# APPENDIX B

# The Breath of Life:
# Medical Technology and the Careers
# of Post-Respiratory Polio Patients

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This paper is based on life historical research supported by NHRDP grant No. 6607-1241-26. A modified version will appear in Sociology of Health and Illness, 1985.

# The Breath of Life: Medical Technology and the Careers of Post-Respiratory Polio Patients

This paper uses data from a study conducted within the Canadian province of Manitoba, designed to examine the long term effects of respiratory poliomyelitis on people who contracted the disease during the epidemics of the 1950's.[1]

Data has been collected by means of medical record audit, structured interviews with post-respiratory polio patients and in-depth interviews selected subjects. In documenting change in the lives of people disabled by poliomyelitis, the study as a whole, addresses a number of issues of concern to the post-polio community.[2] One is the 'post-polio syndrome', a relatively sudden decline in energy levels and physical functioning experienced by some patients during middle age. This syndrome is thought to be due to exhaustion of overworked muscles or the premature death of sipnal horn cells which recovered from the initial infection. The second issue concerns the interaction between normal biological and social aging and polio related disability, and the third, the changing socio-political context of disability.[3] The last refers to changes in medical technology, the emergence of State supported provision for disabled people and the new ideologies of disability growing out of the Disabled Consumer and Independent Living Movements. This paper, however, addresses only one issue; the management of respiratory insufficiency by patients and the impact of changing technology on patient careers.

## Poliomyelitis in Manitoba

Paralytic poliomyelitis is a highly contagious disease, caused by a virus which gains access to the body via the mouth and intestinal tract. The virus tends to lodge in random fashion in the motor nerve cells of the spinal cord and in various parts of the brain. It is the destruction of these motor nerve cells that results in muscle paralysis. Not all parts of the spinal cord are affected in the individual case and not all cells invaded by the virus die. Variations in the location and extent of the destruction process account for the wide variations in paralysis during the acute phase and the wide variations in post-polio disability. The loss of functional capacity during the acute phase, which may be respiratory, physical or both, is followed by a phase in which some motor function may be recovered. While deterioration in respiratory ability sometimes occurs in later years, most patients exhibit a fairly stable pattern of physical disability. It is only as the post-polio population has aged that a sudden loss of functional capacity on the part of some people has given rise to the possibility of a post-polio syndrome.

Between 1950 and 1959 there were 3,645 reported cases of polio in Manitoba with 2,371 of these occurring during the epidemic of 1953.[4] One thousand, five hundred and forty of these patients were treated at one centre, the Winnipeg Municipal Hospitals, and among this group, 264 (18%) developed respiratory paralysis and were placed in a mechanical respirator. The 186 patients who survived the acute phase form the population for the post-respiratory polio study.[5] Medical records show that at the time of discharge or one year post-polio, one third of these were totally free of respiratory support but were sufficiently inpaired to warrant admission to hospital for short term respirator treatment, while the remaining third were dependent to varying degrees on mechanical support. These differences are reflected in the discharge arrangements of the patients. Thirty one remained in hospital, 53 were sent home under the supervision of the newly established Respirator Home Care Programme,[6] and 102 were sent home with no special arrangements for care and support.

Using data from the medical records, an attempt was made to trace all 186 of the above patients. One hundred and thirteen were found and interviewed using a structured schedule. In 1980, when the data was collected, 20 individuals were long term patients in hospital[7] while the remainder were living in the community. The respiratory status of those included in the study was measured in terms of their degree of dependence on mechanical respiratory support. Five levels were used based on the system suggested by Spencer.[8] These are: 1) independent of support, 2) occasional dependence (i.e., during acute respiratory infections), 3) support at night only, 4) support for 12-18 hours a day, 5) support for more than 18 hours per day. Table 1 shows the number of subjects falling into each of these categories and their location in hospital or in the community.

Clearly, those with high levels of dependency on respiratory support were more likely to live in hospital than the community. These differences in living arrangements reflect differences in the availability of support systems in the community and, in some instances, patient choice. All those with high levels of dependency were also severely physically disabled as well.

## Technologies of Respiratory Support

Post-polio respiratory insufficiency is caused by paralysis of the muscles which affect the movement and volume of the chest cavity, i.e., the diaphragm, the intercostals and muscles of the neck, all of which contribute to respiration. Patients who retain function of the diaphragm (responsible for 55% of vital capacity) or the chest and neck musculature (responsible for the remaining 45% of vital capacity) can usually breathe independently and require little in the way of respiratory support. Some patients who retain the function of the neck muscles alone have developed a technique known as glosso-pharyngeal or "frog breathing" in which air is gulped into the lungs. While some mechanical support is necessary for part of the day in order to ensure sufficient oxygen intake, many can breathe independently for several hours. Those patients who have little or no function in all three muscle groups require continuous mechanical assistance.

Nearly all of the machines providing assistance with respiration work on the basis of either negative or positive pressure. Negative pressure machines mimic natural respiration. Perhaps the most familiar of these is the iron lung, a cylindrical tank which covers the entire body with the exception of the head. A pump moves air out of the tank, creating negative pressure in the chest cavity, so that air moves into the lungs. Positive pressure and the natural elasticity of the chest wall expels air from the lungs. While the iron lung is very efficient, its disadvantages are obvious: the patient is totally enclosed within the tank, supine and immobile. All the patients in the study were placed in iron lungs during the acute phase of the disease, although following partial recover of respiratory function, many were able to manage with a rocking bed or used a combination of rocking bed and iron lung. A rocking bed is exactly what the name implies; a mechanical bed which rocks the patient backwards and forwards an appropriate number of times per minute. Movement of the diaphragm and abdominal contents under the force of gravity create the positive and negative pressure necessary to move air in and out of the lungs. Though providing an acceptable level of support for some patients, it is one of the least efficient methods of mechanical respiration and is often used in combination with others. Another crucial disadvantage is that the patient is effectively tied to the bed and rendered immobile.

Early developments in the technology of respiratory support aimed to improve the patient's mobility by providing machinery which was portable or could be transported easily. The chest respiratory and pneumobelt allowed the patient to sit and moved around in a wheelchair, while the body wrap, an iron lung in the form of a plastic bag, could be readily carried from place to place.

More recently developments, from which polio patients are benefitting, were stimulated by the need to provide assisted respiration for patients with abnormal lungs. These people required a more powerful means of moving air in and out of the chest cavity.[9] The solution was found in battery operated positive pressure ventilators which literally blew air into the lungs via the mouth or, where necessary, a tracheostomy. While the physiologic effects of negative and positive pressure machines is the same, positive pressure ventilators effectively reverse the normal process of respiration, and the patient must learn how to control their larynx in order that they function correctly. These machines are readily attached to a wheelchair and allow the patient a high degree of mobility.

Positive pressure ventilators are currently being used by post-polio patients who can no longer be adequately ventilated using the older methods of respiratory support.[10]

As with other technologies, these ventilators have both advantages and disadvantages, allowing welcome modifications in a previously restricted lifestyle, but requiring patients to develop a repertoire of coping mechanisms in order to manage their idiosyncracies.

## Medical Technology and Patient Careers

The changes in the life experiences of post-polio patients over the period since onset can be viewed as a series of conceptually distinct though empirically overlapping biophysical functional and social careers. Here career is taken to encompass both long term life chances and the character and quality of everyday life. These careers may be shaped by any of a number of factors of which changes in medical technology is but one. For example, the possibility of a post-polio syndrome brings with it a new uncertainty and the fear that any deterioration in physical or respiratory function will threaten the somewhat precarious existence of those who have been able to live in the community. The implications and consequences of such deterioration, should it occur, are dependent upon a number of contextual influences. The development of community support services and improvements in medical technology can eliminate many of the negative outcomes associated with increasing levels of disability. Over the years, many of the most severely respiratory impaired people interviewed for this study had experienced a significant decline in their ability to breathe independently. Despite an increasing dependence on mechanical support the introduction of new forms of machinery has not only compensated for their functional loss, but given a quality of life somewhat better than that they enjoyed while less disabled. At the same time, these technologies impact on biophysical careers; improved respiratory efficiency improves general levels of health and increases the chances of survival.[11] In this way, biophysical, functional and social careers interlock in complex ways.

The newer methods of providing mechanical respiratory support enhance the quality of everyday living by improving energy levels, promoting feelings of well being and allowing for more intensive mobility in the community. However, these benefits are only obtained at a cost. While more efficient machines solve some of the problems encountered by post-respiratory polio patients, they give rise to a host of others which respiratory dependent individuals must learn to manage if they are to adapt to their new forms of respiratory support. Technologies form a resource upon which disabled people can draw, incorporating them into the strategies and routines developed to cope with the problems of everyday living; in this case, managing respiratory insufficiency and maintaining an adequate oxygen supply. At the same time, a new set of strategies and routines have to be developed to cope with the machine, its associated hardware and its technical limitations. At a minimum, patients, or more usually their close associates, must develop those technical skills necessary to connect, disconnect and monitor the functioning of the machine. In this way, new technology not only impacts on the quality of everyday living, but may also radically transform its character.

The remainder of this paper attempts to elaborate on this point of view by a detailed examination of the management of respiratory insufficiency and the effect of medical technology on patient careers. The data has been taken from the in-depth interviews mentioned earlier in the paper. Ten of the 29 individuals requiring respiratory assistance for more than 12 hours per day were interviewed on two and sometimes three or more occasions using a semi-structured schedule exploring a wide range of issues and themes. The individuals were selected because they had all experienced a significant decline in respiratory function in the years following the post-acute phase and had been forced to rely on a variety of methods of mechanical support. The formal interviews were tape recorded and transcribed in full. The data was supplemented by extended periods of informal contacts with the respondents and other post-respiratory polio patients and periods of observation in the hospital in which some lived. The demographic characteristics, experience with long term inpatient or community care and history of respiratory support equipment use is summarized in figure 1. Five of the individuals were long term patients in hospital and 5 had spent the majority of lives in the community, 5 were men and 5 were women. Two were less than 50 years and the remainder were 50-66 years old. All had major limb disability, in addition to their respiratory impairment. All were using some form of mechanical respiratory support. At the time of interview 6 used a mini-lung connected to the throat by a tracheostomy and one person intermittantly used a positive pressure ventilator with a mouth tube. The remainder continued to use rocking beds and specialized respiratory therapy machines on a daily basis.

## Learning to Breathe

In common with the other 236 people who developed respiratory paralysis the 10 people interviewed for this study were placed in an iron lung during the acute phase of the disease. The time they spent confined to the lung varied from three to 18 months. Once in the lung, respiration was accomplished by the machine and no effort was necessary on the part of the patient. Following recovery from the acute phase, all patients entered a period of respiratory rehabilitation during which they were encouraged to begin to breathe independently. This transfer from passive breathing in the iron lung to respiratory independence was referred to as "weaning". The aim was to help the patient develop maximum ability with the muscle function that remained; the method used was simply to remove the patient from the iron lung. All described this period as an ordeal. As one of the men said, "The sister came around about ten every morning like a sargeant-major and said 'Everybody breathe'. And the orderlies or the nurses would open up our iron lungs and you'd gasp. I'd just turn blue, it was really grim."[12]

The main problem faced by those patients who had lost the use of a substantial portion of muscle function was that they simply did not know how to breathe. One of the women who has remained in hospital since the acute phase described it in the following way.

> I kept asking the physiotherapist 'How do you breathe?'Cus who thinks how you breathe. And she put a paper tissue above my face and then she'd open up the respirator and told me to blow it and as long as I could lift it for her I knew I was breathing because I had no other feeling of breathing. That was one way of knowing I was getting air in, because if I was getting air out I had to be bringing it in.

The initial periods out of the iron lung might last no longer than half a minute or so, and the patients were encouraged to stay out of the machine for a little longer every day in order to develop and extend their respiratory capacity. Every day they would be timed and every extension of their ability to manage without the machine was seen as a step on the way to recovery.

> It was an endurance test because immediately you came out of the tank you felt as if you were being suffocated and then you would freeze up with panic. You would be gulping air away there and the nurse would be telling you how many minutes. Each time you would try and extend the period a little bit longer and every second made you feel better. Just being out of the respirator was terrific and

> again it was a step forward. It was ten seconds to start, then half a minute until you got to a certain point and you took it by hours. And of course, the first night you ever stayed out all night, that was really something. That gave me confidence that I would be all right and I stayed out then at night.

This process of recovering respiratory and other physical functions was faciliated by two features of the patient's context. The first was a prevailing ideology which stressed independence and minimal resort to mechanical support, and the second was the fact that each patient was one among many struggling towards the same goals. Thirty years later these remain important influences on patient careers.

The ideology of independence is best expressed by one of the female respondents whose respiratory and physical capacities have declined substantially over the years.

> We were encouraged to keep pushing ourselves to the limits. You just kept going, whatever you were doing you just kept on doing it until you were so tired you couldn't go any further. And we sort of had this drilled into our heads.

In the early stages of rehabilitation the respondents subscribed wholeheartedly to this ideology, setting goals for themselves and pushing until they were achieved. Subsequently, when progress was slow or non-existent, the necessity to continue to struggle to become independent only resulted in disappointment and frustration. One of the women said in trying to come to terms with her lack of progress, "I thought it must be something I'm doing wrong that other people are doing right"; and another said, "It was hard not to think I'm not pushing hard enough, I'm not trying hard enough. But no matter how hard I tried I wasn't going to make it anyway". The practical consequences of this ideology became apparent when no further improvement in functioning took place. The patients were made to persevere in order to preserve the capacities they had developed.

> In the later stages, before going home, you know, if it took you half an hour to wheel yourself down the hall that's just fine. Other people they kept just whizzing past you, but you're on your own, and I guess that's the way it has to be to develop you to your fullest potential. But it was sort of frustrating knowing you're not getting any better but you're still struggling along to get from A to B.

It would be an exaggeration to claim that the emphasis on independent achievement was wholly imposed upon patients by the staff of the hospital in which they lived, since the patients themselves were anxious to recover as much function as they could. Nevertheless, some of the respondents accounts give rise to the impression that the ethic was maintained by staff long after it had ceased to be useful or in the patient's best interests. Even after being in hospital for ten years, one respondent was not allowed to use an electric wheelchair: "They said no. If you can wheel yourself, you wheel, even though you could get there faster and get more done without wasting time and energy wheeling yourself". The same attitutde applied to respiratory support and the same respondent reported that one nurse would prevent her from using the rocking bed by simply refusing to turn it on: "That was about the time that I was getting a divorce. She was going on the idea that I was babying myself, that I was feeling sorry for myself". This happened at the time the respondent's respiratory capacity was beginning to decline and it was only by appealing to a doctor that she was allowed the support she desired: "And I was such a bad girl that caused all this disturbance on the ward and I was terrible because I phoned the doctor myself and patients do not phone the doctor themselves".

The attitude of striving to be independent and limiting the use of technology was one some respondents carried with them into the community. However, many seemed to have realized gradually over time that of continually pushing yourself and not giving in to mechanical support was no good and might even have inflicted permanent damage. Some believed that the muscles they retained have been over-burdened as a result and used this to explain what has been previously referred to as the post-polio syndrome. New technology and changing attitudes to technology have produced dramatic changes in the later stages fo these patients' careers. The strategy of fighting disability has gradually given way to a strategy of partial aquiescence in which technology is acceptable as long as it makes a contribution to the quality of life. As further data will show, independence is still valued by these respondents but for different reasons.

Just as the prevailing ideology was a help and a hindrance in the years following the acute attack, living among a community of similarly situated patients had both advantages and disadvantages. One respondent reported that seeing other patients make progress in the early days was an incentive for her to work hard on her own behalf, while another talked of the competition between patients to see who would be the first out of the iron lung saying, "I think it would have been much more difficult if there hadn't been so many of us. If I was on my own I would have had a rough time wiht no one to compare with". Alternatively, it was sometimes depressing when the expectations created by seeing other patients make progress were not met. One man said, "It was kind of grim because the guy next to you might be out for five minutes the first day and half an hour the second and then in two or three days he'd be gone home or something. And then you'd start feeling pretty sorry for yourself".

The process of learning to breathe again was not confined to the immediate post acute stage of polio, but was an imperative faced by the respondents at a number of points in their lives. New technologies meant learning new techniques of breathing and even temporary resort to total support could mean a loss of functional capacity and the necessity to go through the learning process yet again. One respondent even found it hard to switch back and forth from a rocking bed to her positive pressure ventilator since the techniques of breathing with each were quite different, requiring the use of different muscles and different parts of the chest; for example, she did not need to use her neck when on the rocking bed. This was particularly noticeable after she had been away from home. She relied exclusively on the positive pressure machine since it was more easily carried than a rocking bed. She needed to use both since the rocking bed was very relaxing, the natural action it produced facilitating sleep, while the mechanical ventilator she used because it kept her chest cavity expanded and helped to maintain her vital capacity.

One of the hospitalized respondents was so doubtful of her ability to go through the learning process again that she used to be afraid of even a temporary resort to an iron lung.

> I've told the staff that if I got ill don't put me in an iron lung. there's no way I want to go in it because I'll never get out. I know that I don't have the drive to get myself out of it. I've seen it happen to people here. One patient had a bad year and just the contentment of the respiratory and the drugs he was taking, he never did get out. You just don't have the....you've gone past the stage in your life when you've got the push to keep on fighting, relearning and going through all those things, it's going through the whole process again.

Having started using a mini-lung, she had been freed from this fear; "You don't have that because you're using the mini-lung all the time regardless of what happens to you". Six weeks before this interview, the respondent had suffered a minor stroke and was kept adequately ventilated without recourse to an iron lung.

## The Onset of Respiratory Decline

Following rehabilitation in the immediate post-acute phase, all but two of the respndents became independent of respiratory support. One of the two, having suffered onset in childhood, continued to use an iron lung and a chest respiratory, the other, a rocking bed during the day. All enjoyed a period of stability lasting several years before experiencing a decline in respiratory status. Seemingly precipitated by respiratory infection, weight gain or loss of elasticity of the chest walls, this decline often took one of two forms. In some cases, onset was slow and insidious and often went unrecognized for as long as two years, while in the others a crisis indicated respiratory insufficiency and immediately lead to the readoption of mechanical support. In both instances, the diagnosis of inadequate ventilation heralded a new period of adaptation in which patients were forced to adjust anew to the constraints of respiratory technology.

Those respondents who experienced insidious onset complained of a number of symptoms. Prominent among them were tiredness, lack of energy and repeatedly falling asleep during the day, even in mid-conversation. Neither patients nor physicians appear to have anticipated a decline in respiratory function and a diagnosis of $CO_2$ retention was sometime a long time in coming. One respondent said,

> I didn't really know what was wrong with me at the time, I was just falling asleep and hallucinating and feeling just dreadful. My local physician came

> in and couldn't see anything wrong. It was a scary experience.

Given the lack of physical signs and the prevailing ideology of striving for independence, some people initially interpreted tehir problem as motivational rather than physical.

> When our breathing started to go the other way it was hard not to think, you kept feeling, at least I did, that I'm not pushing hard enough, I'm not trying hard enough. I became very depressed, my mind didn't function as well as it should have. Things I should have been able to do my mind had to work a lot harder than it did to do it. I didn't have the get up and go and you couldn't put your finger on what was wrong. I really didn't connect it to respiration, the fact that there had to be a physical reason for it. You see, you could breathe, you're not turning blue, you're all right, and it was hard to give in.

At the time, the technology for blood gas analysis was not available and it was only with the accumulation of cases that patients and physicians became aware of the problem. Accordingly, patients were alerted to the possibility of respiratory insufficiency and better able to monitor their own and their fellow patient's respiratory status. Looking back, many attributed the sudden deaths of friends and acquaintances to inadequate ventilation and the build up of carbon dioxide. Post-respiratory polio patients in Manitoba are now able to take advantage of a clinic at which their blood gases can be measured periodically.

The onset of respiratory insufficiency occurred during the mid to late 1960's, some ten to fifteen years after the acute phase of polio. Some of the respondents reported an initial reluctance to return to mechanical support, with one woman refusing to use her rocking bed until she discovered what a difference it made to her well-being. Those forced back into an iron lung found it particularly hard, even more some if they retained some function in their arms and legs and became tied to equipment after being free.

Among the group of patients who achieved independence from mechanical ventilation, the decline in respiratory status occurred as a two stage process. The first stage has been described above and consisted of a partial return to mechanical support. Here, rocking beds and other forms of technology were used during part of the day or at night. Many reported that during this stage they gradually increased their use of respiratory equipment, almost without realizing it, in an attempt to maintain their oxygen supply, energy levels and quality of life. Subsequently, increasing respiratory impairment led to a search for newer and more effective technologies. For all, the solution was found in the mini-lungs and positive pressure ventilation previously described. The most seriously impaired swapped the older methods of support for permanent connection to a mini lung via a tracheostomy, while the remainder acquired positive pressure ventilators used with a mouth tube to supplement the methods they had always used.

Those respondents using mini-lungs can be considered to have progressed to the second stage in the process of respiratory decline; mechanical ventilation for 24 hours a day. Unlike those who used positive pressure ventilators, there was no point during the day when they breathed independently. This resort to total respiratory dependence, referred to by one respondent as "the end of the road", coincided with the final rejection of the rehabilitation ethic that had been the guiding principle of the respondents' lives during the early years of disability. As the same respondent said, commenting on her own situation and that of a fellow patient:

> You weren't functioning and you had to find something, or hoped you'd find something to make it better and if this wasn't going to work I don't know what was going to work, but at least you had to give it a try. Everybody doesn't think that. There's one patient I feel should be on a mini-lung and isn't. He still has the feeling that the harder you work the better you're going to be. You have to get all that out of your head and go back and approach it from another angle.

