

**Disability and the Aging Process:
A Longitudinal Follow-up Study
of Poliomyelitis Patients in Manitoba**



**Final Report to the National Health Research
Development Program, Health and Welfare Canada
(Grant No. 6607-1241-26)**

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Finally we would like to thank the Manitobans who were willing to share their experience with the acute and long term effects of poliomyelitis.

DISABILITY AND THE AGING PROCESS: A LONGITUDINAL
FOLLOW-UP STUDY OF POLIOMYELITIS PATIENTS IN MANITOBA

INTRODUCTION

The long term effects of polio related disability has been examined in a follow-up study of two representative samples of poliomyelitis cases. The project has explored the impact of polio through documenting the acute care, rehabilitation and current experience with aging processes among survivors. Everyone included in the study population developed polio in Manitoba during the major epidemics of the 1950's.

The Manitoba follow-up studies have documented changes over time in the life of an individual disabled by poliomyelitis. The primary focus has been to document long term disability patterns through describing changes in functional status, reflecting improvement, decline or periods of relative stability. The second dimension of the research involves documentation of current adaptation patterns in which the residual effects of previous impairment may be complicated by normal aging processes or more specific secondary effects of poliomyelitis. This focus upon late polio-related aging effects represents an attempt to respond to the call for wider research initiatives to determine whether changes due to aging occur independently from changes attributable to the long term impact of polio.

In evaluating the long term consequences of early impairment the Manitoba follow-up studies have focused on, not only aging as a physiological process, but aging as a social process in which an individual passes from childhood through adulthood and into later life. Another dimension of the research program has focused on changes in the context of living as an individual with disability. This portion of the research has sought to examine the impact of developments in medical and rehabilitation technology, changes in public policy influencing service delivery and the emergence of the independent living movement.

In investigating these issues, the Manitoba study has utilized a combination of methodological approaches including: medical record review, search of mortality registers, cross-sectional surveys (using direct interviews and mail questionnaires) and in-depth life history interviews with selected informants.

The formal objectives initially projected for the program of research included:

1. documentation of the initial and long-term impacts of polio-related disability;
2. measurement of interaction effects between initial polio-related impairment and longer term chronic disease processes associated with aging;
3. assessment of the impact of life events and other changes in family or informal networks upon support activities and measurement of the reciprocal effect of disability upon resources and adaptation patterns of the family; and

4. analysis of changes in client's level of need for medical and personal care services as they are influenced by variables such as functional ability and family resources and contextual factors such as changes in rehabilitation technology, public benefits and consumer initiatives.

AGING AMONG THE YOUNG DISABLED

As the Canadian population ages, gerontologists are becoming increasingly concerned about the impact of disabling conditions in mid and late life. Gerontological research documents sudden or gradual loss of functional capacity resulting either from the processes of normal aging or the specific impact of chronic diseases among older Canadians. However, gerontological research often focuses on disability associated with chronic disease processes occurring in mid and late life, rather than on the impact of aging on people who have been disabled as children or young adults. Reciprocally, much of the research on disability among younger people tends to focus on individual experience during the initial recovery and rehabilitation. Because of this gap in the literature describing the long term impact of disability through out the life cycle, a key question addressed by Manitoba follow-up studies is to what extent the needs of people disabled during childhood or young adulthood have changed as they and members of their support network age. The current literature on late effects of poliomyelitis suggests that the original adaptations to physical impairment achieved by younger victims may be

unstable. The delicate balance associated with younger disabled peoples' initial adaptation may be threatened by even relatively minor changes in functional status or in their family support system as they grow older.

In designing the Manitoba follow-up studies, the decision was therefore made to collect data on the relationship between disability and aging as a physiological process and disability and aging as a social process. A central question in the Manitoba study is whether differences in functional status can be fully explained by the physiological changes associated with aging or whether changes in care resources, family life events and technological adaptations also have had significant influence upon aging experience.

RESEARCH DESIGN

Recent attention in both scientific and consumer publications on the potential late effects of poliomyelitis have led to the development of several major research initiatives. The client populations followed-up in many of these research projects have included primarily individuals contacted through rehabilitation centres or polio survivor networks. This approach to sampling may tend to overrepresent the experience of surviving patients with the highest levels of disability, greatest propensity to experience post-polio aging effects and highest current levels of contact with rehabilitation facilities and

consumer networks. While there are advantages to focusing on individuals with the highest level of disability and potential need for services, this method of selecting a study population means that those who did not survive are not included in the analysis of the long-term impact of polio. Self-selected survivor groups with ongoing contact with the rehabilitation system may also underrepresent polio patients who recovered so completely that they were no longer counted within the population of the polio-disabled. The omission of either or both these groups limits the ability of any study to generalize from its findings to the experience of the whole generation of people who developed polio. The Manitoba study represented an attempt to document the experience of those who did not survive, via medical record audit and family informant interviews, as well as the less disabled for whom polio had minimal long term effects. (A detailed discussion of the research design is presented in appended articles No. 1 (Kaufert and Kaufert, 1984) and No. 2 (Kaufert, et.al., 1985)).

Ideally, three conditions should be met by a study analyzing the long-term effects of any disabling condition in order to insure that the data are valid and generalizable to the population at risk. Ideal characteristics include: (1) that the study design should be longitudinal; (2) that the sample should be selected from a complete listing of those who developed the condition; and (3) that documentation of disease experience should begin at the

point of disease onset. In research focusing on late polio effects, a true prospective design clearly cannot be developed. However, the alternative of a "historical prospective" design, familiar to epidemiologists, was used in the Manitoba follow-up studies.

In this design, the study population shares a common characteristic, usually exposure to a known risk factor at some designated point in time. By tracing and recording mortality and morbidity within the study population over the years since their initial exposure, an epidemiologist would hope to determine the incidence of a disease. This design is superior to retrospective sampling approaches because it defines the sample in terms of exposure to risk factors rather than from cases of the disease. The historical prospective design approach facilitates calculation of incidence rates of late effects and provides a more accurate estimate of the degree to which those who develop a disease are representative of those initially exposed to the risk factor.

The method of population selection used in Manitoba study of poliomyelitis is an adaptation of the historical prospective design. A unique provincial case register has provided the basis for selecting a sample of acute cases equivalent to an 'exposed population' in epidemiological research. The register developed by Dr. A.J. Alcock provides a complete listing of the 1540 individuals admitted to the

centralized treatment facility between 1950-1959. Two groups were selected from the register: the 186 cases with respiratory impairment and 1150 cases with either other forms of paralytic or non-paralytic polio. This sampling approach avoids the selection bias of most cross-sectional studies by including both those who did not survive until 1980 and those who fully recovered and who are apparently without any residual disability.

The register also provided baseline socio-demographic and medical data, including age, sex, marital status, type of polio, use of respiratory equipment, surgical and rehabilitation procedures and levels of impairment during the acute and early rehabilitation phases. This baseline demographic and medical information was recorded at the time and was therefore not subject to retrospective recall bias. Data from the register and accompanying medical records allowed physicians on the research team to compose a summary profile of acute effects and rehabilitation history. As in any historical prospective study, the type of data available was limited to what which was pertinent to care providers involved in initial patient management. Nevertheless, by correlating information from the case register with information on mortality gathered while tracing this population, it is possible to document basic survival patterns. Furthermore, by using the mortality data, it was possible to examine the association between survival and both disease severity and age at onset. The adoption of this

design coupled with the effectiveness of the case-finding protocol has enabled the Manitoba study to provide documentation on the survival patterns which are characteristic of the trajectory of poliomyelitis over a 25 year period.

The historical prospective design approach has facilitated complex analysis of late aging effects because analysis can control for the influence of age at onset and initial functional status. These correlations suggested that the age at which an individual developed polio was associated with levels of severity and residual impairment. The preliminary analysis suggests that the functional status of an individual in 1980 or 1982 reflects age-related differences which date back over three decades rather than being solely attributable to more recent post polio aging effects. (This finding is elaborated in publication No. 2, Kaufert, et.al. 1985).

The historical-prospective design has other advantages for research exploring aging as a social process. Data on social characteristics provided by the case register included age at onset, sex, marital status, occupational and residential characteristics and a basic profile of disability. These data provided the basis for stratifying the samples of respiratory and non-respiratory cases in terms of the life stage which they had reached at the point of disease onset. The age distribution of patients revealed

two major clusters of patients; younger children below the age of 10 and young adults between 17 and 30 years old. At the time of the 1980 and 1982 follow-up survey both patient groups were adults entering early or late middle age.

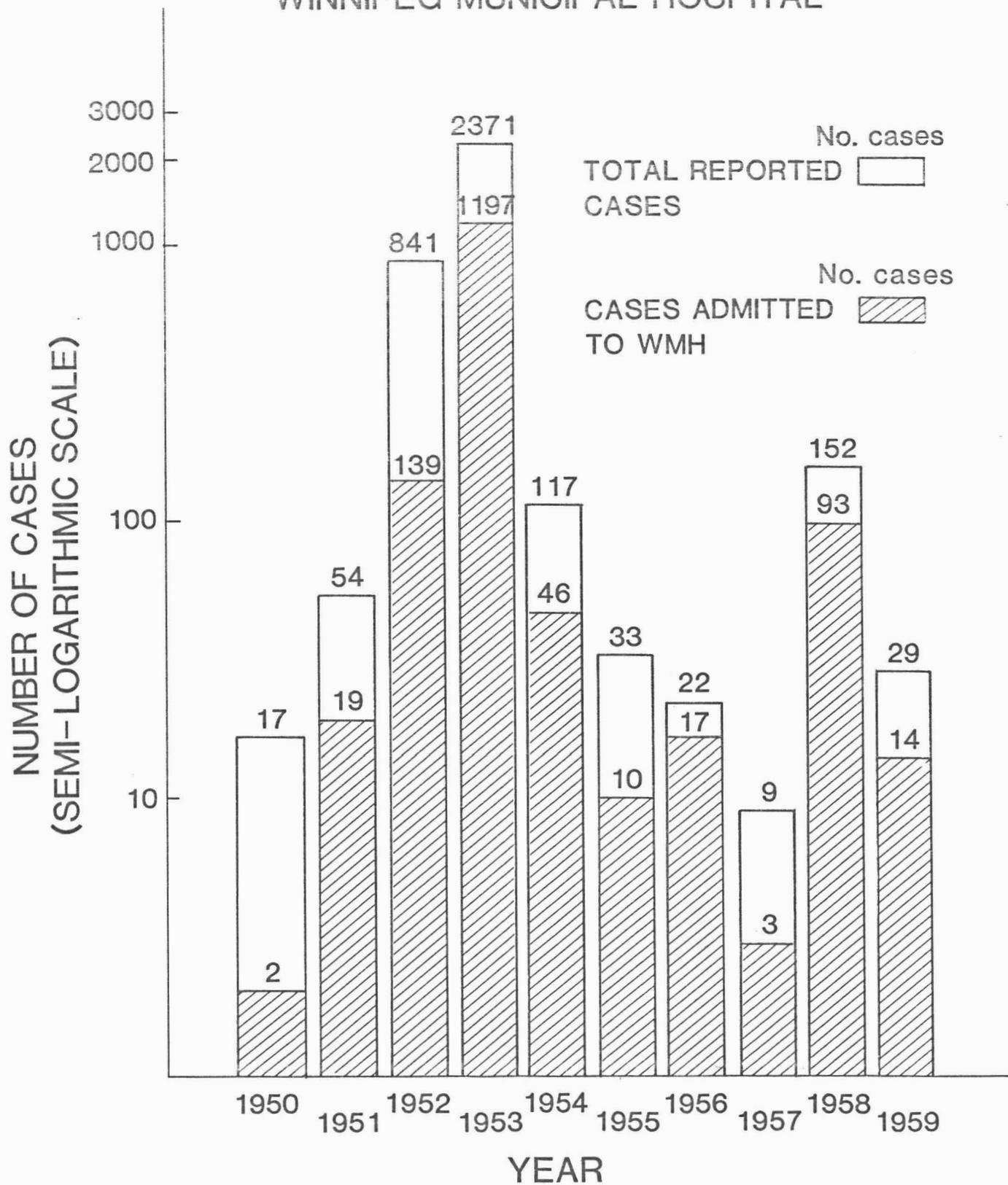
By combining data from the case register, follow-up surveys and data from the indepth interviews, the impact of social factors upon initial and long term adaptations have been assessed. These analyses show the impact of marriage, divorce, child bearing, employment and effects of long term institutionalization or home care arrangements. Variations in family patterns, employment history and independent living experience have been analyzed, controlling for the effect of the type of polio, severity and level of residual impairment. (A detailed analysis of the impact of socio-cultural factors on life carriers of respiratory and non-respiratory samples is presented in publications No. 3 (Alcock, Hildes, Kaufert, 1984) and No. 7 (Locker and Kaufert, 1984)).

SAMPLING DESIGN

The Manitoba polio follow-up studies drew samples from the population effected by the same major epidemics who were triaged and treated within the same medical care system. The follow-up studies have focused upon the last major North American epidemics of the 1950's immediately prior to the development of effective vaccines. A major outbreak of polio occurred in Manitoba during the summer of 1952 and was

FIGURE 1

MANITOBA CASES AND ADMISSIONS
WINNIPEG MUNICIPAL HOSPITAL



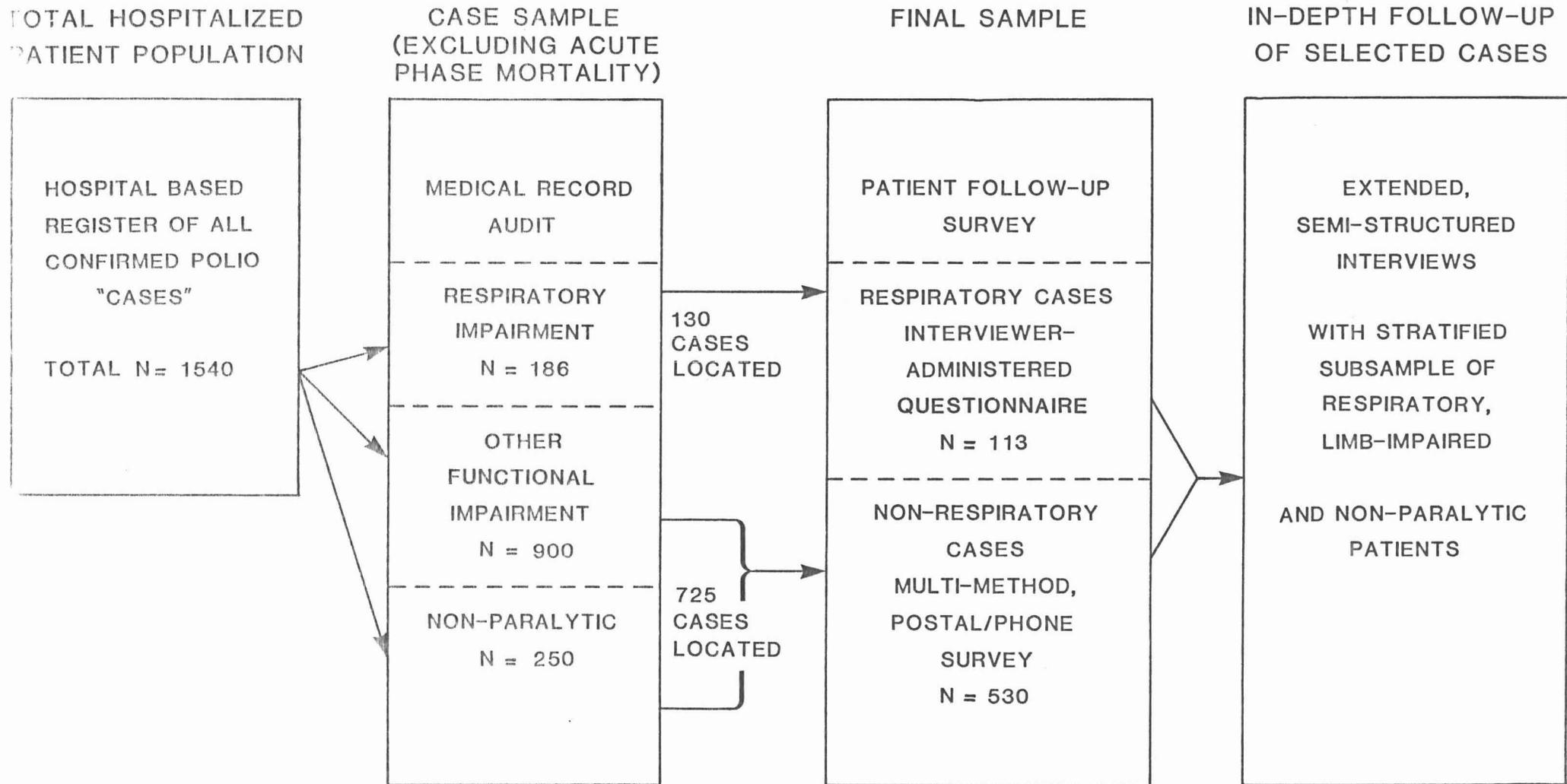
followed in 1953 by a massive epidemic in both urban and rural areas of the province. The total number of cases reached 2,300 representing an incidence of over 300 cases per 100,000 population. In 1954 the number of new cases of polio decreased to 117. In total there were 3,644 cases registered in the Province between 1950 and 1959. The last major outbreak of the decade was in 1958, when 152 cases were reported (Fig. 1).

Patients with respiratory polio required specialized equipment and medical care. Services 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. 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.

The Manitoba follow-up studies used the case register which included all the people with polio who were admitted to the WMH. By using this register as our population frame, we could avoid the selection bias that is inevitable in studies based on contact with a network of polio survivors. The register listed 1,540 patients who had been admitted and for whom the diagnosis of polio had been confirmed through lumbar puncture. In the first stage of the Manitoba study, we selected only those who had required mechanical respiratory support; the second stage extended the survey to

FIGURE 2

SAMPLING DESIGN FOR MANITOBA POLIO FOLLOW-UP SURVEYS



those with nonrespiratory involvement; including limb disabled and so-called non-paralytic patients. The final set of life historical interviews was conducted with stratified subsamples of respiratory and non-respiratory patients and focused on individual experience with disability, rehabilitation and independent living. The sampling design for the study is shown in Figure 2.

RESPIRATORY PATIENT SURVEY

Records were available for all 264 patients who were placed on mechanical ventilation and admitted to the WMH between 1950 and 1959. These records and data from the registry were reviewed by Dr. J. Hildes and Dr. A.S.J. Alcock, both of whom had been members of the medical team that had cared for respiratory 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 in the respiratory follow-up survey sample.

A primary objective of the respiratory follow-up study was to determine what had happened to each of the 186 patients through interviews with the individual or with the next-of-kin; 138 interviews were completed, yielding 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

available through review of 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 or could not be arranged. (Detailed mortality analysis and evaluation of respiratory effects are presented in publication No. 7 (Alcock, et.al., 1980) and publication No. 3 (Alcock, Hildes, Kaufert, 1984)).

Of the 186 patients, 56 were known to have died by March 31, 1980, when the data collection was completed. Examination of the medical records and death certificates provided data on the cause of death. This analysis revealed an inverse relationship 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 the documented fatalities. All the patients who died within the first 10 years after onset died from polio-related causes. Long term effects of respiratory poliomyelitis also resulted in long term vulnerability: 62% of the 16 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. The respiratory questionnaire included items measuring self-reported respiratory status (the patient's reported level of intermittent or daily dependence on respiratory equipment such as a rocking bed, an iron lung 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. Questions were added to measure more complex functions, such as the ability to drive a car, to document the complex adaptations to independent functioning in the community. Other items were included to measure more specific functions that were intended to measure specific forms of neuromuscular impairment related to the specific effects of poliomyelitis.

RESULTS OF RESPIRATORY SURVEY

(A detailed summary of the results of the respiratory survey is presented in publication No. 3 (Alcock, Hildes, Kaufert et.al., 1984) and publication No. 2 (Kaufert et.al., 1985)). However, it may be useful to summarize some preliminary findings of particular relevance to current understandings of late effects of poliomyelitis. Of the 113

ventilator-dependent 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 on the initial respiratory profile recorded in their medical records, they were described as having no residual respiratory problems. Only four individuals using long term mechanical ventilation reported needing more hours of respiratory support, but 33% had sufficient impairment to require occasional admission to hospital for respiratory care. 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 respiratory cases. In the early years, as the patients recovered from acute effects of their functional capacity often improved with rehabilitation and corrective corrective surgery. However, most of the respiratory cases achieved a stable level of 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. (Detailed results on the longitudinal analysis of data on respiratory and functional status change are summarized in publication No. 2 (Kaufert et.al., 1985)).

