapter of the Canadian Hemophilia Society and twenty-four hospitals. Sixty-six doctors were approached, of whom twenty-three were the contacts at the hospitals. Ten of the hospitals responded, as did all of the other three agencies. Of the forty-three doctors who were not hospital contacts, eleven responded. Twenty-nine children were identified by the outlined contact method, and the parent of one of these identified a thirtieth child. Table 1 shows the number of children identified by each source. Identification of study group members was an on-going process throughout most of the study, which meant the total size of the population was not known until the collection of data was close to completion.

TABLE 1

Identification Sources for Study Group Members

	Total Number	Number Identified by One Source Only
Coagulation Laboratory	7	0
Red Cross	13	0
Hemophilia Society	13	0
Hospitals	27	10
Doctors	6	2
Parents	1	1

b. Selection criteria.

Children were included in the study group when their physicians had made clinical diagnoses of hemophilia. Many of the children had not had testing for laboratory confirmation of the type and level of clotting factor deficiency. One child was excluded from the group because he was not identified before completion of the study.

Hemophilia is a congenital and hereditary defect of blood coagulation in which there is a deficiency or total lack of one or more essential clotting factors (Biggs, 1969; Briggs, 1971; Cumming, 1972; Katz, 1970).

2. Control group of children without chronic physical handicap.

The first control group was a sample of children without chronic physical handicap, matched for age, sex and geographical location with the study group.

a. Sources of identification.

The children were selected through their schools because the schools were one of the few sources with precompiled lists and current addresses of the appropriate individuals. The schools contacted were those also attended by the study group members. The reasons for this were that contact could be made simultaneously for the children from both groups, control was facilitated of urban-rural environmental differences between the two groups, and the number of areas to which it would be necessary to travel during the interviewing was not unnecessarily increased. No similar source was available for the children not attending school (of whom there were six in the study group), hence no pre-school or non-school-attending control group members were selected.

b. Selection criteria.

The children in the group were selected from the alphabetical classroom registers of those classes in which the study group children would have been, if at levels appropriate for their ages. The child selected from each register was the one whose name was closest after the name

of the study group child, of the same sex and born in the same year, but not a sibling.

Classroom registers were used because most of the schools did not have school registers. Because of a high possibility that many of the study group children were below the age-appropriate grade level, using their classroom registers might have led to overrepresentation in the control group of children who were behind in school. However, the method used (selection from the registers of classes appropriate to the ages of the study group) introduced the possibility of underrepresentation in the control group of children who were behind in school.

3. Control group of children with spina bifida.

The second control group was a sample of children with spina bifida, matched for sex with the study group. The average age of this group did not differ significantly from that of the other two groups.

a. Sources of identification.

The children were selected from the clients of the Children's Rehabilitation Centre, partially because they had precompiled lists of the appropriate individuals.

b. Selection criteria.

The specifications for the group were that (1) the children should not have a physical condition involving the central nervous system above the brain stem and (2) the

children should have a congenital physical condition rather than an acquired one. The group of children with spina bifida was chosen because the agency identified it as the group which met the specifications and had enough members to permit matching for age, sex, and geographical location with the study group. In fact, the group was only large enough to match for sex, so selection was carried out by chunk sampling (division by sex) from the group of children who were within the extremes of the age range of the school-aged children in the study group. The number of pre-school children with spina bifida was too small to make their inclusion appropriate, particularly since the first control group lacked pre-school children. After a second group of children with hemophilia was identified, the population of children with spina bifida registered with the Children's Rehabilitation Centre was found to be too small to permit further sampling.

Control of differences in psychosocial characteristics which might be attributed to differences between acquired and congenital physical conditions was achieved by selecting a control group of children with another congenital physical handicap. However, spina bifida and hemophilia may differ in heritability, visibility and variability, which may account for some differences between the groups of children.

Spina bifida is "a congenital defect characterized by lack of fusion of vertebral arches, most commonly in the lumbar and/or sacral region." Herniation of meningeal and

neural elements, and protrusion of spinal fluid, as well as a defect of the spinal cord may also be present. (Eakins and Limper, 1967; Henderson, 1967).

C. Contact with the Subjects

1. The study group.

a. Method of contact.

The parents of each of the thirty children in the study group were sent a letter from the investigator, explaining the study and asking that the attached consent and information form be completed and returned in an enclosed pre-addressed stamped envelope. The addressees and child were identified by name, and the study was identified as one dealing with children who have hemophilia.

b. Responses and follow-up.

Fourteen positive responses were received after the initial letters. Four more parents contacted the investigator by telephone for further details of the study, and all expressed positive responses. Written consents were received from three of these parents, making a total of seventeen positive responses from the initial contact.

Follow-up was carried out by telephone for ten of the thirteen non-respondents, and second letters and envelopes were mailed where necessary. All expressed positive responses, but only three written consents were received, making a total of twenty positive responses.

Second telephone follow-ups made to seven of the remaining ten non-respondents yielded six written consents and one negative response, making a total of twenty-six positive responses.

Three families could not be contacted by telephone, so attempts were made to contact a public health nurse in each of the appropriate areas. In two cases the nurses were contacted. One of the families had just moved out of Newfoundland. The other family was visited by the public health nurse, who contacted the investigator to pass along a generally negative response with some enquiries. Written consent was not received.

Excluding the family who had left Newfoundland meant that the group originally contacted numbered twenty-nine, of whom twenty-six gave consent. Five of the consents were for pre-school children and one for a school-age child not attending school.

c. Size of the interviewed group.

Two of the children of school age had to be excluded from the group because interviews could not be carried out. Two attempts were made to visit these children, but both were unsuccessful because of impassable roads and telephone service interruptions. The group of children with hemophilia who were interviewed thus numbered twenty-four, including five pre-school children.

2. Control group of children without chronic physical handicap.

a. Method of contact.

Some of the schools were unable to release the names of children without parental consent, hence it was decided to have the schools carry out the selection procedure previously outlined, and forward letters from the investigator to the parents of the selected children. The letters were similar to those sent to the parents of the study group, and also contained pre-addressed stamped envelopes. However, the addressees and children could not be identified by name, and the study was identified as one dealing with children who have chronic physical handicap for which a comparison group of children without chronic physical handicap was required. The parents were told that the selection had been made through the school, and were asked to forward the name of their child, with some additional information, to the investigator if they were willing to participate in the study. Twenty families were initially contacted, corresponding to the twenty children in the study group who attended school, and for whom consent had been received.

b. Responses and follow-up.

Seven positive responses were received after the initial contact. Because return of the signed consent was the means whereby the individuals were identified to the

investigator, the non-respondents were unknown and follow-up was not possible.

In order to increase the size of this control group, the thirteen schools of the non-respondents were asked to forward a letter to the parents of the next child in the register who met the qualifications. Three more consents were obtained, making a total of ten positive responses.

The ten remaining schools were asked to repeat the procedure a third time. Three more consents were received, bringing the group to a total of thirteen.

Because the selection of control group members depended on receipt of consent from the members of the study group, the schools were approached about selection of control group members at different times. Two of the schools of non-respondents were contacted early enough to allow repetition of the selection procedure four times. No consents were received from these contacts. Fourth contact was prohibited by lack of time in the other five cases. Thus the total number of consents received was thirteen.

Because of the procedure of having the schools of non-respondents forward letters to second, third and fourth choices, forty-five families actually were approached once. As noted, only thirteen consents were received.

c. Size of the interviewed group.

Two consents arrived too late to be included in the study. Three more children had to be excluded because

prearranged interviews could not be carried out. In one case parents cancelled the appointment; in another case no one was at home at the time arranged; and in the other case disruptions in telephone service prevented final confirmation of the appointment time. The group of children without chronic physical handicap who were interviewed thus numbered eight.

4. Control group of children with spina bifida.

a. Method of contact.

For the control group of children with spina bifida, contact was made in a similar manner to that used for the control group of children without chronic physical handicap. The Children's Rehabilitation Centre could not release children's names without parental consent, so they forwarded a letter from the investigator to the parents of the selected children. They also enclosed their own letter of explanation. The letters from the investigator were similar to those sent to the first control group, but the parents were asked that the consents be returned to the Children's Rehabilitation Centre, because the Centre requested that this procedure be used. Letters were sent to nineteen families, which was the number of school age study group children identified at the time of selection.

b. Responses and follow-up.

Seven positive responses were received after the initial contact. Follow-up could not be carried out by the investigator for the same reason as that for the first control group. The Centre carried out telephone follow-up of six local non-respondents. Two more consents were received, making a total of nine positive responses.

c. Size of the interviewed group.

One of the last two consents arrived too late for inclusion, and the other so late that only partial assessment was possible. Another child was excluded because it was found, during interview, that he did not meet the specifications for inclusion. He had a neurological disorder above the level of the brain stem (hydrocephalus).

The group for which collected data was used thus consisted of seven members, one of whom was only partially assessed.

D. Assessment

Information about the subjects was collected by means of:

i, psychiatric interviews with the child, which also incorporated tests of selected neurological features. Intelligence and reading achievement testing was completed for the school-age children. Appendix A is a copy of the interview with the child.

ii. interviews with parents. Appendix B is a copy of the parental interview.

iii. questionnaires completed by teachers. Appendix C is a copy of the teacher's questionnaire.

iv. interviews with doctors involved in treatment of the children. Appendix D is a copy of the interview with doctors.

v. review of medical records of the children.

Criteria used for the determination of psychiatric disorder were those of Rutter, Tizard and Whitmore (1970).

> "..... psychiatric disorder was judged to be present when there was an abnormality of behaviour, emotions, or relationships which was continuing up to the time of assessment and was sufficiently marked and sufficiently prolonged to cause handicap to the child himself and/or distress or disturbance in the family or community."

Identification of children with psychiatric disorder was made on the basis of the interviews with child and parents, and the teacher's questionnaire.

1. The child.

a. The psychiatric interview.

The psychiatric portion of the interview was based upon that described by Rutter and Graham (1968). The purpose of the interview with the child was largely "an assessment of the nature and extent of any abnormality of emotions, behaviour or relationships exhibited by the child rather than an evaluation of the psychodynamic development of such abnormalities."

The form of the interview was two part. The first part was unstructured and of approximately fifteen minutes duration, its aim being to allow the child to relax and talk freely. Possible topics were outlined at the beginning of the interview schedule, but this portion was adapted to the needs of the child. It was necessary to convey to the child interest in him, his ideas, feelings and activities, but to maintain enough neutrality and objectivity to enable effective observation of the child.

The latter part of the interview was a systematic questioning about possible fears, worries, unhappiness, irritability, tempers and peer relationships. The areas to be covered were specified, and the codings to be made categorized, but the wording of the questions was not regulated by the schedule. The children were also asked to perform a number of tasks to assess attention-span, persistence, clumsiness and other neurological features.

Questions also covered the child's experiences with hospitalization and medical treatment. Finally a detailed examination of physical activities and games of the child was carried out.

Rutter and Graham's (1968) study assessed the reliability and validity of the interview, which "was found to be a reasonably sensitive diagnostic instrument which could give rise to reliable and valid judgements on whether the child exhibited any psychiatric disorder. However, on the whole, individual ratings on specific aspects of behaviour

proved to be less reliable than the overall psychiatric diagnosis." It was also pointed out that the interview would be unlikely to identify children with antisocial disorders.

To assess inter-rater reliability for the current study, two sets of ten interviews were carried out with children who had been referred to a child psychiatric unit. The children were seen jointly by the investigator and another interviewer. One interviewer observed, while the other interviewed, and each completed ratings independently. Each interviewer conducted five interviews and observed five in each series. In one series, one hundred per cent agreement was found between interviewers on overall judgement of psychiatric state and degree of abnormality present, with 87.5 per cent agreement on individual items. For the other series, the interviewers agreed on overall judgement of psychiatric state in ninety per cent of the interviews and for ninety-three per cent of the individual items.

b. Intellectual and reading assessment.

Depending on the age of the child, Raven's Coloured or Standard Progressive Matrices was administered. A qualified psychologist was not available, hence this test was chosen because of the limited participation required of the investigator. Also, it was often necessary to complete the entire examination of the child in one session, and in order to maintain the attention of even the younger children,

it was important that a relatively short test be selected.

Achievement was assessed by the reading section of the Wide Range Achievement Test. This measure was chosen for the same reasons as those for which intellectual assessment was selected.

c. Procedure.

Distance and travel difficulties prohibited having the subjects travel to appointments. Instead, the investigator travelled to the twenty-five communities in which the children resided. Considerable practical difficulty would have been entailed in arranging neutral interview settings in so many communities, so the interviews were carried out in the homes of the children. This meant that the important regulation of the physical setting, outlined by Rutter and Graham (1968), was not possible. Considerable variation was encountered in the activity going on in the rooms in which the interviews took place, ranging from only child and interviewer being present, to having many combinations of parents, siblings, other relatives, neighbours and friends, observing and participating in the interviews, as well as carrying on other activities.

In only one case was the interview carried out outside the home of the child. In that case the child requested that the interview take place at the hospital.

The total assessment lasted from 1.5 to two hours.

2. The parents.

a. The child assessment.

This portion of the interview was based on that described by Graham and Rutter (1968). The interview was a structured, but open-ended one, which allowed for "a considerable amount of standardization without limiting the scope of the information obtained."

The interview consisted of two parts. In the first part, the spontaneous complaints of the parents about the child's behaviour were noted, and then explored in detail for duration, frequency and nature of the symptoms. In the second part of the interview, the parents were asked, systematically, a series of questions covering all areas in which symptoms commonly occur. Any positive answers were explored in detail, as for the spontaneous complaints. The presence or absence of the particular symptom which the question was designed to elicit was rated, not necessarily the parents' answers. If a parent gave information about one behavioural item when being asked about another, the rating was applied to the appropriate question, not the one for which the answer was given. In this way, the symptom was only rated as being present when evidence for it was found.

As well as rating individual items, assessment was made of overall psychiatric disorder, and a diagnosis made.

Studies carried out by Graham and Rutter (1968) indicated the interview they used to be reliable and valid for the identification of definite psychiatric abnormality. High diagnostic agreement was achieved. Rating of individual items was more variable, but for items concerned with more overt behaviour, high rates of agreement were found.

b. Family history, life and relationships.

This portion of the interview was based on that of Brown and Rutter (1966). Information was sought about siblings, parents, and various aspects of family life.

Studies by Brown and Rutter (1966) indicated this interview to be reliable and valid, thus minimizing the difficulties of retrospection, and attitudinal bias.

c. Medical history.

This portion of the interview sought information about the child's physical condition, experiences with medical treatment, and reactions to this. Also, the physical activities in which the child participated were explored in detail. The techniques used to elicit information were similar to those used in the other portions of the interview, that is, positive responses were explored in detail for frequency, duration and other aspects.

d. Procedure.

Parental interviews were carried out in the homes, for the same reason this was done for the interviews with

the children. As far as possible, interviews were held while children were in school or after their bedtimes, however the same situations arose as were so for the children's interviews, in that various combinations of other people were often present.

One interview took place at the hospital, at the request of the parents involved.

3. The teachers' questionnaires.

a. Children's behaviour scale.

The questionnaire used was that described by Rutter (1967). It consisted of twenty-six brief statements concerning the children's behaviour, for each of which the teacher rated the child on a three-point scale. Total scores of nine or more designated some disorder. Of the children who had scores of nine or more, those with a subscore from items 7, 10, 17 and 23 exceeding that from items 4, 5, 15, 19, 20 and 26 were designated as having neurotic disorders. The diagnosis antisocial disorder was given to those whose subscore on the latter group of items exceeded that on the former.

Studies by Rutter (1967) indicated a high degree of reliability and high discriminative power for this measure.

b. Supplement.

Teachers were also asked to provide information about the academic status of the children, their attendance records, etc.

4. Interviews with physicians.

a. Description.

The interview with physicians, of one quarter to one half hour duration, was designed to obtain information about the number, frequency and types of contacts which the physician had had with the child, the investigations and treatments carried out, and recommendations made. The physicians were also asked to provide any information they had regarding diagnosis of medical problems and evidence of emotional or behavioural difficulties. Finally, the physicians were asked in detail about physical activities in which the child could participate.

b. Procedure.

Before the trip to each area of Newfoundland, physicians in the area were contacted in order to arrange appointments. Physicians were given priority in the scheduling of appointments, and these were carried out wherever the physician indicated would be most convenient.

Several physicians who were scheduled to be away from their areas at the time of the investigator's visit offered to have other members of their staff assist. This

arrangement was accepted.

c. Difficulties.

One hundred five different doctors were identified as having taken part in the medical treatment of the children in the three groups. Seventeen of these had given treatment outside Newfoundland, or had subsequently left the province.

Of the eighty-eight remaining doctors, fifty-two were involved in a major way in the treatment of one or more of the children. Many of these physicians were treating more than one child, and a number of the children had several physicians involved in their treatment, such that the total number of interviews with the fifty-two physicians would have been one hundred sixty-seven.

Attempts were made to contact all fifty-two physicians. Appointments could be arranged with only thirty-seven, including those who substituted other members of their staff. Several of those with whom appointments were not made did not respond to messages left for them, a number had no vacancies in their appointment schedules, and several were absent from their areas. For the thirty-seven physicians successfully contacted, the number of interviews would have been one hundred twenty-three.

In spite of the prior arrangements, only thirty physicians were interviewed. In two cases impassable roads prevented the investigator reaching the appropriate

communities. The other five physicians were unable to keep the appointments or to make alternate arrangements.

For the thirty physicians with whom appointments were kept, a total of one hundred seven interviews were to be carried out. Due to limited time available to some of the physicians, the total number of interviews attempted was fifty-three. For two children in the study group, four children in the group with spina bifida, and five children who had received medical care in the group of children without physical handicap, interviews with attending physicians could not be obtained.

Very few of the fifty-three attempted interviews were completed, because physicians were unable to answer the questions. Some physicians did not have the appropriate information available, although all were notified prior to the interview of the identity of the children to be discussed and, where possible, the investigator also ensured that hospital files were available for the interview. Some exceptions to the previous situation did occur, in that several physicians supplied complete information about the children being discussed. Insufficient data was collected to allow statistical analysis of any question.

5. Medical records review.

a. Procedure.

Medical records for each of the children were

reviewed to obtain the number and types of contacts with hospitals and agencies. Information was also obtained on reasons for the contacts, diagnoses, and treatments. Any comments on behaviour and emotions were noted.

b. Difficulties.

For one hospital, difficulty was encountered obtaining authorization from the hospital to view medical records, although parental and medical permission had been obtained. Limited authorization was eventually given.

In several cases, children had attended hospitals in areas to which trips for interviewing were not necessary. These hospitals were not contacted.

Even where records were available, some children had had several hundred contacts with varying amounts of information recorded. Complete assessment was not possible.

Sufficient information for statistical analysis was not obtained.

E. Statistical Analysis

1. Comparison of the three groups.

Nominal data pertaining to the three groups of children were analysed by using Chi Square r x c Contingency Tables, with Yates's correction for continuity. Fisher's Exact Probability Test was also used.

Interval and ratio data were analysed by the analysis

of variance.

All items noted in the presentation of results were significant at at least the .05 level of significance.

The data obtained from all groups were analysed and presented. However, the significance of the comparisons of the three groups must be viewed with reservation, because of the high refusal rates and the consequent small size of the samples. Factors which may have affected response rate and final group size are discussed.

2. Comparison of the two groups of children with hemophilia.

Nominal data were again analysed by using Chi Square r x c Contingency Tables, with Yates's correction for continuity. Fisher's Exact Probability Test was also used.

Interval and ratio data were analysed by using Student's t tests.

All items noted in the presentation of results were significant at at least the .05 level of significance.

CHAPTER III

RESULTS

A. Differences between the Three Groups of Children.

Appendix E contains raw data, chi square, Fisher Test, and analysis of variance results.

1. Group size

a. Initial response rates

The parents of seventeen children, or 58.6 per cent, of the group of twenty-nine children with hemophilia agreed to participate in the study following the initial contact. The parents of seven children, or 36.8 per cent, of the group of nineteen children with spina bifida agreed to participate following the initial contact. For the group of children without chronic physical handicap, parents of seven, or thirty-five per cent, of the original group of twenty children agreed to participate after the initial contact. Parents of thirteen children in the same group, or 28.9 per cent, of the forty-five families each contacted once agreed to participate. The differences among the three groups, using the first figure for the group without chronic physical handicap, were not significant. However, the differences among the three groups were significant at the .05 level when the forty-five families contacted once each in the group without chronic physical handicap were

included. Table 2 shows the response rates of the three groups after the initial contact.

TABLE 2

Response Rates of the Three Groups after Initial Contact

	Yes	No	Total
Hemophilia	58.6%(17)	41.4%(12)	100%(29)
Spina Bifida	36.8%(7)	63.2%(12)	100%(19)
No Chronic Physical Handicap	28.8%(13)	71.2%(32)	100%(45)
	39.8%(37)	60.2%(56)	100%(93)

$d_f = 2$, $X^2 = 6.59$, $p < .05$

b. Response rates after follow-up

Telephone follow-up was carried out by the investigator for ten of the non-respondents in the group of children with hemophilia. A public health nurse carried out follow-up for an eleventh child. One family could not be contacted for follow-up. Parents of three children, or 27.3 per cent, of the group of eleven agreed to participate after one follow-up attempt. After two follow-up contacts, the parents of a total of nine children, or 81.8 per cent of the group of eleven had agreed to participate. The Children's Rehabilitation Centre carried out telephone follow-up to the parents of six of the children in the group with spina bifida. The parents of

two children, or 33.3 per cent of the group of six agreed to participate. Second follow-up contacts were not made. Follow-up was not carried out for the group of children without chronic physical handicap. The response rates after follow-up did not differ significantly between the group with hemophilia and the group with spina bifida.

c. Final response rates

Parents of twenty-six children, or 89.7 per cent, of the group of twenty-nine children with hemophilia contacted agreed to participate in the study. Parents of nine children, or 47.4 per cent, of the group of nineteen children with spina bifida contacted agreed to participate. Parents of thirteen children, or 28.9 per cent, of the group of forty-five children without chronic physical handicap agreed to participate. The differences in the numbers of consents received for the three groups was significant at greater than the .001 level of significance. Table 3 shows the response rates after follow-up.