The different angle alluded to in this extract consists of accepting dependence upon technology if it enhances the quality of everyday life.

## Respiratory Insufficiency and Everyday Life

It goes without saying that breathing is the most fundamental, yet the most taken for granted activity of everyday life. Although the most immediate prerequisite for the maintenance of life itself, it is, for the most part, automatic and irgnored. The body has a number of mechanisms which maintain and control respiration and little conscious effort is ordinarily necessary in order to secure an adequate oxygen supply. For those free of disorders which seriously impair the respiratory system, breathing becomes problematic only in the face of specialized activities (e.g. singing or swimming) or unaccustomed effort such as a sudden spring for a bus. For those with severe respiratory impairment, however, the need to obtain oxygen, the need to breathe, is always at the forefront of their minds. Unlike other disabled people, whose main concern is how they are going to perform the activities of daily living, post-respiratory polio patients must constantly address the more basic and more pervasive problem of respiration. At no time during the day are they free of this major concern. As one of the women said, "People wonder how they are going to get from point A to point B. We always wonder how we're going to breathe throughout the day." For the most severely impaired, many of whom could only acquire oxygen by frog breathing, respiration required concentration and sustained effort. one of the men said, "In the old days (before acquiring adequate mechanical support) when I was up in the wheelchair it was just a matter of trying to breathe. That was a day's work." Now that he had been supplied with a mini-lung, "I don't have to work at breathing."

Given the effort and energy required simply to breathe, additional activities such as talking were either impossible or imposed an additional burden. The gulping action necessary to frog-breathe made communication difficult and the production of words and sentences a long and laborious process. While wanting to maintain a degree of freedom from mechanical support, the problems involved in breathing independently made many grateful for the security and relaxation offered by the confines of the iron-lung.

> I would always have to go back to the tank at night because frog breathing all day it was a hard job. People would say what do you do all day. I breathe! They'd say, that's not hard work but for me it's like I'm walking 19 miles. It takes every bit of energy out of you. And talking on top of it, which is my hobby, only adds more stress. When I was in the iron lung it was like heaven cus my whole body could relax and I could sleep.

One connected to a mini-lung by a tracheostomy, this woman found she was no longer forced to go to bed early in the evening. Moreover, she discovered what it was like not to have to concentrate on breathing.

Half of those interviewed obtained mechanical support 24 hours a day by means of a mini-lung and a tracheostomy. The remainder, most of whom were able to breathe independently for up to 12 hours, supplemented their own breathing by using a rocking bed and/or a positive pressure machine with a mouth tube. The latter, activated by a sucking action, allows the individual to take air when and where he or she wishes. Such assistance is necessary to maintain an adequate oxygen level in the blood and prevent the build up of carbon dioxide. These people would sleep on a rocking bed and also had to set aside time during the day when they could use the bed, the positive pressure machine or both. All were forced to stick to a strict daily routine to ensure that their needs for oxygen were met. Most had been advised to use the positive pressure machine for five minutes per hour, but found that too disruptive of daily living, developing their own routines in accordance with the pattern of their everyday lives. One woman would use the positive pressure machine for one hour in the morning and spend an hour or two on the rocking bed in the afternoon. She used the machine whenever it was convenient and it was kept near at hand so she could take advantage of it if she felt she was getting short of breath and needed a boost. Another woman who worked at home, kept the machine by her typewriter, taking five minute breaks from her work in order to supplement her own breathing. She would also spend an hour or two on the rocking bed in the afternoon, but would cut down on the time if she had been able to make frequent use of the machine.

These daily routines were modified or extended in order to cope with extraordinary circumstances, usually social visits or other activities which might keep them away from home for a few hours. Then they would need to prepare for the activity by spending additional time on the bed, the machine or both. The following day's routine would also need to be modified with additional time allocated to respiratory support. This was necessary to cope with the tiredness that always followed an unusually long period of independent breathing. In this way, social activities had to be planned and paid for in terms of additional time given over to mechanical ventilation. Permanent connection to a mini-lung by a tracheostomy freed the individual from these daily routines and the constraints they involved. At the very least, continuous ventilation by a portable machine meant that the person was not forced to stay at home.

Post respiratory polio sufferers encounter three main problems in coping with the demands of everyday life. One is acquiring sufficient oxygen to maintain life; the second, acquiring the additional oxygen to furnish the energy necessary to accomplish the activities of daily living, and the third, findings way of more easily managing their everyday affairs given their respiratory and physical disabilities. Like people with emphysema [13] and rheumatoid arthritis, [14,15] these people attempted to manage with reduced energy levels and functional limitation by means of three distinct strategies; those of selective allocation, pacing and short-cutting.

Selective allocation is one of the ways chronically sick and disabled people attempt to maintain a satisfactory existence in the face of radically reduced physical and other resources. As the term implies, it involves using one's limited reserves of time or energy to accomplish a small number of valued or necessary activities; the others being abandoned or left for another day. Fagerhaugh [14] has documented this process in the lives of people with emphysema, who, like post respiratory polio sufferers, have a reduced oxygen intake and a diminished supply of energy. A good illustration of the strategy was provided by the most severely impaired respondent contacted during the course of the study. Because breathing on her own was exhausting, she used to spend most of the day resting in her iron lung. She would get up late in the afternoo,n the energy saved allowing her to stay up for longer during the evening when family and friends were more often around. Having exchanged her iron lung for a mini-lung, this strategy became redundant. Substantially improved energy levels and freedom from the need to concentrate on breathing, meant that she could now get up at six in the morning and need not go to bed until midnight.

Pacing was initially described by Weiner [17] in her study of people with rheumatoid arthritis. This involves learning what activities can be undertaken, for how long and how often given the limited resources the person has available. This strategy was most evidence in the daily routines which characterized the lives of the majority of the respondents. One woman said that she tired easily but over the years, "I've learned to pace myself. I stick to a definite routine and try not to get over tired as it takes me a long time to bounce back." After a long period of trial and error, she had learned to judge her energy supply and how to manage within its limits. She would lie down every five hours to ensure that she did not overtax herself.

Pacing was also evident in the occupational lives of those respondents who did some kind of work. The man who lived in hospital earned a small income from selling over the telephone. It was a job he could manage despite his disabilities and one which could easily be left for another day if his energy supply was not up to it. Similarly, one of the women who worked at home was able to judge quite accurately how long she should spend at her work, although recently, as her energy levels had declined, she was having to adapt anew.

> I find that difficult right now because I find I want to work longer than I really feel I should or can and if I push it and do more, then I know the next day I'm not going to feel very good. I used to be able to push on for an extra half hour and finish up something that I wanted to attend to and I wouldn't have the consequences of tiredness as of now and I find that really difficult.

The constraints under which this respondent had to live were so ridgidly drawn that even minor infringements, such as an extra few minute's work, would ruin the next day. As she said, "If you push yourself you pay for it in other ways." Pacing thus became the order of the day. Understandably, she was somewhat fearful of her future and uncertain as to what her ultimate fate would be as aging or the post polio syndrome began to take their roll.

Short cutting is a process commonly observed among people with disabilities and involves finding ways of performing the activities of daily living with the minimum of effort.[18] This was not simply a matter of coping with physical disability, but also one of preserving a limited energy supply; less effort meant using less energy. Such as the need to preserve energy that even the smallest details of daily living were consciously planned with this end in mind. For example, one of the respondents had learned how to use the motion of the rocking bed to assist in moving her arms. If she decided to read, she would alway sit on the rocking bed where turning the pages of her book could be almost wholly accomplished by the movement of the machine. Similarly, one man would always prevent his car seat belt from retracting by tucking it into the back of his seat. The next time it was used he did not have to work against the spring mechanism while pulling the belt across his body. The ultimate form of short cutting as an energy saving strategy was to allow someone else to perform the activity. The male respondent who lived in hospital was able to feed himself, something he considered to be "a big plus". Nevertheless, it was "quite a chore to eat" and he would often allow the attendants to do it for him. This constituted a short cut for the attendants as well:

> It's faster for them to throw the food in rather than set me up to do it By the time they've set me up they could have fed me and gone on to the next job.

In this way, personal and organizational imperatives combined to keep this respondent dependent.

## Trading Off: Medical Technology and the Transformation of Everyday Life

Mention has been made at several points during this paper of the advantages and disadvantages derived from a resort to mechanical forms of respiratory support. While there are important gains from the use of technology, particularly the newer technologies such as mini-lungs, there are also losses and the respondents had to balance the benefits and costs in the course of daily life. They had to adapt to the idiosyncracies of the machines they used, find ways of maximizing the benefits derived from them and develop a repertoire of coping skills in order to manage the problems these technologies involved. Conspicuous amongst this group fo respondents was a strategy that may be termed "trading off". This involved reorganizing daily living and, to a lesser extend, psychological orientations to the world, in order to maximize the advantages and minimize the disadvantages of mechanical methods of respiratory support. In short, trading off led to a transformation in the character of everyday life.

All those respondents who had made the final transition to a mini-lung with a tracheostomy readily agreed that it had had a positive impact on their lives. So much so that they often tried to persuade other post-polios to make the transition too. The main benefit was an increased supply of energy and a greater zest for living. They not only achieved more during the course of the day, but felt like achieving more. Breathing was easier, there was no need to concentrate effort on maintaining an air supply, talking was easier, they reported less fatigue, a better appetite, fewer episodes of respiratory infection, fewer problems with the urinary tract previously caused by long hours spent lying down and a better mood derived from better physical health. One of the women, formerly confined fo rhours in an iron lung, said, "I can sit up, I see more of life." During the seven years she had used the ventilator, she had found a job and having persuaded a national airline to carry her with her equipment, had made several trips around the North American content. Another woman attributed her ability to cope with a recent stroke to the benefits derived from the mini-lung: "I could fight my way through without any problem. If I hadn't been on the machine, I couldn't have handled it. I've a lot more energy. You relax for one thing; you don't panic the same way when you're breathing on your own".

Initially, only the most severely impaired respondents were supplied with mini-lungs. Subsequently, others rapidly saw the benefits to be gained and asked that they be allowed the machines too. For some individuals, the necessity to undergo a surgical procedure and be left with a permanent hole in the neck was something of a barrier to accepting this more efficient form of respiratory support. One respondent, currently using a ventilator with a mouth tube, expressed some concern over the implication of a recent decline in her ability to breathe independently. At the time of the interviewing, uncertainty was one of her major problems.

> In the last six months I've developed breathing problems I didn't have before. I've put on weight or I'm not pacing myself as well as I should, I don't know but I'd still like to know what's ahead and if there's any alternative to this tracheostomy. I think that must really change your lifestyle drastically to have that. They all stress the tracheostomy, they all want to shove that in your neck straightaway. It's not knowing what's ahead. Well, I guess you know what's ahead but you sort of fight it and look for alternatives, you know, miracles or something new on the market. ( )

Some of the respondents did report that the tracheostomy had caused some discomfort in the early days, while others expressed surprise at how easy the transition had been and how they rarely noticed the hole or the tube connected to the neck. All, however, did comment on the visbility of the tracheostomy, the machinery and the tube that linked the two and the fears of non-users that this would have interactional consequences. Fear and curiosity seemed to be common reactions on the part of the uninitiated when first they encounter someone using a mini-lung, although to judge by the accounts of these respondents, these initial responses gave way to an easy familiarity with few significant breaches in social relations. Nevertheless, users of mini-lungs were prepared to accept any negative consequences derived from the prominence of their machinery in order to acquire the benefits:

> "I think that anybody that feels that they don't want to go on the mini-lung because of having to have the trach and having to have the hose connected, they don't realize what freedom they've got".

Unlike most forms of mechanical support, mini-lungs and, to a lesser extent, positive pressure ventilators, demand certain skills on the part of the user. In an iron lung or on a rocking bed, the patient is totally passive, with respiration wholly achieved by the action of the device. With the mini-lung, the individual has to learn to work with the machine in order that respiration proceeds efficiently. During this initial period of adaptation, the patient is essentially on his or her own. one woman found that it took her almost a year to get used to the rythym of her machine: "The patient is definitely has to learn the machine. Nobody can tell you, nobody can teach you, you have to learn your machine". Patients have to develop their own way of storing air in order to cough and talking has to be coordinated with the air flow of the machine. One respondent felt that some had not yet fully mastered the technique and because they seemed to wait for the machine to give them air, appeared somewhat uncomfortable with speech. One of the first to be supplied with a mini-lung, she had mastered the air flow to such an extent that she could talk continuously and never needed to stop to take breath: "I just close off my glottis and just the minimum of air is needed over your vocal cords and that´s why I can speak without stopping". This, she felt, was an added advantage in her many disputes with the repsentatives of the formal agencies responsible for her welfare.

As well as learning how to breathe with the machine, the respondents also had to learn to recognize their own needs for air and how those needs change during the day, for the pressure and volume of their flow often had to be modified. It was largely through experience that they learned how their requirements altered during periods of activity or rest and how to ensure that the machine was adjusted accordingly. One woman, not long married, illustrated this problem when discussing the difficulties she and her husband encountered during intercourse.

> When we received our marriage vows the doctors didn't tell us, they didn't know themselves, about the intercourse, that your respirations increase. The machine just gives you your ten or eleven breaths per minute, so I need sixteen breaths per minutes during that time I need more air. My husband and I had to interpret this as another experience - turn the rate button up, increase the pressure, turn this up, and he was paying more attention to the respiratory that he was with...and trying to keep his mind on everything. All of a sudden as you're enjoying intercourse you have to turn the rate button up. He's had to learn to do all these things.

As this quote indicates, the development of skills is not confined to the individuals using the machine; primary helpers must also learn how to manage the equipment and its idiosyncracies. They must learn how to connect and disconnect the machine, alter the volume of air it produces, recharge the batteries, milk the hose,[19] maintain the cascade,[20] to suction the patient,[21] use an ambibag in case of machine failure,[22] and learn to recognize when the machine is about to fail. Primary helpers become involved in the process of trading off. The greater freedom of the disabled person demands a broadening and increased complexity of their caring role. Consequently, only those with a primary helper willing and able to take care of the equipment were able to make the transition to the mini-lung. The respondents in hospital had such a resource in the form of the nursing staff, while those in the community sometimes did not have anyone prepared to fill the role. One respondent initially refused to make the transition from iron lung to mini-lung because her mother did not feel she would be able to master the necessary caring skills.

> The doctor says have this machine and I says no because my mother discouraged me. She says I can't learn something about a machine you're going to be attached to. She said she would never able able to suction me or anything like that and, please, if you go on that machine I'll never be able to look after you so don't even bother trying it. You see, the iron lung was a very easy machine. All you did was put a diaper around the person's neck to stop the irritation from the rubber collar. There was nothing to learn, the gauges were pre-set, they stayed at the same gauge, the same pressure, there was nothing to move. But as soon as I was hoping to go on this machine mum said `I don't know if I'll be able to take care of you, it's gong to be hard to learn'. There was more to remember. With this machine it's more of a nursing technique.

One of the main disadvantages associated with the use of the more advanced forms of respiratory support was a loss of independence. Those using mini-lungs in particular became more dependent upon machinery and more dependent upon skilled technical help. This dependency had negative practical and symbolic consequences.

Although the mini-lung does demand that the patient participate in the respiratory process, the patient is rendered passive to the extent that it is no longer necessary to use the muscles of the chest wall, abdomen or neck in order to breathe. Some felt that after a number of years using this form of support, their ability to breathe independently had declined significantly due to a loss of muscle tone and power. This loss had minimal impact where the individuals felt they were still able to maange for some time should the machine break down; these people remained confident that they would survive until the problem could be solved. The others experienced a loss of self-esteem, feelings of vulnerability and an even greater dependence upon trained personnel. As one of these respondents said, "What's going to happen if I get a problem? How would I breathe on my own? I've got to have someone there all the time, I need constant attention". For one of the institutionalized respondents these problems largely determined the character of his everyday life. When asked if he had ever considered a return to community living he said:

> That's the furthest thing from my mind. When you're in hospital and you're dependent upon people you feel more secure here than at home. The other night I had trouble with a valve that was stuck I couldn't breathe and the nurse was trying to find out the problem. The orderly yelled out to him to use the ambibag. He hadn't done it for a while and he was fumbling around. Meanwhile I'm not breathing and existing on what air I had and starting to get panicky. At home there'd be lots of times I'd be left alone. Even now with people around if I can't breathe I'm in trouble.

Living in hospital under the constant care of professional staff did not entirely do away with this man's feelings of insecurity. Because the emergency buttons were used by other patients to call the nurses for routine matters, "They see that light flashing and it don't mean nothing". He had asked for a special alarm to be fitted, only to be told that it would disturb others on the ward:

> I get a bit apprehensive lying here in this room. I sometimes call and can't be heard. If anything goes wrong I'm good for one good yell. If they don't take me seriously there's no second yell. I don't care if I disturb other patients and I'm sure they don't care as well.

Given his inability to survive in the event of machine failure, he would only leave the hospital if a member of staff was available to accompany him. They had to do this on their own time and his attempts to secure payment for them had not met with success. He was not willing to take advantage of volunteers who took other patients shopping: "I wouldn't want to go with a University student with just 24 hours training. They'd probably just panic. I want experienced staff who won't panic. One day I went shopping and didn't take my ambibag. I was ever so happy to get back here. What would I have done if my machine had stopped? So I don't go out very often".

Another respondent who felt that "You can't rely on an attendant in, a crisis, you've got to rely on yourself" was attempting to learn how to frog breathe and had asked if she might go into hospital periodically in order to develop her respiratory capacity. The doctor said no.

> Breathing on your own gives you a feeling of independence. I'd like to be able to breathe on my own for one hour. So that hurt me. The doctor said 'Don't get fancy.' I wanted to do that to redevelop myself. It's only for a safety feature and not to get smart and start breathing again on my own cus I know I can't. It's just for a safety factor, an added protection for myself.

The extra care and attention required by patients on mini-lungs meant that the respondents using this form of support had no choice but to tolerate additional intrusion by others into their daily lives. While they recognized that extra help was necessary, the manner in which it was provided was not always acceptable. This only served to highlight the crucial relationship between helper and helped and the often subordinate position of the one on the receiving end. While this applied to those living in the community, it was particularly true for those living in hospital who had to manage their relationships with staff very carefully. This often meant tolerating those staff who did not always wash their hands, who did not follow sterile techniques while suctioning or who compromised the individual's privacy unnecessarily. As one respondent complained:

> My aunt and uncle come every Sunday evening and one nurse comes in and changes the cascade then and she's got the whole evening to do it and I bite my tongue. I won't say anything to her in front of visitors cus I won't do that to staff and I just feel, well, we've got all evening, why do it now. It's just as if she's daring me to say

> something to her and I won't do that either, I don't want to be in a row with her. There's no reason to do what she's doing at that time. To me it seems as if she's showing my relatives that she's being efficient. It's a silly thing, but one you have to put up with. You can't make enemies of them cus you're so dependent on them.

Continuing this account later in the interview she said, "My whole day and everybody else's depends on the person who walks through that door in the morning with your breakfast tray, their attitudes and the way they work".

The same sense of vulnerability reported by some of the respondents did have a foundation in fact. Nearly all told of crises or instances of machine failure, some involving physical discomfort or anxiety, while others were potentially or actually life threatening. One woman had experienced a number of such incidents and had since embarked on a campaign to secure improvements in the equipment supplied to those needing respiratory support. On one occasion the batter which powered her respiratory, slung beneath the seat of her wheelchair, caught fire; "and there I was with it burning under my feet". She was later told by her doctor that if she had inhaled the smoke from the fire it might well have killed her. On another occasion her battery charger caught fire. Since it was located in the room where she was asleep, this was another incident she felt might have had serious consequences. Not all the events she reported were as dramatic as this; others involed a sudden loss of power from her battery or the discovery that the charger was not working and could not be used to recharge the battery. In order to enable them to cope with these crises, the respondents had been given extra batteries and, in some cases, back up machinery. Nevertheless, they organized themselves in ways which reduced the chances of crises or enabled them to recognize problems before they reached the crisis stage. One of the respondents said, "You have to get to know what it feels like when the valve is not working or if there's a leak in the hose somewhere and you have to get to know the feel of it when the pressure drops too low", and another outlined her strategy of preventive maintenance:

> I'm always conscious the machine is going to break any moment. You have to constantly remind yourself that the machine has to be kept clean cus hair gets into it. When the machine is ready to go, and I've had it happen several times, you bring it in for a check up. As soon as you feel the rate button, you have to increase the rate button constantly or it seems to die on its own or it fluctuates...We never used to watch for that but now we recognize the machine is going to conk on us so we send it in for repair before...we used to wait till the machine...I'd be sitting there and all of a sudden the machine would go wheeeeeee and it would start blowing air in to me and I couldn't let it out and my lungs were blowing up and my husband he would pull the hose off my neck fast. I'd be scared to go back on the machine. But we're now more cautious and we haven't had that for a year already. So we have to watch for signs and bring it in every month to be cleaned out.

