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NEUROMOTOR DISABILITIES WITHIN THE JAMES BAY CREE PEDIATRIC POPULATION

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ABSTRACT

A search for all Cree children (0-17 years) with a neuromotoric disability was conducted in the James Bay region of Quebec. All eight Cree communities were visited in order to determine the prevalence, functional status and services received by these children. Nineteen in a population of 3654 children were assessed to have a neuromotor disability adversely affecting their ability to function normally, for a prevalence of 5.2/1000. The majority (74 %) were found to have moderate to severe functional impairments. All had received diagnostic and rehabilitative care in tertiary centres, however none were receiving rehabilitation in their communities.

INTRODUCTION

Disabilities among native Canadian children have not been well documented. The health status of native children has repeatedly been demonstrated to be inferior to that of the general population, which leads one to conclude that elevated rates of disability might also occur (1-5). Improved documentation of the prevalence and functional status of disabled native children can serve several purposes. These include guidance in the planning of rehabilitation services and the monitoring of their effect. Disability rates are a useful indicator of a population's health and the quality of medical care provided (6). Permanent neuromotor disabilities among native children living in remote and underserviced regions have frequently been the result of preventable obstetrical complications or neonatal infection (6,7). Continued improvement in health care should, ideally, result in reduced childhood disability rates, to levels comparable with the general Canadian population.

In this article, we present the results of a descriptive survey for neuromotor disabilities among Cree children living in the James Bay region of northern Quebec. This is a remote region, but enjoys relatively comprehensive medical services. These stem from the James Bay Agreement of 1976, in which the provincial government guaranteed the full provision of preventive and primary care, and hospital services for the region. As a result, nursing stations were upgraded in each community and a hospital built in Chisasibi. The hospital predates 1976. It was started in the 1920's by Catholic missionaries.

TABLE I. Physical characteristics of the children identified.

		n
Tone	Normal	5
	spastic quadriplegia	9
	spastic diplegia	2
	hypotonic	3
Postural reflexes	normal	3
	minimal impairment	3
	moderate impairment	7
	severe impairment	6
Gross motor control	normal or minimal loss	2
	moderate loss	7
	severe loss	10

TABLE II. Degree of independence in the activities of daily living.

	Activity		
Degree of Independence	**Feeding**	**Personal Hygiene**	**Dressing**
Independent	8	3	2
Some help	1	-	1
Fully dependent	7	11	8
Not applicable due to age	3	5	7

Additionally, there exist ties with Montreal teaching hospitals in the form of regularly scheduled consultant visits and teaching.

The objectives of this survey were to determine the prevalence of pediatric neuromotor disabilities, to assess the functional status of affected children, and to document what rehabilitation services had been received. It is anticipated this information will be useful in the formulation of specific recommendations affecting the provision of pediatric rehabilitation services in the James Bay region.

METHODS

A descriptive survey was conducted in the eight Cree communities of the James Bay region during the summer of 1985. In each community, prior to the visit of the research team, the medical and social services were notified and asked to prepare a list of all children aged 0-17 years suspected to have a physical disability affecting their ability to function in a normal manner. As well, the upcoming visit was advertised in Cree over the local radio station for the week prior to the visit. Residents were informed about the nature of the survey and asked to notify the nursing station of any child thought to have a physical disability.

Following a signed consent, multiple approaches to data gathering were used. All suspected cases were seen in their home, where they received a functional assessment and evaluation of activities of daily living (ADL) by an occupational therapist. The parent(s) were interviewed by a second member of the team, an anthropologist with prior work experience in Northern Quebec. This interview included a demographic profile, medical and rehabilitation history, functional status inventory (8), and an impact on family scale (9). Medical records were reviewed following the home interview. Subsequently, each case was reviewed with a pediatrician either during or at the end of the study. Any child found to have functional impairment due to a neuromotor deficit was considered a positive case. The impairment had to result in an inability to carry out normal (age appropriate) activities. Any cases residing in institutions located in southern Quebec were not included in this survey.

RESULTS

The survey team was notified of 40 children with a potential physical disability. Nineteen of these children were assessed to have a neuromotor disability which affected their ability to function normally. This equates with a prevalence of 5.2 per 1000 children 0-17.

The etiology of the neuromotor disabilities varied considerably. Four 4 of the children are thought

to suffer from an ill-defined central nervous system (CNS) disease of genetic origin. Of the remaining 15, the suspected causes are: prematurity 2, infection 3, perinatal encephalopathy 3, spina bifida 2, other CNS disease 2, and undetermined 3. Table I summarizes the physical status of these children. Most of these children had additional disabilities; 11 were mentally handicapped, 10 had severe communication problems, and 6 had an active seizure disorder.