TABLE 3

Total Response Rates

	Yes	No	Total
Hemophilia	89.7%(26)	10.3%(3)	100%(29)
Spina Bifida	47.4%(9)	52.6%(10)	100%(19)
No Chronic Physical Handicap	28.9%(13)	71.1%(32)	100%(45)
	51.6%(48)	48.4%(45)	100%(93)

$d_f = 2$, $X^2 = 26.25$, $p < .001$

2. Behavioural and psychological characteristics.

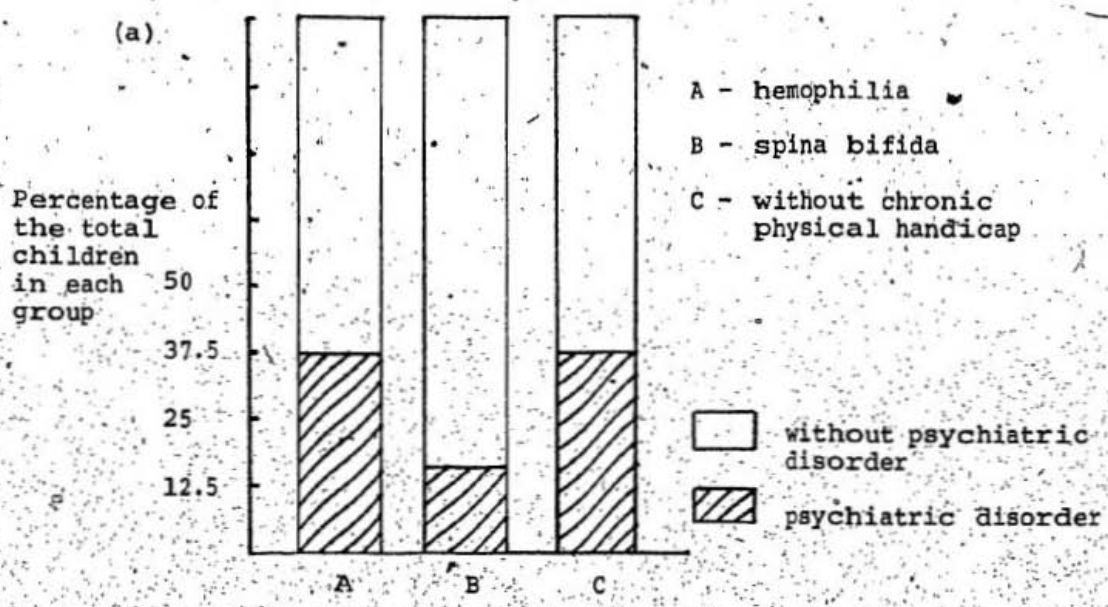
a. Psychiatric disorder.

Nine children, or 37.5 per cent, of the group of twenty-four children who had hemophilia were identified as having psychiatric disorders. None of the preschool children were found to have psychiatric disorders. The nine children with psychiatric disorder constituted forty-seven per cent of the group of nineteen school-aged children with hemophilia. One child, or 14.3 per cent, of the group of seven children with spina bifida, and three children, or 37.5 per cent, of the group of eight children without chronic physical handicap, were found to have psychiatric disorders. Figure 1 shows the percentages of the groups of children who had psychiatric disorder.

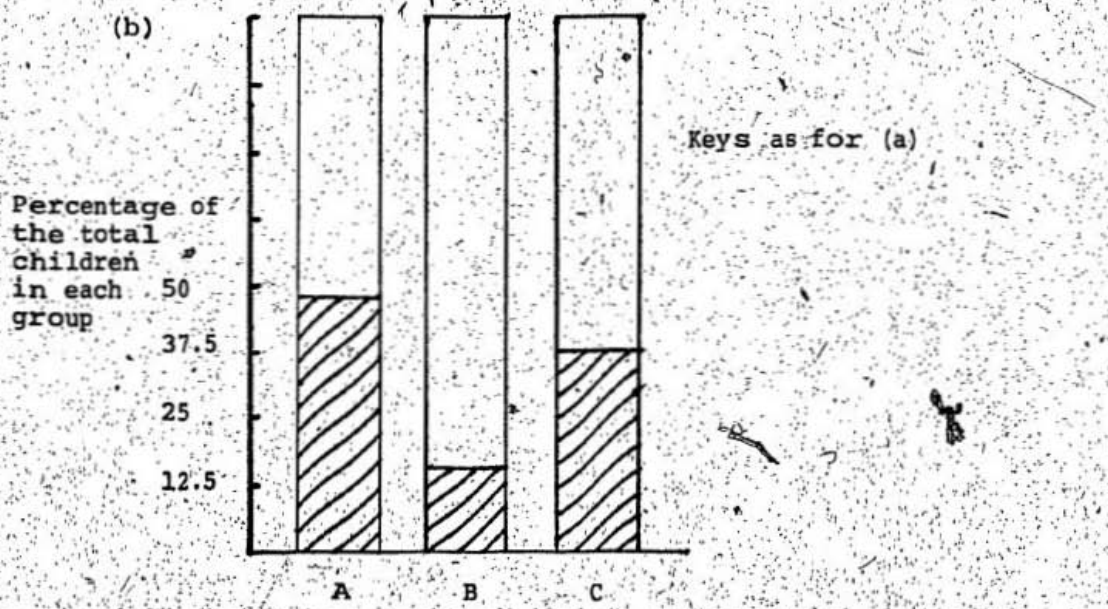
The differences among the three grbups in the

Figure 1

Percentages of Children with Psychiatric Disorder in the Three Groups



Groups including preschool children



Groups excluding preschool children

prevalence of psychiatric disorder was not significant. Table 4 shows the comparison of rates of psychiatric disorder for the three groups.

Table 4

Comparison of Rates of Psychiatric Disorder (Three Groups)

	Yes	No	
Hemophilia	15	9	24
Spina Bifida + No Chronic Physical Handicap	11	4	15
	26	13	39

$d_f = 1$

$X^2 = .12$

	Yes	No	
Hemophilia + Spina Bifida	21	10	31
No Chronic Physical Handicap	5	3	8
	26	13	39

$$p = \frac{31!\ 8!\ 26!\ 31!}{39!\ 21!\ 10!\ 5!\ 3!} = .3062$$

$$p = \frac{31!\ 8!\ 26!\ 31!}{39!\ 20!\ 11!\ 6!\ 2!} = .2917$$

$$p = \frac{31!\ 8!\ 26!\ 31!}{39!\ 19!\ 12!\ 7!\ 1!} = .1390$$

$$p = \frac{31!\ 8!\ 26!\ 31!}{39!\ 18!\ 13!\ 8!\ 0!} = .0254$$

$p(\text{total}) = .7623$

In the group of children with hemophilia, four were found to have neurotic disorders, four to have mixed antisocial-neurotic disorders, and one to have an antisocial disorder. The child in the group with spina bifida who had a psychiatric disorder had a mixed antisocial-neurotic disorder. In the group without chronic physical handicap, one child had a neurotic disorder, one had a mixed antisocial-neurotic disorder, and one had an antisocial disorder. Table 5 shows the distribution of psychiatric disorders in the three groups. These small numbers provided no evidence of association between hemophilia or spina bifida and any particular psychiatric disorder.

For the group of children with hemophilia, the parental interviews were the sources of evidence of psychiatric disorder in seven cases. The parental interview was not the only source of evidence of psychiatric disorder for any of the children. In the same group, the interviews with the children were the sources of evidence of psychiatric disorder in eight cases. The interview with the child was the only source of evidence of psychiatric disorder for one of the children. The teachers' questionnaires were the sources of evidence of psychiatric disorder in six cases, and the questionnaire was the only source of evidence for one of the children. Figure 2 shows the sources of evidence of psychiatric disorder for the group of children with hemophilia.

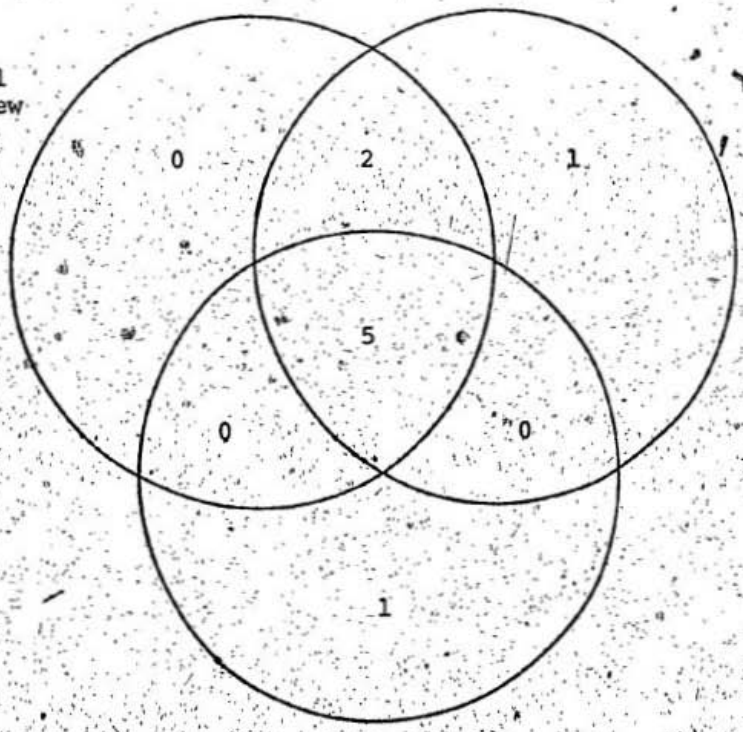
TABLE 5

Distribution of Types of Psychiatric Disorder in the Three Groups

Type of Disorder	Hemophilia	Spina Bifida	No Chronic Physical Handicap	Total
Neurotic	4	0	1	5
Mixed Antisocial-Neurotic	4	1	1	6
Antisocial	1	0	1	2
Total	9	1	3	13

Figure 2

Sources of Evidence of Psychiatric Disorder
Children with Hemophilia



Definite evidence of psychiatric disorder for the child in the group with spina bifida was provided by all three sources of information (parent, child, teacher).

For the group of children without chronic physical handicap, the parental interviews were the sources of evidence of psychiatric disorder in all three cases. The interviews with the children were the sources of evidence in two cases, and the teachers' questionnaires were the sources of evidence in two cases. None of the children in this group was diagnosed as having psychiatric disorder on the basis of information from one source only. Figure 3 shows the sources of evidence of psychiatric disorder for the group of children without chronic physical handicap.

b. Individual items of recent behaviour and emotional state.

From the information reported in the children's interviews, a significant difference was found between groups for the range of peer contacts of the same sex. During one week, the group of children without chronic physical handicap had contacts with more friends of the same sex than did the other two groups. For twenty-two children in the group with hemophilia, the mean weekly number of friends contacted was 6.68. For six children in the group with spina bifida the mean was 8, and for eight children in the group without chronic physical handicap, the mean was 14.12. Raw data is shown in Section 2 of Appendix E. Table 6 shows the comparison of the three groups for the weekly range of same-sexed peer contacts.

Figure 3

Sources of Evidence of Psychiatric Disorder
Children without Chronic Physical Handicap

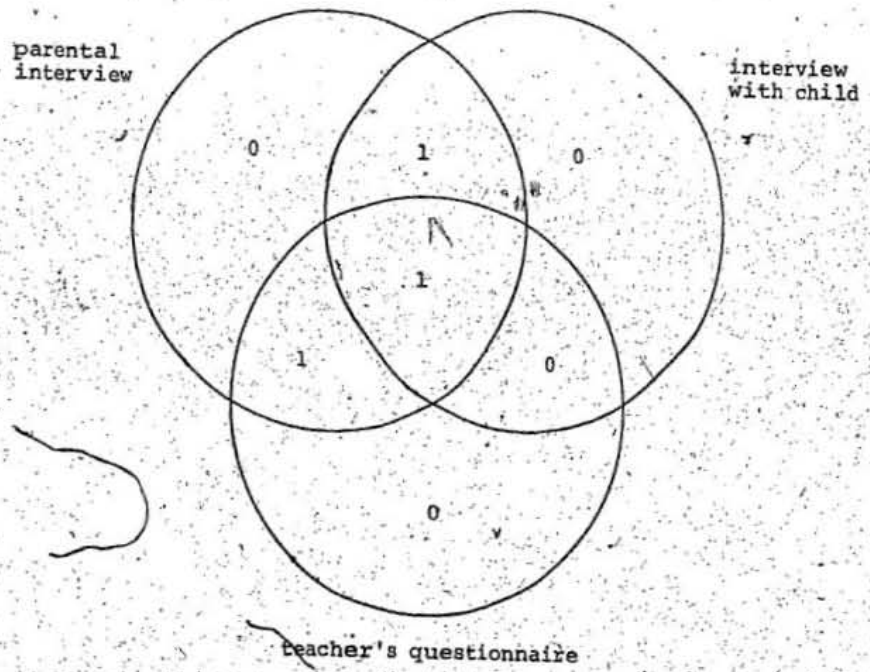


TABLE 6

Weekly Range of Same-sex Peer Contacts

	Mean	Standard Deviation
Hemophilia	6.68	5.6
Spina Bifida	8	5.02
No Chronic Physical Handicap	14.12	6.98

Source	Sum of Squares	d_f	Mean Square
Between Groups	327.25	2	163.63
Within Groups	1125.64	33	34.11
Total	1482.92	35	

$F^2_{33} = 4.8$, $P < .05$

The information from all three sources of data provided no evidence of significant differences between the groups for any other aspect of peer relationships (number of peer contacts with either sex, range of peer contacts with the opposite sex, presence of best friends, disturbances of peer relationships, etc.).

No significant differences between the groups were found for any other items of recent behaviour and emotional state.

c. Intelligence.

The intelligence quotients for the three groups did not differ significantly. The mean IQ score for the group of children with hemophilia was 91, the mean for the group with spina bifida was 96, and the mean for the group without chronic physical handicap was 97. Table 7 shows the comparison of the mean intelligence scores for the three groups. Raw data and the Analysis of Variance table are shown in Appendix E, Section 3.

TABLE 7

Intelligence Quotient and Standard Deviations (Three Groups)

	Mean	Standard Deviation
Hemophilia	91	32.53
Spina Bifida	96	22
No Chronic Physical Handicap	97	19.57

F = .199 (not significant)

d. Achievement.

Standard scores on the reading section of the Wide Range Achievement Test did not differ significantly between the groups. The mean standard score for the group of children with hemophilia was eighty-six and the mean for the group without chronic physical handicap was ninety-

three. Table 8 shows the comparison of WRAT standard scores for the three groups. Raw data and Analysis of Variance table are included in Appendix E, Section 4.

TABLE 8

Wide Range Achievement Test Standard Scores
(Three Groups)

	Mean	Standard Deviation
Hemophilia	86.8	14.28
Spina Bifida	86.33	10.6
No Chronic Physical Handicap	93.13	13.84

F = .68 (not significant)

No significant differences were found between groups for the frequency of standard scores below ninety, frequency of percentile scores below fifty, frequency of reading below a grade level appropriate for age and intelligence, or frequency of reading grade more than two grades below that expected for the child's age.

Approximately half the children in all three groups were more than two years behind the grade levels expected for their ages, according to the Wide Range Achievement Test Manual criteria.

The rates of absenteeism from school did not differ significantly for the three groups. However, school records were obtained only for the year in which the study took place.

From that information, four children in the group with hemophilia were found to have had absenteeism rates considerably higher than all the other children. These four children were not those with the greatest deficits in reading.

2. Social characteristics

a. Parental characteristics, family life and relationships.

The groups did not differ significantly on any of the items of family history, life and relationships.

b. Medical history.

Results in this section which required information about number and frequency of contacts should be regarded with caution. The parents of the children with hemophilia stated that they were unable to provide accurate information for many items, because so many contacts with medical personnel and facilities had been made.

(i) Rehabilitation centre admissions. During the year prior to interview, the group of children with spina bifida had had a significantly higher mean number of contacts with special clinics and with consultant physicians than did either of the other groups. This group had also had a significantly higher mean number of admissions to a residential centre (rehabilitation centre) during the year prior to interview than had the other two groups. Also, the group of children with spina bifida had a significantly greater number of members who had had more than one admission

to the rehabilitation centre during their lifetimes than did the other two groups. All of the preceding data was obtained from the parental interviews. In reports from the children themselves, the group with spina bifida remembered a mean number of admissions to the rehabilitation centre significantly higher than that remembered by the other two groups, however, this information was not particularly useful because only three of the children in the group with spina bifida were able to answer the question, and only one of these three reported any rehabilitation centre admissions. That child reported four admissions.

(ii) Hospital admissions. When data pertaining to the lowest number of hospital admissions in any one year analysed, the group of children with hemophilia was found to be significantly different from the other two groups. During the years in which they had had the least number of hospital admissions, fewer of the children with hemophilia had had no admissions than the other children. In other words, there were fewer children with hemophilia who had spent a full year without hospitalization than children with spina bifida or than children without physical handicap.

(iii) Medical regimes. A significantly higher number of children with hemophilia than children in the other two groups reported that medical personnel had recommended that they not participate in certain games and activities. Of twenty-one children who had hemophilia, fifteen reported recommendations from doctors to restrict activity, while only one each

of the six children with spina bifida and the eight children without chronic physical handicap reported similar recommendations. Also, the parents of significantly more of the children with hemophilia than other parents reported that medical personnel had recommended activity restrictions for their children. Parents of twelve of twenty-four children with hemophilia reported such recommendations, whereas none of the parents of the fifteen children in the other two groups had been given such advice.

However, only two of the children with hemophilia and the parents of only four of these children indicated that they followed the advice which they had been given.

The children's participation in activities, particularly games and sports, was explored in considerable detail, by asking general questions about activities, and by asking about participation in each of the activities in the portion appropriate for the child's age of the detailed activity list. The activity lists were analysed by comparing the total number of activities in which each child did not participate. No significant differences betweeh the groups were found on any of the items which explored the children's actual participation in games and activities. Significant difference between the groups was found for the number of activities from the detailed activity list which parents said they attempted to restrict. The mean number of activities restricted by the parents of the group of children with hemophilia was eight, while the parents of

both other groups reported a mean of three restrictions each.

Methods by which parents attempted to restrict the activity of their children included complete prohibition and participation only when under supervision.

B. Differences between Children with Hemophilia Who Have Psychiatric Disorders and Those with Hemophilia but without Psychiatric Disorder.

Appendix F contains raw data, chi square, Fisher test, and t test results.

The two groups were not significantly different for age and urban or rural residence.

1. Behavioural and psychological differences.

The two groups did not differ significantly on any single item of recent behaviour and emotional state, or of personal history.

a. Intelligence.

The mean intelligence quotient for each group (ten children without psychiatric disorder, and nine children with psychiatric disorder) was 95.3. Raw data and t test results are included in Appendix F, Section 1. Table 9 shows the means and standard deviations of the two groups.

TABLE 9

Intelligence Quotient Means and Standard Deviations
(Two Groups)

	Mean	Standard Deviation
No Psychiatric Disorder	95.3	12.44
Psychiatric Disorder	95.3	10.78

$t = 0$

b. Achievement.

Standard scores on the reading section of the Wide Range Achievement Test did not differ significantly. The mean score for the group without psychiatric disorder was 88.82, the mean for the group with psychiatric disorder was 84.33. Table 10 shows comparison of WRAT standard scores for the two groups. Raw data and t test results are included in Appendix F, Section 2.

TABLE 10

Wide Range Achievement Test Standard Scores
(Two Groups)

	Mean	Standard Deviation
No Psychiatric Disorder	88.82	17.18
Psychiatric Disorder	84.33	10.14

$t = .69$ (not significant)

No significant differences between the groups were found for any of the other reading achievement measures analysed.

2. Social differences.

a. Parental characteristics.

The mothers of a significantly greater number of the children in the group with psychiatric disorder reported disturbances of their own appetites and sleep. The mother of only one child from fifteen children who did not have psychiatric disorder reported that she, herself, had problems with eating, while the mothers of six of the nine children with psychiatric disorder reported that they had eating difficulties. Mothers of five of fifteen children without psychiatric disorder reported sleep difficulties, but the mothers of all nine children with psychiatric disorder reported sleep difficulties for themselves. Table 11 shows the comparison of mothers' appetites for the two groups, and Table 12 shows the comparison of mothers' sleep.

Fathers of the children in the two groups were not significantly different for any item explored.

b. Family life and relationships.

The parents of significantly more of the children with psychiatric disorder were unable to identify a favourite activity which they shared with spouses. Parents of only one of the nine children with psychiatric disorder

TABLE 11

Disturbance of Mothers' Appetites
(Two Groups)

	No	Yes	
No Psychiatric Disorder	14	1	15
Psychiatric Disorder	3	6	9
	17	7	24

$$p = \frac{15!\ 9!\ 17!\ 7!}{24!\ 14!\ 1!\ 3!\ 6!} = .0036$$

$$p = \frac{15!\ 9!\ 17!\ 7!}{24!\ 15!\ 0!\ 2!\ 7!} = .0001$$

p(total) = .0037

TABLE 12

Disturbance of Mothers' Sleep
(Two Groups)

	No	Yes	
No Psychiatric Disorder	10	5	15
Psychiatric Disorder	0	9	9
	10	14	24

$$p = \frac{15!\ 9!\ 10!\ 14!}{24!\ 10!\ 5!\ 0!\ 9!} = .0015$$

were able to identify such shared activity, while parents of ten of the fifteen children without psychiatric disorder did identify a favourite activity shared with spouses.