NON-RESPIRATORY PATIENT FOLLOW-UP SURVEY

A mail survey and review of baseline information on the case register were used to collect data on non-respiratory polio patients. Non-respiratory paralytic cases and cases of non-paralytic poliomyelitis were used as a comparison group in understanding the implications of alternate patterns of functional impairment. The case register and medical record system maintained by the Winnipeg Municipal Hospital was again used to define the sampling frame. The register included 156 patients from the 1952 epidemic and 1,050 from the 1953 epidemic. It provided demographic and clinical information on each case; including level of functional impairment and hospitalization experience. Demographic and functional data from the register provided a starting point for case-finding and assessment of mortality. Four different methods were used to locate former patients included in the register. These included:

- (a) search of hospital and rehabilitation records;
- (b) search of Manitoba provincial marriage and death registries to document mortality and trace women whose names had changed through marriage;
- (c) case location through limited search of name and address files provided by the Manitoba Health Services Commission; and

- (d) use of informal networks including family members, friends and other former patients.

Using this protocol, 700 of the non-respiratory cases were located and current mortality status was established for an additional 10% of the original patient population. Using the multimethod survey design, 530 people with non-respiratory polio completed the questionnaire; representing a response rate of 75% of the identifiable surviving cases. Analysis of the linked files of survey data from respondents and data from the case register of all non-respiratory cases established that the sample of respondents was representative of the original patient population in terms of demographic characteristics, medical history and functional ability.

RESULTS OF NON-RESPIRATORY PATIENT FOLLOW-UP SURVEY

Among the 530 respondents 21% described themselves having bulbar and spinal effects; 13% reported bulbar involvement alone, 42% only spinal involvement and an additional 24% reported no paralytic involvement in the immediate post acute stage. Fifty-six percent of the non-respiratory sample reported significant paralysis in their lower limbs during the acute and early rehabilitation stages of their illness. In describing their current status, only 37% of the respondents indicated that they still experienced significant functional limitations of their lower limbs and

only 25% felt that the lower limb disability imposed limitations on their mobility. Approximately 40% reported major upper body or upper limb paralysis during the acute phases of polio. In describing their status in 1982 twenty percent reported continuing impairment of upper limbs. However, only 12% of the total sample felt that this physical impairment imposed functional limitations in terms of performing activities of daily living. In looking at the impact of the functional impairment upon mobility, 32% of the non-respiratory sample rated themselves as having achieved independent mobility within the 12 month period following disease onset. This proportion increased to 48% after early rehabilitation. In 1982, 75% of the non-respiratory respondents indicated that they had achieved total independence in mobility. This change in functional status is reflected by the finding that the proportion of respondents totally dependent upon a helper or unable to perform basic mobility functions themselves included 36% of cases during the acute phases, 14% following the initial rehabilitation phase and only 4% of respondents to the 1982 survey.

Changes in ability to perform activities of daily living have direct implications for both the provision of formal care services and the need for informal care resources from the network of family and friends. In 1982 twelve percent of the non-respiratory survey respondents indicated that they required significant help with

activities of daily living and mobility. In most cases, this help was not provided by statutory services such as provincial home care workers, visiting nurses or attendants paid by the individuals themselves. Personal care services were most frequently provided by members of the family group. Spouses (11% dependence) and children (12% dependence) were the most significant helpers. Spouses were more likely to be designated as "pivotal helpers", without whose assistance independent functioning would not have been possible. Unpaid helpers other than family members formed the primary support for only 5% of the non-respiratory cases. While home care services were originally provided to 56 or nearly one-third of the respiratory patients, only about 5% of the non-respiratory respondents reported that they currently received home care services.

Current patterns of medical care utilization among the respondents to the non-respiratory survey contrasted directly with patterns of use among respondents to the respiratory survey. About two thirds of the respiratory patients had continuing contact with specialists, respirologists or rehabilitation specialists. The non-respiratory sample reported less regular consultation patterns with specialized medical care providers. Twenty-nine percent of the non-respiratory sample indicated that they had sought medical advice for polio-related problems within the previous year. The most frequently consulted type of practitioners were orthopedists. Medical consultation

also occurred with surgeons and general practitioners. Some indication of the extent to which consultation about orthopedic problems may involve patients in going outside of traditional rehabilitation medicine was the finding that the second most frequently consulted type of practitioner for polio-related problems were chiropractors.

Twenty-five percent of the non-respiratory patients reported experiencing significant problems with arthritis. Although arthritis is a prevalent disease among middle aged and elderly people in the general population the high level of reported incidence may reflect late effects of compensating for neuromuscular and orthopedic impairment over many years. Levels of reported hypertension may also have been slightly higher than among the general populations with 14% of the respondents reporting that they currently were receiving clinical consultation for hypertension. Reported levels of other chronic disease effects were comparable to those reported among normal aging populations with similar characteristics.

LIFE HISTORY INTERVIEWS

The third stage of the Manitoba follow-up survey involved conducting a series of in-depth interviews with a subsamples of respondents with specific types of respiratory and non-respiratory impairment. Using the profile of socio-demographic data from the sample survey, selected informants were chosen because they had specific patterns of functional

impairment, or because they had developed specific patterns of adaptation (such as continuing use of respiratory support equipment). Another group was selected because they had had specific experience in developing programs for other disabled people.

The series of in-depth interviews were completed as the final stage in the research program. These life historical interviews explore the subjective experience of living with polio-related disability from the perspective of selected informants. The interview format allows the in-depth examination of issues which are less accessible through a structured survey questionnaires. Life historical interviews have been used in studies of disability by medical anthropologists and medical sociologists. One criticism levelled at indepth interviews with selected informants is that investigators usually cannot relate the characteristics of those interviewed to the characteristics of the population. Through linkage of the life historical interviews with the epidemiological data from the follow-up surveys and record audit it was possible to assess the representativeness of the selected respondents whose experience was documented in greater depth.

The in-depth interviews provided an alternative method of exploring the relationship between aging as a social process and disability changes defined in terms of functional ability. Life historical interviews generated

detailed verbal reconstructions of rehabilitation experience and descriptions of more recent life crisis events such as respiratory insufficiency or equipment failure. At a more general level, individual life historial summaries provided a means of understanding what impact an event, such as respiratory paralysis, had on the course of the persons' adaptation. By using the in-depth interview, it was possible to examine the persons' perception of the relationship between residual disability and aging processes from the perspective of individuals who were currently developing alternate adaptations and coping strategies.

In addition to the information obtained from life historical interviews focusing upon individual experience with disability, the final stage of the project has also included a series of directed interviews with clinicians, rehabilitation specialists and representatives of consumer organizations representing the perspectives of the disabled community. These interviews were provided documentation of the contextual factors which have influenced the life experience of people who were disabled by polio in the 1950's.

The context of disability at the time of the polio epidemics could therefore be reconstructed using descriptions of acute care and rehabilitation approaches of the 1950's, 60's and 70's. A comprehensive review of press archives and rehabilitation literature dealing with public

responses to polio was also undertaken. Sources included medical and rehabilitation literature, media coverage of the epidemics and government documents describing public policy influencing rehabilitation services and equalization of opportunity for the disabled. These sources were used to supplement data from interviews with patients or care givers. This combination of archival research and interviews with specialist informants was used to expand archival data on issues such as public policy changes in the fields of medical care and rehabilitation, the role of voluntary organizations in rehabilitation and the emergence of independent living movement among disabled consumers. One set of interviews was conducted with people who were active in bringing about change in opportunities for disabled people, at the national and local levels.

IMPACT OF POLIO UPON LIFE TRAJECTORIES

Analysis of data from both surveys and from the life historical interviews revealed that as individuals described the impact of polio on their lives, most did so in terms of an 'expected' pattern or life trajectory. The concept of "trajectory" was applied to describing the way in which respondents perceived their life would have proceeded had polio not occurred. As they aged, respondents' actual life trajectory were described in terms of the degree of fit which they had been able to achieve with idealized trajectories (eg., whether respondents were able to return

home, whether they were able to go to school or to the university, whether they were able to continue with their previous work, whether they were able to remain married or to get married, if they were single).

It is clear both from responses to the life historical interviews and from an analysis of the survey-based data, that age at onset was a critical variable in understanding the social consequences of long term disability. Individuals who were adults when they developed polio had already established the attributes of an adult career: marriage, parenthood and economic independence through work force participation. Respondents who were young adults tended to describe life trajectories which were much more focused on the disruption of established life career patterns. Individuals who were children when they developed polio had still to pass through the stages of later childhood and/or adolescence and entry into adulthood. Their access to education, access to marriage partners and parenthood, and access to employment, were all influenced to a greater or lesser extent by the level of impairment and relative access to care resources during the acute stage of illness.

The characteristics the family to which an individual returned following rehabilitation was a function of the individual's age when impairment occurred. The young children returned to their parents; the adults often returned to families of their own creation. Some of the

women had young children or were pregnant when they contracted polio. The divorce figures among respiratory respondents provide the most dramatic insight into the impact of polio on the family. One-third of the marriages which existed before polio onset ended in divorce, and 80% of those divorced mentioned the impact of poliomyelitis as a causal factor. Less obvious is the impact of polio in decreasing the opportunities of younger patients to become married. Assuming that the children and the single adults constitute a group which was potentially eligible to marry, only 46% of those with respiratory polio did, in fact, become married.

The family structure of the person at the time of polio onset was a critical determinant of the long term prospects of institutionalization or return to the community among the subsample of cases with severe respiratory impairment. Among the respiratory patient sample, the majority of those who were children (86%) had returned home after rehabilitation; another 11% had been discharged under the provision of the home care program; only one of these former children remained in long term hospital care. On the other hand, 29% of the single adults and 23% of those married when they developed polio were in long term care environments in 1980. Discharge arrangements were also related to changes in marital status. Among the individuals in long term care who had been married when they developed polio, 77% were divorced or widowed. These variations in discharge

arrangements clearly must be more fully analyzed in terms of age-related gradients in the levels of initial and current functional status, in order to understand the interaction between disability measures and family characteristics influencing social support.

Uncertainties attributed to late polio-related aging effects may also influence and be influenced by the family and friendship providing support. Both surveys included measures of the degree to which people were dependent on help in order to maintain mobility and to be able to carry out the functions of daily living. A major concern for many individuals who depended upon others was the impact of aging on those on whom they depend for maintaining independent adaptations. This concern about the impact of aging upon members of family support systems was repeated in responses to life historical questions. Over the years, many respondents established a complex, but relatively durable system of support, but one which depended on a single other person. Any threat to the latter posed an indirect but potent threat to their own independence. Aging, with its associated risk of morbidity and mortality was seen as such a threat. Furthermore, the possibility of finding alternative resources within the public sector was viewed as being directly influenced by changing policies towards income maintenance, employment of disabled people and by current initiatives of the disabled consumers movement.

(Details of the analysis of the life historical data are presented in, Locker, D. and Kaufert, J., 1985).

Publications Summarizing Results of N.H.R.D.P. Supported
Follow-up Studies of Poliomyelitis Patients

(Reprints of Publications Appended as Appendix A)

1. Kaufert, P.A. and Kaufert, J.M. "Methodological and Conceptual Issues in Measuring the Long Term Impact of Disability: The Experience of Poliomyelitis Patients in Manitoba", Social Science and Medicine, Vol. 19, No. 6, pp. 609-618, 1984.
2. Kaufert, J.M., Syrotuik, J., Kaufert, P. and Gilbert, P.K. "Epidemiological Issues in Follow-Up Studies of the Impact of Poliomyelitis" In: Halstead, L.S. and Weichers, D.O. ed. Late Effects of Poliomyelitis, Symposia Foundation, pp. 135-152, Miami, 1985.
3. Alcock, A.J.W., Hildes J.A., Kaufert, P.A., Kaufert, J.M. and Bickford, J. "Respiratory Poliomyelitis: A Follow-up Study", Canadian Medical Association Journal, Vol. 130, May 15, 1984.
4. Kaufert, J.M. Alcock, A.J.W., Kaufert, P.A. and Bickford, J. "Rehabilitation of Rural and Urban Poliomyelitis Patients: The Manitoba Experience" In: Proceedings, Internatinal Conference on rural Rehabilitation Technologies, UMO Press, Grand Forks, pp. 21-25, 1984.
5. Kaufert, J.M. and Kaufert, P.L. "Aging and Respiratory Polio", Rehabilitation Digest, Vol. 13, No. 2, pp. 15-17, 1982.
6. Kaufert, J.M. "What Factors Today Must be Considered to Meet the Complex Health Care Needs of Polio Survivors", Proceedings of First International Post-Polio Conference, Rehabilitation Institute of Chicago, March of Dimes, pp. 93-95, 1982.
7. Alcock, A.J.W., Hildes, J.A., Kaufert, P.A., Kaufert, J.M., and Bickford, J. "Respiratory Polio Rehabilitation in Manitoba", University of Manitoba Medical Journal, Vol. 50, No. 3, pp. 83-93.

Submitted for Publication

1. Locker, D. and Kaufert, J. "The Breath of Life: Medical Technology and the Careers of Post-Respiratory Polio Patients", (currently under review for publication in Sociology of Health and Illness), 1985.
2. Kaufert, J. and King, A. "Alternate Approaches to Normalization: The Experience of Polio Survivors with Rehabilitation Medicine and the Independent Living Movement", (submitted for publication).

Scientific Papers Presented 1981-84 on Methodology and Results of Manitoba Polio Patient Follow-Up Surveys

(Reprints of Selected Abstracts and Papers Included in Appendix B)

1. Kaufert, J. and King, A. "Alternate Approaches to Normalization: The Experience of Polio Survivors with Rehabilitation Medicine and The Independent Living Movement", American Anthropological Association, Nov. 15, 1984.
2. Kaufert, J., Alcock, J. and Kaufert, P. "The Experience of Rural and Urban Polio Patients. International Rehabilitation Technologies Conference, Grand Forks, Oct. 15, 1984.
3. Kaufert, J.M., Syrotuik, J., Kaufert, P.A. and Gilbert, P. "Epidemiological Issues in Follow-up Studies of the Impact of Poliomyelitis". Research Symposium on the Late Effects of Poliomyelitis. Warm Springs Georgia Institute for Rehabilitation, May 26, 1984.
4. Kaufert, J.M. "Research Problems in the Analysis of Post-Polio Aging". Grand Rounds Presentation, Royal Ontario Rehabilitation Hospital, Ottawa, January 24, 1983.
5. Kaufert, J.M. "Problems of Validity in Measuring the Functional Ability of Former Polio Patients". Presentation as Visiting Professor, Department of Rehabilitation Medicine, Royal Ontario Rehabilitation Hospital, Ottawa, January 25, 1983.

6. Kaufert, J.M., Gilbert, P., Wong, K. "Disability and Changing Rehabilitation Policy: The Long Term Impact of Polio Epidemics". Annual Scientific Meeting, Society for Applied Anthropology, San Diego, March 18, 1983.
7. Kaufert, J.M. "Epidemiological Approaches to the Study of Post-Polio Aging Effects Among Non-Respiratory Cases". Second International Post-Polio Conference and Symposium on Independent Living, St. Louis, May 6, 1983.
8. Kaufert, J.M. "Disability and Aging Processes in the Middle Years: The Experience of Post-Polio People in Manitoba". Keynote address, Canadian Rehabilitation Council for the Disabled Annual Meeting, St. Catherines, June 10, 1983.
9. Kaufert, P. and Kaufert, J.M. "The Long Term Impact of Disability: Examples from a Study of Polio", American Anthropological Association Annual Meeting, Chicago, December 5, 1983.
10. Kaufert, J.M. "Disability and the Aging Process: A Longitudinal Follow-Up Study of Poliomyelitis Patients". International Meeting, Society for Applied Anthropology, Edinburgh, April 16, 1984.
11. Kaufert, J. "What Factors Must be Considered in Meeting the Complex Health Care Needs of Polio Survivors". International Conference on Respiratory Rehabilitation and Post-Polio Aging Problems, Rehabilitation Institute of Chicago, Chicago, October 14, 1981.
12. Kaufert, P. and Kaufert, J. "Disability and the Aging Process: The Experience of Respiratory Polio Patients". Scientific Meeting, Combined Meeting AGA and Canadian Association on Gerontology, Toronto, November 5, 1981.
13. Alcock, A.J.W., Hildes, J., Kaufert, P.A., Kaufert, J.M. and Bickford, J. "Respiratory Polio, the Long Term Impact", International Conference of World Rehabilitation International, July, 1980.

APPENDIX A

METHODOLOGICAL AND CONCEPTUAL ISSUES IN MEASURING THE LONG TERM IMPACT OF DISABILITY: THE EXPERIENCE OF POLIOMYELITIS PATIENTS IN MANITOBA

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Abstract—This paper is based on a Canadian study which is examining the long term impact of disability among people who developed respiratory or non-respiratory polio during the epidemics of the 1950s and who were admitted to the same Manitoba hospital, the centralized treatment centre for the Province. This research is exploring change in the lives of these individuals by focusing on three conceptually distinct, although empirically overlapping areas or dimensions. The first is called the 'trajectory of disability' and refers to changes in functional status. The second includes those changes which are the product of the interaction between the normal processes of aging and the long term impact of poliomyelitis. The third is changes in the context of disability. This refers not only to changes in medical and technological knowledge, but sociopolitical developments including the emergence of a Disabled Rights Consumer Movement. This paper discusses the methodological and conceptual issues involved in the study, particularly its combination of different methods of data collection and the value of its historical-prospective design for capturing the effects of change over time in each of these different dimensions.

INTRODUCTION

The long term effects of polio related disability are being examined in a study taking place in the Province of Manitoba, Canada. This project is exploring the impact of polio in terms of both the changes which people have experienced in the past and those they anticipate in the future. Everyone included in the study population developed polio during the 1950s when there were two major epidemics in Manitoba, one in 1952 and a second, larger one, in 1953.

The Manitoba study is looking at changes over time in three conceptually distinct, although empirically overlapping, dimensions in the life of an individual with poliomyelitis. The first dimension, labelled the 'trajectory of a disability', refers to changes in functional status, reflecting improvement, decline or periods of relative stability after recovery. The second dimension includes those changes which are a product of an interaction between the processes of normal aging and polio related disability. There is currently a debate over whether changes due to aging occur independently from changes attributable to the long term impact of polio or whether each may influence the other. The Manitoba study is concerned not only with aging as a physiological process, but with aging as a social process in which an individual passes from childhood through adulthood and into later life. There are specific events associated with each stage, such as entry into school, becoming employed, marriage and parenthood. The Manitoba study has looked at the impact of polio on individual experiences of each of the life stages through which they have passed during the previous 25 years.

The third dimension focuses on changes in the context of living as an individual with disability. These include developments in medical and rehabilitation technology, public policy and programs for the disabled and public attitudes towards individuals

with disability. The period since 1950 has also witnessed the emergence of the Disabled Rights Movement whose activities have transformed the social and psychological context in which any individual with disability lives. Many of the leaders in this movement had polio. In examining the life experience of the group who developed polio during the 1950s, the Manitoba study is looking at the factors which might explain their role within the Disabled Rights Movement.

In its exploration of each of these dimensions, the Manitoba study has used a medical record review, the collection of mortality data, two cross-sectional surveys, 70 in-depth interviews and analysis of historical materials. These methods have been drawn from epidemiology, sociology, anthropology and contemporary history—a multi-disciplinary approach which was a response to the multi-issue character of the project.

This paper presents a discussion of the methodological and conceptual issues involved in the Manitoba study. First, it will discuss the combination of methods used to explore each dimension, the reasons for choosing a particular method and the overall advantages of combining multiple methodologies in disability research. Second, each dimension will be described in more detail, using material from the Manitoba study as illustration. While the effects of polio provide the focus for this discussion, many of the concepts involved can be applied in research on the long term impact of any disabling condition. The first part of the paper focuses on methodology.

METHODOLOGICAL ISSUES

The study population

The Manitoba study takes its population from a case register which lists the 1540 patients admitted to

the Winnipeg Municipal Hospital (WMH) with a confirmed diagnosis of polio between 1950–1959. This hospital was the officially designated treatment centre of the Province of Manitoba during the 1952 and 1953 poliomyelitis epidemics. In the sampling design for the study (see Fig. 1), subsamples with different types of impairment were selected from the register. The composition of each group was partly determined by the practical difficulties of case finding after an interval of over 25 years. Sampling also depended on the methodology being used at that point in the project and on the fact that the study was divided into two stages, one focusing on respiratory and one on non-respiratory poliomyelitis.

When the Manitoba study began in 1980, it included only the 186 individuals who had required respiratory support during their initial treatment and who had survived for 3 months; we were able to determine what had happened to 174; 130 were known or thought to be alive and 113 were interviewed. The second stage in the study included all the non-respiratory cases admitted to the WMH during the 1952 and 1953 epidemics. The register held sufficient information on 1150 individuals; 725 could be located, of whom 530 completed and returned a mail questionnaire. A third stage consists of 70 in-depth interviews for which individuals were selected, either because they are representative of people with particular types of impairment or because they have been active as change agents, whether at an individual, local or national/international level.

