

Chronic illness and functional limitation in Ontario children: findings of the Ontario Child Health Study

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The Ontario Child Health Study (OCHS) was based on interviews of 1869 Ontario families who were selected by means of a stratified, multistaged sampling method from the 1981 census of Canada. Its primary purpose was to determine the prevalence and distribution of mental health problems in Ontario children aged 4 to 16 years and their families, but it also allowed an estimate of other significant medical conditions and provided an overview of these children's use of health care, education and social services. Our results are based on questionnaire responses concerning 3294 children. Limitation of function without a chronic illness or medical condition was reported in 1.9%, the converse in 14.0%, and a chronic illness or medical condition with limitation of function in 3.7%. When the three groups are considered together, 19.6% of Ontario children had a chronic health problem. Children of lower socioeconomic status were much more likely to have chronic health problems. Overall, children with chronic health problems were more likely to use

physician, special education, social and mental health services. These findings have implications for those who provide services for children, plan community programs or train professionals in caring for children.

Description de l'Ontario Child Health Study, fondée sur des entrevues auprès de 1869 familles ontariennes choisies à partir des strates du recensement canadien de 1981 par une méthode d'échantillonnage à stades multiples. Si son but premier était d'établir les taux et la distribution des troubles de santé mentale chez les enfants de 4 à 16 ans et leurs familles, cette enquête a permis d'estimer l'importance de certains autres problèmes médicaux et le recours de la part des enfants aux services sanitaires, éducatifs et sociaux. Les réponses au questionnaire concernent 3294 enfants. On trouve chez 1,9% d'entre eux une incapacité fonctionnelle sans maladie chronique, l'inverse chez 14,0% et les deux chez 3,7%, soit pour l'ensemble un taux global de mauvaise santé chronique de 19,6%. Ce taux est le plus élevé parmi les enfants défavorisés du point de vue socio-économique. Or, dans l'ensemble, ce sont les enfants en mauvaise santé chronique qui ont le plus souvent recours au médecin, à l'orthopédagogie, aux services sociaux et d'hygiène mentale. Le tout doit intéresser tous ceux qui s'occupent de l'enfance, organisent des services à la collectivité et forment des professionnels qui servent les enfants.

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This paper has two objectives. The first is to report the findings of the Ontario Child Health Study (OCHS) concerning the prevalence and distribution of chronic illnesses or medical conditions as well as limitations of normal function in Ontario children 4 to 16 years of age. We use the term "chronic health problems" to refer to all of these problems collectively. The second objective is to provide an overview of the use of health, special education and social or mental health services by children with chronic health problems.

There is increasing evidence that, relative to acute illness, the burden of morbidity associated with chronic childhood illness and limitations of function (or disability) in our society is large and growing.¹⁻⁴ It has been suggested that an increasing amount of pediatric health care will be directed to children with chronic health problems, which has important implications for the content of professional training, manpower requirements and services in the health care, education and social service systems.⁵ In Ontario recent legislation calls for cooperation between health care and education professionals in the care of many children with chronic health problems.^{6,7}

While several surveys pertinent to the epidemiologic features of chronic health problems in children have been conducted in other countries, available Canadian data are limited. The OCHS was an interview survey of 1869 Ontario families, including 3294 children aged 4 to 16 years, selected in a clustered random sample drawn from the 1981 census of Canada with the cooperation of Statistics Canada. The principal goal of the OCHS was to determine the prevalence and distribution of mental health problems in Ontario children and families. However, considerable information was also collected on the health and disabilities of children, and these data form the basis of this report.

Methods

We have previously reported in detail the study design of the OCHS, including sampling and measurement development procedures.^{8,9} The following is a summary of the design.