Also, the mean family size of the children with psychiatric disorder was greater than that of the children without psychiatric disorder. The families of children with psychiatric disorder had a mean of 6.22 children, while the families of children without psychiatric disorder had a mean of 3.93 children. (Difference significant at the .05 level). The children with psychiatric disorder had a mean number of siblings with hemophilia of 1.75, compared with a mean for the group without psychiatric disorder of .4. This difference was significant at the .01 level.

The only feature of the family homes which was significantly different for the two groups was ownership of electric stoves. The families of seven of the children with psychiatric disorder did not own electric stoves, while the families of only three of the children without psychiatric disorder did not own one of these appliances. This difference was not a reflection of urban-rural difference, or social class difference between the groups. For neither of these items were the groups significantly different.

Another area of family life which differed significantly between the two groups was the provision of pocket money for the study group children. The children with psychiatric disorder reported receipt of a mean weekly allowance of

$6.66, while their parents reported giving these children a mean of $5.85 per week. The children without psychiatric disorder reported a mean weekly allowance of $1.76, while their parents reported providing a mean of $4.72 per week. The difference between groups was significant for both parents' and children's answers.

No other item distinguished the families of the children with psychiatric disorder from those of the children without psychiatric disorder.

c. Medical history.

The only significantly different aspect of the medical history of the two groups was the number of contacts with consultant physicians during the year prior to interview. The children without psychiatric disorder had had a mean of .83 contacts during the year, while none of the children with psychiatric disorder had had any contacts with consultants during the same time. This information was reported by the parents, but it was found, in those cases where it was possible to review medical records and interview physicians, that the parents tended not to have reported their children's contacts with consultants, when these had occurred during inpatient admissions to hospital.

The groups were not significantly different on any other aspect of their medical histories.

C. Summary of Results

The response rate from parents of the control group members after initial contact was low, and significantly different from the response rate of the group with hemophilia. Follow-up of non-respondents in the two control groups was not possible to the same extent as for the group with hemophilia. Hence the total number of consents received from the three groups was significantly different.

The three groups of children were not found to differ significantly for rates of psychiatric disorder, mean intelligence quotients, or mean WRAT standard scores. No aspect of family history, life or relationships differed significantly for the three groups.

The three groups did differ significantly with regard to the weekly range of same-sex peer contacts. The group of children without chronic physical handicap reported a range of about twice that of the two groups with chronic physical handicap. Significantly fewer children with hemophilia than children in the other two groups had spent a full year without hospitalization during their lifetimes. Also, significantly more children with hemophilia and their parents reported medical recommendations for activity restrictions than children and parents of the other groups. No differences were found between the three groups for the children's participation in activities, but parents of the children with hemophilia did attempt to restrict significantly more activities

than parents of the other two groups of children.

Children who had hemophilia and psychiatric disorder did not differ significantly from those with hemophilia but without psychiatric disorder for any single item of recent behaviour and emotional state, nor for mean intelligence quotient or mean WRAT standard score.

Mothers of significantly more of the children with psychiatric disorder had disturbances of their own appetites and sleep than mothers of the children without psychiatric disorder. Fathers did not differ significantly. The mean family size of the children with psychiatric disorder was significantly greater than that of the children without psychiatric disorder, and the former children had significantly more siblings who also had hemophilia than the latter children. The children with psychiatric disorder were provided with significantly higher weekly allowances than the children without psychiatric disorder.

Finally, the children with psychiatric disorder had had significantly fewer (none) contacts with consultant physicians, either medical or psychiatric, during the year prior to interview than the children with psychiatric disorder.

CHAPTER IV

DISCUSSION AND CONCLUSIONS

In this chapter, consideration is first given to the problem encountered obtaining adequately large control groups for the study. The interview settings for the study are also discussed, as these differed from those specified by the designers of the instrument. The first hypothesis, that children with hemophilia differ behaviourally, psychologically and socially from other children is then considered, using the results of the comparisons of the children with hemophilia, the children with spina bifida and the children without chronic physical handicap. The discussion of factors related to differences within the population of children with hemophilia employs the presence or absence of psychiatric disorder as the differentiating item, and uses the results of the comparison of the two groups thus formed. Conclusions are presented at the end of the chapter.

A. Study and Control Group Size

At all stages of this study, greater difficulty was encountered obtaining consents from, and completing interviews with the members of the control groups than with the members of the study group. The greater difficulties resulted in the sizes of the two control groups being considerably

smaller than the size of the study group. Thus the significance of the comparisons of the three groups must be viewed with caution.

The factor which appeared to have played the most important role in the final difference in group size was the difference in the extent to which follow-up of non-respondents was possible to each group. Follow-up was necessary before receipt of the final third of the consents from the group with hemophilia. Follow-up was possible for only part of the group with spina bifida and for none of the group without chronic physical handicap.

Other factors which affected the final sizes of the three groups were the necessity of contacting varying numbers of people in the three groups initially, and the response rate after the initial contact. The initial response rates may have been affected by the necessity of using different methods of contacting the three groups and by the differing descriptions of the study presented to each group. The response rates of the groups decreased in the same direction as decreasing personal experience of the family with the subject of the study as it was presented to them. If degree of personal experience with the subject under study did affect response rates, identifying the subject of study (hemophilia) to all groups would not have provided a solution to the difficulty of obtaining larger control groups, and might have jeopardized the confidentiality of the

participation of study group members from the smaller communities, where their condition was known to most residents. Conversely, to have described the study in general terms to all groups, without identifying hemophilia, might have reduced the response rate from parents of children with hemophilia. This would have endangered the second aspect of the study, which involved only the children who had hemophilia. The only group in which assessments were not carried out due to parents cancelling or missing appointments after consent had been given was the group without chronic physical handicap. This again suggests the possibility that personal experience with the subject of the study as it was presented influenced the degree of participation.

Future studies might be more successful in acquiring adequately large control groups if arrangements could be made to obtain names of candidates for all groups prior to the initial contact. Follow-up could then be carried out, and the initial contact methods made more similar. Research would be necessary to determine the actual extent of effects on response rates of personal experience with the subject of the study.

B. Interview Settings

Rutter and Graham (1968) indicated the importance of the regulation of the physical sitting for the interviews with children, particularly. For this study, interviews with

both children and parents were conducted under variable circumstances. People other than the interviewees were often present. A number of consequences were observed. First, the reminders and comments of others present in the room sometimes led to the description of symptoms or events which the interviewee originally denied. In a more structured setting the interviewer would not have gained knowledge of these. This seemed to have occurred most often with regard to observable items of behaviour, or events of which the others had knowledge. It might be speculated that items which were not observable by others, and which the interviewees did not want revealed to others, might have been denied in these circumstances, more often than in private interviews.

Some events in histories seemed to have been reported differently when others were present, particularly in relation to timing. Collaboration of those present, and reminders from them led to different reports than those initially offered by the interviewees. The interviews of Rutter and Graham (1968), Graham and Rutter (1968), and Brown and Rutter (1966) were researched in structured settings without the extra participants. Interviews in the clinical setting, particularly community clinics, often take place outside structured settings, as they did in this study. Research into the effects of such variation on the reliability and validity of the interviews would be worthwhile.

C. Comparison of Children with Hemophilia to Other Children

1. Behavioural and psychological characteristics.

a. Psychiatric disorder

The interviews with children and parents, and the teachers' questionnaires sought information primarily about the year previous to the interview. Usually, children were considered to have psychiatric disorder only when symptoms were present at the time of interview, and had been evident for at least one year. The study was not an attempt to determine how many of the children had had psychiatric disorder in the past, nor could it predict how many of the children would develop psychiatric disorder in the future. Hence the study was not an attempt to assess, for the three groups, the overall risk of developing psychiatric disorder at some time during childhood. Had it been possible to identify all children who would have psychiatric disorder during childhood, a more accurate picture would have been possible of the relationship between hemophilia and psychiatric disorder, and of factors which influence that relationship.

This study employed assessment methods used by Rutter, Tizard and Whitmore (1970). The results of this study agree with those of Rutter, Tizard and Whitmore (1970) who found that most children with chronic physical handicaps

showed no psychiatric disorder. However, this study found rates of psychiatric disorder in all three groups which were much higher than those found in the general population of Rutter, Tizard and Whitmore (1970), or in their group with chronic physical handicap. Figure 4 shows comparison of the rates of psychiatric disorder found in this study and that of Rutter, Tizard and Whitmore (1970).

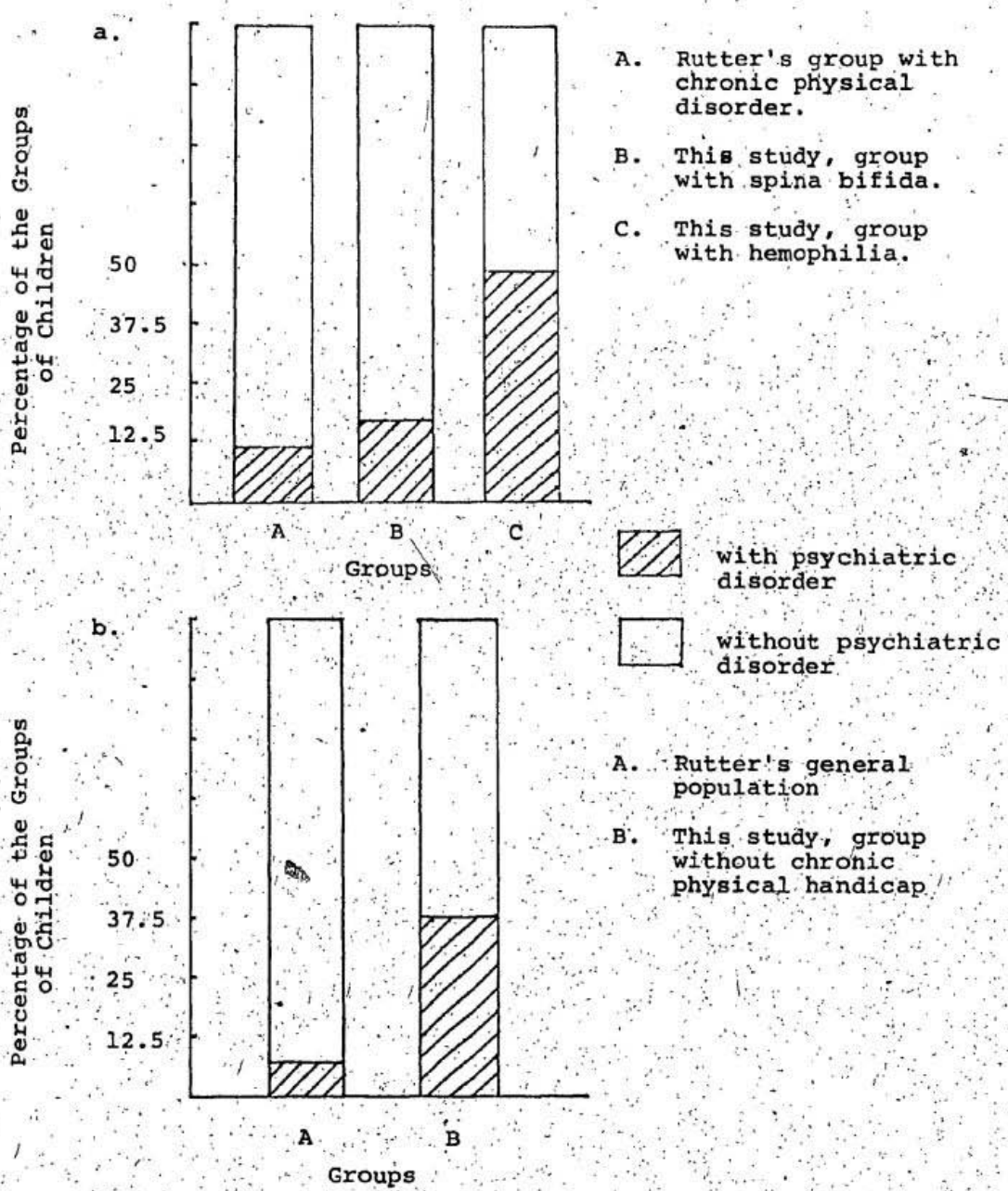
Unlike other studies such as Rutter, Tizard and Whitmore (1970), Pless and Roghmann (1971), Pless, Roghmann and Haggerty (1972), neither of the groups with chronic physical handicap in this study had a significantly higher rate of psychiatric disorder than the group without chronic physical handicap. One possible explanation is that factors may have been operational which, although they were related to an increase in the rate of psychiatric disorder for all three groups of children, had the most adverse effects on children without chronic physical handicap.

Only three of the thirteen children with psychiatric disorders had received treatment by physicians for these difficulties. One other child had received help from school personnel. Insufficient information was obtained from physicians to permit examination of whether or not they had detected psychiatric disorder in any of the children.

The children in this study were not assessed with reference to particular behavioural constellations, such as risk-taking behaviour, which were considered by Agle and

Figure 4

Comparison of Rates of Psychiatric Disorder Found in this Study and those Found by Rutter et al (1970)



Mattsson (undated), Mattsson and Gross (1966 a, 1966 b), Katz (1963, 1970), and Gentil (1971) to be psychiatric syndromes, or forms of emotional disturbance. However, in this study the relationship of particular psychiatric disorders to particular physical handicaps was examined. In agreement with findings of Rutter, Tizard and Whitmore (1970) no relationship was found. However, the number of children in this study with each type of psychiatric disorder was small, therefore validity of the comparison of the groups may be questioned.

In summary, children with hemophilia were not found to differ from other children with respect to the rate of psychiatric disorder nor the rate of particular types of psychiatric disorder.

b. Individual items of recent behaviour and emotional state.

(i) Peer relationships. The weekly range of peer contacts of the same sex for children without chronic physical handicap was about twice that for either of the groups with chronic physical handicap. The weekly number of peer contacts with either sex did not differ for the three groups. Hence, the children with chronic physical handicaps had fewer friends of the same sex than the children without chronic physical handicap, but they saw their friends more frequently. This indicated that children with chronic physical handicap did not lack peer companionship.

No differences were found between the groups for having a best friend, playing with groups and on teams, belonging to clubs, exchanging visits with friends, being teased or bullied, bullying other children, fighting, loneliness, being disliked by other children, being solitary or withdrawn. Thus the quality of peer relationships for the three groups did not appear to differ.

(ii) Other items. Significant differences between the groups were not found for any other items of recent behaviour and emotional state. Thus this study agreed with the finding of Rutter, Tizard and Whitmore (1970) of no association between items of antisocial behaviour and chronic physical handicap. This was contradictory to findings of Pless and Roghmann (1971). No support was provided by this study for the previous research which found many other differences in behaviour and emotional state between children with and without chronic physical handicap.

(iii) Summary. The group of children with hemophilia differed from the group without chronic physical handicap in terms of their weekly range of peer contacts. The range of peer contacts for the children with spina bifida was similar to that of the children with hemophilia.

c. Intelligence.

Intelligence quotients for the three groups in this study did not differ significantly. Thus the results closely resembled those of Rutter, Tizard and Whitmore (1970) who found little difference between the intelligence quotients

of groups of children with and without chronic physical disorder.

This study did not support findings by Olch (1971 a, 1971 b), Weise (in Malikin, 1971), Kos-Robes and Zapotoczky (1971) and Grunfeld (1971) of intelligence quotients for children with hemophilia being higher than other groups.

d. Achievement.

The three groups in this study were not significantly different for scores obtained on the Wide Range Achievement Test reading section. However, approximately half of all the children in each group in this study were more than two grades behind the reading levels expected for their ages. Thus this study agreed with findings by Rutter, Tizard and Whitmore (1970), Olch (1971 b), and Kerr (1971) of academic delay for children with chronic physical handicap and hemophilia. However, this study did not support findings of Rutter, Tizard and Whitmore (1970), and Pless and Roghmann (1971) who found academic delay to be more common for children with chronic physical handicap than for other children.

However, the Wide Range Achievement Test has not been standardized for the Newfoundland population. In view of the finding that nearly half of all the children, including those without chronic physical handicap, were more than two years behind the grades expected for their ages,

using the WRAT standard, it is possible the standards are not appropriate for the Newfoundland population.

The situation for academic achievement appeared to be analagous to that for psychiatric disorders. The number of children with academic delay was high in all groups, but the groups did not differ significantly. Again, it was possible to postulate that factors were operational which were selectively more detrimental for children without chronic physical handicap.

Rates of absenteeism from school during the current year for children with hemophilia did not differ significantly from those of the other two groups, unlike the study by Lazerson (1972). Other research (for example, Britten, Spooner, Dormandy and Biggs (1966)) into absenteeism for children with hemophilia found what appeared to be high rates, but control groups were not used.

2. Social characteristics

a. Parental characteristics, family life and relationships.

The three groups in this study did not differ for any aspect of family life. Thus, no support was found for research which described mothers of children with hemophilia as being more anxious and overprotective than other mothers, nor for research which found differences between any aspect of the family life of children with and without chronic physical handicap or hemophilia.

b. Medical history.

(i) Contact with medical personnel. This study initially included an attempt to examine systematically the experiences of the children in all three groups with medical personnel and facilities. However, because of the difficulties which prevented collection of information from physicians and hospitals, statistical analysis of any information from these sources was not possible. The information which was obtained indicated that even had all physicians and all hospital records been available, information obtained would have been incomplete. In several of the hospital charts which were reviewed, recording of outpatient visits to hospitals did not include various combinations of the presenting problem, its cause, the treatment given, or the identity of the person assessing the child. Physicians were notified of the identities of the children to be discussed prior to the scheduled interviews, but often did not have the required information available.

The study revealed that most of the children who had been involved with medical personnel, particularly those children with chronic physical handicap, had been cared for by several different physicians. While data was too scanty to allow statistical analysis, it was noted that for such children, parents and children sometimes had difficulty identifying all of the physicians involved, the reasons for their involvement, and their advice.

It was also noted that where physicians were aware

of the involvement of other physicians, the view was expressed several times that the other physician had assumed responsibility for certain aspects of care, usually teaching of parents and patients, and dealing with emotional responses. Sometimes such views were correct, but situations also arose in which each physician treating a child thought the other had assumed responsibility for aspects of care for which neither had taken responsibility.

(ii) Hospitalization. This study also included an attempt to obtain information about the reactions to hospitalization of the children in the three groups. Very few of the doctors who were interviewed could provide such information. Medical records reviewed, in spite of their length, contained a maximum of four comments about the reactions of the children to hospitalization. These comments were usually found in nursing notes, but nursing notes were frequently not available. They had often been either destroyed or moved to less accessible storage areas than the remainder of the file, particularly for older files.

Parents' reports of reactions to hospitalization were incomplete because of the frequency of hospitalization at distances from home too great to have allowed visiting. Thus parents had had little or no opportunity to observe the reactions of their children during hospitalization. Most parents had not received reports about their children's behaviour from hospital personnel. From the information which was obtained from parents, no significant difference

was found between groups for reactions of children to hospitalization.

Studies by Prugh, Staub, Sands, Kirschbaum and Lenihan (1953), Schaffer and Callender (1959) and Stacey, Dearden, Pill and Robinson (1970) found reactions to hospitalization for some children which lasted from eighty days to six months. Information from parents in this study indicated an increased number of children with hemophilia over the other children who had never experienced a full year without hospitalization. For some of these children rehospitalization took place within eighty days to six months after the previous hospitalization, that is, before reactions to the first hospitalization, where reactions had occurred, would have subsided. Further research would be required to identify the effects of that situation.

(iii) Medical regimes. In this study, significantly more children with hemophilia than children in other groups reported that physicians had recommended activity restrictions for them. Most of the children said that they did not follow medical advice, and these statements were supported by finding no differences between the three groups for any aspect of actual participation in games and activities. The parents of significantly more of the children with hemophilia than other parents also said that they did not follow the medical advice, but these parents attempted to restrict significantly more activities for their children than did the parents of the other two groups.

This may have been an indication that the parents did attempt to carry out physicians' recommendations, even though they denied doing so.

The lack of compliance with the medical regimes may reflect findings of Francis, Korsch and Morris (1969) that complex regimes, particularly those recommending change of activity level, decreased compliance.

One method of restriction which was attempted by the parents was supervision of some activities of their children. This tended to support the finding of Browne, Mally and Kane (1960) that parents of children with hemophilia restricted the activity of the children by supervision.

No support was found for results of studies which found various other methods by which parents of children with hemophilia restricted the children's activities. Contrary to the findings of previous research, the activity of children with hemophilia was not significantly different from the other two groups in either quantity or quality. No evidence was found to indicate that activity level was the basis for anxiety, worry, or conflict with parents, or was in any way more problematic for children with hemophilia than for other children.

3. Conclusions.

Practical difficulties encountered and the small sizes of the two control groups limited the validity of comparison of the three groups of children in this study. However, the results indicated that results of studies which failed to use control groups of children with other physical handicaps and without physical handicap may be misleading. For example, results of this study which showed academic delay for children with hemophilia might have been considered to indicate a relationship between such delay and the presence of hemophilia, had it not also been found that the other two groups had equally high rates of academic delay.

Two areas which have received little systematic research attention, and which the results of the study indicated may have particular significance for children with chronic physical handicap, were peer contacts of the same sex, and multiple hospitalizations.

Children with hemophilia were found to differ from children without physical handicap with respect to the range of peer contacts of the same sex. Children with spina bifida were similar to those with hemophilia.

The children with hemophilia differed from both of the other groups with respect to the frequency of hospitalization they experienced.

Differences from the other groups were also found in respect to attempts by physicians and parents to restrict the activities of children with hemophilia.

The hypothesis that children with hemophilia differ from other children has received limited support from the results of this study. The results suggested that the children may differ from all other children only with respect to aspects of the treatment for their physical condition. However, the results also suggested that children with hemophilia share, with other children who have chronic physical handicap, differences from children without chronic physical handicap in respect to peer relationships.

