CHRONIC ILLNESS AND MALADJUSTMENT IN CHILDHOOD

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Abstract

This investigation aimed to assess the prevalence of chronic illness in childhood and its association with psycho-social maladjustment. Data from a primary care survey, conducted in 1979 in New York State, were analyzed. The prevalence of chronic physical illness among 10,164 children aged 4 to 16 years was 14.7%. Pediatricians diagnosed behavioral (2.0%) and emotional (3.3%) disorders more often in patients with chronic illness than in those without such illnesses (1.1% vs 2.3%). High prevalence rates of behavioral (13.1%) and emotional (7.1%) disorders were found in children with 'communication' disorders, while no association between 'minor' chronic disorders and maladjustment was found. Patients with 'serious' chronic disorders showed elevated prevalence rates of behavioral (1.5%) and emotional (3.5%)disorders but this increase did not reach statistical significance. The negative impact of maladjustment on the child and family was more severe when a chronic illness was also present.

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Résumé

Cette étude visait a determiner la prévalence de maladies chroniques chez les enfants, en association avec l'inadaptation psychosociale. Les données analysées provenaient d'un sondage effectué en milieu de soins primaires dans l'etat de New York en 1979. La prévalence de maladies chroniques physiques parmi 10,164 enfants âgés de 4 a 16 ans etait de 14.7%. Les pédiatres diagnostiquèrent des troubles comportementaux (2.0%) et émotionels (3.3%) plus souvent chez les patients atteints de maladies chroniques que chez ceux depourvus de ces conditions (1.1% vs. 2.3%). Des taux de prevalence élevés de troubles comportementaux (13.1%) et emotionels (7.1%) furent observes chez les enfants avec des troubles de 'communication', tandis qu'aucune association entre maladies chroniques mineures et inadaptation fut retrouvee. Les patients atteints de troubles chroniques 'sevères' demontraient des taux de prevalence elevés de troubles comportementaux (1.5%) et emotionels (3.5%) mais cette augmentation n'atteignit pas la significativite statistique. L'influence néfaste de l'inadaptation sur l'enfant et la famille etait plus severe en présence de maladie chronique.

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Chapter One

Introduction

Major advances in biomedical research in the last few decades have changed morbidity and mortality in the pediatric population (1). Today a large share of the health professional's time is devoted to preventive health measures, psycho-social problems, and chronic illness (2). Advances in disease specific therapy allow children with a wide variety of even major congenital, metabolic, neurologic or other chronic problems to survive into adolescence and adulthood. Approximately 10%-20% of today's child population is afflicted by chronic health problems (3).

Chronic physical illness is a stressful experience for both the afflicted child and parent. In the last few decades research has investigated whether this stress places chronically ill children at increased risk for the development of psycho-social maladjustment. The latter term, in the context of this thesis, refers to behavioral or emotional disorders, or both. In contrast to the more general terms "mental" and "psychiatric" disorders it excludes mental retardation and specific learning disorders.

Many early studies in this area focused on specific disorders such as cystic fibrosis, diabetes or epilepsy, etc. (4,5,6).

Pless and Pinkerton (7), however, advocated a non-categorical approach arguing that "the chronicity of the illness and the impact that it has on the child, his parents, and his siblings, is more significant than the specific character of the disorder, be it diabetes, cerebral palsy, hemophilia, etc. In other words there are certain problems common to all chronic illnesses over and above particular challenges posed by individual needs". This newer approach stresses similarities across specific disease categories, but does not preclude the desirability of work aimed at identifying subgroups of children that are at particularly high risk.

Investigations examining the association between chronic illness and psycho-social maladjustment differ widely in their methodology and not surprisingly the findings are inconsistent. Many studies conclude that there is a definite increased prevalence of maladjustment among chronically ill children (2,8,9,10), while others (4,5) fail to find an association. Thus the association remains not entirely understood and further research is needed.

A major problem with studies in this area is the assessment of psychiatric disorders. There is no "gold standard", or criterion for a disorder that all would agree is accurate (11). In the absence of a "gold standard" the most accepted criterion is the psychiatrist's judgement. This method, however, is expensive and limited therefore in its

applicability to the large number of subjects that is needed. A less expensive approach is the use of structured interviews or checklists. Instruments with sound psychometric properties, however, are scarce and there is still controversy whether the resulting syndromes are clinically meaningful (11).

An alternative method is to accept the diagnoses of pediatricians, who are known to be conservative in their assessment (12), as the measure of maladjustment. The current study is one of the first to adopt this approach. Data from a primary care survey (13), conducted in 1979 to determine the prevalence and management of mental health problems among children seen in pediatric practice, included information about the medical and mental condition of each child. This provided an opportunity to identify children with chronic physical disorders and those with psycho-social maladjustment among a sample of 10,164 subjects between 4 and 16 years of age.

The investigation at hand aims to assess the prevalence of chronic physical illness in childhood and its association with behavioral and emotional disorders.

CHAPTER TWO

LITERATURE REVIEW

There is a large body of literature concerning the prevalence of chronic physical illness and its association with behavioral, emotional or social disorders in children. This review is divided in three parts. The first deals with the assessment, prevalence and distribution of chronic illness. The second discusses different approaches to define mental disorders, and correlates of mental disorders. Finally the third part will present what is known about the association between chronic physical illness and psycho-social maladjustment.

2.1 Assessment, prevalence and distribution of chronic physical illness

Assessment of chronic physical illness

The concept of 'chronic illness' consists of two notions. Both have been defined variously in different studies. The first notion, expressed by the term 'chronic', refers to the inherent time element. Most studies require a chronic illness to have been present between 3 and 12 months prior to the assessment (2,10,14). In the International Classification of Impairments, Disabilities and Handicaps (15), issued by the WHO in 1980, it is argued from a conceptual perspective that 'chronic' simply means 'long, continued' and that the dimensions that distinguish chronic health problems from acute ones are so varied that it is unnecessary to develop a more precise formulation of the temporal boundary. The annual National Health Interview Survey (16), however, which is frequently used as a reference, defines chronic as 'present for at least three months'.

The second notion is expressed by the word 'illness' and means some kind of deviation from what is considered to be 'normal health'. In the Isle of Wight Studies (10) illness is defined as an 'association with persisting or recurrent handicap of some kind'. Other studies used a list of chronic conditions similar to those used for the National Health Interview Survey (16) and allowed the respondent to include additional conditions, when they were comparable in severity and chronicity with those already on the list (2,9,14). Reports of hay fever and allergy are sometimes judged as 'less serious' and not counted as 'chronic health problems' (9,14).

Many terms are used interchangeably in this area which may prove confusing. Clarification of these terms is important both conceptually and semantically. Pless and Pinkerton (7) suggest that the terms "impairment, disease, illness, defect, disorder and condition" are often used synonymously to

describe the underlying pathophysiological processes e.g. arthritis, asthma, heart disease etc.. In contrast "disability" is the immediate direct manifestation of the disease as it affects behaviour, such as attacks of wheezing or shortness of breath experienced by an asthmatic child. The term "handicap" refers to the consequences of disablement in relation to the performance of 'specific goal related activities'. They assert that this refers to the extent to which patients are disadvantaged in the performance of some specific action. This distinction is important, because the notion of a generalized handicap e.g. imposed by spina bifida, or epilepsy, is misleading and may have deleterious psycho-social consequences for the affected child (7).

Along quite similar lines WHO (1980) gives the following definitions (15):

<u>Impairment</u>: concerned with abnormalities of body structure and appearance and with organ or system function, resulting from any cause; in principle, impairments represent disturbances at the organ level.

<u>Disability</u>: reflecting the consequences of impairments in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of persons.

<u>Handicap</u>: concerned with the disadvantages experienced by the individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaptation to the individual's surroundings.

Prevalence of chronic illness

Comprehensive data on the prevalence of specific chronic disorders in childhood are not readily available (3). Estimates of the population prevalence of chronic illness vary widely depending upon the definitions used, the methods of study, and the population under investigation (2,9,10,14,18).

One of the most important studies in this field is the Isle of Wight survey conducted by Rutter and colleagues (10,18). The educational, emotional and physical disabilities of an entire cohort of 3,271 children born between 1 September 1952 and 30 August 1955 were studied. In 1965 a two stage procedure was used to identify those with chronic physical disorders. In the first stage multiple sources such as school medical examinations, hospital records, and records of speech therapists, as well as questionnaires sent to teachers and parents, were used. Children identified were then studied individually and a final decision about the presence or absence of a chronic disorder was made from information collected through an interview with the parents. Disorders were included when they 1. usually lasted at least one year in childhood, 2. were associated with persisting or recurrent handicap of some kind and 3. were known to have been present during the twelve months preceding the survey. One hundred and eighty-six of these 10 to 12 year old children, or 5.7%, were thereby identified as having a chronic physical disorder.

Pless and colleagues (2) conducted in 1969 the Rochester Child Health Survey to establish the prevalence of chronic physical disorders among school age children in Monroe County, New York State. In a 1% random sample of households 1,756 children between 7 and 18 years of age were first screened for symptoms of chronic illness. Parents of those with symptoms were then further interviewed to establish whether a child had a chronic illness. A list of 'chronic conditions' was provided to identify the presence of chronic illness, which was defined as one present for at least three months. Two hundred and six children (11.9%) were found to have a chronic disorder.

A more recent community survey, the Ontario Child Health Survey (9,14,19,20), was carried out in 1984. It was based on interviews with 1,869 Ontario families selected by means of a stratified, multistage sampling method from the 1981 census of Canada. While its primary purpose was to determine the prevalence and distribution of mental health problems among

Ontario children aged 4 to 16 years, it also allowed an estimate of the prevalence of 'chronic health problems'. The results were based on questionnaire responses concerning 3,294 children. Chronic disorders were classified as 'limitations of normal function' and 'chronic illness or medical condition'. 'Chronic functional limitation' was operationally defined as a limitation of physical activity, mobility, self-care or role present for at least 6 months. The same time was required for a 'chronic illness or medical condition'. A list of conditions was provided and the respondents were allowed to check 'other chronic health problems' when these were comparable in severity and chronicity with those already on the list. A 'chronic illness or medical condition' with 'limitation of function' was reported in 3.7%, a 'chronic illness or medical condition' without 'limitation of function' in 14%. When the two latter groups were considered together, 17.7% of Ontario children had a chronic physical disorder. Reports of allergy or hay fever were not included as chronic conditions.

The figures given for limitations of function correspond well with data from the National Health Interview Survey (NHIS) in the USA (21,22). Over two million children, or 3.8% of the US population under 17 years, were afflicted by chronic conditions that caused some limitation of activity. The limitations ranged from complete inability to attend school to limited ability to engage in athletics or other social

activities for school age children, or inability to engage in play for preschoolers. (It is important to note that the concept of 'limitation of activity' includes limitations caused by mental disorders.) Leading causes of activity limitation that account together for approximately 50% of all limitations include: respiratory disease; speech, special sense and intelligence related impairments; mental and nervous system disorders. The increase of this provalence from 1.8% in 1961 to 3.8% in 1979 was restricted to less severe levels of limitation and appears to be attributable to a shift in the perception of parents, educators, and physicians (22).

In 1969 Pless and colleagues (23) studied the pattern of care provided by primary physicians for children with chronic illness in Upstate New York. Data were collected from a sample of 82 physicians surveyed in nine rural counties and one urban county. Even though the study was not designed to estimate precisely the prevalence of chronic illness, they reported that 7.4% of the children seen annually had one or more chronic conditions. The difference between this estimate and the prevalence of 11.9% obtained from the household survey (2), carried out in the same urban county one year earlier, is probably due to underreporting by the physicians, and the referral of children with chronic illness to medical specialists.

Demographic correlates of chronic illness

Slightly higher rates of chronic disorders for males were found in the surveys conducted on the Isle of Wight (10) and in Monroe County (2). Both surveys found lower rates among nonwhite children and among children living in broken families (18). Children of higher socioeconomic status on the Isle of Wight (10) showed elevated rates, while the opposite was found in Rochester (2). The Ontario Child Health Survey (9,14) reported increasing rates with age, higher rates for males and children of low socioeconomic status.

2.2 Assessment, prevalence and correlates of psychiatric disorders in childhood

Assessment of psychiatric disorders

There are at least two different approaches to the classification of child psychiatric disorder. The first, the diagnostic approach, uses clinically derived categories that are defined by characteristic patterns of behavioral or somatic signs. Children presenting these patterns of signs are then classified under specific categories. The Diagnostic and Statistical Manual of Mental Health Disorders (DSM-III), published by the American Psychiatric Association in 1980 (24), the International Classification of Diseases (25), or the WHO Classification Scheme (26,27) are examples of this approach, which is widely used in clinical settings.

A problem with this method is the relatively low level of inter-rater agreement on specific diagnoses. Rutter and colleagues (27) reported an inter-rater agreement of 67% among psychiatrists for the WHO-classification scheme, which was used in a slightly modified version in this study. Another problem with this approach is that clinicians seem to be cautious in their diagnosis and concerned about 'labeling' a child as psychiatrically disturbed (29). Finally, this method is expensive and time consuming, and limited therefore in its application to epidemiologic research.

The second approach to classification, the empirical approach, relies not on clinically derived categories but on statistical techniques such as factor or cluster analysis to identify syndromes and classify children (11). One method assesses dimensions of common behavior in the child population and establishes extreme forms of these dimensions as abnormal. A second method determines characteristics that are empirically associated with psychiatric disorders. Cluster of symptoms are used to define syndromes (11).

