Silenced voices: narratives of polio and postpolio syndrome

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DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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Abstract

The polio epidemics of the 1940s and 1950s are largely forgotten now, but thousands of people in the UK and millions worldwide who had polio are now reporting new deterioration. This is referred to as postpolio syndrome (PPS), about which the medical profession is often sceptical or ignorant. The thesis explores the experiences of long-term disability after childhood illness and recent contested symptoms in people who had polio as children or young adults. The study consisted of an initial survey of 170 people who had polio, concerning their polio history and recent PPS symptoms, followed by in-depth biographical interviews of 31 people who had varied severity of polio at different ages. Most of the people interviewed had recovered well after a lengthy rehabilitation and sometimes later surgery.

The principal themes of the narratives encompass independence, forgetting polio, working hard, resisting discrimination, and achieving as much or more than other people. Within this dominant narrative are smaller stories of vulnerability and not being listened to as children; a key theme being the general lack of understanding, and especially the lack of acknowledgement by the medical profession in relation to subjective symptoms such as fatigue and pain. Using analytical frameworks from medical sociology, medical anthropology, and disability studies, the thesis demonstrates the complex and paradoxical nature of narratives about long-term disability. These are narratives in which people live in a liminal world, both physically and socially, and attempt to find a balance between normality and difference.
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1. Introduction

To restore the human subject at the centre -- the suffering, afflicted, fighting, human subject -- we must deepen a case history to a narrative or tale; only then do we have a 'who' as well as a 'what', a real person, a patient, in relation to disease -- in relation to the physical. (Sacks 1987: viii)

The history of polio is the history of forgetting polio. (Shell 2005: 23)

1.1 Background

In 1843, the name 'morning paralysis' was given to an illness in which children who went to bed healthy, woke in the morning with a weak or paralysed leg (Paul 1971). This mysterious sudden paralysis, later called Heine-Medin disease, infantile paralysis and then poliomyelitis, or polio, was an endemic illness which became epidemic in the late 19th century as sanitation improved and natural immunity in infancy became less common (Silver 2001). Paul, who established the Yale Poliomyelitis Study Unit in 1931, wrote A history of poliomyelitis (1971), which covers three different approaches to polio research over the past 200 years: the early, mainly 19th century, descriptions of childhood paralysis, the turn-of-the-century Swedish painstaking, door-to-door epidemiological studies, and, after the discovery that polio was a viral illness in 1908, the more experimental US research which was eventually geared solely to a vaccine. A virulent epidemic in New York in 1916 with 8991 cases, a quarter of which were fatal (Sherman 1944), prompted new research and set the scene for polio to be seen as a terrifying 'Crippler' (Gould 1995). The history of polio research, which began as closely observed childhood symptoms, ended by mostly ignoring those who had polio, their symptoms, their long-term prospects, and how the virus affected the nervous system, in order to concentrate on the vaccine, which was introduced in the US in 1955.

A disease that had been causing dread and panic each summer was quickly forgotten in western countries after the vaccine (Halstead 1998b, Silver 2001, Wilson 2005). In 1952 there were almost 60,000 cases in the US, with paralysis in one third, and in the UK, the largest epidemic was in 1950 with 7760 cases (Halstead 1998b, Health Protection Agency online). After 1965, there were never more than 20 cases/year in the UK. Polio treatment
commenced with several weeks of isolation and complete bed rest (with ventilatory assistance if necessary), and, from around 1940, this was followed by the Sister Kenny method of hot packs (steaming wet blankets on muscles), stretching and passive exercise. Previously, immobilisation with casts and splints was common, although earlier theories, including suggestions by Heine in the 1800s, favoured baths and exercise (Gould 1995). Controversies about the benefit or harm of exercise after polio, and the ability to gain or lose strength, have been ongoing (Bennett and Knowlton 1958, Halstead et al. 1995, Agre 1995, Silver 2001). During the often long rehabilitation period comprising physiotherapy, exercise and sometimes surgery, doctors stressed independence and achievement, minimising polio after-effects, and encouraging those who had polio and their families to do the same (Mulder 1995, Kaufert and Locker 1990). Independence is also a deeply ingrained value in society, so "polio survivors also faced tremendous pressure from their families and society to integrate themselves into the mainstream", which involved ignoring and forgetting the weakness and other symptoms (Wilson 2005: 200). Halstead (1998b:xi), a rehabilitation specialist who had polio, wrote:

Beginning with our first encounter with this summer plague, many polio survivors tell a story of struggle and triumph... which led us to believe we had put polio behind us. This story, for most, was made possible by denying our disability and the reality of what was lost and the life that might have been. While this kind of denial is not unique to polio, its unyielding persistence is unusual. Virtually every polio survivor I have met has displayed an element of this self-deception.

1.2 Forgotten stories and disrupted lives

This study of polio narratives focuses on the interactions between the cultural and medical forgetting of polio, and the experiences of the individual. Before the vaccine made polio rare in western countries, polio patients wrote autobiographies of their recovery and 'triumph over adversity', but often not of their later lives, as polio was seen as conquered and past (Wilson 1994). Wilson (1994) studied 50 accounts of polio patients, either autobiographies or shorter pieces, written from 1947-1991, and suggests the themes of work and redemption as important to all the stories. The Protestant work ethic and the rehabilitation ideology of hard work and acceptance were strong forces in
published autobiographies, which may have been the stories people wanted to tell or felt they had to tell (Westbrook 1996). Only one account mentioned by Wilson (LeComte 1958: 96) was sceptical of the rehabilitation belief that "whether you ever walk again is up to you!"

A new generation of autobiographies began to surface in the 1990s, mainly in the US, following new interest in polio and postpolio syndrome (PPS). In the 1980s, those who had polio began to come forward with symptoms such as new weakness, fatigue, muscle fatigability, pain and breathing and swallowing problems. Although further deterioration years after polio had been recognised by Charcot in 1875, it was not until the large population from the 1940s and 1950s epidemics began to have symptoms in the 1980s that research was initiated and the cluster of symptoms became known as postpolio syndrome (Dalakas 1995a). There was considerable scepticism about PPS, especially the widespread nature of the symptoms, as polio research and the few earlier studies into late polio deterioration had been forgotten. Two of these later autobiographies delved deeply into the difficulties and emotional experiences of living with polio, from the point of view of men who could clearly remember having severe polio, being 20 and 14 at the time (Gallagher 1998, Mee 1999). However, these narratives still include a fragmentary element -- Mee only describes his life between the ages 14-18 and recently, while Gallagher compiled a disparate group of essays, diaries and autobiography. Mee (1999: 40) writes:

Intact people should write intact books with sound narratives built of sound paragraphs that unfold with a sense of dependable cause and effect, solid structures you can rely on. That is not my experience of the world.

During the epidemics, autobiographies were written mainly by those who were adults when they had polio, but even by the 1990s, there were no autobiographies written by those who had been young children. Black (1996), an exception of a kind, was very young (four years old) when her mother became completely paralysed by polio, and six when her mother died. She has written a sensitive biography of her mother, interspersed with a polio social history, in search of the story her family had erased to diminish their painful memories.
When I set out to discover what I could about the disease that took her, I knew little about the woman who was my mother — very little, even, of the most basic facts about my family background. And I had gone 37 years into my life without realising how odd the gaps in my knowledge were. (Black 1996: 49)

A new wave of polio histories and autobiographies has been published for the 50th anniversary of the Salk vaccine in 2005. Two books have been written by men who were six when they had polio, one autobiography (Cockburn 2005), and one cultural history interspersed with autobiography (Shell 2005). A study of autobiographical writing of polio experiences in the US has been produced by Wilson (2005), a historian who had polio. Cockburn, a war correspondent, became interested in his ignorance about the epidemic he was part of in Cork in 1956, after seeing a ward of injured children in Iraq in 1998. He describes his own experience in hospital, the history of the hysteria surrounding this last Irish epidemic before the vaccine, and the subsequent historical silence about it. Cockburn (2005: 286) does not discuss polio's effects on his later life, although he ends his book saying:

Very occasionally well-meaning people suggested to me as a child that sufferings build character and endurance. Even at the age of seven or eight I suspected I had acquired these supposed benefits at an excessive price.