Fear, anxiety and coping with the occasional crisis are not the only discomforts associated with machines which supplied air via a tracheostomy. In moving around the community, obstacles such as curbs, ramps, steps and uneven surfaces often caused water from the cascade to gush into the hose and enter the lungs: The individual can literally be drowned by their machine. Consequently, when mobile or when transported in a vehicle, the cascade would be disconnected. This meant that air from the machine was not humidified before entering the lungs and caused an uncomfortable drying out of the tissues of the respiratory tract. Some said that when restored, the humidified air seemed to cause such heavy secretions that suctioning was necessary: "The other day we forgot and I nearly gagged and choked to death". Given these problems and the amount of equipment that had to be carried with them, the ambibag, catheters, respirometer, suctioning machine, sterile water to replenish the cascade, mobility was possible, but always an effort.

Trading off as a strategy for coping with disability was not confined to the respiratory problems experienced by these respondents. It was also observed in the other spheres of their daily existence. In accepting electric wheelchairs some lost a valuable source of exercise and reported diminishing strenth in their arms. These were readily swapped for rapid and easy mobility about hospital or home and the other activities that could be accomplished with the time and energy they saved. One woman with very little residual movement in her arms or legs refused to have a head control for her electric wheelchair saying, "I´d sooner sit in one place than have my head restricted". Eventually, she found an innovative rehabilitation engineer who designed a control which she could operated with the movement left in one foot. Similarly, the woman who had lived in hospital since the onset of polio readily tolerated the many problems associated with institutional life, such as lack of privacy and lack of control, in return for the benefits derived from the company of similarly situated patients. Talking about moving out into the community she said, "How lonely it would be. In hospital there's always someone keeping an eye on you just as you always keep an eye on the other guy". Here, trading off becomes in part, a practical strategy for maximising the benefits to be derived from a finite set of resources and in part a psychological strategy for making institutional living tolerable. Because trading off involved losses as well as gains, many also employed what might be regarded as the ultimate strategy for coming to terms with disability and the disadvantage it implies: in the words of one respondent, "You have to learn how to accept these things".

## Discussion

The foregoing description has attempted to assess the impact of technology in the form of newer and more complex forms of respiratory support, on the careers of people with polio related disability. Using data from a small number of individuals with severe respiratory problems, we have examined the effect of technological innovation on life changes and the quality and character of everyday life. The overall conclusion confirms an observation derived from earlier work; the problems of people with disabilities are never solved, they are merely transformed, exchanged for problems of a different order.[23]

While the positive pressure ventilators used by many respiratory dependent individuals are more efficient than the older forms of support, bringing improved physical health, higher energy levels, longevity, increased mobility and improved chances of participating in community life, the benefits that accrue are always acquired at a cost. The individual becomes even more closely tied to and dependent upon machinery, they must learn to manage their devices and anticipate and cope with crises brought about by the limitations or fallibility of technology and they must accept a loss of independence, in all its forms, and changed relationships with others. Clearly, adapting to new technology can involve fairly dramatic changes in the pattern and conduct of everyday life involving new routines, the development of new strategies and new worries and concerns. Nevertheless, while all those contacted regretted their loss of independence, in particular the loss of respiratory ability, none expressed regret at the transition to positive pressure methods of ventilation. These and other losses were readily tolerated in return for actual and anticipated gains.

The contribution of technology to the welfare of post respiratory polio patients does not end with an analysis of the impact of machinery on individual well-being; other types of innovations have had an influence on the careers of this group of people. They have not been discussed in the body of the paper since their effects are not so readily perceived by patients themselves. The most obvious is the development of vaccines and immunization programs during the 1950's and 1960's which almost wholly eradicated polio within North America and Western Europe. The epidemics of which these respondents were a part are a thing of the past. Such interventions are of little direct relevance for individuals who have already been disabled by the disease although they have been very much affected by their outcomes. The end of the polio epidemics has meant that the disease and its victims have lost their high profile among both the public and the medical profession. The number of sufferers has declined as age and disease have taken their toll. In short, polio no longer constitutes a major problem. Knowledge of polio has not developed significantly since the days of the epidemic and the number of physicians with any substantial experience of polio has declined through mortality. During the 1950's, the sudden emergence of large numbers of young, previously healthy, but now severely disabled people stimulated the development of services that are the direct forerunners of the community programmes offered to disabled people today. While polio sufferers continue to benefit from innovations designed to improve the lot of the disabled population as a whole, specific initiatives have been limited and research funding to study the effects of polio hard to come by.[24] It is only recently, as a result of pressure from the community of polio sufferers, that polio is once again becoming an issue. The research programme of which this study is a minor part has been stimulated by the realization that knowledge of the course and effects of polio is inadequate and needs to be developed in order that the needs of this group can be predicted and met. At the very least, post respiratory polio sufferers are a reminder that the needs of disabled people are not static; changes in functional status, broader changes associated with biological and social aging and the precarious nature of their support systems see the emergence of new and different needs. Since technology can spawn new needs, it can only partially compensate for the complex functional, personal and social consequences of respiratory poliomyelitis.

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4. The 1953 cases represent an incidence rate of over 300 per 100,000 population, the highest in the North American continent. Case fatality rates were low, only 3.7/100,000 population.

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10. For the purposes of the paper, the term "mini-lung" refers to a mechanical ventilator used with a tracheostomy, while "positive pressure ventilator" refers to a similar type of machine used with a mouth tube. With the latter, patients can take in air as and when they wish. This terminology is not strictly accurate, for reasons it is not necessary to pursue, but has been adapted to distinguish between the two types of air intake.

11. It has been estimated that more efficient respiration adds 2 years on to the life span of the post-respiratory polio patient.

12. Because of the small number of people interviewed for the study and because of their unique situation and location, extracts from the interviews are presented in a way to preserve, as far as possible, the anonymity of the speaker. This may not be ideal from the point of view of the reader, making it more difficult to identify continuities in the characteristics of individual use.

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19. The procedure of "milking the hose" refers to the act of moving droplets of pooled condensation down the connecting hoses and away from the trachea in order to avoid blowing fluid into the lungs of respirator-dependent patients. Monitoring moisture buildup in the connecting hoses was possible because the tubes were corrigated and transparent. Ward staff or respiratory home care attendents, family members or patients themselves monitored and "milked" hoses every two or three hours.

20. The procedure of "maintaining the cascade" refers to the protocol for changing the portable system for humidifying air flow from minilungs before it entered the individuals trachea and lungs. People who received respiratory home care were provided with a supply of sterilized cascade cannisters which atomized water via a spinning disk, using a mechanism similar to home humidifiers. Ward staff, paid attendents or family members had to change the cascade modules daily. Logistical arrangements for providing a regular supply of sterile and refilled modules were established with respiratory technology units in hospitals or the home care equipment pool.

21. "Suctioning the patient" refers to the procedure of removing mucus around the site of the uncuffed tracheostomy where the mini lung is connected to the patient. This procedure was performed by ward staff, home attendents or family members as a part of regular care regimes.

22. "Use of the ambibag in situations of machine failure" refers to emergency procedures instituted in sitatuion of machine malfunctions although most respiratory care protocols used in inpatient or home care settings provide for at least one other respirator as a backup, people using mini lungs mounted on their wheelchairs also carry hands.

23. See Locker D., op cit.

24. During the initial conference dealing with late polio related aging effects there were several speakers and follow-up discussion in consumer publication examining the prospects for re-involving the March of Dimes. Speakers pointed out that the society had built its base on the rehabilitation of polio patients in the era before and immediately after the availability of the Salk and Sabine vaccines. The epidemics and the associated mobilization of massive voluntary contributions, often using the public images of disabled children, led to the creation of rehabilitation centres in Canada and the U.S. which were eventually supported by public resources. With the elimination of new acute cases and the diminished visability of people with polio-related disability in the rehabilitation system the March of Dimes changes its orientation in fund raising and research support to the area of birth defects. The perception that the society's original identification with "fighting polio" on the part of survivors of epidemic polio and volunteers who had been involved in the rehabilitation and consumer networks, generated pressure for reinvolvement of the society in the current round of research dealing with post-polio

aging. Over the past two years the March of Dimes has maintained its continuing level of funding to individuals with disability on long standing programs. Despite making major contributions to two research symposia dealing with recent research on post-polio aging, to date no reorientation of the foundations support priorities, to include work on late polio related aging have been included.

# THE LONG TERM IMPACT OF DISABILITY

## EXAMPLES FROM A STUDY OF POLIO

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Paper presented at the Scientific Meeting of the American Anthropological Society December, 1983. Research was supported by grant no. 6607-1241-26 from the National Health Programs Directorate.

# ACKNOWLEDGEMENTS

The authors wish to acknowledge the contribution of the multidisciplinary team who carried out the initial follow-up study of former respiratory polio patients in Manitoba including Dr. J. Hildes, Dr. J. Alcock and Ms. J. Bickford. The Manitoba Medical Services Commission supported the initial follow-up of people with respiratory polio. The continuing study of aging among post polio groups was supported by the National Health Programs Directorate, Health and Welfare Canada. Dr. Patricia Kaufert was supported by an NHRDP career award as a National Health Scholar. Statistical analysis was coordinated by Dr. K.P. Gilbert and Ms. K.D. Wong, and editorial work on the manuscript was completed by Ms. Lynn Zdan.

## INTRODUCTION

A follow-up study in the province of Manitoba is currently examining the long term impact of poliomyelitis on the lives of people who developed the disease during the major Canadian epidemics of the nineteen-fifties. In documenting the long term effect of polio-related disability, the follow-up has focused upon change occuring in three parallel, but conceptually distinct areas. The first area or dimension of change has been referred to as the trajectory of a specific disabling condition. The concept of trajectory has been used to summarize the changes over time in the levels of impairment and future implications for health associated with acute infectious diseases (such as polio), traumatic injuries or progressive degenerative conditions (such as multiple sclerosis). As one way of summarizing the natural history of a disabling condition, trajectories reflect decline, improvement or stabilization in functional status. The second area focuses on the processes of aging influencing the long term impact of disability, tracing the passage of the individual from childhood to adulthood and through the aging processes of later life. From this perspective, aging must be studied as both a physiological and a social process. Descriptions of the long term impact of disability must therefore document the interaction between processes of change in the individual and the conditions of their disability. The third and final area of focus considers the impact of changes in the context of disability which influence long term experience. In documenting the context of disabled peoples′ experience, we must examine the impact of changes in medical and rehabilitation technology, changes in public policy and voluntary resources and changes in public attitudes and values which directly or indirectly modify the experience of living with disability.

The ultimate objective of examining each of these dimensions would be to develop a model of disability which can move from the specifics (whether of a particular disease, age cohort or historical period) towards a more general statement about the long term impact of disability. The more immediate objective is to understand what this experience has meant for the study group of individuals who were disabled by poliomyelitis during the epidemics of the nineteen-fifties. This paper has two aims. The first is to examine the methodological implications of studying each dimension of the long term impact of disability. In the Manitoba follow-up study, it was found that no single methodological approach was sufficient, but that it was necessary to draw on the methodology and data bases of epidemiology, sociology, ethnography and oral history. The first portion of each section will therefore, discuss the methods used to document trajectories, aging effects and contextual changes. The second aim is to explore the conceptual bases for each dimension using material from the polio study as illustration. The paper is not a detailed presentation of the results of the Manitoba follow-up study, but an exploration of what is involved in studying disability as a process occuring over time.

## I. THE TRAJECTORY OF DISABILITY

The concept of a trajectory is drawn from the work of Glaser and Strauss (1963) on terminal illness, but has been applied here to the study of disability. As is true of terminal illness, disabling conditions have trajectories which will vary with the specific characteristics of the disabling condition and their interaction with characteristics of the individual. Some trajectories, such as that of people with multiple sclerosis, are marked by high levels of uncertainty in which the direction of change may reverse, or stabilize or decline rapidly. In other trajectories, an initial rapid loss of functional capacity may be followed by a recovery period and then a plateau, marked by a relative absence of further change. This type of trajectory has been used to characterize the long term experience of the person disabled by polio. The beginning stages of polio have been comprehensively documented by Davis in Passage Through Crisis (Davis, 1963). During the acute stage of poliomyelitis, even prognosis for survival is uncertain. This stage was followed by a recovery period in which medical and rehabilitation professionals initially determined the probable degree of long term functional impairment. Patients and members of their families experienced a delay in establishing their own definitions of their functional abilities through negotiating access to clinical information and experience with the initial problems of adapting to disability. Although the Davis study was longitudinal, it focused only on the 2-4 year period following the acute phase of polio. The objective in the Manitoba follow-up study was to trace the trajectory of polio-related disability from onset through intermediate and later stages of the lifestyle.

## THE TRAJECTORY OF DISABLING CONDITIONS: METHODOLOGICAL ISSUES

Although the concept of trajectory is directly applicable to the study of impairment, successful application in field setting requires re-examination of methodological approaches. Ideally, a project to examine the long term impact of disability should be longitudinal in design. There are a few such studies and Davis's follow-up of a small sample of patients was relatively typical in terms of its methodological approach and duration experience at disease onset and followed people through the initial stages of recovery and rehabilitation. However, constraints of time and cost limit the duration and representativeness of prospective studies. They cannot describe what happens to a representative sample of people with the same condition as they age and experience the long term consequences of being disabled.

Although there is a growing body of research documenting longer term changes among older disabled populations (Maddox, 1974; Harris, 1971), most utilize a cross-sectional design and define their sample in terms of their current functional status or eligibility for specific treatment services. While retrospective data may be collected, such studies are limited in their ability to document change in the trajectory of a disease because they have no base line for comparison. Furthermore, their samples may be limited to people who have both survived and who are accessible to the researcher.

In epidemiology, when longitudinal studies are not possible, an alternative to the retrospective study is the so-called "historical prospective" or "retrolective" study. These studies select their sample from a population of individuals who are known to have shared a common characteristic or risk factor at a defined point in the historical past. For example, the population may include all individuals who were exposed to the same causative agent, such as asbestos. This population is then followed through time in order to monitor the incidence of a disease such as lung cancer. Among the advantages of this design approach is that it provides much more accurate estimates of the degree to which those who develop a disease or who survive are representative of those initially exposed to the causative agent.

In designing the follow-up study of former poliomyelitis patients in Manitoba, it was possible to adapt this design to measure the long term effects 21-30 years after the onset of disability (this study design is shown in Figure 1). Rather than defining the study population in terms of those who had survived, the project started by including everyone who developed polio between 1950-59 and who was admitted to a single centralized treatment centre which received most of the respiratory and limb-impaired cases (Alcock, et al., 1980). Systematic follow-up of a representative sample was possible because the hospital had kept its case register and its medical records. Case files included information on sociodemographic characteristics such as age, sex, marital status, residence and employment. The case register was used to trace and to determine what had happened to over 86% of the survivors of the initial population of 186 people who had respiratory polio and required mechanical zrespiratory support. Among the larger group of over one thousand patients who had limb impairment or acute symptomatology without residual paralysis, approximately seventy percent were traced and 530 were surveyed using a multi-method (mail questionnaire plus telephone) follow-up protocol.

A medical record audit was used to define the characteristics of the population during the acute phase. Medical records provided information on type of polio, the use of respiratory equipment, surgical and rehabilitation procedures, and some information on initial impairment. It was possible to compose a summary sketch of what had occurred to each individual during the acute and initial recovery stages of the disease trajectory using information recorded at the time the events took place. Although the data were limited, it was possible to address some epidemiological questions relating to the long term impact of disease by correlating information from the medical record audit with information on survival patterns gathered during the process of tracing the population. For example, it was possible to examine the association between survival characteristics and disease severity at onset, age, sex, and level of residual respiratory capacity. While these are very limited questions, they are basic to understanding the long term impact of any form of disability.

Information on the current status and perceived needs of surviving respiratory cases was gathered using a standard cross-sectional survey in which the 113 people (86% of the 132 who were believed to be alive) were interviewed and data collected on their current functional status. The multi-method mail survey protocol also provided data on the current status of approximately half (530) of the original population of non-respiratory cases. Both samples were found to be representative of the initial population in terms of their demographic characteristics and disability profile.

## THE TRAJECTORY OF DISEASE: CONCEPTUAL ISSUES

One of the issues involved in the study of long term disability is the degree to which an individual predicts any future change in their level of impairment. A patient's or clinician's ability to predict the trajectory of a disabling condition may range from complete certainty to total uncertainty and will depend on the characteristics of the specific disease or form of impairment. Defining a trajectory will depend partly on the predictions made in the medical literature on the probable course of the condition. However, at the level of the individual disabled person, clinical information will be integrated with personal experience on specific functional and psychosocial impacts of disability over time.

By using the medical records in combination with the interview data, it was possible in the Manitoba study to chart three points on the disease trajectory of polio for each of the 113 people included in the cross-sectional survey. The trajectories began with their condition during the acute phase, their condition during recovery phase, and finally, their condition twenty-one to thirty years later. In terms of our preliminary analysis, the longitudinal data on changes in functional status appear to confirm the hypothesis that polio-related trajectories reflected relatively stable health status and adaptation. The majority of the sample of former respiratory patients reported themselves as maintaining the same level of functional capacity in 1980 as recorded in their charts as their condition stabilized twenty-five to thirty years earlier.

On the other hand, this stability does not necessarily imply certainty. If one looks beyond the 113 who were interviewed and examines survival data for the whole population, there is another dimension. All people who had polio, and particularly those with the lowest residual level of respiratory capacity, may have been left with a permanent vulnerability; mortality and morbidity associated with the residual impact of polio may occur decades after people developed the disease (Alcock, et al., 1981). While the degree of risk of polio-related mortality decreases with time and is influenced by the initial level of impairment, the uncertainty of survival remains a permanent characteristic of the disease trajectory (Alcock, et al., 1983).

A model showing the differences between the trajectories of an individual's functional status and the relative level of uncertainty (using Davis's framework) is shown in Figure 2. Even when the trajectory of physical disability is stable, people must live with the question of whether this stability will continue. The key concern for people with polio is whether they can predict from the earlier pattern of their disease trajectory into the future. This was the central concern of two recent conferences focusing upon problems of aging among polio survivors (Oleson, Henning, 1981; Laurie, 1983). Physicians attending the meetings reported an increase in people complaining of new symptoms, such as pain, muscle fatigue and tiredness (Bailey, 1981). There were two explanations offered; one explanation dealt with unique residual effects associated with the specific pathological effects of polio (Bailey, 1981). The second explanation was that the recent symptom experience and perceived changes in functional status were primarily associated with chronic diseases processes in "normal aging" which complicate the long term adaptation of all young disabled people.

The climate of uncertainty which Davis (1963) described as characterizing the perspective of patients and clinicians during the acute and early rehabilitation stages appeared to be paralleled by a period of renewed uncertainty as the post-polio person aged. Using Davis's framework, the trajectories of physical function and relative uncertainty can be applied to modeling the longer term disability experience of the aging post-polio person. The first or bottom curve represents the individual's actual level of functional status; this went into sharp decline during the acute phase of the disease, but improved gradually over the initial phases of rehabilitation, and reached an apparent plateau within ten years after the acute phase. The key question in the literature on post-polio aging is whether the same stable pattern will continue or whether functional status will decline unexpectedly.

In the figure the other two curves represent the levels of uncertainty characterizing the trajectory of disability as perceived by the polio patient and trajectory as perceived by clinicians. As described by Davis (1963), the health care team caring for the polio patient was initially uncertain as to the outcome. As the patient started to recover and to go through rehabilitation, the medical team became better able to predict the eventual level of functional status to be attained, although often slow to share this information with patients or their families. Because of this delay in obtaining access to clinical evaluations of long term functional ability and because of the influence of the rehabilitation ideology that "full recovery" was achievable through individual will and hard work, levels of uncertainty remained high for the longest interval among patients and members of their families. As the earlier discussion showed, this is changing and post-polio aging is characterized by new medical uncertainty. The uncertainty curve of people with polio follows the same pattern, but at a higher level. In the post-acute phase, this was because as patients they did not have access to the same information as clinicians. However, today, both clinicians and post-polio peoples share a renewed uncertainty in interpreting subjective symptom experience indicating increases in fatigue, pain, and perceived respiratory function. People are uncertain whether these represent some temporary condition, chronic morbidity associated with "normal aging" or the beginning of a trajectory characterized by a rapid decline in functional status. The design approach documenting long term changes in functional status and current perception of disability among a representative cohort involved a current attempt to assess current trajectories and levels of uncertainty.

## II. AGING AND DISABILITY: THE PHYSIOLOGICAL AND THE SOCIAL PROCESSES

In documenting the long term, disease specific trajectory of polio, a second closely related objective was to examine the physiological and social dimensions of aging among younger disabled people. As mentioned in section I, some preliminary research on post-polio aging effects suggests that the cumulative stress of 25 to 30 years of impaired functioning may create disease-specific effects, others argued that the problems were a product of the normal processes of aging. When the balance between residual impairment and functional capacity is delicate, it could shift in response to relatively minor declines in physiological capacity.

Because of the orientation of the ethnographic and life historical dimensions upon aging as a social process, another focus of the Manitoba study was on the subjective perception of changes in disability impact, adaptation and the aging of family support systems. The concern was not simply with the impact of aging, but with people's perceptions of moving through different stages in the life cycle as an individual with disability. We have written elsewhere on the polio study and the effects of aging (Kaufert and Kaufert, 1981). in this paper, only the methodological and conceptual issues will be discussed.