The instruments used are of two types. Checklists are designed for screening purposes and are usually short and easy to administer. Structured interviews are more complex and more time consuming. They provide a standardized way to gather information and aim to identify specific syndromes. They can be administered by trained interviewers or by clinicians. The final diagnosis is made by a clinician or by computer scores (30).

One problem with the empirical approach is the degree to which the resulting syndromes are clinically meaningful or accepted by clinicians. There is, however, some convergence between the diagnostic and empirical approaches. For example, both approaches agree that the two major categories of child psychiatric disorders are: 1) aggressive, antisocial, or externalising disorders, and 2) shy, anxious, withdrawn, or internalising disorders (11,29).

Four approaches are used to test the construct validity of instruments used to assess psychiatric disorder. The most frequently used method examines the extent to which an instrument can distinguish between a hospitalized and non-hospitalized population (30). This approach is problematic because hospitalization is often related to tactors other than the presence or severity of psychiatric disorder. A second approach compares the findings of the instrument with the judgement of psychiatrists. The third method examines the extent to which the instrument is congruent with other instruments (31). The fourth centers on replication of similar data in two or more similar settings (32,33).

A major problem in child psychiatry is that there is no "gold standard', or criterion for a disorder that all would agree is accurate (11). A disorder thus becomes what a clinician judges it to be or what an instrument measures it to be. In the absence of a "gold standard" the most accepted criterion is the psychiatrist's judgement. The scarcity of instruments with sound psychometric properties is a serious deficit in the epidemiology of child psychiatry. There are instruments, however, that show promise for epidemiologic research such as the checklist developed by Achenbach and Edelbrock (34). This has been standardized on large samples of normal children aged 4-16 (12). Others are structured interviews like the Diagnostic Interview Schedule for parents or children (DISC) (35). This generates computer-scored psychiatric diagnosis with known validity and reliability according to the DSM-III (24).

The accuracy of the diagnosis of primary care physicians the approach used in this study to measure of mental disorder - was studied by Costello et al. (12). Seven hundred and eighty-nine children between 7 and 11 years of age attending pediatric primary care clinics were screened for psychiatric disorder using the Child Behavior Checklist (34). Twentyseven per cent of the children were identified by the checklist as disturbed. These then received a detailed psychiatric assessment using the Diagnostic Interview Schedule for Children (30,35). A randomly selected group of 174 non-disturbed children was also assessed by the structured interview. The pediatrician's judgement about the presence of emotional or behavioral problems at the index visit, was compared with the results of the structured interview.

Pediatricians diagnosed behavioral or emotional problems in 5.6% of the children compared with 11.8% based on the structured interview. Pediatricians were highly specific (84%), but showed a low sensitivity (17%). No information is given whether the reported sensitivity and specificity differ with the type of disorder. Pediatricians diagnosed maladjustment more often among children with high levels of service use, a trend that was not confirmed by the structured interviews.

Prevalence and correlates of psychiatric disorders

Different methods of defining deviance, along with other methodological differences, result in different prevalence rates of mental disorders in a series of community surveys carried out in various locations (36,37). In the Isle of Wight Studies (10) an individual psychiatric interview was used after a screening procedure. About 5.4% of all 10 to 12 year old children were diagnosed to have a 'clinically significant psychiatric disorder'. The Ontario Child Health Survey (14,20) used a slightly modified version of the Child Behavior Checklist. They found a prevalence of psychiatric disorders of 18.1% among a random sample of 4 to 16 year old children. These two examples clearly demonstrate the wide range of prevalence rates with reports ranging between 6% and 25% (10,13,17,38,39). This variability supports the caution with which Gould and colleagues (37) estimated the prevalence of mental disorders among children in the US as probably no less than 11.8%. Similar rates were found among children attending primary care settings. In general, the prevalence is believed to be slightly higher in service users (40).

Many factors have been found to be correlated with mental disorders. Higher prevalence rates are reported among children of lower socioeconomic status, those not living with both parents, and those with mental retardation (10,36,37). Behavioral disorders are more frequent in prepubertal boys, while emotional disorders are more prevalent in adolescent girls (11,37). The prevalence of mental disorders increases slightly with age (36,37).

2.3 Association between chronic illness and psychiatric disorders

In this section the quality of evidence for the hypothesis that chronic illness increases the risk for psycho-social maladjustment in childhood is examined. The large body of literature published over the last 20 years will be reviewed

not comprehensively but through examples selected to illustrate various types of studies and findings.

Most of the evidence arises from cross-sectional studies. These studies are characterized by the fact that the exposure and the outcome are determined at the same point in time (41). An important limitation of such studies for etiologic research is that it can not be assumed that psycho-social maladjustment found did not exist prior to the onset of the physical condition.

In such studies three different designs are used:

Case series.

The term case series refers to studies involving children with one or different chronic disorders without a comparison group. The published case series differ in their methodology and findings.

Boyle et al. (42) studied 27 adolescents and young adults with cystic fibrosis. Each patient had a psychiatric interview and was evaluated by psychological tests including the Rorschach Test and Draw-a-Person Test. Four factors leading to emotional disturbance were reported: altered physical appearance, strained interpersonal relationships, conflicts in upbringing, and increased awareness of the

future or death.

Tavormina et al. (5) studied 144 children aged 5 to 19 years with hearing impairment, diabetes or cystic fibrosis. They used the Piers Harris Scale, along with a Locus Control Scale for children, the Eysenck Personality Inventory, the Missouri Children's Picture Test, and a Psychological Screening Inventory. Comparisons were then made with published norms. All but hearing impaired children, who scored worse, scored better than the norms of the Piers-Harris Scale, whereas no significant differences from the norms were found on any of the other measures. The conclusion was drawn that the strengths and coping abilities of those with chronic disorders "noticeably outweighed their weaknesses".

Twenty-seven children between 7 and 13 years of age with latency-aged diabetes were studied by Grey, Genel, and Tamborlane (43) using Rodger's Parent Interview and Coopersmith's Self Esteem Inventory. Fifty-five per cent showed moderate or severe maladjustment, a rate well above the published norm of 7%. Psycho-social maladjustment was correlated with the parent's self esteem, the quantity of urinary glucose excretion, and family functioning, as measured by the Family Functioning Index.

Cantwell and Baker (44) examined 352 children under the age of 16 years presenting with communication disorders to a

community clinic. A psychiatric diagnosis was made using an interview with the parent, an interview with the child, and the Connors and Rutter parent and teacher rating scales. The children had a mean age of 6.3 years and 70% were boys. The intelligence quotient was slightly decreased but with a mean value of 95.6 within the normal range. Fifty-one per cent were diagnosed as being maladjusted. 30% had a behavioral disorder, 21% had an emotional disorder, 33% had a developmental disorder, and 9% were mentally retarded.

Ungerer et al. (45) studied the psycho-social functioning of a sample of 363 children and young adolescents with juvenile arthritis aged 7 to 31 years. A questionnaire, developed to assess aspects of psycho-social functioning, and the Piers-Harris Self-Concept Scale were administered. This study was unusual because of the diversity and size of its sample and the developmental perspective with which it approached the question. Adjustment, measured as self-concept, was similar to normative samples of Australian children across all three age-groups. Indices of psychological functioning and disease severity were associated with self-concept in the primary and high school age-group. The association between these variables was minimal for young adults. Only in the high school group were social relationships highly associated with adjustment. The authors emphasize the importance of using a developmental model for better understanding the adjustment of individuals with juvenile arthritis.

Only modest conclusions can be drawn from these studies. The diversity in the methods used to assess maladrustment, the lack of appropriate comparison groups, and the focus on only one type of chronic disorder make the interpretation difficult. Studies without any comparisons, like the one conducted by Boyle and colleagues (42), provide little evidence for the underlying hypothesis but simply highlight problem areas faced by children with cystic tibrosis. Studios that used measures with standardized norms to compensate for the lack of comparison groups provided better information but did not consistently find maladjustment more often in chronically ill children (5,43,45). An exception to these considerations is the study of children with speech and language disorders by Cantwell and Baker (44). Because individual psychiatric interviews were performed, the sample size was large, and high rates of disorders were found, it provided good evidence that children with communication disorders are at increased risk for psycho-social maladjustment. The children, however, were taken from a clinic and the results may not be valid for all children with speech and language problems. In summary, with the above mentioned exception, case series generally failed to provide clear evidence for or against the underlying hypothesis because of methodological weaknesses and conflicting results.

Comparison studies.

These studies compare the frequency of maladjustment in healthy and chronically ill children. A critical issue in such studies is the selection of appropriate controls.

Hayden et al. (46) studied 20 children between 10 and 19 years of age with myelodysplasia and normal intelligence. They were compared with physically healthy children of the same age and gender from the same hospital. The Offer Self-Image Questionnaire, the Tennessy Self-Concept Scale and the Wahler Self-Description Inventory were administered. Significantly poorer adjustment and lower self-esteem was found in the myelodysplasia group.

Drotar et al. (4) examined 137 children aged 3 to 13 years with cystic fibrosis, or other chronic respiratory illnesses (chiefly asthma). Those with cystic fibrosis were compared to their siblings; those with other respiratory disease to unmatched controls from the same health center. Mothers tilled out the Louisville Behavior Checklist, while teachers completed the School Behavior Checklist. On the parent ratings the frequency of maladjustment was more than 2 times elevated among those with cystic fibrosis and other chronic illnesses. The rate of maladjustment, however, was consistent with estimates for the normal population. No significant difference was found on the teachers' ratings.

Lewis and Kwaw (47) randomly selected 31 children with cystic fibrosis and 26 children with asthma aged 7 to 12 years from the population being treated as outpatients at the Boston City Hospital. They were compared to 27 physically healthy children who were drawn from the school that seemed to best match the socioeconomic level of the patients and then frequency matched by age and sex. The Family Adaptability and Cohesiveness Evaluation, the Behavior Problem Checklist and the Piers-Harris Children's Self-Concept Scale were administered. The frequency of behavior problems was significantly increased among both groups of chronic disorder, while no significant difference in self-concept was found. When there was statistical control for family functioning, however, the increase in the frequency of behavior problems in children with cystic fibrosis was no longer statistically significant. Unfortunately, this analysis was not done for the children with asthma. The authors argue that children with cystic chronic illness adjust in basically normal ways and that any deficits result from mediating factors such as family functioning.

Hoare (48) studied 123 children with epilepsy or diabetes and compared them with 123 healthy controls frequency matched by sex and age. Children with chronic illness were classified as 'newly diagnosed', if the first diagnosis was made and treatment was begun within three months prior to the assessment, or chronic, if the condition had been diagnosed earlier. Psychiatric morbidity was assessed by Rutter Scales administered to parents and teachers. Children with both 'newly diagnosed' (45%) and 'chronic' epilepsy (48%) had very high and statistically significant elevated rates of maladjustment on both scales. Children with chronic diabetes (17%) also showed significantly increased rates on the parent ratings. Those with 'newly diagnosed' diabetes (17%) also showed twice the rates of maladjustment when rated by the parents, but this difference was not statistically significant.

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The observation that the findings show so little difference between children with 'newly diagnosed' and longer existing conditions was explained by the trauma of the disease manifestation and the beginning of treatment. All epileptic children were attending normal high schools. Their on average slightly lower intelligence, in comparison with the nealthy and diabetic children, can only in part explain the high rates of maladjustment in this group. The author argued that the high rates among the epileptic children and the fact that the presence of maladjustment was associated with EEG abnormalities and/or complex partial seizures, support the hypothesis that children with impairment of the brain's functioning are particularly vulnerable to psychiatric disturbances.

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Court et al. (49) studied 127 children appeld to point of the diabetes mellitus and 51 non-drabetic children most on the family physician's register within the same approximpt the Rutter Parent Scale was administered and showed that the of the diabetic children were maladjusted compared to 14% of the non-diabetic children. Families more knowledgeable about diabetes were, however, less likely to have disturbed children.

Although the measures used to assess maladjustment in the studies described above again vary widely, most results support the hypothesized association. In general, studies using comparison groups provide stronger evidence. However, the results should be interpreted cautiously because most studies were restricted to few chronic disorders, and sometimes the sample sizes were small and the selection of the control groups inadequate. Siblings, used by Drotar et al. (4), are imperfect because they themselves might have higher rates of maladjustment due to their sibling's illness, which could cover an existing association. Another issue is that only a few studies used a matched analysis, when possible, or multivariate analysis to control for additional factors. Perhaps the most convincing findings are those reported by Hoare (48) and Breslau (8), in both of which a relatively large number of children were studied. Furthermore, in the latter the controls were a random sample from the community and multivariate analysis was used to control for demographic factors. Both studies give strong evidence that the type of condition, involving or not involving the brain, is an important factor. In two studies family functioning was found to be an important mediating

factor (47,49).

Prevalence studies.

Community based prevalence surveys, provided the use of proper sampling or screening procedures, avoid the critical risk of selection bias inherent in most other studies, especially those that are hospital based (41). The very nature of these studies, however, often precludes a detailed examination of the children.

The Isle of Wight survey conducted by Rutter and colleagues (10,18) studied the educational, emotional and physical disabilities of all 10 to 12 year old residents. One hundred and seventy-four of these children (5.7%) were found to have a chronic physical disorder. Mental disorders among these children were identified by psychiatric interview and psychological tests and were contrasted with the healthy population. Seventeen per cent of the chronically ill children were diagnosed as maladjusted compared with 6.6% among the general population. Very high rates of psychiatric disorders (38.9%) were found in children suffering from disorders involving the brain, while those with disorders not involving the brain showed only a moderate increase (10.4%). No increase was found in the 'eczema' group (5.6%). Among the chronically ill children there was no consistent tendency for neurotic or antisocial behavior to predominate. For children
with disorders not involving the brain the relative increase in neurotic disorders was larger, while those with disorders involving the brain tended to have more antisocial disorders. The difference in the rates of mental disorders between children with disorders involving the brain and those with other physical conditions were one of the most important findings of this survey and led the authors (10) to postulate two different underlying associations:

- I. Direct somatopsychic relationship: Body disturbances directly affect the brain function e.g. disorders involving the brain like cerebral palsy or hydrocephalus.
- II. Indirect somatopsychic relationship: Psychological reactions to somatic disorders. These consist of conscious and unconscious reactions to bodily dysfunction.