D. Differences between Children with Hemophilia Who Have Psychiatric Disorders and Those without Psychiatric Disorder.

1. Behavioural and psychological differences.

a. Psychiatric disorder.

Nearly half of the school-aged children with hemophilia had psychiatric disorder at the time of interview. None of the pre-school children had psychiatric disorder. Only two of the children were reported to have had psychiatric treatment during their lives.

b. Recent behaviour and emotional state.

This study found no significant differences between these two groups for any item of recent behaviour and

emotional state. Agle and Mattsson (undated), Mattsson and Gross (1966 a, 1966 b), Katz (1963, 1970), and Gentil (1971) used good and poor adjustment as the criteria for selection of groups, rather than presence or absence of psychiatric disorder, which was the criteria used in this study. Research by these authors found a number of differences between their groups with respect to individual items of behaviour and emotional state. This study did not confirm any of the findings of previous research, but the studies were not strictly comparable.

c. Intelligence.

The average intelligence quotients, measured by Raven's Coloured and Standard Progressive Matrices, were identical for the groups with and without psychiatric disorder. Thus no evidence was found to suggest a relationship between intelligence and psychiatric disorder for children with hemophilia.

d. Achievement.

No significant difference between the two groups was found for reading achievement on the Wide Range Achievement Test. Both groups showed academic delay. Agle and Mattsson (undated), Mattsson and Gross (1966 a, 1966 b), and Katz (1970) all reported compensatory intellectual effort or appropriate use of cognitive function to have been features of well-adjusted children with

hemophilia. The manner in which this was accomplished was not clear, in view of findings of academic delay by this study and those of Olch (1971 b), and Kerr (1971).

2. Social differences

a. Maternal characteristics

Mothers of the children in the group with psychiatric disorder had a higher rate of disturbed sleep and appetite than did mothers of the group of children without psychiatric disorder. These disturbances were not found to be related to depression for these women.

Although the results of this study were not directly comparable to those which used adjustment as the criteria for selection of groups, findings by Agle and Mattsson (undated), Mattsson and Gross (1966 a, 1966 b) that mothers of poorly adapted children were anxious and overprotective were not confirmed. Nonetheless, this study did indicate that maternal behaviour and emotional state were related to psychiatric disorder for their children who had hemophilia, and should thus be explored during research into the adjustment of children to hemophilia.

b. Paternal characteristics

Fathers of the two groups were not significantly different. Browne, Mally and Kane (1960), Agle and Mattsson (undated), Mattsson and Gross (1966 a, 1966 b) found fathers of poorly adapted children to be absent from their

homes, or to remain uninvolved in child care. The groups in this study did not differ for presence of fathers in the home or involvement of fathers in child care.

c. Family life and relationships

(i) Family activity. This study found that parents of the children with psychiatric disorder were less often able to identify a favourite activity shared with spouses than parents of the children without psychiatric disorder. This did not appear to be an indication of marital difficulties. It may have indicated lack of time or energy, since the families of the children with psychiatric disorder contained more children and more children with hemophilia than did the families of children without psychiatric disorder. No differences were found between the groups for any other aspect of activities shared with spouses or children.

(ii) Family size. Further research would be necessary in order to determine whether larger number of children per se or larger number of children with hemophilia was the factor primarily related to the presence of psychiatric disorder. Further research would also be required in order to determine the nature of such relationships.

(iii) Facilities in the home and pocket money. The children with psychiatric disorder received more pocket money than did the children without psychiatric disorder. This study did not examine the amount of pocket money received by the siblings of the children, so it was not possible to state whether the children in the group with psychiatric disorder received more pocket money than their siblings, or similar amounts. The socio-economic level of the group with psychiatric disorder was not significantly different from that of the group without psychiatric disorder, but the number of children in the families of the former group was larger than that in the latter group. If all of the children in the families received similar amounts of pocket money, the families of children with psychiatric disorder appear to have provided their children with considerably larger portions of the family income than the families of children without psychiatric disorder. Fewer families of children with psychiatric disorder owned electric stoves, which may have indicated another area of difference between the groups in the allocation of family funds. No other differences in the facilities of the homes were found, but parents were not questioned about ownership of luxury items. Further research would be necessary to confirm these explanations, and determine the nature and extent of the differences.

d. Medical history

(i) Consultant visits. Half of the children without psychiatric disorder had received assessment and/or treatment by consultant physicians during the year prior to interview. None of the children with psychiatric disorder had been recipients of the services of consultant physicians during the year prior to interview. The previous information was obtained from the parental interviews, but verification from medical records and interviews with physicians was not possible. Where information from medical sources was obtained, it was found that parents had failed to report some of the contacts of their children with consultant physicians during inpatient hospital stays. Whether parents had forgotten these contacts, or had not known about them was not explored.

The year prior to interview was the period of time for which the children were assessed for psychiatric disorder. This means that the children in the group with psychiatric disorder had no contacts with consultant physicians (including psychiatrists) during the year in which they had psychiatric disorder. This may have been an indication that the physical disorders of the children with psychiatric disorder were less severe or complicated than those of the children without psychiatric disorder. Alternatively, the finding may have reflected differences in medical treatment received by the two groups, or

differences in the awareness of parents of the nature of the treatment received by their children.

(ii) Bleeding episodes, emotional factors, and activity. It was intended that this study would use the results of laboratory analyses of the type and level of clotting factor deficiencies of the children with hemophilia. However, these had been done for only eight of the children. Consequently, it was not possible to determine whether the frequency and severity of bleeding episodes, and physicians' recommendations regarding activity, reflected laboratory-determined levels of clotting factor deficiencies.

The findings of Browne, Mally and Kane (1960), Agle and Mattsson (undated), Salk, Hilgartner and Granich (1972), Bronks and Blackburn (1968) and Garlinghouse and Sharp (1968) indicated emotional factors to have been at least as important as trauma in the precipitation of bleeding episodes. Egeberg (1963) found that adrenalin infusion shortened bleeding time for individuals with severe classical hemophilia, and that exercise and adrenalin infusion had varying effects on antihemophilic A factor blood level, and bleeding time for other individuals. In view of such findings, it was possible that maintaining activity levels similar to those of other children was not harmful for children with hemophilia in this study, and may even have been beneficial. Certainly, terms such as "risk-taking" behaviour should be reconsidered with regard to their relevance.

Such findings also have important implications for

physicians treating children with hemophilia. Reports of children and parents in this study indicated that physicians had emphasized activity restrictions as an important factor in bleeding, whereas it might have been more relevant to assess emotional factors and deal with emotional problems.

Physicians appeared to have emphasized activity restrictions, and parents seemed confused about the issue, in that they denied following medical regimes, but did attempt to restrict activity. The children maintained activity which was comparable to that of other children. Activity restrictions were not identified by this study as a major source of conflict for children with hemophilia, however, the children did appear to have been in the situation of having to ignore medical and parental instructions in order to maintain normal activity. If trauma is less important in the precipitation of bleeding than are emotional factors, such a situation may have been unnecessary, and even harmful where it created emotional conflict for the children.

3. Conclusions

The two groups of children with hemophilia did not differ for any individual item of behaviour or emotional state. Intelligence and achievement did not differ for the two groups.

The mothers of the children with psychiatric disorder more often reported disturbances of sleep and appetite for themselves than did the other mothers. The

parents of children with psychiatric disorder less often identified a favourite activity shared with spouse than did the other parents. No other aspect of family relationships differed between groups.

Families of the children with psychiatric disorder contained larger numbers of children than the other families, and the children with psychiatric disorder had more siblings who had hemophilia than did the children without psychiatric disorder.

The children with psychiatric disorder received more pocket money than did the other group of children. Further research would be necessary in order to determine whether this reflected differences between the groups for financial priorities.

It appears that one factor which might be considered by research into the adaptation of children with hemophilia is the severity and frequency of bleeding episodes and their relationship to emotional factors. This suggests that, for all children with chronic physical handicap, the frequency and severity of manifestations of the physical conditions should be considered by research into the adaptation of these children to their physical conditions.

The results of this study provided support for the hypothesis that difference (presence or absence of psychiatric disorder) within the population of children with hemophilia is related to factors within the home and to medical treatment. No support was found for relationship of the

difference to factors within the child, however, information about such factors as the severity of the physical condition was not available. Many factors within the home showed relationships to the presence of psychiatric disorder for the children with hemophilia.

E. Overall Conclusions

The significance of comparisons made between the group of children with hemophilia and the other groups of children must be viewed with caution. However, the results indicated that physicians and parents attempted to deal with the activity of children with hemophilia differently than for other children. Attempts to limit the activity of the children appeared to have been unsuccessful. Further studies might examine whether or not such restrictions are necessary by examining the effects of activity and other factors on frequency and severity of bleeding episodes. If activity restrictions prove to be necessary, factors which affect the compliance of the children should be studied.

Comparison of the children with and without psychiatric disorder who also had hemophilia provided indication of some aspects of family life and relationships which are related to psychiatric disorder. Future studies might explore the extent of effects of these factors individually and the interaction effects of the factors with each other and the physical condition. Availability

of such information should lead to identification of the factors easiest to influence for the purpose of reducing psychiatric disorder in this group of children.

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APPENDIX A

INTERVIEW WITH THE CHILD

INTRODUCTION:

Note the child's entrance to the interview.

This section of the interview should last about five minutes and should be unstructured with the aim of putting the child at ease and learning about him in order to facilitate later questioning.

This could include:

(a) Introduction of the interviewer
(b) Making sure you have child's correct name (enquire about what he likes to be called)
(c) Asking when his next birthday is
(d) Asking about what he likes to do
(e) Asking what he would be doing now if he weren't with you
(f) Asking how many brothers and sisters he has

The introduction should also include a brief simple explanation of what is being done.

(a) Talking to boys and girls all over the province
(b) Trying to find special difficulties of children with physical problems/bleeding disorders and see if there are ways we can help
(c) Mention interview with parents and doctors

Always note:

emotional responsiveness and ability to form relationship
evidence of anxiety
mannerisms or tics
fidgetiness
overactivity
difficulties in concentration
spontaneous remarks
note critical remarks

CHILD'S NUMBER BIRTHDATE

A. LIFE AND ACTIVITY

For all questions involving frequency try to identify specified period from some particular occasion (holiday, birthday, etc.)

A - 1 Do you have friends at school? What are their names? How old are they? How many times did you play with each last week? Is that about the same as other weeks? Do you play with them outside of school?

A - 2 Do you have friends living near you? What are their names? How old are they? How many times did you play with each in the last week? Is that about the same as other weeks?

PEER CONTACTS (past week) (number of children times the number of contacts with each)

Code the exact number and the appropriate range

0	None	3	Four - six
1	One	4	Seven or more
2	Two - three	11	Not known

Code for same sex and opposite sex

RANGE OF PEER CONTACTS (past week) (number of children)

Code as above

A - 3 Do you have a special friend/best friend?

Coding

0	No	2	Definite
1	Dubious	11	Not known

Code for school friend and home friend

A - 4 Do you usually play with a group of friends? When was the last time?

Coding

0	No	2	Definite - school oriented
1	Dubious		

3	Definite - home oriented	5	Definite - not in the last week
4	Definite - both areas	11	Not known

A - 5 Do you visit your friends' houses? Have you done so in the last two weeks?

Coding

0	No visits	3	Visits to both
1	Visits to school friends	11	Not known
2	Visits to home friends		

A - 6 Have you had any of your friends visit your house in the last two weeks?

Coding

0	No	3	Visit from friends of both areas
1	Visit from school friend	11	Not known
2	Visit from home friend		

A - 7 Have your parents ever said anything about your friends? What did they say? Did they ever tell you not to play with them? Did you do what they said?

Coding

0	No comments or approval	3	Effective prohibition
1	Disapproval, no prohibition	11	Not known
2	Ineffective prohibition		

A - 8 Do you have TV at home? How often do you watch it?

What programmes do you like best? How much time did you spend watching TV in the last week?

Coding

0	No TV or set broken
11	Not known

Code exact number of hours

A - 9 Do you go to movies? How often in the last month? What did you see:

Coding

0	No	3	Four or more times
1	Once	11	Not known
2	Two - three times		

A - 10 Do you belong to a club? Which one? How often have you gone in the last month?

Coding

0	No attendance	3	Four or more times
1	Once	11	Not known
2	Two - three times		

A - 11 Do you play on any teams?

Coding

0	No	2	Regular
1	Occasional	11	Not known

A - 12 Do you read comics or magazines? Which ones? How often in the last month?

Coding

0	None	2	Weekly or more
1	Less than weekly	11	Not known

A - 13 Do you like to read books (apart from schoolbooks)? What books have you read? Did you like them? Do you borrow books from the library? Can you tell me the story of one of them?

Coding

0	None	3	More than five
1	One	11	Not known
2	Two - five		

A - 14 Do you go out with your parents? Does anyone else go with you? Where do you go? What do you do? How many times have you gone out in the last month?

Coding

0	No	3	Out with parents and others
1	Out but less than weekly (with parents only)	4	More than one of above
2	Weekly or more (with parents only)	11	Not known

A - 15 What other things do you like to do? LIST WITH FREQUENCY. Have you ever had difficulty taking part in any of the activities we have mentioned, or been injured? LIST

CODE Yes No Unknown

Are there any things you would like to do but don't? Why? Could you do them? LIST WITH REASON FOR NONPARTICIPATION. Code as above for (1) Physical Condition limiting Activity (2) Desired Activity not Done for Other Reason.

Have your parents ever told you not to do certain things? Did you? LIST WITH COMPLIANCE. Code as above for (1) Parental Restriction (2) Compliance. Have doctors or nurses told you not to do certain things? Did you? Did your parents say anything about this? LIST WITH COMPLIANCE AND PARENTAL COMMENTS. Code as above for (1) Medical Restrictions (2) Compliance. Have doctors or either of your parents ever told you not to do any of the following things? Which of the following things do you do?

ACTIVITY LIST

Under 5 years	CHILD	MOTHER	FATHER	DOCTOR
1. Sledding				
2. Tumbling				
3. Tobogganing				
4. Snow-balling				
5. Jumping				
6. Climbing				
7. Swinging				
8. Tricycling				
9. Playing cowboys and Indians				
10. Running				
11. Building				
12. Street hockey				
13. Skating				
14. Swimming				
15. Punch-balls				

5 - 12 years

1. Skating
2. Hockey
3. Baseball
4. Rough-housing
5. Sledding
6. Swimming
7. Tumbling
8. Softball
9. Darts
10. Tobogganing

5 - 12 years (cont'd) CHILD MOTHER FATHER DOCTOR

11. Snow-balling
12. Fishing
13. Bowling
14. Jumping
15. Racing
16. Carpentry
17. Bicycling
18. Gym
19. Climbing
20. Chopping wood

13 - 17 years

1. Skating
2. Hockey
3. Baseball
4. Sledding
5. Chopping wood
6. Swimming
7. Tumbling
8. Softball
9. Darts
10. Tobogganing
11. Snow-balling
12. Shooting
13. Fishing
14. Bowling
15. Jumping
16. Racing
17. Carpentry
18. Bicycling
19. Gym
20. Climbing
21. Dancing

A - 16 Do you get pocket money from home? How much? What do you spend it on? Code exact amount.

A - 17 Do you have to be in at any special time at night? What time? What happens if you're late? What do you think of this?

Coding

0	No set curfew	3	Curfew, child agrees
1	Curfew without enforcement	11	Not known
2	Curfew, child disagrees		

A - 18 What time do you go to bed? (Probe as for number 17)

Code as for number 17

A - 19 Are you allowed to jump or climb on the furniture at home? Code as for number 17

A - 20 Do you think your parents are more or less strict than most parents or about the same?

Coding

0	Average	3	More strict
1	Less strict	11	Not known
2	Generally average, more severe restrictions		

A - 21 Do you help out around the house (shopping, washing-up, etc)? How often? Is this a regular thing (e.g. everyday, every weekend)? How do you feel about this?

Coding

0	Never done	4	Regularly and daily
1	Occasionally done	11	Not known
2	More than once per week, but not regularly		
3	Regularly, less than daily		

Feelings:

Coding

0	Likes chores	3	Strongly dislikes - has to be coerced
1	Likes occasional chores	11	Not known
2	Dislikes - tries to avoid		

A - 22 Have you ever been in hospital? When? Why? For how long? Have you had to go to the doctor's office or hospital outpatients? Have you ever had to go to the Children's Rehabilitation Centre?

For each question code the exact number of visits

OBTAIN DETAILED ACCOUNT OF REASONS, TREATMENTS AND FEELINGS ABOUT THESE.

A - 23 Apart from being in hospital have you ever been away from home without your parents? Has either one of them been away for as long as one month?

Coding

0	None	3	Separation from both
1	Separation from father only	11	Not known
2	Separation from mother only		

B. ATTITUDES

Code from remarks in Section A.

B - 1 Criticism of Mother

Coding

0	None	3	Four or more remarks
1	One remark	11	Not known
2	Two-three remarks		

B - 2 Rejection of Mother

Coding

0	None	2	Definite
1	Possible	11	Not known

B - 3 Criticism of Father

Coding

0	None
1	One remark
2	Two - three remarks
3	Four or more remarks
11	Not known

B - 4 Rejection of Father

Coding

0	None
1	Possible
2	Definite
11	Not known

B - 5 Criticism of school or teachers. Code as for number 3.

B - 6 Rejection of school or teachers. Code as for number 4.

B - 7 Criticism of hospital or medical personnel. Code as for number 3.

B - 8 Rejection of hospital or medical personnel. Code as for number 4.

C. NEUROLOGICAL ASSESSMENT

SIGHT AND HEARING

C - 1 Observe for any abnormalities of eyes (eg. squint)

Do your eyes ever pain?

ASK DETAILS FOR POSITIVE ANSWER.

Have you ever had to see a doctor about your eyes?

Do your eyes ever go blurry?

ASK DETAILS FOR POSITIVE ANSWER.

Coding

0	No difficulties
1	Physical abnormality noted
2	Complaint of eye difficulty (last twelve months)
11	Not known

C - 2 Ask the child to read Snellen Chart from twenty feet with eyes alternately covered.

Coding

0	20/10 (Snellen #11) to 20/20 (Snellen #8)
1	20/25 (Snellen #7) to 20/30 (Snellen #6)
2	20/40 (Snellen #5) to 20/200 (Snellen) #1)
11	Not known

C - 3 Do you ever have difficulty hearing?

ASK DETAILS OF POSITIVE ANSWER.

Do your ears ever pain?

How often do you have earaches?

What do you do?

Coding

0	No difficulties
1	Complaint of hearing difficulty (last 12 months)
2	Complaint of pain
3	Complaints of pain and hearing difficulty
11	Not known

C - 4 Examine child's ears for the presence of wax. Seat the child with his back to the interviewer, begin moving a watch towards each ear alternately until the child is able to hear it. Record the distance in inches.

Left

Right

C - 5 Move to a distance of 20-25 feet from the child, face him and repeat the following word list in low but audible tones, asking the child to repeat these.

WORD	RESPONSE
fat	
cat	
rat	

C - 5 (continued)

WORD	RESPONSE.
scat	
pat	
bat	
sat	
hat	

Coding

0	No abnormality
1	Two or less misinterpreted
2	More than two misinterpreted
11	Not known

C - 6 Ask the child to write or print letters.

Ask the child to throw a ball towards the wall.

Ask the child to peep through a keyhole.

Ask the child to use a funnel made from paper as a telescope.

Ask the child to stand on one leg, then hop.

Ask the child to kick a beanbag towards the wall.

(NOTE ALSO FOR CO-ORDINATION)

Laterality:

Coding

0	Consistent (note (R) or (L))
1	Hand differing from eye-foot
2	Eye differing from hand-foot
3	Foot differing from eye-hand
4	Other
11	Not known

C - 7 Ask the child to touch his nose with the finger of his left hand. Hold 5 minutes, eyes open, then closed. Then ask him to repeat with his right hand (Note also for CO-ORDINATION)

Ask him to pick up coins with his right hand then his left (note also for CO-ORDINATION)

Ask him to identify interviewer's right hand.

Ask him to touch his left foot with his right hand.

Ask him to touch interviewer's right hand with his left hand.

RIGHT-LEFT DIFFERENTIATION

Coding

0	No abnormality
1	Right-left confusion
11	Not known

C - 8 Ask the child to walk around a chair.

Ask the child to walk about 10 feet, heel to toe gait.

Code also from number 6 (hopping and kicking the bean bag).

CO-ORDINATION LOWER LIMBS

Coding

0	Within normal limits
1	Dubious abnormality
2	Definite
11	Not known

C - 9 Ask the child to touch the tip of each finger rapidly in succession with the thumb of the same hand.

Code also from number 7 (touching his nose and picking up coins).

CO-ORDINATION UPPER LIMBS

Code as for number 8

C - 10 Ask the child to see how long he can keep his eyes closed, protrude his tongue, open his mouth. Record time in seconds.

MOTOR IMPERSISTENCE

Eyes

Tongue

Mouth

Coding

0	No abnormality
1	Motor impersistence
11	Not known

C - 11 Ask the child to copy the shapes of a triangle, diamond, L, cross and star using matches. Code accuracy.

CONSTRUCTION ABILITIES

Coding

0	All shapes comparable
1	Star only distorted
2	Cross and star only distorted
3	Three or more shapes distorted
4	Other combination of two distorted
11	Not known

C - 12 Ask the child to draw a picture. If asked "of what" answer "anything you wish".

Note hand used.

Engage in activities such as moving, closing a drawer to gain estimate of distractibility.

Ask about the picture in general terms.

Assess speech and language, descriptive ability, grammer, and articulation.

Ask the child to draw a man.

DISTRACTIBILITY

Coding

0	None
1	Dubious
2	Definite
11	Not known

C - 13 Ask the child to name objects at which the interviewer points.

Nominal dysphasia

Coding

0	Not present
1	Dubious
2	Definite
11	Not known

C - 14 Ask the child to find objects named by the interviewer (use names he has used in number 13).