## METHODS

In a study which was cross-sectional in design, questions about the physiology of aging can be answered only by comparing levels of impairment between different age groups. For example, if analysis was restricted to the survey data from the 1980 follow-up survey of respiratory patients and 1982 multi-method survey of non-respiratory cases, there is an apparent association between being older and being more impaired. However, when data on the initial effects of polio from the medical audit is introduced into the analysis, the relationship between age and impairment becomes more complex; account has to be taken of the initial association between age at onset, severity of disease impact and the point reached at the end of the recovery stage.

The methodological advantages of having the medical records as a data source were equally apparent in terms of exploring the social, rather than the physiological processes of aging. While the information was sparse, it included the age, marital and parental status, occupational and residential characteristics of each patient entering the centralized treatment centre. These data were at least sufficient to locate an individual at the point reached in the life cycle when they developed polio. By comparing the medical records and the 1980 survey data, one could get some indication of the changes that had occurred during the intervening years, in terms of life events such as marriage and divorce, employment history and general patterns of living independently or within institutions. The retrospective reconstruction of general life experience was obtained from responses to structured questionnaires of the 113 respiratory cases and the 530 non-respiratory cases (see Figure 3).

The structured interviews with 113 respiratory and 530 non-respiratory survivors provided comprehensive data on current adaptation patterns and general aging effects for the representative sample of survivors. However, it was necessary to move a multi-method design using life historical analysis obtained from in-depth interviews with a small, stratified sample. As people described their lives, they discussed the impact of polio. Simic (1981) 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 also 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 same sense, the impact of disability may be best understood by attending to what people say and analyzing how they integrate an event (such as polio) into their life history. In the life history interview, the anthropologist is not aiming for an accurate reconstruction of the past in the same sense as an epidemiologist aims at an accurate reconstruction of the trajectory of a disease. For epidemiologists, the selective recall and re-interpretation of their past by informants are major methodological hurdles. In the life-history approach, the anthropologist makes conscious and deliberate use of the process of restructuring disability experience. Respondents document their past as they have brooded over it and attempted to make sense out of it.

The purpose of incorporrating multiple methods from epidemiology, sociology and anthropology, was to document aspects of the relationship between disability and aging.

## CONCEPTUAL FRAMEWORK

Aging, as seen as a transition through time, has social as well as physiological implications. In research on the long term impact of disability, there are three conceptually distinct, although interactive, dimensions of the aging process to be considered. The first is aging as the passage of the individual through the different stages of the life cycle encountered after the onset of disability. At issue is the impact of disability on the ability of the individual to manage the tasks and experiences considered appropriate to each life stage. The second dimension of aging is the impact on the individual with disability of the aging of those people who make up their social network, whether parent or spouse, physician or the technician maintaining essential equipment. The ability to manage a particular environment may be critically dependent on a key provider of services and the aging of the provider may disturb a balance delicately maintained. The third dimension (that of the social, technological and political context of disability) will be discussed in the final section of this paper. The focus in this section upon context, emphasizes that aging involves the experience of being a member in an age cohort which moves together through historical time. The experience of being disabled varies between different age cohorts as educational, occupational and other opportunities for the disabled individual have changed and developed.

## AGING, DISABILITY AND THE INDIVIDUAL

Smelser, (1980) 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 probably 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" (Smelser, 1980: p. 11-12). 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 a polio-related disability) disrupts the pattern. It is an exploration of what happens when one or more in a series of contours have to be redrawn because disability has introduced a new constraint on their form.

In the life historical interviews, it became clear that as people have talked about the impact of polio on their lives, most also maintained an image of an "expected" pattern or life trajectory; a 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 idealized pattern; whether they were able to return home, whether they were able to go to school or to university, whether they were able to continue teaching, or farming or whatever was their previous work; whether they were able to remain married or to get married if they were single.

It is clear both from the life history analysis and from an analysis of the survey collected data that age at onset is a critical variable to understanding not only the physiological, but also the social, consequences of long term disability. People who were adult 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 are much more concerned with the disruption of established life career patterns. People who were children when they developed polio had still to pass through the stages of childhood, adolescence and into adulthood. Their access to education, access to marriage and parenthood, access to employment, were all influenced to a greater or lesser extent by the level of impairment and relative access to care resources.

## AGING, DISABILITY AND NETWORKS OF SUPPORT

One of the secondary objectives in the polio study was to document changes in dependency patterns. Levels of functional capacity and mobility were measured using an adapted version of the Katz "Activities of Daily Living Scale," determining for each item whether the activity could be performed only with the help of others. Other items in the interview schedule collected information on the composition of each individual′s support network and utilization of statutory services.

The availability of and use of family members as care givers has been a critical determinant of what happened to many people over the years since they developed polio. A Provincial Home Care program which offered equipment, home modification, financial support and a paid attendant was, nevertheless, keyed on the assumption that there was a family setting into which the individual returned. In the early years, the only alternative for the severely impaired was to remain in hospital (as was done by a group of twenty taking part in this study).

The form of family into which an individual returned was a function of their age when they developed polio; the young children returned to their parents; the adults returned to families of their own creation; some of the women had young children or were pregnant when they started polio.

The divorce figures among respiratory respondents provide the most dramatic insight into the impact of polio on the family. A third of the marriages which existed before polio onset ended in divorce; 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% did in fact become married.

Family status at onset was significantly related to the pattern of discharge reported by former respiratory patients interviewed in 1980. (chi. sq.=14.01, df=4, $p \leq .007$). 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 a 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 when we interviewed them in 1980. Discharge arrangements were also related to changes in marital status; out of the people in the long stay hospital who had been married when they developed polio, 77% were divorced or widowed by 1980.

Even among the less dependent people without respiratory involvement, the type and degree of impairment had direct implications for dependence upon informal networks. Twelve percent of the 530 non-respiratory cases indicated that they required significant help with activities of daily living and mobility. In most cases, this help was not provided by statutory services including personal care attendants, home nursing services or attendants paid by the individuals themselves, but was provided by members of the family grouping. Spouses (11% dependence) and children (12% dependence) were the most significant helpers. Spouses were more likely to be designated "crucial helpers" without whose assistance independent functioning would be impossible. Nonkinship, unpaid helpers formed the primary support for only 5%.

## III. CHANGES IN THE CONTEXT OF DISABILITY

The third methodological and conceptual area which was considered in our own analysis of the long term impact of polio related disability was that of assessing the impact of changes in context. The context of disability refers to the array of political, economic and social environments within which an individual must live and which influence the adaptation of cohorts of people to their disability.

During the almost thirty years which have elapsed since the polio epidemics of the early nineteen-fifties, the context of disability has been transformed. These changes must be examined for they are as pertinent to research on the impact of long term disability as the physiological or psychological history of individual adaptations. The more recent changes in economic and welfare policies are themselves part of the new climate of uncertainty with which people must deal as they grow older.

Three major areas of change were identified at the Chicago Post-Polio Conference in 1981. The first is changes in medical and technological knowledge and its application; the second is changes in public policy and service provisions; the third is changes in attitudes and behaviour, particularly instrumental in the establishment of the independent living movement. A time line showing the parallel developments which formed the context of individual long term disability experience is presented in Figure 4. In each area some changes were specifically targeted at the needs of one or more groups within the community of people with disabilities; for example, the Home Care Program for Respiratory Polio Patients was developed in 1956 by the Manitoba government to meet the particular needs of a particular group. Other changes had more general implications, but had specific consequences for the disabled individual; for example, the emergence of consumer oriented, activist movements within the community of the disabled has its ideological and organizational roots in the minority group movements of the sixties and seventies. The current formation of a loose political coalition between the Black, the Feminist, the Gay and the Disabled movements is evidence of a commonality of ideology and purpose.

## METHODS

The objective was to trace the impact of changes in the context of disability on the lives of people who had had polio; the approach had to be multi-method. The mail questionnaire and structured interview schedule was appropriate for collecting basic data on such topics as 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. Changes in the equipment and techniques of rehabilitation and medical care were discussed with experts within each field, both in Manitoba and elsewhere. Information was also gathered from the scientific and more consumer-oriented publications, particularly those dealing with rehabilitation medicine. This combination of literature search and interview with specialist informants was used to record the impact of public policy changes, the role of voluntary organizations, the emergence of political activism from within the community of the disabled. The in-depth interviews were used to discuss these changes and how the individual had responded to the new conditions which had been created.

One set of these interviews were arranged with people who had been active in bringing about change, whether at an individual, a local or at the national/international level. While from the epidemiologist's perspective it had been important to collect data on a broad and representative group, the study of long term disability is also the recreation of a period of history. The historical method required that these events be discussed with people who had effected change, not simply been affected by it. Not only in Manitoba, but elsewhere, people with polio had been key change agents. This activism is part, therefore, of the experience of having had polio which could only be captured by using the targeted interviews and field observation methodology of the anthropologist or contemporary historian.

This is not the place to provide a detailed reconstruction of all the changes which have occurred within the context of disability over a thirty year period. The following discussion will simply touch on some of the key issues in each of the areas (medical and technological, public policy and community change) and will describe their contributin to the new climate of uncertainty (some of these events are shown in the time line in Figure 4).

## CHANGES 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 fifties and the Sabine live virus vaccine in 1958. 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 effected by its development.

The end of the recurrent epidemics of polio meant that the disease and therefore, its victims, lost their former high profile. There was an end to new research on the disease, its processes and its management. This meant that knowledge about epidemiology and pathology of polio was essentially stalled at the level of medical knowledge in the mid-nineteen fifties. In response to the new uncertainty about the trajectory of the disease, there has been a call for further research, but a problem is to attract research interest and funding. 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 request for research backing was that its monies were fully committed. The recent increase in news stories on the fate of former polio victims may serve the useful purpose of encouraging new research investment. Part of the context of any particular disability is its topicality in the medical or in the public eye. Like cancer today, polio attracted attention beyond its actual level of threat in the population; however, once immunization removed that threat, polio become a "non-issue."

Another effect of immunization was a reduction in the number of physicians directly familiar with polio and with its implicatios 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 1950's. 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, 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 due to ignorance, but also due to the refusal of medical professionals to recognize that a patient 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 medical knowledge which have been applicable to their needs. For example, breakthroughs in ventilation technology have been of major importance to those left with severe respiratory involvement. Until the 1960's, the only equipment was the rocking bed, the cuirasse and the tank respirator. In Manitoba, the majority of those needing respiratory support had been gradually transferred to the new positive pressure equipment in which ventilation is maintained by their mouth sip tubes or 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 aged.

## 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 nineteen-forties and fifties. 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 often the factor in common. In Canada, for example, the Canadian Council for the Disabled was formed in 1962 by a union between the Canadian Council for Crippled Children and the Canadian Foundation for Poliomyelitis and Rehablitation. In 1973 at a conference in Toronto, the rights of the CRCD 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 (1980) credits this conference as the "catalytic factor in stimulating the consumer movement throughout Canada and is a milestone in consumer history for handicapped persons". Local provincial organizations, such as the <u>Manitoba League for the Physically Handicapped</u> were formed by people returning from that conference; in 1975, they came together to form COPOH, (the Coalition of Provincial Organizations of the Handicapped) with a central office in Winnipeg. It was also in Winnipeg, at the 1981 Conference of Rehabilitation International that there was another political challenge made to the rights of medical and rehabilitation specialists to speak for the community of the disabled.

The roots of the disabled consumer movement are usually traced to the United States, to the origins of the Independent Living Movement in California and Boston, to the Civil Rights Movements and to its later expression in a diversity of minority group political movements, whether of Chicano, of Women, of Gays, or of the Disabled. 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 was partly true for these were the characteristics of the original movement. It developed on the college campuses and its priorities were an expression of the ideologies of the student movements of the late sixties and seventies. The demand was for an end of prejudice and discrimination and for equal rights and a share in decision making. On the other hand, 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 perceptions have benefitted the the non-activist, the older, the minority group disabled.

The disabled consumer movement took on as its opponents the institutions and groups with which its members had had to deal; that is the charitable foundations, the medical profession and the rehabilitation experts.

FIGURE 1

SAMPLING DESIGNS LINKING EPIDEMIOLOGICAL APPROACHES WITH IN-DEPTH MICRO STUDIES

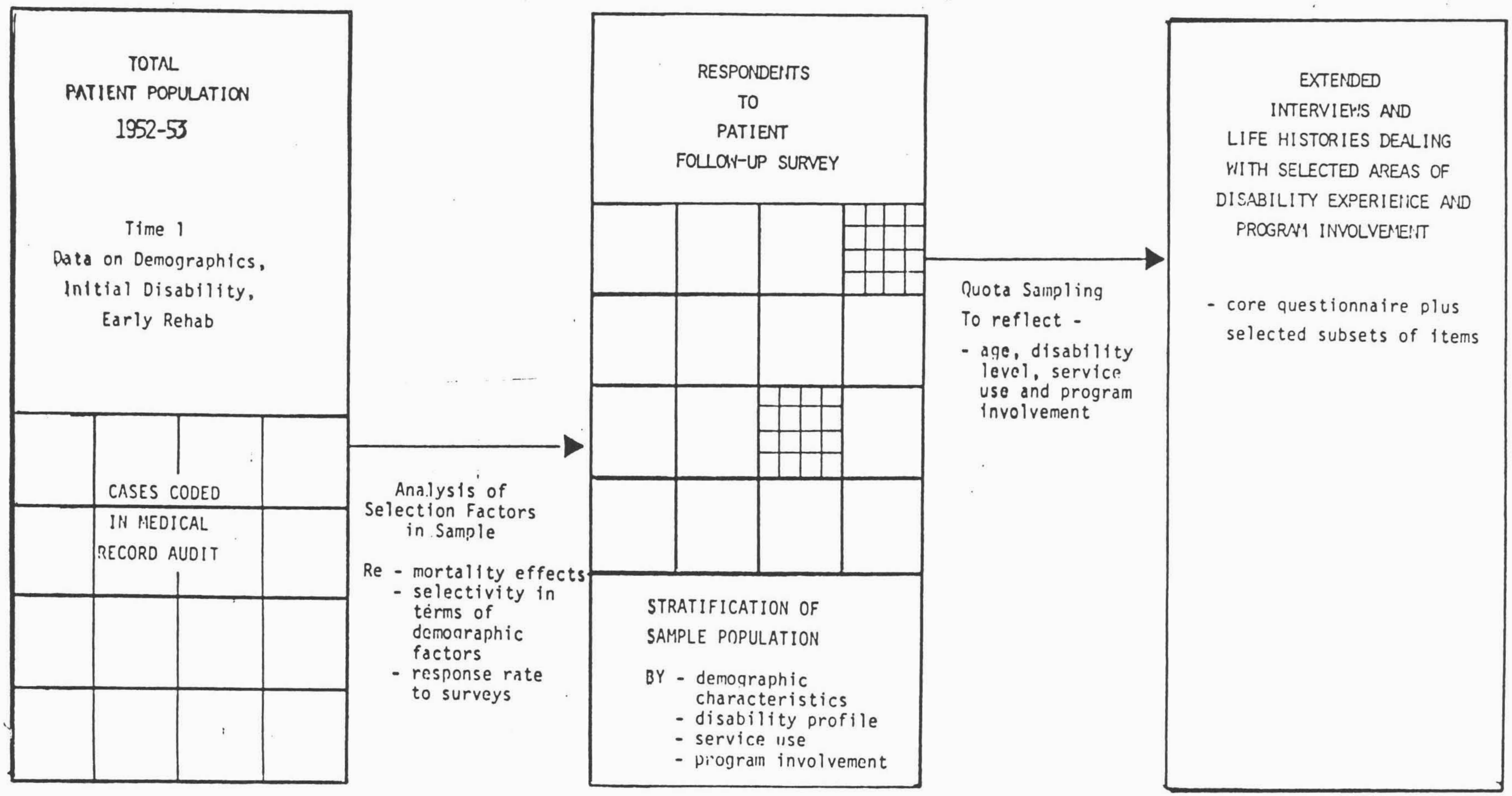
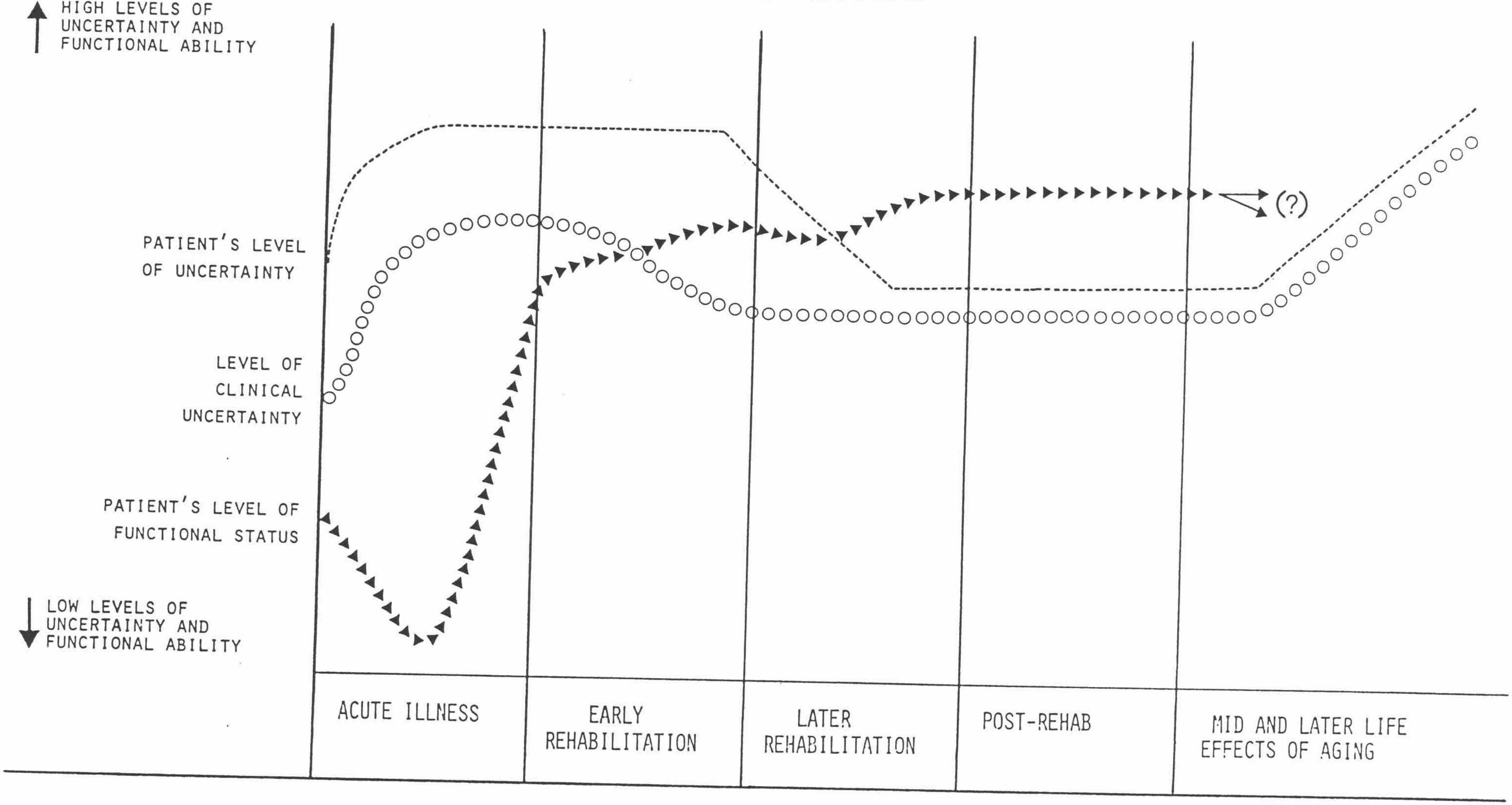


FIGURE 2

CHANGES IN LEVEL OF UNCERTAINTY AND
FUNCTIONAL ABILITY LEVELS
IN POLIO PATIENTS' "CAREERS"