The Rochester Child Health Survey was carried out to establish the prevalence of chronic physical disorders among school age children in Monroe County, New York State (2). In a 1% random sample of households, 206 children (11.8%) were identified as having a chronic physical disorder. The California Personality Inventory, Coopersmith's Self-Esteem Inventory, the Children Manifest Anxiety Scale, Cowen's Teacher's Behavior Scale, and Kearsley's Behavior Symptom Questionnaire were administered to these children and to a random sample of 77 healthy children matched for age, sex, and socioeconomic area of residence. The prevalence of maladjustment among the former ranged between 238-308 in contrast to 138-168 among the healthy children. The highest rates of maladjustment (448) were found among children with sensory disorders, a category that included children with speech, hearing and visual problems. The frequency of maladjustment was related to the duration of the disorder, while the severity of the disorder, assessed in terms ot interference with normal daily activities, had only a small influence.

The Ontario Child Health Study (9,14) was based on questionnaire responses concerning 3,294 children aged 4 to 16 years from 1,869 randomly selected Ontario families. A slightly modified version of the Child Behavior Checklist (34) was completed for all surveyed children. Seventeen per cent had a chronic illness and maladjustment was found in 33% of these compared with 14% among the children without a chronic illness. The prevalence rates of all three diagnostic categories, neurosis, conduct disorder, and hyperactivity, were more than doubled among the children with chronic impairments. Those with chronic disability showed an increase in the rates for neurosis and hyperactivity by a factor of 4 (9,14).

In 1985 Beichtmann and colleagues (50) carried out a study to

establish the prevalence of speech and language disorders and their association with psychiatric disorders in 5 year old children. Ten per cent of a representative sample of 1,655 children from Kindergartens in a suburban Ontario area were diagnosed to have a speech and language disorder. These children and the same number of controls matched for age and sex were screened by a Child Behavior Questionnaire. A random sample of 61 children from the cases and controls with abnormal scores on the screening questionnaire were given a psychiatric interview. Psychiatrists diagnosed psychiatric disorders according to Axis I of the DSM-III in 48.7% of those with speech and language disorders, as opposed to only 11.9% among the controls. Behavioral disorders were more than two-fold more often diagnosed than emotional disorders among those with speech and language disorders. The IQ scores of the speech and language impaired were lower than those of the controls, but on average within the normal range.

The results of these studies are important not only because of their size and relative freedom of bias in the selection of children with and without chronic illness, but also because they tend to use a range of measures with generally sound psychometric properties. Although the actual proportions of maladjusted children differ widely - probably due to different methods of assessment - the prevalence ratio in each study exceeds 2.0. Unfortunately, however, in all the above described studies only univariate analyses were

performed.

Cohort studies

Theoretically a prospective design provides more conclusive evidence for a postulated causal sequence of events and permits more valid assessment of the strength of an association (41).

Peckham and Butler (6) investigated 13,509 children 11 years of age, who were part of the National Child Development Study, which included all children born in one week in 1958 in England. Parents reported that 4.9% of these children had suffered from at least one attack of asthma or wheezy bronchitis during the year prior to assessment. For each child the Rutter Scale was administered to the parents, while teachers completed the Bristol Social Adjustment Guide (BSAG). Asthmatic children scored significantly worse on the Rutter scale than children without asthma. This difference persisted after controlling for sex and social class using multivariate analysis. Those with at least monthly attacks scored the worst. Among the asthmatic children, increased rates of maladjustment were also found on the BSAG, but this increase was not significant after statistical control for sex and social class.

Seventy-four children aged 8-13 years with newly diagnosed

diabetes were followed over a period of one year by Kovacs and colleagues (51). Maladjustment was assessed using a semi-structured Interview Schedule for children. Based on parent interviews and clinical evaluation of the children, 14% were found to have been maladjusted prior to the onset of their physical condition. Thirty-six per cent of the children became maladjusted within three months of the initial diagnosis. These reactive disorders were not continuations or exacerbations of preexisting mental disorders. Ninety-three per cent of the maladjusted children had recovered after no more than 9 months no matter how severe the initial reaction had been. Maladjustment was more likely among children whose parents were of low socioeconomic status or who had marital distress.

Heller et al. (52) studied 140 children aged 4-13 years with cleft lip/palate, heart disease or hearing defects over a period of one year. The Child Behavior Checklist and the Children's Self Report Psychiatric Rating Scale were administered. Thirty-three per cent of these children were maladjusted at the first assessment, compared with 24% after one year. The main goal of this study was to identify factors associated with progressive or persistent maladjustment. The tindings suggested that the type and severity of physical condition, as well as male gender, are associated with becoming or remaining maladjusted. Family functioning, assessed by the Family Functioning Inventory, however, was

not significantly related to maladjustment.

Again the reviewed studies differ widely in sample size, study populations, and periods of follow-up. Unfortunately, none succeeds in establishing whether children with chronic illness who later display maladjustment were unequivocally free of such problems prior to the onset of their physical condition. Investigations like the one by Peckham and Butler (6) do not include an assessment of the earlier behavior, whereas Kovacs et al. (51) tried to address this issue but their findings may have been affected by recall bias. Heller et al. (52) identified factors that are associated with the development of maladjustment once the chronic condition was present, but the follow-up period of one year was rather short. The findings, however, mostly point to elevated rates among chronically ill children.

To summarize, the prevalence of chronic illness in children lies somewhere between 10% and 20%, depending on the definition used and the population studied (3). Even though many studies reach the same conclusion - that those with chronic disorders have an increased risk of psycho-social maladjustment when compared with healthy peers - few studies cited provide conclusive evidence in support of a causal connection. Conflicting results, methodological problems, and evidence of important mediating factors, suggest a complex association that is not fully understood. However,

the reported magnitude of risk, although not exceedingly large, is sufficient to be of concern to clinicians. Furthermore, limited information is available about characteristics that might modify the risk for maladjustment. Evidence exists for the type of condition, namely disorders involving the brain and speech and language disorders, for which high rates of maladjustment were consistently found (8,10,44,48,50,53). Some authors suggest a possible importance of gender (52) while others point to the role of age (49). Family functioning was found in several studies to be a possible mediating factor (47,49,54), whereas the influence of the severity of the disorder in medical terms is far from clear. In the past it was generally assumed that the more severe the disorder, the greater the likelihood that maladjustment would occur. The severity of condition, however, appeared to have had little influence in the Isle of Wight Study (10) and the Rochester Child Health Survey (2).

It remains the task of clinicians to identify among the population with chronic disorders those with psycho-social maladjustment or those for whom the risk of such is the greatest. The study at hand is one of the first to use data from a primary care survey. It examines whether primary care pediatricians diagnose maladjustment more often among children with chronic illness, how they perceive the impact of these problems, and what measures they take to prevent turther impairment in the child's development.

CHAPTER THREE

OBJECTIVES

This investigation, based on the data of a primary care survey (13), addresses the association between chronic physical illness and behavioral or emotional disorders among children between 4 to 16 years of age. An estimate of the prevalence of chronic illness, recognized and reported by primary care pediatricians, will be obtained. The prevalence of behavioral or emotional disorders among these children will be compared with children without chronic illness. Characteristics of chronically ill children with maladjustment will be analyzed to determine factors that might increase the susceptibility to emotional or behavioral disorders. Finally, the impact of such disorders on those children and their families, as well as the pediatrician's referral to specialty care, will be compared with children without chronic illness.

The specific objectives are as follows:

Primary objective

1. to determine whether pediatricians in primary care diagnose behavioral or emotional disorders more often among children with chronic physical illness than among children without chronic i'lness;

Secondary objectives

- to obtain an estimate of the prevalence and demographic correlates of chronic physical illness among children seen in pediatric practice;
- 2. to determine the association between patient characteristics and behavioral or emotional disorders among chronically ill children;
- 3. to determine whether the impairment of the patient's or the family's functioning due to behavioral or emotional disorders and referral to special care is different for chronically ill children when compared with children without such illnesses.

CHAPTER FOUR

METHODS

4.1 Overview

This study is based on a secondary analysis of a data set containing information from an ambulatory care survey. The latter was conducted between January 1979 and January 1980 in Monroe County, N.Y., to assess the prevalence and management of mental health problems among children seen in pediatric practice (13). Along with information about mental health problems the data also include information about the reason for the visit and the medical condition of each child. The goal of the present analysis is to obtain an estimate of the prevalence and type of chronic physical illness among children seen in pediatric practices, and to compare the prevalence and management of behavioral or emotional disorders among these children with those without a chronic illness.

4.2 Survey design and conduct

Objectives and design

The three primary objectives of the original survey were to determine through a probability sample of pediatric practices

in Monroe County:

- the prevalence of behavioral, emotional, and school problems in the patient population seen by pediatrician;
- 2. the management of these health problems;
- 3. the pediatrician's perception of such problems.

To satisfy these objectives, it was essential that the sample be large enough to yield data on approximately 1,000 children with mental health problems. A feasibility study had shown that a sample of approximately 20,000 children visiting their pediatrician would accomplish this. The study was to be carried out over a full calendar year (1979) in a manner that would assure a high rate of participation among the pediatricians by limiting the response burden i.e. by not interfering with the normal practice of the participants.

Period and Locale

The survey was conducted in Monroe County, New York State, during the period from January 1979 to January 1980. Monroe County encompasses the City of Rochester and 19 towns and had a population of approximately 702,000 as enumerated in the 1980 census. The population less than 18 years of age in the county was 191,000 by 1980. The racial composition of the child population of the County in 1980 was approximately 83% white, 16% black, and 1% other races.

Sample Plan

A list of the 74 pediatric practices in the County was prepared and stratified by type of practice. When the survey was initiated, pediatricians were distributed as follows: 13 were in solo practices, 38 in group practices (including partnerships), and 23 in health centres. A complex sample design was used starting with a stratified systematic random sample of pediatricians. Each pediatrician was asked to report on all eligible patients seen over a 2-month period during 1979. During each month of the year at least one pediatrician from each stratum participated, so that each type of practice was represented for 12 months.

An overall sample fraction of 40.5% (30/74) of all practitioners was included in the final sample. Twenty wix per cent of those approached initially refused to participate. This included two in solo practice and nine group practitioners. Reasons for refusal fell into four categories: 1. two had participated in the earlier feasibility study; 2. three had partners who had already participated; 3. three had "trouble with personnel"; 4. three were not interested.

Encounter form and reporting procedure

All physicians received the Physician Visit Records (PVR)

and the accompanying instruction manual with a definition of terms. The first section (A) of the PVR contains the following information about the patient: demographic characteristics, census tract of residence, household composition, Medicaid status, prior use of the pediatric practice, present complaint, pediatrician's diagnostic impression, and a determination as to whether or not the patient, to the knowledge of the pediatrician, had a mental health problem. There was no specific probing for the presence of such problems. (Appendix A)

When a current mental health problem was known, the pediatrician completed the second section (B) describing the nature and management of that problem, including information on diagnosis, duration, degree of impairment, and referral for specialty care. Information dealing with demographic characteristics and previous contacts was generally completed by the receptionists. All medical information relating to the visit was completed by the pediatrician and was based on the pediatrician's routine procedures without additional inquiry or probing for the presence of mental health problems. To assure confidentiality the patient's identity was only known to the pediatrician seeing that patient. A tear-off portion carrying a code number was sent to the research center.

Each pediatrician completed the encounter form (PVR) for each visit during the 2-month period of participation. The form

did not indicate whether this visit was by a child who had made a previous visit during the study period. An office visit was defined as "a direct personal encounter between an ambulatory patient and a physician, including visits made after regular office hours, for the purpose of seeking care and rendering health services in which a medical judgement was made". Visits only for immunization or other technical procedures that did not require medical judgement were excluded. Also excluded were home or inpatient visits and phone contacts.

Study staff who maintained frequent contact with the participating practices collected the completed encounter forms weekly. Information was coded, punched and verified centrally shortly after collection. Missing information or inconsistent responses were corrected after follow-up with the reporting pediatrician within 2 weeks of the date of the encounter.

4.3 Chronic illness

4.3.1 Identification of medical conditions

In Question 4 of the doctor's section, the pediatrician was asked to give a medical impression of the child's current condition. The original instruction for this question was: " D 4.: Be as specific as you can. The first diagnosis should

be regarding the reason for this visit. The second diagnosis should cover any associated condition or chronic illness. In so far as possible use ICDA terminology so that we can code accordingly."

All answers to this question were coded following the eighth Revision of the International Classification of Diseases (25).

4.3.2 Identification of chronic disorders

In this study information about the medical condition of the child is limited to the diagnostic impression of the attending pediatrician. Little is known about the duration of conditions before the doctor visit.

An operational definition using two criteria was used to identify children with chronic physical illness. The first, the time criteria, was met by selecting ICD-categories that include only conditions that, according to medical knowledge, usually last longer than 3 months. The second, the severity criterion, was included to insure that the disorder was serious enough for the physician to report it.

A chronic physical illness was therefore operationally defined as one that:

- usually lasts longer than three months;

- is severe enough for the physician to report it.