The trajectory of disability

Strauss and Glaser [1], used the term 'trajectory' to describe the course of terminal illness, but the concept is equally applicable to the course of a disabling condition. As in the case of terminal illness, the path followed by a trajectory will vary with the characteristics of that condition and their interaction with the characteristics of the individual. Some trajectories, such as those associated with multiple sclerosis, are marked by high levels of uncertainty as the direction of change may reverse, stabilize or move rapidly into decline. In other diseases, after an initial loss of functional capacity, a recovery period is followed by a relative absence of further change. This latter type of trajectory is characteristic of poliomyelitis according to all but the most recent medical literature.

Most studies of disability are limited in their ability to discuss change by their cross-sectional design. For example, a cross-sectional study, based on a population of people who had polio 25 years earlier, would exclude those who did not survive and those who recovered so completely that they were no longer counted within the population of the polio disabled. The absence of either group would bias any effort to assess the long term impact of poliomyelitis. Furthermore, such studies can only describe an individual's functional status at a single point in time and cannot deal in any satisfactory manner with past or future changes. Applying the concept of a trajectory in disability research requires a different methodological approach; one capable of studying disability as a process occurring and changing over time.

Ideally, research using the concept of trajectory should be longitudinal in design and should begin at the point of onset. Some studies have looked at long term changes in older, disabled populations [2, 3] but longitudinal studies of disability are few in number. Among those which exist, Davis' [4] study of children with polio is typical in that it followed a small group of individuals through the initial stages of recovery and rehabilitation. Most prospective studies last only 2 or 3 years as they are limited by factors of both time and cost. There is little information available on what happens after the first few years, although most of the studies were looking at forms of disability which would remain and effect the rest of an individual's life.

Given the impossibility of a true prospective research design, the Manitoba study adopted the historical prospective design familiar to epidemiologists. In this design, the study population shares a common characteristic, usually exposure to a known risk factor at some designated point in time. For example, a population might include everyone in a shipyard work force with a known exposure to asbestos. By tracing and recording mortality and morbidity within the study population over the years since their initial exposure, an epidemiologist would hope to determine the incidence of lung cancer. This design is preferred to the retrospective study because by starting from exposure to risk rather than from cases of the disease, it can provide incidence rates and a more accurate estimate of the degree to which those who develop a disease are representative of those initially exposed to the risk factor.

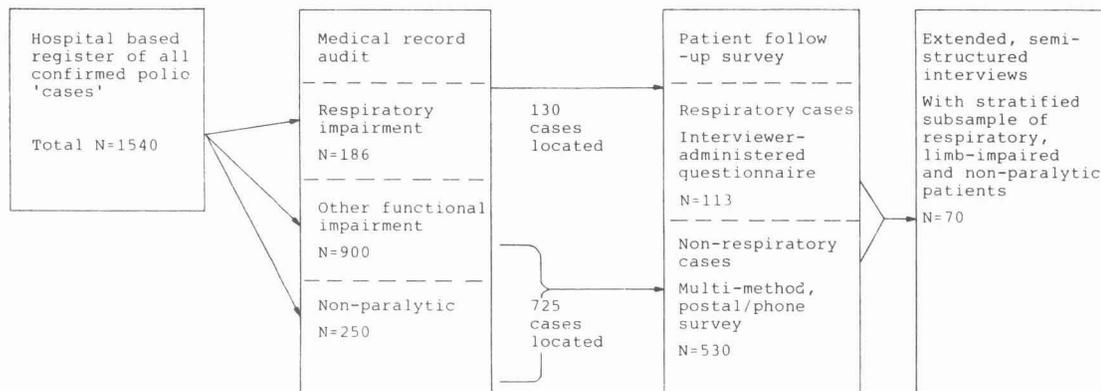


Fig. 1

The method of population selection used in the Manitoba study of poliomyelitis is an adaptation of the historical prospective design. The case register provides the equivalent to an 'exposed population' in epidemiological research, for it is a complete listing of the 1540 individuals admitted to the WMH between 1950-1959. As shown in Fig. 1, two groups were selected from the register; the 186 cases with, and 1150 cases without, respiratory polio. This method avoids the selection bias of most cross-sectional studies by including both those who did not survive until 1980 and those who fully recovered and who are apparently without any residual disability.

The register provides basic socio-demographic and medical data, including age, sex, marital status, type of polio, the use of respiratory equipment, surgical and rehabilitation procedures and levels of impairment initially and after rehabilitation. All this information was recorded at the time. As this is not retrospective data, it becomes possible to compose a summary profile, which is not subject to recall bias, of what occurred to each individual during the acute and initial stages of polio.

As in any historical prospective study, the type of data available is limited by what was pertinent to those making the initial record rather than by what would currently interest the researcher. Nevertheless, by correlating information from the case register with information on mortality gathered while tracing this population, it is possible to look at basic survival patterns. Furthermore, by using the mortality data, the association can be examined between survival and either disease severity at onset, or age at onset or residual respiratory capacity. The adoption of this design coupled with the effectiveness of the case-finding protocol has enabled the Manitoba study to provide documentation on the survival patterns which are characteristic of the trajectory of poliomyelitis over a 25 year period.

There is less complete coverage on changes in functional status over the course of the trajectory as there can be no information on those who died or on those we were unable to trace. Data on functional status in 1980 or 1982 are available only from the interviews with the 113 individuals with respiratory polio and from the mail questionnaire completed by 530 non-respiratory respondents. Both the interview schedule and the questionnaire included the same measures of functional status; these were extended and modified versions of the Katz [5] 'Activities of Daily Living Scale', plus summary self-assessments of respiratory capacity, mobility and ability to perform the activities of daily life. Two clinicians, using the same scales, summarized the data on functional status as recorded in the case register and medical records on the same individuals [6]. This combination of survey data and medical record audit provided measures of functional status at three points in time; at onset, after rehabilitation, and in 1980 or 1982. Inevitably, the analysis of these data can describe change only among those for whom there is this third measurement. Despite this limitation, the Manitoba study has the great advantage of being able to use measures based on data recorded at the time rather than retrospectively.

Survival and changes in functional status are two

aspects of the trajectory of poliomyelitis; a third aspect is the meaning of the trajectory to the individual concerned. Answers to this question required a different methodology. A series of 70 in-depth interviews are currently being completed as the final stage in the research (Fig. 1). These are being used to explore the subjective experience of having polio from the perspective of representative informants. The interview format allows the in-depth examination of issues which are less accessible through a structured questionnaire. This method of data collection has been used in studies of disability by medical anthropologists or ethnomethodologists [7, 8]: one criticism levelled at such research is that it is usually incapable of relating characteristics of those interviewed to the characteristics of the population they represent. By contrast, in the Manitoba study, it is possible to assess how representative of the whole population are any of the subgroups involved in different stages, including this in-depth interview phase.

To summarize the discussion of these different methodologies: the historical-prospective design of the Manitoba study is taken from epidemiology; the measures of functional status used in the surveys come from the sociology of disability; the in-depth interviews are more the techniques of the ethnologist. The objective of using these different methodologies is to build an understanding of the trajectory which would be inaccessible by one method alone. The same multi-method approach was used to explore the other two dimensions, 'Aging and Disability' and the 'Context of Disability'. The next section will describe the methods used to explore each of these dimensions.

Aging and disability

Data was collected on the relationship between disability and aging as a physiological process and disability and aging as a social process. A central issue in the Manitoba study is whether differences in functional status can be explained by the physiological changes associated with aging. Research done using cross-sectional data suggests such an association exists. The Manitoba study's historical prospective design allows a more complex analysis of this issue, because data can be introduced on the age and functional status of the individual when they developed polio. These data showed that the age at which an individual developed polio was related to its severity and the level of residual impairment. This analysis suggests that the functional status of an individual in 1980 or 1982 reflects age related differences which date back over 25 years rather than being simply a product of current aging.

The historical-prospective design has other advantages when exploring aging as a social process. Data on social characteristics as provided by the case register are limited to age, sex, marital, parental, occupational and residential characteristics. Although scanty, these data are sufficient to locate each individual according to the stage they had reached in the life cycle. The study population falls into two main clusters, children under 10 and adults below 30 at age of onset; by 1980, this meant a population of adults in early or late middle age.

Building on these data, other comparisons can be

made between a social characteristic at onset and the same characteristic in 1980. Such analyses show whether people married, divorced, had children, worked; whether they remained permanently or intermittently in hospital; whether they lived independently of aid or required assistance from others. This information can be related to the type of polio, its severity and its level of residual impairment. By examining the events which did or did not occur in the life of an individual, one can begin to understand how the interaction between polio and aging can be interpreted in terms of its social consequences. For example, severity of impairment after respiratory polio is related to permanent hospital residence only for those who were adult at onset; this group also had a much higher probability of divorce. The implications of these data are discussed later in the paper.

The in-depth interviews were the third method of exploring the relationship between aging as a social process and disability. Simic [9] has argued that the collection of life histories (which he sees as a central tool of the anthropologist) is a method particularly pertinent to the anthropology of aging. He claims that "questions of change and accident in studying human behaviour and culture" may be best understood by examining the accounts that individuals, particularly elderly individuals, give of their lives. In the Manitoba study, Simic's arguments are applied to the use of the life history as a means of understanding what impact an event, such as polio, has on the course of an individual's life. By using the in-depth interview method, it becomes possible to look at the relationship between polio and aging from the perspective of the individual and to ask how they interpret the interaction between the two.

The context of disability

The third dimension refers to the array of political, economic, social and medical changes which have altered the context in which an individual with polio has lived over the past 25 years. The case register and medical records contain little information beyond data on the technology and rehabilitation procedures in use at the time of the Manitoba epidemics. The two surveys collected data on service and equipment use, rehabilitation, training and employment histories, residential and income data, membership in societies of the disabled or the use of services provided by societies for the disabled. The majority of these data relate to current practice, but some are reconstructions of past experience, such as the employment and educational histories.

The context of disability at the time of the polio epidemics can be reconstructed using what people recall of events from that period and by consulting material written at the time. The latter includes medical and rehabilitation literature, media coverage of the epidemics and government documents describing public policy. The use of these accounts supplements the data obtained from interviews with those involved in the epidemics, whether as patients or care givers. This combination of archival research and interviews with specialist informants was used to collect data on such issues as public policy changes, the role of voluntary organizations and on the emergence of political activists from within the com-

munity of the disabled over the period from 1952 to 1981. The individual's perception of changes in the context of disability is another issue discussed during the in-depth interviews. One set of these interviews is with people who were active in bringing about change, whether at a national, local or individual level. The aim is to recreate history from the perspective of people who effected change and were not simply affected by it.

This combination of archival material and of interviews with key informants is the fourth method used in the study. Like each of the others, its use was determined by the nature of the questions being asked. These were the product of the concepts which underlie this study. It is these concepts which are to be discussed in the second half of this paper.

CONCEPTUAL ISSUES

The trajectory of disability

The term 'trajectory' was chosen because it expresses the concept of disability as a process occurring through time rather than as a static condition to be understood at any one point in time. By taking a more dynamic perspective, change in levels of impairment becomes a central issue. In any medical situation, the ability to predict change will depend on the characteristics of the specific disease or type of impairment and also on the knowledge level and amount of information available to the individual making the prediction. A clinician can draw on the medical literature and on clinical experience; the individual patients must use their own experience, their observation of other patients with the same condition and whatever clinical information they can gather from their physician or other members in a health care team.

The passage of both patient and clinician from uncertainty to certainty about the future course of the disease has been described in Davis' [10] study of polio. During the initial acute stage, survival itself could be uncertain. This stage was followed by a recovery period. The rehabilitation ideology of the 1950s was that full recovery was attainable through will power and hard work. Yet, it was characteristic of poliomyelitis that an individual's condition would stabilize within the first five years or sooner with the possibility of little further change. In Davis' [4] account, the medical and rehabilitation experts were the first to recognize what would be the permanent level of functional impairment for many individuals, but were slow to share this knowledge with patients or their families. Families, partly because they did not have the same access to clinical information or experience, partly because they were influenced by the prevailing rehabilitation ideology, were slower to recognize that further physical recovery was unlikely [4].

The relationship between levels of clinical and patient uncertainty and actual changes in a patient's level of functional status are shown in Fig. 2. Davis' [4] study describes only the first three of the five stages illustrated. The complete figure describes the trajectory of poliomyelitis in terms of the long term experience of the population followed-up in Manitoba. The use of the case register and medical record

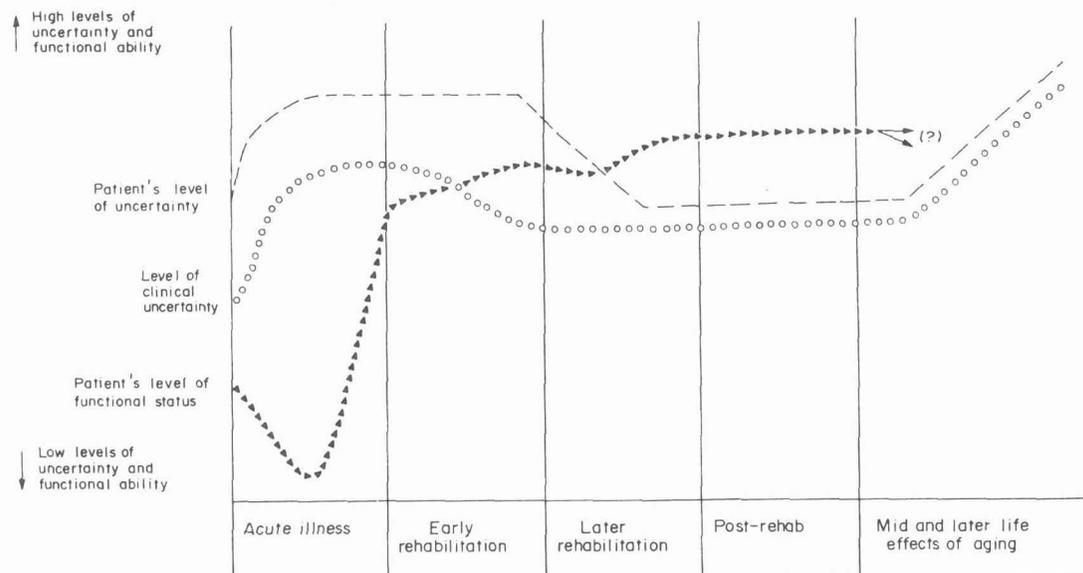


Fig. 2. Changes in level of uncertainty and functional ability levels in polio patients' careers'.

data were necessary to describe the 'Acute Illness', 'Early' and 'Late Rehabilitation' stages. Data on the fifth stage comes from the cross-sectional surveys. A comparison between person's definition of his or her status in 1980 or 1982 and the status after rehabilitation suggested that the fourth stage in the trajectory was best described by a straight line. Few of those taking part in either survey reported either increases or decreases in their functional ability since the end of the third stage.

One caveat must be made. Although the overall impression is of stability, an analysis of the survival data showed that for some groups, the absence of change did not imply certainty. Particularly among respiratory patients, mortality associated with the residual impact of polio could occur many years after its onset [11]. In the sense that some have remained at continued risk, their uncertainty about the future has continued despite the apparent stability of their condition.

A renewed uncertainty about the future now faces many more of those who had polio. This is why the mid- and later life trajectory of functional status is characterized by unresolved questions. Changes in functional status have been discussed at two recent conferences on polio and aging [12, 13]. The question is whether the stable pattern which is characteristic of the rehabilitation and post-rehabilitation portions of the trajectory followed by poliomyelitis, will continue or whether people will experience marked decreases in their functional ability as they age.

Physicians attending the two conferences reported that former polio patients were complaining of new symptoms, such as pain, muscle fatigue and tiredness [14, 15]. Some argued that long term pathological processes specific to polio were the cause of these symptoms. Others suggested that the cumulative stress of over 25 years of impaired functioning creating the effects reported by patients. A third explained was that these functional problems are a product of the normal processes of aging. The proponents of this latter perspective suggest that rela-

tively minor declines in functional capacity due to aging were sufficient to disturb a physiological balance which was already but marginally maintained [16].

Fuller understanding of these questions will depend on both laboratory and clinical research as well as epidemiological research, such as the Manitoba study. Preliminary analyses of the Manitoba data suggest that when looking at the current processes of aging, it is essential to control for related differences in the initial impact of polio.

The Manitoba study is looking not only at questions of post-polio aging but also at the re-emergence of uncertainty about the future course of the trajectory of disability. Uncertainty about the future was a persistent theme in the in-depth interviews. It was evident not only when respondents discussed change in their functional status, but in relation to other areas of their life as they grew older and as the socio-political and economic environments also change. The paper will return to the issue of uncertainty in the next sections on aging and disability and the context of disability.

Aging and disability

Smelser [17], suggests that change in an individual over time should be seen in terms of a pattern or a series of contours. The events which shape the different contours are sometimes inevitable such as death or growing older, and sometimes highly probable although not inevitable, such as marriage, parenthood, beginning work. This will "vary historically and cross-culturally as values, norms and social structures vary" and "according to the ways in which they are interrupted by unanticipated events, such as premature death, debilitating illness, unemployment and so on" [17]. Smelser was concerned with delineating the 'normal', the 'expected' pattern. Research on the long term impact of disability is concerned with what happens when an event, such as the onset of polio, disrupts the pattern and the contours have to be redrawn because disability creates a new con-

straint on their form. In the data derived from the in-depth interviews, it became clear that as individuals talked about the impact of polio on their lives, most did so in terms of an 'expected' pattern or life trajectory; the way in which their life would have proceeded had polio not occurred. As they aged, their actual life trajectory was described in terms of the degree of fit which they had been able to achieve to this 'expected' pattern. For example, whether they were able to return home, whether they were able to go to school or to the university, whether they were able to continue with their previous work, whether they were able to remain married or to get married, if they were single.

It is clear both from the in-depth interviews and from an analysis of the survey collected data that age at onset is a critical variable in understanding not only the physiological, but also the social consequences of long term disability. Individuals who were adults when they developed polio had already established the attributes of an adult career: marriage, parenthood and being economically productive, whether in the work force or as housewives. Their life histories were much more focused on the disruption of established life career patterns. Individuals who were children when they developed polio had still to pass through the stages of later childhood and/or adolescence and into adulthood. Their access to education, access to marriage and parenthood, and access to employment, were all influenced to a greater or lesser extent by the level of impairment and relative access to care resources.

The form of the family into which an individual returned was a function of the individual's age when polio occurred. The young children returned to their parents; the adults often returned to families of their own creation. Some of the women had young children or were pregnant when they contracted polio. The divorce figures among respiratory respondents provide the most dramatic insight into the impact of polio on the family. One-third of the marriages which existed before polio onset ended in divorce, and 80% of those divorced ascribed the end of their marriage to polio. Less obvious is the impact of polio in decreasing the opportunities of younger patients to become married. Assuming that the children and the single adults constitute a group which was potentially eligible to marry, only 46% of those with respiratory polio did, in fact, become married.

Family status at onset was significantly related to the pattern of discharge reported by former respiratory patients. The majority of those who were children (86%) had returned home after rehabilitation; another 11% had been discharged under the provision of the home care program; only one of these former children was in long term care. On the other hand, 29% of the single adults and 23% of those married when they developed polio were in long term care environments in 1980. Discharge arrangements were also related to changes in marital status. Among the individuals in long term care who had been married when they developed polio, 77% were divorced or widowed.

The uncertainties of aging relate not only to the possibility of physiological change, but to whether individuals will be able to maintain the social fabric

of their life unchanged. This uncertainty is felt most strongly by those who depend on others for support and help. Both surveys included measures of the degree to which people were dependent on help in order to be mobile and to be able to carry out the functions of daily living; 39% of those with respiratory, and 12% of those with non-respiratory polio were dependent upon others. In the majority of cases, the support provider was a family member, occasionally a parent or a child, but more usually a spouse. A major concern for many was the impact of aging, not on themselves, but on those on whom they depend in order to maintain their accustomed pattern of independent living. This concern about the aging process was voiced frequently during the in-depth interviews. Over the years, an individual may have established a complex, but relatively durable system of support, but one which depended on a single other person. Any threat to the latter posed an indirect but potent threat to their own independence. Aging, with its associated risk of morbidity and mortality was seen as such a threat. Furthermore, the possibility of finding alternative resources within the public sector was becoming uncertain. This is an area of concern which will be discussed in the next section, which focuses on the context of disability.

The context of disability

During the years which have elapsed since the polio epidemics of the early 1950s, the context of disability has been transformed. These changes are as relevant to understanding the impact of long term disability as the physiological and psychological history of the individual. Furthermore, the more recent changes in economic and welfare policies contribute to the climate of uncertainty with which individuals must deal as they grow older. Cutbacks in service provision, reductions in medical spending and research, a tight employment situation, are all factors which may reduce the options available to an individual who has had polio and increase the uncertainties with which they must live.