Receptive dysphasia

Code as for number 13

C - 15 Ask the child to fold a sheet of paper and place it in an envelope, then describe how it would be mailed.

Apraxias of Ideational, Ideamotor or Motor type

Code as for number 13

C - 16 Then ask the child to identify letters traced on the palms of each hand.

Conditions eyes opened

Conditions eyes closed

Graphesthesia

Letters		Response	
L	R	L	R

Coding

0	Not present
1	Dubious
2	Definite
11	Not known

Speech and Language

Use all relevant information to assess speech or language abnormality.

Code as for number 13

D. PSYCHIATRIC ACCOUNT

I would now like to ask a few more questions.

D - 1 Do you ever get teased at school?

What about away from school?

What is it usually about?

Do you get teased more than other children?

D - 1 (continued)

How do you feel about it?

Coding

0	No
1	Less than average
2	Average
3	More than average
11	Not known

D - 2 Do you ever get bullied/picked on?

More than other children?

Coding

0	No
1	Less than average
2	Average
3	More than average
11	Not known

D - 3 Do you ever get into trouble for hitting other children or picking on them?

More trouble than other children?

Why?

Code as for number 2

D - 4 Most boys have times when they feel pretty lonely. Do you ever feel that way?

How often?

Are there any particular times you feel lonely?

Can you remember the last time?

What do you do when you feel lonely?

D - 4 (continued)

Coding

0	Never felt
1	Rarely
2	Often
11	Not known

D - 5 What kinds of things make you angry or upset?

DISCUSS ALL AREAS MENTIONED.

D - 6 Most people get into trouble at times what sorts of things do you get into trouble for?

How do you feel about this?

Have there been things you could have gotten into trouble for?

Coding

0	None
1	Minor (mischief)
2	Some definite antisocial activities
3	Much definite antisocial activity
11	Not known

D - 7 Do you know what a worry is? (define if necessary).

Everyone worries about some things.

What do you worry about?

Do you ever worry so much you can't think about what you're supposed to be doing?

Does worrying ever keep you awake at night?

Coding

0	None
1	Dubious
2	Definite
11	Not known

D - 8 Do you ever worry about your health?

Have you ever felt you might be physically sick?

What did you think was the matter?

Do you have any other worries about your health?

WORD APPROPRIATELY FOR CHILDREN WITH CHRONIC PHYSICAL DIFFICULTIES.

NOTE EXACT RESPONSES CAREFULLY AND PROBE CAUTIOUSLY IN ORDER TO ASCERTAIN DENIAL OF ILLNESS, REALISTIC WORRIES, GENERALIZATION OF HEALTH WORRIES, ETC.

HEALTH WORRIES

Coding

0	None
1	Realistic worries
2	Denial of condition
3	Unrealistic worries
4	Generalization of worries
11	Not known

HYPOCHONDRIASIS

Coding

0	Not present
1	Dubious
2	Definite
11	Not known

D - 9 Do you ever find that you get nervous all over or really scared for no particular reason?

When?

What does that feel like?

Does anything in particular make you feel that way?

Coding

0	None
1	Dubious
2	Non-situation specific anxiety
3	Non-situation specific panic attacks
11	Not known

D - 10 Are there some things that make you frightened or scared?

PROBE USING EXAMPLES

Going to school

Dressing when people around, changing for gym

School exams

Being in crowds

Meeting new people

Being alone in the house

Being alone in the dark

Dogs

Other animals

Insects

Thunder and lightning

Hospitals

Nurses and doctors

Coding

0	None
1	Dubious
2	Situation specific anxiety
3	Situation specific panic attacks
4	Avoidance of object or situation
11	Not known

D - 11 Do you sometimes feel unhappy and miserable?
How does that feel?
Do you ever want to cry? Do you?
Do you ever feel so badly you want to get away from everything or run away?
What things make you feel like that?
When was the last time you felt like that?
How often do you feel that way?

Coding

0	None
1	Dubious
2	Marked or often
11	Not known

D - 12 Do you ever feel like you don't matter very much, that you're not as important as other people?

Coding

0	None
1	Slight
2	Definite
11	Not known

D - 13 Do you ever feel like you'd rather be somewhere else than where you are at the time?

Where?

Would you rather be anywhere else?

Did you ever want to stop living?

What did you do?

Coding

0	No suicidal thoughts
1	Suicidal thoughts only
2	Thoughts of suicidal methods
3	Active step, but no attempt
4	Suicidal attempt
11	Not known

D - 14 Do you ever get a tune in your head that you can't stop? Or get silly thoughts or words in your mind that won't go when you want them to?

Coding

0	No obsessional ruminations
1	Dubious
2	Definite
11	Not known

D - 15 Do you ever find yourself doing silly things, like touching every door you pass, washing your hands over and over?

Coding

0	No obsessional rituals
1	Dubious obsessional rituals

D - 15

Coding (continued)

2	Definite obsessional rituals
11	Not known

D - 16 Sometimes people feel like other people are looking at them and talking about them, or laughing at them. Do you ever feel like that?

Can you remember the last time?

Were they really doing this?

Coding

0	No ideas of reference
1	Dubious
2	Definite ideas of reference recognized as unfounded
3	Delusional ideas of reference
11	Not known

D - 17 How do you get on with your brothers and sisters?

What are they like?

How often do you squabble?

What about?

What happens?

Coding

0	No difficulty
1	Dubious
2	Definite
3	No siblings
11	Not known

D - 18 How do you get along with your teachers? (Explore)

Coding

0	No difficulty
1	Dubious
2	Definite
11	Not known

D - 19 How do you feel you're doing in school?

Coding

0	Better than average
1	Average
2	Below average
3	Failing
11	Not known

D - 20 How do you find the work compared to the others in your class?

Coding

0	Easier
1	Same
2	More difficult
11	Not known

E. OBSERVATION OF CHILD AT INTERVIEW

Coding

0	None
1	Dubious or minimal
2	Definite
11	Not known

MOOD

Apprehension on entering the interview

Anxiety, tension or panic

Depression or unhappiness

Tearfulness

Abnormally little emotional response

Suicidal ideas expressed

Abnormal elevation of mood

Depersonalization or derealization

'Conversion' hysterical symptoms (NOT histrionic behaviour)

Preoccupation with anxiety topics

Other

MOTOR

Underactivity, little spontaneous movement

Gross overactivity

Fidgetiness, restlessness, or squirminess

Tics

Other mannerisms or abnormal movement

Abnormalities of co-ordination

SPEECH

Stammer or stutter

Disorder of articulation

Disorder of comprehension or production of language

Elective mutism

RELATIONSHIP

Autism, withdrawal, aloofness, or detachment to a marked degree

Markedly shy or inhibited

No smiling

Disinhibited, over-friendly

Hostility

Fewer than four spontaneous remarks

Other abnormality

CONCENTRATION

Attention span short or persistence low (needs prompting and reminding to complete tasks)

Abnormally distractible (Diverted by usual or slightly unusual stimuli from tasks)

CONCLUSION

I've asked you many things. Would you like to ask me anything?

Thank you very much for your help.

PSYCHIATRIC DISORDER

Coding

0	Absent
1	Dubious
2	Present
11	Not known

Behaviour and Emotion Symptoms:

PSYCHIATRIC DIAGNOSIS:

APPENDIX B

PARENTAL INTERVIEW

Interview times will be arranged prior to interviewer's arrival in the community and parents notified by telephone when interviewer has arrived (as appointment confirmation).

Introduction includes:

1. My name is ..... .
2. As you know I am studying difficulties and problems encountered by children who have bleeding disorders. I will be including all children in the province who have bleeding disorders, as well as a group of children with other physical problems, and a group without physical difficulties.
3. It may be possible to identify factors which help children cope with physical problems - in particular bleeding disorders, and to identify some things which are special problems for these children.
4. I appreciate your co-operation with this and will keep all that you say confidential.

CHILD'S NUMBER:

BIRTHDATE:

A. CHILD'S HEALTH (PRESENT)

First of all, I would like to ask about .....'s health.

G.P.'s

A - 1 Has ..... had to see the doctor (apart from at a hospital) during the past year?

0 - No
1 - Once
2 - More than once, less than once per month
3 - Average of once per month
4 - More than once per month, less than once per week
5 - Average of once or more per week
19 - Not known or unsure

If Code 0 omit # 2-8 inclusive.
If Code 19 omit # 2.
If Code other than 5 & 19 omit # 3-5 inclusive

A - 2 When did these visits take place?

A - 3 How many times has ..... had to see the doctor in the last week?

0 - None
1 - Once
2 - Twice
3 - 3-5 times
4 - More than 5 times
19 - Not known

Note exact number:

A - 4 Was this an average week, or are visits usually more or less frequent?

0 - Visits less frequent

1 - Average

2 - Visits more frequent

19 - Not known

If Code 1 omit #5

A - 5 How frequent are visits in an average week?

Code as for #3.

Note exact number:

A - 6 What were the reasons for these visits?

0 - Regular check-ups (not related to chronic physical handicap)

1 - Childhood diseases (including colds, influenza, PUO)

2 - Accidents (not related to chronic physical handicap)

3 - Regular check or treatment related to chronic physical handicap

4 - Accident related to chronic physical handicap

5 - Other treatment related to chronic physical handicap

18 - Other

19 - Not known

Continue questioning until coding accurate.

Note exact responses:

A - 7 What treatment was given at these visits?

0 - None

1 - Orders for regime at home (e.g. rest, dieting)

2 - Pills or medicine for medical reasons

3 - Pills or medicine for psychiatric reasons

4 - Tests

5 - Treatment for chronic physical handicap (e.g. cryoprecipitate)

6 - Referred to hospital O.P. or consultant

7 - Admitted to hospital

8 - Surgery

18 - Other

19 - Not known

Continue questioning until coding accurate.

Note exact responses:

A - 8 What were the names of the doctors?

HOSPITAL OUTPATIENTS

A - 9 Has ..... visited hospital emergency or outpatients during the past year?

0 - No

1 - Once

2 - More than once, less than once per month

3 - Average of once per month

4 - More than once per month, less than once per week

5 - Average of once or more per week

A - 9 (continued)

19 - Not known

If Code 0 omit #10-16 inclusive

If Code 19 omit #10

If Code other than 5 & 19 omit #11-13.

A - 10 When did these visits take place?

A - 11 How many times has ..... visited hospital emergency or outpatients' during the last week?

Code as for #3

Note exact number:

A - 12 Was this an average week or are visits more or less frequent usually?

Code as for #4

If Code 1 omit #13

A - 13 How frequent are hospital visits in an average week?

Code as for #3

Note exact number:

A - 14 What were the reasons for these visits?

0 - Regular check-ups

1 - Childhood diseases

2 - Accidents

3 - Regular check or treatment related to chronic physical handicap

4 - Accident related to chronic physical handicap

5 - Other treatment related to chronic physical handicap

18 - Other

A - 14 (continued)

19 - Not known

Continue questioning until coding accurate

Note exact responses:

A - 15 What treatment was given at these visits?

0 - None

1 - Orders for regime at home

2 - Pills or medicine for medical reasons

3 - Pills or medicine for psychiatric reasons

4 - Tests

5 - Treatment for chronic physical handicap

6 - Referred to hospital O.P. or consultant

7 - Admitted to hospital

8 - Surgery

18 - Other

19 - Not known

Note exact responses:

A - 16 To which hospitals were these visits made?

SPECIAL CLINICS

REPEAT ALL HOSPITAL OUTPATIENT QUESTIONS, PHRASING APPROPRIATELY

A - 17 to A - 24

CONSULTANT VISITS

Repeat all HOSPITAL OUTPATIENT questions, phrasing appropriately.

A - 25 to A - 32

HOSPITAL INPATIENT

A - 33 Has ..... been admitted to hospital during the past year?

Code as for #1.

If Code 0 omit #34-40 inclusive

If Code 19 omit #34

If Code 1 - 2 omit #35-37 inclusive

A - 34 When did these admissions take place?

A - 35 How many times has ..... been admitted to hospital during the last month?

Code as for #3.

Note exact number:

A - 36 Was this an average month or are admissions usually more or less frequent?

Code as for #4.

If Code 1 omit #37.

A - 37 How frequent are hospital admissions in an average month?

Code as for #3.

Note exact number:

A - 38 What were the reasons for these admissions?

Code as for #6.

Continue questioning until coding accurate.

Note exact responses:

A - 39 What treatment was given during these admissions?
Code as for #7.
Continue questioning until coding accurate.
Note exact responses:

A - 40 In which hospitals did these admissions take place?

RESIDENTIAL TREATMENT CENTRES

Repeat all HOSPITAL INPATIENT questions, phrasing appropriately.
A - 41 to A - 48.

TOTAL

A - 49 Have there been any illnesses or physical problems not treated during the past year?

0 - None
1 - Childhood disease
2 - Accident
3 - Episode of chronic physical illness
18 - Other
19 - Not known
Note exact response:

A - 50 How many times has this happened?

0 - Once
1 - 2-5 times
2 - 5-10 times
3 - More than 10 times
19 - Not known
Note exact response:

CHILD'S HEALTH (PAST)

HOSPITAL INPATIENT

B - 1 Prior to this year, has ..... been admitted to hospital?

0 - No

1 - Once

2 - 2-5 times

3 - 5-10 times

4 - More than 10 times

19 - Not known

If Code 0 omit #7-8 inclusive

Note exact number:

B - 2 Was this year about the same as previous years for the number of hospital admissions?

0 - Yes

1 - No

19 - Not known

If Code 0 omit #3-6 inclusive.

B - 3 In which year was the number of admissions highest?

B - 4 How many times was ..... admitted to hospital that year?

0 - 1-5 times

1 - 5-10 times

2 - More than 10 times

3 - None

19 - Not known

Note exact number:

B - 5 In which year was the number of admissions lowest?

B - 6 How many times was ..... admitted to hospital that year?

Code as for #4.

Note exact number:

B - 7 Where did admissions prior to this year take place?

B - 8 What were the reasons for these admissions?

Code as for #A-6. Continue questioning until coding accurate.

Note exact number:

SPECIAL CLINICS

Repeat all Hospital Inpatient questions, phrasing appropriately.

B - 9 to B - 16.

CONSULTANT VISITS

Repeat all Hospital Inpatient questions, phrasing appropriately.

B - 17 to B - 24.

RESIDENTIAL TREATMENT CENTRES

B - 25 to B - 32.

B - 33 What are the names of the doctors who have treated ..... before this year?

B - 34 Have there been any/any other physical illnesses or physical problems present for more than one year - at any time?

What?

0 - None

1 - Kidney or Genito-urinary tract disorder

2 - Metabolic or endocrine disorder

3 - Circulatory system disorder (excluding bleeding)

4 - CNS disorder above the brain stem (exclude epilepsy)

5 - Epilepsy

6 - CNS disorder at brainstem or below

7 - Phenylketonuria

8 - Below 3rd percentile in height

9 - Above 97th percentile in weight

10 - Neoplasm

11 - Leukaemia

12 - Asthma

13 - Ulcerative colitis

14 - Disorder of sense organs (exclude squint)

15 - Bleeding disorder

18 - Other

19 - Not known

If Code 0 omit #35-39 inclusive.

Note exact response:

B - 35 When did you know that ..... had this condition?

0 - At birth

1 - During first year

2 - 1-5th year

3 - 6-12th year

4 - 13-17th year

19 - Not known

Note exact age:

B - 36 When did ..... first have treatment for this?

0 - Immediately after diagnosis

1 - During first year after diagnosis

2 - 1-5 years after diagnosis

3 - 5-10 years after diagnosis

4 - More than 10 years after diagnosis

5 - Never

19 - Not known

B - 37 What treatment has ..... had prior to this year?

Code as for #A-7.

Continue questioning until coding accurate.

Note exact responses:

B - 38 How far from your home is the closest place where treatment is available?

0 - In same community

1 - Outside community, within 1 hour driving distance

2 - Journey of 1-24 hours necessary

3 - Journey of greater than 24 hours necessary

19 - Not known

Note exact response:

B - 39 How long did ..... have this condition?

0 - One year

1 - 2-5 years

2 - 5-10 years

3 - More than 10 years

4 - Always

19 - Not known

Note exact response:

C. EMOTIONAL AND/OR BEHAVIOUR DIFFICULTIES (as seen by Parent)

Now I would like to ask about .....'s behaviour and emotions.

C - 1 Do you think ..... has any behaviour problems or emotional difficulties?

Or problems with his nerves?

0 - No

1 - Yes

19 - Not known

If Code 0 omit remainder of Section C.

C - 2 Do you feel ..... has more difficulties than most children?

About the same, or less?

0 - Less

1 - The same

2 - More

19 - Not known

C - 3 What are these difficulties?

List:

C - 4 Does he have any other difficulties? (Repeat until parent answers NO)

List:

C - 5 What do you think is causing these difficulties?

List:

C - 6 Have you ever consulted anyone about these difficulties?

0 - No

1 - G.P.

2 - Paediatrician

3 - Psychiatrist

4 - Counselling service

5 - School personnel

6 - Clergy

18 - Other

19 - Not known

If Code 0 omit #7-11 inclusive.

C - 7 When did this take place?

C - 8 Where did this take place?

C - 9 Whose idea was it to seek this help?

0 - Child

1 - Mother

2 - Father

3 - Other family member

4 - Non-family member

C - 9 (continued)

5 - Doctor

19 - Not known

Note exact response:

C - 10 Is ..... still attending any treatment for these problems?

0 - Yes

1 - No

19 - Not known

C - 11 Do you feel you are receiving enough help?

0 - Yes

1 - No

19 - Not known

C - 12 Do you need or want (more) help from anyone with these difficulties?

0 - Yes

1 - No

19 - Not known

C - 13 Who do you feel would be able to provide this help?

0 - Spouse

1 - Other family member

2 - Clergy

3 - School Staff

4 - G.P.

5 - Paediatrician

6 - Psychiatrist

7 - Counselling service

C - 13 (continued)

18 - Other

19 - Not known

Note exact response:

C - 14 Obtain a detailed account of each of the behavioural or emotional difficulties noted in numbers 3 & 4.

Factors necessary are:

a) Description of the behavioural items - Would you describe exactly what ..... does when he is showing these difficulties?

For non-behavioural items: How does ..... show this?

b) Severity - Is this worse than for most children or about the same? Does ..... do this when those outside the immediate family are present?

c) Frequency - How often does this happen?

d) Date of onset - When did this first happen?

e) Precipitants - Does this happen in relation to anything of which you are aware?

What seems to bring on this behaviour?

f) Ameliorating factors - Does anything make it better?

C - 15 Has this been getting better or worse in the past year?

0 - Better

1 - Same

2 - Worse

19 - Not known

SYSTEMATIC QUESTIONING

RECENT BEHAVIOUR & EMOTIONAL STATE

REACTIONS TO HOSPITALIZATION

Omit questions covered by answers in Section C.
Omit starred questions if no medical contacts noted.
Behavioural items not noted during past year probe only if related to Medical Contacts.

I would like to ask about some (other) health and behavioural problems often shown by children.

D. SOMATIC SYMPTOMS

D - 1 Does he ever have severe headaches?
Is he ever sick with them?
Do they affect his sight?
0 - Not present
1 - Dubious or minimal
2 - Present
9 - Not known
Note exact responses:

D - 2 Does he ever have stomach aches?
Does he vomit when he has them?
Does he have them at any particular time of day?
Is there any difference between weekends and the rest of the week?

D - 2 (continued)

0 - Not present

1 - Dubious or minimal

2 - Present

19 - Not known

* Has he ever had them during or after hospitalization?

Code as for #1.

D - 3 Does he ever wet his bed?

Was he ever dry?

What was the longest period he was dry?

What about when he was away from home?

Code as for #1.

* Did this ever happen during or after hospitalization?

Code as for #1.

D - 4 Does he ever wet his clothes?

Was he ever dry?

What was the longest period he was dry?

What about when he was away from home?

Code as for #1.

D - 5 Does he ever have pain when voiding?

Code as for #1.

D - 6 Does he ever dribble between visits to the bathroom?

Code as for #1.

D - 7 Does he ever soil/dirty his clothes or bed?

Is this just staining or actual pieces of bowel movement?

D - 7 (continued)

Was he ever clean?

What was the longest period he was clean?

What about when he was away from home?

Code as for #1.

D - 8 Does he ever smear feces (bowel movement) on himself or other things?

D - 9 Does he have any other difficulties with voiding or his bowels? Specify:

D - 10 Is there any difficulty with .....'s eating?

Does he refuse some or all of his food?

If so, how does he react when persuaded to eat?

Will he eat these things at a friend's home or in a restaurant?

* Have there ever been feeding disturbances during or after hospitalization? (Refusal, anorexia, overeating, chewing problems, smearing)

D - 11 Has ..... ever eaten unusual things (e.g. paper, grass, insects)?

D - 12 Does ..... have any difficulty sleeping?

Does he have a problem getting to sleep?

Does he wake during the night?

Does he ever scream at night?

Does he ever come to your bed at night?

Does he ever have nightmares or wake with bad dreams?

Does he sleep walk?

D - 12 (continued)

* Has any of the above ever happened during or after hospitalization?

D - 13 Does he ever bang his head repeatedly?

If necessary, explain.

Or rock?

* Has he ever done this during or after hospitalization?

D - 14 Does he ever purposely hold his breath?

How long?

What happens?

D - 15 Does he ever faint or have fits?

D - 16 Has there been any loss of weight this year?

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

E. SPEECH SYMPTOMS

Code all questions as for #1.

E - 1 Does ..... stutter or stammer?

0 - Not present

1 - Dubious or minimal

2 - Present

19 - Not known

E - 2 Does he have any other difficulties with speech?

Does he use baby-talk?

Does he lisp?

E - 2 (continued)

Does he have difficulty with pronunciation?

Note exact response:

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

F. MOTOR SYMPTOMS

Code all questions as for #1.