# FIGURE 3

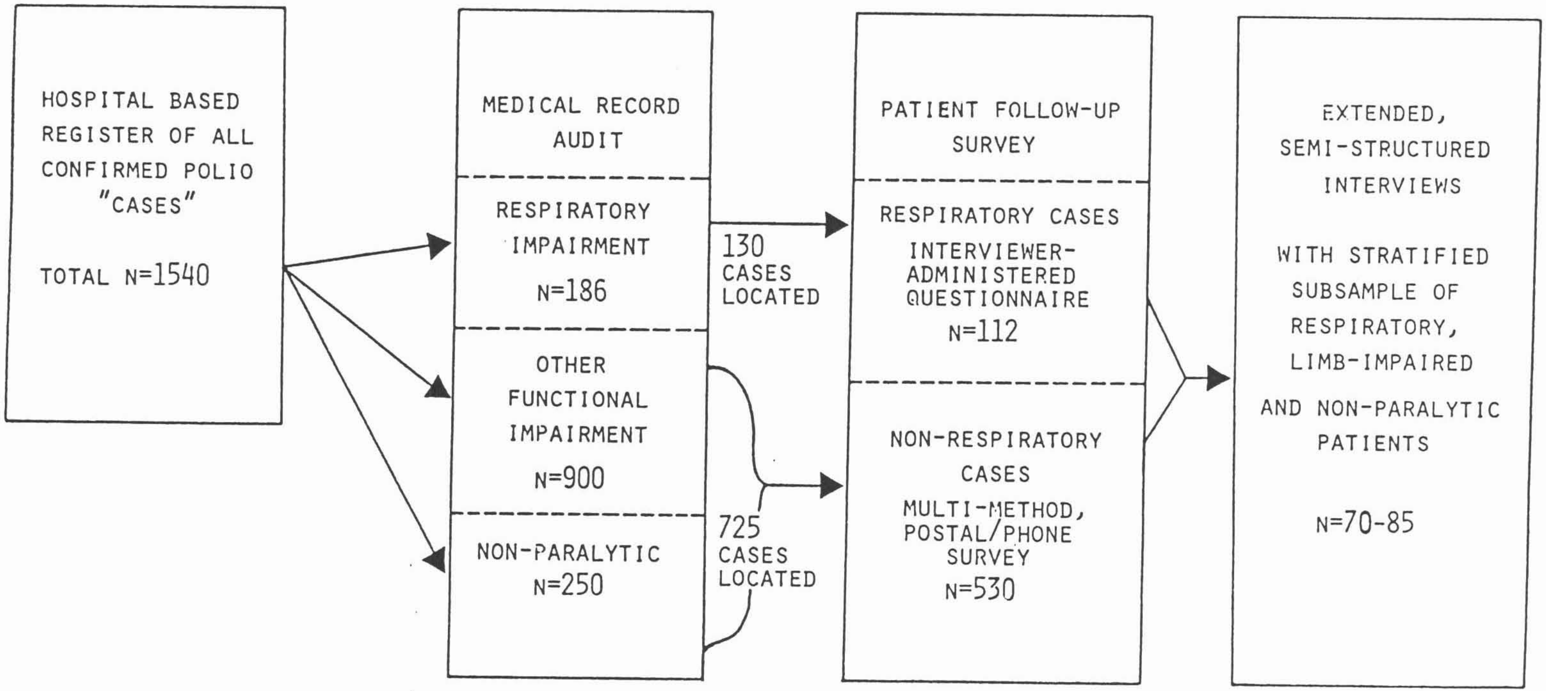
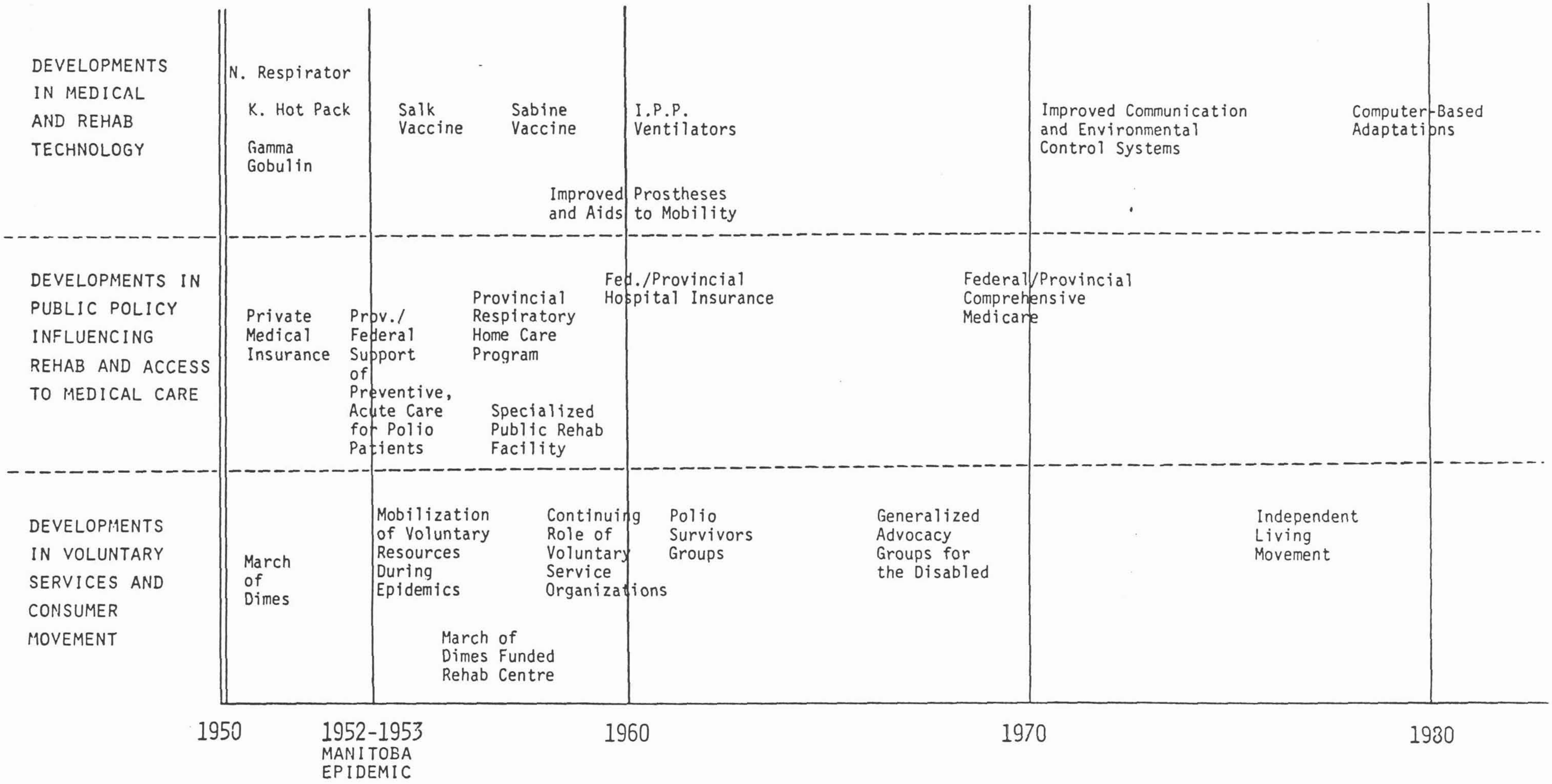

HOSPITAL BASED REGISTER OF ALL CONFIRMED POLIO "CASES"
TOTAL N=1540
MEDICAL RECORD AUDIT
RESPIRATORY IMPAIRMENT
N=186
OTHER FUNCTIONAL IMPAIRMENT
N=900
NON-PARALYTIC
N=250
130 CASES LOCATED
725 CASES LOCATED
PATIENT FOLLOW-UP SURVEY
RESPIRATORY CASES
INTERVIEWER-ADMINISTERED QUESTIONNAIRE
N=112
NON-RESPIRATORY CASES
MULTI-METHOD, POSTAL/PHONE SURVEY
N=530
EXTENDED, SEMI-STRUCTURED INTERVIEWS
WITH STRATIFIED SUBSAMPLE OF RESPIRATORY, LIMB-IMPAIRED
AND NON-PARALYTIC PATIENTS
N=70-85

FIGURE 4

## DEVELOPMENTS INFLUENCING THE REHABILITATION EXPERIENCE OF THE POST POLIO PERSON



NOT TO BE QUOTED WITHOUT PERMISSION OF THE AUTHORS.

# DISABILITY AND THE AGING PROCESS:
## THE EXPERIENCE OF RESPIRATORY POLIO PATIENTS

Paper presented at the Canadian Association on Gerontology Meeting, November, 1981.

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*The authors wish to acknowledge the contribution of the multidisciplinary team who carried out the initial follow-up study of former respiratory polio patients in Manitoba including Dr. J. Hildes, Dr. J. Alcock, Ms. J. Bickford. Ms. K.D. Wong carried out the statistical analysis. The Manitoba Medical Services Commission supported the initial follow-up of people with respiratory polio. The continuing study of aging among other post polio groups and National Health Scholar Award supporting P.L. Kaufert utilized NHRDP grants from Health and Welfare Canada. The second stage of the research was supported by NHRDP grant no. 6607-1241-26.

Abstract:

This paper examines the interaction which develops when the normal processes of aging are imposed on the long-term experience of and adaptation to disability. In Manitoba, between 1950-59, 186 people developed respiratory polio and survived. In 1980, 75% of these former patients were traced and interviewed. In addition, there was audit of the clinical records of each subject. A series of comparisons were made between the assessment made of the individual in the first year after polio onset and the assessments the same individuals make of their condition today, twenty to thirty years later. This paper discusses the impact of aging not only upon their physical adaptation to the paralysis residual to their polio, but also upon their social and psychological management of their disability. Data from a subset of in-depth interviews will provide insight into the perspective on the aging process among the long-term disabled.

## AGE AND DISABILITY: PEOPLE WHO HAD POLIO

A question which is currently being raised and which is critical to planning services, is the extent to which the needs of people disabled by polio are changing over time as they and members of their support network age. The original adaptations to physical impairment and achievement of independence when younger reflected a delicate balance which may be threatened by even relatively minor changes in the individual functional status or in their support system as they grow older. In an ongoing research project, the impact of aging on one group of individuals, all of whom developed polio between 1950-1959, is being studied.

The project developed from a 1980 study which examined the long-term consequences of the disease for people who had been respiratory polio patients in Manitoba between 1950-1959. In contrast with degenerative conditions such as multiple sclerosis, the residual effects of polio are permanent, but relatively stable. The use of standard measures of functional status over time indicated that minimal changes have occured among former respiratory patients during the twenty year period following the initial rehabilitation period. From a research perspective, there was marked contrast between this apparent stability of functional status and the respondent's perception of their adaptation over time. They saw the past and the future in terms of complex and continuously changing adaptation. More specifically, many were deeply concerned with a series of age related issues and their potential impact on the balance in their lives between their disability and their care needs.

Concern with aging is not particular to survivors of respiratory polio in Manitoba. An international conference held in Chicago, in October 1981, brought together people with polio and experts in the field to discuss problems of aging. (Goldberg, A. et al 1981). In this paper, we will take the issues raised at that conference and discuss them in the light of the data collected in the 1980 study.

## BACKGROUND

Between 1950-1959, a total of 3,644 cases of polio were registered within the Province of Manitoba. The highest incidence was in 1953 when there were 2,371 cases. (Slide 1:Histogram of case distribution). Many of the cases were triaged to one central medical facility, the Winnipeg Municipal Hospitals. A case register and individual medical records were maintained on each patient with a confirmed diagnosis of polio by Dr. John Alcock, a respiratory physician and co-researcher on the study. This register has been used to define the population base and sampling frame from which people are being selected for the current project. (Slide 2: Population pyramid of sampling frame).

In the 1980 study, a complete list of everyone who had respiratory polio between 1950-1959, was abstracted from the register; a total of 264 people (Alcock et al, 1980). Those who died within the first three months (76 cases) were omitted, leaving 186 cases to be followed-up. We were able to trace and interview 113 people who were still alive in 1980. Interviews were also carried out with the next of kin of 26 of the deceased patients.

In the initial study of respiratory patients, two forms of data collection were used; a medical record audit and a face to face structured interview. The record audit was carried out by two clinicians, both members in the medical team which had treated these patients during the epidemics. The interviews were used to collect socio-demographic data, including educational, occupational and family histories. The main focus, however, was on a series of indices measuring respiratory status, mobility and the ability to carry out the activities of daily living. The record audit was used to develop measures of these functions based on the medical assessments one year after polio onset, when people had recovered from the acute phase. In addition, the people interviewed were also asked to recall what their status had been one year after polio. The purpose of this question was to provide a measure which would show how they perceived changes in their functional capacities over the twenty to thirty year period following the acute stages of their illness.

To provide a socio-demographic profile of the respiratory polio population, the next slide (Slide 3: Histogram of Age/Sex distribution) shows all 186 cases included in the medical record audit. There were 116 men (62%) and 70 women. Their age distribution at onset ranged from 1 to 66, but there are two peaks the 5 to 9 age group and the 25 to 30 age group. (This age distribution was typical of polio epidemics in the fifties (Horstmann, D. 1955). Although all had either spinal or bulbar involvement and required respiratory support during the acute phase, residual levels of functional ability varied greatly. Some improved to the point of no longer requiring any form of respiratory assistance (66%) and other recovered their normal range of mobility and self care ability. At the other extreme were patients who remained partially or totally dependent on mechanical respiratory support and who recovered only minimal degrees of mobility. (Slide 4:Histogram of Proportion of patients discharged under various categories).

Members in the first group could be discharged from hospital to resume normal lives; others who had recovered with some residual paralysis, could nevertheless return home without problems. This left a group of patients who required more complex discharge arrangements, but who were anxious to resume their lives outside hospital. A home care program for respiratory polio patients was developed by a multidisciplinary team and supported by the provincial government to meet the needs of this group (Dunnell, K. et al, 1972, Creese et al, 1977). The program included the provision of respiratory equipment and its maintenance; modifications in home living environments; support of paid attendants or in some cases payment of a family member; and back-up medical care (Desmarias et al, 1956). Decisions about which patients were eligible for the program were based on a careful assessment of the family resources available which could then be matched with the provisions made by the Government. A total of 52 patients entered the program; in 1980 24 of these individuals were still living independently in the community. The balance between medical and social needs and the resources to meet them was often delicate and, in some cases difficult to maintain; a cluster of thirty patients remained in hospital; sixteen were alive in 1980 and in the Municipal Hospitals together with four people who have left the home care program.

In the 1980 study we traced as many as possible of this original group of 186; 56 had died, but we were able to interview 113 (86%) of those who had survived. It is these interview data which we will present in the rest of this paper.

## THE LONG-TERM IMPACT OF POLIO

The literature on the polio epidemics is extensive and includes a group of 9 papers summarizing clinical aspects of the Manitoban epidemics of the 1950's. However, this literature tends to focus on the years immediately following the onset of polio. In common with the most research on disability and rehabilitation (Deutsch, C. and Goldston, 1960), the medical and psychosocial aspects of adaptation to disability are examined, but over a relatively short space of time following the initial injury or disease onset. (A particular characteristic of the polio literature is that it dates back to the'fifties and early sixties'; people with polio ceased to be of research interest just as they have also tended to be forgotten as a group by the general public).

The literature on polio includes the classic study by Davis (1962) which was as concerned with the impact of polio on the family as on the individual child. Davis' study was longitudinal, as were a number of others in the polio literature; nevertheless, their time scale is short and does not extend beyond five years after the acute stage. Most of these studies imply that after the post acute stage and within the time frame considered, people achieve a "steady state" of functional adaptation which will be maintained through time. This literature is of little relevance to those who, twenty to thirty years later, become concerned with the impact of aging.

An alternate perspective on aging and disability is presented by the literature on gerontological research. Gerontological studies document sudden or gradual loss of functional capacity resulting either from the processes of normal aging or the impact of chronic diseases among the elderly (Pfeiffer, 1974: Wright, 1972). Their focus is on disability as a consequence of the aging process rather than on the impact of aging on people who are alredy disabled.

The issues raised at the Chicago conference on polio and aging, as by the people whom we interviewed in Manitoba, stem from a different premise. From the perspective of those who had polio in the fifties, the relationship between care needs and the care resources available has not been static and they do not anticipate that it will be in the future. As they have grown older, their needs have changed whether as disabled children growing into adulthood or young adults entering early and late middle age. Over the same time period, those who support them have also aged and have already changed, or may change, in their ability to provide care in the future (Litman, 1972). The environment within which the balance between care needs and resources must be maintained has also been transformed over the years. There have been medical and technological innovations; experimental programs for the disabled have been introduced or, more recently, are threatened by economic cutbacks. There are new attitudes towards them; both among those officially involved with service provision and among the general public. On the other hand, with the implementation of immunization programs, polio is no longer seen as a threat by the general public and polio survivors have relatively little visibility. Finally, a politically aware and articulate group has emerged within the community of the disabled and includes within its membership, a number of those who had polio.

In their different ways, these developments have all impinged on the original relationship between the individuals's needs for care and the resources available. Each was raised as topic at the Chicago conference but the central issue was the impact of aging on people who had polio.

## AGE GROUPS AND THE IMPACT OF POLIO

In order to understand why aging is becoming an issue, it is necessary to look at the age groups to which the people interviewed in the 1980 study belong. For this paper, people have been grouped into three age categories: 1) Young adults; these are people who are 28-44 years in 1980, but were 1-17 when they developed polio; 2) Middle adulthood; people who were 45-54 in 1980 and 18-27 at polio onset; 3) Late adulthood; people 55 and over in 1980, who were 28 and over when they developed polio. By the terms of a gerontology conference, only the last group would be conventionally be considered as "elderly" but all are concerned in the process of aging and its relationships to disability.

There are several reasons why age at onset is important. First, the impact of polio on respiratory function does vary within this population by age group; second, the implication for dependency patterns was not the same for a child with parents as for a parent with children. Finally the impact of polio on life career patterns varied with age group. Many in the two older groups had already completed their education, started work, married and had children; members in the third group were children whose access to these different career stages was sometimes to be blocked by polio. Later in this paper, we will discuss the relationship between age group membership, dependency and family structure; however, first to present the relationship between respiratory status and age.

## RESPIRATORY STATUS

Time series data showing respiratory status at multiple points during the previous twenty to thirty years was only available on a small and unrepresentative group who had either remained in hospital or had returned frequently for clinical care. The only measurements consistently available on everyone in the study were those made as people recovered from the acute stage and as their condition stabilized. In both the medical record audit and the interview we used one year after onset as the point at which to measure respiratory status.

Respiratory status was measured by the degree of dependence on 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 (Spencer et al 1974). They are: 1) independence of support; 2) occasional dependence (eg. when an infection interfered with respiration); 3) support only at night; 4) support for 12-18 hours a day; 5) support for more than 18 hours a day. For presentation in this paper, levels 1 and 2 are combined and referred to independence from respiratory support; levels 3,4,5 are combined as dependence.

Respiratory status by age group is shown in Table 1. The people in the young adult group are significantly more likely than those in the older groups to be independent of respirator support. This was a characteristic of the young both in 1980, when they were interviewed, and in terms of the recollection of their condition one year after polio onset.

As these data show only the two points in time, fluctuations in respiratory status could have occurred within the intervening time period and yet not be apparent here. However, people were asked for the years in which they had been at their worst level or had reached their best. For the majority (77%) their worst year remained the one after they had recovered from the acute phase. Most people (87%) then placed their best year shortly after and within five or six years of having developed polio. It was at this, their best level, that the majority have remained.

The major concern of the Chicago conference was with the theory that people who have been respirator independent for years, are showing signs that may need this support again. Yet, the evidence from the Manitoba study suggests that respiratory status has remained stable for the last twenty years, even in the older age groups. The issue is an important one; the aim of the Chicago conference was to encourage further research and to alert people and their physicians to the problem. The only evidence to support the theory is that approximately two-thirds of those taking part in the Manitoba study reported lack of energy as a health problem. This is one of the symptoms associated with an increased need for respiratory support. There was also a small group of 19 who did say their condition had regressed and that their worst year had occurred within the last decade. However, they belong to all age groups and represent only 17% of those interviewed. The advantage of the ongoing study in Manitoba is that this problem can be investigated within a population representing all respiratory polio patients in the province.

In terms of the concerns expressed by people taking part in the 1980 study, no one currently independent of respiratory support spoke about a decline in their respiratory capacity as they grew older. Those who were concerned about the impact of aging were already dependent, but were concerned that they might need a mini-lung at some time in the future. Whereas most can manage outside a tank respirator or off a rocking bed for some time each day, attachment to a mini-lung is continuous. Vulnerability to maching failure is seen to increase by some of those we talked to; a prospect they declared to be intolerable. On the other hand, the eight people who had mini-lungs argued in their favour. Their energy level was higher than on other forms of respiratory support. Moreover, they become mobile to an extent impossible when they had to spend hours each day on a tank respirator. For them, the mini-lung was a major technological development which had markedly improved their lives. Yet for the others, aging was feared as it might force them to accept a new form of dependence on machinery and one which they feared.

Another issue raised at the Chicago conference was indirectly related to age. It is that people who need respirators and rocking beds are beginning to outlast both the technicians who can service this equipment and the supply of spare parts. In Manitoba, nine people have iron lungs and 28 have rocking beds; these figures in themselves indicate that this is a small scale market from a manufacturer's point of view. Both the iron lung and the rocking bed are old, but relatively simple technology; new machinery available for respiratory patients, such as the mini-lung, is complex and more expensive and difficult to maintain on a home basis than the older respiratory support.

How to keep the machinery in functioning order is one of the many problems facing people on home care. In 1980, there were only 17 people using respiratory support equipment and living outside the Municipal Hospital. Their independence was always fragile as it depended on others, usually a spouse or a parent, being able to provide care. For this group, the key issue was not their own aging, but that of those on whom they depend. For example, one man spoke of the need to keep his own weight under control as his wife could not manage to lift as much as before. Another worried about the health of his parents and his own future. The alternative to family support was not necessarily re-entry to the Municipals. A few people in the study did manage on their own using paid helpers, or they entered various types of personal care home. These forms of independence can be difficult to manage, especially for those accustomed to care at home. It was noteworthy that four of the people whose outside support systems had failed them did, in fact, return to the Municipal Hospital.

The relationship between dependency and aging will be discussed further later in this paper. In the next section, we will look at the impact of aging on mobility and the ability to carry out the activities of daily living.

## MOBILITY AND THE ACTIVITIES OF DAILY LIVING

A series of twenty-five questions were used 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 on equipment; 4) dependence on equipment and people; 5) complete inability to contribute in any way to the performance of the function in question (Kaufert, 1979). For presentation in this paper, these have been collapsed into independence (level 1 and 2 combined) and dependence (3,4, and 5 combined).