Three major areas of change were identified at the Chicago Post-Polio Conference in 1981 [12]. The first includes changes in medical and technological knowledge and their application; the second is change in public policy and service provision; the third is change in public attitudes and behaviour. This includes the emergence and acceptance of the independent living movement. Developments in these three areas paralleled each other in time (Fig. 3 shows a time line summarizing the contextual changes in the experience of the post-polio person). In each area, some changes were a specific response to the needs or demands of people with polio; others were a response to those of any individual with disability. A third category includes changes which had an impact on the lives of the disabled, but which were not specific responses to the needs of disabled people. An example of a specific response to the needs of polio victims was the development of a home care program for respiratory polio patients in the mid-50s by the Manitoba government [18, 19]. By contrast, the introduction of the Canadian system of health insurance is an example of the third category. Although it was a general policy initiative, it changed access to medical care for

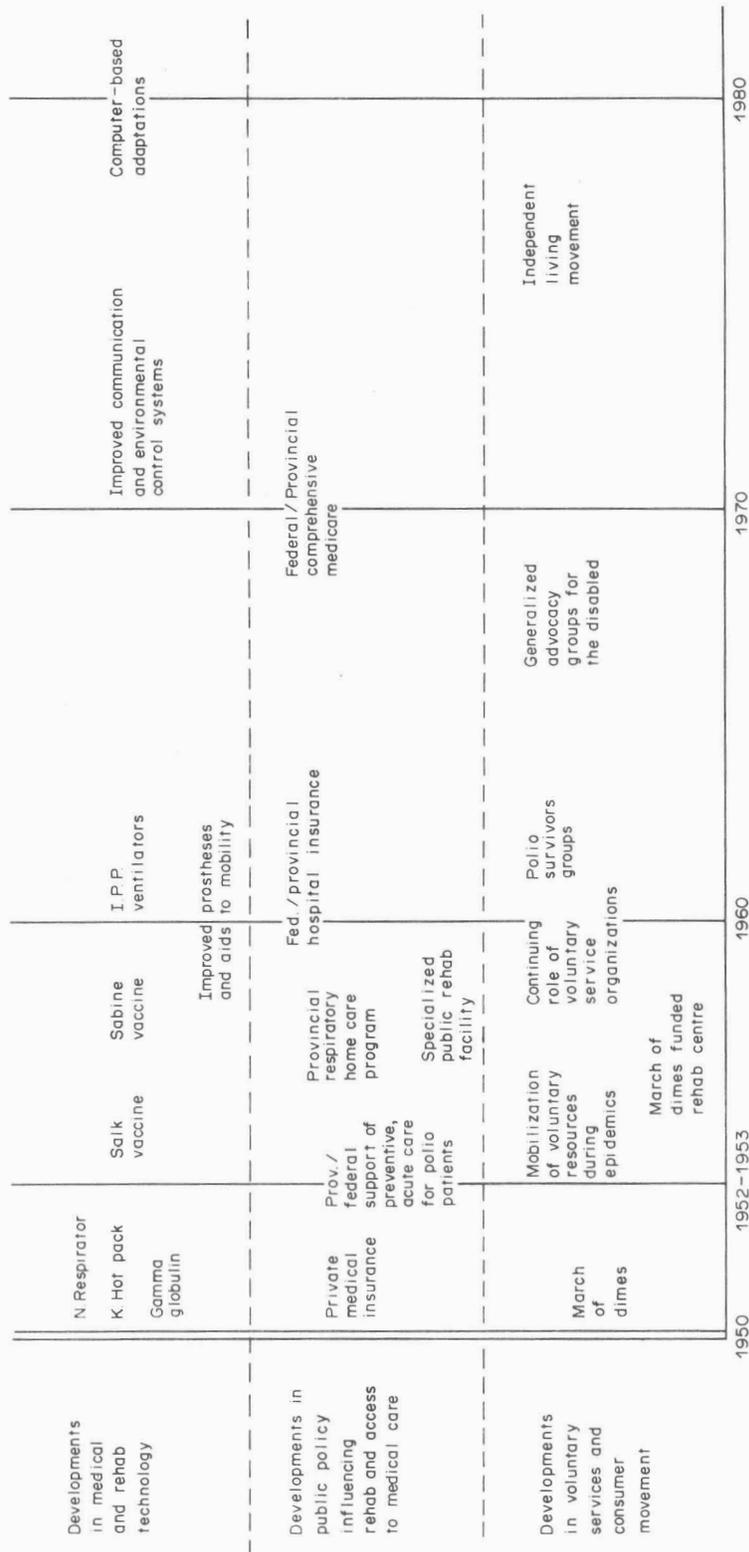


Fig. 3. Developments influencing the rehabilitation experience of the post-polio person.

the individual with disability as well as for the rest of the population.

The second category is illustrated by the emergence of consumer oriented, activist movements from within a community of people with all types of disability, including those who had polio. Ideological and organizational roots lay in the minority group movements of the 60s and 70s but were also formed by the specific experiences of people with polio, their needs and their encounters with the bureaucracy of rehabilitation. The current formation of a loose political coalition between the Black, the Feminist, the Gay and the Disabled Consumer movements provide evidence of a commonality of ideology and purpose.

This paper cannot provide a detailed reconstruction of all the changes which have formed the context of disability over the past three decades. Its focus is on a few of the key issues in the areas of medicine, technology, public policy and community change which contribute to the new climate of uncertainty.

Change in medical and technological knowledge

The medical innovation which most people would associate with polio is the development of an effective method of immunization with the Salk vaccine in the middle 50s and the Sabine live virus vaccine later in the decade. Polio is still widespread in many of the countries of the Third World, but it has been virtually eliminated within North America and Western Europe. Although in one sense, immunization came too late to change the lives of people who already had polio, in another sense they were very much affected by its development.

The end of the recurrent epidemics of polio meant that the disease and therefore, its victims, lost their high profile. There was a reduction in new research on the disease, its process, and its management. This meant that knowledge about the epidemiology and pathology of polio has been essentially stalled at the level of medical knowledge in the mid-1950s. In response to the new uncertainty about the trajectory of the disease, there has been a call for further research, but there may be problems in attracting research interest and funding for a disease which is seen as a threat of the past. Even the March of Dimes, which had its origins in the fight against polio, has diverted its funds to other issues. The Foundation's response to a recent request for further research backing was that its monies were fully committed. The recent increase in news stories on the fate of former polio victims may serve a useful function in encouraging new research focusing upon long term adaptation. Part of the context of any particular disability is its topicality in the medical or in the public eye. Like cancer today, polio once attracted attention beyond its actual level of threat in the population; however, once immunization removed that threat, polio became a 'non-issue'.

Another effect of immunization was a reduction in the number of physicians directly familiar with polio and with its implications for patient care. This is true not only of physicians, but of anyone in the health and rehabilitation professions who qualified after the epidemics of the 1950s. As a result, there has been a

gradual decline in the percentage of people working in any health institution who understand the special needs of a patient who has had polio, needs which exist regardless of the reason for needing medical care. A recurrent fear voiced by participants at the Chicago meetings was that they would receive inappropriate or inadequate medical care because of ignorance, and the refusal of medical professionals to recognize that former polio patients might have expertise in their own condition.

As counterbalance to the decline in polio-related research, people who had polio have been able to benefit from advances in general medical knowledge which have been applicable to their needs. For example, breakthroughs in ventilation technology have been of major importance to those who were left with severe respiratory involvement. Until the 1960s, the only equipment was the rocking bed, the cuirasse and the tank respirator. In Manitoba, the majority of those needing respiratory support have been gradually transferred to the new positive pressure equipment in which ventilation is maintained by tracheal airways. This newer equipment is portable, a major innovation for those whose mobility had been curtailed by their dependence on the older, cumbersome rocking bed or tank respirator. It is more efficient as a method of ventilation and, therefore, to be preferred, particularly for people complaining of a decline in respiratory function and energy level as they grow older.

THE POLITICS OF DISABILITY: THE CONSUMER MOVEMENT

One of the ironies of the disabled consumer movement in Canada, as in the U.S., was that it brought into opposition individuals and groups, many of whose origins lay in the polio epidemics of the 1940s and 1950s. On the one hand, there were medical and rehabilitation experts and charitable foundations, such as the March of Dimes. On the other hand, there were their former patients or recipients: polio was the common factor. In Canada, for example, the Canadian Rehabilitation Council for the Disabled (CRCDD) was formed in 1962 by a union between the Canadian Council for Crippled Children and the Canadian Foundation for Poliomyelitis and Rehabilitation. In 1973 at a conference in Toronto, the rights of the CRCDD to speak for the disabled were challenged from the floor by a group in which many of the leaders were people who had had polio when they were children. A Canadian government report [20] credits this conference as the "catalytic factor in stimulating the consumer movement throughout Canada and as a milestone in consumer history for handicapped persons". Local provincial organizations, such as the Manitoba League for the Physically Handicapped were formed by people returning from that conference. In 1975, they came together to form the Coalition of Provincial Organizations of the Handicapped (COPHO) with a central office in Winnipeg. It was also in Winnipeg, at the 1980 conference of Rehabilitation International that another challenge was made to the rights of medical and rehabilitation specialists to speak for the community of the disabled.

The disabled consumer movement took on as its opponents the institutions and groups with which its members had had to deal; i.e. the charitable foundations, the medical profession and the rehabilitation experts. The roots of the movement are usually traced to the United States and the origins of the Independent Living Movement in California and Boston within the context of the Civil Rights Movement and its later expression in a diversity of minority group political movements. As with feminism, the disabled consumer movement can be criticized as representing only the young, the white and the middle class. As with feminism, the charge is partly true for these were the characteristics of the original movement as it developed on college campuses. Its priorities were an expression of the ideologies of the student movements of the late 60s and 70s as seen in the demand for an end to prejudice and discrimination and for equal rights and a share in decision making. These were not necessarily the priorities which would be agreed on by everyone with disability, yet many of the changes achieved by the movement, whether the practical improvements in public access and transportation or the more subtle changes in attitudes and perception, have benefitted the non-activist, the older, the minority group disabled.

The Disabled Consumer Movement developed in an era of relative prosperity. It now faces uncertainty about the future, not only in terms of whether it can make further advances, but whether it can retain its present gains. Special services to the disabled have become victims of financial cutbacks in education, health, employment and other areas of government provision. Further cuts are a possibility and could threaten the economic base necessary to the independent living movement. The difference from the past is that changes affecting the disabled do not go unchallenged. As was seen in Canada during the debate over the Charter of Rights and Liberties, the movement is capable of orchestrating a well-articulated political campaign and can draw on a better public understanding of the rights and demands of the disabled community.

CONCLUSION

As the Manitoba study has shown, the consequences of having had polio are complex. In order to understand its impact on the lives of people who developed the disease over 25 years ago, the Manitoba study took its methodologies from a number of disciplines; the choice of method being determined by the nature of the issue and how it could best be explored. While this eclecticism was dictated by the multi-faceted nature of the study, it would be appropriate to other projects concerned with the long term impact of disability. For example, the historical-prospective design, which is central to the Manitoba study, could be adapted to other situations in which it is possible to define a population by using a review of medical records. Equally, any understanding of the implications of a disability must look at change not only as a consequence of disease processes, but also in terms of changes in the medical or social environments in which those processes occur. For example, people with severe respiratory impairment became

free of the tank respirator as a consequence of technological change, not because of any change in their physiological condition. Mobility increased as a result of campaigns for better access for the disabled and not because people recovered any functional capacity. In sum, the experience of living as an individual with disability is multidimensional and cannot be explained by unidimensional research.

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Epidemiological Issues in Follow-Up Studies of the Impact of Poliomyelitis

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Introduction

This paper is based on a study which took place in the Province of Manitoba, Canada, the purpose of which was to examine the long-term impact of disability among people who developed respiratory or nonrespiratory polio during the epidemics of the 1950s. The findings of this study are reported by Alcock et al.^{1,2} There were 3,644 cases of polio registered in the Province between 1950 and 1959. The highest incidence was in 1953, when there were 2,371 cases. Most acute cases and all cases with respiratory involvement were triaged to one central medical facility, the Winnipeg Municipal Hospitals (WMH). This hospital complex was the officially designed treatment center for the Province. The patients admitted to the WMH are the focus of the Manitoba project on the long-term impact of poliomyelitis. The study was developed in two stages; the first stage was restricted to people with respiratory involvement; in the second stage, the study was extended to all those with non-respiratory polio.

The objective is to discuss some of the methodological and conceptual issues involved when researching the long-term consequences of any chronic disability, although the specific reference

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is to polio. The first section will focus on survey design and the difficulties of controlling for selection bias when studies are based on the networks of those who have survived, but who are also the most severely impaired. The second section will look at the problems of measuring functional status among populations of post-polio people. The third section will examine the problems of validating retrospective, self-reported measures of functional status. All three sections will use the design of the Manitoba study to illustrate how these problems may be handled. The final section will present an analysis of data from that study, using it to discuss aging-related changes in functional status.

Section One

Selection Bias and the Historical Prospective Study

The current concern over the relationship between the aging process and the long-term impact of polio has encouraged a spate of new research. The people on whom many of these studies have been based have been contacted through the rehabilitation or polio survivor networks³ or through the networks of specialized rehabilitation centers.⁴ Inevitably, such study populations tend to overrepresent groups with the highest levels of disability, greatest propensity to experience post-polio aging effects and highest current levels of contact with rehabilitation and mutual support programs for disabled people. There are advantages to focusing on individuals with the highest level of need. However, this method of selecting a study population means that those who did not survive are not included in the analysis of the long-term impact of polio. Furthermore, there is a tendency to underrepresent those who recovered so completely that they were no longer counted within the population of the polio-disabled. The omission of either or both these groups limits the ability of any study to generalize from its findings to the experience of the whole generation of people who developed polio. We also need to document the experience of those who did not survive into the 1980s as well as the less disabled for whom the experience of polio is only a vague memory from childhood.

Ideally, three conditions should be met by a study analyzing the long-term effects of any disabling condition and making generalizations applicable to the population at risk: (1) the study

SAMPLING DESIGN FOR MANITOBA POLIO FOLLOW-UP SURVEYS

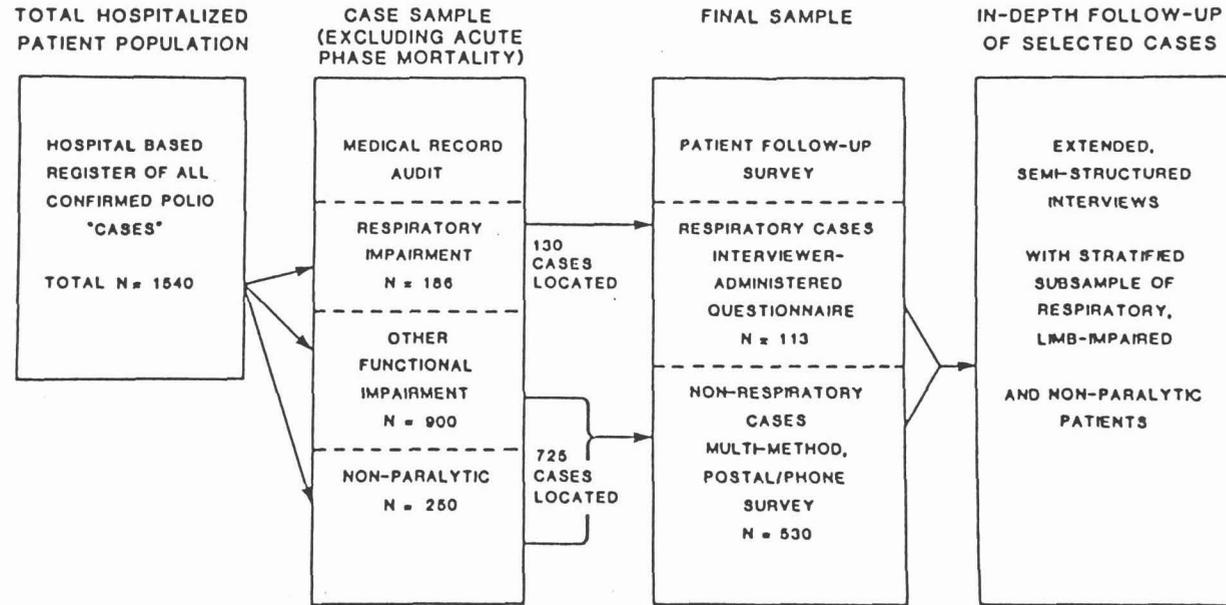


FIGURE 1

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should be longitudinal in design, (2) it should select its sample from as complete a listing as possible of those who developed the condition and (3) it should begin at the point of disease onset. In research on polio and aging, a true prospective design is impossible, but one can use the "historical prospective" design familiar to epidemiologists. For example, rather than starting from a population of patients with lung cancer and inquiring about earlier exposure to asbestos, a "historical prospective" study includes everyone who shared a common exposure to asbestos at some point in their occupational histories. The research objective is to determine how many in this group subsequently developed lung cancer. Such a design provides data on those who did not survive as well as those in whom the asbestos had no apparent effect. Transferring this methodology to research on polio means going back to a list of people as they developed the disease. The aim is to determine what happened to everyone who had polio, including those who did not survive and those who, having completely recovered, had no further contact with specialized services.

Our advantage in the Manitoba study was that we had access to a case register which included all the people with polio who were admitted to the WMH. By using this register as our population frame, we could avoid the selection bias that is inevitable in studies based on contact with a network of polio survivors.

The register listed 1,540 patients who had been admitted and in whom the diagnosis of polio had been confirmed. In the first stage of the Manitoba study, we selected only those who had required mechanical respiratory support; the second stage extended the research to those with nonrespiratory involvement. The sample design for the study is shown in Figure 1; 264 of the patients listed in the register had required respiratory assistance, but those who died within the first 100 days after admittance were excluded from the study, leaving 186 individuals to be traced. In only eight cases was it impossible to determine whether the individual was still alive, although no more than mortality data were available on a few individuals.

Within this group of 186 people, 56 were known to have died prior to March 31, 1980; 24 had died in the hospitals within the first few years and their medical records provided all the infor-

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mation necessary for the study. Among those who had lived longer and outside the hospital, we did contact and interview the next-of-kin of 26 of the remaining 32 people in the group (in six cases the next-of-kin could not be traced or refused to be interviewed). Of the 130 people who were known or thought to be alive, we were able to interview 113. It proved more difficult to trace those with nonrespiratory polio. The register provided sufficient information on only 1,150 patients in this group. We were able to locate and determine what had happened to 725 and questionnaires were sent to and completed by 530.

As you can see from these figures, not everyone we had set out to contact was traced. Inevitably, there are problems of bias. In the first stage we have interview data on 138 out of 186 people, a 74% response rate, but although some next-of-kin interviews were completed, the interview data are biased toward those who survived. Looking only at the representatives of the interview data on the 130 known to be alive, there is bias toward those with the more severe levels of respiratory impairment. (Ninety-seven percent completed questionnaires compared with 76% of those whose medical records indicated minimal effect on the respiratory system.) The reason is that the most impaired were the easiest to find; they were more likely to have remained in Manitoba and to be in touch with the WMH. (This center has remained the main provider of specialist care for respiratory problems associated with polio.)

Despite the difficulties involved in tracing people after such an interval, there are major advantages to the historical prospective design as used in the Manitoba study. We can, for example, document survivorship over the years since the epidemics and can determine which deaths are polio-related. Although the interview data are not representative of the group, we do know where the bias lies. The medical records and the case register allow one to document the age, sex, residential characteristics and levels and types of impairment of all those omitted from the interview process for one reason or another. Any generalizations we would make can be qualified by reference to the representativeness of the group on whom the information is based. It is partly for this reason that the use of the historical prospective design has proved to be important to the Manitoba study. A second reason, however, is that this design has allowed us to deal with one of

the other major problems plaguing research on the long-term impact of disability—the difficulty of establishing a baseline of information on initial impairment levels against which to measure change over time.

Section Two

Measurement of Changes in Functional Ability Among Survivors

The case register provided basic sociodemographic and medical data on each individual. This included age, sex, marital status, type of polio, the use of respiratory equipment, surgical and rehabilitation procedures and levels of impairment both before and after rehabilitation. All these data were recorded as the individual entered the WMH and during the course of their stay in that hospital and are not subject to any recall bias.

Without medical record-based data on people's status during the acute and early rehabilitation phases, most studies of disability have to rely on what individuals can recall about their initial condition. In terms of current research interest in polio and aging, this requires asking people to think back over 20 to 30 years, a problem further complicated by the fact that many were children at the time and have only limited memories of that period in their lives. The design of the Manitoba study provided us with a double opportunity. First, we could use medical records rather than people's memories as a source of information on their functional status at onset; second, we could ask people to recall what their condition had been and then compare what they said with the medical record data. These comparisons are methodologically interesting as a means of validating retrospective data, but they also provide insight into how people retain the memory of traumatic events in their lives.

