

## Respiratory poliomyelitis: a follow-up study

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Data from the medical records of 113 patients living in Manitoba who had contracted respiratory poliomyelitis between 1952 and 1959 were compared with information obtained from interviews with these patients in 1980. The study was designed to determine whether the patients' respiratory function, mobility, ability to perform daily tasks, and employment, residential and marital status had changed between 1 year after the onset of polio and 1980. The patients' dependence on mechanical aids and other people was also studied. More than half (56%) of the patients perceived their respiratory impairment to be the same as it was 1 year after the onset of polio, 27% perceived the impairment to be increased, and 17% perceived it to be decreased. There was an association between level of respiratory function, mobility and ability to perform daily tasks. The 69 patients who lived at home had better respiratory function, mobility and ability to perform daily tasks than the 24 patients who were assisted by a home care program and the 20 who lived in hospital. The latter group had the lowest levels of respiratory and functional ability.

Des données inscrites au dossier médical de 113 patients au Manitoba qui avaient contracté une poliomyélite de forme respiratoire entre 1952 et 1959 ont été comparées avec des informations recueillies au cours d'entrevues menées avec ces mêmes patients en 1980. Cette étude a été élaborée afin d'établir s'il y avait eu changement quant à la fonction respiratoire, la mobilité, la capacité pour accomplir des tâches quotidiennes, l'emploi, le lieu

de résidence et l'état civil des patients à partir d'un an après l'apparition de la polio jusqu'en 1980. On a aussi étudié la dépendance des patients envers des appareils ou envers d'autres personnes. Plus de la moitié (56%) des patients ont jugé que leur insuffisance respiratoire s'était maintenue au même niveau que ce qu'elle était 1 an après l'apparition de la polio, 27% ont noté une augmentation de l'insuffisance et 17% en ont noté une diminution. On a constaté une corrélation entre le niveau de fonction respiratoire, la mobilité et la capacité pour accomplir des tâches quotidiennes. Les 69 patients qui vivaient à domicile avaient une meilleure fonction respiratoire, une meilleure mobilité et une meilleure capacité pour accomplir des tâches quotidiennes que les 24 patients qui participaient à un programme de soins à domicile et que les 20 qui vivaient à l'hôpital. Ce dernier groupe possédait le niveau le plus faible de capacité respiratoire et fonctionnelle.

Since the development of effective vaccines, acute respiratory poliomyelitis has virtually disappeared from Canada. However, the people who were left permanently disabled by the polio epidemics in the 1940s and 1950s are still in need of rehabilitative medicine. Many polio victims continue to face health and social problems and have special needs. They share some of these needs with other disabled individuals, but different needs arise as a consequence of polio.<sup>1-7</sup>

Two conferences, one in Chicago in 1981 and one in St. Louis, Missouri in 1983, brought together individuals with polio and experts in rehabilitation medicine to discuss the impact of ageing, particularly on those with respiratory polio.<sup>8,9</sup> These discussions have been limited by the absence of any systematic data on what happened to a representative group of people who contracted polio during the epidemics in the 1950s.

A major outbreak of polio occurred in Manitoba during the summer of 1952 and was followed in 1953 by a massive epidemic in both urban and rural areas of the province. According to a contemporary account, "the total number of cases reached 2,300 representing an incidence of over 300 cases per 100,000 population".<sup>10</sup> In 1954 the number of new cases of polio decreased to 117. The last major outbreak of the decade was in 1958, when 152 cases were reported (Fig. 1).

The paralytic effects of polio varied, depending on the segments of the nervous system affected. High spinal cord involvement paralyzed the respiratory muscles, and

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the patient frequently needed mechanical ventilation. Bulbar paralysis (often associated with high spinal cord paralysis) affected the muscles of deglutition and phonation, and a tracheostomy was often required. Polio encephalitis could suppress the respiratory centre to a degree where respiratory failure was imminent.

Patients with respiratory polio required specialized equipment and medical care. Both were centralized at the Winnipeg Municipal Hospital (WMH), which was officially designated as the main polio treatment centre for Manitoba during the 1952 and 1953 epidemics.<sup>11</sup> This hospital admitted 42% of all patients with polio in the province between 1950 and 1959, and all patients with respiratory polio were referred there.