Wilson barely mentions his own story but writes about the deep emotional effects that polio, polio treatment and PPS had for many people. Shell, like Cockburn, mainly writes about his early experience, in his case of having relatively mild polio in Quebec, but asks why people did not talk about polio, why polio was forgotten, why those who were young did not write their experiences and how this silence and forgetting had affected him. He asks several questions that underline this study about forgetting, silence and the medical controversies about PPS, and discusses links between the polio epidemics and the Holocaust, similarities of historical time and what he calls the "silent treatment and tough love" accorded to both (Shell 2005: 59). Sontag (1991: 3) has united illness and emigration in her metaphor about dual citizenship, suggesting the problematic quality of having to leave one life for another.
1. Introduction

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick.

In sociological studies of trauma and suffering (Wilkinson 2005, Frank 1997a, Kleinman et al 1997, Becker et al 2000, Skultans 2004), experiences of chronic illness, the Holocaust, emigration and humanitarian disasters are brought together to inform theory, as they share aspects of loss and marginalisation, and similar reactions are found in multiple life disruptions (Becker 1997). The silence about polio developed from a specific period of epidemics, which had a certain resonance in the stoical, but also changing, attitudes of the postwar 1940s and 1950s. Lying behind the historical individuality of the polio experience is a general discomfort and silence about traumatic experiences, particularly chronic illness and disability, in society and the medical profession.

In the past 20 years, polio has re-emerged because of the number of PPS cases arising from the 1940s and 1950s epidemics, including those who had mild or unknown cases of polio (Halstead 1998b, 2000). A recent estimate of the prevalence of PPS in Europe is 250,000 and 20 million worldwide (Bosch 2004). However, there has been continuous scepticism about PPS due to the subjective symptoms, lack of test, and ongoing controversies in the research. As there had been no follow-up studies of patients after the vaccine, information and understanding were lacking (Halstead 1995). This situates the current study among other contested illnesses and is relevant for understanding some of the conflicts between doctors' and patients' beliefs about symptoms and disease (Kroll-Smith 1997, Malterud 2000, Malterud 2001).

1.3 Research aims

Problems relating historically to polio and PPS, such as the silence and the medical controversies, are examples of more common and widespread dilemmas for chronic illnesses and disabilities. The major aim of this study is to examine the perceptions of the effects of polio and PPS, particularly exploring the cultural narrative of silence and normalisation that has been found to be deeply embedded in many polio stories, and
which is mirrored in medical attitudes about polio and other disabling illnesses. As a result of the historical amnesia and lack of clear new pathology, doctors are sceptical of these new symptoms and interpret them as ageing or stress (Halstead 1995). Narratives of polio and PPS will be used to examine several tensions for disabled and chronically ill people concerning being different but living in the normal world, and the artificial divisions between medical disease and patient illness. The theoretical framework for this study derives from several strands of research relating medicine and the social sciences: the sociology of chronic illness and disability, medical anthropology, disability studies and qualitative studies in rehabilitation medicine. Two further important sources are autobiographies (and autoethnographies) by people with chronic illnesses and disabilities, especially social scientists, and the polio and PPS scientific research.

1.4 Research questions

What perceptions do people have of the effects of polio and PPS?
How do polio and PPS narratives relate to the wider culture and history of polio and disability in general?
Does age at onset affect the kinds of stories people tell?
What is the medical polio and postpolio paradigm and how does this relate to patients’ perceptions and understanding of PPS?

In order to answer these questions, two approaches to polio and PPS have been taken. Through a preliminary survey of 170 people who had polio, and in-depth interviews with 31 people, the experience of having polio and PPS was explored. Most of the people in this study had recovered relatively well from polio and had led ordinary lives. New weakness, muscle fatigue and pain in their 40s and 50s, which, at first, they rarely connected with polio, eventually forced them to think again about their childhood.

A narrative method was used as a means to connect the personal, physical (embodied), social and historical, as the study revolved around the biographies of people caught up in a specific series of epidemics, which may also elucidate other examples of childhood
illness and long-term effects. Whole biographies are often important in understanding chronic illness (Lawton 2003), and using narrative it is possible to keep the integrity and also the fragmented, confused and emotional nature of the biographical story. Good (1994: 157) describes illness as "grounded in human historicity, in the temporality of individuals and families and communities. It is present as potent memories and desire. It embodies contradictions and multiplicity." Illness is also present as symptoms, discomfort and physical limitations.

The next two sections will provide background information on some of the complexities and controversies about polio and PPS. This will be followed by a section on the genesis of this study, which is partly autoethnographical, as I also have PPS. A section of autobiography/ethnography will follow in each chapter (formatted as a quotation), situating myself within the research. The chapter ends with a preview of the thesis chapters.

1.5 Defining polio

The polio virus may cause two forms of illness: 95% of cases consist of minor symptoms such as nausea, vomiting, fever, sore throat and headache, but in 5% the virus enters the nervous system. Most of these cases involve a meningitis, encephalitis, or nonparalytic polio, with stiff neck, back and muscle pain, and headache. In only 1% will the virus invade the motor neurons, causing weakness, paralysis, muscle cramps, muscle pain and sometimes bulbar or brain stem symptoms such as respiratory problems, swallowing problems, cardiovascular dysfunction, lethargy and facial weakness (Jubelt and Drucker 1999). These are the paralytic cases, and about 50% recovered completely, or appeared to (Paul 1971). The death rate was 7-8%, mainly in bulbar cases with respiratory or cardiovascular problems (Jubelt and Drucker 1999). According to Bodian (1949, 1985), who conducted autopsies on primates and fatal human cases, early in the disease 95% of neurons appeared damaged, even in mild cases. The average proportion of destroyed neurons was almost 50%, scattered unevenly so that one muscle might be paralysed and another of normal strength. Sharrard (1955) demonstrated that a muscle could retain
clinically normal strength when 50% of the motor neurons to that muscle were lost. However, the definition of paralytic polio specified 'demonstrable' muscle weakness.

Diagnostic criteria set out in 1948 for paralytic poliomyelitis were:

1. history compatible with poliomyelitis
2. fever; stiff neck and/or stiff back
3. 10-500 cells/ml of spinal fluid from acute or early convalescent period
4. elevated spinal fluid protein
5. demonstrable muscle weakness or paralysis (detected during at least two examinations at an interval of at least several hours) (Windebank 1995: 71).

As the definition of paralytic polio included demonstrable muscle weakness, many patients who appeared to have normal strength but had significant motor neuron loss would have been diagnosed as nonparalytic polio. Two studies of careful muscle testing in supposedly nonparalytic cases suggested that very few cases had no muscle weakness (Moskowitz and Kaplan 1953, Shaw and Levin 1954). The question of how to assess which patients had motor neuron loss was never resolved. Although the polio virus is often described as destroying motor neurons, another unresolved question is how many neurons were left damaged and what effects these may have had. Electromyogram (EMG) tests document enlarged motor units (nerve cell plus nerve fibres), which indicate the death of motor units causing overgrowth of nearby units, but not damaged motor neurons. Dalakas (1995c) hypothesised from muscle biopsy studies that there could be five types of remaining motor neurons in the paralytic polio patient:

1. Normal unaffected neurons
2. Normal neurons near destroyed neurons, which sprout more fibres to increase strength
3. Affected neurons, seemingly fully recovered
4. Affected neurons, normal in appearance but smaller in size
5. Damaged, incompletely recovered neurons, abnormal shape and function
No research has examined what effects different types of neuron damage could have. When doctors began to conceptualise the cause of the new postpolio symptoms, these dilemmas remained unresolved.