The medical record data had been recorded according to the needs of the hospital at that time. To be of use in the research context, they needed translating into categories which could also be used when asking individuals to make their own assessment of their past and present condition. To achieve this result, three indices were developed measuring, respectively, respiratory status, mobility, and the ability to carry out the activities of daily living. The format of the indices was designed for use in self-

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administered or interviewer-administered questionnaires as well as the protocol for the medical record audit. This audit was separate from the follow-up survey and was carried out by two clinicians who had been members of the medical team involved in the 1952 and 1953 epidemics in Manitoba. Therefore, they were familiar with the records and the manner in which data had been entered at that time.

In view of the diversity of functional assessment systems currently being used in research on post-polio aging, it may be useful to summarize each of the three dimensions of functional ability used in the Manitoba study: respiratory status, mobility and the ability to perform the activities of daily living.

Measures of Respiratory Status

Respiratory status in both the questionnaire and medical record audit was measured by the degree of dependence upon mechanical support to maintain respiratory function. The range is from no dependence to almost complete dependence on a 24-hour basis. Five levels were used based on a system developed by Spencer.⁵ They are (1) independence of support; (2) occasional dependence (e.g., when an infection interfered with respiration); (3) mechanical support only at night; (4) support for 12 to 18 hours a day; (5) support for more than 18 hours a day. People were asked during the interview to rate their respiratory status as it was one year after they developed polio and as it was at the time they took part in the study. In addition, they were asked in which year they felt they had reached their "best" or their "worst" levels of respiratory status. (For the majority [77%] the lowest level was one year after onset and most had achieved their optimal level five to six years after developing polio [87%], a level which they continued to maintain.) The clinicians used the medical records to assess what each individual's respiratory status had been one year after onset.

Measures of Mobility and Activities of Daily Living

Both the questionnaire used with the nonrespiratory sample and the interview schedule used in the research on respiratory polio included a battery of individual items and summary scales to measure mobility and self-care activities. On each question,

people were asked to rank their ability to perform the function on a five-point scale: (1) independent performance with ease; (2) independent performance with difficulty; (3) dependence upon equipment; (4) dependence upon equipment and people; (5) complete inability to contribute in any way to the performance of that particular mobility or self-care function.

The mobility index developed for the initial respiratory study consisted of eight basic mobility functions. These included bed and chair transfer, mobility on a level surface, the ability to manage stairs and mobility out of doors in winter and in summer. (The Manitoba climate makes this a pertinent distinction.) Because mobility depends upon the ability to use transportation systems, three other functions were added to the list: the ability to ride in transport specially designed for the disabled and to ride in or to drive a car. People using portable positive pressure breathing equipment can manage the first, but not the second or third; others can ride in a car, but have insufficient use of their upper limbs to drive it.

A modified version of Katz's "Index of Daily Living Schedule" was used.⁶ It was augmented by questions on the ability to turn door handles or to lift objects above the head. These were to measure the effects of polio on upper limb movements. Other questions were added to measure performance of more complex daily living activities such as shopping, cooking and cleaning.

In addition to completing these banks of individual items making up the mobility and Activities of Daily Living scales (ADL), people used the same five-point ranking system to make an overall assessment of both their mobility and ADL status. They were asked how they would assess their current capacities, their capacity at one year after onset and when their mobility and ADL had reached their "best" and their "worst" levels. (Given the current concern with aging and polio, it should be noted that 14% of the respiratory sample said that mobility and ADL had declined within the previous ten years.) The clinicians responsible for the medical record audit used the same ranking systems when assessing mobility status and ADL at one year after onset.

The third section of this paper will present some of the comparisons made between how individuals remember their condition as it was in the past and how the same condition was recorded

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in their medical record. Comparisons will also be made between current status and status one year after onset. Before presenting these analyses, we will discuss what people taking part in the Manitoba study said about the processes of recalling their past experience when they first developed polio.

The questionnaire sent to those with nonrespiratory impairment asked whether they thought they could recall the most significant features of their experience during their first months in hospital: 45% thought they could recall most things that happened to them, 25% were less confident, and 29% said they could remember little or nothing from that period. Age at onset was the major factor determining how much people said they remembered, but the seriousness of their condition, the length of time in the hospital and the degree of residual impairment were also involved.

The questionnaire also asked whether information had come from others who had been involved during the acute and early rehabilitation phases of their illness. Fifty-five percent said that in recalling the early phases of their illness, they had used information provided by other people. Parents were most often named as informants by 45% of the nonrespiratory group, 5% referred to a spouse and 2% listed siblings or other family members. (Physicians were only occasionally named as information sources.) These data suggest that recollection data are not simply what people remember for themselves; they are a composite of what people directly recall from that period plus a series of anecdotes told them by others which they have incorporated into their version of the past.

Section Three

Validation of Retrospective, Self-Reported Measures of Functional Status

In a preliminary attempt to assess the convergent and discriminant validity of retrospective measures of functional status (i.e., respiratory status, mobility and performance of ADL functions) drawn from questionnaires, correlations between these indices and clinical audit measures were computed. (Medical record audit data for ADL functions did not exist because functional ability indices were not systematically used until 1960.) In con-

sidering these correlations it should once again be noted that all measures were based on identical five-point scales. This consistency in the measurement of functional status across methodologies is important in that it allows for a metrically unambiguous comparison of the correlations among the indices. Inspection of the correlation matrix shown in Table 1 indicates that the medical record audit-based ratings of respiratory status were most highly associated with the self-reported recall-based measures of respiratory status from the patient interview. Measures of mobility from the medical record audit were associated with interview-based measures of mobility and ADL performance to about the

Table 1. Medical Record Audit/Interview Disability Measure Correlations (Respiratory Follow-up Study)

		<i>Medical Record Audit-Based Assessments of Functional Status</i>	
		<i>Respiratory Status (1-yr Post-Acute)</i>	<i>Mobility (1-yr Post-Acute)</i>
	Respiratory status		
	One-year post-acute	.83	.64
	1980	.83	.61
Self-reported functional status from interview	Mobility		
	One-year post-acute	.59	.73
	1980	.64	.71
	ADL*		
	One-year post-acute	.68	.75
	1980	.74	.72

All correlations are significant at the $p < .01$ level.

*Medical assessments of ADL performance were not available from the full sample of respiratory patients.

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same degree. The later associations, however, were more pronounced than the correlation between the medical record audit-based measure of mobility and the interview-based measure of respiratory status.

Analysis of the correlations between self-reported, retrospective measures and medical record audit-based measures using case notes from the onset of disability provides tentative evidence for the validity of survey-based measures. In order to understand the factors which may account for the variations in self-assessed and record audit-based measures of all areas of functional status, cross-tabulations of the two measures were evaluated. These tables generally showed that discrepancies between self-assessed and record audit-based measures reflected differences of "degree" in terms of patients' recall of the number of hours of respiratory equipment dependence, or differences in degree of need for aids and helpers in mobility and ADL performance, rather than major disagreement about whether people were respirator-dependent or totally unable (or fully able) to perform self-care or mobility functions.

Correlations Between Post-Acute and 1980 Measures of Functional Status

In the comparison of the medical record and interview-based measures of functional status for the one-year post-acute and 1980 measurement periods (Table 1), we found that there was little difference between the magnitude of the 1980 interview-based one-year post-acute record audit-based relations and the one-year post-acute (interview-based)/one-year post-acute (medical record audit-based) correlations. This pattern would, in fact, be expected given our overall finding that there were no dramatic shifts in the relative levels of functional status or overall disability levels among respiratory patients over the 20-30 year period between the one-year post-acute measurement and the 1980 questionnaire.

Intercorrelations Between Measures of Alternative Dimensions of Functional Status

A second dimension in evaluating the validity of questionnaire-based measures of disability relates to the concept of convergent or concurrent validity involving comparison of

several alternate measures of a concept to identify dimensions of an instrument that are highly intercorrelated or that provide unique information. Table 2 shows the correlations between the three dimensions of disability reflected in functional status measures of respiratory dependence, mobility and ADL performance. The correlations between each of the interview-based measures would suggest that respiratory status, mobility and ADL performance represent highly correlated dimensions of overall functional capacity of residual disability among respiratory polio patients. Consistent with conceptual expectations and supportive of the measures' validity is the fact that respiratory status emerges as a somewhat distinct measure, with mobility and ADL performance exhibiting the greater association.

Table 2. Correlations Between Primary Functional Status Measures (From Respiratory Patient Follow-up Interviews)

	<i>Respiratory Status</i>		<i>Mobility</i>		<i>ADL</i>	
	<i>One-Year Post-Acute</i>	<i>1980</i>	<i>One-Year Post-Acute</i>	<i>1980</i>	<i>One-Year Post-Acute</i>	<i>1980</i>
Respiratory status						
One-year post-acute	—	.83	.62	.66	.69	.74
1980	—	—	.61	.70	.65	.78
Mobility						
One-year post-acute	—	—	—	.78	.78	.71
1980	—	—	—	—	.67	.85
ADL						
One-year post-acute	—	—	—	—	—	.80
1980	—	—	—	—	—	—

Section Four

Evaluating Aging Effects in Functional Status Measurement

Initial univariate analyses designed to examine the relationships between age, sex and the health status variables are presented in Table 3. As indicated, age was significantly related to all three health status variables with respect to 1980 levels. For one-year post-acute levels, generally weaker associations with age were observed. Specifically, although age was significantly related to one-year post-acute ratings of mobility, only marginally significant relationships were found for ratings of respiratory status and ADL. With respect to sex effects, only the mobility ratings of men and women differed, with males exhibiting higher levels of mobility compared to women. This sex difference was marginally significant for one-year post-acute ratings.

Paired t-test analyses of one-year post-acute and 1980 ratings suggested that for the sample as a whole there was a significant improvement in levels of mobility ($t = 9.03$; $df = 112$; $p < .001$) and ADL ($t = 7.21$; $df = 110$; $p < .001$). Only a marginally significant improvement in respiratory status ($t = 1.72$; $df = 111$; $p = .09$) was observed, however.

The self-reported functional status ratings for one-year post-acute levels are retrospective. Given the cross-sectional orientation of the survey design, the analysis of change in functional status over "time" is, in the present case, clearly limited to the more restricted notion of changes in health status as they were

Table 3. Pearson Correlation and t-test Statistics for Relationships Between Age, Sex and Health Status Variables

Respiratory Status		Mobility		ADL	
One-Year Post-Acute	1980	One-Year Post-Acute	1980	One-Year Post-Acute	1980
Age $r = .15^*$	$r = .29^{***}$	$.20^{**}$	$.25^{***}$	$.17^*$	$.23^{***}$
Sex $t = .27$	$t = .72$	1.93^*	2.16^{**}	1.15	1.02

* $p \leq .10$ ** $p \leq .05$ *** $p \leq .01$

perceived in 1980. Within the scope of this limitation, however, one-year post-acute ratings can be treated as a lagged variable in a longitudinal model. Accordingly, in the present analysis, stepwise multiple regression was deemed to be the most appropriate technique for examining the relationships between age, sex and the change in ratings of functional status for the one-year post-acute/1980 interval. A separate, although structurally similar, regression analysis was performed for each of the three functional status variables. For example, in the analysis of respiratory status, the dependent variable was the 1980 ratings. The independent variables, in terms of their order of entry into the prediction equation, were one-year post-acute ratings of respiratory status, followed by age and sex. This order of entry (i.e., entering one-year post-acute levels into the equations first) allows for an evaluation of the importance of age and sex as predictors of change in the ratings of respiratory status for the time period referenced. In addition to the main effects of age and sex, two-way interaction terms defined as the products of (1) sex X age, (2) sex X one-year post-acute respiratory ratings and (3) age X one-year post-acute respiratory ratings were tested for significance with controls for main effects. Similar analyses were performed for ratings of mobility and ADL.

With respect to main effects, sex was not related to changes in any of the three functional status variables. Age, in turn, was not related to changes in either mobility or ADL, but was associated with changes in respiratory status ($F = 9.75$; $df = 1, 108$; $p = .002$). The negative correlation between changes in respiratory status and age ($r = -.23$; $df = 100$; $p = .02$) corresponding to this effect would indicate that age was associated with less improvement in respiratory status over time. This interpretation of the effect was considered most appropriate given the marginally significant positive shift in respiratory status cited above.

Test of the age X one-year post-acute interaction effect indicated that age was, in fact, differentially related to change in respiratory status as a function of one-year post-acute disability levels ($F = 10.54$; $df = 1, 107$; $p = .002$). The correlations corresponding to this effect (Table 4) indicate that age was associated with less improvement in respiratory status only among individuals who were most disabled in terms of one-year post-acute ratings.

EPIDEMIOLOGICAL ISSUES

A similar age X one-year post-acute interaction effect ($F = 10.13$; $df = 1,106$; $p = .002$) was found for changes in ADL ratings. The correlations corresponding to this effect (Table 4) indicate that age was related to less improvement in ADL among the initially most disabled individuals. At the same time, however, the significant positive correlations between age and change in ADL among initially less disabled individuals would indicate that for this group, age was associated with more improvement in ADL ratings.

It is noteworthy that the age X one-year post-acute interaction effect was not significant ($F = .55$; $df = 1,108$; $p = .46$) for changes in mobility ratings. As with univariate effects, however, sex appeared to be an important consideration for explaining the variance of this variable, with the sex X age interaction effect emerging as significant ($F = 8.25$; $df = 1,108$; $p = .005$). The within-sex correlations corresponding to this effect indicated that age was associated with less improvement among men ($r = -.27$; $df = 65$; $p = .03$) but was unrelated to changes in mobility among women ($r = .23$; $df = .44$; $p = .12$).

This pattern of results indicates, then, that age has a significant main effect upon changes in mobility among men, but not among women. The analyses reported do not test for the possibility of a significant within-sex age X one-year post-acute interaction effect. Given the apparent importance of sex for understanding mobility ratings, a separate regression analysis was performed for the male and female subsamples in order to test for this ef-

Table 4. Pearson Correlation Coefficients for Relationships Between Age and Changes in Health Status Variables for High and Low One-Year Post-Acute Disability Levels

Respiratory Status		Mobility (Males)		ADL		
High Disability	Low Disability	High Disability	Low Disability	High Disability	Low Disability	
Age	-.61***	-.13	-.41***	-.25	-.30***	.31**
N	28	84	33	34	65	46

** $p \leq .05$ *** $p \leq .01$

fect. For males, as previous analyses indicated, there was a significant main effect of age ($F = 10.89$; $df = 1,64$; $p = .002$) upon changes in mobility. In addition, however, the age X one-year post-acute interaction effect emerged as significant ($F = 4.24$; $df = 1,63$; $p = .04$). Inspection of the age/change in mobility correlations corresponding to this effect (Table 4) indicates a pattern similar to that observed for respiratory status and ADL. Specifically, age was related to less improvement in mobility among the initially more disabled group. For the female subsample, on the other hand, no significant main or interaction effects for age were found.

The correlations presented suggest that the association between age and change in the functional status variables is, for the most part, limited to those individuals reporting high initial disability levels. This observation, coupled with the fact that there was a perceived shift to less disability over the referenced interval, would suggest that this correlation pattern might be understood in terms of the difference in the variability of functional status changes for the initially low and high disability groups. More specifically, this correlation pattern might be attributed to the greater degree or variance of change (i.e., improvement) in health status for the high as compared to low disability groups. In order to test for this possibility, comparisons of the variance of changes in health status were made for initially low and high disability groups. These comparisons indicated that there were significant differences in the variances of changes in ADL ($F = 3.15$; $df = 64,45$; $p < .001$) and respiratory status ratings ($F = 2.17$; $df = 83,27$; $p = .003$). This effect was not significant for mobility status of males ($F = 1.69$; $df = 32,33$; $p = .14$). In all cases, however, groups with initially high levels of disability exhibited a greater variance of change than did low disability groups.

Data collected for the sample of 527 nonrespiratory polio patients allowed for comparative analyses of mobility ratings. Univariate analyses of one-year post-acute and 1980 ratings indicated that there was a significant improvement in overall levels of mobility ($t = 11.51$; $df = 517$; $p < .001$). Age was associated with 1980 ratings ($r = .19$; $df = 523$; $p < .001$) but for this sample, there were no sex differences in mobility for either one-year post-acute ($t = .54$; $df = 515$; $p = .59$) or 1980 ratings ($t = .19$; $df = 527$; $p = .85$).

EPIDEMIOLOGICAL ISSUES

Regression analysis for the sample of nonrespiratory patients indicated that changes in mobility were significantly related to age ($F = 67.86$; $df = 1,509$; $p < .001$), but were not associated with sex ($F = .83$; $df = 1,509$; $p = .36$). Tests for interactions indicated that neither the sex \times age ($F = .09$; $df = 1,508$; $p = .76$) nor the sex \times one-year post-acute mobility ratings ($F = 2.75$; $df = 1,508$; $p = .10$) effects were significant. However, the age \times one-year post-acute mobility rating effect was highly significant ($F = 145.73$; $df = 1,508$; $p < .001$). Within-sex analyses suggested that this effect was more pronounced among men ($F = 126.90$; $df = 1,279$; $p < .001$) than among women ($F = 43.14$; $df = 1,225$; $p < .001$). The zero order sample correlation indicated that age was associated with less improvement in mobility ($r = -.22$; $df = 511$; $p < .001$). Here again, however, this association was only significant among the initially more disabled group ($r = -.58$; $df = 77$; $p < .001$) and not among those with relatively high initial levels of mobility ($r = .03$; $df = 412$; $p = .60$). As in the analysis of the respiratory sample, this effect was attributable to a significant difference in the variance of changes in mobility ratings ($F = 5.55$; $df = 79,415$; $p < .001$) between the initially high and low disability groups.

Summary

Our experience in developing follow-up studies of populations of respiratory and nonrespiratory poliomyelitis patients has demonstrated the feasibility of applying epidemiological approaches to the study of post-polio aging. We have found that it was possible to apply a historical prospective approach to document the experience of a representative population from the point of disease onset and thereby control for selection bias and recall artifacts inherent in cross-sectional studies of self-selected groups of survivors. To facilitate cumulative research, we advocate the development of comparable measures of functional status that are based on widely accepted indices of ADL performance, respiratory status and mobility. In our evaluation of the validity of retrospective, self-reported measures of functional status, through comparison with data on post-acute status from the medical record audit, we found a high degree of correlation between the two overall measures. Finally, our preliminary attempts

to evaluate post-polio aging effects indicate that age at onset was significantly correlated with changes in functional status variables. This association is apparently a function of initial disability levels.

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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

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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.¹⁻⁷

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.^{8,9} 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".¹⁰ 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

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.¹¹ 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.¹² 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

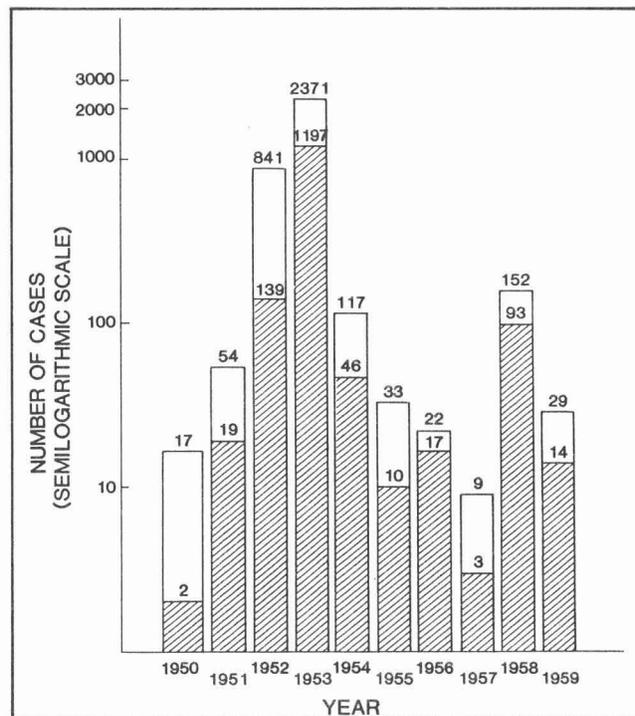


Fig. 1—Numbers of new cases of poliomyelitis in Manitoba between 1950 and 1959. White areas represent total numbers, hatched areas numbers in which patient was admitted to Winnipeg Municipal Hospital.

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

Variable	No. (and %) of patients
Sex	
Male	116 (62)
Female	70 (38)
Age at onset (yr)	
0–14	53 (28)
15–24	40 (22)
25–34	66 (35)
≥ 35	27 (15)
Type of polio	
Spinal	73 (39)
Bulbospinal	113 (61)
Tracheostomy	
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.¹³ 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.¹⁴

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.¹⁵ 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;¹⁶ 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

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		
	At home		
	In hospital (n = 20)	Receiving home care (n = 24)	Not receiving home care (n = 69)
Mobility			
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
ADL			
Washing	0	46	96
Bathing or showering	0	13	75
Dressing	0	21	91
Using toilet	0	29	93
Feeding	5	75	98
Other			
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.