In this paper we present the results of a study in which people who had contracted respiratory polio in Manitoba between 1950 and 1959 were traced and interviewed.<sup>12</sup> The information was obtained from a unique case register and medical records that summarized the experience of all patients who had required respiratory support and were admitted to the WMH. The objects of our study were to describe the patients' current health and respiratory and functional status, to determine what changes had occurred by comparing these data with those in the medical records made more than 25 years earlier and to explore the effect of chronic disability on career patterns. We interviewed the patients to determine the experiences of those who had spent the intervening years in hospital, those who had received specialized home care services and those who had been discharged from hospital to live in the community.

#### Medical record audit

Records were available for all 264 patients with respiratory polio admitted to the WMH between 1950 and 1959 and were reviewed by two clinicians, both of whom had been members of the medical team that had cared for such patients during the epidemics. Because our study was designed to document the long-term impact of polio, only the 186 patients who had survived 100 days or more after admission to hospital were included. A medical record audit was used to retrieve the basic sociodemographic information that had been recorded at the time of a patient's first admission to the WMH. The data extracted from the medical records also included the type of polio, the number of days a patient had required assisted ventilation, whether a tracheostomy had been done, and the types of respiratory support, aids and adaptations the patients had used following the acute phase of the disease. The distribution of the 186 patients according to sex, age, type of polio and whether they had required a tracheostomy is shown in Table I. The patients were most frequently aged 5 to 9 or 25 to 29 years at the onset of polio.

During the acute phase of the disease some of the patients required respiratory support for as little as 1 week, while others became permanently dependent on it. The records were reviewed to determine the patients' respiratory status after their condition had stabilized. One third of the patients had little or no residual impairment and had become totally independent of

mechanical respiratory support, and another third had some impairment and on occasion required admission to hospital and respiratory support. Of the remaining patients 20 required respiratory support for up to 12 hours a day, 14 for 12 to 18 hours a day and 29 for more than 18 hours a day.

There were marked variations in the severity and combinations of residual impairment among the 186 patients. In the early years, as the patients recovered from polio, their functional capacity often improved with rehabilitation, sometimes as a consequence of corrective surgery. However, apart from a few special problems, most of the patients achieved a stable level of

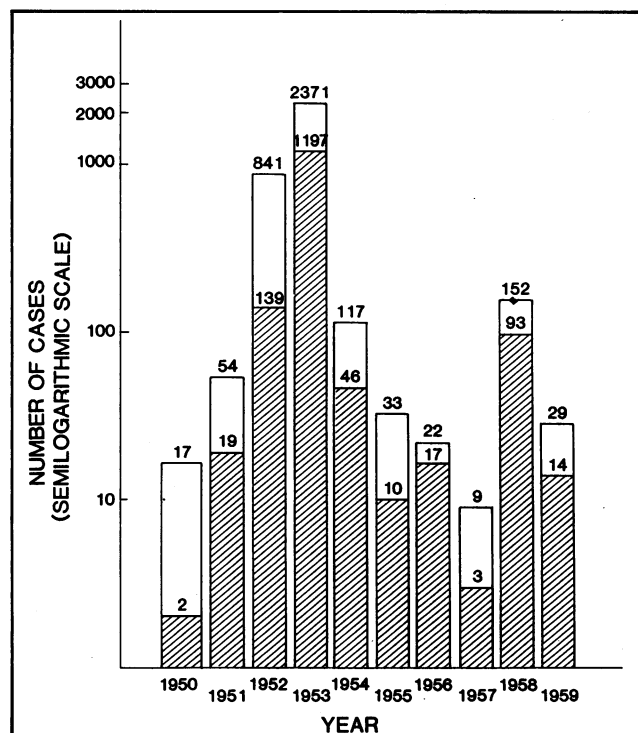


Fig. 1—Numbers of new cases of respiratory poliomyelitis in Manitoba between 1950 and 1959. White areas represent total numbers, hatched areas numbers in which patient was admitted to Winnipeg Municipal Hospital.

Table I—Distribution of 186 patients with respiratory poliomyelitis contracted in Manitoba in 1950–59

Variable	No. (and %) of patients
<b>Sex</b>	
Male	116 (62)
Female	70 (38)
<b>Age at onset (yr)</b>	
0–14	53 (28)
15–24	40 (22)
25–34	66 (35)
≥ 35	27 (15)
<b>Type of polio</b>	
Spinal	73 (39)
Bulbospinal	113 (61)
<b>Tracheostomy</b>	
Required	83 (45)
Not required	103 (55)

respiratory function within 2 or 3 years after the onset of polio.