Survey methods

The target population included all children born between Jan. 1, 1966, and Jan. 1, 1979, whose usual place of residence was in a household dwelling in Ontario. At the time of the survey there were an estimated 1 610 000 eligible children in the province, of whom 951 000 were aged 4 to 11 years and 826 000 were boys. The sampling unit consisted of all household dwellings listed in the 1981 census of Canada, the sampling frame was the 1981 census, and the sampling selection was done by stratified, clustered, random sampling

from the census file of household dwellings. The survey excluded three groups of children, who constituted 3.3% of the population of children aged 4 to 16 years: those living on Indian reserves, those living in collective dwellings such as institutions and those living in dwellings constructed after June 1, 1981 (census day).

The major strata for the survey consisted of the four administrative regions of the Ontario Ministry of Community and Social Services, with each region subdivided into three strata based on the 1981 population: large urban areas with a population over 25 000, small urban areas ranging in population from 3000 to 25 000, and rural areas with a population of less than 3000. A simple random sample of households was selected from all urban areas within each ministry region, while a two-stage sampling procedure was used for small urban and rural areas. In the first stage, areas or clusters were selected; in the second stage, specific households were selected. Statistics Canada interviewers visited all sampled households to screen for eligibility and conducted interviews at home with the female head of eligible households. Of all those eligible, 91% agreed to participate.

Because of the complex sampling method, survey responses for prevalence estimates were weighted to reflect the probability of selection of the household, its size and the age and sex distribution of the children. Prevalence estimates (and their precision) for Ontario children 4 to 16 years of age were calculated as the expected number per 1000 population in this age group based on OCHS survey observations and the weighting factor.⁸ Thus, the unadjusted rates found in the OCHS sample differ slightly from the weighted population estimates presented in the results section of this report. Variance estimates that took into account the sampling method were used to calculate the 95% confidence intervals.⁸

Measures of limitation, chronic illness and use of services

Following a review of available measures, our measures of limitations of normal function and chronic illnesses or medical conditions were closely adapted from several sources, including the functional limitations scales of the Rand Corporation's Measure of Children's Health^{10,11} and checklists of chronic illnesses or conditions used in population surveys by Walker and colleagues³ and Haggerty and associates¹² and in the Canada Health Survey.¹³ The specific functional limitations inquired about are listed in Table I. The questions were preceded by an instruction to each respondent to consider limitations due to an illness, injury or medical condition and to exclude limitations due to being young. The one exception to this was the question pertaining to limitations in the type and the amount of schoolwork: the respondents' instructions were to include all limitations due to

physical, emotional or learning problems.

It has been argued that from a conceptual perspective "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 precise formulation of the temporal boundary.¹⁴ However, for the purposes of the OCHS the operational definition of chronic functional limitation was a limitation of function present for at least 6 months. This period of time was chosen to exclude more transient limitations in order to increase the specificity of our measure to detect the most troublesome problems. In the analyses presented in this report limitation is treated categorically (i.e., one or more limitations of function of at least 6 months' duration at the time of the survey either present or absent).

The survey was not designed to estimate the prevalence of specific diseases in the population. Because of growing evidence and opinion that the impact of chronic illness is not related to specific diagnoses, our main interest during the OCHS has been to contrast children with and without health problems that are usually chronic.^{1,15-17} Thus, in the analyses presented in this paper chronic illnesses and conditions are treated categorically (i.e., one or more chronic illnesses or medical conditions at the time of the survey either present or absent).

All questions about limitations and about chronic illnesses and medical conditions were asked of all respondents, unlike surveys in which information about limitation is sought only with respect to each illness. This permitted formation of the category "limitation of normal function alone".

Questions about the type and amount of physician services, medication and mental health or social services used in the 6 months preceding the interview and about lifetime use of special

education services by children were included in the survey.

In the tables that present prevalence rates, three mutually exclusive and collectively exhaustive categories of children with chronic health problems are described: children with limitation of normal function alone, those with a chronic illness or medical condition alone and those with both a chronic illness or medical condition and limitation of normal function. These tables present weighted prevalence estimates.