F - 1 How active is ..... ?

Is he unusually overactive or restless?

Will he stay still if expected to?

What is the longest time he can spend at something interesting?

How does he react if forced to be still for a short time?

0 - Not present

1 - Dubious or minimal

2 - Present

19 - Not known

Note exact responses:

* Has ..... ever been overactive or underactive during or after hospitalization?

F - 2 Is ..... a fidgety child?

F - 3 What is .....'s concentration like?

Can he concentrate for half an hour?

F - 3 (continued)

How easily is he distracted from what he is doing?

F - 4 Is ..... clumsy?

F - 5 Does ..... have any mannerisms or tics?

Does he twitch his face or shoulders?

Does he blink excessively?

F - 6 Does ..... make any other repetitive movements?

(e.g. flapping hands?)

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

G. HABIT DISORDERS

Code all questions as for #1.

G - 1 Does ..... suck his thumb?

Does he suck anything else? (pencils, clothing, etc.?)

What does he suck?

Is this at night only?

0 - Not present

1 - Dubious or minimal

2 - Present

19 - Not known

* Has he ever done this during or after hospitalization?

G - 2 Does ..... bite his nails?

Does he bite them right down?

Does he make them bleed?

G - 2 (continued)

Does he bite anything else?

What?

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

H. DISTURBANCE OF RELATIONSHIPS

FRIENDS

H - 1 Does ..... have friends at school?

0 - Enough friends

1 - Some friends, not as many as most children

2 - No friends

19 - Not known

H - 2 Are .....'s friends his own age?

Does he prefer older or younger children?

0 - Friends same age

1 - Friends younger

2 - Friends older

3 - Preference difference from actual age of friends

18 - Other

19 - Not known

H - 3 Does ..... see these friends outside school?

How often?

Do they ever come home with him?

If he doesn't see them, why?

H - 3 (continued)

0 - Has school friends home regularly

1 - Sees school friends outside regularly, at home occasionally

2 - Sees school friends outside only regularly

3 - Sees school friends outside occasionally

4 - Never sees school friends outside due to distance

5 - Never sees school friends outside (other reason)

19 - Not known

How many times did ..... see his school friends outside school last week?

H - 4 Does ..... have friends other than school friends?

0 - Enough

1 - Some, not as many as most children

2 - None

19 - Not known

H - 5 Are these friends his own age, older or younger?

0 - Friends same age

1 - Friends younger

2 - Friends older

3 - Preference different from actual age of friends

18 - Other

19 - Not known

H - 6 How often does ..... see these friends?

How often has he seen them during the past week?

PEER CONTACTS (PAST WEEK)

	None	One	2-5	5-10	10+	Not Known
Home friends	0	1	2	3	4	19
School Friends	0	1	2	3	4	19
Special friend (a) home	0	1	2	3	4	19
Special friend (b) school	0	1	2	3	4	19

H - 7 Does ..... have a special friend?

0 - Yes

1 - No

19 - Not known

How many times has he seen him/her in the past week?

H - 8 Does ..... generally go around with a group of children?

Boys, girls or both?

0 - Group - same sex

1 - Group - mixed

2 - Group - opposite sex

3 - Dubious membership

4 - Not a group member

19 - Not known

When did he last go out with this group?

H - 9 Where does ..... usually meet his friends?

Do other children call for him?

Does he call for other children at their homes?

H - 9 (continued)

0 - Contact with friends initiated at own home

1 - Contact with friends initiated at their homes

2 - Contact with friends initiated elsewhere

19 - Not known

H - 10 Do friends visit ..... at home?

Does he visit friends at their homes?

0 - Regular visiting at home & friends' homes

1 - Occasional visiting at home & friends' homes

2 - Regular visiting at own home, occasional at friends'

3 - Regular visiting at friends' homes, occasional at own

4 - Regular visiting at own home, none at friends'

5 - Regular visiting at friends' homes, none at own

6 - No visiting at homes

18 - Other

19 - Not known

H - 11 What do you think of .....'s friends?

Have you ever told him this?

0 - Parental approval of friends

1 - Parental disapproval of friends

2 - Parental indifference to friends

19 - Not known

H - 12 Have you ever had to tell him not to play with certain children?

Did he obey?

0 - Many parental restrictions on friends with compliance

1 - Some parental restrictions on friends with compliance

2 - No parental restrictions on friends

3 - Many parental restrictions on friends without compliance

4 - Some parental restrictions on friends without compliance

19 - Parental restriction on friends, compliance unknown

H - 13 How does ..... get on with other children?

Does he prefer to do things on his own?

Is he ever lonely?

Is he a leader or a follower with other children?

Do other children tease him?

About what?

Is he teased more than other children?

Does he get bullied?

More than other children?

Does he bully or pick on other children?

Has there been trouble because of this?

H - 13 (continued)

0 - Normal relationship with other children

1 - Prefers solitary activity

2 - Sometimes lonely

3 - Often lonely

4 - Excessive teasing

5 - Bullied excessively

6 - Bullies excessively

18 - Other

19 - Not known

SIBLINGS

H - 14 How does .... get on with his brothers and sisters?

Do they squabble?

More than most brothers and sisters?

Over what?

Do they ever come to blows?

0 - Relationship with siblings normal

1 - Excessive squabbling with siblings

2 - Excessive physical fights with siblings

3 - Diminished squabbling with siblings

18 - Other

19 - Not known

H - 15 Is ..... jealous of his brothers and sisters?

0 - No jealousy of siblings

1 - Some jealousy of siblings

2 - Excessive jealousy of siblings

19 - Not known

PARENTS

H - 16 How does ..... get along with you? (mother)

0 - Relationship with mother satisfactory

1 - Relationship with mother slightly unsatisfactory

2 - Relationship with mother unsatisfactory

19 - Not known

* Did he ever behave differently towards you during or after hospitalization?

Clinging?

Crying when you left?

Demanding more of your time when he came home?

0 - No difference

1 - Clinging

2 - Crying at separation

3 - More demanding post hospitalization

18 - Other

19 - Not known

H - 17 How does ..... get along with your husband?

0 - Relationship satisfactory

1 - Relationship slightly unsatisfactory

2 - Relationship unsatisfactory

19 - Not known

* Did he ever behave differently towards your husband during or after hospitalization?

As for #28.

H - 17 (continued)

Or

Apprehension?

Panic or screaming when father approached?

Crying when father approached?

0 - No difference

1 - Clinging

2 - Crying at separation.

3 - More demanding post-hospitalization

4 - Apprehensive

5 - Panicky or screaming when approached

6 - Crying when approached

18 - Other

19 - Not known

H - 18 Is ..... affectionate towards you and your husband?

How does he show this?

0 - Affectionate

1 - Somewhat affectionate

2 - Not affectionate

19 - Not known

H - 19 What activities do you do with ..... ?

0 - Many joint activities

1 - Some joint activities

2 - No joint activities

19 - Not known

H - 20 Does ..... help around the house?

0 - Much help in house

1 - Some help in house

2 - No help in house

19 - Not known

H - 21 Does ..... get pocket money?

How much?

Does he earn money doing odd jobs?

Is this adequate?

How does he spend his money?

Code exact amount.

H - 22 Does ..... have to be in at a certain time at night?

What time?

Does he comply?

Does ..... have a set bedtime?

What time?

Does he comply with this?

Do you know where he goes when he is out?

What do you think of these places?

Do you discuss where he goes and what you think of these places with him?

How does he respond?

Are there any arguments about curfew, bedtime, or places frequented?

How often have there been arguments in the past month?

H - 22 (continued)

With whom?

0 - Parental restrictions with disagreement

1 - Parental restrictions without disagreement

2 - No parental restriction

19 - Not known

H - 23 Are there some games and activities in which you do not allow ..... to participate?

Which ones?

Why?

How do you decide?

Does he comply?

Do you discuss this with him?

How does he respond?

Are there any arguments about this?

How often have there been arguments in the past month?

With whom?

0 - Parental restrictions with disagreement

1 - Parental restrictions without disagreement

2 - No parental restriction

19 - Not known

Do you or your spouse restrict any of the following activities?

Code Yes or No.

ACTIVITY LIST

Under 5 years	CHILD	MOTHER	FATHER	DOCTOR
1. Sledding				
2. Tumbling				
3. Tobogganing				
4. Snow balling				
5. Jumping				
6. Climbing				
7. Swinging				
8. Tricycling				
9. Playing cowboys and Indians				
10. Running				
11. Building				
12. Street hockey				
13. Skating				
14. Swimming				
15. Punch-balls				

5 - 12 years

1. Skating
2. Hockey
3. Baseball
4. Rough-housing
5. Sledding
6. Swimming
7. Tumbling

5.- 12 years (continued)	CHILD	MOTHER	FATHER	DOCTOR
8. Softball				
9. Darts				
10. Tobogganing				
11. Snow-balling				
12. Fishing				
13. Bowling				
14. Jumping				
15. Racing				
16. Carpentry				
17. Bicycling				
18. Gym				
19. Climbing				
20. Chopping wood				
13 - 17 years				
1. Skating				
2. Hockey				
3. Baseball				
4. Sledding				
5. Chopping wood				
6. Swimming				
7. Tumbling				
8. Softball				
9. Darts				
10. Tobogganing				
11. Snow-balling				
12. Shooting				

13 - 17 years (continued) CHILD MOTHER FATHER DOCTOR

13. Fishing
14. Bowling
15. Jumping
16. Racing
17. Carpentry
18. Bicycling
19. Gym
20. Climbing
21. Dancing

H - 24. Are there some activities in which he decides for himself not to take part?

Which ones?

Why?

Could he do these if he wished?

Does he ever take part in activities which you think are dangerous?

Which ones?

What happens when he does these things?

What do you do?

How does he respond?

Are there any arguments about this?

How often have there been arguments in the past month?

With whom?

H - 24 (continued)

0 - Activity normal

1 - Restricts own activity to reasonable limits

2 - Restricts own activity excessively

3 - Takes part in dangerous activity without arguments from parents

4 - Takes part in dangerous activity with parental argument

19 - Not known

Does he take part in the following activities? (Use list from H-23)

H - 25 Have doctors or nurses ever suggested limiting ....'s activities?

Which activities?

Have you done this?

1 - Medical personnel suggest limitation, parents carried out

2 - Medical personnel suggest limitation, parents have not carried out

19 - Not known

Have physicians suggested restricting any of the following activities? (Use list from H-23)

H - 26 How do you know or determine when ..... is having an episode of chronic physical illness?

0 - Child tells parent before signs visible

1 - Child tells parent when signs visible

2 - Parent notices signs

H - 26 (continued)

3 - Parent checks routinely after certain activities

4 - Parent checks at regular intervals

18 - Other

19 - Not known

H - 27 Who reprimands ..... when this is necessary?

How is he punished?

1 - Mother primary disciplinarian

2 - Father primary disciplinarian

3 - Both discipline

19 - Not known

H - 28 Most parents are irritable at times. Do you ever get irritable with ..... ? (mother)

When was the last time?

What were the reasons for this?

How often does this happen?

Do you ever lose control?

Do you yell?

How do you feel at these times?

How long does this last?

Does this ever become more than is necessary?

How many times in the last month have you (a) shouted?

(b) lost control?

Include previously mentioned arguments in coding.

H - 28 (continued)

0 - Never argue

1 - Occasionally minor argument (1-4/month)

2 - Frequently minor arguments (weekly - daily)

3 - Frequently minor arguments and occasionally extremely irritable

4 - Frequently minor arguments and occasionally extremely irritable (with loss of control)

5 - Occasionally loses control only

6 - Frequently loses control

18 - Other

19 - Not known

H - 29 Repeat #28 for Husband.

Code as for #28.

TEACHERS, MEDICAL PERSONNEL

H - 30 How does ..... get along with teachers in school?

0 - Relationship with teachers satisfactory

1 - Some difficulties with teachers

2 - Definite difficulty with teachers

19 - Not known

H - 31 How does ..... get along with doctors and nurses when he has contact with them?

0 - Relationship with medical personnel satisfactory

1 - Some problems with medical personnel

2 - Definite problems with medical personnel

19 - Not known

H - 31 (continued)

* Has he ever reacted to them during or after hospitalization by

(a) becoming apprehensive

(b) panic or screaming at their approach

(c) crying at their approach

0 - Reaction to medical personnel satisfactory during hospitalization

1 - Apprehension

2 - Panic or screaming

3 - Crying

18 - Other **

19 - Not known

OTHER ADULTS

H - 32 How does ..... get along with other adults?

0 - Relationship satisfactory

1 - Total lack of fear of strangers

2 - Excessive fear of strangers

18 - Other

19 - Not known

* Has he ever reacted to other adults during or after hospitalization by apprehension, panic or screaming, crying?

Code as for #31.

I. NEUROTIC OR EMOTIONAL SYMPTOMS } Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course over last year

Obtain details of all positive answers.

I - 1 Is ..... usually happy or miserable?

0 - Happy

1 - Neither happy nor miserable

2 - Miserable

19 - Not known

* Has he ever been miserable during or after hospitalization?

0 - No

1 - Yes

19 - Not known

I - 2 Does ..... ever cry?

Does he cry excessively?

0 - No crying

1 - Some crying

2 - Excessive crying

19 - Not known

* Has he ever cried excessively during or after hospitalization?

0 - No

1 - Yes

19 - Not known

I - 3 Does ..... tend to blame himself for things that don't seem important?

0 - Not present

1 - Dubious or minimal

2 - Present

19 - Not known

I - 4 Has ..... ever said that life isn't worth living?

0 - No

1 - Yes

19 - Not known

I - 5 Has ..... ever tried to harm himself or take his life?

0 - No

1 - Dubious

2 - Yes

19 - Not known

I - 6 Have you ever been worried that he might harm himself or take his life?

0 - No

1 - Yes

19 - Not known

I - 7 Has ..... ever felt that people were against him?

0 - No

1 - Dubious

2 - Yes

19 - Not known

I - 8 Has ..... ever accused you of things?

0 - No

I - 8 (continued)

1 - Dubious

2 - Yes

19 - Not known

I - 9 Has ..... felt people wanted to harm him?

0 - No

1 - Dubious

2 - Yes

19 - Not known

I - 10 Has ..... ever behaved strangely in any way?

0 - No

1 - Dubious

2 - Yes

19 - Not known

I - 11 Does ..... become worried easily?

What does he worry about?

0 - Not present

1 - Dubious or minimal

2 - Present

19 - Not known

* Has he ever worried excessively during hospitalization?

0 - No

1 - Dubious

2 - Yes

19 - Not known

I - 12 Does ..... worry about his health?

I - 12 (continued)

Does he talk about his physical illness?

(Ask for groups with chronic physical handicap)

What does he say?

Does he ask questions about this?

How do you respond?

0 - Not present

1 - Dubious

2 - Worries about realistic features of physical handicap

3 - Worries excessively about physical handicap

4 - Worrying about health

19 - Not known

I - 13 Does ..... get cross and irritable?

0 - Not present

1 - Dubious or minimal

2 - Present

19 - Not known

* Has he ever become cross and irritable during or after hospitalization?

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

I - 14 Does ..... sulk?

0 - No

1 - Dubious or minimal

I - 14 (continued)

2 - Yes

19 - Not known

I - 15 Does ..... have temper tantrums?

(In description of behaviour ask about (a) screaming, (b) lying on floor, (c) breaking things. Also ask for length.)

Do these ever occur at school, or when friends or relatives are present?

How do you deal with these?

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

* Does he ever have temper tantrums during or after hospitalization?

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

I - 16 Does ..... ever cry about going to school, or refuse to go?

0 - No

1 - Dubious or minimal

2 - Tears before school

3 - School refusal

19 - Not known

I - 17 Is ..... overly fussy?

(Probe by examples of clean hands, forks, the way his clothes are put away.)

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

I - 18 Does ..... insist on doing some things a special way?

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

I - 19 Does ..... ever do silly things?

(Probe by examples of washing over and over, having to touch certain things every time he passes them.)

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

I - 20 Does ..... become worried or frightened in certain situations?

(Probe using the following examples:)

(a) Changing his clothes when there are people around?

(b) In crowds?

(c) At parties?

I - 20 (continued)

(d) With new people?

(e) When alone in the house?

(f) In the dark?

(g) With certain animals?

(h) Of insects?

(i) Thunder and lightning?

(j) Needles?

(k) Doctors or nurses:

Code separately for: Anxiety Panic Attacks Avoidance

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

* Make a separate note where fears of medical or hospital related items present:

I - 21 Does ..... ever become really anxious or seem to panic?

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

* Has this ever happened during or after hospitalization?

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

J. ANTISOCIAL SYMPTOMS

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

Obtain details of all positive answers.

J - 1 Is ..... disobedient?

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

J - 2 Is ..... ever destructive?

Is this deliberate?

Whose belongings does he destroy?

Has there been any trouble about this?

0 - Not present

1 - Non-deliberate destructiveness

2 - Some deliberate destruction of own belongings

3 - Much deliberate destruction of own belongings

4 - Some deliberate destruction of other's belongings

5 - Much deliberate destruction of other's belongings

6 - Combination of destructiveness of own and others belongings

19 - Not known

J - 3 Does ..... ever set fires?

Has there been any trouble about this?

0 - Not present

1 - Dubious or minimal

2 - Present

J - 3 (continued)

19 - Not known

J - 4 Does ..... tell lies?

What kind?

Does he tell lies to people outside the family?

0 - No

1 - Minimal lie-telling to family

2 - Severe lying in family

3 - Minimal lying to outsiders

4 - Severe lying to outsiders

5 - Lying to family and outsiders

19 - Not known

J - 5 Has ..... ever taken things that don't belong to him or stolen things?

What things?

From where did he steal these things?

How did you deal with this?

Did he steal on his own or with others?

What did he do with the stolen articles?

0 - No stealing

1 - Some stealing from home on own

2 - Some stealing from home with others

3 - Much stealing from home on own

4 - Much stealing from home with others

5 - Some stealing outside on own

6 - Some stealing outside with others

7 - Much stealing outside on own

J - 5 (continued)

8 - Much stealing outside with others

9 - Combination of the above

19 - Not known

J - 6 Has ..... ever truanted?

Was this alone or with others?

Where did he go?

0 - No truanting

1 - Truanting alone

2 - Truanting with others

19 - Not known

J - 7 Has ..... ever run away from home?

Was this alone or with others?

Where did he go?

0 - No

1 - Threatened but not done

2 - Ran away alone

3 - Ran away with others

19 - Not known

J - 8 Has ..... ever stayed out all night?

Was this alone or with others?

Where did he go?

0 - No

1 - Stayed out alone

2 - Stayed out with others

19 - Not known

J - 9 Has ..... ever used drugs (illegal)?

0 - No

1 - Yes

19 - Not known

J - 10 Has ..... been in trouble with the police or been to court?

0 - No

1 - Police contact

2 - Court contact

3 - Both

19 - Not known

J - 11 Sexual misbehaviour (assault, exposure, promiscuity, etc) Code from Q-2

J - 12 Sexual perversion (including transvestism) Code from Q-2

J - 13 Threatened with exclusion or excluded from school (Code from H-30, L-6 to L-8, and M-2)

K. OTHER SYMPTOMS

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

K - 1 Has ..... ever tended to withdraw from the family?

Has he spent a lot of time in his room or out of the house?

Has he not done things with the rest of the family?

Has he stayed in bed a lot?

K - 1 (continued)

0 - No withdrawal

1 - Some withdrawal always present

2 - Marked withdrawal always present

3 - Some withdrawal since earlier years

4 - Marked withdrawal since earlier years

5 - Slightly increased family contact since earlier years

6 - Marked increased family contact since earlier years

19 - Not known

* Did he ever seem distant after hospitalization when very young?

0 - No

1 - Dubious or minimal

2 - Yes

19 - Not known

K - 2 Have you ever had difficulty "getting through" to ..... ?

Is it difficult to know how he feels?

Does he talk to you about his activities and plans?

Does he talk to you about how he feels?

Is this different than when he was younger?

From what age?

0 - No communication difficulty

1 - Some difficulty always

2 - Marked difficulty always

K - 2 (continued)

3 - Some difficulty lately

4 - Marked difficulty lately

5 - Some increase in communication

6 - Marked increase in communication

19 - Not known

* Code for communication about his physical illness # I-12.

Does ....., worry about his physical illness?

What does he say?

Does he ask questions about this?

How do you respond?

0 - No communication difficulty

1 - Some difficulty always

2 - Marked difficulty always

3 - Some difficulty lately

4 - Marked difficulty lately

5 - Some increase in communication

6 - Marked increase in communication

19 - Not known

K - 3 Do you have any other concerns about .....'s behaviour or nerves?

EDUCATION

I would now like to ask about .....'s schoolwork.

L. PARENTAL ATTITUDE TO CHILD'S EDUCATION

L - 1 What grade is ..... in at school?

Code exact grade.

L - 1 (continued)

How do you think .....'s schoolwork compares with other children his age?

0 - Much better than average

1 - Better than average

2 - Average

3 - Below average

4 - Very much below average/failing

19 - Not known

L - 2 Does ..... have much homework?

How much time does he spend at homework during the week?

0 - No homework assigned

1 - Homework irregularly

2 - Less than one hour per day

3 - One-two hours per day

4 - More than two hours per day

5 - Homework assigned but not done

19 - Not known

If code 0 omit questions 3-4.

L - 3 Where does ..... do his homework?

0 - No set place, no family concession

1 - No set place, family concession

2 - Set place at home

3 - Library or other place outside home used

4 - Done in school

19 - Not known

L - 4 Does anyone help ..... with homework?

0 - Mother helps

1 - Father helps

2 - Both parents help

3 - Siblings help

4 - Parents and siblings help

5 - Other help

6 - No help

19 - Not known

L - 5 Have you had any contact with the teachers?

Was this at a regular parent-teachers meeting?

Who initiated the contact?