This definition is unlikely to identify all chronic disorders because some conditions may have been reported in ICD-categories that include conditions that are not chronic. All medical conditions were reported by the attending physician and the reliability and validity of this assessment should be high. This operational definition was chosen to increase specificity at the cost of lower sensitivity.

As in many other studies (2,9,10,14) it was also decided to classify speech and language disorders as chronic physical illnesses. Patients with these disorders were identified by Question 11-B. All children with a primary or secondary diagnosis of speech and language disorder, or stuttering were included. The original definition for speech and language disorders was:

" Q. 11-B: Delays or distortions in the development of speech or language or both should be coded here if they are not part of any other psychiatric syndrome and not part of a structural neurological disorder (such as cerebral palsy)." All reported medical conditions were classified as either chronic or non-chronic. The chronic conditions identified would be called "impairments" using the WHO definition (15). Little can be said about the actual consequences for the afflicted children due to these impairments. In the following

sections the terms impairment, illness, disorder and condition are used synonymously. (The term "chronic" will imply that the disorder is physical). Appendix B gives a complete list of all identified chronic disorders.

4.3.3 Grouping of children with chronic disorders

All children with any chronic disorder as defined above were further divided into subgroups to learn more about the groups of chronic disorders and to enhance comparability with other studies. Two different classifications were used. In the first, Grouping A, all disorders were classified as either 'serious disorder', 'speech and language disorder', or 'hay fever or dermatitis'. The 'serious disorder' group comprises all chronic disorders other than speech and language disorder, hay fever or dermatitis. Speech and language disorders were separated because of their borderline status between physical and mental conditions (27,45). Hay fever or dormatitis are frequent, but usually less serious than other chronic disorders, and for this reason are considered as a separate group (9,14). The category of 'serious' disorders was turther subdivided based on the functional system attected. The group 'Other conditions' comprises disorders that are difficult to assign in this scheme. (Figure 1)

The purpose of Grouping A was to estimate the prevalence of individual disorders and therefore it was not mutually

exclusive, e.g. it was possible for a child with two different chronic disorders to be counted twice. With the exceptions of the grouping of 'serious' disorders based on the affected functional systems this classification was not used to determine the association between chronic conditions and behavioral or emotional disorders.

Grouping B was performed to assess the association between chronic physical disorders and psychiatric disorders. To prevent one child with two conditions being counted twice in different categories this classification was mutually exclusive. All children with a 'serious' disorder under Classification A were again classified as such. Of the remainder, all children with speech and language problem were classified as 'communication' disorder. All remaining children with only hay fever or dermatitis were combined under 'minor' disorder. 'Serious' disorders were further subdivided following the reasoning of Rutter and colleagues as described earlier (10). All children with a 'serious disorder involving the central nervous system (CNS)' were grouped in one category. The remaining children were combined in a category called 'serious disorder not involving the CNS'. (Figure 1)

Figure 1. Grouping of children with chronic disorders



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4.4 Psychiatric disorders

4.4.1 Identification of psychiatric disorders

Information from two questions were used to identify children with psychiatric disorders. In Question 6 of section A physicians were asked whether the child was mentally retarded or developmentally delayed.

All further information stems from Question 11-B in section B. Here the pediatricians were asked to record the patient's problems according to a slightly modified version of the WHO-Classification of Mental Disorders in Children, originally a tri-axial classification scheme developed in 1969 (26,27). The definition of terms was intended to be operational and capable of clinical application. Even though the diagnostic categories were also intended to be mutually exclusive, two diagnoses were possible (26,27). In the modified scheme employed in this study it was possible to check more than one diagnosis and to indicate whether a diagnosis was 'Primary' or 'Not primary'.

As described above, children with a primary or secondary diagnosis of speech and language disorder, or stuttering were classified under chronic illness. A single diagnosis of abnormal clumsiness was not considered as an independent psychiatric disorder because of vagueness in the definition. All remaining children with any diagnosis following the WHO-classification or a diagnosis of mental retardation from Question 6 were defined as having a psychiatric disorder.

4.4.2 Grouping of psychiatric disorders

Children with any psychiatric disorder were then further classified as follows:

- All children described as mentally retarded in Question
 or with a primary or secondary diagnosis of mental subnormality, or specific learning disorder in question
 Hentally retarded' group.
- 2. Of the remaining disturbed children, all those with a primary or secondary diagnosis of hyperkinetic disorder, or a primary or secondary diagnosis of conduct disorder were classed in the 'Behavioral disorder' group.
- 3. All remaining disturbed children were placed in a category called the 'Emotional disorder' group.

The 'Behavioral disorder' group and the 'Emotional disorder' group were also combined into a category called 'Maladjustment'. (Figure 2)

The main reason for these groupings was to isolate children with mental retardation or specific learning disorder, which have clearly been shown to be associated with behavioral or Figure 2. Grouping of children with psychiatric disorders ⁴⁸ (Mutually exclusive)



emotional problems (10,11). The separation of children with mental retardation beforehand also follows the recommendations of the DSM-III, the classification scheme developed by the American Psychiatric Association (1).

Further grouping was done to discriminate the remaining disorders into externalising and internalising disorders. The combination of hyperkinetic and conduct disorders, as the major externalising disorders, is well accepted and there is still discussion about the extent to which these disorders are independent (11). The group 'emotional disorders' consists mainly of children diagnosed as having adaptation reactions, neurotic disorders, personality disorders or psychosomatic disorders. Because double diagnoses were allowed, however, these diagnostic categories may represent more than one type of disorder. Table 1 shows the frequency of individual psychiatric disorders classified under the different categories. In the following sections the term maladjustment will refer to both behavioral and emotional disorders. The terms disorder, problem, and disturbance will be used interchangeably when they refer to mental disorders.

| Type of chronic disorder | Mental retardation | Behavioral disorder | Emotional disorder |
|-------------------------------------|-----------------------|------------------------|-----------------------|
| Any disorder | 157 | 64 | 117 |
| Adaptation reaction | 21 | 7 | 75 |
| Specific development disorder | al | | |
| Hyperkinetic Disord | er 32 | 42 | 0 |
| Other specific learning disorder | 90 | 0 | 0 |
| Enuresis as isolated disorder | 6 | 2 | 9 |
| Encopresis as isolated disorder | 0 | 0 | 7 |
| Tics | 2 | 0 | 2 |
| Conduct disorder | 15 | 33 | 0 |
| Neurotic disorder | 3 | 0 | 12 |
| Psychosis | 2 | 0 | 1 |
| Personality disorder | 5 | 4 | 5 |
| Psychosomatic disorder | 2 | 2 | ნ |
| Anorexia nervosa | 0 | 2 | 1 |
| Other clinical symptoms | 7 | 2 | 15 |
| Mental subnormality | 73 | 0 | 0 |

Table 1. Frequency of psychiatric disorders by diagnostic category.

4.5 Other variables

4.5.1 Demographic characteristics

Sex, age, race, Medicaid and family status of the patient were taken from section A. The children were divided in three age-groups: 4-7 years, 8-11 years, or 12-16 years of age. Medicaid status was used as an approximation for socioeconomic status and coded yes or no. Race was coded white or non-white. Family status was classified as living with both biological parents or not.

4.5.2 Familiarity with the patient

It has been reported that patients with mental health problems are frequent primary care users (13). Later reports suggest that this may be not the case but that physicians merely diagnose mental health problems more often in frequent users (12). Children with chronic illness might be frequent users, and it was therefore decided to control for this officet. Because no data about the frequency of visits in the period before the reported visit were available, the period between the previous and current visit was used as an approximation (13). The period was calculated as the difference between the date of the current and that of the previous visit and then classed as less than 3 months, between 3 and 12 months, or more then 12 months. 4.5.3 Impairment of the patient's and family's functioning

In Question 12 of section B the physicians were asked to classify the impairment of the patient's and the family s functioning caused by the mental health priplem. The original instruction for this question was as follows: " D12: This is intended to be a crude, global judgement on your part about the extent to which the family or child is troubled by the patient's condition. For example, does it prevent the patient from attending school regularly, or is it proving stressful for the parents and affecting their marriage?"

Moderate and severe impairment were combined and compared with minor or no impairment.

4.5.4 Referral to specialty care

To determine the pediatrician's referral of maladjusted children to specialty care Question 14-A was used. The physicians were asked whether "in dealing with this patient or his/her parents, have you or anyone in this practice, today or previously, referred for psychological care or consultation?". Those ever referred were compared with those never referred.

4.6 Data analysis

4.6.1 Preparation of the data set

The original SPSS System file was transferred into a SAS System file. Because an encounter form was filled out for each visit, and the encounter form did not carry the name of the patient, a distinction had to be made between visits and children served. This was done by a computer sort of all encounters by date of birth, sex, race, date of first contact with the pediatric office, and census tract of residence using the SAS Proc Sort procedure. Sequence matching on all these variables was considered as representing multiple visits of the same child.

This procedure reduced the initial number of 21,537 visits to 18,475 children seen by the pediatrician. Furthermore, to assure better comparability, patients of less than 3 years and more than 16 years of age were excluded, leading to a final number of 10,164 children between 4 and 16 years of age.

4.6.2 Reduction of the data set

After estimating the prevalence and demographic correlates of chronic illness among the study population using the complete data set, the further objectives of this study concentrate on a comparison of chronically ill children with children without chronic illness.

Because the number of subjects in the complete data set was large (10,164), and multiple comparisons using logistic regression analysis were planned, it was decided to reduce the number of subjects to save computer time and costs. In the first step all children of other than white or black race were excluded.

All remaining 1,477 children with any chronic disorder were retained as the 'study group'. In the next step the number of 8,598 subjects in the 'comparison group' was reduced. This was done using the SAS procedure for random selection without replacement. Of all these children without chronic illness a random sample of 2,954 children was generated, corresponding to a ratio of subjects in the 'study group' and the reduced 'comparison group' of 1:2.

The rationale for this was that the random sample provides a good representation of the characteristics of the complete 'comparison group'. By reducing the number of observations, however, a loss of precision in the estimation of odds-ratios was accepted (55,56). The magnitude of the loss of precision decreases when only subgroups of those with chronic illness are considered. Because the entire random sample served as the 'comparison group' for all further analysis, the subject ratio increases when smaller subgroups of children with chronic disorders are considered, leading to a reduction in the loss of precision. Tables 2 and 3 demonstrate the close similarity in demographic characteristics and prevalence of psychiatric disorders among all children without chronic illness and the random sample selected. None of the comparisons were statistically significant.

4.6.3 Data Analysis

The data were analyzed using the statistical packages of SAS (1986) and BMDP (1987). SAS was used for univariate and bivariate analyses and BMDP for the unconditional logistic

regression analyses.

Univariate analyses were performed to determine the prevalence of chronic illness and psychiatric illness in the study population and to describe demographic characteristics of those with and without chronic illness. The complete data set after exclusion of multiple visits was used for this part of the analysis.

Bivariate analyses were used to assess the association between two variables. Chi-square tests and crude estimates of odds-ratios with 95% confidence intervals were calculated using the Mantel-Haenszel statistic.

| Table 2. Demographic characteristics of all children without chronic physical illness (8,598) and a random sample of these children (2,954). | | | | | | |
|--|---|---|--|--|--|--|
| Demographic characteristics | <pre>% of all children (n=8,598)</pre> | <pre>% of random sample (n=2,954)</pre> | | | | |
| Age in years | | | | | | |
| 4 5 6 7 8 9 10 11 12 13 14 15 16 | 10.5 11.4 9.3 8.8 10.0 8.1 8.5 6.5 6.5 6.7 5.3 5.6 5.3 3.8 | $ \begin{array}{c} 11.0\\ 10.5\\ 8.6\\ 8.7\\ 9.9\\ 8.3\\ 8.4\\ 7.1\\ 6.9\\ 5.1\\ 5.9\\ 5.4\\ 4.2\end{array} $ | | | | |
| Age-group in years | | | | | | |
| 4-7 8-11 12-16 | 40.0 33.0 27.0 | 38.8 33.7 27.5 | | | | |
| Sex | | | | | | |
| Male Female | 50.7 49.3 | 51.8 48.3 | | | | |
| Medicaid | | | | | | |
| No Yes | 94.6 5.4 | 94.7 5.3 | | | | |
| Race | | | | | | |
| White Other | 91.4 8.6 | 92.6 7.4 | | | | |
| Living with both parents | | | | | | |
| No Yes | 14.6 85.4 | 15.2 84.8 | | | | |

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Table 3. Psychiatric disorders among all children without chronic physical illness (8,598) and a random sample of these children (2,954).

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| Type of disorder | <pre>% of all children (n=8,598)</pre> | % of random sample (n=2,954) | |
|-----------------------------|--|------------------------------------|--|
| | | | |
| Mental retardation | 1.7 | 1.7 | |
| Behavioral disorder | 1.2 | 1.1 | |
| Emotional disorder | 2.4 | 2.3 | |
| Any psychiatric disorder | 5.2 | 5.1 | |

<u>Multivariate analyses</u> were performed to adjust for the effects of multiple variables on the association between chronic disorders and psychiatric disorders using unconditional logistic regression analysis. The 'dependent' variable was defined as the category of psychiatric disorders of interest. Chronic illness, or subgroups of chronic disorders, was defined as the 'determinant' of interest.

Variables significantly associated with psychiatric disorder, in the bivariate analysis, or known to be associated with psychiatric disorders on the basis of results from other studies, were assessed in terms of potential contounding on effect modification. These variables were the patient's sex, age, race, Medicaid status, whether s/he was 'living with both parents', and the 'period between current and previous visit'. Only variables found to be at least marginally significant (p-value less than 0.10) associated with psychiatric disorders were included in the final model. Groups of chronic disorders as the 'determinant' of interest were kept in the model even when their association with the 'dependent variable' of interest was not statistically significant. Their estimated odds-ratios with 950 confidence intervals and p-values in the final model are referred to an "adjusted" in the following tables.