1.6 Defining postpolio syndrome

New muscle weakness, atrophy and fatigability (also described as muscle fatigue or an endurance or stamina problem) occurring some years after an initial polio illness was first described by Raymond and Charcot in 1875. In the next hundred years, about 20 studies were conducted on new postpolio weakness, and various theories were suggested relating to the previous polio damage, the overuse of remaining neurons, a genetic predisposition in the nervous system or a latent viral infection (Kayser-Gatchalian 1973). In the late 1970s, the people who had had polio in the 1940s and 1950s epidemics began to approach doctors about new weakness, and also stamina problems and muscle pain. Doctors, who may have accepted a rare case of new progressive weakness in someone who had had polio, were sceptical about many people having new weakness, fatigue and pain (Dalakas 1995a). There are no tests for PPS as damage in those who had polio (with PPS or not) is similar (Cashman et al 1987). Dalakas (1986), a neurologist at the National Institutes of Health (NIH), Washington DC, began research in the mid-1980s with a retrospective study. He subsequently convinced himself of the progressive nature of the weakness after conducting a study of swallowing muscles, as the tests are especially sensitive and the muscles are not exercised outside ordinary use (Sonies and Dalakas 1995). The scepticism about muscle fatigue remains. Researchers invariably refer to the first 1875 postpolio case study as describing "new weakness and atrophy" (Dalakas 1995a, Halstead 1998b) but Nollet and de Visser (2004: 1142) describe the symptom as muscle fatigue, translating that the patient, a 19-year-old tanner, "complained that his right arm increasingly felt heavier and more rapidly fatigued during the past 2 years", which then led to weakening and wasting. Cashman (1997: 7) has described PPS weakness as "an endurance problem in most patients".
The generally accepted theory explaining PPS involves the enlarged, overworked neurons that have sprouted more fibres to compensate for destroyed neurons. It is hypothesised that these enlarged neurons begin to lose fibres and can no longer grow new ones (Dalakas 1986). A few researchers have developed a more complex theory suggesting that these overworked neurons die and that smaller, possibly damaged neurons remain (Grimby et al 1998). Grimby et al (1998) have found evidence, through a long-term study using muscle biopsies and electrophysiological tests, that while muscle strength decreased, motor unit size was increasing in attempts to compensate for the weakness, and then reached a breaking point and began decreasing. Fibre loss was, therefore, a result not cause of weakness. Cashman and Trojan (1995) have also not found a decrease in motor unit size, which would be necessary to prove the fibre loss theory, but the theory remains. In order to be as objective as possible, Dalakas (1986) used strict criteria in his PPS definition, including muscle atrophy, weakness and areflexia (absent reflex) in at least one limb since the original polio. Muscle weakness was a necessary new symptom.

A more recent, wider definition includes:

1. A prior episode of paralytic poliomyelitis with residual motor neuron loss (confirmed through a typical patient history, a neurologic examination, and, if needed, an electrodiagnostic exam)
2. A period of neurologic recovery followed by an interval (usually 15 years or more) of neurologic and functional stability
3. A gradual or abrupt onset of new weakness or abnormal muscle fatigue (decreased endurance), muscle atrophy, or generalised fatigue
4. Exclusion of medical, orthopaedic, and neurologic conditions that may be causing the symptoms (Jubelt and Drucker 1999)

New neuromuscular symptoms occur in up to 78% of people who had polio and the frequency of new weakness ranges from 20-60%. The average interval from polio to PPS onset is 36 years (Trojan and Cashman 2005). Treatment for PPS consists of medication, mainly for pain, pacing (alternating activity and rest), exercise, and the use of braces and mobility aids. The muscle fatigue, general fatigue and pain common in PPS patients are still not well understood, partly because polio was never well understood and existing knowledge was forgotten. Lack of consistency in the terminology used for fatigue has increased the confusion and made it difficult to compare studies. Some of the
ambiguities in this research will be discussed in Chapter 3. Douglas (1987: 77) suggests that the pattern of forgotten scientific discoveries "is not random", and that scientists "are baffled to meet discordant facts that do not fit their categories; the profession loses from practices of secrecy, which contradict intellectual openness" (Douglas 1987:75). Oliver Sacks (1997: 153) has written about how theories and beliefs may hinder understanding in science and medicine, so that research is forgotten for years:

The first difficulty, the first barrier, lies in one's own mind, in allowing oneself to encounter new ideas and then to bring them into full and stable consciousness, and to give them conceptual form, holding them in mind even if they do not fit, or contradict, one's existing concepts, beliefs, or categories.

1.7 Autoethnography: the genesis of this project

My interest in research on the experience of having polio and postpolio syndrome began with my own experience of not being able to get a diagnosis for increasing weakness and muscle fatigability. After several years of inconclusive tests following a diagnosis of myasthenia gravis in the late 1980s, I found a study of postpolio syndrome in cases of previously severe polio, which matched my symptoms since early childhood, and began searching for information on mild polio and possible after-effects. I became intrigued by an article mentioning coxsackieviruses and mild polio in the same area of the US where I was born in 1948 (Melnick et al 1950). From the article, I found that blood samples were being used from a study of mild polio by Sabin and Steigman (1949), who were working in the city where I lived as a child. Sabin had been concerned by epidemics of what was called summer grippe, thinking that this might have been the mode of polio transmission and also that nonparalytic polio cases were going undetected. He brought 10 children with mild fever into hospital to be observed and tested. Of the 10 children, two had nonparalytic polio, three had abnormal spinal fluid, and another 2 had polio virus in throat swabs. All of these children would have gone undiagnosed. This piece of research by Sabin and Steigman had been lost and I felt there was a forgotten story hidden away somewhere, which needed finding, a story about both a disease and the children who had it. My own story, which was more clear-cut than the 'summer grippe', included one leg temporarily not growing, spinal curvature and many visits to the doctor in 1950 when I was two. Probably a diagnosis was made, as Sabin's study had just been published, but I was never told. Like Shell (2005) I came from a Jewish immigrant family that had experienced discrimination and did not speak about their pasts, and I was propelled to understand this silence and discover a story through other stories.
1. Introduction

The original impetus for this study was that I perceived a lack of fit in the medical research between the patients' description of PPS symptoms and the medical terminology in the research. From an MSc (Science) survey on postpolio symptoms, I found that most people experienced a muscle fatigueality not mentioned in the epidemiological studies and that those who had polio as younger children had more widespread PPS symptoms than expected from the research and their milder original disease. Here were two anomalies. For some reason patients had a symptom that doctors avoided in their studies, and the expected linear relationship of more severe PPS with more severe polio in older patients did not seem to be holding up. Also in the survey, people wrote stories about how difficult it was now to be disabled as they had never felt disabled previously. Their families had never spoken about polio and had considered them the same as everyone else.

As part of this research into the often untold narratives of polio and postpolio syndrome, I knew that I would need to place myself in the research, having had polio myself, although my case had been mild, before my memory, and had never been spoken about. How to put into words these shadowy, complex stories without falling into the stereotypes of hero or victim, stoicism or suffering, was deeply problematical, mirroring the paradoxes of disability itself. How do people who are different live in a normal world? How can they talk about their ordinariness without words for being both healthy and ill, strong and weak, happy and sad?

1.8 Thesis plan

In this section, the plan of the thesis and purpose of each chapter will be outlined. The Introduction has briefly described the historical background of polio, some of the problems inherent in defining and understanding polio and PPS, the changing tone of polio autobiographies over the past half-century, the research questions, and some of the ideas behind the development of this project.