0 - No contact

1 - Contact at PTA meetings

2 - Meetings initiated by parent

3 - Meetings initiated by teacher

4 - Combination

19 - Not known

L - 6 Has ..... ever gotten into difficulties at school?

Were these because of schoolwork or behaviour?

0 - No difficulties

1 - Academic difficulties

2 - Behaviour difficulties

3 - Academic and behaviour difficulties

19 - Not known

L - 7 How did you find out about these difficulties?

0 - Child informed parent

L - 7 (continued)

1 - Teacher informed parent at regular meeting
2 - Teacher informed parent at special meeting
3 - Principal informed parent at regular meeting
4 - Principal informed parent at special meeting
5 - Principal and teacher informed parent
6 - Telephone call from school
7 - Other children or parents informed parent
18 - Other
19 - Not known

L - 8 What was done about these difficulties?

0 - No action taken
1 - Referral to Public Health Nurse
2 - Referral to school Medical Officer
3 - Referral to counsellor
4 - Additional or remedial teaching
5 - Special class placement
18 - Other
19 - Not Known

L - 9 How much time has ..... missed from school since September?

0 - None
1 - One day to one week
2 - More than one week to one month
3 - More than one month
19 - Not known

L - 10 Is this about average?

0 - Yes

1 - No

19 - Not known

If code 0 omit #11.

L - 11 About how much time does ..... miss from school during an average year?

0 - None

1 - Less than one week

2 - One week to one month

3 - More than one month

19 - Not known

L - 12 What was the most time ..... missed from school in any one year?

0 - Less than one month

1 - One to five months

2 - Five months to full year

19 - Not known

L - 13 Why did ..... miss time from school?

M. SCHOOL HISTORY

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

M - 1 Which schools has ..... attended?

0 - No school changes

1 - One school change during school life

2 - Two or more changes, less than one per year

M - 1 (continued)

3 - One change per year

4 - More than one change per year

19 - Not known

If code 0 omit #2-4 inclusive.

Note exact answer and ask what type of school each was.

M - 2 How did ..... get along at the previous schools?

0 - No difficulties

1 - Academic difficulties

2 - Behaviour difficulties

3 - Both

18 - Other

19 - Not known

M - 3 Why did ..... change schools?

0 - Completion of highest grade available

1 - Family move

2 - Parental dissatisfaction with child's progress

3 - School felt other placement suitable

4 - Expelled

18 - Other

19 - Not known

M - 4 Did the teachers at any of the previous schools contact you about ..... ?

Code Yes or No

PERSONAL HISTORY

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course over last year

I would like to ask about other aspects of .....'s development.

N. PREGNANCY AND DELIVERY

N - 1 Were there any complications while you were pregnant with ..... or at delivery?

0 - None
1 - Venereal disease
2 - Vaginal infections
3 - German measles
4 - Diabetes
5 - Toxaemia
6 - Rh incompatibility
7 - Prolonged labour
8 - Threatened abortion
9 - Breech
10 - Placenta previa
11 - Cording
12 - Caesarian section
13 - Twinning
14 - First birth
15 - Disproportion
16 - Forceps used
17 - Abruptio placenta
18 - Other
19 - Not known

N - 2 Was ..... born in hospital or at home?

Who was in attendance?

0 - Hospital with obstetrician

1 - Hospital with other doctor or midwife

2 - Hospital with nurse

3 - Home with doctor or midwife

4 - Home with other medical or paramedical attendant

5 - Other location or attendant (including self)

19 - Not known

N - 3 Was ..... a full term baby?

If he was premature, by how many weeks?

If he was late, by how many weeks?

Who decided maturity?

0 - Full term

1 - Post mature (1-3 weeks)

2 - Post mature (4 or more weeks)

3 - Premature (1-3 weeks)

4 - Premature (4 or more weeks)

19 - Not known

N - 4 How much did ..... weigh at birth?

0 - 5 lbs. 9 ozs - 8 lbs. 8 ozs

1 - 8 lbs. 9 ozs or more

2 - 4 lbs. 9 ozs - 5 lbs. 8 ozs

3 - 4 lbs. 8 ozs or less

19 - Not known

N - 5 How was your health during and after pregnancy?

0 - Good health

1 - Tiredness

2 - Exposure to infections

3 - Major illness

4 - Depression or other psychiatric complaint

18 - Other

19 - Not known

O. DEVELOPMENT IN INFANCY, NEONATAL PERIOD AND PRESCHOOL PERIOD

O - 1 Did ..... have any difficulties breathing or feeding?

Did he go blue at times?

Did he seem to be gagging at times?

Did he have any difficulty sucking or getting his milk?

0 - No abnormality

1 - Dubious or minimal

2 - Abnormality

19 - Not known

O - 2 Did ..... have convulsions (fits) shortly after birth?

0 - Not present

1 - Dubious

2 - Present

19 - Not known

O - 3 Was ..... jaundiced after birth?

0 - Not present

1 - Dubious

2 - Present, no transfusion

O - 3 (continued)

3 - Present, transfusion given

19 - Not known

*O - 4 ASK FOR BOYS:

Was ..... circumcised?

Were there any difficulties?

0 - Not circumcised

1 - Circumcised, no difficulties

2 - Circumcised with bleeding difficulties

3 - Circumcised with other difficulties

19 - Not known

O - 5 Was ..... an active or placid baby?

Did he respond to you?

0 - No abnormality

1 - Baby unresponsive

19 - Not known

O - 6 When did ..... sit up on his own?

When did he stand?

When did he walk?

0 - No abnormality

1 - Dubious or minimal

2 - Abnormality

19 - Not known

* Was there any excessive bruising at this time?

0 - No

1 - Yes

19 - Not known

O - 7 When did ..... say his first words?
When did he start to use three-word phrases?
Code as for #6.

O - 8 When was ..... dry during the day and night?
When was he clean during the day and night?
Code as for #6.

O - 9 How does .....'s development up to that time compare with his brothers and sisters?

0 - Development same as sibs
1 - Development ahead of sibs
2 - Development behind sibs
3 - No sibs
18 - Other
19 - Not known

P. SEPARATIONS FROM PARENTS Factors: Severity
Frequency
Onset date
Precipitants
Ameliorating factors
Course in last year

P - 1 Apart from the times ..... was in hospital or at the residential treatment centre, has he ever been away from you or your husband for as long as one week.
(Probe using examples of:
(a) Parents being hospitalized
(b) Husband working away from home
(c) Parents or child visiting away from home separately)

P - 1 (continued)

0 - None

1 - Separation from father only

2 - Separation from mother only

3 - Separation from father and mother at different times

4 - Separation from both parents simultaneously

18 - Other

19 - Not known

Q. SEXUAL MATURITY

Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

GIRLS

Q - 1 Have ....'s periods started yet?

When did they start?

OR Are there any signs of puberty yet, such as breast development or body hair?

BOYS

Q - 1 Has ..... begun to develop body hair yet?

Is this under his arms, around his genitals?

0 - Pre-pubertal

1 - Pubescent

2 - Pubertal

19 - Not known

Q - 2 Does ..... have any interest in the opposite sex yet?

How does he show this?

Q - 2 (continued)

Are there any difficulties with this?

0 - No interest

1 - Interest without difficulties

2 - Interest with minor difficulties (shyness, etc.)

3 - Sexual misbehaviour (assault, exposure, promiscuity, etc.)

4 - Sexual perversion

19 - Not known

Q - 3 Have you told ..... anything about sex, or where babies come from?

What have you told him?

What do you think he knows?

Where did he get this information?

0 - No information

1 - Information from parents

2 - Information from school

3 - Information from peers

4 - Information from others

18 - Other

19 - Not known

FAMILY HISTORY, LIFE AND RELATIONSHIPS

I would now like to ask a few things about the rest of the family.

R. FAMILY STRUCTURE

R - 1 How many children do you have living at home?

Are any of these adopted, foster or step children?

Name	Age	Sex	Status

Code exact number.

R - 2 Do you have any children living away from home?

Why are they away?

Name	Age	Sex	Status	Reason for absence

Code exact number.

R - 3 Were there other children who are no longer living?

When did they die and at what age?

What was the cause of death?

Name	Age at death	Sex	Status	Cause of death

Code exact number.

R - 4 So you have had ... children of your own and ... step/foster/adopted children.

Code total number of children born alive.

Code number of step/foster and adopted children.

R - 5 Phrase #5-9 appropriately if father is interviewed.

Then there is your husband. Is he living with the family?

0 - Yes

1 - No

19 - Not known

If Code 0 omit #6-9 inclusive.

R - 6 Why is this?

0 - Not married

1 - Desertion

R - 6 (continued)

2 - Legal separation

3 - Divorce

4 - Dead

18 - Other

19 - Not known

If Code 4, omit #7. If Code 0 omit #8. If Code other than 4 omit #9.

R - 7 Does your husband ever visit the children?

How many times in the past year has he visited?

0 - None

1 - Once

2 - 2-11 times

3 - Monthly

4 - Weekly

5 - More often than weekly

19 - Not known

R - 8 When did your husband leave the family/die?

0 - Before birth of .....

1 - During .....'s first five years of life

2 - When ..... was between 5 and 10 years of age

3 - When ..... was between 10 and 17 years of age

19 - Not known

R - 9 What was the cause of death?

0 - Accidental

1 - Related to chronic physical illness

18 - Other

19 - Not known

R - 10 How long have you been/were you married?

Code exact number of years

R - 11 Have either of you been married before?

How many times?

0 - None

1 - Once

2 - More than once

19 - Not known

R - 12 Code again for husband.

R - 13 How old is/was your husband?

Code age in years

R - 14 How old are you?

Code age in years

R - 15 Is there anyone else besides you, your husband and the children living in your home?

0 - Child's grandparent

1 - Child's unmarried aunt or uncle

2 - Child's married aunt or uncle and family

3 - Child's married brother or sister and family

4 - Another family

5 - Boarder or lodger

6 - No

18 - Other

19 - Not known

ORDINAL POSITION

0 - Only child

1 - Eldest

2 - Youngest

3 - One of set of multiple births

18 - Other

19 - Not known

PARENTAL STATUS (BIOLOGICAL PARENTS)

0 - Married and living together
(include common law union)

1 - Unmarried

2 - Separated

3 - Divorced

4 - Widowed

18 - Other

19 - Not known

PARENTAL SITUATION OF CHILD

0 - Both natural parents

1 - Adopted child, both parents

2 - Natural mother only

3 - Natural father only

4 - Natural mother and another male

5 - Natural father and another female

6 - Relatives other than parents

7 - Non-relatives (friends, foster parents)

PARENTAL SITUATION OF CHILD (continued)

8 - Institution

18 - Other

19 - Not known

S. HISTORIES OF OTHER CHILDREN Factors: Severity
Frequency
Date of onset
Precipitants
Ameliorating factors
Course in last year

S - 1 Have any of the other children besides ..... been to the doctor in the past year?

Code number of siblings treated.

Code reasons:

0 - Regular check-ups

1 - Childhood diseases

2 - Accidents

3 - Regular check or treatment related to chronic physical handicap

4 - Accident related to chronic physical handicap

5 - Other treatment related to chronic physical handicap

18 - Other

19 - Not known

S - 2 Have any of the others besides ..... been to the hospital or to clinics in the past year?

Why?

S - 2 (continued)

When was this?

Which ones?

How long did he stay in hospital?

Code as for #S-1.

S - 3 Have any of the others besides ..... been to specialists in the past year?

Why?

Code as for #S-1.

S - 4 Have any of the others besides ..... had to take pills or medicine for sleeping, worrying or their nerves?

0 - No

1 - Yes

19 - Not known

S - 5 Have any of the other children had to go into hospital when they were young?

Why?

When?

Where?

Code as for #S-1.

S - 6 Have any of the others had to see specialists when they were younger?

Why?

When?

Where?

Code as for #S-1.

S - 7 Do any of the others have chronic physical illness?

Code number of siblings affected.

What?

0 - None

1 - Kidney or Genito-urinary tract disorder

2 - Metabolic or endocrine disorder

3 - Circulatory system disorder (excluding bleeding)

4 - CNS disorder above the brain stem (exclude epilepsy)

5 - Epilepsy

6 - CNS disorder at brain stem or below

7 - Phenylketonuria

8 - Below 3rd percentile in height

9 - Above 97th percentile in weight

10 - Neoplasm

11 - Leukaemia

12 - Asthma

13 - Ulcerative colitis

14 - Disorder of sense organs (exclude squint)

15 - Bleeding disorder

18 - Other

19 - Not known

S - 8 What grades are the other children in?

Have any of them had difficulties in school?

Name	Grade	Difficulty Noted

Code number of siblings affected.

T. FATHER'S HEALTH IN PAST YEAR

Obtain details of all positive answers.

Inquire only if father has lived with the family during the past year.

T - 1 How has your husband's health been in the past year?

Has he had to see the doctor?

Why?

0 - No medical contact

1 - Regular check-up

2 - Regular prescription

3 - Accident

4 - Chronic physical illness

5 - Psychiatric

18 - Other

19 - Not known

T - 2 Has he had to take tonics or nerve pills?

Has he had pills for sleeping or depression?

0 - No

1 - Yes

19 - Not known

T - 3 Has he been off work because of illness in the last year?

How many times?

How long?

What was wrong?

Has he been off work for other reasons?

T - 3 (continued)

0 - Less than one week

1 - Retired

2 - Unemployed (not for health reasons)

3 - Off work one week to one month

4 - Off work one month to six months

5 - Off work more than six months

6 - Unemployed or retired for health reasons

18 - Other

19 - Not known

HOSPITALS AND SPECIAL CLINICS

T - 4 Has your husband had to go to hospital or a special clinic in the last five years?

Code Yes or No.

Why?

How long was he there?

When?

Which hospital?

Code as for #T-1. Note details of all visits.

Does he have any chronic physical condition? What?

Code Yes or No.

When did you first know this?

BEHAVIOUR AND EMOTIONAL STATE

For all positive answers note:

(a) if this interferes with what he is doing.

(b) if this interferes with concentration.

BEHAVIOUR AND EMOTIONAL STATE (continued)

(c) if this interferes with work.

(d) if this changes the way he is at home.

T - 5 Does your husband worry a lot?

(Probe using examples of worrying about children, his work)

Does he ever lie awake worrying?

0 - None

1 - Dubious

2 - Definite

19 - Not known

T - 6 Does he worry about his health?

Did he ever wonder if he had a physical disease?

What did he do?

0 - No

1 - Dubious

2 - Definite

19 - Not known

T - 7 Does he have any fears?

(Probe using examples of fear of going out, being alone)

Has he stopped doing ..... (whatever activity produced the fear)?

0 - None

1 - Dubious

2 - Definite

19 - Not known

T - 8 Is he an anxious person?

0 - No

1 - Dubious

2 - Definite

19 - Not known

T - 9 Does he have periods of great anxiety or panic?

0 - No

1 - Dubious

2 - Definite

19 - Not known

T - 10 Has he been depressed or miserable?

Did this affect the amount he went out?

0 - No

1 - Dubious

2 - Definite

19 - Not known

T - 11 Has he ever been tearful, cried a great deal?

0 - No

1 - Dubious

2 - Definite

19 - Not known

T - 12 Has he ever said that life was not worth living?

Has he ever tried to harm himself or take his life?

Have you been worried that he might?

0 - No

1 - Dubious

2 - Definite

19 - Not known

T - 13 Has he ever blamed himself for things that weren't really important?
Has he ever felt that people were against him?
Or that they were looking at him or talking about him?

0 - No
1 - Dubious
2 - Definite
19 - Not known

T - 14 Has he ever been jealous of you, or the children?

0 - No
1 - Dubious
2 - Definite
19 - Not known

T - 15 How is his appetite?
Has this ever changed?

0 - Appetite normal
1 - Excessive appetite always
2 - Excessive appetite recently
3 - Poor appetite always
4 - Poor appetite recently
19 - Not known

T - 16 Has he lost any weight recently?
Was this deliberate (dieting)?

0 - No
1 - Deliberate weight loss
2 - Unintentional weight loss
19 - Not known

T - 17 How has his sleep been?

0 - No problem

1 - Dubious disturbance

2 - Definite disturbance

19 - Not known

T - 18 Is he unusually fussy or particular about anything?

(Probe using examples of germs and cleanliness)

0 - No

1 - Dubious

2 - Definite

19 - Not known

T - 19 Does he keep checking things he knows are done?

(Probe using examples of turning off the stove, locking the door).

0 - No

1 - Dubious

2 - Definite

19 - Not known

T - 20 Does he have rigid routines which he has to follow?

0 - No

1 - Dubious

2 - Definite

19 - Not known

EDUCATION

T - 21 How far did your husband go in school?

T - 21 (continued)

0 - No formal education

1 - Grade 1-6

2 - Grade 7-13

3 - Post secondary vocational attendance

4 - Post secondary vocational training completed

5 - University attendance

6 - University degree

7 - Postgraduate degree

18 - Other

19 - Not known

T - 22 Did he have any difficulties at school?

0 - None

1 - Academic

2 - Behavioural

3 - Both

19 - Not known

EMPLOYMENT

T - 23 What is your husband's job?

What does he do?

Does he have a second job?

T - 24 What hours does he work?

0 - Regular work hours

1 - Regular work hours plus overtime

2 - Rotating shifts excluding nights

3 - Rotating shifts including nights

T - 24 (continued)

4 - Permanent nights

5 - Unemployment

18 - Other

19 - Not known

T - 25 Does his job take him away from home overnight?

How often in an average month?

Is that seasonally or throughout the year?

0 - Never or rarely away on business

1 - Away during the week, at home on weekends

2 - Away less than one week every month

3 - Away more than one week every month

4 - Away for one month or more at different times of the year

19 - Not known

U. MOTHER

Factors: Severity
Frequency
Date of onset
Ameliorating factors
Precipitants
Course in last year

Repeat #T-1 to T-22 inclusive phrasing appropriately for the mother.

Code as for #T-1 to T-22

Obtain details of all positive answers.

Health in past year

U - 1 to U - 3

Hospitals and Clinics

U - 4

Behaviour and Emotional State

For all positive answers note factors as for Section T.

Use "How did you feel" to probe positive answers.

U - 5 to U - 11

U - 12 Have you ever felt that life wasn't worth living?
Have you ever felt so badly that you thought of ending it all?
Have you ever tried to do this?

U - 13 to U - 19

U - 20 Add "even though you know they're silly"

Education

U - 21 to U -22

Employment

U - 23 Do you have a job outside your home?
Do you work all year?
Have you worked outside your home since January 1972?

U - 23 (continued)

When did you leave?

0 - Less than one month employment

1 - Part-time seasonal employment, less than 6 months

2 - Part-time seasonal employment, more than 6 months

3 - Full-time seasonal employment, less than 6 months

4 - Full-time employment, more than 6 months

18 - Other

19 - Not known

U - 24 What is your job?

What do you do?

U - 25 What hours do you work?

Code as for #T-24.

U - 26 Are you usually at home when ..... is home?

Who looks after him when you are not there?

0 - Mother has not worked for as long as one month

1 - Mother at home when child is home

2 - Child cared for by relative over 16 years

3 - Child cared for by neighbour or friend

4 - Child cared for by paid caretaker

5 - Child cared for by relative under 16 years

6 - No arrangement

18 - Other

19 - Not known

V. EXTENDED FAMILY

V - 1 Have any relatives of yours or your husband had any chronic physical illness?

What illness?

Whom?

0 - No familial chronic physical illness

1 - Chronic illness but not bleeding disorder

2 - Family history of bleeding disorder

19 - Not known

When did you first know this?

V - 2 Have any relatives died of chronic physical illness or died early for unknown reasons?

0 - No deaths due to chronic illness or unknown causes

1 - Deaths due to chronic illness (not bleeding disorder)

2 - Deaths due to bleeding disorder

3 - Deaths due to unknown causes

18 - Other

19 - Not known

When did this happen?

W. FAMILY LIFE Factors: Severity
Frequency
Ameliorating factors
Precipitants
Date of onset
Course in last year

Phrase questions appropriately.

W - 1 I would now like to know how household chores are divided up in the family.

(If further explanation is necessary, ask who does specific things such as shopping or dusting.)

How much do the children and your husband do?

0 - Mother does chores

1 - Parents do chores

2 - Mother and children do chores

3 - All share chores

18 - Other

19 - Not known

W - 2 Who decides things in the family?

Who decides what will be bought for the house?

Who decides what the children can do?

Have you disagreed with any of the decisions made recently?

0 - Husband decision-maker

1 - Wife decision-maker

2 - Joint decision making

3 - Family decision making

18 - Other

19 - Not known

W - 3 How often do family discussions take place?

Are these ever about family problems?

W - 3 (continued)

0 - No family discussion

1 - Family discussion not re problems

2 - Family discussion re problems only

3 - Family discussion including problems

18 - Other

19 - Not known

W - 4 Most parents get irritable with their children sometimes. How often do you get like that with the children?

(Obtain a description of one such incident.)

When was the last time this happened?

What sorts of things make you irritable?

How often does this happen?

Do you ever find yourself losing control when this happens?

Do you yell?

How do you feel when you do this?

How long does it last?

Is it sometimes more than necessary reprimanding?

How many times in the last 3 months have you (a) shouted (b) lost control (c) been excessively cross?

0 - Less than once per month

1 - Once per week to once per month

2 - 2-6 times per week

3 - Daily

4 - More than daily

W - 4 (continued)

19 - Not known

W - 5 Repeat #4 for <u>father</u>.

W - 6 Most families quarrel at times. How often does this happen in your family?

(Obtain a complete description of the last quarrel, including the length. Find out if that one is typical, also find out typical things said, and whether name calling, shouting, hitting occur.)

How do you resolve quarrels?

How many have there been in the last three months?

For coding include only quarrels involving length of 1/2 hour for interchange, or non-speaking for one hour after, or denigration of other or shouting or violence.

<u>Code number of quarrels</u>.

Account of life pattern and interviewee's attitude.