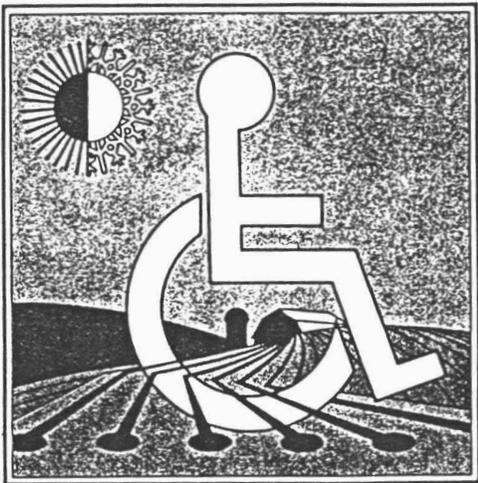
We are grateful to the respondents and their families for their cooperation in the data collection.

This study was funded by the Manitoba Department of Health and a national health scholar award (no. 6607-1213-48) to Dr. P.A. Kaufert. The analysis was funded by a national health research and development project grant (no. 6607-1241-46).

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REHABILITATION OF RURAL AND URBAN POLIOMYELITIS PATIENTS: THE MANITOBA EXPERIENCE

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BIOGRAPHICAL SKETCH

Joseph M. Kaufert, Ph.D. is an Associate Professor, Department of Social and Preventive Medicine and Adjunct Professor, Department of Anthropology, University of Manitoba. Formerly the head of the social science section, Department of Community Medicine, St. Thomas's Medical School, he has developed and taught in behavioural science programs in medical schools in both Britain and Canada. He is the co-editor (with David Tuckett) of Basic Readings in Medical Sociology (Tavistock Publications, 1978). Dr. Kaufert has carried out research on the political economy of disability. He is currently completing a multidimensional follow-up of polio survivors supported by the National Health Programs Directorate, Health and Welfare Canada (Project No. 6607-1241-46).

REHABILITATION OF RURAL AND URBAN
POLIOMYELITIS PATIENTS: THE MANITOBA EXPERIENCE

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ABSTRACT

This paper summarizes the findings of a follow-up study examining experience of poliomyelitis patients living in rural and urban areas of Manitoba. The longer term impact of disability and compensating effect of rural and urban rehabilitation programs were studied in terms of their impact upon a client group whose experience parallels the development and diffusion of rehabilitation medicine over the last three decades. The Manitoba studies of poliomyelitis patients represent an epidemiological and historical follow-up of the experience of a young disabled population in terms of their initial rehabilitation experience and current adaptations. The follow-up studies identified representative samples of respiratory and non-respiratory cases from a comprehensive register of cases admitted to a centralized treatment centre (The Winnipeg Municipal Hospital). Medical record audit and questionnaires were used to document the experience of 74% of respiratory patients and 60% of nonrespiratory cases.

Analysis of survey and medical record data on 113 respiratory patients and 530 nonrespiratory patients was used to document impact of polio-related disability on care requirements and referral of patients from rural areas. Data from the province-wide samples are used to measure the impact of polio upon rural residents in terms of urban treatment experience and potential for returning to rural communities. The development of an innovative polio home care program is described and the adaptations of home care patients are compared with the experience of individuals who remained in long stay hospitals or who were discharged without special care arrangements.

Introduction

This paper is based on a Canadian study which is examining the long term impact of disability among people who developed respiratory or nonrespiratory polio during the epidemics of the nineteen-fifties and who were admitted to the

same centralized treatment centre for the Province. The compensating effect of rural and urban rehabilitation programs were studied in terms of their impact upon a client group whose experience parallels the development and increasing availability of rehabilitation services over the last three decades. The Manitoba studies of poliomyelitis patients represent an epidemiological and historical follow-up of the experience of a young disabled population in terms of their initial rehabilitation experience and current adaptations (Alcock et al, 1984).

There were 3,644 cases of polio registered in the Province between 1950-59; the highest incidence was in 1953, when there were 2,371 cases. Most acute cases and all cases with respiratory involvement were triaged to one central medical facility, the Winnipeg Municipal Hospitals (WMH) (Alcock et al, 1980). This hospital complex was the officially designed treatment centre for the Province. It is the patients admitted to the WMH who are the focus of the Manitoba project on the long term impact of poliomyelitis. The study has developed in two stages; the first stage was restricted to people with respiratory involvement; in the second stage, the study was extended to all those with nonrespiratory polio.

Case-finding and assessment of the representativeness of the final sample utilized a case register which included all the people with polio who were admitted to the Winnipeg Municipal Hospitals (WMH). The register listed 1,540 patients who had been admitted and in whom the diagnosis of polio had been confirmed. In the first stage of the Manitoba study, we selected only those who had required mechanical respiratory support; the second stage extended the research to follow-up people with nonrespiratory involvement. Among the 264 patients listed in the register who required respiratory assistance, only 186 individuals survived 100 days after disease onset and were included in the follow-up study.

The Respiratory Patient Follow-Up Study

A medical record audit protocol was used to retrieve basic socio-demographic information as recorded at first admission for these 186 respiratory cases. The data extracted from the medical records also included the type of polio, the number of days of assisted ventilation, whether a tracheostomy was done, together with a profile of respiratory support and aids and adaptations used by people following the acute phase of the disease. The records were used to review respiratory status after their condition had stabilized. One third of the cases had become totally independent of mechanical respiratory support and had little or no residual impairment; another third had some impairment and on occasion required hospital readmission and respiratory support. The remaining cases in the group can be divided into those who required respirator support for up to 12 hours (20 people), those needing 12-18 hours of support (14 people) and those who spent over 18 hours a day on a respirator (29 people).

There were marked variations in the degree and combinations of residual impairment among the 186 patients. It was clear from the MRA, that in the early years as people recovered, functional capacity often improved with rehabilitation sometimes as a consequence of corrective surgery. However, apart from a few special problems, most people reached a stable level of functional status within two or three years.

The MRA was also used to assemble information on the discharge arrangements made for each of these 186 individuals. Twenty-nine remained permanently in the WMH. Among the 156 people discharged from the hospital, a group of 53 returned home under the special arrangements made for them under a home care program set up for people who had respiratory polio. (The long term experience of these patients

will be considered in the final section of this paper). Another two were transferred to other hospitals.

The first objective of the initial follow-up study of respiratory cases was to determine what had happened to each of these 186 individuals by interviewing those who were still alive or the next-of-kin of those who had died; 138 interviews were completed. Exactly half (24) of the 48 people who were not interviewed had died in the WMH within the first few years after their illness. No effort was made to find or interview their families as all the data which could be obtained was already available from their medical records. Among the remaining 24, twelve could not be traced, three were known to have died, but their next-of-kin could not be found. A further nine were omitted because an interview was either refused or could not be arranged (three of these refusals were made by next-of-kin). Given that 48 people were not interviewed, the overall response rate is 74%. However, the 24 people who died in the WMH had not been included in the population of 162 people on whom interview data was sought; if they are also excluded when calculating the response rate, it becomes 85% rather than 74%.

There were 130 people who were known or believed to be alive in 1980; 113 (87%) were interviewed in the follow-up study. The sample included 67 men and 46 women. The majority of the respondents were interviewed directly, but 6 interviews were conducted by telephone with individuals who had moved out of Province.

Almost a third of the people had been living on a farm or in a small hamlet when they developed polio and another quarter lived outside Winnipeg in one of the smaller towns. By contrast, almost two-thirds now live in Winnipeg. While there has been a general shift from the rural areas to the urban, 28% attribute their change in residence to having had polio.

Respiratory status was a major determinant of whether or not people worked after having polio; half those dependent on respiratory equipment compared to a quarter of those without this dependence, never worked after polio. On the other hand, a number of those in hospital or on home care had found an opportunity to work. Some became self-employed and others worked on a part-time or casual basis.

The interview schedule used in the respiratory follow-up study included questions on self-perceived respiratory status, which was assessed by the individual's reported level of occasional or daily dependence on respiratory equipment (such as a rocking bed, tank respirator or more recently acquired endotracheal respirators). The same categories were used as measures of respiratory dependence in the medical record audit. Mobility and capacity for self care were measured using a modified version of Katz's Activities of Daily Living Index to which questions had been added dealing with the more complex mobility functions (such as the ability to drive a car). Other items measured those functional limitations experienced by some people after polio (such as the inability to turn a door handle, although able to use the hands for other functions). An additional set of questions dealt with changing needs and utilization of personal care services provided by the home care program and by family members.

The register was also used as the sampling frame for a follow-up of nonrespiratory, limb impaired and nonparalytic cases. It proved more difficult to trace the people with non-respiratory polio. The register provided sufficient information on only 1,150 patients in this group. We were able to locate and determine what had happened to 725 and questionnaires were sent to and completed by 530. This paper will concentrate on experience of respiratory patients because they were the primary recipients of the initial home care program.

The Home Care Program

The Manitoba polio home care program was developed to provide an alternative to prolonged or permanent hospitalization for those with respiratory impairment who could be maintained on machines in their own homes (Desmarais et al, 1956). People with severe impairment of their mobility were also eligible for this program. It was the earliest, publicly financed home care program in Canada and pioneered many of the features which have since been incorporated into many other programs. One of the key provisions was a guarantee of temporary or permanent hospital readmission for social and/or medical reasons (Fyles et al, 1962).

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

The original program was hospital based, but as patients returned to rural areas, a variety of modes of service delivery became established. The experience of developing the Respiratory Polio Home Care program has been subsequently applied in emergence of a comprehensive home care program and centralized home care equipment pool in Manitoba.

A total of 53 patients (32 males and 21 females) were discharged under the terms of this program. Over half (55%) were young adults between 20-29. The program was of particular relevance to this age group as its members were young adults who were anxious to resume a family life and their position as mothers or fathers of young children. However, the care of severely disabled adults at home could present greater problems -- economic, social and in terms of nursing care -- than were presented by similarly disabled children.

A majority of those released required mechanical respiratory support for some hours each day (60%) and many others needed to keep the equipment at home to use in a respiratory emergency. In fifty of these cases, respiratory equipment (tank respirators, rocking beds and cuirasses) were supplied and maintained under the Home Care Program. This included the provision and guarantee of adequate power supplies. Only 10% in this group of home care patients could be counted as mobile without the use of equipment; fifty patients required wheel chairs and hydraulic hoists were supplied in 27 cases. The respondent population in the respiratory follow-up study included thirty people from the initial group of fifty-three members in the respiratory polio home care program; the remaining twenty-three had died before the follow-up study was begun. Twenty-four out of the thirty were still living at home; six had reentered hospital.

Discussion

Given the current concerns with the impact of aging on people who had polio, the Manitoba study has been able to take advantage of the unique opportunity presented by the careful preservation of medical records. It was possible not only to trace and interview 85% of the people who had respiratory polio and who were alive in 1980, but also to compare their present respiratory and functional status with the records made in the first year after they developed polio. The experience

of patients enrolled in the respiratory home care program for almost three decades provides a unique longitudinal record of the long term impact of community care alternatives which may be generalizable to the experience of younger disabled populations currently benefiting from such programs.

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Aging and Respiratory Polio

*Issues raised at the 1981 conference in Chicago**

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*The initial follow-up of respiratory polio patients described was supported by the Province of Manitoba in collaboration with the Manitoba Health Services Commission and the Winnipeg Municipal Hospitals. We wish to express our appreciation to the members of the research team who participated in the original study, including: Dr. John Alcock, Dr. John Hildes, and Ms. Joan Bickford, R.N., MSc. During this research, Patricia Kaufert was supported by a National Health Scholar Award (No. 6607-1213-48).

The objective of the 1981 conference, "Respiratory Rehabilitation and Post-Polio Aging Problems," was to examine the long-term implications of polio-related disability from a number of different perspectives. Among the range of topics discussed at the conference, questions relating to the design, provision, costs and maintenance of new and old equipment were given high priority. In this paper we will first discuss some of the concerns expressed at the conference. In the second half, we will relate some of these points to current research in the Province of Manitoba, which is examining some of the issues considered at the Chicago Conference.¹

Discussions in Chicago focused on the interface between a changing technology and changing needs. The experience of people who had polio spans at least twenty-five to thirty years. During this period, there have been dramatic developments in the technological, psychosocial, medical and economic base of rehabilitation. Some of these changes could be seen in the background characteristics of those attending the conference. The participants included bio-engineers and patient-rights advocates, respirologists and other rehabilitation specialists, many of whom were former polio patients themselves.²

The emphasis was on the importance of integrating the new tech-

nology (such as positive pressure breathing equipment or modular wheel chair systems) with the changing needs of people with polio. Several speakers discussed the fallacy of assuming that these needs would remain constant over time. They argued that levels of functional ability will decline as people age. As a consequence, their equipment needs and their use of aids and personal services will change as they readjust to these new levels of function.³ British and American physicians attending the conference both predicted increased use of positive pressure equipment and new aids to mobility as people began to compensate for losses in their physical capacities as they aged.⁴

A number of conference participants reviewed the difficulties surrounding the distribution, maintenance and financing of equipment. These problems are sometimes shared by polio survivors in Canada and the United States, but there are apparently also major differences between the two societies because of disparities in their respective health care delivery systems and in their policies towards providing services for the disabled.

In both countries, people with polio have played a significant role in the development of services, whether as consumers, service providers or advocates. Conference speakers referred to the role of polio

survivors in the leadership of the independent living movement. This involvement has created new ways of looking at service needs and also spurred innovation in all forms of equipment, including respiratory technology. Speakers emphasized that support services have to include organizational systems through which equipment can be distributed and maintained at the community level. Originally, the March of Dimes Centres were involved in this responsibility in the United States and some areas of Canada. In Manitoba, in the mid-fifties, an innovative home care program, which included the provision and maintenance of equipment, was established with the support of the provincial government, and has been expanded to serve other groups.

At the Chicago meeting, several participants' descriptions of the past served as introduction to their concerns about the role of polio survivors in the future. Among the issues raised at the conference were the availability of financial resources, the distribution and scarcity of medical experts, the dissemination of medical information, the dearth of technicians and of spare parts, the problem of reactivating the public's awareness of polio and the continuing impact of polio-related impairment on people's daily lives.

people. On this evidence then, looking at a cross-section of former polio patients, respiratory function was not perceived as declining with age.

On the other hand, it would be quite compatible with the experience of many respiratory survivors to find that the aging process does seriously affect respiratory function in a minority of cases. Using the medical record data, the physicians participating in the Manitoba Respiratory Follow-up Study took a series of vital capacity measurements, which provided a more objective and physiologically-based indication of change in respiratory function. Unfortunately the representativeness of the group of patients on whom these measurements are available cannot be assessed and is too small to control for age or variations on intervals between tests. Nevertheless, when these data are combined with the experience of these two clinical researchers, they suggest that the question of deteriorating function continues to require careful and collaborative research between epidemiologist and clinician.

Although the emphasis of the Chicago meetings was primarily on the aging of the individual, in the next stage of our follow-up study at Manitoba we are attempting to document the aging process as it affects people in family groups. Established patterns of adaptation may be threatened not just by changes in the post-polio persons themselves, but also by the effects of aging upon the parents, spouses, children and friends upon whom they depend. As post-polio people have grown older, their needs have changed, whether as disabled children growing into adulthood or as young adults, now entering early or late middle age. The continuing dependence upon respiratory support equipment and personal care services among polio survivors has significant implications both for their own experience in aging and also for the aging of the members of their families and informal support systems.

Request for Participation in Follow-up Study of Manitoba Polio Survivors of 1952 and 1953 Epidemics

In order to obtain a representative of former polio patients in Manitoba, we are attempting to locate and interview non-respiratory survivors who were diagnosed as having polio in 1952 and 1953 and who were admitted to the Winnipeg Municipal Hospitals. If you feel you may be a member of this group of former patients, we would like to invite you to participate in the follow-up study by completing a brief questionnaire.

Please write: Dr. Joseph M. Kaufert or Ms. K.D. Wong, Department of Social and Preventive Medicine, Faculty of Medicine, University of Manitoba, 750 Bannatyne Avenue, Winnipeg, Manitoba R3E 0W3

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SEATING THE DISABLED CHILD
cont'd from page 14

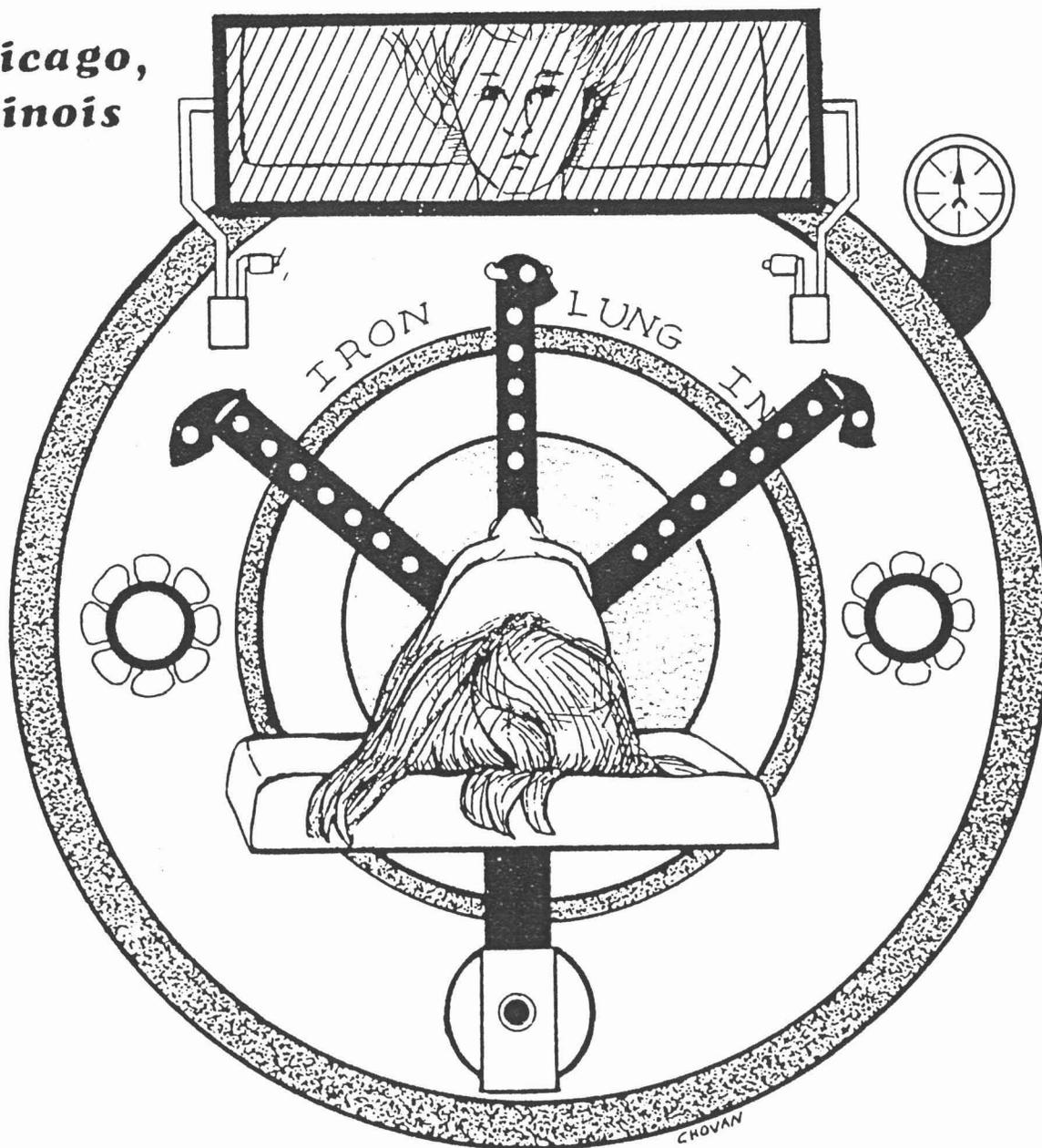
In addition to providing postural support, seats are designed to minimize tissue trauma or 'skin breakdown' which results from sitting for a period of time without any pressure relief. Special foams that distribute pressure are used in the seat and in some instances where there is a very high risk of tissue trauma, air support cushions are incorporated.

One new development in the seating program is the use of a standard transfer wheelchair to support a seat, as shown in the above photograph. This format allows for an inexpensive, stable and adaptable base for a custom seat for the child who is dependent upon others to push the wheelchair. □

**proceedings of an
international symposium**

**What Ever Happened
to the Polio Patient ?**

**Chicago,
Illinois**



Sponsors :

**Rehabilitation Institute of Chicago,
National Foundation — March of Dimes,**

GROUP DISCUSSION

WHAT FACTORS TODAY MUST BE CONSIDERED TO MEET COMPLEX HEALTH-CARE NEEDS?

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Russell L. Beeson

LIFECARE Services, Inc., Pacheco, California
Contracted polio and requires respiratory assistance

A comprehensive need survey has been done in Manitoba. This model would serve other studies with similar objectives.