All variables were treated as categorical. Observations with missing values were excluded from the analysis. All figures

given for crude and adjusted odds ratios, as well as for the limits of the 95% confidence intervals, are rounded to the nearest first decimal. The only exception to this rule are figures for the lower limit of the 95% confidence interval. All numbers between 0.9 and 1.0 are expressed as 0.9 to indicate that 1.0 is included in the confidence interval. Unless specified otherwise, the terms "significant" or "statistically significant" will refer to a p-value of less than 0.05.

CHAPTER FIVE

RESULTS

5.1 Chronic illness: Prevalence and demographic correlates

Prevalence of chronic illness

There were 905 children among the 10,164 subjects who had a 'serious' chronic disorder, corresponding to a period prevalence of 8.9%. One hundred and six others, a proportion of 1.0%, had a speech or language disorder, while 523 (6.8%) were reported to have hay fever or dermatitis. At least one condition as defined above was reported for 1,490 children. Because it was possible for a child to have more than one disorder this is not the simple total of all children with any condition. The 1-month period prevalence of any chronic physical illness among the children between 4 and 16 years seen in pediatric practice was 14.7%. (Table 4)

The goal of this analysis was to provide a rough estimate of the burden of chronic illness among the study population, because the data of the original study do not provide the necessary information to accurately estimate the prevalence of chronic physical illness. The figures given are the unweighted proportions without confidence limits. If

| Type of disorder | No. of Patients | % of all children | % of all disorders | |
|---------------------------------|--------------------|----------------------|-----------------------|--|
| 'Serious' d.sorder | 905 | 8.9 | 60.7 | |
| Speech and Language disorder | 106 | 1.0 | 7.1 | |
| Hay fever or dermatitis | 523 | 5.1 | 35.1 | |
| Any disorder | 1490 | 14.7 | 100.0 | |

Table 4. Prevalence of chronic physical illness among 10,164 children between 4 and 16 years of age seen in pediatric practice.

a uniform distribution of first visits across the 2-month reporting period is assumed, the average observation period for each child was 1 month. Thus the figures indicate a 1-month period prevalence.

An analysis of all 'serious' disorders by the affected functional system is shown in Table 5. Disorders of the respiratory and musculoskeletal system and 'other' disorders were the most frequent, followed by disorders of the skin, the sensory system, the neurologic system, and the endocrine system. Disorders of the circulatory, genitourinary, hematologic and digestive systems were much less frequent.

Demographic characteristics of children with chronic illness

The prevalence of chronic disorders increased with age from 11.5% for those between 4 and 7 years to 18.9% for those aged 13 to 16 years. Boys had a higher prevalence than girls, as did non-white children compared with white. Children on Medicaid also had a higher prevalence compared to those not on Medicaid. Whether the child was living with only one of both parents, however, did not influence the prevalence. (Table 6)

The period between the previous and current visit was used as an approximation for the physician's familiarity with the patient. Fourty-eight per cent of the children without
Table 5. Prevalence of 'serious' chronic disorders by affected functional system among 10,164 children between 4 and 16 years of age seen in pediatric practice.

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| Functional system | Disorder present(No.) | % of all children | <pre>% of 'serious' disorders</pre> |
|---------------------------------|--------------------------|----------------------|-------------------------------------|
| Endocrine system | 48 | 0.5 | 5.3 |
| Hematologic system | 33 | 0.3 | 3.6 |
| Neurologic system | 75 | 0.7 | 8.2 |
| Sensory system | 82 | 0.8 | 9.0 |
| Circulatory system | 47 | 0.5 | 5.2 |
| Respiratory system | 165 | 1.6 | 18.2 |
| Digestive System | 31 | 0.3 | 3.4 |
| Genitouri nary system | 41 | 0.4 | 4.5 |
| Dermatologic system | 88 | 0.9 | 9.7 |
| Musculoskeletal system | 125 | 1.2 | 13.8 |
| 'Other' disorders | 179 | 1.8 | 19.8 |
| Any 'serious' disorter | 905 | 8.9 | 100.0 |

| Charac- | Patient | s without | Patien | ts with | Presence of | |
|--|---|--|---|---|--|-------------|
| teristics | chronic (No.) | illness (%) | chroni (No.) | c illness (%) | illness amo all children | ng n (3) |
| Age in years | | | | | | |
| 4 5 6 7 8 9 10 11 12 13 14 15 16 | 913 985 811 764 867 703 735 551 596 462 488 459 331 | 8.9 11.4 9.4 8.8 10.0 8.1 8.5 6.5 6.5 6.9 5.3 5.6 5.3 3.8 | 130 110 104 105 133 145 108 110 129 128 113 97 78 | 8.7 7.4 7.0 7.1 8.9 9.7 7.3 7.4 8.7 8.6 7.6 6.5 5.3 | 12.4 10.8 11.4 12.0 13.3 17.1 12.8 16.4 17.8 21.7 18.8 16.9 19.0 | |
| Age-group in years | | | | | | |
| 4-7 8-12 13-16 | 3473 2866 2335 | 40.0 33.0 27.0 | 449 496 545 | 30.1 33.3 36.6 | 11.5 14.7 18.9 | |
| Sex | | | | | | |
| Male Female | 4398 4276 | 50.7 49.3 | 855 635 | 57.4 42.6 | 16.3 12.9 | |
| Medicaid | | | | | | |
| No Yes | 8206 468 | 94.6 5.4 | 1379 111 | 92.6 7.4 | 14.4 19.2 | |
| Race | | | | | | |
| White Other | 7924 750 | 91.4 8.6 | 1308 182 | 87.8 12.2 | 14.2 19.5 | |
| Living wit both parer | :h its | | | | | |
| No Yes | 7375 1299 | 85.6 14.4 | 1243 247 | 83.4 16.6 | 15.9 14.4 | |

Table 6. Distribution and demographic characteristics of 1,490 patients with chronic illness and of 8,674 patients without chronic illness.

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chronic illness had seen the physician within three months, and 82.9% within one year. The frequency of visits for children with chronic illness was very similar throughout each of the subgroups. (Table 7)

5.2 Psychiatric disorders: Prevalence and association with chronic illness

Prevalence of psychiatric disorders among all children

The prevalence of any psychiatric disorder in the study population was 6.4%. Adaptation reactions, specific learning disorders, hyperkinetic disorders, mental subnormality and conduct disorders were most frequently diagnosed. (Table 8)

The classification used for this analysis grouped 2.6% of all children as having an emotional disorder. Behavioral disorders had a prevalence of 1.4%, while 2.4% were diagnosed as being mentally retarded. (Table 9)

Association between psychiatric disorders and chronic illness

Mental retardation. As shown in Table 10 mental retardation was, not surprisingly, more frequent among children with chronic illness. Those with 'serious' disorders involving the CNS or with 'communication' disorders had very high prevalence rates, ranging from 31.9% for the former to 50.0%

| Table 1 - Ferioa des Frysiolas - expressed | | | • • • |
|---|-------|--------------|---------------------------------------|
| Type of Leoraer | | ···: ···: | · · · · · · · · · · · · · · · · · · · |
| | | ~ | |
| No onzonio iliness | -3 5 | ~ ~ | |
| Any onronio alsoraer | 4 ° 5 | :; . | |
| Serious aisoraer | 52 : | · · · | v |
| Involving CNS | 52 8 | :: | ۰. |
| Not involving CNS | 50.1 | : ` , | 'n |
| 'Communication aisoraer | 45.3 | :, .: | |
| 'Minor' aisorder | 48.6 | 3 (s - (s | |

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| Type of disorder | Disorder present(No.) | % of all children | <pre>% of all disorders</pre> |
|-------------------------------------|--------------------------|----------------------|-------------------------------|
| Adaptation reaction | 225 | 2.4 | 34.7 |
| Specific developmental disorder | | | |
| Hyperkinetic Disorder | 124 | 1.2 | 19.1 |
| Other specific learning disorder | 143 | 1.4 | 22.0 |
| Enuresis as isolated disorder | 30 | 0.3 | 4.6 |
| Encopresis as isolated disorder | 11 | 0.1 | 1.7 |
| TLCS | 9 | 0.1 | 1.4 |
| Conduct disorder | 98 | 0.9 | 15.1 |
| Neurotic disorder | 42 | 0.4 | 6.5 |
| Psychosis | 4 | 0.0 | 0.6 |
| Personality disorder | 20 | 0.2 | 3.1 |
| Psychosomatic disorder | 26 | 0.2 | 4.0 |
| Anorexia nervosa | 4 | 0.0 | 0.6 |
| Other clinical symptoms | 40 | 0.4 | 6.2 |
| Mental subnormality | 102 | 1.0 | 15.7 |
| Nny psychiatric Hisorder | 649 | 6.4 | 100.0 |

Table 8. Prevalence of psychiatric disorders among 10,164 children between 4 and 16 years of age seen in pediatric practice. (WHO-Classification)

Table 9. Prevalence of psychiatric disorders among 10,164 children between 4 and 16 years of age seen in pediatric practice. (Diagnostic categories)

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| Type of disorder | Disorder present(No.) | % of all children | % of all disorders |
|-----------------------------|--------------------------|----------------------|-----------------------|
| Mental retardation | 248 | 2.4 | 38.2 |
| Behavioral disorder | 140 | 1.4 | 21.6 |
| Emotional disorder | 261 | 2.6 | 40.2 |
| Any psychiatric disorder | 649 | 6.4 | 100.0 |

for the latter. The adjusted odds-ratio for children with 'serious' disorders not involving the CNS was 2.1 (p < 0.02). Mental retardation was also more frequent in children with 'minor' disorders. (Table 10)

<u>Behavioral disorders.</u> The prevalence of behavioral disorders was increased among children with chronic illness (OR=1.7, p < 0.04). This increase, however, was mainly due to the high rates of behavioral disorders among children with 'serious' disorders involving the CNS (3.7%), and especially those with 'communication' disorders (13.1%). Subjects with 'serious' disorders not involving the CNS showed only a minimal increase of the prevalence. The adjusted odds-ratio of 1.0 (0.5, 2.1) indicates no significant association. The same holds for children with 'minor' disorders. Adjustment for potentially confounding variables was not possible for the effect of disorders involving the CNS, because of too few maladjusted children in this subgroup. (Table 11)

Emotional disorders. Among chronically ill children the prevalence of emotional disorders was increased. The adjusted odds ratio, however, was only 1.3 (p < 0.13). Again the prevalence was particularly high among children with 'communication' disorders (7.1%). Patients with 'serious' disorders not involving the CNS showed also an increased prevalence with an adjusted odds ratio of 1.4 (p < 0.15). Among subjects with disorders involving the CNS the

| Type of chronic illness | Menta retar prese (No.) | l dation nt (%) | Crude A OR | Adjusted OR Ad (95% Cl) p- | justed value |
|-------------------------------|----------------------------------|--------------------------|---------------|-------------------------------|-----------------|
| | | | | | |
| No chronic illness | 49 | 1.7 | 1.0 | - | |
| Any chronic | | | | | |
| disorder | 109 | 7.4 | 4.7 | 4.5 (3.4, 5.9) | 0.00 |
| 'Serious' | | | | | |
| disorder | 53 | 5.9 | 3.7 | 3.5 (2.2, 5.5) | 0.01 |
| Involving CNS | 23 | 31.9 | 27.8 | 27.6 | 0.00 |
| 5 | | | | (14.8, 49.4 |) |
| Not involving CNS | 30 | 3.6 | 2.2 | 2.L (1.3, 3.2) | 0.02 |
| 'Communication' | | | | | |
| disorder | 42 | 50.0 | 59.3 | 80.8 (54.7, 145. | 0.00 5) |
| 'Minor' | | | | | |
| disorder | 14 | 2.8 | 1.7 | 1.5 (0.8, 2.8) | 0.19 |

Table 10. Mental retardation: Distribution and association with chronic illness.

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| Type of chronic illness | Behav disore presen (No.) | ioral C der (nt (१) | rude OR 95% CI) | Adjusted OR (95% CI) | Adjusted p-value |
|-------------------------------|------------------------------------|-------------------------------|--------------------|-------------------------|---------------------|
| | | # | | | |
| No chronic illness | 34 | 1.1 | 1.0 | - | - |
| Any chronic dilorder | 30 | 2.0 | 1.8 | 1.7 (1.0, 2.9) | 0.04 |
| "Serious" disorder | 13 | 1.5 | 1.3 | 1.2 (0.7, 1.5) | 0.50 |
| * Involving CNS | 3 | 4.2 | 3.7 (1.2, 1 | - 1.4) | - |
| Not involving CNS | 10 | 1.2 | 1.0 | 1.0 (0.5, 2.1) | 0.96 |
| "Communication" diforler | 11 | 13.1 | 12.9 | 9.9 (4.7, 21.3) | 0.00 |
| Million (cr | 6 | 1.2 | 1.0 | 1.0 (0.4, 2.4) | 0.95 |

Table 11. Behavioral disorder: Distribution and association with chronic illness.