Results

The completeness of responses to the questions varied slightly, from 2888 for 3294 eligible children (87.7%) to 3163 for 3294 eligible children (96.0%), depending on the question. The actual numbers of complete responses for the cross-tabulations of health problems with age, sex, socioeconomic status and use of service thus vary slightly but are all based on a minimum denominator of 2888 observations. Children for whom data were missing were compared with those for whom the data were complete, and no statistically significant differences were found in age, sex or proportion of families below the poverty line.

Table I shows the number of children with one or more limitations of normal function. The weighted prevalence rate of at least one limitation was 56 per 1000 Ontario children 4 to 16 years of age (95% confidence interval 47 to 65). Forty-seven children (weighted prevalence rate 19/1000) had a limitation but none of the listed chronic illnesses or conditions. Of the 47, 35 were limited in the kind or amount of schoolwork they could do, which suggests that the main reason for limitation alone may stem from intellectual or emotional impairment in this group.

The number of children with one or more chronic illnesses or medical conditions is shown in Table II. The item "other chronic health problem" was included at the end of the checklist, and respondents were asked to report only health problems of severity and chronicity similar to those of the other items on the list. Children with "other chronic health problems" were compared with children with the remaining chronic health problems as well as with healthy children with regard to age, sex, presence of limitation, socioeconomic status and use of health care services and medication. Since they closely resembled children with the listed chronic health problems but not healthy children, "other chronic health problems" were included in our definition of a chronic illness or medical condition. There were 537 reports of allergy or hay fever, which are common but usually less serious problems; these were not included in this listing or in subsequent analyses in order to increase the specificity of our measures to identify children with the most troublesome chronic health problems.

Table I — Limitations of normal function in 157 children

Limitation	No. of children
Physical activity	
Limited in the kind or amount of vigorous activity	83
Trouble walking several blocks or climbing few flights of stairs	29
Trouble bending, lifting or stooping	14
Unable to walk without assistance	1
Mobility	
Needs help or supervision in using transportation	12
Needs help or supervision in getting around neighbourhood	15
Self-care	
Needs help with eating, dressing, bathing or using toilet	10
Role	
Limited in kind or amount of ordinary play	51
Limited in kind or amount of schoolwork	73
Unable to attend school	12

The weighted prevalence rate of at least one chronic illness or medical condition was 177/1000 (95% confidence interval 160 to 194). There were 418 children (weighted prevalence rate 140/1000) who had a chronic illness or condition without any limitation of function. Since the sample size of the survey was not selected to provide estimates of the various individual health problems listed, estimates of the prevalence of specific illnesses would be imprecise and consequently are not reported. A total of 110 children (weighted prevalence rate 37/1000) were reported to have both a chronic illness or condition and limitation of function.

Overall, 196 per 1000 children aged 4 to 16 years had some chronic health problem. The weighted prevalence rates of chronic health problems by age and sex and overall are shown in Table III. Boys had more chronic health problems than did girls, and children 12 to 16 years of age had a higher rate of health problems than did younger children.

Table IV shows the weighted prevalence rates

of chronic health problems by socioeconomic status.

The rates of use of physician services, medication and social or mental health services in the 6 months preceding the survey and of lifetime use of special education services are shown in Table V. The rates for children with chronic health problems were strikingly greater than those for children with no chronic health problems.

Discussion

We believe that the study design has allowed us to estimate with a minimum of bias the prevalence of chronic health problems in Ontario children aged 4 to 16 years. We feel that our selective list of chronic illnesses or conditions (which was very similar to lists used in other epidemiologic surveys^{2,3,11,18,19}) represents most of the clinically significant, moderate to severe chronic problems in Canadian children. We excluded common but usually less severe chronic conditions such as hay fever and allergy from our analyses. Similarly, the limitations of normal function were defined to measure moderate to severe disability of long duration. There is apparent agreement among many studies as to the types of survey items used to define functional status.¹¹

Functional limitations and chronic illnesses or medical conditions were found to be common in Ontario children: one in five children in the