The next two chapters comprise the literature review, which is divided into a review of work exploring the experience of chronic illness and disability, and a second chapter on doctors, patients, contested illnesses and PPS research. Chapter 2 Literature: the experience of chronic illness and disability, begins with a brief historical survey of chronic illness research in medical sociology followed by a more in-depth examination of a selection of narrative studies. This is followed by a review of some of the controversies between the sociology of disability and disability studies, including autoethnographical
work. Both sections include studies that involve children or look back to childhood. The chapter ends with a section on different approaches in the social sciences to studies of contested illnesses. Chapter 3 Literature: the medical profession, contested illnesses and PPS research describes recent research on doctor-patient interactions, particularly in relation to contested illnesses and unexplained symptoms. This is followed by an analysis of the recent work of three PPS research teams and the evolution of their understanding of subjective PPS symptoms.

Chapter 4 Research design describes the methods chosen for the study and how the study was carried out. A survey was conducted in order to recruit a wide selection of people who had had polio, and to obtain an overview of PPS symptoms in different age and gender groups. The results of the survey are in Appendices 4 and 5. Following the survey, 31 in-depth biographical interviews were conducted and analysed principally using narrative theories. The chapter describes how the interviews were carried out, my position as interviewer, the ambivalence sometimes found towards telling these often previously untold stories, and the approach to analysis.

The next six chapters comprise the analysis of the interviews and are divided chronologically into three sections, childhood, middle years, and postpolio syndrome, with two chapters in each section, in order to be able to link perceptions of attitudes in childhood to later life, and because different themes related to either childhood, adulthood, or recent years with PPS. Chapter 5 Childhood: polio stories, memories and silence explores people's memories of the initial polio. The first section uses several striking stories within the main narrative to elucidate how important themes could be slipped into very brief stories. The rest of the chapter examines how respondents often told stories of not talking about polio, and the different ways that stories, and particularly feelings, were silenced. Chapter 6 Childhood: recovery, ambivalence and being normal focuses on the long recovery period. Particularly because children were growing and changing, coupled with the silence about the initial polio, there was often ambivalence and confusion about any remaining disability and what constituted 'normal'. There was also resistance to the negative attitudes of other people and this had repercussions
throughout their lives and is echoed in later chapters. The chapter ends by returning to hospital experiences, as many of those who were children had multiple surgeries, sometimes with extended stays in hospital.

In Chapter 7 Middle years: work, independence and interdependence, I explore an important theme in most of the narratives, work, which signified independence. Often linked to the idea of independence was the importance of interdependence, such as helping others or working successfully with others. It was also important to many people that they feel natural in their work, and able to forget having had polio. Chapter 8 Middle years: identity and relationships centres around relationships with family and friends. Again, having a family was a measure of independence, but also involved interdependence. This chapter continues to explore the ambivalent ideas people had about self and disability.

The first chapter about postpolio syndrome, Chapter 9 Postpolio syndrome: connecting polio and new symptoms describes PPS symptoms and how people who had spent years ignoring polio eventually came to link new weakness, fatigue and pain with having had polio. The chapter ends with an exploration of the difficult dilemma people found themselves in of having to tell friends and colleagues, who did not know they had had polio, about PPS, and possibly ask for help, something they had avoided all their lives. Chapter 10 Postpolio syndrome: doctors, symptoms and looking back returns to the subject of the medical profession's scepticism about PPS and the problems people had returning to doctors after many years. The chapter ends with a section on the complex feelings people had about having to readmit polio into their lives and think about its long-term effects. The Conclusion and discussion bring together the main findings and themes of the study, consolidating these into overarching ideas about narrative, liminality and complexity.
2. Literature: the experience of chronic illness and disability

I was now the child of whom my parents' friends would say, 'Oh, I'm sorry, I'm so sorry' (Mee 1999: 65)

2.1 Introduction

This study confronts two tensions for ill or disabled people reflected in the sociology research on chronic illness. One is the paradox of being different but living in the normal world which often involves compromises in the areas of independence and interdependence, autonomy and community. The second concerns the artificial division between scientific and experiential thinking, which complicates and confuses the doctor-patient relationship, and medical and sociological understanding of disease and illness. The myriad definitions of the two words 'disease' and 'illness' suggest the futility of attempting any clear division. Both tensions are part of much larger themes, alienation and the Cartesian mind-body separation, but this study will focus on an example that polarises these issues in relation to illness and disability. The thesis will attempt to demonstrate through the use of polio and postpolio narratives that the separation of these two concepts, disease and illness, has led to misunderstandings in research, which also mirror society's attitudes to chronic illness and the problems of being different. Chronic diseases are multifaceted and embedded in everyday life, so there is no easy division between physical disease and the experience of illness. Illness narratives are both about symptoms affecting everyday life (illness experience) and symptoms in relation to the body (disease). In order to investigate these tensions, literature from the sociology of chronic illness and disability, medical anthropology, disability studies, qualitative studies in rehabilitation medicine and polio and PPS scientific research, has been employed. Another important source is autobiographies (and autoethnographies) by people with chronic illnesses and disabilities, especially social scientists.

The literature review will be divided into two chapters, the first focusing on the person's experience of chronic illness and disability, and the second on the doctor-patient relationship in contested illnesses, and controversies in PPS research. This chapter will commence with a historical survey of the problems studied in early medical sociology
research and the development of more narrative approaches to understanding how people live with illness and disability. The review will pay particular attention to studies of children and young people, in order to provide a context for the experiences of the respondents in this study. The next section will concentrate on studies about disability, and differences between the sociological view of disability and the social model of disability. Living with disability will be explored through several autobiographies, narratives studies and qualitative research on children and those who had polio. The final section will demonstrate some of the complexities in defining illness and disease, and examine the patient's experience of living with a contested illness, as it is in these controversial illnesses that the division between disease and illness can be seen as most problematical.

The review will develop chronologically toward recent narrative studies, as researchers are finding that it is through narrative that people attempt to make sense of disruptive and ambivalent situations, whether illness or other personal, social or political disruptions (Riessman 1993, Becker et al 2000, Garro and Mattingly 2000, Bruner 2002, Skultans 2004). Researchers are demonstrating that illness narratives and narratives of other disruptive experiences have similarities (Becker 1997) and that illness cannot be separated from the larger social and political picture (Skultans 1999, Williams G. 2004). Narratives are "a window upon society" (Williams G. 2004: 280), and open up the question of why people tell stories the way they do, and less often asked, what stories people do not tell. Because of their paradoxical nature, illness and disability stories are "difficult to tell as well as to hear" (Zola 1981: 356). The difficulties involved in talking about chronic illness and disability may result from there being both too much and too little meaning, so that "All users of wheelchairs know that when they are in public places, they are commonly noticed by everyone and acknowledged by nobody." (Murphy et al 1988: 239)
2. Literature: the experience of chronic illness and disability

2.2 Sociology of chronic illness and disability

*Disability and ambivalence*

In the early 1960s, three influential books were written about disability: Beatrice Wright's (1960) *Physical disability -- a psychological approach*, Fred Davis' (1963) *Passage through crisis: polio victims and their families*, and Erving Goffman's (1963) *Stigma: notes on the management of spoiled identity*. Why disability and why the early 1960s? Gradually, from the early 20th century, the focus of medicine began shifting from acute infectious diseases to chronic illness, as mortality from these diseases fell due to better nutrition and living conditions (McKeown 1979). This change was accelerated by the development of penicillin during the war and antibiotics in the post-war 1950s. The lives of disabled people also became prolonged once infections could be cured (Gallagher 1998). Both Davis and Wright had a personal understanding of disability, having had polio, which had proliferated in the 1940s and 1950s, becoming a major cause of disability, particularly in children. Wright's study is a wide overview of living in society with disability, encompassing psychological research and personal autobiographies, which she uses to pinpoint the effects of social interaction and the paradox and ambivalence of the disabled person who wants to and is expected to act normally. In a sociological study of 14 families with a polio-disabled child who were interviewed and observed from the initial illness through the period of rehabilitation, Davis focused on the emphasis by parents of life continuing as normal though, in many ways, completely changed. Goffman chose the much wider subject of stigma but narrows the focus to casual interactions between stigmatised and non-stigmatised people, highlighting the significance of momentary everyday experiences to identity, leaving out what Nussbaum (1995: 5) emphasises as "the effect of circumstances on the emotions and the inner world". All three books describe the ambivalence, and resultant hiding or 'passing' surrounding being different in a normal world. The current study will examine the long term effects of paradox and ambivalence in men and women who became ill at different periods in childhood or young adulthood.
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**Medical sociology and chronic illness**