The mobility index consists eight basic mobility functions, including 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 seasonal distinction is necessary to allow for the impact of Manitoban climactic conditions on mobility). Three other functions were added to these eight. Mobility in its wider sense depends on the ability to use motor vehicle transportation systems, therefore, the three additions are: ability to ride in transport specially designed for the disabled; ability to ride in a car and ability to drive a car. People with mini-lungs or tank respirators can manage the first but not the second and 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 Scale" was used (Katz, 1976). It was augmented by questions to measure functional ability on such activities as turning door knobs or lifting objects above the head. (These were to deal with the effect of polio on upper limb movements which could not be measured adequately by the Katz Index). Other questions were added to measure performance of more complex daily life activities such as shopping, cooking and cleaning.

In addition to the banks of items to measure mobility and ADL, people were asked to make a summary assessment of their mobility and of their performance of the activities of daily life. Using the same five item scale, people rated their mobility and ADL, at one year after polio onset and at the time of the interview. They were also asked in which year their performance was best and in which year it was worst. It is these data which we are using for this paper.

In the next slide we show mobility levels for each of the three age groups at the two points in time. There appear to be no significant differences in the levels of mobility among the three age cohorts, but there is a marked shift from dependent to independent mobility when mobility at one year is compared with mobility today. The majority of people said their worst mobility level was in the years immediately after polio; the majority had reached their best and stable level within the next five to six years. The transition from one level to another does, therefore, reflect the impact of rehabilitation and corrective surgery taking place in first years of recovery. A comparison of this slide with the preceding one on respiratory status shows that in each age group, a higher proportion are dependent in terms of their mobility than are dependent in terms of their respiratory status. Although everyone had respiratory polio, fewer people were left permanently impaired in terms of their respiratory capacity than were left with other forms of paralysis.

The next slide shows the performance of the activities of daily living by age group. The distribution is very similar to the pattern on mobility. There is no significant difference by age group, but there is a marked shift from dependence to independent performance which occurred within the recovery period in the first five to six years after polio.

In one sense, people who can manage their mobility and the other functions of daily life through the use of equipment, but who are not dependent on people, should be ranked as independent. The decision to exclude them from the independent category was made to ensure that developments in equipment did not obscure any change in status due to aging. A current argument in the rehabilitation literature is that: "Some previous polio patients loose strength rapidly in middle age" ... "muscles most commonly affected are those that recovered well from the initial attack, but have been used strenuously since" (Bailey, In Laurie, 1980). Others, including Spencer from the Institute of Rehabilitation Research, argue that the changes observed in polio patients are simply "the well-known aging effects of decreasing strength common to us all". This debate was taken up at the Chicago conference.

Both Bailey and Spencer, while disagreeing on the cause, do anticipate a loss of function. However, there was no evidence of such a decline among the people interviewed in the 1980 study, regardless of the age group to which they belonged. There are two possible explanations for this apparent discrepancy. One is that finer, more detailed assessments might reveal there had been a deterioration in functional ability within our population, but without an absolute loss in functional capacity having occurred. The other possibility is that the rehabilitation specialists are seeing only a select group of people who are running into problems. They could be the equivalent of the 12% to 14% in the Manitoba study who rated their worst level of mobility and ADL as occurring in the decade of the seventies. Given a representative sample of a post-polio population, such as the one in our own study, loss of function with aging may only be effecting a minority.

The issue is an important one because, if there is deterioration, attention should be paid to detecting it early. Its advance could be delayed through treatment, advice and the provision of equipment which might cut down on the use of over-exercised muscles. On the other hand, if deterioration effects only a few select cases, the potential damange from labelling of all former polio patients as victims of accelerated aging should be considered carefully.

## FAMILY STRUCTURE AND DEPENDENCY

In the 1980 study, we began an initial exploration of the impact of polio upon the family. People were first asked what their family status had been when they developed polio: 31% had been children; 19% had been single adults and 50% had been married; 90% of those who were married had children. People were then asked what their family status was at the time of the interview: 25% were single adults, 50% were married and 25% had once been married, but were now divorced, separated or widowed. A third set of questions dealt with marriages, births and deaths as events occurring within the last 20-30 years which had modified the family structure: 23% had married, 16% had been divorced; 63% had seen the death of a parent and 8% the death of a spouse.

The divorce figures provide the most dramatic insight into the impact of polio on the family. A third of the marriages which existed before polio onset ended in divorce; 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% did in fact become married.

Family status at onset is significantly related to the pattern of discharge reported by those whom we interviewed in 1980. ($x^2$=14.01, df=4, $p \leq .007$). 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 the Municipal hospital. On the other hand, 29% of the single adults and 23% of those married when they developed polio were in the Municipal hospital when we interviewed them in 1980. Discharge arrangements are also related to changes in marital status; out of the thirteen people in the Municipal hospital, who had been married when they developed polio, 77% were divorced or widowed by 1980.

It is against these data on family structure, that patterns of dependency must be interpreted. As we have shown, degrees of disability vary from complete functional ability to almost complete dependence on respiratory equipment for survival and extensive paralysis of the upper and lower body. Associated with these varying degrees of functional impairement are varying degrees of dependence upon others for help. Helpers are often, although not always, members of the person's family.

To measure this dimension of the resources available to the individual, people were asked how essential different members of the family were in facilitating their mobility and functions of daily life.

In this paper, we will distinguish between two levels of help. First, help which was essential, in the sense that without it mobility or daily life activities were impossible. Second, help which was not essential but did make a major contribution to performance. A list of relatives was provided and people were asked to assign the level of help received from each relative in the list. (People in the Municipal hospitals were excluded as, although relatives and friends contribute to the quality of their life, their help is not prerequisite to functional performance).

The people in the young adult group are less likely to be dependent on relatives as helpers than are the middle and older adult groups. The simple measure of dependency patterns is to count the number of times a family member is said to be an essential or important helper; there are 15 such citations made by people in the young adult group, 26 and 22 respectively made by those in the middle or older age groups. However, the pattern of family dependency cannot be properly understood in isolation from family structure. For example, only 5 young adults say that their spouse is important or essential to their mobility, but slightly less than half are married compared to 60% of the middle adult group and 80% of the older adult group. In the latter two groups, the spouse is more often said to be essential (55% and 43% respectively) or important to mobility (22% and 24% respectively). It is not only that young adults are less likely to be married; those who married were less likely to depend on their married partner.

Spouses are not the only type of family member cited as helpers, although dependency on the spouse is the pre-eminent pattern. There are twelve people living with their parents; the majority are in the young adult age group; 33% say their parents are essential to their mobility and 33% say they are important. Children are more rarely essential helpers; only 5% of the 35 cases in which children are members in the same household; however, in almost half these cases (49%) the children are important in terms of the help they contribute to mobility. Friends and other relatives are cited as helpers, only rarely; on the other hand when paid outsiders are used, whether hired by the individual or paid directly by the government, they usually are said to be essential to mobility: 17% of the people interviewed had this form of outside help.

Few people depend exclusively on one helper; a husband's care for his wife may be supplemented by a paid housekeeper; children may help their mother, or siblings may help the parents, in caring for an individual. Nevertheless, their ability to remain at home was often seen by those interviewed as contingent on the care offered by a particular family member. A series of open-ended questions asked people what they saw as the impact of polio on the lives of their family. It was in the answers to these questions that many expressed their concern about the future and about impact of aging on their main source of support.

Several respondents saw their independence as directly related to the ability of their marriage partner to care for them. To quote one statement: "I depend so much upon my husband, that if anything happens to him I would have to go back to the hospital". Another worried about her ability to manage since the death of her husband. A man, talking about the extent to which his parents had changed their lives because of his polio, now worried more about their aging than about his own.

At the Chicago conference, the orientation was still primarily towards the patient as an individual seen in isolation rather than within the family setting. Yet, for many people their family are integral to their pattern of managing their disability. Their comments suggest that focus on the individual is too narrow a perspective on aging; account must be taken of its impact on the family as well as on the individual. In some ways, the current situation is similar to the time when the original decisions on discharge were being made. Although the key variable was medical condition, people with the same level of functional disability could remain in hospital or be discharged. It depended on the support system available to them in the outside community. In the same way, people with similar functional status may or may not re-enter hospital; it will depend on the vulnerability of their support system to the impact of aging and mortality.

## CONCLUSION

Given the limitations of the data, the conclusions to be drawn from the 1980 study are limited. At present, they suggest that no major deterioration in respiratory or functional status is taking place with age. More subtle changes may be occurring and this possibility will be investigated further in our ongoing research. However, while not confirming the theory that people regress as they reach forty, the study did raise other issues not considered at the Chicago conference. The impact of aging has to be viewed within the total context in which the individual lives. Growing older happens not just to people who had polio, but also to those on whom they depend and even to their respiratory equipment. In the next stage of our research, extended open ended interviews will be used to explore family change, both in the past and as it is anticipated in the future. In a parallel survey, interviews will be carried out with family members or with others on whom people depend. One aim will be to document in more detail how people perceive the impact of aging not only on their physiological capacity to function, but also on the complex social and psychological dimensions of their life as it is today, twenty to thirty years after they developed polio.

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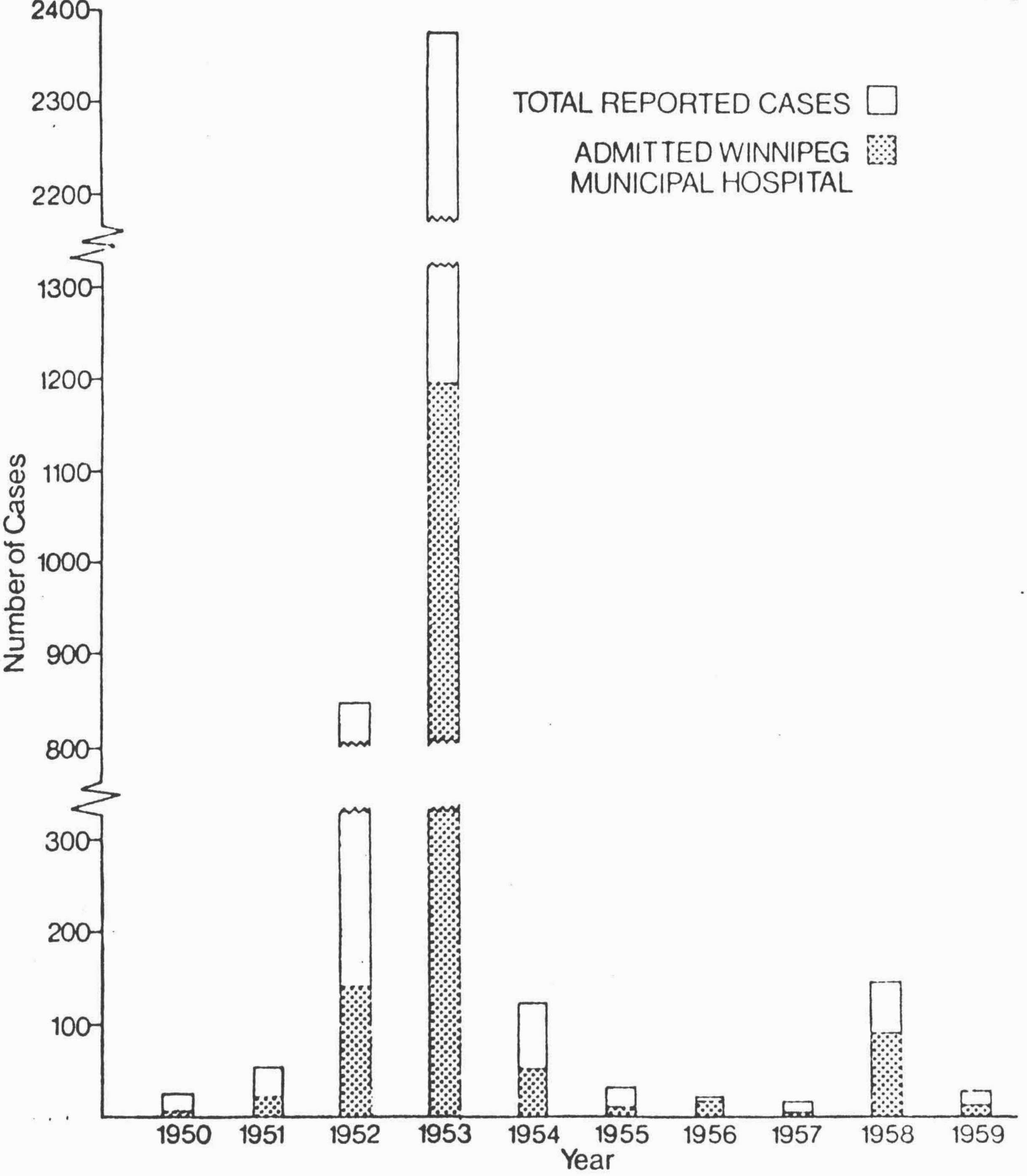
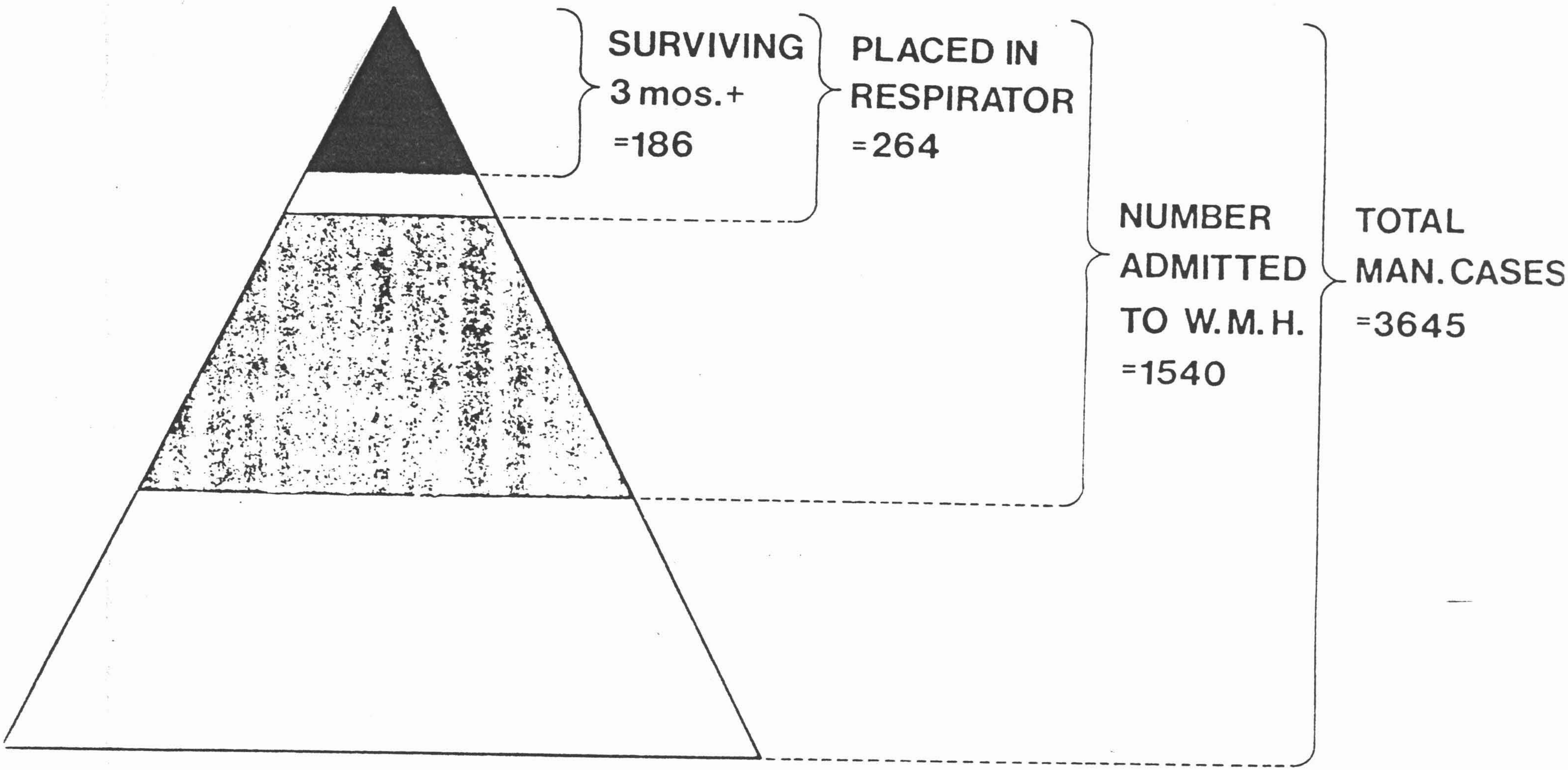
SLIDE ONE