Table II — Chronic illnesses or medical conditions in 528 children

Illness/condition	No. of children
Total blindness in one or both eyes*	10
Vision problem even with glasses*	26
Deafness*	14
Hearing problem but not deafness*	33
No speech*	7
Speech problems*	95
Moderate or severe pain*	83
Asthma	94
Heart problem	55
Epilepsy or convulsions without fever	23
Kidney disease	9
Arthritis or rheumatism	25
Cerebral palsy	3
Muscular dystrophy or muscle disease	2
Spina bifida	1
Diabetes	3
Cancer	2
Cystic fibrosis	2
Missing limb(s)	3
Physical deformity	74
Paralysis or weakness of any kind	12
Other chronic health problem	135

*Of at least 6 months' duration.

Table IV — Weighted prevalence rates of chronic health problems per 1000 children, by socioeconomic status

Health problem	Rate; socioeconomic status	
	Below poverty line	Above poverty line
Limitation of normal function alone	31	16
Chronic illness or condition alone	160	133
Chronic illness or condition and limitation of normal function	46	34
Total	237	183

Table III — Weighted prevalence rates of chronic health problems per 1000 children, by age and sex

Health problem	Rate (and 95% confidence interval); age, yr				
	Boys		Girls		Total
	4-11	12-16	4-11	12-16	
Limitation of normal function alone	18	27	8	28	19 (13-25)
Chronic illness or condition alone	163	146	115	138	140 (125-155)
Chronic illness or condition and limitation of normal function	29	58	18	52	37 (29-45)
Total	210	231	141	218	196 (179-213)

general population has at least one of these problems. This high prevalence rate is similar to rates reported from other surveys in developed nations in North America and Europe.^{2,3,11,18,19} Despite differences in the measures and definitions of chronic health problems and disabilities, the methods of data collection and the sociodemographic characteristics of study populations between various surveys, 10% to 20% of children are consistently identified as having a long-term illness or medical condition.^{2,3,11,18-20} Similarly, rates comparable to those we have found for functional limitation associated with chronic illness have previously been reported.^{3,4,11}

It is not easy to compare results of the Canada Health Survey¹³ and the Survey of Non-institutionalized Physically Handicapped Persons in Ontario²¹ with the findings of the OCHS. The main reasons for this lie in the different definitions of disability, different wording of questionnaire items and much wider age ranges in the former surveys, which greatly limit the specificity of reported findings for children 4 to 16 years of age. This difficulty in comparing results points out the desirability of more uniform definitions and questionnaire items in surveys of this type.

Unpublished data from the 1978-79 Canada Health Survey indicate an overall prevalence rate of disability of 2.4% for Ontario children under 15 years of age (W. Bradley, Statistics Canada: personal communication, 1985). Disability was defined as an inability to carry on the normal activities for one's age because of health reasons. The OCHS definition was broader and more specific.

Patterns of chronic health problems

Chronic health problems were found to be slightly more prevalent among boys and older children, associations that have been reported elsewhere.^{11,22} These health problems are not evenly distributed throughout socioeconomic groups: children of families whose income was below the official Statistics Canada poverty line²³ had higher rates of chronic illness and functional limitation than other Ontario children.

Data from the US Health Interview Survey

showed that the rate of physical limitations and disabilities is 1.4 times higher in children of families below the poverty line, as defined by a family income below \$6000 US in 1978.⁴ In the Canada Health Survey most disabled children were from families in the two lowest quintiles of family income adjusted for family size and place of residence (W. Bradley, Statistics Canada: personal communication, 1985). The role of reporting bias in the apparently large burden of chronic health problems among children of poor families compared with other children has not been completely resolved.²⁴