During the 1960s, medical sociology was concentrating on the patient in relation to medical care and the medical profession -- the sick role, illness behaviour, how people interpreted symptoms and decided to seek help, and the lay view of illness causation (Zola 1973, Fitzpatrick 1984, Conrad 1990). The important concerns were maximising the benefits of healthcare, improving doctor-patient relationships and compliance in treatment. How the patient experienced illness outside medical institutions was not part of the agenda until the focus turned from acute illness to the complexities of chronic illnesses and disability, which exist as part of life away from the medical gaze. Freidson (1970) incorporated the concept of illness over time (the illness career) into medical sociology thinking, but the concept remained abstract until Strauss and Glaser (1975) focused on the management of individual chronic diseases in people's everyday lives. They introduced the concept of an illness trajectory (living with an illness over time) and the way in which people normalise their lives.

Until the early 1980s, there was still an emphasis in medical sociology on the illness in relation to the medical profession and medical care. Freidson (1970) had made a clear demarcation between the physical disease state independent of human knowledge, and the social state of illness shaped by human knowledge, but in the 1980s, Bury (1986) critically argues that social constructionists, such as Armstrong (1984, 1987), often through the influence of Foucault, began to suggest that both medical knowledge and the objects of medical knowledge are inventions. Whether or not this relativism influenced the medical profession to become more stringent in defining diseases, the 1980s became a time of controversies over contested illnesses (Holmes et al 1988, Goldenberg 1988) and the doctor-patient relationship (Mishler 1984), as well as increasing interest in understanding the patient's experience of chronic illness (Anderson and Bury 1988). At the same time, the wave of 1970s feminism sparked narratives of women's experiences of child abuse and illness, leading to a new openness to the long-term effects of traumatic experiences among both the public and professionals (Davis 2002). For example,
2. Literature: the experience of chronic illness and disability

Holocaust and illness narratives, such as polio, began to become public in the late 1970s. Karpf (1996) dates international public debate of the Holocaust to the American television series *Holocaust* in 1978, and Gawne and Halstead (1997) describe the first public mention of new polio deterioration as an article in a 1979 newsletter from a polio respiratory centre, *Rehabilitation Gazette*. This was followed by a television programme and an international conference organised by patients in 1981.

In the 1980s, medical sociology began to seriously consider the patient's experience of illness as important in itself and for policy, investigated through in-depth interviews, often concentrating on narratives and the "social and emotional consequences" of chronic illness (Anderson and Bury 1988: 246). Lawton (2003) identified three particularly influential studies of this period, Bury (1982), Williams (1984) and Charmaz (1983). Bury (1982), in a study of recently diagnosed rheumatoid arthritis patients, highlighted the 'biographical disruption' or critical situation caused by illness and the attempt to normalise life afterwards. Bury argued that chronic illness could be seen, like war, as the kind of disruption which illuminates what is ordinarily implicit in social interactions. Later, he divided the meaning of illness into 'consequences', the practical aspects of everyday life with illness, and the 'significance', the cultural and symbolic connotations, which interact and cannot be separated (Bury 1991). Two important explanatory themes developed through the concept of 'biographical disruption' were uncertainty and dependency, which was feared because of the "strong cultural emphasis on achievement, action and success in contemporary society and the essentially ambiguous situation this creates for those 'failing' through illness or other misfortune" (Bury 1988: 90). Being dependent (Charmaz 1983), fearing dependence (Wiener 1975), and being seen as dependent (Zola 1993) are crucial to understanding the disruption of illness, but, in later studies using the concept of 'biographical disruption', the subtlety and complexity developed by Bury about why life is felt to be disrupted is sometimes lost in an overemphasis on aspects like identity (Asbring 2001) or metaphor (Becker 1997). Disease and illness might be brought closer together by moving forward with Bury's 'significance' and examining the physical or bodily significance of symptoms -- how
people think and learn about their symptoms in relation to their bodies, and how this is interwoven with emotional, social and political narratives.

Williams (1984) delved more deeply into the moral and political interpretations of the cause of illness in his study of rheumatoid arthritis, suggesting the term 'narrative reconstruction'. He concentrated on how people use narrative to "repair ruptures between body, self and world". Instead of seeing illness in terms of medical or lay conceptions, it is seen as a moral and biographical problem, which people attempt to solve. In studies using narrative and biography, a bridge is constructed between the everyday interaction and the patient's perception of self over time. Although Williams (1984: 175) does not explicitly discuss emotions or embodiment, by beginning "We are seated in the living-room of a modern, urban council house somewhere in north west England" and describing Bill as having "a strained voice" and "a look of exasperated incomprehension", he is using narrative in his writing to convey feelings and embodiment. Lawton (2003: 27) suggests that Williams' analysis pre-empts "Bury's (1991) call for sociological studies to examine the positive steps people take in response to chronic illness" by emphasising the imaginative attempts people make to restructure meaning in their lives.

Whereas Bury and Williams concentrated on processes that took place relatively early in a chronic illness, the disruption and reconstruction of meaning, Charmaz (1983) examined the long-term effects of illness and developed the theme of dependence and restricted activity in relation to loss of self. She suggests that chronic illness incorporates a morality of success and failure from the Protestant work ethic. As independence and hard work are valued identities in society, and "the self is fundamentally social in nature" the chronically ill must lose their sense of self through isolation and dependence (Charmaz 1983: 170). Nussbaum (2001: 372), a philosopher interested in the narrativity of emotion, has a wider view, reflecting Bury's "ambiguous situation", that "we do not want to say, either, that every deprivation of activity is a loss in goodness; for this would leave us too much, intolerably, open to loss. So we find an uneasy balance". Kelly and Field (1996: 248) argue for a more complex self, so that "Self and identity not only change in chronic illness but they also have an enduring quality." Charmaz's sample
2. Literature: the experience of chronic illness and disability

consisted of seriously ill people, so her theory of suffering and loss of self may not be applicable to many chronically ill people who are able to carry on with fairly ordinary lives, but she opened the discussion more explicitly to the emotions surrounding illness. Charmaz (1999: 364) feels that, although people resist describing themselves "in a way that might undermine (her) worth", their lives are permeated with suffering, which researchers also avoid. Charmaz (1999: 365) answers why people do not talk about suffering when she says that "suffering also slips into the background", and research is needed to clarify the meaning of this background suffering. Zola (1993: 170) argues that "no person with a disability is automatically 'suffering' or 'afflicted' except in specific situations".

Bury (1991) argues that sociology is moving on from an initial interest in problems, to one of seeing people as agents dealing with, living with, and finding meanings in situations, which may not even be defined as problems. The present study of polio will examine, retrospectively, these long-term experiences and how people become agents, letting certain aspects of their lives slip into the background. By investigating narratives, the shifting between normal and ill or disabled may become manifest through stories of everyday routines and encounters. The aim is not to envisage illness positively or negatively, to see people as suffering or not suffering, or as managing well or badly, but to see how people navigate the complexity of illness, in order to live 'worthy' (Charmaz 1999) or 'virtuous' (Williams G. 1993) lives. To be ill in our society is already to be considered less worthy (Kirmayer 1988, Conrad 1994, Rosenberg 1997, Galvin 2002), as are other marginalised groups, such as emigrants and those who are poor or elderly (Myerhoff 1979).