Of the 157 patients who were discharged from the WMH, 53 returned home under the provisions of a home care program that had been developed for people with respiratory polio. Another two patients were transferred to other hospitals.

### Home care program

The polio home care program was developed to provide an alternative to a prolonged or permanent stay in hospital for patients with respiratory impairment or severely impaired mobility who could be cared for in their own homes.<sup>13</sup> It was the earliest publicly financed home care program in Canada, and, as such, it pioneered many of the features that have since been incorporated into other programs. One of the key provisions was a guarantee of readmission to hospital for social or medical reasons.<sup>14</sup>

Eligibility for the home care program was based on flexible criteria that accommodated the range of medical, social and economic circumstances of the patient and the family. Home care arrangements also took account of the availability and adaptability of the patient's family and community resources. The program included the provision and maintenance of mechanical respiratory support equipment and orthotic devices and aids, as well as structural and electrical modifications of homes to accommodate the necessary equipment. Attendant services were arranged on a full-time, part-time or temporary basis; in slightly more than a third of the cases the paid attendant was a relative of the patient.

### Follow-up study

The first object of the follow-up study was to determine what had happened to each of the 186 patients through interviews with them or with the next-of-kin of those who had died; 138 interviews were completed, for a response rate of 74%. Of the 48 patients who were not interviewed 24 had died in the WMH within the first few years after the onset of their illness. No effort was made to find or interview their families as the data were already in their medical records. Of the remaining 24 patients 12 could not be located, and 3 were known to have died but their next-of-kin could not be found. The other nine patients were omitted from the study because an interview was either refused by them or their next-of-kin or could not be arranged.

To determine the representativeness of the 138 patients for whom interview data were available we compared their respiratory status with that of the 48 patients who could not be interviewed, 50% of whom had died from severe respiratory impairment in the WMH. If the comparison is restricted to the patients who were alive in 1980, those with severe respiratory impairment (97%) were more likely to have been interviewed than those with minimal respiratory impairment (76%). The latter patients had been more difficult to find as they had not remained in contact with the WMH and were more likely to have moved from Manitoba.

Thus, the patients included in this study are not entirely representative of the 186 patients in whom respiratory polio had developed.

Of the 186 patients 56 were known to have died by Mar. 31, 1980, when the data collection was completed. Examination of the medical records and death certificates provided data on the cause of death. There was an inverse relation between the probability of survival and the severity of the initial respiratory impairment. Yet, despite their higher risk status, 14 of the 29 patients who required 18 or more hours of respiratory support a day were still alive in 1980. Complications resulting from polio had directly or indirectly been the cause of death in 73% of those who died. All the patients who died within the first 10 years after the onset of disease died because of polio. Nevertheless, polio could result in a permanent vulnerability: 62% of the 16 deaths that occurred between 10 and 19 years and 47% of the 17 deaths that occurred more than 20 years after the onset of polio were ascribed to the long-term consequences of the disease.

There were 118 patients who were known or believed to be alive in 1980; of these, 113 (96%), including 67 men and 46 women, were interviewed. Most of the respondents were interviewed in person, but six, who had moved out of the province, were interviewed by telephone.

Of the 113 respondents 30 had initially participated in the respiratory polio home care program, but 6 were subsequently readmitted to the WMH. Fourteen other patients had been continually cared for in the hospital.

The interview included questions on self-perceived respiratory status, which was assessed by the patient's reported level of occasional or daily dependence on respiratory equipment (such as a rocking bed, a tank respirator or an endotracheal respirator). The same categories were used as measures of respiratory status in the medical record audit. Mobility and capacity for self-care were measured with a modified version of Katz's Activities of Daily Living (ADL) Index.<sup>15</sup> We added questions on more complex functions (such as the ability to drive a car). Other items measured more specific functions that were impaired in some (such as the ability to turn a door handle). We also compared the patients' health, age, marital status and place of residence as they were at the time of onset of polio and in 1980.

### *Respiratory status*

Table II compares the respiratory status of the 113 patients in the 1950s (according to the medical records 1 year after the onset of polio) and in 1980 (according to the patients' reports). Of the 113 patients 56% reported that their level of respiratory impairment was the same as that noted in the medical records 1 year after the onset of polio, 27% reported that it had increased, and 17% reported that it had decreased. Most of those whose condition appeared to have deteriorated reported occasional respiratory problems, whereas according to their medical records they had had no residual problems. However, only four reported needing more hours of respiratory support. The introduction of

endotracheal respirators may explain some of the increase in the number of hours of dependence because many of the patients preferred to use the equipment continuously. These respirators afford greater mobility because they are attached to an electric wheelchair or walker.