Use of services

Epidemiologic data provide a useful indication of health care services that may be needed in a population. It is increasingly recognized that the problems of and types of services needed by children with chronic illness and disability are often not related to specific diagnoses.¹⁵ Use of services by those who might benefit from them is dependent on the amount, quality, availability and accessibility to the target groups. Most authorities in the care of children with chronic illness or disability recognize the need for comprehensive physical, social and mental health care as well as attention to educational needs.^{1,3,5,25-27} Recent legislation in Ontario calls for increasing cooperation among professionals in these different fields, such as in the provision of some medical services to disabled children in regular schools.^{6,7}

The rates of use of physician services by children with chronic health problems appear fairly high, as would be expected given the nature of the problems. Rates of visits to physicians by children with chronic health problems ranging from much lower than we have found (55% in a 1-year period) to about the same have been reported from surveys in the United States.³ Thus, it is difficult to attribute differences in rates of use of physician services primarily to differences in the availability of health insurance plans. The high rates of use of special education services among these children underscore the importance of carefully coordinated collaboration of health and education professionals.

Table V — Rates of use of physician services, medication, and special education and social or mental health services per 1000 children

Health status	Rate; type of service			
	Physician	Medication	Special education	Social or mental health services
Limitation of normal function alone	645	55	596	229
Chronic illness or condition alone	679	164	221	105
Chronic illness or condition and limitation of normal function	804	329	433	125
No chronic health problem	550	28	127	41

Many chronically ill children with or without limitation had recently used mental health or social services. This finding is in keeping with current knowledge of the increased rates of mental health problems in this group. Other community surveys have shown an association between behaviour and emotional problems on the one hand and chronic illness or limitation on the other.^{3,11} In the OCHS we found a substantial increase in clinically significant mental health problems in this group of children (unpublished observation). Thus, overall rates of use of services seem to be commensurate with measures of prevalence or need. However, our findings do not necessarily mean that patterns of service use are ideal: we were unable, in this survey, to determine the extent to which individual children receive coordinated service. Pless and colleagues²⁶ and other investigators^{25,27} have emphasized that poor collaboration and liaison among professionals who care for chronically ill children is a major problem, and this should be an area of further study in Canada.

Methodologic strengths and limitations

We believe that the sampling strategy, sample size and high response rate have resulted in unbiased estimates of prevalence that are generalizable to the population of Ontario children aged 4 to 16 years. We used measures of chronic health problems that in most instances were similar to those used in other surveys.

The main limitation of our study lies in the use of reports by parents as proxy measures for direct examination of children's physical health and function. In general, the extent of ill health may be underestimated in reports by parents.¹¹ However, this appears to vary with the problem being reported, and for chronic illness this approach may overestimate prevalence.³ Nevertheless, several investigators have shown that in most cases parents' reports are confirmed by a clinical examination or review of health records, and they have concluded that such reports are generally valid.^{3,11,18} Moreover, it has been pointed out that parents' perceptions of chronic health problems may be a more important determinant of use of health care services than other, more direct, measures of health, and as such this type of data is much more germane to planners.³

Conclusion

Chronic illnesses, medical conditions and limitations of function are common in Ontario children, affecting about one child of every five between the ages of 4 and 16 years. These findings strongly support the need for attention to these problems by health care, education and social service professionals who deal with children, plan services or train new professionals.

The association between chronic health problems and poverty must be faced by society. The causes of this relation must be better understood through careful research, and this knowledge should be applied to efforts to determine whether this excess illness is preventable through medical, public health or social policies.

The high rate of use of physician, special education, social and mental health services by these children emphasizes the need for a coordinated approach to their care and for productive, collaborative relationships among professionals who provide care to children.

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Quebec Hilton International, Quebec City
Canadian Association on Gerontology, 238 Portage Ave., 2nd Floor, Winnipeg, Man. R3C 0B1; (204) 944-9158

Nov. 6, 1986

Computers in Medical Education
Mount Sinai Hospital, Toronto
Continuing Medical Education, University of Toronto, 116-150 College St., Toronto, Ont. M5S 1A8; (416) 978-2718

Nov. 8, 1986

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Shangrila Hotel, Montreal
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