Results from the ADL evaluations are found in Table II. These data closely coincide with parental assessment of their child's functional status; 26 % of parents reported no functional problem, 42 % mild to moderate problems and 32 % assessed their child's functional status to be severely impaired. Remediation of functional impairments often is accomplished through the use of technical interventions (special seating, orthotics) and individualized early stimulation programs. A majority of children had received these services, but were no longer benefitting from them. The number affected and utilizations of these interventions are presented in Table III.

It was found that all 19 children had been transferred to Montreal or Quebec City for diagnostic and treatment services. Ten children (53 %) had been transferred on four or more occasions. In Table IV the length of time away from home resulting from these transfers is summarized. The average number of days per visit was 31.

DISCUSSION

This survey found the prevalence rate for neuromotor disabilities within the pediatric Cree population of the James Bay region to be moderately increased in comparison to reports from other parts of Canada and other developed countries (Table V). This survey applied a relatively broad definition of neuromotor disability, which could tend to increase prevalence estimates relative to other investigations. Higher rates will also be found in direct population surveys as opposed to record reviews or telephone surveys. The prevalence rate will be underestimated if existing cases have not been found. Within a small population, even a few missed cases will result in large discrepancies. We do not feel this was the case in this survey. Multiple information sources were searched and each community was well prepared for the survey. Bias will also occur if the likelihood of premature death is increased. A search for the death of children who may have survived longer in southern Quebec was not included in this survey.

Can the prevalence rate found in this survey be generalized to other native communities? We are unaware of other published data from native communities with which to compare these results. We had anticipated higher prevalence rates. It is our conclusion that these results reflect what will be found under relatively optimal circumstances and may not truly reflect the situation in less serviced and economically depressed

TABLE III. Continuity of rehabilitation: Services received and their utilization.

	Service Received (n = 19)		
Utilization	Seating	Orthotics	Home Program Exercise/Stimulation
Received and used	4	1	1
Received but used incorrectly	1	-	4
Received, not used	7	4	10

TABLE IV. Total number of days spent in southern Quebec.

Duration of stay (days)	Number of children	Percentage of total days
30	2	11 %
30-59	5	26 %
60-89	5	26 %
90-179	3	16 %
180	4	21 %

native communities. These findings do suggest that childhood neuromotor disability rates can be reduced to levels equivalent with the general Canadian population.

A wide spectrum of disability was found, with a large proportion moderately to severely disabled. These children require comprehensive, long-term services. All of these children had received extensive diagnostic and subsequent therapeutic evaluations, as is evidenced by their multiple trips to tertiary care centres. Most received rehabilitation therapy (physiotherapy or occupational therapy) during these visits, but carryover in their communities was found to be non-existent. Medical personnel in the James Bay region were largely unaware of what therapeutic interventions had been received and had no formal instruction in such care. Parents often had received written instructions for home exercise or stimulation programs, but were notcompliant and received no reinforcement or clarification. Because therapy has always necessitated transfer of their children outside the community, parents were reluctant to report physical or functional deterioration. As seen in Table III, the large majority of children who had received technical devices had either discarded them or were using them improperly.

The findings of this descriptive survey point out several important deficiencies in the care of disabled children residing in a remote northern community. Such deficiencies need not occur and could be significantly reduced through the training of rehabilitation coordinators/advocates residing in these communities. This should be linked with regular visits by therapists and the sensitization of local medical and nursing personnel Lengthy visits to tertiary treatment centers should be where possible and improved local autonomy in the care of these children be fostered.

TABLE V. Prevalence of pediatric neuromotor disabilities in developed countries and James Bay.

Setting	Year	Ages	Disabilities	Prevalence (per 1000)
Quebec, James Bay	1985	0-17	Neuromotor cerebral palsy	5.2
Abitibi-Témiscamingue (10)	1980	0-17	Neuromotor	3.9
Ontario, Windsor (11)	1960	5-18	Cerebral palsy	1.7
British Columbia (12)	1979	0-19	Neuromotor Cerebral palsy	3.3 1.9
Great Britain (13)	1962-78	0-16	Neuromotor Cerebral palsy	 0.5
Sweden (14)	1976	4-16	Cerebral palsy	2.0
United States (13)	1959-66	7	Neuromotor	5.0

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