* * * * *

Dr. Joseph Kaufert

Introduction to the Manitoba Need Study

A number of groups have discussed the need to define the problem of health care by obtaining a more comprehensive profile of the needs of the whole population of polio survivors. In this regard, our experience in Manitoba may be relevant. A research study, carried out in 1980, attempted to trace everyone who had developed respiratory polio between 1950 and 1959 in the province. This research was funded by the Manitoba government and was conducted with the collaboration of Joan Bickford, Patricia Kaufert, and two physicians, Drs. John Alcock and John Hildes, who had been medically involved with polio patients during the 1952-1953 epidemics in Manitoba.

The Study Population

The study included a review of the medical records of 196 former patients

who had respiratory polio and had survived the initial onset of the disease. We traced over 80% of these people and were able to collect information by interview on approximately 75% of them. Because the study was based on a representative cross-section of people, it was a useful source of information. Although all the respondents had had respiratory polio, the residual impact ranged from minimal to severe respiratory involvement. Some were young children when they developed polio and were now in their early thirties; others had been young adults in the 1950s and now were approaching their sixties and seventies. A few had never left the hospital center to which they were first brought for care; others had been discharged after only a few months and never had to return.

The Importance of Appropriate Definition of Criteria to Determine Real Needs

The range of experience of the survivors included in the Manitoba study is pertinent to the problem of defining current needs. The objective of our Manitoba Respiratory Rehabilitation Conference was to look at the impact of aging, but the group of post-polio people who would attend this kind of meeting may not be typical. They were, for example, often

people who had remained in need of specialist care. In the Manitoba study, such individuals were a minority whose characteristics were distinctive and from whose experience it would be unwise to generalize.

One aspect of defining the current health crisis relates to the experience of people whose level of respiratory function has deteriorated with aging. Using our Manitoba data, we have looked at this question. During the interview, people were asked to assess their respiratory function as it was one year after they developed polio and as it is today. They were also asked what their worst and best level of function had been as measured by their dependence on respiratory equipment. The majority of the Manitoba respondents described a stable functional level which they had reached in the early years after developing polio and which they continued to maintain. There was an important minority (19) who said their condition had become worse, but they belonged to no special age group. Clearly, the impact of the aging process on respiratory function requires much further research.

Other Benefits from the Need Survey

One spin-off of a comprehensive follow-up study, such as the Manitoba one, was to put post-polio people into contact with their former networks of polio survivors and clinicians who can relate to their current problems. Although more than half of the Manitoba people had lost contact with the clinicians and were not active in the disabled consumers' movement, a high proportion participated in two follow-up meetings where they discussed their experience.

Future Directors for Need Assessment

The relationship between care needs and care resources was a major concern of members of the discussion groups. Never has it been a static relationship.

As people have grown older their needs have changed, whether as disabled children growing into adulthood or as young adults entering early and late middle age. At our first conference, the emphasis was primarily on the aging of the individual; in the next stage of the Manitoba study, we want to broaden this perspective and look at the aging process as it affects people in wider family settings and their ability to provide support. Established patterns of living may be threatened not only by changes in the individual who has had polio but by the aging of those on whom they depend, such as a parent or spouse.

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Russell L. Beeson

As a post-polio survivor, I would like to tell you or remind you that a lot of the ideas presented from an earlier era will not work today because, as post-polios, we are a different breed. The very nature of the illness was different from a lot of the illnesses we are dealing with today. Post-polios have guts. A lot of us would not be here today if we were not using our own resources.

RESPIRATORY POLIO REHABILITATION IN MANITOBA

Proceedings of the Manitoba Symposium
Rehab International Congress
Winnipeg, June, 1980

83 The Physical and Social Consequences and
Rehabilitation of Respiratory Polio

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Medical Journal

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The Physical and Social Consequences and Rehabilitation of Respiratory Polio

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Presented by Dr. J. A. Hildes

Mr. Chairman, Ladies and Gentlemen.

As you have already heard from both our Chairman and from Mr. Sherman this paper is concerned with the follow-up of the great polio epidemics in Manitoba of the 50's. The reason why we undertook this study, and why we are making this presentation is because we think that the lessons of polio are applicable to the rehabilitation of many other conditions.

What is Respiratory Polio?

I should begin by saying something about the disease poliomyelitis itself since some of you may not know why it was such a dreaded condition.

Polio is a viral infection which can give rise to paralysis by attacking the nerve cells which control our voluntary muscles. The paralytic effects are quite variable from case

to case depending on the part of the nervous system affected. The legs and arms are often involved and it can affect breathing in two ways. High spinal paralysis affects the muscles of breathing directly – the muscles of the chest and the diaphragm. This requires that a machine take over the breathing function. In the 1950's the only type of machine available for this purpose was the iron lung or the tank respirator into which a patient was placed for as long as he required it.

The other way polio affects breathing is by paralysing the muscles of swallowing and speaking. This is called bulbar polio. It causes obstruction to the airways and aspiration of saliva into the lungs. This requires an operation called a tracheostomy to keep the airway clear. Often the two types occur together; so many bulbospinal cases require both a respirator and a tracheostomy.

Polio Manitoba 1950-1959

Figure 1 shows a map of Manitoba. In the 1951 census there were three quarters of a million people in Manitoba,

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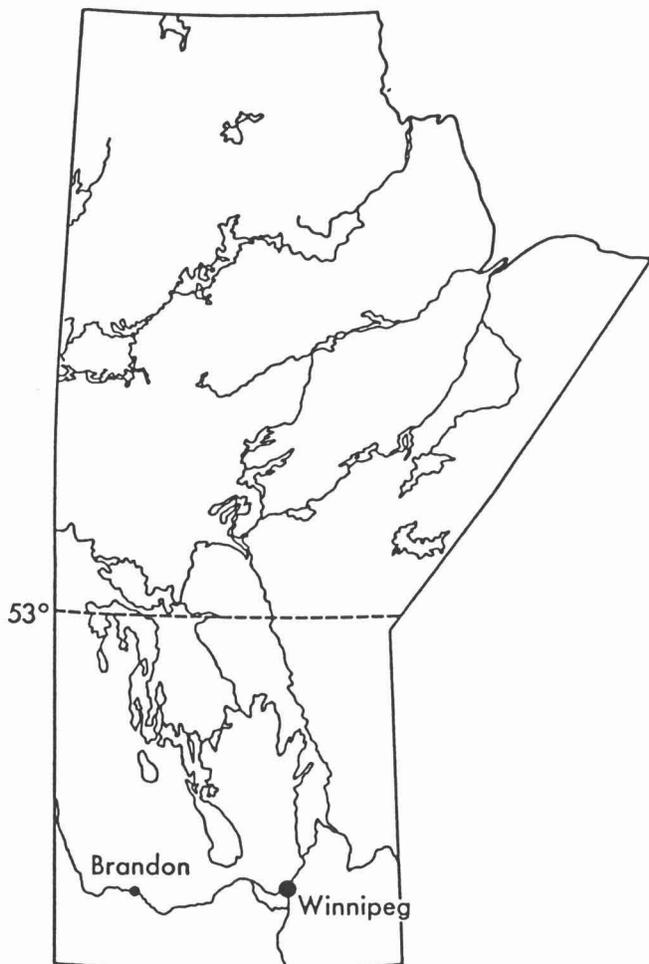


Figure 1 – Map of Manitoba.

45% of them living in Winnipeg; and aside from Brandon, the remainder were in widely scattered small towns and farms. The Manitoba Northland was even more sparsely inhabited then than now since Thompson did not exist then.

At that time comprehensive public hospital insurance and health insurance as we know them now in Canada were not available. There were no formal home care programmes in place at that time; and although many people had private insurance for acute illness, and although a few had private insurance against medical calamities, polio posed not only a terrible threat to life and limb, but also a very great economic threat to families.

Mr. Sherman mentioned the very great shortage of respirators in the province. He failed to say that half of them were old, wooden affairs, charitably donated years before to all hospitals in the Commonwealth by the British industrialist, Lord Nuffield. They were mostly lying unused and deteriorating in storage sheds.

Figure 2 shows cases year by year in Manitoba and admissions to the Winnipeg Municipal Hospital. In 1952

there was a major outbreak with 139 cases admitted to the Municipal Hospital. The King George wing was the local fever hospital for quarantine of cases with contagious diseases, and although at that time some other hospitals, particularly the Children’s Hospital in the city and small rural hospitals, took in poliomyelitis, the rural hospitals had serious problems handling respirator cases because of the lack of equipment and lack of experienced personnel. Such cases had to be transported to Winnipeg, often with respirator assistance, by road or air ambulance.

The experience in 1952 led to the decisions mentioned by Mr. Sherman that the Municipal Hospital be the major provincial resource for poliomyelitis, the King George wing for acute and respiratory cases, and the new Princess Elizabeth unit for rehabilitation. The Manitoba Rehab Hospital now in Winnipeg did not exist at that time, and the Princess Elizabeth, designated for geriatrics, was wheelchair accessible, and had a good Physiotherapy Department. That was later to be supplemented by the Hydrotherapy Department and a workshop for aids and devices. As Figure 2 shows – in 1953 the epidemic exceeded all expectations, and admissions to the Municipal Hospital, now limited to paralytic cases only, were close to 1200.

MANITOBA CASES AND ADMISSIONS WINNIPEG MUNICIPAL HOSPITAL

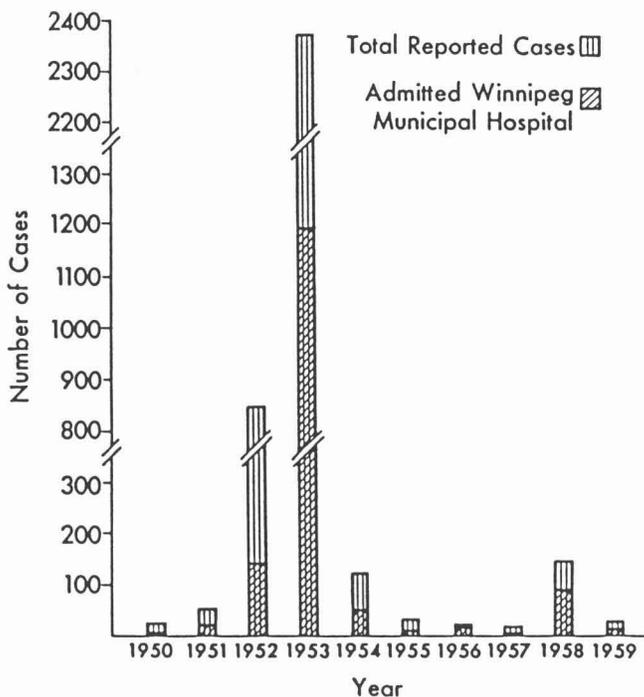


Figure 2 – Admission of polio cases to Winnipeg Municipal Hospital by year

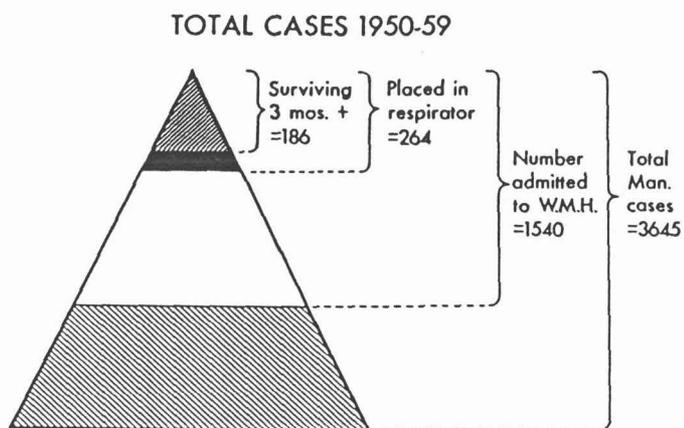


Figure 3 – Total number of cases of Poliomyelitis, 1950-59 and numbers admitted to hospital, placed in respirator, and surviving more than three months

In 1954 the cases dropped off to 117 and although there was a flurry of activity in 1958, that was the end of polio epidemics in Manitoba.

Figure 3 shows the same basic information presented in another way. The largest triangle shows all the cases of the decade in the province. The next triangle shows those admitted to the Municipal Hospital. The next shows the cases who required respirator treatment, and the tip of the figure represents 186 cases who were in respirators and survived for three months or more. This group is the cohort of 186 patients, the rehabilitation of which is the subject of this presentation.

DISTRIBUTION OF CASES BY AGE AT ONSET

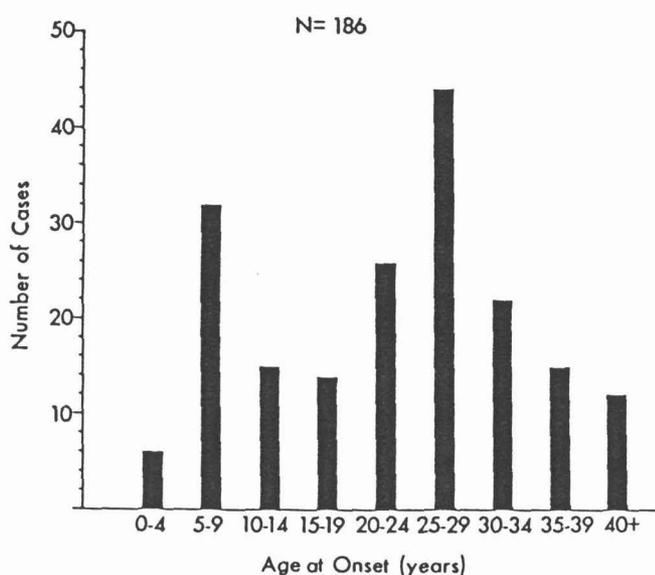


Figure 4 – Distribution of cases by age at onset

When we started to put together material for this presentation we found that although we maintained close contact with many of these patients – those who were still on respirators, and also we knew about a number who, although they had survived for three months, died without leaving hospital within the next few years – there were about 150 cases that we hadn't seen for years. We set about to trace them in order to gain their collaboration for this study. We managed to find all but 13, and all but two agreed to an interview and questionnaire concerning their health and life over the past 25 to 30 years. We have recently completed interviews with 113 ex-patients, and with 25 spouses, or other close family members of ex-patients who had died in the interval after leaving hospital.

We are very grateful for the co-operation received from these 138 people. As you have heard a number of them are here today to listen, and hopefully to comment on this presentation.

Table I

	SPINAL	BULBO-SPINAL	TOTAL
With Tracheostomy	2	81	83
Without Tracheostomy	71	32	103
Total	73	113	186

Table I – The number of patients requiring tracheostomy, spinal vs bulbospinal polio.

Figure 4 shows the age distribution of the 186 patients at the time of onset. They ranged from under one year of age to 66 years, but there appear to be two peaks – one is in the five to nine age group and the second and major peak is made up of young adults between 25 and 30 years old.

Table I shows a simple breakdown of cases by types of polio. I mentioned earlier the distinction between the high spinal type, which generally requires only a respirator, and the bulbospinal type which also requires the operation of tracheostomy to keep the airway open. As you can see in this table, of the 186 respirator cases most of the 113 bulbospinal cases had a tracheostomy, but only a few of the 73 high spinal cases did.

However, there is another difference between these two types. The speed and degree of respiratory recovery are much more favourable in the bulbar cases than in the pure high spinals. I will refer to this again later.

I have already mentioned that the 186 cases presented in this paper excludes the patients who died within the first three months. There were also a number of deaths which occurred after that time and these are shown in Figure 5.

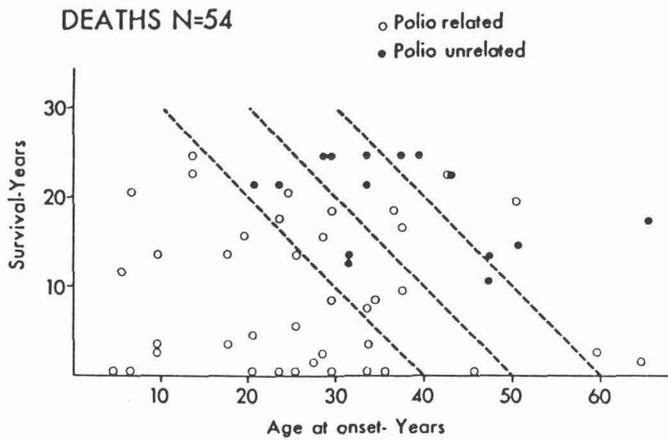


Figure 5 – Distribution of 54 deaths by age at onset & surviving years. Open circles are polio-related deaths. Closed circles are polio-unrelated deaths.

There were 54 such deaths up to 1st of January 1980 and they are plotted on this diagram. On the horizontal axis is the age at onset, and on the vertical axis is the survival time in years. The three dotted lines represent the ages of 40, 50 and 60 years of age. For example, take a patient who was age 40 at the time of onset, lived for another 25 years, and died – at age 65 of arteriosclerotic heart disease which was not related to poliomyelitis. She and the other deaths not related to polio are represented by solid dots. These solid dots tend to cluster in the upper right hand part of the figure, most of them above the lines which represent the age contours of 40, 50 and 60 years. The open circles which are largely clustered to the left and below, represent polio-

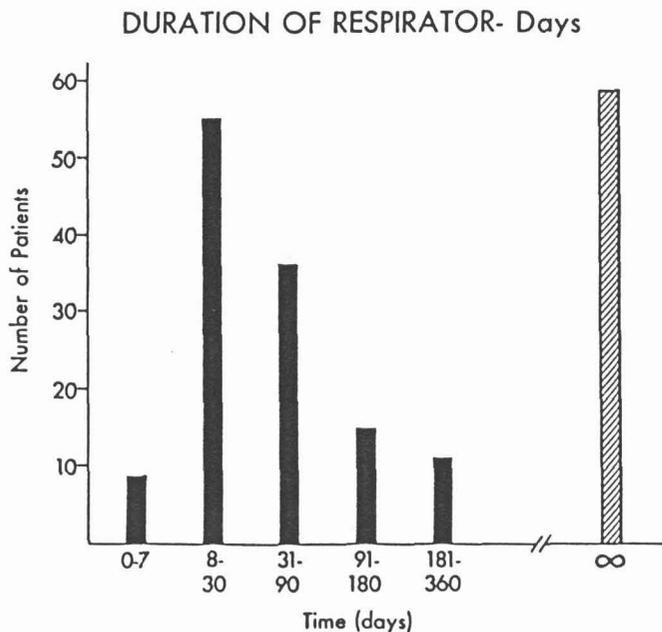


Figure 6 – The duration of time spent in respirators in days

related late deaths, due to respiratory infection, renal failure secondary to stones, or heart failure secondary to chronic respiratory insufficiency.

Not shown on this figure are two of the cohort who died since the 1st of January of this year, 1980.

Next, I will show data which relate to the duration of stay in respirator, the degree of residual respiratory disability and the discharge arrangements.

Figure 6 shows the length of time the 186 patients spent in respirators. On the left part of the diagram are all of those who were eventually able to manage without mechanical respirator assistance. The largest number of patients spent 8 to 30 days in a respirator but the range in time is very wide. The right hand bar on this figure represents those cases who were never able to be free of a respirator.

The few cases at the extreme left, who were in a respirator only for a few days, are paradoxically those who were most at risk of dying during the acute stage, but since they suffered mainly from bulbar paralysis, if they survived the acute stage, they made the best recoveries, sometimes so complete as to be considered almost miraculous.

Table II

POST-ACUTE RESPIRATORY STATUS

		N=186	
		No.	%
Respirator Free	No Disability	62	33
	Disability	61	33
Respirator Bound	Night Only	20	34
	12-18 hours	14	
	18+ hours	29	

Table II – Post-acute respiratory status.

Table II shows the distribution of cases with regard to their residual respiratory difficulty based on our objective assessment at the time of discharge or one year post polio. One third of the patients became totally free of the respirator and had little or no residual respiratory difficulty. Another third, those who spent a longer time in the respirator were left with more severe problems. Although normally free of the respirator, they had difficulty with respiratory tract infections and they might require to be re-admitted to hospital for short term respirator treatment. The remaining third remained dependent to varying degrees on the continued use of respiratory equipment. Some only needed such aids at night – others had to spend 12 to 18 hours a day in a respirator or on a rocking bed, and others could tolerate being outside the respirator only for very short periods of time. These latter patients could free them-

selves from their respirator only through the technique of frog breathing. This is an acquired skill of pumping air into the lungs with the muscles of the pharynx. It is a handy trick and about one third of our patients learned how to do it.

The 54 deaths shown in Figure 5 occurred throughout these groups but more of the late polio-related deaths occurred in those with the most severe residual respiratory disability.

As well as the risk of dying, the degree of residual respiratory disability has a significant effect on the rehabilitation potential — perhaps even to a greater degree than does residual paralysis of trunk and limbs.

Figure 7 is a summary of the distribution of cases by discharge arrangements. Of the 186 cases, 54% were discharged home in the ordinary way. Those were the ones who had achieved independence easily from their respirators. They were either followed up privately or they came back to our polio follow-up clinic. This left a large number of patients who were either tied to a respirator for part of each day, or so precariously free from the respirator that they required close surveillance and could not be far from a respirator. And yet many of them were anxious to leave hospital and return home and take up their normal lives again.