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No adjustment was performed for 'serious' disorders involving the CNS because of too few maladjusted children in this subgroup. prevalence was only slightly increased (OR=1.2). The low number of maladjusted children in this subgroup precludes adjustment for other variables. Subjects with 'minor' disorders showed no association. (Table 12)

An analysis of the association of maladjustment with 'serious' disorders by the affected functional system is shown in Table 13. The crude odds ratio was elevated in out of eleven groups. These groups represent 643 of all children with any 'serious' disorder. The highest prevalence was found in children with disorders of the neurologie, endocrine, or musculoskeletal systems and among children with 'other' disorders. Only disorders affecting the endocrine system and 'other' conditions, however, had an increased crude odds ratio with a p-value of less than 0.10. It is interesting to note that the prevalence among subjects with respiratory disorders, a group that consists mainly of children with asthma, had a lowered prevalence. The group with neurologic disorders represents the children with disorders involving the CNS. The prevalence of maladjustment in this group was elevated but this increase was not statistically significant. However, the results of this part of the analysis must be interpreted cautiously because of the relatively low number of maladjusted children in most subgroups. For the same reason no adjustment for potentially confounding variables was performed. (Table 13)

| Type of chronic illness | Emotic disorc preser (No.) | onal der nt (%) | Crude OR (95% CI) | Adjusted OR (95% CI) | Adjusted p-value |
|-------------------------------|-------------------------------------|--------------------------|----------------------|-------------------------|---------------------|
| | | | | | |
| No chronic illness | 69 | 2.3 | 1.0 | - | - |
| Any chronic disorder | 48 | 3.3 | 1.4 | 1.3 (0.9, 2.0) | 0.13 |
| 'Serious' disorder | 31 | 3.5 | 1.5 | 1.4 (0.9, 2.1) | 0.16 |
| * Involving CNS | 2 | 2.8 | 1.2 (0.3, 4.9 |) – | 0.43 |
| Not involving CNS | 29 | 3.5 | 1.5 | 1.4 (0.9, 2.2) | 0.15 |
| 'Communication' disorder | 6 | 7.1 | 3.2 | 3.2 (1.4, 8.0) | 0.01 |
| 'Minor' disorder | 11 | 2.2 | 1.0 | 1.0 (0.5, 1.9) | 0.95 |

Table 12. Emotional disorders: Distribution and association with chronic illness.

* No adjustment was performed for 'serious' disorders involving the CNS because of too few maladjusted children in this subgroup.

| Affected | Mala | djustment | Crude OR | Chi-square |
|--------------------------|--------|--------------|-------------------|------------|
| system | (No. | ent) (%) | (95% CI) | p-value |
| No chronic disorder | 103 | 3.5 | 1.0 | _ |
| Endocrine system | 5 | 10.4 | 3.2 (1.3, 8.3) | 0.01 |
| Hematologic system | l | 3.0 | 0.9 (0.2, 6.4) | 0.89 |
| Neurologic system | 5 | 7.0 | 2.1 (0.8, 5.1) | 0.11 |
| Sensory system | 4 | 4.9 | 1.4 (0.5, 3.9) | 0.50 |
| Circulatory system | 1 | 2.3 | 0.6 (0.1, 4.3) | 0.61 |
| Respiratory system | 3 | 1.8 | 0.5 (0.2, 1.5) | 0.25 |
| Digestive system | 1 | 3.3 | 0.9 (0.1, 6.8) | 0 94 |
| Genitourinary system | 1 | 2.5 | 0.7 (0.5, 3.7) | 0.72 |
| Dermatologic system | 4 | 4.6 | 1.4 (0.5, 3.7) | 0.59 |
| Musculoskeleta system | 1 7 | 5.6 | 1.6 (0.8, 3.6) | 0.21 |
| 'Other' conditions | 11 | 6.3 | 1.9 (0.9, 3.5) | 0.06 |

Table 13. Maladjustment: Distribution and association with 'serious' disorders by affected functional system.

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5.3 Correlates of maladjustment among children with chronic

This part of the analysis aimed to find correlates of maladjustment among chronically ill children. Because in the earlier analyses the type of chronic condition was an important factor, this was included in the analysis. Children with 'minor' disorders, who had shown almost no increase in the prevalence of behavioral or emotional disorders, served as the comparison group for all children with any other chronic disorder.

Correlates of behavioral disorders

Bivariate analyses confirmed the earlier described effect of the type of chronic disorder. The difference between 'minor' and 'serious' disorders, however, was only small. The crude odds were increased for boys, for black children, and for those not living with both parents. The prevalence decreased with an increase in the period between visits or an increase of age (Table 14)

In the logistic regression model 'communication' disorders were significantly associated with behavioral disorders. The multivariate analysis also showed increased adjusted odds ratios for boys (OR=3.0) and for those not living with both parents (OR=2.2). Age, race, Medicaid status, and period Table 14. Behavioral disorders: Distribution and association with patient characteristics among children with chronic physical illness. (Bivariate analysis)

| Patient characteristic | Disorder present (۴) | Crude OR (95% CI) | Chi-square p-value |
|-----------------------------|-------------------------|------------------------|-----------------------|
| 1. Type of chronic disorder | | | |
| 'Minor' disorder | 1.2 | 1.0 | - |
| 'Serious' disorder | 1.5 | 1.2 (0.5, 3.2) | 0.7 ' |
| 'Communication' disorder | 13.1 | 12.3 (5.4, 28.0) | 0.00 |
| 2. Sex | | | |
| Female | 0.8 | 1.0 | - |
| Male | 2.9 | 3.8 (1.4, 9.9) | ().01 |
| 3. Age in years | | | |
| 4 – 7 | 3.2 | 1.0 | - |
| 8-11 | 2.4 | 0.8 (0.4, 1.7) | ().5() |
| 12-16 | 0.7 | 0.3 | 0.01 |
| 4. Race | | (0.1, 0.0) | |
| White | 1.9 | 1 0 | - |
| Black | 3.0 | 1.5 (0.6, 4.2) | ().36, |
| 5. Medıcaid | | | |
| No | 2.0 | 1.0 | - |
| Yes | 1.8 | 0.9 (0.2, 3.8) | 0.88 |

Table 14 (cont).

| Patient characteristic | Disorder present (%) | Crude OR (95% CI) | Chi-square p-value |
|--|-------------------------|------------------------|-----------------------|
| 6. Living with both parents | | | |
| 105 | 1.6 | 1.0 | - |
| No | 4.1 | 2.6 (1.2, 5.4) | 0.01 |
| 7. Period between visits in months | | | |
| 12 | 1.3 | 1.0 | - |
| 3-12 | 1.8 | 1.4 (0.6, 3.1) | 0.42 |
| } | 2.5 | 2.1 (0.6, 7.0) | 0.25 |

between visits were only correlated with a p-value of more than 0.10 and were not included in the final model. (Table 15)

Correlates of emotional disorders

The type of chronic disorder again had an effect on the prevalence of emotional disorders. Further, the frequency of emotional disorders was approximately twice as large among children on Medicaid and those not living with both parents. Elevated rates were also found among male, older, and black children. The physician's familiarity with the patient was an important factor as well. It is interesting to note that compared with behavioral disorders the effect of age is reversed. (Table 16)

The multivariate model showed an adjusted odds ratio of 1.5 (p < 0.19) for children with 'serious' disorders, and of 3.9 for those with 'communication' disorders when compared to subjects with 'minor' disorders. Not living with both parent, (OR < 2.4) was again significantly associated with maladjustment (p < 0.02). This analysis also showed a significant correlation with age and the physician's familiarity with the patient, approximated as the period between visits. All other variables were not kept in the final logistic regression model. (Table 17.) Table 15. Behavioral disorders: Maximum likelihood estimates of logistic regression parameters relating patient characteristics to the presence of behavioral disorders among children with chronic illness.

| Patient characteristic | Adjusted Odds-ratio | 95% Confidence Interval | p-value |
|--------------------------------|------------------------|----------------------------|---------|
| | | | |
| l. Type of chronic disorder | | | |
| 'Serious' disorder | 1.3 | (0.5, 3.5) | 0.63 |
| 'Communication' disorder | 10.2 | (3.7, 27.1) | 0.00 |
| 2. Sex | | | |
| Male vs Female | 3.0 | (1.1, 8.3) | 0.02 |
| 3. Living with both parents | | | |
| No vs Yes | 2.2 | (0.9, 4.9) | 0.06 |

All moducal conditions were compared with 'minor' disorders alone.

Table 16: Emotional disorders: Distribution and association with patient characteristics among children with chronic physical illness. (Bivariate analysis)

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| Patient characteristic | Disorder present (%) | Crude OR (95% CI) | Chi-square p-value | |
|-----------------------------|-------------------------|------------------------|-----------------------|--|
| 1. Type of chronic disorder | | | | |
| 'Minor' disorder | 2.2 | 1.0 | | |
| 'Serious' disorder | 3.5 | 1.6 (0.8, 3.2) | 0.10 | |
| 'Communication' disorder | 7.1 | 3.4 (1.3, 8.9) | 0.01 | |
| 2. Sex | | (, , | | |
| Female | 3.3 | 1.0 | - | |
| Male | 3.2 | 1.1 (0.6,1.9) | 0.91 | |
| 3. Age in years | | | | |
| 4 – 7 | 2.0 | 1.0 | - | |
| 8-11 | 3.5 | 1.7 (0.8, 3.8) | 0.19 | |
| 12-16 | 4.1 | 2.0 (0.9, 4.4) | ().()7 | |
| 4. Race | | | | |
| White | 3.2 | 1.0 | - | |
| Black | 3.6 | 1.1 | 0.82 | |
| 5. Medicaid | | (0.5, 2.7) | | |
| No | 3.1 | 1.0 | - | |
| Yes | 5.5 | 1.9 (0.8, 4.4) | 0.17 | |

Table 16 (cont).

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| Patient characteristic | Disorder present (%) | Crude OR (95% CI) | Chi-square p-value |
|--|-------------------------|------------------------|-----------------------|
| 6. Living with both parents | | | |
| Yes | 2.7 | 1.0 | - |
| No | 6.1 | 2.4 (1.3, 4.4) | 0.01 |
| 7. Period between visits in months | | | |
| > 12 | 1.7 | 1.0 | - |
| 3-12 | 2.2 | 2.1 (1.1, | 0.03 |
| 4.3) < 3 | 4.5 | 2.8 (0.9, 8.1) | 0.04 |

Table 17. Emotional disorders: Maximum likelihood estimates of logistic regression parameters relating patient characteristics to the presence of emotional disorders among children with chronic illness.

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| Patient characteristic | Adjusted Odds-ratio | 95% Confidence Interval | p-value |
|--|------------------------|----------------------------|--------------|
| 1. Type of chronic disorder | | | |
| 'Serious' disorder | 1.5 | (0.7, 3.0) | 0.29 |
| 'Communication' disorder | 3.9 | (1.3, 11.4) | 0.01 |
| 2. Age in years | | | |
| 8-11 vs 4-7 12-16 vs 4-7 | 2.1 2.7 | (0.9, 4.9) (1.1, 6.0) | 0.07 0.02 |
| 3. Living with both parents | | | |
| No vs Yes | 2.2 | (1.1, 4.1) | 0.02 |
| 4. Period between visits in months | | | |
| 3-12 vs > 12 | 2.2 | (1.1, 4.4) | 0.03 |
| < 3 vs > 12 | 3.2 | (1.1, 9.3) | 0.03 |

All medical conditions were compared with 'minor' disorders alone.

5.4 Functional impairment and referral of maladjusted children

The goal of this part of the analysis was to determine whether the negative impact of maladjustment was more severe for children with chronic illness. The impact was assessed using the physician's judgement of the impairment of the patient's and the family's functioning due to maladjustment. Further it will be determined whether the physician's referral of maladjusted children to specialty care differs when a chronic illness is present.

Impairment of the patient's functioning

The physicians reported moderate or severe impairment of the patient's functioning in 40.8% of the maladjusted children without chronic illness. These rates were higher among children with 'serious' disorders (56.9%) and 'communication' disorders (76.5%). The odds ratios were 1.9 (0.9,3.9) for 'serious' disorders and 4.7 (1.4,15.5) for 'communication' disorders. The p-values for the associations of both 'serious' disorders, and 'communication' disorders were less than 0.10. Children with 'minor' disorders showed a lowered trequency of at least moderate impairment. (Table 18)

Table 18. Moderate or severe impairment of the patient's functioning due to maladjustment: Distribution and association with presence of chronic illness.

| Type of disorder | No. of Patients | Impairment present (% | * Crude OR 5) (95% CI) | Chi-square p-value |
|-----------------------------|--------------------|--------------------------|---------------------------|-----------------------|
| No chronic illness | 103 | 40.8 | 1.0 | |
| Any chronic disorder | 78 | 53.9 | 1.7 (0.9, 3.1) | 0.08 |
| 'Serious' disorder | 44 | 56.8 | 1.9 (0.9, 3.9) | 0.07 |
| Involving CNS | 5 | 40.0 | 0.9 (0.2, | 0.97 |
| 6.1) Not involving | CNS 39 | 59.0 | 2.1 (0.9, 4.4) | 0.05 |
| 'Communication disorder | , 84 | 76.5 | 4.7 (1.4, 15.5) | 0.01 |
| 'Minor' disorder 0.18 | 17 | 23.6 | 0.5 | , 1.5) |

* Moderate or severe impairment

*

Impairment of the family's functioning

47.6% of the maladjusted children without chronic illness caused moderate or severe impairment of the family's functioning. This proportion was again increased for children with 'serious' and 'communication' disorders. The odds ratios, however, were generally lower than those for the patient's impairment and the p-values were not less than 0.10. The rate of severe impairment for children with 'minor' disorders was slightly decreased. (Table 19)