Loss of energy may be associated with a decline in respiratory function;<sup>16</sup> 92% of the patients receiving home care and 70% of those in hospital reported having reduced energy levels. However, the same problem was reported by 51% of the patients who did not require respiratory support.

### Mobility and performance of daily activities

The patients were asked to assess their overall level of mobility and their ability to perform standard ADL 1 year after the onset of polio (to the best of their recollection) and in 1980. Both functions were ranked on a scale according to the level of difficulty, the use of equipment and dependence on others for assistance. The scales ranged from unassisted performance with ease to dependence on both equipment and helpers. The results are shown in Table III.

Most of the patients reported their level of mobility and ADL performance as unchanged in 1980; only 2% assessed their current levels of mobility and self-care to be decreased. The patients with only minor impairment were more likely than those with severe impairment to perceive their functioning as improved. The higher levels of performance in 1980 may be explained by several factors, including natural recovery, rehabilitation, re-education and improvements in mechanical aids.

There was an association between respiratory status and the levels of mobility and ADL performance. However, polio could be idiosyncratic in its consequences: patients whose arms were paralyzed but whose legs were functional could have reported a high level of mobility although they were dependent on respiratory equipment and had a low level of self-care.

### Home care, hospital care and current patterns of disability

Of the 113 patients 20 were in hospital and 24 were

**Table II—Respiratory status of 113 patients according to medical records 1 year after the onset of polio and as reported by the patients in 1980**

Variable	% of patients	
	One year after onset*	1980
No disability	39	34
Occasional respiratory problems	33	32
Respiratory support needed for		
< 12 h/d	9	7
12–18 h/d	7	13
> 18 h/d	12	14

\*No data on respiratory status were available for three patients.

receiving home care. All the patients in hospital and most of those receiving home care were dependent on respiratory equipment and used it daily. Almost half (46%) of the remaining 69 patients reported some residual impairment of respiratory function, but none of them regularly used respiratory equipment. However, 33% of these patients did need equipment and help in order to be mobile, and approximately 17% reported that mobility presented difficulties. The functional activities used to measure the levels of mobility and ADL performance are listed in Table IV. The difference between mobility in winter and in summer is indicative

**Table III—Level of mobility and activities of daily living (ADL) performance**

Level of performance	Function and % of patients			
	Mobility		ADL	
	1 year after onset of polio	In 1980	1 year after onset of polio	In 1980
Unassisted with ease	14	34	14	40
Has difficulty but needs no help or equipment	22	12	22	9
Requires equipment but no help	6	26	6	12
Requires equipment and help	58	28	58	39

**Table IV—Proportions of 113 patients with specific functions of mobility and ADL**

Functions	% of patients		
	In hospital (n = 20)	At home	
		Receiving home care (n = 24)	Not receiving home care (n = 69)
<b>Mobility</b>			
Getting in and out of bed	5	29	95
Getting in and out of chair	5	33	91
Negotiating stairs	5	17	92
Walking			
Inside	70	79	99
Outside			
Summer	65	62	94
Winter	5	21	72
<b>ADL</b>			
Washing	0	46	96
Bathing or showering	0	13	75
Dressing	0	21	91
Using toilet	0	29	93
Feeding	5	75	98
<b>Other</b>			
Gripping	20	71	97
Lifting and holding	20	71	97
Reaching	0	17	87
Writing or typing	45	92	99

of the impact of Manitoba's climate on the lifestyles of disabled individuals in general, and particularly those whose respiratory function is impaired as a result of polio.

### Dependence on equipment and other people

The scales used to measure respiratory function, mobility and ADL performance provided an indication of the patients' dependence on equipment or other people. For example, a third of the patients had to use respiratory equipment permanently and another third used it only occasionally. In terms of mobility, 26% needed only equipment, whereas 28% needed both equipment and help from other people. In terms of ADL, 12% needed equipment, and 39% needed both equipment and help from other people.