X. MARITAL RELATIONSHIP

The aim of the first part of this section is to involve the interviewee in the subject of her marital relationship as much as possible in order to elicit her view of it. Neutral probes are used to avoid influencing the response as much as possible and may also be used as a crude measure of interaction.

Last questions are more direct.

I would like to ask a little about you and your husband together.

X - 1 How do you spend the evenings you are at home?
What do you do?
What do you do together?
0 - No joint activities
1 - Joint activities without communication (T.V. without conversation)
2 - Joint activities with communication related to activity (card game)
3 - Joint activities involving general communication
19 - Not known

X - 2 Do you go out together?
0 - No joint outings
1 - Joint outings with family
2 - Joint outings alone
3 - Joint outings alone and with family
19 - Not known

X - 3 Are there some things you especially enjoy doing together?
0 - Yes
1 - No
19 - Not known

X - 4 In general, how do you get along together?
Description of responses #1-4.
Include information from all questions of Section X in coding.

X - 4 (continued)

Coding

0 - No difficulties

1 - Dubious

2 - Definite marital problems

19 - Not known

X - 5 Do you chat about everyday things?

Do you talk about family problems?

Are there things you would like to talk about, but can't?

0 - No discussion

1 - Discussion, not about problems

2 - Discussion about problems only

3 - Discussion, general and problem oriented

4 - Discussion absent, desire expressed

19 - Not known

X - 6 What about getting irritable with your husband?

Obtain an account of what is said and done by both, causes, frequency in last 3 months.

0 - Less than once per month

1 - Once per week to once per month

2 - 2-6 times per week

3 - Daily

4 - More than daily

19 - Not known

X - 7 How does he get irritable or cross with you?

Probe and code as for #6.

X - 8 Apart from this, how often do you quarrel?

Obtain a complete description of the last quarrel, including the length. Find out if that one is typical, also find out typical things said, and whether name-calling, insulting each other's families, shouting and violence occur.

Have you slept apart because of a quarrel?

How do you resolve the quarrels?

Code the number of quarrels involving length of

1/2 hour for interchange

or one hour non-speaking subsequently

or denigration of other or other's family

or shouting or violence

Y. HOME

Finally I would like to know about your home.

Y - 1 Do you own your home or is it rented?

0 - Owners

1 - Rented

19 - Not known

Y - 2 Is it a house or an apartment?

Describe:

0 - Detached

1 - Semi-detached

2 - Apartment building

Y - 2 (continued)

3 - Apartment in another house

4 - Shared

18 - Other

19 - Not known

Y - 3 How many rooms do you have?

Code exact number.

Y - 4 What are the sleeping arrangements?

List:

Y - 5 Do you have:

Coding: 0 - present, not shared

1 - shared

2 - not present

19 - not known

(a) a fixed bath

(b) a kitchen

(c) electricity

(d) electric stove

(e) refrigerator

(f) running cold water

(g) running hot water

(h) indoor toilet

Y - 6 Are you satisfied with your housing?

0 - Satisfaction

1 - Mild dissatisfaction

2 - Dissatisfaction

19 - Not known

Y - 7 Do you have financial difficulties?

0 - None

1 - Some difficulty

2 - Great difficulty (unable to meet commitments)

19 - Not known .

CONCLUSIONS

That is all I wished to ask.

Are there things you would like to ask me?

Thank you for your time and help.

Once again, all you have said will be confidential.

Z. INTERVIEW

Describe conditions:

0 - Mother alone

1 - Father alone

2 - Both parents

3 - Other informant

4 - Parent or parents with child present

5 - Other informant with child present

18 - Other

DURATION OF INTERVIEW

Number of minutes

Comment on informant: (rapport, co-operation, etc.)

DURATION OF INTERVIEW (continued)

Attitudes demonstrated towards child:

warmth

criticism

rejection

SUMMARY

Psychiatric Disorder: 1 - Present

2 - Absent

19 - Not known

Psychiatric Diagnosis:

Behaviour and Emotion Symptoms:

APPENDIX C

TEACHERS' QUESTIONNAIRE

ADDENDUM

1. Number of half-days missed from school since the start of this school year (September, 1973)?
2. Excused from certain classes or activities, (e.g. gym). Please specify activity with reason.
   1.
   2.
   3.
   4.
3. Special measures taken in any classes. Please specify measures and reasons. (e.g. Does not use bunsen burner in chemistry lab, or is supervised during recess period.)
   1.
   2.
   3.
4. Achievement level (Tick appropriate answer or answers)
   Below expected grade
   Better than average child in present grade
   Average
   Lower than average child in present grade
   Much lower than average child in present grade (failing)

5. Difficulty with work (Tick appropriate answer)

   Appears to find work easier than most children

   Appears to find work about the same as most children

   Appears to find work harder than most children.

6. Special class or tutoring (Tick appropriate answer)

   In a special class (specify type of class and academic level) .....

   Has a tutor instead of or as well as regular school

   Receives special help from teacher in some or all areas (specify areas, nature of help)

   Other (specify)

   Please give reason for the above:

7. Difficulties the teacher encounters with this child apart from any covered by this form or Scale B.

   Specify:

   1.

   2.

   3.

STRICTLY CONFIDENTIAL

FOR OFFICE USE ONLY

SCALE B

TO BE COMPLETED BY TEACHERS

Name of Child _____ Boy/Girl _____ School _____

Code _____

Date of Birth _____ Grade _____

Below are sets of descriptions of behaviour often shown by children. After each statement are three columns:— "Doesn't Apply", "Applies Somewhat" and "Certainly Applies". If the child definitely shows the behaviour described by the statement place a cross in the box under Column 2 "Certainly Applies". If the child shows the behaviour described by the statement but to a lesser degree or less often place a cross in the box under Column 1 "Applies Somewhat". If, as far as you are aware, the child does not show the behaviour, place a cross in the box under Column 0 "Doesn't Apply".

Please complete on basis of child's behaviour IN THE PAST 12 MONTHS.

Put ONE cross against EACH statement. Thank you.

STATEMENT	0 Doesn't Apply	1 Applies Somewhat	2 Certainly Applies	FOR OFFICE USE ONLY
1. Very restless, has difficulty staying seated for long	☐	☐	☐	☐
2. Truants from school	☐	☐	☐	☐
3. Squirmy, fidgety child	☐	☐	☐	☐
4. Often destroys or damages own or others' property	☐	☐	☐	☐
5. Frequently fights or is extremely quarrelsome with other children	☐	☐	☐	☐
6. Not well liked by other children	☐	☐	☐	☐
7. Often worried, worries about many things	☐	☐	☐	☐
8. Tends to be on own—rather solitary	☐	☐	☐	☐
9. Irritable. Touchy. Is quick to 'fly off the handle'	☐	☐	☐	☐
10. Often appears miserable, unhappy, tearful or distressed	☐	☐	☐	☐
11. Has twitches, mannerisms, or tics of the face or body	☐	☐	☐	☐
12. Frequently sucks thumb or finger	☐	☐	☐	☐

STATEMENT	0 Doesn't Apply	1 Applies Somewhat	2 Certainly Applies	FOR OFFICE USE ONLY
14. Tends to be absent from school for trivial reasons	☐	☐	☐	☐
15. Is often disobedient	☐	☐	☐	☐
16. Cannot settle to anything for more than a few moments	☐	☐	☐	☐
17. Tends to be fearful or afraid of new things or new situations	☐	☐	☐	☐
18. Has many particular fears	☐	☐	☐	☐
19. Often tells lies	☐	☐	☐	☐
20. Has stolen things on one or more occasions in the past 12 months	☐	☐	☐	☐
21. Unpopular, loner or isolate	☐	☐	☐	☐
22. Often complains of aches or pains	☐	☐	☐	☐
23. Has had wets or soiled at school or has refused to come for the holiday in the past 12 months	☐	☐	☐	☐
24. Has a stutter or stammer	☐	☐	☐	☐
25. Resentful or aggressive when corrected	☐	☐	☐	☐
26. Bullies other children	☐	☐	☐	☐

Is there anything else unusual about this child's behaviour?—or are there any other comments you would like to make?

☐

☐

Signature: Mr./Mrs./Miss

THANK YOU VERY MUCH FOR YOUR HELP

APPENDIX D

DOCTORS' INTERVIEW

INTRODUCTION

Schedule interview in advance, supplying the doctor with the name of the child so that he is able to obtain any written records he requires for the interview.

Where possible, the interviewer should review medical records of the child prior to the interview, note the relevant information and confirm this information with the doctor during the interview.

Introduction to the physician should include a brief summary of the aims of the study.

CHILD'S NUMBER:

BIRTHDATE:

A - 1 Obtain a complete list of all the child's contacts with this doctor, including the following information about each:

The nature of the contact (office visit, O.P., hospital admission)

The date and duration of the contact.

The reason for the contact.

The treatment given.

The diagnosis (level for children with bleeding disorder).

A - 2 Obtain a complete list of all referrals of this child to other doctors and agencies by this doctor. The dates and reasons for referral are also needed.

A - 3 Have there been any physical illnesses or physical problems present for more than one year at any time? What? List.

A - 4 Dates of diagnosis for all physical illness of greater than one year's duration.

A - 5 Date first treated for these conditions.

A - 6 Duration of any physical illness lasting longer than one year.

B. EMOTIONAL AND/OR BEHAVIOUR DIFFICULTIES

B - 1 Do you think ... has any behaviour problems or emotional difficulties?

0 - No

1 - Yes

6 - Not known

B - 2 What are these difficulties? List:

B - 3 Have you recommended treatment or treated these difficulties?

0 - Yes

1 - No

6 - Not known

(Ascertain nature of any treatment given or recommended and dates given.)

C. REACTIONS TO HOSPITALIZATION

Code: 0 - Absent
1 - Dubious
2 - Present
6 - Not known

Code each question separately for:
A - Hospital inpatient
B - Other contacts

Have you ever noticed any of the following during or after hospitalization?

C - 1 Stomach aches, other alimentary disorders
A B

C - 2 Enuresis
A B

C - 3 Feeding disturbances
A B

C - 4 Sleeping difficulties
A B

C - 5 Rocking, head-banging
A B

C - 6 Encopresis, fecal soiling
A B

C - 7 Under or overactivity
A B

C - 8 Thumbsucking or similar comfort habit
A B

C - 9 Clinging to mother or crying at separation, more demanding post hospitalization.
A B

C - 10 As for C - 9 for father.
A B

C - 11 Apprehension, panic or screaming, or crying at father's approach.

A B

C - 12 Reaction to medical personnel as in C - 11.

A B

C - 13 Reaction to other adults as in C - 11.

A B

C - 14 Child having been miserable

A B

C - 15 Excessive crying

A B

C - 16 Excessive worrying

A B

C - 17 Child having been cross and irritable

A B

C - 18 Had temper tantrums

A B

C - 19 Non-situation specific anxiety or panic attacks

A B

C - 20 Distant to parents after hospitalization

A B

D.

D - 1 Have you ever seen evidence of fear of medical personnel or hospitals?

Has he ever been afraid of you?

D - 1 (continued)

0 - No

1 - Dubious

2 - Definite

6 - Not known

D - 2 Does he communicate with you about his physical condition?

Does he ask questions?

Does he talk about his feelings?

0 - Communication re factual matters and feelings; questions asked

1 - Communicates factual matters only

2 - Asks questions only

3 - Communicates feeling only

4 - Combination of two areas

5 - Non-communicative

6 - Not known

D - 3 Have you noted any other behaviour difficulties with ..... during contacts with him?

What?

D - 4 Have his parents complained of other difficulties?

What? List.

D - 5 Have you ever suggested limiting .....'s activities, or taking certain precautions?

Which activities and precautions? List.

Did ...../'s parents agree?

Did ..... agree?

Was this carried out as far as you know?

(For the next three questions, use the section of the following activity list appropriate to the age of the child.)

Have you ever suggested limiting any of the following activities?

Does the child's mother or father limit these activities?

Does the child participate in these activities?

(Code Yes or No for each person in regard to each activity).

ACTIVITY LIST Under 5 years	CHILD	MOTHER	FATHER	DOCTOR
1. Sledding				
2. Tumbling				
3. Tobogganing				
4. Snow balling				
5. Jumping				
6. Climbing				
7. Swinging				
8. Tricycling				
9. Playing cowboys and Indians				
10. Running				
11. Building				
12. Street Hockey				
13. Skating				

Under 5 years	CHILD	MOTHER	FATHER	DOCTOR
14. Swimming				
15. Punch-balls				
5 - 12 years				
1. Skating				
2. Hockey				
3. Baseball				
4. Rough-housing				
5. Sledding				
6. Swimming				
7. Tumbling				
8. Softball				
9. Darts				
10. Tobogganing				
11. Snow-balling				
12. Fishing				
13. Bowling				
14. Jumping				
15. Racing				
16. Carpentry				
17. Bicycling				
18. Gym				
19. Climbing				
20. Chopping wood				

13 - 17 years	CHILD	MOTHER	FATHER	DOCTOR
1. Skating				
2. Hockey				
3. Baseball				
4. Sledding				
5. Chopping wood				
6. Swimming				
7. Tumbling				
8. Softball				
9. Darts				
10. Tobogganing				
11. Snow-balling				
12. Shooting				
13. Fishing				
14. Bowling				
15. Jumping				
16. Racing				
17. Carpentry				
18. Bicycling				
19. Gym				
20. Climbing				
21. Dancing				

D - 6 Does ..... have relatives, who have a chronic physical illness?

Who and What?

SUMMARY

Psychiatric Disorder

0 - Absent

1 - Dubious

2 - Present

6 - Not known

Psychiatric Diagnosis

Behaviour and Emotion Symptoms

APPENDIX E

RAW DATA AND CALCULATION RESULTS THREE GROUPS

A. - Children with hemophilia

B. - Children with spina bifida

C. - Children without chronic physical handicap

A_1 - Children with hemophilia, excluding pre-school children

1. Responses after follow-up

	Yes	No	
A	3	8	11
B	2	4	6
	5	12	17

$$p = \frac{11!\ 6!\ 5!\ 12!}{17!\ 3!\ 8!\ 2!\ 4!} = .3999$$

$$p = \frac{11!\ 6!\ 5!\ 12!}{17!\ 4!\ 7!\ 1!\ 5!} = .3199$$

$$p = \frac{11!\ 6!\ 5!\ 12!}{17!\ 5!\ 6!\ 0!\ 6!} = .0746$$

p(total) = .7944

(one follow-up, each group)

	Yes	No	
A	9	2	11
B	2	4	6
	11	6	17

$$p = \frac{11!\ 6!\ 11!\ 6!}{17!\ 9!\ 2!\ 2!\ 4!} = .0667$$

$$p = \frac{11!\ 6!\ 11!\ 6!}{17!\ 10!\ 1!\ 1!\ 5!} = .0053$$

$$p = \frac{11!\ 6!\ 11!\ 6!}{17!\ 11!\ 0!\ 0!\ 6!} = .0001$$

p(total) = .0721

(two follow-ups, group with hemophilia)

2. Range of Peer Contacts, Same Sex

A	B	C
3	9	5
3	5	9
7	3	11
0	5	28
5	9	14
10	17	19
12		12
5		15
10		
5		
4		
7		
26		
8		
8		
0		
10		
5		
3		
12		
2		
2		

3. Intelligence

A	B	C
100	127	73
89	89	127
111	73	120
89	89	111
100	80	89
100	120	89
89		80
80		89
80		
89		
89		
111		
100		
73		
111		
100		
111		
89		
100		

Source	Sum of Squares	d_f	Mean Square
Between Groups	320.6	2	160.3
Within Groups	24,153.47	30	805.12
Total	24,474.07	32	

F = .199

4. Achievement WRAT Standard Scores

A	B	C
63	101	107
71	76	105
76	98	83
88	78	101
91	84	85
96	81	105
81		68
77		91
63		
86		
89		
101		
98		
114		
90		
76		
97		
93		
74		
112		

Source	Sum of Squares	d_f	Mean Square
Between Groups	254.16	2	127.08
Within Groups	5,775.4	31	186.3
Total	6,029.56	33	

F = .68

5. Hospital Admissions during Year of Fewest Admissions

	0	1+	
A	2	18	20
B+C	9	2	11
	11	20	31

$$p = \frac{20!\ 11!\ 11!\ 20!}{31!\ 2!\ 18!\ 9!\ 2!} = .0001$$

$$p = \frac{20!\ 11!\ 11!\ 20!}{31!\ 1!\ 19!\ 10!\ 1!} = .0000$$

$$p = \frac{20!\ 11!\ 11!\ 20!}{31!\ 0!\ 20!\ 11!\ 0!} = .0000$$

p(total) = .0001

6. Activity Restrictions by Physicians. Children's Reports

	Yes	No	
A	15	6	21
B+C	2	12	14
	17	18	35

$d_f = 1$

$X^2 = 8.81$

$P < .01$

	Yes	No	
A_1	14	5	19
B+C	2	12	14
	16	17	33

$d_f = 1$

$X^2 = 9.14$

$P < .01$

7. Activity Restrictions by Physicians
Parents' Reports

	Yes	No	
A	12	12	24
B+C	0	15	15
	12	27	39

$$p = \frac{24!\ 15!\ 12!\ 27!}{39!\ 12!\ 12!\ 0!\ 15!}$$

$$= .0007$$

8. Number of Activities in which Children Did Not Participate

A	B	C
4	1	5
2	10	4
3	19	3
12	8	3
2	4	4
12	2	4
14		3
2		4
8		
9		
3		
3		
2		
3		
2		
12		
7		
5		
9		
4		
14		

Source	Sum of Squares	d_f	Mean Square
Between Groups	52.42	2	26.21
Within Groups	1155.12	32	36.1
Total	1207.54	34	

F = .73 (not significant)

9. Number of Activities which Parents Restricted

A	B	C
7	1	4
10	1	3
11	14	1
0	2	1
11	0	2
10	0	2
12	0	4
12		5
1		
6		
12		
9		
3		
3		
4		
2		
8		
6		
3		
15		
17		
7		
5		
10		

Source	Sum of Squares	d_f	Mean Square
Between Groups	230.9	2	115.45
Within Groups	456.54	36	12.68
Total	687.44	38	

$F = 9.1,\ p < .01$

APPENDIX F

RAW DATA AND CALCULATION RESULTS

TWO GROUPS

D. Children with hemophilia without psychiatric disorder.

E. Children with hemophilia and psychiatric disorder.

1. Intelligence

D	E
100	89
100	111
89	89
80	100
89	80
111	89
73	100
111	111
100	89
100	

$$s^2 = \frac{92,213 - 90,820.9 + 82,726 - 81,796}{10 + 9 - 2}$$

$$= 136.59$$

$$t = 0$$

2. Achievement

WRAT Standard Score

D	E
63	71
91	76
81	88
63	96
89	77
101	86
114	98
90	93
76	74
97	
112	

$$s^2 = \frac{89,727 - 86,775.36 + 64,831 - 64,009}{11 + 9 - 2} = 209.65$$

$t = .69$

3. Favourite Activity Shared with Spouse (Parents)

	Yes	No	
D	10	5	15
E	1	8	9
	11	13	24

$$p = \frac{15!\ 9!\ 11!\ 13!}{24!\ 10!\ 5!\ 1!\ 8!} = .0108$$

$$p = \frac{15!\ 9!\ 11!\ 13!}{24!\ 11!\ 4!\ 0!\ 9!} = .0005$$

$p(\text{total}) = .0113$

4. Number of Children in the Families

D	E
4	3
3	3
2	12
4	2
4	9
4	6
4	3
3	9
3	9
4	
4	
4	
9	
2	
1	

$$s^2 = \frac{245 - 232.07 + 454 - 348.44}{15 + 9 - 2}$$

$$= 5.39$$

$$t = 2.34$$

$$p < .05$$

5. Number of Siblings with Hemophilia

D	E
0	1
0	1
0	2
0	0
0	3
0	1
0	3
0	3
0	
1	
1	
0	
3	
1	
0	

$$s^2 = \frac{12 - 2.4 + 34 - 24.5}{15 + 8 - 2}$$

$$= .91$$

$$t = 3.29$$

$$p < .01$$

6. Homes Equipped with Electric Stoves

	Yes	No	
D	12	3	15
E	2	7	9
	14	10	24

$$p = \frac{15!\ 9!\ 14!\ 10!}{24!\ 12!\ 3!\ 2!\ 7!} = .0083$$

$$p = \frac{15!\ 9!\ 14!\ 10!}{24!\ 13!\ 2!\ 1!\ 8!} = .0005$$

$$p = \frac{15!\ 9!\ 14!\ 10!}{24!\ 14!\ 1!\ 0!\ 9!} = .0000$$

p(total) = .0088

7. Pocket Money, Parents' Reports

D	E
0	3.50
0	1.75
50.00	25.00
0	1.00
1.00	0
1.00	20.00
10.00	0
1.75	.70
1.75	.70
.25	
0	
3.00	

7. Pocket Money, Parents' Reports

D	E
0	
.25	
1.75	

$$s^2 = \frac{2620.31 - 333.7 + 1042.29 - 308}{15 + 9 - 2}$$

$$= 137.31$$

$$t = 3.66$$

$$p < .01$$

8. Pocket Money, Children's Reports

D	E
5.00	5.00
0	.50
1.00	25.00
1.00	.70
1.00	5.00
1.00	20.00
1.75	1.00
3.15	2.00
.80	.70
5.00	
0	
1.05	

$$s^2 = \frac{168.73 - 37.1 + 1081.23 - 398.67}{12 + 9 - 2} = 42.85$$

$t = 13.43$, $p < .001$

9. Contacts with Consultant Physicians Past Year

D	E
2	0
0	0
0	0
2	0
0	0
0	0
1	0
2	0
0	
0	
2	
1	

$$s^2 = \frac{18 - 8.33 + 0 - 0}{12 + 8 - 2}$$

$$= .54$$

$t = 2.37$

$p < .05$