In order to meet their special needs it was decided to set up a home care programme. This was a very innovative step for the Province of Manitoba at that time, although it seems not unusual today.

Fifty-three patients (29% of the cohort of 186) were discharged under these special arrangements and shown as the middle bar of the figure. At the bottom are the 17% who were not able to be discharged and are shown here as permanent hospital cases.

The polio home care programme for these 53 cases was designed as a comprehensive package which met many needs of such patients, some of which are shown on the next table.

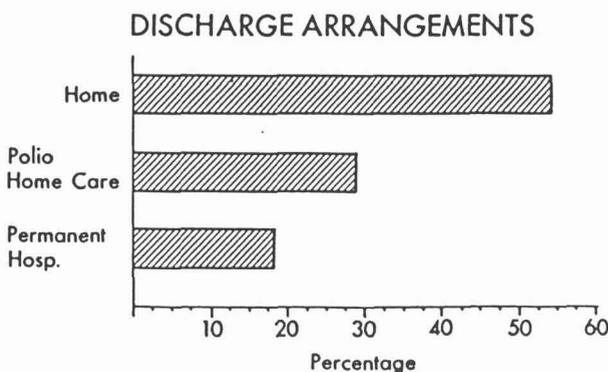


Figure 7 — Percentage of cases discharged to home, polio home care and not discharged.

Table III — Practically all of them required mechanical respirator equipment in the home. Sometimes this equipment was a tank respirator, other times a rocking bed; and chest respirators were also used for mobility. Given the importance of this equipment, meticulous arrangements had to be made to insure the regular inspection, servicing, and repair of that equipment.

Table III

INITIAL HOME CARE ARRANGEMENTS- 53 PATIENTS

	No.
Home Respiratory Equipment	50
Hydraulic Hoists	27
Wheel Chair	50
Homemaker or Attendant	
-Hired Attendant	34
-Spouse	10
-Parent	6
-Offspring	1
Home Modifications	

Table III — Initial home care arrangements for 53 patients

Mechanical aids were also supplied for those who were severely immobilized — hoists to get them in and out of bed, in and out of the house, and in and out of a car. This equipment required space and an adequate power supply. Most homes had to be re-wired to accommodate the load. The wheelchairs required that doors be widened, ramps built, and bathrooms and kitchens modified.

The second major component of the home care programme was a full or part-time attendant. There were 34 such attendants hired specially for this purpose and paid for by the programme, but payment was also made in certain cases to a spouse, a parent or a child who acted as a full or part-time attendant.

People who went home under this programme were leaving the medically more protective environment of the hospital. As a response to this risk a commitment was made that, should any health problem arise, respiratory or otherwise, immediate readmission to hospital would be available to them.

The heavy demands on the patient, the family, and the attendant of home care were also recognized and arrangements were made that readmission to hospital was available when the attendant or spouse went on holidays.

Table IV shows what has been achieved quantitatively with this home care programme. This table shows that on the average each of the 53 cases has been readmitted to the Municipal Hospital eight times, mostly for respiratory tract infection, but also for the respite for holidays I mentioned, and for other medical needs. On the average each has been on home care for close to 16 years but during that time has accumulated over a year's readmission time to hospital.

Table IV

POLIO HOME CARE PROGRAMME

N= 53

Mean Number of Readmissions per Patient	8
Mean Number of Readmitted Hospital Days	412
Mean Duration Home Care Program in Years	15.8

Range: 3 mo.-26 yr.

STATUS- JANUARY 1, 1980

Still on Home Care	25
Permanent Hospital Care	7
Deaths after Readmission	4
Died on Home Care	17

Table IV - Polio home care programme

The lower half of the table indicates what has happened to these 53 home care cases over the last 25 years. Half of them are still on home care and enjoying the benefits of that programme. Seventeen of them died while on home care and 11 were readmitted to hospital on a permanent basis, often due to the loss of a spouse, or some other reason important enough to destabilize the family and social arrangements upon which the home care programme was contingent.

I now wish to turn to the data which we obtained from the interviews carried out during the past few weeks to determine the functional state of the patients today and to obtain their perception of the changes which have happened to them in a number of spheres since they developed polio. You will remember that we interviewed 113 directly and we also obtained information from the spouses or other close relatives on 25 of the cohort who had died.

Table V shows their current respiratory status as they perceived it at the time of interview. For this purpose we have used the interview data from the 113 ex-patients who were able to give us direct information. In this table, as well as in subsequent tables, we have divided the 113 into 70 who were discharged home in the ordinary way, 23 who

were discharged home under the home care programme, and 20 who remain in the Municipal Hospital. As is shown to the right of the table the totals for the 113 patients are remarkably similar to those estimates of pulmonary function which we made objectively at the time of discharge or a year post polio; that is approximately one third respirator free and had little or no disability, another third continued to have some respiratory disability but were free of the respirator and one third were using respirators at least some part of each day.

However when we look at these data for the three categories of discharge we see that those who had ordinary discharges and the shorter period of hospitalization were all free of the respirator whereas those who remain in the Municipal Hospital and those who are on home care depend heavily on their respirators at least at night.

Table V

REPORTED RESPIRATORY STATUS TODAY

	% Home N=70	% Home Care N=23	% W.M.H. N=20	% of Total
Respirator Free				
No Disability	54	9	—	35
Disability	44	22	—	32
Respirator				
Night	—	35	—	}-----33
12-18 hours	2	26	35	
18+ hours	—	9	65	

Table V - Reported respiratory status today

So overall it seems that their respiratory status has not changed much. Some patients have improved somewhat in their respiratory function, but others have deteriorated. This is shown in Figure 8. These two graphs show serial readings of the vital capacity - a simple, reliable measurement of how big a breath one can take. The vital capacity for a normal adult is up to four or five litres. The first vital capacity test was taken within a few weeks of coming out of a respirator. Most of these shown here are under one litre. When that value is plotted against a second reading of the vital capacity taken some 10 months later, the second reading is better than the first and all the points fall below the line of identity. If the second reading was identical to the first the point would fall on the line. A few years later when a third reading is taken and then plotted against the fourth reading taken many months later, the situation is a little more complex. Those subjects who had a fair recovery of their respiratory function and had vital capacities of two

VITAL CAPACITY- Changes with Time N=35

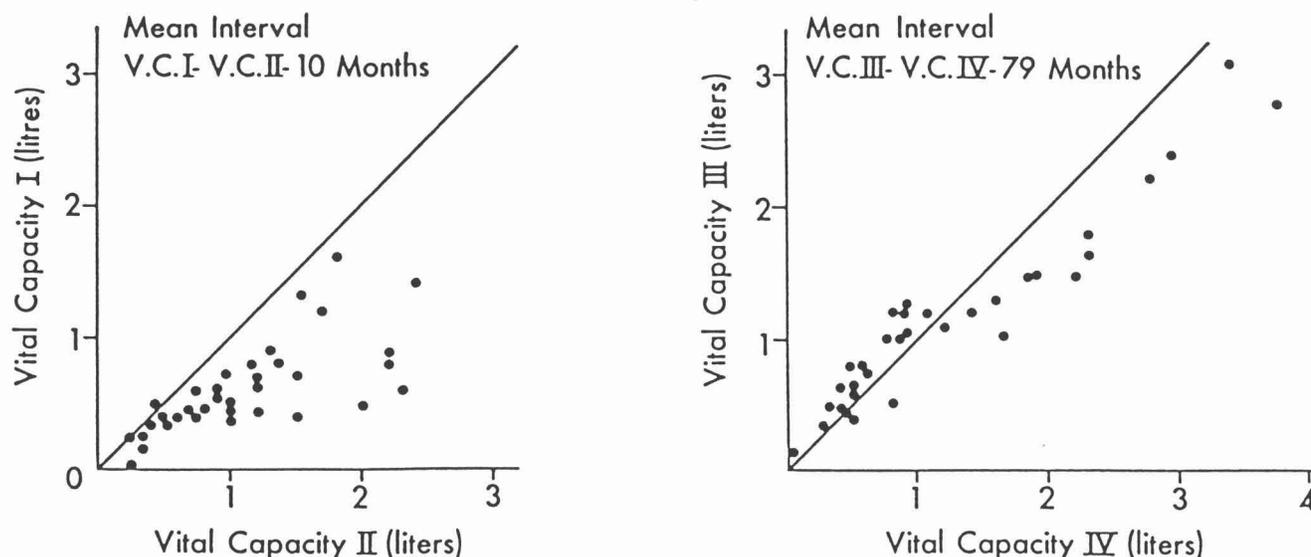


Figure 8 – Changes in vital capacity with time. Left hand graph compares vital capacity test 1 with vital capacity test 2. The right hand graph compares vital capacity test 3 against vital capacity test 4.

litres or more continued to improve in the interval between vital capacity test 3 and test 4 and their points are also below the line of identity. However, at the lower left hand corner of this right hand graph most of the points rise above the line of identity which means that there has been a deterioration in vital capacity between the 3rd and 4th test.

Perhaps Dr. Kirk will comment on ways in which this late deterioration of respiratory function can be avoided or minimized.

I would like to turn now to some functional parameters which are commonly used in rehabilitative medicine as a measure of residual disability. A series of questions were developed for our interview questionnaire which were based on Katz's Activities of Daily Living Index. The subjects could rate themselves for a particular activity at one of five possible levels of performance. They could carry out the activity with ease, level 1; or with difficulty but without equipment or outside help, level 2. The third level would be still without outside help but using equipment. The fourth level is when they required help in spite of the addition of equipment, and the fifth level was when they were totally unable to make any contribution to that particular activity.

For the purpose of the next two tables we have made a cut-off after level 3 (i.e. what a person does without outside help).

Table VI shows the results in terms of mobility – the ability to get around. A number of activities are indicated – getting into bed, sitting down in a chair, level mobility (this includes the use of wheel chairs, including motorized wheel

Table VI
MOBILITY

Individual Activities	% 'DOES NOW' (No Helper)		
	Home N=70	Home Care N=23	W.M.H. N=20
Into Bed	94	30	5
Sit Down in Chair	90	35	5
Level Mobility**	99	78	70
Stairs	71	17	5
Outdoor Mobility			
-Summer	93	65	65
-Winter	70	22	5

SUMMARY

General Mobility	Home N=70	Home Care N=23	W.M.H. N=20
One Year Post Polio	63	17	0
Current	93	61	10

** includes wheel chairs

Table VI – Current level of mobility

chairs), management of stairs; and in our Manitoba situation, we had to look at outdoor mobility and the difference between summer and winter. The columns show the same 113 ex-patients divided into three groups identified by their method of discharge from hospital — 70 discharged home in the ordinary way, 23 discharged to home care and 20 still in the Municipal Hospital.

The differences in mobility which exist between these three groups is very marked. The only dimension of mobility on which the three groups are relatively close is mobility on the level surface when they can use wheel chairs.

One can see how formidable a barrier stairs are even for a quarter of the largest group of 70. Some individuals have told us that they have had to leave a job, or to refuse a promotion because a flight of stairs blocked their access.

One can also see what a barrier to mobility a Manitoba winter can be.

The bottom of the table shows the general improvement in mobility in all three groups comparing one year post-polio with now.

Table VII
ACTIVITIES OF DAILY LIVING

ACTIVITY	% 'DOES NOW' (No Helper)		
	Home	Home Care	W.M.H.
Hand Grip	96	74	20
Hold & Lift	96	74	20
Reach Up	86	17	0
Write/Type	99	91	40
Wash	94	48	0
Bath/Shower	81	13	0
Dress	90	22	0
Toilet	91	30	0
Hair/Shave	96	52	0
Feed	97	78	5

Table VII — Current activities of daily living

Table VII shows a number of activities of daily living. There are a lot of figures on this table but I will lead you through them. These are the same three columns we saw before and the numbers in each are the same totalling 113 who were interviewed directly: 70 individuals who were discharged home in the ordinary way, 23 to home care and 20 still in. The figures in the columns are the percent of

those who actually carry out the activity without help but perhaps using mechanical aids and devices. The descriptions of the activities have been shortened for purposes of presentation on this Table. I am sure many of you are familiar with this type of activity measurement.

The data show again a very marked difference between the three groups. The 70 who were given normal discharges from hospital are almost all regularly doing all of these activities of daily living. Taking a bath or a shower is difficult for some and only 81% carried out this particular activity without the help of an attendant.

Table VIII
MAJOR HEALTH PROBLEMS

	% Home N=70	% Home Care N=23	% W.M.H. N=20
Urinary Tract	26	43	40
Heart	7	17	20
Hypertension	17	22	40
Ulcers & G.I.	16	26	35
Psychiatric	6	9	15
Polio Related Surgery			
Other Surgery	41	35	30
Accidental Injury	47	43	45
Polio Related	19	22	5
Other	7	4	0

Table VIII — Major health problems

In the next column of the 23 discharged to home care, many of them are not able unaided to reach above their head, to wash, bath, dress or go to the toilet whereas most of them are able to manage by themselves to grip the door handle, hold and lift an object, write or type, and feed themselves. Practically all of those still in hospital need help for almost all of the activities of daily living shown on this table.

Table VIII shows the health problems over the intervening 25 years as perceived by the people themselves who were interviewed. In this case the differences between the three sub-groups of subjects is not so marked but some differences remain. You must remember that this is no longer a young population. All of them are at least 30 years of age and a number are in the geriatric age group. Thus, it may not be surprising that a fair number of them report having urinary tract problems, heart disease, or hyperten-

sion. The number with mental health problems are relatively few. Some in each group have had operations which are polio related, as well as other operations. Twenty percent of them had polio related accidental injuries such as having a heavy fall because their limbs are unstable due to residual paralysis.

Table IX

SELF ASSESSMENT OF CURRENT HEALTH

	% Home & Home Care N=93	% W.M.H. N=20
Excellent	19	5
Good	61	45
Fair	16	35
Poor	2	10
No Answer	0	5

Table IX – Self-assessment of current health

Table IX indicates that their personal assessment of their general health is quite positive, even 50% of those still in hospital say their health is good or better, and only 2% of the 93 in the left hand column and 10% of the 20 on the right, or a total of only four of 113 individuals feel that they are in poor health.

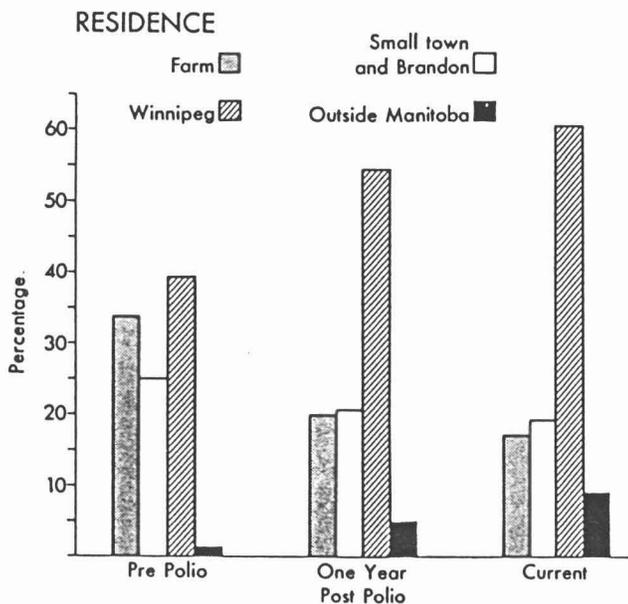


Figure 9 – Change in residence after polio

Figure 9 is a histogram showing that post-polio changes in the place of residence of all the 138 cases on whom we have interview information.

Although there is a secular trend to urbanization, many more of the post-polio patients have left the rural areas for the city than one would expect for the population shifts at large. In fact a number of them have informed us directly that they have moved into the city because of problems in rural areas with mobility, availability of help both domestic and medical, and opportunities for employment.

Table X shows data we have extracted to date from our 138 interviews on employment. Sixty-four of the 138 or approximately half of them had been wage earners before they got polio. Twenty-four of those or 40% of them went back to their old jobs post-polio. A total of 85 of the 138 were employed at sometime post-polio. This included some of those who were children when they got polio.

Table X

EMPLOYMENT EXPERIENCE

PRE POLIO	Nos.
Wage Employment	64*
Children	41
Homemaker	31
Other	2
POST POLIO	
Wage Earners* Returning to Pre Polio Jobs	24
Employed Some Time Since Polio	85

Table X – Employment experience

May I draw your attention to the category listed here of homemaker. The number shown here had that occupation before polio. We have responses on 38 female individuals who regard themselves as homemakers now. Half of them claim they manage to do all their housework; a quarter of them do some housework but not all of it; and a quarter of them can do very little actual work but still do the planning and supervision required to run their homes.

Table XI considers some personal and family events which occurred post-polio and which have considerable impact on the care and support available in the home.

Twenty-six or half of the eligible single adults including the children now grown up got married in the post-polio years. Half of those eligible (married) have had children.

But most of the children that the polio patients had (93% of them) became married and 12% of those married

children begat children of their own, shown here as grandchildren.

Time also takes its toll and 71 (63%) of the 113 post-polio suffered the loss of parents and eight of the 83 married ones suffered the death of their spouse. Eighteen were divorced or separated.

Table XI

FAMILY EVENTS OF POLIO PATIENTS

	N=113		
	No.	%	No. Eligible
Marriage	26	48	54
Birth of Children	42	50	83
Children Married	53	93	57
Grandchildren Born	10	12	83
Death of Parent(s)	71	63	113
Death of Spouse	8	10	83
Divorced/Separated	18	22	83

Table XI - Family events

Table XII - The final table depicts the responses of our 113 interviewed subjects when shown the ladder of events which you see at the left side of the table and asked to indicate where on that ladder of personal stresses ranging from traffic ticket to the death of a spouse they would place polio.

The question posed so much difficulty that 20% of them could not, or did not want to answer.

Not surprisingly, 15 of the 16 still in hospital who did answer (75% of this group) felt that polio was as stressful, or more so, than the death of a spouse. However almost one quarter of the patients who went home as ordinary discharges thought that polio was not more stressful than getting married or having a spat with the relatives.

This wide range of responses is contributed to by a number of factors. At one extreme we have those who have been left completely paralysed and dependent on a machine for breathing and an attendant for all their daily needs. At the other extreme are the people who, although they spent time in a respirator, had mainly bulbar involvement and made quick and good recoveries and are now leading a normal life with no or minimal disability.

To sum up, we have reviewed those polio patients from the epidemics of the 50's who required respirator treatment and who survived the acute stage of the disease. There were 196 of them and they spent widely varying times in hospi-

tal and in respirators. Some of them never left the hospital or the respirator even to the present, some 27 years later.

Table XII

IMPACT OF POLIO VS. OTHER LIFE STRESSES

	% Home N=70	% Home Care N=23	% W.M.H. N=20
_____ 24	19	35	40
Death of Spouse { _____ 22	13	4	35
_____ 20			
Divorce { _____ 18	27	26	0
_____ 16			
_____ 14			
_____ 12	23	13	5
Marriage _____ 10			
_____ 8			
Trouble with _____ 6			
Relatives _____ 4			
Traffic Ticket _____ 2	19	22	20
_____ 0			
No Answer/Refused			

Table XII - Ladder demonstrating the perceived effect of polio compared to other life stresses.

The majority were discharged home including a group of 53 for whom a special home care programme was developed and tailored to their individual needs for equipment and attendants. Many are still home in that programme 25 years later. In the intervening years 30% of the original cohort have died - many from polio-related conditions but also several from advancing years and conditions which are common causes of death for adults in our society.

We have traced over 85% of the original cohort and with their co-operation and the co-operation of the surviving relatives of those who died, we have obtained and presented information on their current level of functioning in matters of health, activities of daily living, employment and personal and family life.

Although we have been obliged to present a rather brief overview of our findings I think we have shown you sufficient data to support the following concluding statements:

1. Many patients with respiratory polio are left with considerable disability; and, in spite of new

equipment and new treatments, the human, social and economic costs of polio are devastating.

2. Therefore our aim must be to extend the use of already available methods – vaccines – to prevent the disease.
 3. We should acknowledge a silver lining to the polio cloud. In a way similar to thalidomide, and to some extent comparable to war injuries, polio has spawned, or at least contributed to, many innovations which have enhanced the quality of life for the physically handicapped, including the elimination of barriers both architectural and social. A related concern was eloquently expressed on Tuesday when Dr. Chigier was speaking about severely disabled Israeli veterans. They, like our polio cases, became disabled as young healthy people, but as the years pass they become older, and intercurrent disease and changing social and family affairs compound their original disability.
 4. In our re-examination of the long-term results of polio we have noted some areas where vigilance must be maintained against routine complacency. The long-term course of respiratory function is one such concern. Another is the changing needs of a group of aging people disabled by what was once called Infan-
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tile Paralysis. These concerns should stimulate us to a renewed dedication to maintain active and imaginative rehabilitation for the polio patients of the 1950's and for others with severe long-term disabilities.