Referral to specialty care

The physicians' perception of the patient's and family's impairment due to maladjustment is reflected in their referral to specialty care. While 45.6% of the children without chronic illness were referred, the proportion was increased for children with 'serious' disorders (56.8%) and with 'communication' disorders (52.9%). The association between chronic illness and referral, however, is not statistically significant for any subgroup. (Table 20)

Table 19. Moderate or severe impairment of the family's functioning due to the patient's maladjustment: Distribution and association with presence of chronic illness.

| Type of disorder | No. of Patients | Impairment present (%) | Crude OR (95% CI) | Chi-square p-value |
|----------------------------|--------------------|---------------------------|----------------------|-----------------------|
| No chronic illness | 103 | 47.6 | 1.0 | - |
| Any chronic disorder | 78 | 53.6 | 1.2 (0.7, 2.2) | 0.50 |
| 'Serious' disorder | 44 | 56.8 | 1.5 (0.7, 2.9) | 0.30 |
| Involving CNS | 5 5 | 40.0 | 0.8 (0.1, 4.6) | 0.74 |
| Not involving | CNS 39 | 59.0 | 1.6 (0.8, 3.3) | 0.22 |
| 'Communication disorder | 17 | 64.7 | 2.0 (0.7, 5.9) | 0.17 |
| 'Mırər' dısorder | 17 | 29.4 | 0.5 (0.2, 1.4) | 0.17 |

* Moderate or severe impairment

| Type of disorder | No. of Patients | Referral present(%) | Crude OR (95% CI) | Chi-square P-value |
|-----------------------------|--------------------|------------------------|----------------------|-----------------------|
| No chronic illness | 103 | 45.6 | 1.0 | |
| Any chronic disorder | 78 | 50.0 | 1.2 (0.7, 2.1) | 0.56 |
| 'Serious' disorder | 44 | 56.8 | 1.6 (0.8, 3.2) | 0.21 |
| Involving CNS | 5 | 40.0 | 0.8 (0.1, 4.9) | 0.81 |
| Not involving | CNS 39 | 58.9. | 1.7 (0.8, 3.6) | 0.15 |
| 'Communication' disorder | 17 | 52.9 | 1.4 (0.5, 3.7) | 0.58 |
| 'Minor' disorder | 17 | 29.4 | 0.5 (0.2, 1.5) | 0.21 |

Table 20. Referral to specialty care of patients with maladjustment: Distribution and association with presence of chronic illness.

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Summary

Behavioral and emotional disorders were more frequently diagnosed among children with chronic illness. Very high rates of both types of disorder were found in patients with communication disorders. Subjects with disorders involving the CNS showed a smaller increase in the rates of behavioral and emotional disorders. These findings, however, must be interpreted cautiously because of the small number of maladjusted children in this group. Children with 'serious' disorders not involving the CNS showed only minimally elevated rates of behavioral disorders. The increase in the prevalence of emotional disorders in this group was larger (OR=1.5, p < 0.15). An analysis of 'serious' disorders by the affected functional system found high rates of maladjustment among children with disorders of the neurologic and endocrine system, and those with 'other' conditions.

Among chronically ill children behavioral disorders were more frequent among boys and children not living with both parents. The prevalence of emotional disorders increased with age, the patient's familuarity to the physician, and when the child was not living with both parents. The type of chronic disorder was an important correlate for both behavioral and emotional disorders.

Physicians judged the impairment of the patient's and the

family's functioning due to maladjustment to be more severe
for children with 'serious' disorders or 'communication'
disorders. This was also reflected in the increased rates of
referral to specialty care among chronically ill children.

CHAPTER SIX

DISCUSSION

This investigation aimed to assess the prevalence of chronic physical illness in childhood and its association with behavioral and emotional disorders. In this chapter the findings will be discussed in relation to each of the objectives.

Prevalence and correlates of chronic illness

The first issue to be discussed is bias in the assessment of chronic illness. Data concerning the medical condition of each child were gathered according to the routine of the participating pediatricians. No special attention was given to the detection of chronic disorders. It is possible that not all existing chronic conditions were reported because of negligence or simply because the physicians were not aware of some existing conditions. Furthermore, although all reported medical conditions, coded in ICD-categories, were reviewed and classified as chronic or non-chronic, it is likely that not all chronic disorders were identified because some had been reported in categories that included non-chronic conditions. Finally, it is possible that a child presented with two acute conditions and additional chronic disorders were not reported. Thus the prevalence rates presented presumably underestimate the true prevalence in the study population. The identified conditions, however, were diagnosed by the attending physician and the reliability and validity of this assessment should be high.

The prevalence rate of chronic physical illness of 14.7% is consistent with other studies (2,3,9,10,14). In this case it is most appropriate to compare the findings with the rate of 11.8% from a community survey (2) and 7.5% from a primary care survey (23) carried out in the same urban community some ten years earlier. Although the rate in the current study is higher than the rate in the earlier community survey, this is mainly due to higher rates of hay fever and dermatitis. This cannot be explained by seasonal differences because both studies had covered a period of one year. The lower rate from the earlier primary care survey (23) was probably due to a restriction to more severe disorders and, at least in part, to underreporting on the part of the surveyed physicians. It could also be that physicians in 1979 paid more attention to the existence of more minor chronic conditions, or that patients with such conditions were more likely to consult a doctor in 1979 than they had been ten years earlier.

The prevalence of speech and language disorders is low but in keeping with other studies (50,53) which yield rates between 1.0% and 10.0%. The pattern of demographic correlates is also consistent with findings from other studies (2,10,14,18).

Another important point is that the study population consisted only of children seen by a pediatrician. In recent years an increasing proportion of chronically ill children may receive their care exclusively from specialists and therefore not be represented by the study population.

Pless and colleagues (2) reported in 1969 that 32% of all children with chronic illness had only seen a specialist in the previous year. Another study (23) showed that primary care physicians share the treatment of 52% to 89% of children with disorders like asthma, diabetes, or cerebral palsy with specialists and assume primary responsibility for 61% to 93% of these patients. Thus it is likely that in the current study a considerable number of patients with chronic conditions were not seen by primary care physicians. This hypothesis is supported by the finding that in comparison with previous community surveys (2,9,10,14) the prevalence of 'minor' disorders, such as hay fever and dermatitis was higher, while the prevalence of more severe disorders, which are more likely to be referred to specialists, was similar, or even lower. In summary, the findings suggest that the prevalence of chronic illness in the population of children seen by physicians is higher than in the community.

The period between the current and previous visit was taken as an approximation for the frequency of visits and the physician's familarity with the patient. The close similarity

in the rates between children without chronic illness and those with an illness across all subgroups of chronic disorders is somewhat surprising. It is possible that this crude measure does not accurately reflect the true trequency of visits and that children with chronic illness are actually seen more often by their physician than their 'healthy' peers.

Association between chronic illness and psychiatric disorders

Before a discussion of the findings, other weaknesses in the study design must be examined. The pediatrician's routine diagnosis was used to determine the presence of a psychiatric disorder. Earlier studies have shown that primary care physicians are conservative in such assessments (12). They have a high specificity (84%) but a low sensitivity (17%) when compared with the results of a structured psychiatric interview.

In this study a modified uniaxial version of the WHO-Classification Scheme for Mental Disorders was used (26,27). A reliability study of this classification scheme had shown an inter-rater agreement of 67% on specific diagnoses among psychiatrists (28). No data are available concerning the inter-rater agreement among primary care physicians, but it is likely to be lower. The broad classification of disorders as mental retardation, behavior disorder, or emotional disorder, however, might have improved the accuracy of the assessment. If it is assumed that there is no systematic difference in the assessment of psychiatric disorders among children with chronic illness and those without, misclassification is likely to cover an association (41). In other words, any effect found using this assessment probably underestimates the true underlying association. The specific type of psychiatric disorder, however, should be interpreted with caution.

Another matter to be considered before discussion of the association between chronic illness and psychiatric disorders is the identification of children with speech and language disorders. These disorders have a borderline status between physical and psychiatric disorders (10,26,53). In the current study, as in many other prevalence studies (2,9,10,14), they were classified as a physical disorder. The physicians, however, reported them in the WHO-Classification Scheme of Mental Disorders (26,27).

Two potential sources of bias arise from this part of the study design. First, the children with speech and language disorders were taken from section B of the questionnaire. This section was to be completed only when in section A a diagnosis of 'mental retardation', 'developmental delay', or an 'emotional, behavioral or school problem' was made. Speech and language disorders are most properly reported as

'developmental delay' (26). However, only 35% of the children with speech and language disorders were reported to have an 'emotional, behavioral or school problem'. It is possible therefore that the rate of maladjustment in these children was inflated because they were only reported in section B because of maladjustment. Hence selection bias might have been present.

The term 'emotional, behavioral or school problems', however, was intended to screen broadly for mental health problems and was therefore deliberately not clearly defined (13). Thus it is justifiable and likely that some physicians classified speech and language disorders under this broad category. Furthermore, the prevalence of maladjustment in this group of children was lower than in those who had been classified under 'developmental delay'. (This analysis is not shown)

Second, it is possible that the physicians were more likely to indicate additional mental disorders when they reported speech and language disorders as mental disorders in the WHO-Classification Scheme in section B than in the situation when only a physical or no physical condition was reported in section A; i.e. detection bias might have been present.

The association between speech and language disorders and maladjustment has only recently been studied in detail (53). The correlations found in these studies (44,50) were

astonishingly high and further investigations are needed. It for this reason that children with 'communication' disorders were kept in the analysis, despite possible bias in the assessment. The results of this part of the analysis, however, must be interpreted cautiously.

The prevalence of psychiatric disorders of 6.4% in the study population corresponds well with findings from other studies that used clinicians judgement to assess psychiatric disorders (10,12). Likewise, the distribution of specific disorders is in keeping with previous reports (36,37).

Montal retardation was more frequent among children with chronic illness, with particularly high rates among the children with disorders involving the central nervous system (CNS) and communication disorders. These findings were expected based on previous reports in the literature (10,11).

The prevalence of behavioral disorders was approximately twice as high among chronically ill children, while the trequency of emotional disorders among these patients was elevated by a factor of 1.4. These findings are lower, but in keeping with reports from earlier community surveys (2,9,10, 14).

Major differences between children with subgroups of chronic disorder were found. Earlier studies (8,10,48) had pointed

out that children with disorders involving the CNS were at particularly high risk for maladjustment. Therefore, children with these disorders were considered as a separate group in the current study.

The rate of maladjustment in this group increased more than two-fold, but was still lower than expected and only reached statistical significance in the case of behavioral disorders. The small number of subjects in this group, however, makes the interpretation difficult and may partly be responsible for the lack of statistical significance. Another reason might be that patients with mental subnormality or specific learning disorders were not considered as maladjusted in this study, while Rutter et al. (10), for example, had only excluded severely retarded children.

Patients with conditions not involving the CNS showed little increase in the prevalence of behavioral disorders. The prevalence of emotional disorders among these children was elevated by a factor of 1.5, but the adjusted odds ratio of 1.4 was not statistically significant. The observation that children with such disorders tend to have more emotional disorders than behavioral disorders replicates findings from other studies (8,10).

The presence of emotional disorders was also associated with the period between visits. This suggests that the judgement

is influenced by the physician's familiarity with the patient. Although this was adjusted for in the multivariate analysis, it is still possible that the increased prevalence of emotional disorders among children with conditions not involving the CNS can at least in part be explained by the greater familiarity of the physicians with these patients. This effect could not be controlled for adequately with the data available.

Children with 'communication' disorders showed very high rates of mental disorders. The physicians diagnosed 50% of these children as being mentally subnormal, or to have a specific learning disorder. Thirteen per cent of these children had a behavior disorder, while 7.1% were emotionally disturbed. These results have to be interpreted cautiously because of the above mentioned possible selection and detection biases. It is, however, questionable whether the observed effect can entirely be explained by these biases.

In fact, although the findings of mental subnormality and specific learning disorders were slightly higher than earlier reports (44,50,53), the prevalence rate of maladjustment in the current investigation was lower than in other studies (44,50,53). The observation that these children are more lukely to develop behavioral disorders than emotional disorders replicates earlier reports. The findings suggest that this group of children is at high risk for
maladjustment. Furthermore, the high prevalence of mental subnormality and specific learning disorders, even though earlier studies (44,50,53) found only slightly lower IQ scores in this group of children, suggests a need for special attention to these patients.

There is no comprehensive theory of the causes of speech and language disorders. Environmental deprivation, middle-ear disease, birth and pregnancy complications, familial influences, as well as genetic factors have been suggested (53). Others (44) suggest subtle defects in the central nervous system function which could explain the similarity in the frequency and pattern of mental disorders between these children and those with disorders involving the central nervous system, and the tendency for them to develop behavioral rather than emotional disorders (50).

The observation that children with 'minor' disorders showed no association with maladjustment confirmed the findings of the Isle of Wight study (10) where no association was found for children with 'eczema'.

Is chronic illness associated with psycho-social maladjustment? The results of this study give no clear answer to this question. The findings provide evidence that children with 'communication' disorders are at increased risk for maladjustment, while no association with 'minor' disorders

was found. Children with disorders involving the CNS were more often maladjusted, but the small number of subjects with these disorders does not provide a conclusive answer.

There was a consistent trend for children with 'serious' disorders not involving the CNS to be more maladjusted than their 'healthy' peers. Nevertheless, apart from the fact that the association was not statistically significant, the observed effect was also not very strong. This does not mean that no such association exists. The following weaknesses in the study design may have covered a stronger association.

First, and probably most important, is the fact that many children who are only seen by a specialist were not included in the study population. It is likely that these patients are afflicted by more severe physical disorders. Further, it is also possible that maladjustment itself makes chronically ill children more likely to be referred for medical or psychiatric specialty care. This hypothesis is supported by the findings in this study that chronically ill children were more often referred because of maladjustment than were maladjusted children without chronic illness. This association has also been reported elsewhere (9).