# MANITOBA CASES AND ADMISSIONS WINNIPEG MUNICIPAL HOSPITAL



SLIDE TWO

# TOTAL CASES 1950-59



SURVIVING 3 mos.+ =186

PLACED IN RESPIRATOR =264

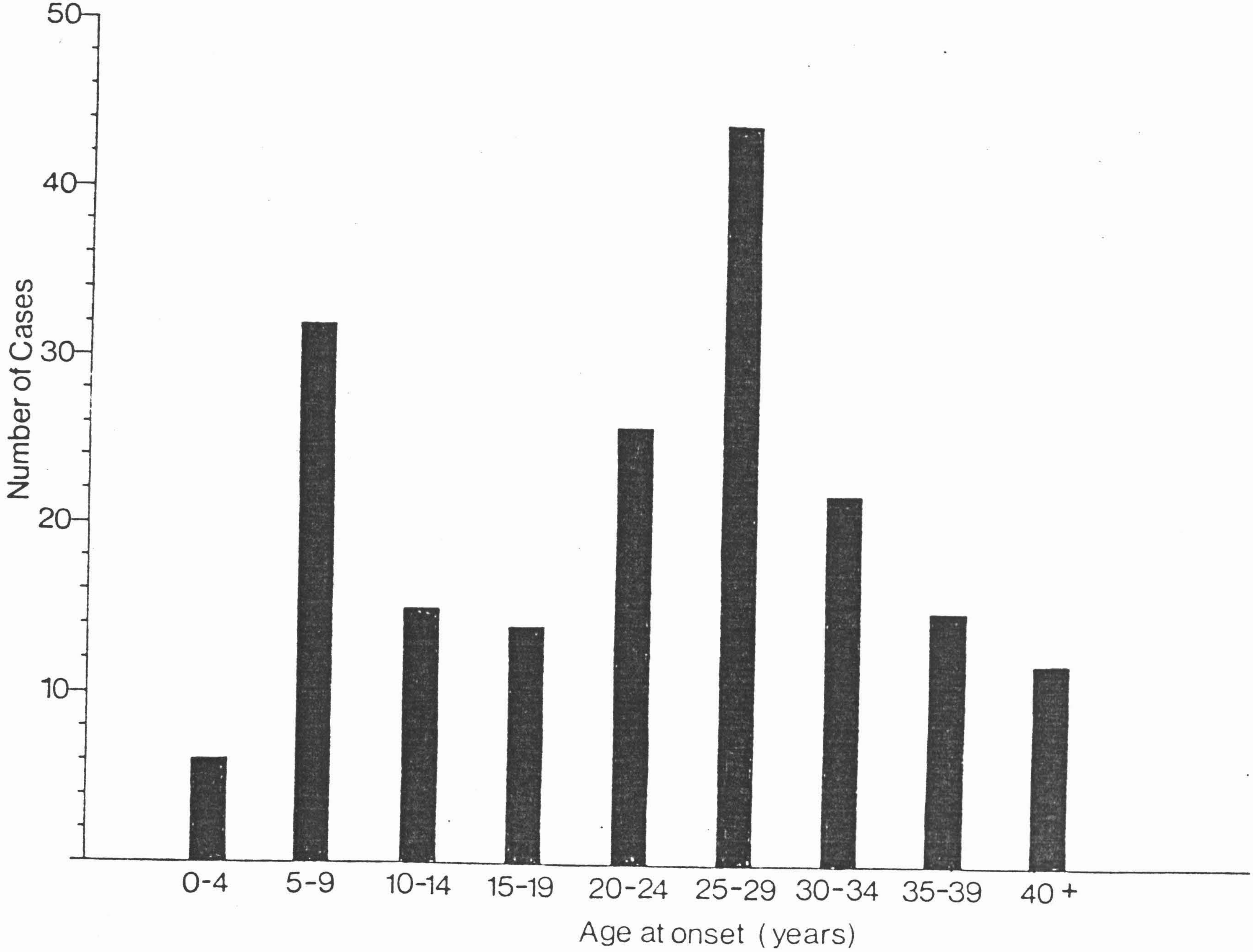
NUMBER ADMITTED TO W.M.H. =1540

TOTAL MAN. CASES =3645

# DISTRIBUTION OF CASES BY AGE AT ONSET

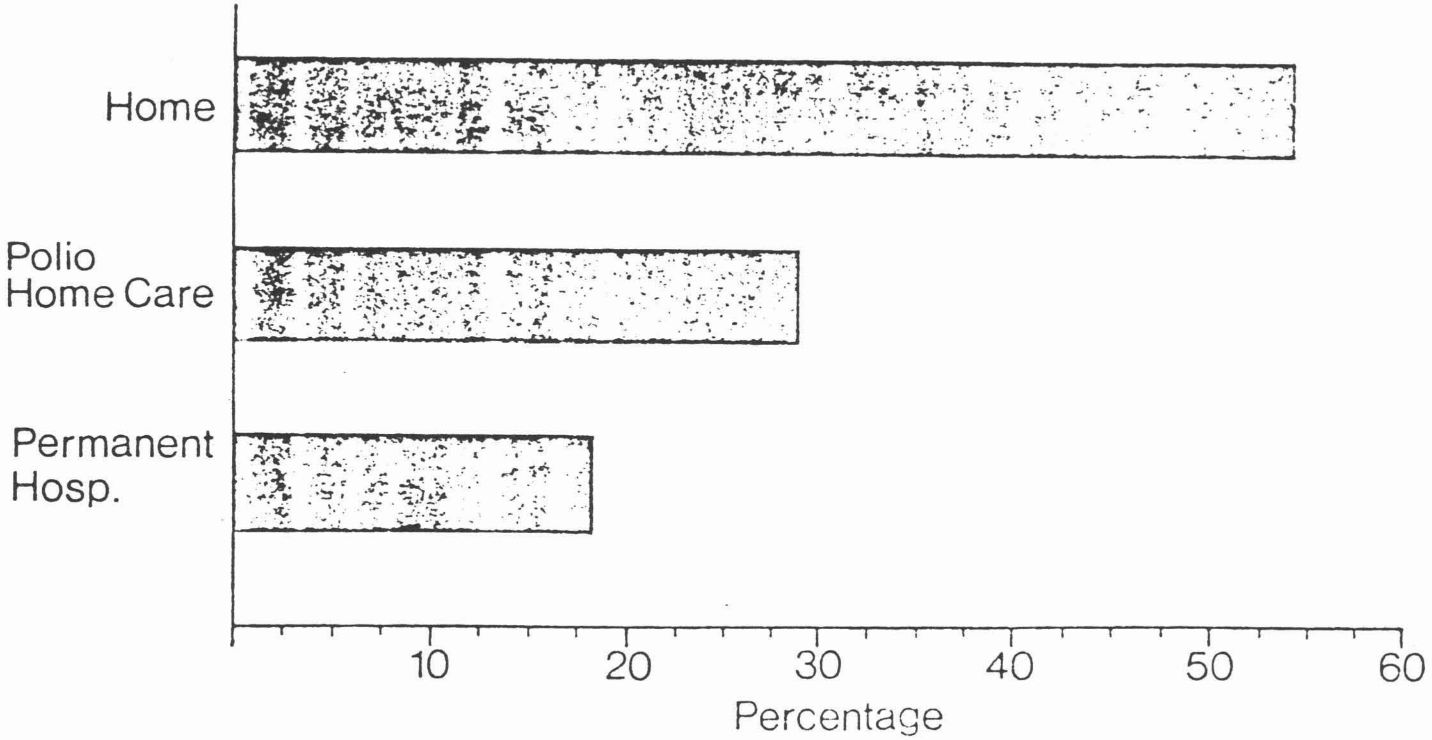
SLIDE THREE

N=186



SLIDE FOUR

# DISCHARGE ARRANGEMENTS



# TABLE 1

## DEPENDENCE UPON MECHANICAL RESPIRATORY SUPPORT

## BY AGE GROUP

| | 1 YEAR POST ACUTE | | | 1980 | | |
|---|---|---|---|---|---|---|
| | YOUNG ADULT 28 - 44 YRS | MIDDLE ADULT 45 - 54 YRS | LATE ADULT ≥ 55 YRS | YOUNG ADULT 28 - 44 YRS | MIDDLE ADULT 45 - 54 YRS | LATE ADULT ≥ 55 YRS |
| % INDEPENDENT OF RESPIRATOR | 81 | 54 | 66 | 87 | 49 | 69 |
| % DEPENDENT UPON RESPIRATOR | 19 | 46 | 34 | 13 | 51 | 31 |
| TOTAL %<br>(N) | 100<br>(36) | 100<br>(41) | 100<br>(35) | 100<br>(37) | 100<br>(41) | 100<br>(35) |
| | | TOTAL N=112 | | | TOTAL N=113 | |

$x^2 = 6.19$
df = 2
$p < .05$

$x^2 = 12.60$
df = 2
$p < .02$

# TABLE 2

## UNASSISTED MOBILITY* BY AGE GROUP

| | 1 YEAR POST ACUTE | | | 1980 | | |
|---|---|---|---|---|---|---|
| | YOUNG ADULT 28 - 44 YRS | MIDDLE ADULT 45 - 54 YRS | LATE ADULT ≥55 YRS | YOUNG ADULT 28 - 44 YRS | MIDDLE ADULT 45 - 54 YRS | LATE ADULT ≥55 YRS |
| % INDEPENDENTLY MOBILE FUNCTIONS | 41 | 22 | 23 | 60 | 37 | 40 |
| % DEPENDENT FOR MOBILITY | 59 | 78 | 77 | 40 | 63 | 60 |
| TOTAL %<br>(N) | 100<br>(37) | 100<br>(41) | 100<br>(35) | 100<br>(37) | 100<br>(41) | 100<br>(35) |
| | | TOTAL N=113 | | | TOTAL N=113 | |
| | | N.S. | | N.S. | | |

*UNASSISTED MOBILITY = PERFORMS MOST MOBILITY FUNCTIONS WITHOUT THE ASSISTANCE OF AIDS, ADAPTATIONS OR HELPERS.

## TABLE 3

### UNASSISTED PERFORMANCE OF ACTIVITIES OF DAILY LIVING BY AGE GROUP

| | 1 YEAR POST ACUTE | | | 1980 | | |
|---|---|---|---|---|---|---|
| | YOUNG ADULT 28 - 44 YRS | MIDDLE ADULT 45 - 54 YRS | LATE ADULT ≥55 YRS | YOUNG ADULT 28 - 44 YRS | MIDDLE ADULT 45 - 54 YRS | LATE ADULT ≥55 YRS |
| % INDEPENDENTLY PERFORMING ACTIVITIES OF DAILY LIVING | 46 | 27 | 34 | 68 | 37 | 49 |
| % REQUIRING ASSISTANCE WITH ACTIVITIES OF DAILY LIVING | 54 | 73 | 66 | 32 | 63 | 51 |
| TOTAL %<br>(N) | 100<br>(35) | 100<br>(41) | 100<br>(35) | 100<br>(37) | 100<br>(41) | 100<br>(35) |
| | | TOTAL N=111 | | | TOTAL N=113 | |
| | N.S. | | | N.S. | | |

# Disability and The Aging Process
# in the Middle Years: The Experience of
# Poliomyelitis Patients in Manitoba

by

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Keynote address: Canadian Rehabilitation Council for the Disabled,
June 9-10, 1983.

The research program providing the database for this report was supported by research grant no. 6607-1241-26 from the National Health Research and Development Project, Health and Welfare Canada.

# AGING AMONG THE YOUNG DISABLED

As the Canadian population ages, gerontologists are becoming increasingly concerned about the onset of disabilities related to age. Gerontological (research) documents sudden or gradual loss of functional capacity resulting either from the processes of normal aging or the impact of chronic diseases among the elderly. However, the focus is on disability as a consequence of the aging process rather than on the impact of aging on people who are already disabled. Reciprocally, much of the literature on disability among the young tends to focus on the years immediately following the onset of the condition. In common with the most research on disability and rehabilitation, the medical and psychosocial aspects of adaptation to disability have been examined, but over a relatively short space of time following the initial injury or disease onset.

Because of this gap in our understanding of the overall life cycle of disabled people, a question which is currently being raised and which is critical to planning services, is the extent to which the needs of people disabled during childhood or young adulthood are changing over time as they and members of their support network age. The original adaptations to physical impairment and achievement of independence when younger reflected a delicate balance which may be threatened by even relatively minor changes in the individual functional status or in their support system as they grow older.

The gap in our knowledge of normal aging and change in the middle years took on a personal meaning for me as I reached my fortieth birthday and began to interview post polios from the 1952 and 1953 epidemics in which I was a non-paralytic case. Clearly midlife and the prospect of aging involves risk and change for each of us; normal human development and aging involves changes in our functional abilities in which we progress from infancy to old age. Every human develops through dependence to independence and back to dependence again. Disability can happen at any point in the life cycle and, depending on the extent of disability, can dramatically alter the kinds of goals and trajectories which we have projected for our lives. Images in the media of so-called "normal aging" gives us some preparation for increasing disability and dependence with aging (although some of the message of the current emphasis upon lifestyle is that we can avoid it). In chronic disease processes which are seen as a part of normal aging, disability and depndence occur later in life and we prepare for them and provide through our various community and family support networks. Even with some diseases of young adults, we expect increasing disability with progressive conditions such as MS and MD and we attempt to provide support through education, preparation and supportive counselling, wherever possible.

Let's contrast this view of late disability in normal aging with the experience of people for whom initial impairment dates from childhood, or young adulthood, who are now entering middle age. As in the case of the population of post polio people, this group includes people who have been disabled, worked hard to achieve initial rehabilitation, and who have regarded themselves or been regarded by the rehabilitation system as achieving and maintaining a constant level of functional ability and adaptation to independent living.

processes among people with any one type of disease or impairment which is generalizable to all disabling groups or even from one individual to another. However polio-related disability was well documented and seemed to have precipitated many of the major changes in the system of rehabilitation medicine over the past three decades. I would like to present some of the preliminary findings from our follow-up study of post-polio people in Manitoba, not so much to provide specific information on specific aging-related problems among survivors, but in terms of the more generalizable insights which they provide about the experience of young disabled people facing middle age.

## Recent Focus on Post-Polio Aging

Our own interest in following up post-polios began with the efforts of Drs. Hildes and Alcock who had treated Manitoba victims during the 1952-53 epidemics and undertook a follow-up of respiratory cases for the 1980 Rehabilitation International Meetings. The need to explore aging phenomena was highlighted in a 1981 NBC prime time program and culminated in the convening of an International Symposium on Aging among Respiratory Survivors in Chicago in 1981 (sponsored by Rehabilitation Gazette, Northwestern Rehabilitation Institute).

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 time, 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.

Perhaps the most significant insights about the aging experience of the young disabled emerged from the personal descriptions of 17 polio survivors describing recent changes in their own adaptation. Audrey King has summarized this in her report on the meeting for Rehabilitation Digest:

> Paraplegics, increasingly unable to push their chairs for any significant distance due to fatigue, pain and loss of strength, are having to consider electric chairs in order to remain mobile. Those who have been respirator-dependent for many years, or have become so during the last decade, are fraught with an anxiety which stems from the knowledge that they have outlived the companies and technicians producing and maintaining such equipment on a home-service basis.
>
> (King, p. 18)

The Chicago meetings and a recent follow-up symposium in St. Louis last month prfoundly influenced the directions of our ongoing follow-up of post-polio people in Manitoba. In studying aging among young disabled we realized we must also understand the relationship between changing needs and parallel changes in: (1) rehabilitation technology, (2) public policy towards support of disabled people and, (3) the evolution of self-help and advocacy in the disabled consumers movement. We felt that these three dimensions in the environment of the polio survivor's life experience needed to be documented at both an individual level through extending our follow-up survey to non-respiratory survivors and through more development of research on Canadian post-polio rehabilitation experiences.

## Why Follow Representative Groups to Understand the Aging Experience Among Populations of Young Disabled?

An initial question which might be mentioned is why place so much emphasis on an intensive follow-up of a total representative population of individuals with a particular condition to understand their experience with aging. At Chicago, discussions of normal aging were sometimes limited by the small amount of systematic data which might describe what had happened to a representative group of the people disabled as children or young adults. Much of what we think we know about the middle aging or aging among disabled people as children may be based upon the experience of relatively small samples of people who are unrepresentative, but who maintain ongoing contact with the rehabilitation system or who are publically visible. A major difference between the two recent post-polio conferences attended by some of us was a desire to develop more representative information on polio survivors and avoid labelling the post-polio aging syndrome.

## Slide 1: Pyramid showing total case distribution

In our follow-up we attempted to obtain a representative view of aging by looking at the case distribution of all post-polios in the Manitoba epidemics of the 1950's, emphasizing the need to base our understanding of people disabled young in life on a representative sample of individuals. We were able to achieve this in the Manitoba study because a register was maintained of all patients admitted to hospital by Dr. Alcock. The distribution of disability experience represented by the pyramid, in terms of respiratory, non-respiratory and non-paralytic polio also emphasized the potentially different aging experiences of all groups of disabled people.

## Why Study Groups Disabled in the Same Time Frame?

(ie. We did use the epidemics as baselines in trying to understand the more general aging experience of young disabled people over the past 30 years).

At the Chicago meetings, many of the presenters emphasized the variation in post-polio experience of people who had the acute phase of the disease and rehabilitation in the 30's, 40's and 50's. Because of this need to relate post-polio experience to a specific time, we were interested in focusing upon people who had polio in two major epidemics of the 1950's and whom we treated in comparable rehabilitation programs. The decision was therefore taken to focus upon specific epidemic years and utilize a defined catchment population.

Slide 2: Histogram showing years of 1950's polio epidemics in Manitoba

Our own decision to follow-up post-polio aging problems with the survivors of specific epidemics related to the recognition that the experience with aging of people disabled early in life is that their life experience is very different than people who experience disability in old age.

## The Manitoba Study

Between 1950-1959, a total of 3,644 cases of polio were registered within the Province of Manitoba. The highest incidence was in 1953 when there were 2,371 cases. This constituted highest incidence rates in North American and reached a level of 300 per 100,000 population.

The high incidence rate had an impact on the aging experience of the post-polio person in Manitoba in that they were part of a whole generation who had either been patients, family, friends or a member of the total society which was threatened by the disease. The aging experience of post-polios disabled in massive epidemics is therefore, very different from disability among diseases such as MS or MD or among quads or paraplegics from traumatic injuries. In some ways it has some similarities to disability among war amputees who were injured in the same situation and where there was a public awareness of the event.

(MENTION OWN EXPERIENCE OF INTERVIEWING SURVIVORS OF WW1 AND VIETNAM.)

This recognition by the generation who experienced polio epidemics also changes with the aging of the society. Aging of the non-disabled population means that the memory of the acute and immediate rehabilitation phases of of polio epidemics diminishes. This presents problems for survivors who are trying to increase public awareness and remobilize resources as in the March of Dimes era. The aging of the society also means that, as Audrey King indicated, the generation of physicians and rehabilitation specialists has aged. Many post-polios talked about surviving their physicians.
(ALSO MENTION LACK OF UNDERSTANDING OF EPIDEMIC IMPACT AMONG MEDICAL STUDENTS)

## Case Finding

(A BIT ABOUT FOLLOW-UP OF YOUNG DISABLED PEOPLE WHICH IS REQUIRED FOR RETROSPECTIVE STUDIES OF AGING)

Surviving former patients were identified using a complex case-finding protocol involving: (1) record search of hospital and rehabilitation centres; (2) search of death registry and vital statistics files to determine deceased (polio and non-polio related), or former patients whose names changed through marriage; (3) location of a limited number of cases through the provincial medical information system; and, (4) finally, through the informal patient network. Approximately 85% of the surviving respiratory patients were eventually interviewed. Within the non-respiratory people, we utilized a phone contact follow-up with three mail questionnaires and achieved a 70% response rate among people who were correctly identified as post-polios. We were able to assess the representativeness of our initial sample through comparison with the characteristics of the total population on the population registry.

In the initial phases of our follow-up of both respiratory and non-respiratory cases, two forms of data collection were used; a medical record audit and structured questionnaire, (administered to the respiratory patients by an interviewer and to the non-respiratory cases using a mail questionnaire). The mail and direct interview surveys were used to collect socio-demographic data, including educational, occupational and family histories. The more epidemiological portion of the instrument included a series of indices measuring respiratory status, mobility and the ability to carry out the activities of daily living. A central objective of the questionnaire was to provide a measure which would show how they perceived changes in their functional capacities over the thirty year period following the acute stages of their illness.

### Slide 3: Acute Epidemic Picture

### Slide 4: Sampling Design

In addition to updating our knowledge of the 186 respiratory patients included in the initial study, we were also interested in non-respiratory people who experienced non-respiratory paralysis and individuals without paralytic effects following the acute phase of the disease (we completed interviews with 530). Non-paralytic cases were not seen as a control groups, but rather as a group which had experienced similar acute effects, but not initial disability.

### Slide 5: Time line showing parallel developments in the aging experience of post-polio people

The aging experience of post-polio people cannot be considered only in terms of the phenomenon of individual aging, but must be viewed within the context of the developments in environment that they have lived with over the thirty years since the epidemic. Specifically, three areas were discussed at the post-polio conferences in terms of the effects upon middle-aging of three sectors in the lives of post-polios:

1. Changes in the technological and medical knowledge base of rehabilitation and independent living;
2. Changes in public policy towards the disabled, ie. the movement from models stressing the charitable provision of services and development of a more broad public committment to the rights of the disabled;
3. Developments in voluntary services and the emergence of the consumer movement for independent living.

Let me use the example of technological change and aging effects. The effect of technological chae and the aging of the technology is illustrated by the experience of post-polios, but can be generalized to aging among many other groups. Let's focus on the interaction of respiratory technology and the needs of the post-polio person.

<u>Slide 6: Iron Lung method of life support during the epidemics</u>

(Problems of obtaining service and spare parts for aging equipment; problems of recently trained professionals not understanding people's life-long adaptations to what is perceived as old equipment)

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.

<u>Slide 7: Rocking Bed</u>

At Chicago, several speakers also felt that there were few technicians who were familiar with old respiratory equipment, and a scarcity of spare parts for maintaining older equipment. This problem could not always be met by replacing older machines with the new technology; people were unfamiliar with the new equipment and there were difficulties in financing its manufacture, purchase and distribution because of the small market.

### Slide 8: Postive Pressure Breathing Equipment

As shown by the crude time line, technological change introduced positive pressure breathing equipment, and within the last decade, the more sophisticated control systems. Each of these developments interfaces with the physical changes related to aging.

### Respiratory Status

The longitudinal data on respiratory support indicated that 65% of the initial group who were on respirator~~y~~s, today are independent of support. Although both reported data on respiratory status and limited data on changes indicated that 77% achieved and maintained their highest level of respiratory function within 5-6 years after the acute stage; seventeen percent reported a declining status within the 1970-1980 period consistent with post-polio aging effects.

The issue of energy level related to respiration and general energy costs of ambulation also appeared to be reflected in non-respiratory patients aging. Forty-eight percent indicated that they had experienced a recent lack of energy, however, only one quarter of the group experiencing change attributed their decreased level of energy to the secondary effects of polio.

## Slide 9: Time Line 2

## Changing Public Support and Policy - Changing services

Individual aging experience must also be placed in the context of changes in services for the disabled which have occurred over the careers of post-polio people.

From the perspective of those who had polio in the fifties, the relationship between care needs and the care resources available has not been static and they do not anticipate that it will be in the future. As they have grown older, their needs have changed whether as disabled children growing into adulthood or young adults entering early and late middle age. The environment within which the balance between care needs and resources must be maintained has also been transformed over the years. There have been medical, social and physiotherapy programs for the disabled introduced that have recently been threatened by economic cutbacks. There are new attitudes towards them; both among those officially involved with service provision and among the general public. On the other hand, with the implementation of immunization programs, polio is no longer seen as a threat by the general public and polio survivors have relatively little visibility. Finally, a politically aware and articulate group has emerged within the community of the disabled and includes within its membership, a number of those who had polio. (This third dimension of the emergence of the independent living movement is well dealt with in Audrey King's recent workshop and an earlier paper by Dirksen). The time line shows formal service provison has changed with hospitalization benefits and Medicare in Canada. Also specific programs such as home care have been developed in response to the needs of the young disabled and most accomodate the aging of the young disabled.

## Family Impacts and Aging

Home care programs provide an excellent example of this area in which changes in the family with aging interact with changes in programs. Here, the implications of aging among post-polio people has to do with the general impact of family aging for the initial care arrangements and for the changes in the balance between family and publicly provided resources required by people as they age.

## Slide 10: Initial Discharge Arrangements

The initial discharge arrangements reflect one of the first home care programs in North America and the recognition that it was necessary to augment family resources with statuatory services. Functional status people varied greatly in terms of their dependency status and needs among the discharge groups. One determinant of the initial and the continuing care arrangements was the kind of family who could initially provide care and the residual effect upon this group.

## Slide 11: Discharge arrangements by age group and type of family support system available to provide care

This slide shows the impact of the age at disability onset on the kind of support system in terms of the family group eligible to provide support. The implications for changes in individual functional ability with aging and parallel aging among family members are profound in terms of both the provision of formal helping services and the availability of informal helpers. In our continuation of the follow-up study, we have interviewed both family helpers and patients. Twelve percent of the non-respiratory cases indicated that they required significant help with activities of daily living and mobility. Sixty percent of the respiratory post-polios required help. In most cases, this help was not provided by statuatory services including personal care attendants, home nursing services or attendants paid by the individuals themselves, but was provided by members of the family grouping. Spouses (11% dependence) and children (12% dependence) were the most significant helpers. Spouses were more likely to be designated as "crucial helpers" without whose assistance independent functioning would be impossible.

Among the respiratory group, a third of the marriages which existed before polio onset ended in divorce; 80% of those divorced ascribed the end of their marriage to polio. Less obvious is the impact of disability early in life 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% did in fact become married. The people in the young adult group are less likely to be dependent on relatives as helpers than are the middle and older adult groups.