The respiratory equipment included not only respirators and rocking beds, but also wheelchairs, hoists and other mechanical aids. The patients' homes had been either modified or custom-built; doorways had been widened, and wheelchair ramps had been constructed in the patients' homes and sometimes at their workplaces. Only a few of the patients still used the orthotic devices, such as leg braces or crutches, that they had used early in their rehabilitation.

### Health status

Of the 113 patients 26% described their health as poor or fair. Among those in hospital 55% described their health as good or excellent, although they all had severe respiratory and other functional impairment.

The interview included a series of questions on specific chronic health problems that, on the basis of clinical experience, should have been expected as a

consequence of polio or of ageing. Of the 113 patients 51% reported respiratory problems, 42% back problems and 32% urinary problems, all of which could have been attributed to polio. However, the peptic ulcer (in 21%), hypertension (in 22%) and cardiovascular problems (in 12%) may have reflected the impact of environmental stress and ageing: 31% of the patients were more than 55 years of age. Only 8% of the patients reported psychiatric problems. There was no significant association between the prevalence of health problems and whether the patients were in hospital or at home.

### Sociodemographic characteristics

Table V shows the patients' age, marital status and place of residence at the time of onset of polio and in 1980. Of the 113 patients, 18 were divorced in 1980; 15 (83%) of these patients had been married at the time of onset of polio. Of the patients in hospital who were married at the time of onset of polio, 77% were divorced in 1980.

Of the 113 patients, 32% had been living on a farm or in a hamlet and 25% had been living outside Winnipeg in a smaller town at the time of onset of polio. By contrast, almost 75% were living in Winnipeg in 1980. While there has been a general shift from rural to urban residence, 28% of the patients attributed their move to Winnipeg to their having had polio.

The patients' respiratory status was a major factor in whether they continued to work after the onset of polio. Half of those who were dependent on respiratory equipment, compared with a quarter of those who were not, stopped working. On the other hand, a number of those in hospital or receiving home care became self-employed or found part-time or temporary employment.

### Discussion

Given the current concerns with the impact of ageing on patients with respiratory poliomyelitis we were able to take advantage of the unique opportunity presented by the careful preservation of medical records by the WMH. It was possible not only to trace and interview most of the patients who were alive in 1980 but also to compare their respiratory and functional status in 1980 with that recorded in the first year after the onset of polio. Because all the patients had been referred to one centralized treatment centre, we were able to include those with minimal impairment whose need for a specialist's care had been minimal. While the 138 patients in our study were not fully representative of the 186 patients who presented to the WMH between 1950 and 1959, we feel that our study was more comprehensive than other North American follow-up studies, which have had to include patients who were still receiving specialist care.

In assessing the health effects of ageing on patients with respiratory polio, we discovered some indication of a decline in respiratory function when the patients' condition in 1980 was compared with that 1 year after the onset of polio. Loss of energy was another reflection of possible respiratory impairment.

We found no evidence of a deterioration in mobility

Table V—Sociodemographic characteristics of 113 patients at onset of polio and in 1980

Variable	% of patients	
	At onset of polio	1980
Age (yr)		
0-14	26	-
15-24	26	-
25-34	36	13
35-44	10	20
45-54	2	36
≥ 55	-	31
Marital status*		
Married	50	51
Widowed	2	8
Divorced	-	16
Single	31	25
Place of residence		
Rural	32	14
Urban (other than Winnipeg)	25	16
Winnipeg	41	61
Outside Manitoba	2	9

\*Excluding 17% of the patients, who were less than 18 years of age and unmarried at the time of onset of polio.

or ability to manage daily activities. However, a recent decline may have been masked by the patients' recollection of their condition 1 year after the onset of polio. These are both areas in which technologic advances (such as motorized wheelchairs) have increased functional ability and reduced expenditure of energy.

Our study provides some evidence of the dependence of patients with polio on a combination of mechanical aids and assistance from other people, the latter often being provided by members of the patient's family. It is the balance between the need for support and the support available that characterizes the remarkable success of the home care program in helping patients in their own homes over long periods.

We are grateful to the respondents and their families for their cooperation in the data collection.

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### Providing information services

Health professionals usually think of a library as a source of books and journals rather than of information services. The growth of science and technology resulted in concern over the "information explosion". Library user studies were based on the idea that if general needs and preferences were identified, effective systems could be designed. Since the mid-60s more sophisticated methods have been introduced to collect such information. Libraries must improve their image as places of access to resources and services. They must be active rather than reactive.