Narrative, emotion and chronic illness

While research on the practical management of chronic illness as rational decision-making and biographical work over time continued to develop (Locker 1981, Corbin and Strauss 1988, Kaufert and Locker 1990), more studies began to use narrative methods to investigate the moral and emotional experiences of chronic illness. Becker (1997: 14, 17)
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argues that "narrative is a conduit for emotion" and people use narrative in times of
disruption as "moral accounts of their lives." In this section, I will describe ways that
emotion has been characterised and used in medical sociology, especially in narrative
studies of chronic illness.

Becker (1997: 16) describes stories of disruptive experiences as "stories of difference"
which lead to uncomfortable social relations, emotional pain and a desire to restore
normalcy. She argues that life begins with a growing understanding of the body's orderly
functioning, and that any disruptive experience is embodied. The concept of emotion is
complex, from its biological substrate to its cultural refinement, but may be described on
one level as "an experience of involvement...That it matters, that a person cares about
something" (Barbalet 2002: 1). A story may give minimal information but, for the
listener, it may still carry meaning (Riessman 1993). Cole (2004: 38), a
neurophysiologist, wrote about a spinal cord injury narrative that "I listened to an almost
academic account of life with tetraplegia; once on the page, I saw the enduring rawness
of his feelings after nearly thirty years of spinal cord injury." How people feel about
stories will determine whether they are able to tell them or listen. Radley (1999)
describes how the opposing emotions of fear and compassion surrounding illness are
often eliminated in communication, and possibly experience, because they acknowledge
the failure of the ill person, and cause ambivalence and discomfort, the discomfort of
confronting an anomaly (Douglas 2002).

Hochschild (1979: 558), who describes the way people experience and manage their
emotions as 'emotion work', "conscious, deliberate efforts to suppress or evoke feeling"
suggests a way that people might deal with the discomfort and 'stickiness' (Davis 1964)
of this ambivalent situation. 'Emotion work' is placed between Freud's theory of
unconscious drives and Goffman's interactional theory where "actors actively manage
outer impressions, but they do not actively manage inner feelings" (Hochschild 1979:
557). Werner and Malterud (2003) argue that Goffman (1990b) concentrated on
embarrassment and behavioural aspects of stigma, but his subject is actually shame. By
including conscious inner feelings, Hochschild widens Goffman's theory but still loses the dimension of unconscious emotion management.

Gradually, science and the social sciences are moving away from a focus on humans as rational decision-makers (Kirmayer 1988) to a conception of emotion as inseparable from the body and thought (Damasio 1996, 2000, Williams and Bendelow 1998, Bruner 2002). The mind and rationality have been seen as superior to emotion, which is conceptualised as disorder, irrationality and lack of control (Kirmayer 1988). Rosaldo (1989) suggests the term 'nonorder', between order and disorder, as a merging of rationality and emotion, and Becker (1997) argues that chaos theory may facilitate a new understanding of disorder as having positive qualities. Wikan (1991) uses the word 'feel-think', translated from the Balinese, and Midgley (2003: 9) suggests that "Thought and feeling are not opponents, any more than shape and size." Using biographical narrative, and listening for the unintended stories embedded within, contradictions, silences, and voice changes, some of the unconscious and embodied dimension of feelings can become apparent (Wikan 2000). For instance, in a narrative study of chronic illness, Lillrank (2002) has attempted to use her own emotional reactions to analyse the tension between interviewer and interviewee, caused by 'covert emotion', in stoical interviews of parents whose children had been diagnosed with cancer.

An early example of a narrative approach in chronic illness was Robinson's (1990) study of written stories of people with MS, in which he aimed to combine the emergent and ambiguous character of the illness story with its links to past biography, by looking at the structures of whole stories. The majority of stories were positive, not only about life but even about the disease itself, and it is suggested that this is influenced by social forces to meet the challenge or 'fight' the disease. Using this narrative approach, the emotional experience of living with chronic illness was brought to the fore, but he notes that sometimes a flatness in a medically-oriented story can create drama through the absence of emotion. Most researchers look for the richest narrative, and there is a lack of investigation into the minimal, socially unacceptable or confused story as meaningful (Järvinen 2000).
A later influential theory developed by Frank (1997a), based mainly on cancer remission stories, categorises chronic illness narratives as quest stories (self-development and learning), chaos stories (inability to cope) and restitution stories (recovery and life returning to the way it was). He suggests that the quest story represents the possibility of being "successfully ill" through witnessing and telling the story (Frank 1997b: 137). Frank argues that telling illness stories is "to give voice to the body" but that "the body eludes language" (Frank 1997a: 2). Telling stories of illness is also "the attempt, instigated by the body's disease, to give a voice to an experience that medicine cannot describe", the "experience of suffering" (Frank 1997a: 18). In other words, the illness narrative, for Frank, is the story of suffering and not disease, a separation of medical and personal story. Although suffering is also embodied, Frank eliminates the embodied disease. As an example of the connection of disease and illness, Mee (1999), in his polio autobiography, describes his knowledge of surfaces, which gives a window into a world of muscle weakness and instability, as well as showing the impact on his daily life and expressing a certain wonder in such subtlety.

I am expert on surfaces. I can tell you, by its footfeel, within a margin of error, roughly how old a given stretch of asphalt road is, just how long ago a hardboard floor was polyurethaned. On the beach, I know, by how far my crutch tip sinks into the sand, about how long ago the tide went out and left the beach to dry. (Mee 1999: 110)

An integration of the physical and social has been theorised by Turner (Turner 1992, Frank 1990) but remains elusive and abstract (Hughes and Paterson 1997, Williams S. 1999, Sparkes and Smith 2002). Empirically, an integrated mind-emotion-body has been described by doctors like Sacks (1987, 1990) and Cole (2004). In the social sciences, emotions may be underemphasised (Seymour 1998) or overemphasised and divorced from the body as suffering (Bendelow 1993, 2000, Charmaz 1991). It is mainly in autobiographical illness narratives that social scientists have brought together the social and physical (Zola 1982a, Murphy 1990, Greenhalgh 2001, Frank 2002). Williams G. (1996: 201) argues that these autobiographical illness narratives are "some of the most powerful phenomenological analyses", while in other cases phenomenology may remove
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the body from society and even enter a spiritual realm. Williams G. (1996: 202) criticises Frank and others who use embodiment to promote a "quasi-religious or spiritual quest for the truth which illness is supposed to reveal".

Frank privileges a spiritual illness story, the quest story, saying "the ill person gradually realises a sense of purpose, the idea that illness has been a journey emerges" (Frank 1997a: 117). The privileged quest story involves illness as a vocation, which includes a responsibility for testimony. Instead of listening to all stories, Frank wants to establish "the authenticity of specific kinds of experience" (Atkinson 1997: 338). However, it is not necessary in a quest story to privilege this experience or, as often happens, to lose the body or the disease. In an article based on Radley's (1995) "elusory body", Wheatley (2005) describes how the analysis of her study of heart disease patients moved from initial emotional interviews with several fit, young heart patients, to a Foucauldian analysis of risk factor management in which the body disappears, and then, after her own cancer scare and surgery, an analysis, after Frank, based on vulnerability, uncertainty, the possibility of bad luck, and the witnessing of others' suffering. Wheatley (2005: 87) finds a balance between person and body, combining both her sensation that she was "balanced atop a cantaloupe-sized water balloon", fears of cancer and surgery, and an understanding that beyond risk factors, sometimes, things just happen. The author is humbled by her experience, judges patients less, and does not expect any particular kind of narrative from her respondents.