# Aging and Its Impact Upon Changing Family Support System

by

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Paper presented at Second International Post-Polio Conference and Symposium on Independent Living, St. Louis, Missouri, May 6-8, 1983. Reprinted in Conference Proceedings, Rehabilitation Gazette, 1984. Research was supported by grant no. 6607-1241-26 from the National Health Programs Directorate, Health and Welfare Canada.

## INTRODUCTION

I should begin by indicating that this paper represents a response to needs identified at the Chicago meeting which brought together individuals who had polio and experts in the field to discuss the impact of aging, particularly as it may be effecting those who contracted respiratory polio. My contacts with many of you, including people more aware of rehabilitation alternatives in Canada like Audrey King, Nancy Skinner and Theresa Ducharme, emphasized the necessity of broadening our follow-up of post-polio people in Manitoba to try to understand the relationship between changing needs and parallel changes in: (1) rehabilitation technology, (2) public policy towards support of disabled people and, (3) the evolution of self-help and advocacy in the disabled consumers movement. We felt that these three dimensions in the environment of the polio survivor's life experience needed to be documented at both an individual level through extending our follow-up survey to non-respiratory survivors and through more development of research on Canadian post-polio rehabilitation experiences.

## OBJECTIVES

The rational used to support the value of more indepth follow-up of post-polio people in applications to Health and Welfare Canada stressed the benefits of understanding the effects of aging among other groups. (In this way it paralleled the attempt to maintain generalizability in terms of knowledge of post-polio people in the same way that the initiatives at the Gazette by Gini and Joe Laurie have pioneered.

## SLIDE 1: OBJECTIVES

The formal objectives included:

1. To measure the initial and long-term of polio-related disability.

2. To measure interaction effects between initial polio-related impairment and longer term chronic disease processes associated with aging.

3. To assess the impact of life events and other changes in family or informal networks upon support activities and measure the reciprocal effect of disability and resources implications for the family.

4. To develop models for predicting change in need and demand for medical and personal care services related to adaptation patterns of former patients and their families.

## THE NEED FOR FOLLOW-UP OF REPRESENTATIVE POPULATION OF POST-POLIO PEOPLE

An initial question which might be mentioned is why place so much emphasis on an intensive follow-up of a total representative population of post-polio people. As I have indicated, the Chicago meetings profoundly influenced the directions of our ongoing follow-up of post-polio people in Manitoba. However, our discussions were sometimes limited by the small amount of systematic data which might describe what had happened to a representative group of the people who developed polio. I feel that the broader surveys of polio survivors across North America including Alice Nolan and Dr. Alba's study, and the work of Chick Weimer and Dr. Bailey has added a great deal to our understanding of the post-polio phenomenon. However, at the Chicago conference, the statements of both rehabilitation specialists tended to reflect the experience of selected groups of severly impaired post-polios who have the most continuous contact with the system of rehabilitation medicine. We simply did not know about the larger majority of individuals who did not maintain contact with medical or consumer networks.

Our work group therefore, felt that it was vital to gather information on the whole population of post-polio people. The extension of our follow-up study to non-respiratory survivors represents an attempt to build this kind of epidemiological base. It presents results from a Manitoba study which traced and interviewed people who had contracted polio during the years 1950-59. The project was based on a unique case register and set of medical records which included everyone who was admitted to the main treatment centre for the Province of Manitoba and who had required respiratory support and all centrally hospitalized non-respiratory patients. This register has been used to define the population base and sampling frame from which the subsamples for the follow-up survey and indepth interviewers were selected. This case register was also used to assess the selectivity of the respondent population. In other words, we could tell how representative in terms of personal characteristics.

SLIDE 2: CASE PYRAMID

## WHY STUDY GROUPS EFFECTED BY THE SAME POLIO EPIDEMICS

At the Chicago meetings, many of the presenters emphasized the variation in post-polio experience of people who had the acute phase of the disease and rehabilitation in the 30's, 40's, and 50's. Because of this need to relate post-polio experience to a specific time, we were interested in focusing upon people who had polio in two major epidemics of the 1950's and whom were treated on comparable rehabilitation programs. The decision was therefore taken to focus upon specific epidemic years and utilize a defined catchment population.

## SLIDE 3: EPIDEMIC YEARS

Between 1950-1959, a total of 3,644 cases of polio were registered within the Province of Manitoba. The highest in incidence was in 1953 when there were 2,371 cases. This constituted highest incidence rates in North America and reached a level of 300 per 100,000 population. The extension of our follow-up to non-respiratory polios attempted to focus upon: (1) interaction between polio-related disability and subsequent aging processes; (2) changes in family networks and informal support systems associated with aging; and (3) changes in rehabilitation policy which have influenced opportunities for independent living.

In the initial phases of our follow-up of both respiratory and non-respiratory cases, two forms of data collection were used; a medical record audit and structured questionnaire, (administered to the respiratory patients by an interviewer and to the non-respiratory cases using a mail questionnaire). The mail and direct interview surveys were used to collect socio-demographic data, including educational, occupational and family histories. The more epidemiological portion of the instrument included a series of indices measuring respiratory status, mobility and the ability to carry out the activities of daily living. A central objective of the questionnaire was to provide a measure which would show how they perceived changes in their functional capacities over the thirty year period following the acute stages of their illness.

## LOCATING NON-RESPIRATORY POST-POLIOS

For both surveys, our experience with case finding made us envy Gini Laurie who has maintained an active network over 25 years. Surviving former patients were identified using a complex case-finding protocol involving: (1) record search of hospital and rehabilitation centres; (2) search of death registry and vital statistics files to determine deceased (polio and non-polio related), or former patients whose names changed through marriage; (3) location of a limited number of cases through the provincial medical information system; and, (4) finally, we did use the Rehabilitation Gazette approach of finding people through the informal patient network. Approximately 85% of the surviving respiratory patients were eventually interviewed. Within the non-respiratory people, we utilized a phone contact follow-up with three mail questionnaires and achieve a 70% response rate among people who were correctly identified as post-polios. We were able to assess the representativeness of our initial sample, through comparison with the characteristics of the total population on the population registry. The non-respiratory sample proved to closely match the population of post-polios in terms of age and disability characteristics.

SLIDE 4: SAMPLING DESIGN

In addition to updating our knowledge of the 186 respiratory patients included in the initial study, we were also interested in non-respiratory people who experienced non-respiratory paralysis and individuals without paralytic effects following the acute phase of the disease. Non-paralytic cases were not seen as a control group, but rather as a group which had experienced similar acute effects, but not initial disability.

## RESULTS

We distributed a preliminary summary of the follow-up of respiratory polios at the Chicago meetings (there are 100 copies available this evening and a summary of the medical effects will be published in the fall). In closing, it may be useful to review a few of the preliminary findings which contrast with the experience of the respiratory patients.

1. First - non-respiratory post-polio's recall of initial phases of their illness and rehabilitation
   - and, their awareness of post-polio aging effects

In our questionnaire we also asked people about their level of awareness of the acute stage, their reliance on others to help with recall and the degree to which they were currently participating in networks in which information about post-polio people was available. By comparing clinical information on polio effects during the acute stage and during their subsequent rehabilitation with their recollections of polio effects in the questionnaire, we were able to get an indication of the reliability of people's recall and also get a feeling for the ways people organized their recall of their experience over thirty years. Among our sample of 530 non-respiratory patients, 45% felt that they had virtually complete recall of the major aspects of their acute care and early rehabilitation. Twenty-five percent indicated they had partial recall of this experience, and 29% indicated that they had little or no recall. In comparing patient experience with clinical records, it was clear that age was one primary determinant of accuracy, but that the type of disability and length of contact with the medical rehabilitation system were also important. The role of family members was critical in the way in which non-respiratory polio survivors reconstructed their experience. Fifty-five percent indicated that they relied upon an informant in recalling their initial experience with polio and their initial rehabilitation. Forty-five percent mentioned parents, 5% spouses, 2% siblings, and 5% physicians as providers of information which had provided triggers or filled in details. Another significant question for the people attending this conference is how post-polio people who are not connected with rehabilitation or independent living networks find out about the current crisis relating to post-polio aging. In our survey of non-respiratory polios from the '52 and '53 epidemic in Manitoba, we attempted to assess levels of awareness and sources of knowledge about post-polio aging effects. Although, given the geographic location of Manitoba dn the tundras, one might argue that polio survivors were more isolated than those in other areas of North America. In contrast to the respiratory survivors, where 40-50 percent had ongoing contact with medical and rehabilitation resources and a third had involvement in consumer organization, non-respiratory polios were not generally actively involved in consumer groups for the disabled, had relatively little awareness of the

the post-polio aging issue and maintained their contact with other people in the polio survivor's network largely through informal rather than organizational contacts. Only 17% of the sample indicated that they had recently been made aware of the current concern for post-polio aging problems through some external sources such as television, newspapers, or specialized publications. Only 6% of our sample routinely received publications targeted on groups with a specific interest in disability, rehabilitation or independent living. Only 8% were active members of advocacy groups such as the Canadian Paraplegic Association, voluntary groups within the Society for Crippled Children, or groups such as COPHO. A finding with direct implications for mobilizing polio survivors in initiatives in post-polio aging was that 34% of our sample had regular contact with other survivors. Only 20% of this group maintained this contact through formal organizational linkages such as clubs for disabled people. Centralization of treatment and rehabilitation programs in Manitoba may have supported these informal networks. However wider casefinding and information efforts which were prposed at Chicago may be able to draw on these networks to reach people who have lost contact with the rehabilitation system and independent living movements. These networks have been used to organize two meetings of survivors in 1980 and 1981.

## AGING AND REPORTED CHANGES IN FUNCTIONAL STATUS, RESPIRATION AND SERVICE UTILIZATION

One of the most significant challenges to come out of the 1981 meetings in Chicago was the need for more systematic study of the proportion of representative samples of polio survivors who felt that they were experiencing recent changes in their health status related to the residual effects of polio. Among our sample of non-respiratory cases, 26% reported recent changes in their overall health status which they felt were polio related.

## Respiration

The issue of energy level related to respiration and general enery costs of ambulation also appeared to be reflected in people's responses. Forty-eight percent indicated that they had experienced a recent lack of energy, however, only a quarter of the group experiencing change attributed their decreased level of energy to the secondary effects of polio. This finding among cases classified as non-respiratory can be contrasted with our finding in the earlier study of respiratory patients in which 66 percent reported energy level changes, half of which were attributed to respiratory effects. The longitudinal data on respiratory support indicated that 65% of the initial group who were on respirators, today are independent of support. Although both reported data on respiratory status and limited data on changes indicated that 77% achieved and maintained their highest level of respiratory function within 5-6 years after the acute stage; seventeen percent reported a declining status within 1970-1980 period consistent with post-polio aging effects.

## Mobility

To measure mobility changes, both respiratory and non-respiratory people were asked to make a summary assessment of their mobility and of their performance of the activities of daily life. Using the same five item scale, people rated their mobility andADL, at one year after poli onset and at the time of the interview. Data on the level of mobility among both respiratory and non-respiratory polios show a marked shift from dependent to independent mobility when mobility at one year is compared with mobility today. Initial improvements in mobility reflect in muscular recovery the impact of rehabilitation and corrective surgery taking place in first years of recovery. Later improvements in mobility status reflect changes in equipment and environmental adaptations. Among the respiratory patient cohort, 12-14% of the respondents reported recent declines in mobility status during the 1970-1980 period. In the non-respiratory follow-up, we ended up with 530 respondents including 21% of patients with bulbo-spinal impacts, 13% with bulbar involvement, 42% with spinal involvement and 24% with no paralytic involvement in the immediate post acute stage. Fifty-six percent of the respondents reported significant paralysis in their lower limbs during the acute stage and early rehabilitation stage of their illness. In characterizing their current status, only about 37% of the total respondents indicated that they still had significant major paralysis in their lower limbs and 25% felt that the lower limb disability imposed limitations on mobility. Approximately 40% reported major upper body or limb paralysis during the acute phases of polio. Today, 20% reported continuing impairment of upper limbs, but 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 for mobility, only 32% of the non-respiratory sample rated themselves as having relative ease of independent mobility during the first year. This proportion rose to 48% during the immediate recovery period to 75% today. Thie proportion of respondents totally dependent upon a helper or unable to perform basic mobility functions themselves included 36% of respondents during the acute phases of polio and dropped to 14% following the initial rehabilitation phase and included only 4% today.

## IMPLICATIONS FOR HELPING SERVICES AND INFORMAL NETWORKS

The implications for these changes in mobility and ability to perform activities of daily living are clear in terms of both the provision of formal helping services and the availability of informal helpers. Twelve percent of the non-respiratory cases indicated that they required significant help with activities of daily living and mobility. In most cases, this help was not provided by statuatory services including personal care attendants, home nursing services or attendants paid by the individuals themselves, but was provided by members of the family grouping. Spouses (11% dependence) and children (12% dependence) were the most significant helpers. Spouses were more likely to be designated as "crucial helpers" without whose assistance independent functioning would be impossible. Nonkinship, unpaid helpers formed the primary support for only 5%. Although home care--which will be discussed by Theresa Ducharme on Sunday, provided some services to 56 or nearly one-third of the respiratory patients, only about 5% of the non-respirators received home care services.

## A FINAL NOTE ON FAMILY IMPACTS

### Preliminary analysis fo the data for non-respiratory polios

Among the respiratory group, a third of the marriages which existed before polio onset ended in divorce; 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% did in fact become married. The people in the young adult group are less likely to be dependent on relatives as helpers than are the middle and older adult groups.

# APPENDIX C

The University of Manitoba
Faculty of Medicine

CONFIDENTIAL

# Polio Survivors and Their Health
# Mail Follow-up Questionnaire

Your health and life experience following polio are very personal matters. If you agree to complete and return this questionnaire, all your answers will be treated with the strictest confidence.

If you have any problems or queries about the study or you require a translation of this questionnaire, please telephone 786-3798 or 786-3677.

**Return this questionnaire to:**
**Dr. Joseph Kaufert**
**or**
**Katherine Wong**
**Research Coordinator**
**Department of Social**
**and Preventive Medicine**
**University of Manitoba**
**750 Bannatyne Avenue**
**Winnipeg, Manitoba**
**Canada, R3E 0W3**

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1☐☐☐☐

5☐☐☐

## POLIO SURVIVORS AND THEIR HEALTH

### INSTRUCTIONS

Most questions can be answered by placing a check in the appropriate [✓] or by entering a number on the lines provided. A few questions require that you write in your answer. Some questions have more than one part; please follow the arrows provided to see which part you should answer. If you wish to comment on any questions or to qualify your answer, please feel free to use the margins or to write on a separate sheet.

1. In what year did you develop polio paralysis and/or symptoms of polio? 8☐☐

19 ________

2. What was your age at the onset of polio paralysis and/or its symptoms? 10☐☐

__________ YEARS OLD

3. How much do you remember about the time when you developed polio? 12☐
Do you remember...

[ ] ALMOST EVERYTHING
[ ] SOME THINGS BUT NOT EVERYTHING
[ ] VERY LITTLE
[ ] NOTHING

4. Has anyone told you since what happened when you developed polio? 13☐

[ ] NO
[ ] YES

Who told you most about this time in your life? 14☐

______________________________________________

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7. During the acute phase in your illness with polio, did you have any respiratory paralysis?

25 ☐

[ ] NO ----> GO TO QUESTION 8
[ ] YES

Did you require any form of respiratory support (i.e. an iron lung, a rocking bed)?

26 ☐

[ ] NO
[ ] YES

8. After the acute phase of your illness was over did you have any respiratory support (i.e. an iron lung, a rocking bed)?

27 ☐

[ ] NO
[ ] YES

We would like to know about your present state of health.

9. How would you describe your present state of health? Is it...

28 ☐

[ ] EXCELLENT
[ ] GOOD
[ ] FAIR
[ ] POOR

10. If you compared your health with the health of other people of your age, would you say your health is...(Check one only)

29 ☐

[ ] BETTER THAN AVERAGE
[ ] AVERAGE
[ ] WORSE THAN AVERAGE

11. Do you have any disability in your right upper limb (i.e. in your arm, your hand or your shoulder)?

30 ☐

[ ] NO ----> GO TO QUESTION 12
[ ] YES

Does this disability affect your day to day activities?

31 ☐

[ ] NO
[ ] YES

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16. Do you have any urinary problems? 40 ☐

[ ] NO
[ ] YES

17. Do you require respiratory support (i.e. iron lung, rocking bed, IPPE, mini-lung) 41 ☐

[ ] NEVER NEED RESPIRATORY SUPPORT
[ ] ONLY WHEN TIRED OR ILL i.e. WHEN YOU HAVE FLU OR PNEUMONIA
[ ] NEED RESPIRATORY SUPPORT ON A DAILY BASIS

What type of respiratory equipment do you need? 42 ☐

______________________________________________

How many hours a day do you use it? 43 ☐☐

__________________________

18. Do you have problems with your breathing (i.e. asthma, chronic bronchitis, shortness of breath, emphysema)? 45 ☐

[ ] NO
[ ] YES

19. Do you often feel tired or lacking in energy? 46 ☐

[ ] NO
[ ] YES

20. Do you think this tiredness is related to any problems with your breathing? 47 ☐

[ ] NO
[ ] YES

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column

24. Some people who had polio have difficulty getting around. Listed below are levels of performance to be used for the following <u>six</u> questions (24a to 24f). PLEASE READ CAREFULLY.

EASILY = Consistently free from pain
Activities done freely, naturally and spontaneously
Not hurried, anxious, or strenuous

WITH DIFFICULTY BUT WITHOUT HELP = Activities done independently but in varying degrees. There are some definite problems with consistency of performance.

WITH SPECIAL EQUIPMENT, BUT NO HELP = No requirement of personal assistance but there is a dependence upon wheelchairs, crutches, calipers, splints, orthopaedic support, etc., and other manipulations of environmental structures and supports.

WITH HELP FROM SOMEONE = Able to accomplish task only with some personal assistance.

COMPLETELY UNABLE TO DO THIS = Personal assistance is required with the assistance assuming the accomplishment of the task. One is unable to accomplish tasks independently.

24 a) How would you have described your general over-all ability to get around just after the period in which you developed symptoms of polio? (General ability to get around includes such items as getting in and out of bed, sitting in a chair, managing a flight of stairs, etc.) 67 ☐

Easily ☐
With difficulty but without help ☐
With special equipment, but no help ☐
With help from someone ☐
Completely unable to do this ☐
Other (explain) ____________________ ☐

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column

25. Are you presently experiencing any recent changes in your health that you believe could be related to having had polio? 71 ☐

[ ] NO ----- GO TO QUESTION 26
---[ ] YES
↓
What are these changes? ______________________________

______________________________

26. In carrying out your daily activities, do you need help? 72 ☐

[ ] NO
---[ ] YES
↓
Do you receive any help from your husband/wife? 73 ☐

[ ] NO
---[ ] YES
↓ [ ] NOT MARRIED

How important is their help to your daily activities? 74 ☐

[ ] VERY IMPORTANT
[ ] SOMEWHAT IMPORTANT
[ ] OF NO IMPORTANCE

27. Do you receive any help from any of your children? 75 ☐

[ ] NO
---[ ] YES
[ ] NO CHILDREN
↓
How important is their help to your activities of daily living? 76 ☐

[ ] VERY IMPORTANT
[ ] SOMEWHAT IMPORTANT
[ ] OF NO IMPORTANCE

80 1

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31. Are you a member of any organizations or associations that are related to your disability? (i.e., Manitoba League of the Physically Handicapped, Canadian Paraplegic Association, Manitoba Society for Crippled Children and Adults, etc.)

13 ☐

☐ NO
☐ YES

Please specify the association( s).

14 ☐☐

______________________________________________

______________________________________________

32. Do you receive any magazines or newsletters by or about disabled people?

16 ☐

☐ NO
☐ YES

Please specify.

______________________________________________

33. Do you have contact with people who had polio?

17 ☐

☐ NO
☐ YES

34. Are these contacts maintained by your involvement with polio or disability-related organizations or associations?

18 ☐

☐ NO
☐ YES

If no, please explain other contacts.

______________________________________________

______________________________________________

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38 c) If separated/divorced/widowed, for how long? ______________ YEARS 29 ☐☐

39 a) How many children do you have? ____________________________ 31 ☐☐

39 b) For each of the following, please give the number who live with you.

______ NUMBER OF DAUGHTERS 33 ☐☐
______ NUMBER OF SONS 35 ☐☐
______ NUMBER OF OTHER FEMALE RELATIVES 37 ☐☐
______ NUMBER OF OTHER MALE RELATIVES 39 ☐☐
______ NUMBER OF NON-RELATED FEMALES 41 ☐☐
______ NUMBER OF NON-RELATED MALES 43 ☐☐

40. What is your present level of education? 45 ☐☐

ELEMENTARY SCHOOL (GR. 1-6) ☐
JUNIOR HIGH SCHOOL (GR. 7-9) ☐
SENIOR HIGH SCHOOL (GR. 10-12) ☐
TECHNICAL/VOCATIONAL ☐
COMMUNITY COLLEGE ☐
UNIVERSITY ______ YEARS
  BACHELORS ☐
  MASTERS ☐
  PH. D. ☐
OTHER (Explain) ☐
______________________________
NEVER WENT TO SCHOOL ☐

41. Are you currently employed? 47 ☐

☐ NO
☐ YES
  ☐ FULL TIME 48 ☐
  ☐ PART TIME

How long have you been employed at this job? ____________________ 49 ☐☐

______________________________________________________________