Second, the study design only examined the coexistence of chronic illness and maladjustment at one point in time. It was not possible to determine how long either condition had

existed prior to the assessment. Especially it was not possible to determine whether the physical condition preceded the manifestation of behavioral or emotional disorders. The onset of at least some chronic conditions might have been just prior to the assessment. This would have diminished the effect of the hypothesized causal sequence of chronic illness and subsequent maladjustment.

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Third, it is questionable whether the population of children attending primary care services, who may have a higher prevalence of maladjustment than the general population (40), are the most appropriate controls for all children with chronic illness. While they might be appropriate for children with minor disorders that do not necessarily lead to a medical consultation, their appropriateness is questionable for children with more severe disorders like myelodysplasia, diabetes, or cystic fibrosis.

Finally, this study compared the prevalence of 'clinically significant' psychiatric disorders as recognized by physicians. This might be too strong a measure to assess the negative impact of chronic illness on the mental well being of the afflicted children.

Correlates of emotional and behavioral disorders among chronically ill children

The analysis confirmed that among children with chronic disorders those with 'serious' disorders and those with 'communication' disorders were at higher risk for maladjustment than children with 'minor' disorders. Boys were more likely to develop behavioral disorders than girls. Behavioral disorders were more frequent in young children while emotional disorders were more common in older age groups. Not living with both parents was used as an approximation of family functioning and was associated with both behavioral and emotional disorders. The latter finding suggests that children with chronic illness are sensitive to social influences and confirms earlier reports of this dissociation (4,8,54). These variables have also been shown to be associated with maladjustment in children without chronic illness (36,37).

Functional impairment and referral of maladjusted children

The negative impact of maladjustment on both the patient and the family was more severe when a chronic illness was present. This observation demonstrates the negative effect of an additional handicap. The fact that maladjusted children were referred more often to specialty care when a chronic illness was present suggests that primary care physicians

consider this impact when they decide whom to refer.

<u>Conclusion</u>

Although the findings of this study give no conclusive answer whether children with chronic illness are at increased risk for maladjustment, the prevalence rates of behavioral and emotional disorders were consistently elevated in children with 'serious' and 'communication' disorders. Furthermore, the negative impact of maladjustment was more severe when a chronic illness was present. The implication of these results for clinical practice is to emphasize the need for more 'comprehensive' care for these patients. Children with chronic illness need not only high-standard biomedical treatment but also close monitoring of their mental health. It is the task of the clinician to identify among the population with chronic disorders those with maladjustment, or those for whom the risk is the greatest, and to provide them with whatever services seem most likely to prevent or diminish the impact of a secondary handicap on the child's development (57). Unfortunately little is yet known about what types of interventions or services are likely to be the most effective (54,58).

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| R DATA PROCESSIN | GONLY | Gensus T act 1 | Numper | |
|--|--|---------------------------------------|--|---------------------------|
| FOR ALL OFFICE | /ISITS | | ************************************** | |
| 7a Race | 1 American Indian or Alaskan Native 3 Black | 2 | an or Pacific Inder Itt | |
| b Ethnicity His | panic 1 🛄 No | 2 🗍 Yes | 3 🗌 0/ | on t Khow |
| Ba With whom do | es this dation we? THAT APPL - | | | 004 T K 100 |
| Mother Father | | | 2 | 3 □ 9 □ |
| Siblings | | , [] | 2 | , |
| Other Relatives | | ' 🗆 | 2 | э 🔲 |
| Other (specify) | | י 🗖 | 2 | 9 |
| b is mother or fa or foster paren | ther a step adoptive | • 🗖 | 2 | ۹ 🗖 |
| OR | | | | |
| 5 Does this patie | nt appear to be depresse | <u></u> | | |
| 6 * Has this patien | t any mental relardation o | r dev i mental | delay? | |
| ICHECK ALL | 2 TYES Mental | Retardation | | |
| | 3 🗍 YES Other D | elav <i>'specify)</i> | | |
| | | | | |
| 7 • In your opinio to a behavioral | n is the reason for THIS vi emotional or school prob | isit primarily or lem? | secondarily | related |
| 1 🛄 No | 2 TYES Primar t | у 3 🗋 | YES Seco | ndariiy |
| 8 • REGARDLESS CURRENTL / | S of the purpose of this visi have a pehavioral emotion | it in your opini Naligt school pro | on does this | patient d or untreated |
| 1 No | 2 YES | 9 <u>[</u> | | w |
| | - 1 YES is a | 'his 'he patientis F problem? | RST behavio | rai lemot onai |
| | 1 🛄 V | o 2 <u> </u> | × ∃ | Don' Show |
| 3 Has this patient isihe has recov | t EVER had a behavioral a ered? | emotional or scr | lool problem | from which |
| 1 <u>No</u> | 2 YES Recover 3 YES Recover | ed Anthin Lost Ye ed More Than a Y | ar 3 Har Ago | Jun + Know |
| *** **** 1888 FRED ** • OU COMPLETED ** | YES TO FEENSE ' IND OF 9 | CMPLETE THE REN US ISIT JUST CH | ERSE SIDE DE | THIS FORM F |

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| 10a | Approximately how long altogether would bothered by this behavioral emotional or s | ydu say this patient has a chool problem? _ | 96411 |
|-----|--|--|-------------|
| ъ | Is this the first time the problem has been p t No 2 Yes | presented to you?) [] Dan Know | |
| 11a | In your opinion does this patient's behappresent | ivioral emotional or sch | ool problem |
| | a PRIMARY asychiatric entity or hisorder? Id | the the periodice in a setty i | [_] ו |
| | | | |
| | a SECONDARY emotional disorder mamery o | nesecondary o | |
| | medical problems | | 1 |
| | stress or non-medical problems water fy? | | , - |
| | | - | -1 |
| | | - | |
| Þ | Please classify the problem according to th ICHECK ONLY ONE BOX IN THE PRIM CHECK ALL THAT APPLY IN THE NO | e following citegories FARY - COLUMN FPRIMARY - COLUMN | , |
| | Adaptation reaction | PRIMARY | PHIMARY |
| | Specific developmental disorder | | |
| | Hyperkine tic disorder | 2 | 2 |
| | Speech & language disorder Other specific learning, disorder | | 4 |
| | Abnormai Clumsires | | 5 |
| | Enuresis (as isolated disorder) | <u>,</u> 🗖 | <u>"</u> 🖓 |
| | Tics | 9 | |
| | Stuttering | | <u>م</u> ا |
| | Conduct Jisorder Neurotic disorder | | |
| | Psychosis | ¹² 🖸 | 12 |
| | Personality disorder | | |
| | | | با ۱۰ |
| | Anorexia Nervosa | 15 | 5 |
| | Gther | ·• 🗍 | 16 Č |
| | Mental subnormatity | 17 | 17 🗋 |
| 12 | How much do you feet this patient's Denay problem impairs | ioral imorionaliarizhoo | ł |
| | his her funktioning? his her family sound in rige | | |
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| | Сихина Сециян | , ~ | : |
| | viourain migren Minor fegren | ; | - |
| | No funnt anal, mean that | ÷ | <u>ت</u> ۱ |
| | Don t know |) [] | 1 |
| 13 | As tar as you know loes this patient or the patient having his proviem? | ዋ ⁸ ያጠት የአንድ ዋናታ እር ትርዝ ግር ፡ | Wiserige |
| | ICHESK ONE IN EACH LOLIUMNI | PATIENT | FAMIL / |
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| | *10 | - | ! |

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| RED YES TO | DOUEST | IONS = | 5° 7° | AND | OR | 8 . | | | |
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14a In dealing with this patient or his/her parents, have you or anyone in this practice roday or previously

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15 Is there any meatment referral or any other way of dealing with this patient's condition you would recommend but did not for any leason? (CHECK ALL THAT APPLY) - -

| | -Inadequacy inaccessibility or absence of local treatment facility Unsatisfactory division of responsibility between you and consumant -Patientis an family sirefusal or dislike of psychiatric referral -Financial cost to patient -Disativantage to patient of being fabelled as a mental case -Other isperify (| |
|----|---|--|
| 16 | On what basis was the assessment of patient is condition made? ICHECK ALL THAT APPLY) -Information from parent or quardian -Examination of patient <i>courrent or or ori</i> -Medical chart -Scheol freeds -Other specify | |
| | THANKYOU | |

Appendix B. List of chronic disorders grouped by functional system with ICD-Code and frequency ICD Diagnoses Freq. Endocrine and metabolic system: 48 Simple unspecified goitre 240 1 242 Thyrotoxicosis without goitre 6 243 Congenital hypothyroidism 1 244 Acquired hypothyr 250 Diabetes mellitus Acquired hypothyroidism 4 26 251 Other disorders of pancreatic secretion 2 Polyglandular dysfunction 258 3 Other nutritional deficiencies 269 2 Other and unspecified disorders of metabolism 273 3 Hematologic system: 33 207 Leukemia 1 Iron deficiency anemia 280 9 282 Hereditary hemolytic anemia 9 Other and unspecific anemia 285 10 286 Coagulation defects 3 Hereditary capillary fragility 1 287 75 Nervous system: 343 Cerebral spastic infantile paralysis 6 344 Other cerebral paralysis 3 345 Epilepsy 32 346 Miqraine 11 Other diseases of brain 5 347 348 Other conditions of brain 2 740 Anencephalus 1 741 Spina bifida 4 743 Neurofibromatosis743 Congenital anomalies of nervous system 1 4 2 780 Convulsions 780 Abnormal involuntary movement 6 Sensory system: 82 Refractive errors 34 370 373 14 Strabismus 389 Other deafness 34

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Appendix B. (cont).

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| ICD | Diagnoses | Freq. |
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| | | |
| Circul | atory system: | <u>47</u> |
| 401 | Essential hypertension | 7 |
| 424 | Chronic diseases of endocardium | 5 |
| 427 | Symptomatic heart disease (dysrhythmias) | 8 |
| 458 | Other diseases of circulatory system | 4 22 |
| 740 | Other congenital anomalies or circulatory system | 1 |
| / - / | ocher congenicar anomaries or orroutacorr system | |
| Respir | atory system: | <u>165</u> |
| 492 | Emphysema | 2 |
| 493 | Asthma | 163 |
| | | |
| Digest | ive system: | <u>31</u> |
| 530 | Diseases of oesophagus | 1 |
| 532 | Duodenal ulcer | 2 |
| 533 | Peptic ulcer | 2 |
| 560 | Intestinal obstruction without hernia | 1 |
| 563 | Chronic enteritis and ulcerative colitis | 2 |
| 504 750 | other congenital anomalies of upper | 21 |
| / 50 | digestive tract | ٦ |
| 751 | Other congenital anomalies of digestive system | ī |
| | | |
| Genito | urinary system: | <u>41</u> |
| 189 | Malign neoplasm of the kidney | 1 |
| 582 | Chronic glomerulonephritis | 1 |
| 583 | Nephritis, unqualified | 2 |
| 590 | Infections of kidney | 2 |
| 598 | Urethral stricture | 2 |
| 605 605 | Hyarocele Redundant propuse and phimagic | 4 |
| 610 | Chronic cystic disease of breast | 1 |
| 611 | Other diseases of breast | 14 |
| 626 | Disorders of Menstruation | |
| 752 | Congenital anomalies of genital organs | 6 |

Appendix B. (cont).

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| ICD | Diagnoses | Freq. | | | |
|---|--|--|--|--|--|
| | | 448 468 468 668 669 669 669 666 | | | |
| Dermatologic system: | | | | | |
| 691 696 701 706 707 | Infantile eczema and related conditions Psoriasis and similar disorders Keloid scar Diseases of sebaceous glands Chronic ulcer of skin | 11 20 1 55 1 | | | |
| Muscu | lo-skeletal system: | <u>125</u> | | | |
| 712 722 733 735 736 738 754 755 756 | Rheumatoid arthritis and allied conditions Osteochondrosis Vertebrogenic pain syndromes Other diseases of muscle, tendon and fascia Curvature of spine Flat foot Other deformities Clubfoot Other congenital anomalies of limbs Other congenital musculoskeletal anomalies | 4 21 13 2 65 2 10 1 2 5 | | | |
| Other | conditions: | <u>179</u> | | | |
| 215 217 220 222 227 277 381 455 456 457 502 503 524 526 744 745 749 757 758 | Benign neoplasm of connective tissue Benign neoplasm of breast Benign neoplasm of ovary Benign neoplasm of male genital organs Benign neoplasm of other endocrine glands Obesity not of endocrine origin Chronic otitis media without mastoiditis Haemorrhoids Varicocele Noninfective disorders of lymphatic channels Chronic pharyngitis and nasopharyngitis Chronic sinusitis Dentofacial anomalies including malocclusion Diseases of the jaws Congenital anomalies of eye Congenital anomalies of ear, face neck Cleft palate and cleft lip Congenital anomalies of skin, hair and nails Other and unspecified congenital anomalies | 1 2 1 4 112 6 1 4 2 7 7 1 2 2 2 1 5 1 | | | |
| 758 759 | Congenital syndromes affecting multiple systems | 17 | | | |

Appendix B. (cont).

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| ICD | Diagnoses | Freq. |
|------------|--|------------|
| | | |
| Hay fe | ver and dermatitis: | <u>523</u> |
| 507 692 | Hay fever Contact dermatitis and other eczema | 318 205 |
| Speech | and language disorders: | 106 |
| | Speech and language disorders | 106 |

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