Studies of chronic illness have examined whether there is a morality of successful and unsuccessful illness narratives, and whether there is resistance to discourses about illness. Crossley (1999) quotes Frank (1997a: 158) on the "requirement to reshape that self-story if the wrong self is being shaped" suggesting an ethic to be reflexive and take responsibility for one's illness and its meaning. Crossley (1999) debates the two sides of Foucault's 'technologies of the self', the positive side of giving people agency and the power to resist, and the negative side of increased surveillance and decreased agency, and asks how we distinguish between liberating and repressing technologies of the self in illness stories. She uses the example of a young married haemophiliac with HIV, who
ignores his HIV status and carries on a normal life of work and family, to question whether "emancipatory politics results in enhanced engagement with moral and existential concerns" or whether the result is immaturity and removal from the "nitty-gritty of real relationships and everyday life" (Crossley 1999: 1693). Instead of certain stories inherently being liberating, reflective and good, there may need to be a "fit between the story and the conditions that form the basis for the life of the individual" (Crossley 1999: 1694).

Other studies show the complexities, ambivalence and mixed emotions that emerge from chronic illness narratives, reminiscent of the paradoxes noted by Wright (1960), Davis (1963), Goffman (1990b) and Bury (1988). Thomas-Maclean (2004: 1651) attempts to place 12 breast cancer narratives into Frank's categories, but finds that most people tell a story of ambivalent recovery, of being "the person I was before breast cancer, but I have changed." In contrast to cancer studies of relative recovery, a study of diabetic renal disease with diverse complications found extreme stoicism tempered with periods of uncertainty and despair (King et al 2002). Unlike Charmaz's study of suffering and loss of self in chronic illness, this study found people downplaying the seriousness of their disease and concentrating on their sense of agency and control. The authors question why, in a society where emotional confession is popular, these patients remain stoical, and conclude that emotional self-disclosure is accepted when a traumatic event is past and recovery is possible, but in chronic illness the problems and the confessions would be endless and "alienate the chronically ill from the healthy world" (King et al 2002: 343).

Sinding and Aronson (2003) explored the failure to live up to expected social discourses in two studies of elderly women needing care and people caring for the dying. The two discourses were the 'good death' and 'active ageing' and it was found that both groups often did not want to talk about their feelings because their narrative did not match the ideal. The stories that are expected are hero stories, either the stoical hero, or more recently Frank's spiritual hero, both divorced from important ordinary stories which include feelings of unhappiness and disappointment (Craib 1994). Wikan (2000: 234) suggests that narrative does not offer privileged or authentic access to lived experience.
and "to understand lived experience, we need narratives, stories of unfinished, muddled, in-the-midst-of experiences whose only certainties are the beginnings or turning points -". Narrative studies are showing the wide range of stories people tell, both acceptable stories of getting on and difficult stories of dependence and fear, but there is a dearth of studies relating to childhood illness and disability that have been able to grasp this in-the-midst-of experience. I will now turn to studies that deal more specifically with chronic illness in childhood, polio having always been primarily a disease of children and young adults.

Chronic illness and stigma in childhood

An early sociological study of children, families and disability was conducted by Davis (1963: 179), mentioned earlier, who ends with the perceptive observation that for these children, being different had "markedly less to do with their own wishes, attitudes, and fears than it did with the persons and social arrangements they confronted daily." He found that parents steadfastly asserted that nothing in their lives had changed, while incidental remarks and stories showed otherwise. He found a variation of strategies used to deal with disability, from extreme normalisation, ignoring the disability and carrying on as usual, to disassociation, avoiding situations where the disability might be apparent. Both strategies avoided facing the differences head on. In a later study of parents of disabled children, Voysey (1975) also found that parents tell the story of normal family life, a story promoted by clinics, support groups and the press. However, the parents are placed in the ambivalent position of teaching their disabled children to define themselves as normal while also teaching strategies to manage stigma. This conflict is particularly acute in illnesses where there is significant recovery or remission, or little visibility. In adults, a few examples are cancer remission (Frank 1997a), the fluctuations of arthritis (Pinder 1995) and contested illnesses such as repetitive strain injury (Arksey 1998) and chronic fatigue syndrome (Ware 1992, Cooper 1997). Research has also been conducted on several childhood illnesses with remission or invisibility, such as epilepsy (Schneider and Conrad 1983), autism (Gray 2002) and cancer (Comaroff and Maguire 1981).
Schneider and Conrad (1983) move on from Davis, combining symbolic interactionist and phenomenological perspectives in a study of patients' experiences of epilepsy, which often commences in childhood or the teenage years. They enlarge on Goffman's study of stigma by examining how people thought, and suggest that the way parents shaped their child's life by making sense of complex situations could have immense repercussions on the child's later identity. "Children's earliest memories of how parents reacted to the diagnosis seemed to set the stage for how they themselves would interpret epilepsy subsequently" (Schneider and Conrad 1983: 83). Doctors were also in a position to create stigma by avoiding the epilepsy diagnosis and therefore any candid discussion. Two styles of parenting are described: open (normalizing) and closed (denial and silence). Although writing about the other end of life, Gordon and Paci (1997) explain the silence around illness as a balancing act within families, not without costs, of protecting each other from suffering. The current polio study will focus on an aspect not delved into by Schneider and Conrad, which is how the adults being interviewed felt they had been affected by their parents' different strategies.

In the opposite direction to examining stigma, Stewart (2003) notes how the disruptions of illness may become ordinary. In a study of children aged 9-12 undergoing cancer treatment, 'ordinary' was redefined to include the everyday life of hospital visits and treatment (Stewart 2003). More complex is the unfolding of life after treatment, when everyday life has become ordinary but differences remain. Comaroff and Maguire (1981: 120) quote from a mother of a child with leukaemia, "They say: 'Take him home and treat him as normal', but it's hardly a normal situation, is it?" Like Schneider and Conrad (1983), Drew (2003) studied childhood experiences of cancer from the perspective of young adults, about its lasting effects. She describes "successful survival", a dynamic, flexible approach to the future, although this often took many years and sometimes involved bitterness over lack of information about long-term recovery and pressure to be thankful and not complain. A more comprehensive study of Asian and Afro-Caribbean teenagers with thalassaemia, dealing with both the physical complications of the disease and social reactions, also describes the dynamic complexity of growing up with a chronic condition (Atkin and Ahmad 2001). From the age of 10-12 there was a growing
2. Literature: the experience of chronic illness and disability

awareness of difference from others, mixed emotions, learning to normalise and be positive, ambivalence about overprotective parents and the insensitive behaviour of others, including medical professionals.

Studies of chronic illness in adults and teenagers have gradually, over the past 25 years, moved, with the help of narrative approaches to illnesses, from categorising attitudes and methods of coping to exploring the complexities of emotions, reactions to others' attitudes, and the lives people come to live. These studies have examined chronic illness in adults and children over significant stretches of time (childhood to young adulthood), but it is in disability research and the autobiographies of disabled people that the experience of many decades of a chronic illness or disability has been examined.

2.3 Ill or disabled

History and definitions

Disabled people have always been 'different' and, in some ways, separate from society, but every culture also makes some attempt at integration, and how this is done indicates important aspects of the culture (Stiker 2002). Modern medicine, and especially advances in injury treatment during World War I, spawned the rehabilitation ethic of returning people to 'normal'. In both the US and the UK, government benefits and equal rights have gradually been ceded to disabled people since the 1940s, but these were generally felt to be token gestures and subservient to the medical and rehabilitation model of the disabled person as someone to be cured (Gallagher 1998). The civil rights movement and feminism in the 1960s began a change in thinking from needs to rights. Since the 1970s in the UK, disability has been explained by sociologists through a socio-medical model concentrating on people's experience of illness and impairment, and the social model, which defines disability as social oppression (Bury 1996). It was not until 1990 that the American Disabilities Act and, in the UK in 1995, the Disability Discrimination Act, came into force. How much progress has been made for disabled people since then is questionable, as prejudice, discrimination and poverty are still common (Shakespeare 2005). An early debate in the disability movement related to
definitions, which were important in clarifying some causes of continuing discrimination. The World Health Organisation (WHO) definition from the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) separates impairment, disability and handicap:

**Impairment**: any loss or abnormality of psychological, physiological, or anatomical structure or function.

**Disability**: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

**Handicap**: a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that was normal, depending on age, sex, social and cultural factors, for the individual. (Wood 1980 cited in Oliver 1996: 40-41)

This definition was rejected by the disability movement because disability is seen as the result of impairment and they conceptualise disability as the result of social oppression and totally irrelevant to the individual and their body. In the social model, impairment is defined as "the functional limitations within the individual caused by physical, mental or sensory impairment" and disability as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Oliver 1996: 41, Thomas 1999: 15). The WHO have since devised a new classification, the International Classification of Functioning (ICF), which divides the consequences of health conditions into three main categories: body structures or functions, personal activities, and participation in society. The emphasis is on function, not disease, but it is still about the problem of impaired people, not society. The language is no longer negative, but it may have lost meaning, and it becomes difficult to express negative experience with this language. The difficulty in finding agreement about concepts and language demonstrates the deep discomfort in society about chronic illness and disability (Zola 1993). In this study, the word 'disability' will be used as it is used by the people interviewed, meaning a complex combination of impairment, limitations and attitudes to the impairment.
After a decade of some increasing freedoms and acceptance, people within the disability movement have opened new debates concerned with widening the social model to include the personal and physical experience of impairment or illness (French 1993, Crow 1996, Shakespeare 1996, Thomas 1999). On a theoretical level, the difficulty has always existed of losing sight of the body through emphasising language, everyday interaction, or existential phenomenology (Williams G. 1996, Hughes and Paterson 1997). Impaired bodies have also been silenced by both society and the disability movement, in order to demonstrate assimilation into normal life or disability as oppression by society. Stiker (2002) had originally written in the early 1980s that although disabled people were being integrated into society, it was only on condition that they became normal, and denied any difference, whether positive or negative. Shakespeare (1996) presents the basic identity contradiction for disabled people in the disability movement, of creating a positive sense of their difference, but at the same time, wanting inclusion in mainstream society. Crow (1996) opens the debate further to mention the unmentionable in disability politics, that social factors do not create all disability and handicap, but that the impairment and any associated weakness, pain and fatigue, may also be a relevant and important factor. It is not only society that silences disabled people, but disabled people themselves, recreating the original societal message that they must not complain.

French (1993) questions another aspect of the social model, the presumption that social changes giving disabled people equal rights will necessarily change how disabled people are treated by others in everyday circumstances, which she sees as the profoundest problem. The discomfort she describes in ordinary encounters because of her partial sight is also palpable in families, and can silence disabled children. "All of this taught me from a very early age that, while the adults were working themselves up about whether or not I could see rainbows, my own anxieties must never be shared" (French 1993: 70).

Shakespeare (2005) argues that the next step for disabled people is more cooperation between disabled and non-disabled people. Tregaskis (2004: 146 ) has begun this project with an ethnographic study of a leisure centre in order to highlight disabling attitudes, which, she suggests, may be ignored in disability theory as "nebulous and intangible", but
may be all the more "insidious and pervasive". Laws do not change these subtle attitudes, and Williams G. (1996: 208) argues that "there will be no simple revolutionary change in medicine or in politics which will deliver liberation."

**Being disabled: disability studies and sociology**

Thomas (1997: 624), as a sociologist who is disabled, proposes the incorporation of the sociological emphasis on the experience of living with disability, including the ordinariness, into disability theory because "personal experience can powerfully illuminate aspects of these 'social barriers', and so point to areas for social change." Williams G. (1996) also argues for the sociological analysis of the experience of disability on the basis of the subtlety of discrimination due to the difficulty of separating illness and disability, both of which may emerge slowly, fluctuate or be temporary. And "disability is, at some level, undeniably to do with the pain or discomfort of bodies" (Williams G. 1996: 206). Williams and Busby (2000: 173) describe disability as "a relational phenomenon that emerges out of the interaction between a person with impairments and an 'environment' which includes everything from low income and inaccessible transport to a pitying glance from a passing stranger." Pinder (1995) similarly accentuates the necessity but difficulty of bringing ambiguous, fluctuating, invisible symptoms into the normal world of work, because chronic illness and disability are part of everyday life for most people at some time in their life. Williams S. (1999), however, argues that both sociology and disability theory conflate the ontological and epistemological, with the result that the real physical body and the real disease disappear, and the two must now be teased apart.

Wendell (1996) and Thomas (1999) have developed disability theories which include the personal. Wendell (1996) bases her theory on a myth of control, which she suggests is fuelling the discourses of the possibility of perfect health and the responsibility for people to obtain this state of health. She argues that a vicious cycle exists of people needing control because they fear illness and death. If they could relinquish some control and learn about limitations and uncertainty from disabled people, they would be less fearful
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and need less control. Thomas (1999) has evolved a social relational theory of disability which adds the social undermining of disabled people's emotional well-being to the social oppression involving restrictions of activity. Primarily Thomas (1999: 46) is concerned with the current emphasis on what people do, which ignores that people also are "how we feel and think about ourselves". This harks back to Bury's (1988) argument that the chronically ill can only fail in a society which values, above all, achievement and action.

Following the few inroads to include the personal in disability theory, Watson (2002: 525) has conducted an empirical study on the contradictions surrounding disability identity, finding that people "challenge the idea of normality and refuse to be categorised on the basis of bodily difference." He shows how people, who have been disabled for a long time, reject a disability identity without rejecting their disability, and form their identity positively by "establishing the sense of unity between themselves and non-disabled people", focusing on the ordinary and everyday (Watson 2002: 516). As one man put it, "I don't wake up and look at my wheelchair and think, 'Shit, I've got to spend another day in that', I just get up and get on with it" (Watson 2002: 519). They do not deny the everyday problems that their bodies present, but they reject this as part of their identity. Sociologists like Kelly and Field (1996) and Pinder (1995), who incorporate bodily experience into studies of identity, have stepped into this area of the complex interactions between the disabled person, their disease and symptoms, and the reactions of other people. Pinder (1995) suggests, citing Douglas (2002), that people will ignore the ambiguity of illness as long as possible, and similarly, Kelly and Field (1996) describe the self and identity in ill people as basically unaltered, although changed on some levels. Although Shakespeare (1996: 100) argues that identifying as normal is not "psychologically or socially healthy" for the disabled person, Watson (2002: 522) asks "who is being the more radical; those who reject disability as an identifier or those who embrace it?"

As reflected in Watson's study, Bury (1991) has emphasised positive attitudes to illness, instead of earlier sociological work which saw illness and disability only as a problem, but other studies have continued to focus on suffering (Charmaz 1983, 1999, Frank
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2001). Counteracting this, Fine and Asch (1988) turn the view of disabled people as suffering victims on its head by suggesting that researchers assume the disabled person is a victim who, if positive, is either denying their suffering or reinterpreting it as positive. They suggest other ways of looking at disability -- that it might not be central to the person's identity and that disabled people may not be any more dependent or lacking in control than many non-disabled people. Similarly, Herskovits (1995) demonstrates how a swing towards conceptualising the Alzheimer's patient as having a loss of self instigates a counter-reaction concerning the humanity of the patient. Ever since Goffman (1990b) described the perception of the stigmatised as 'not quite human', the stigmatised have tried to reassert their humanity. Both Herskovits (1995) and Fine and Asch (1988) argue that stories of illness and disability are stories of the fears of researchers about difference and vulnerability and make disabled people become "the object, not the subject, of study and distances the research from the disabled person's life experience" (Fine and Asch 1988: 17). Radley (1999) suggests that the ambivalent emotions people feel about illness and disability, which he terms abhorrence and compassion (seen as pity), are both displaced as being unacceptable, and therefore marginalised and made invisible. Without ignoring the fears, uncertainties and vulnerability created by illness and disability, research is needed that focuses on the ordinary aspects of life and how people find a balance between being stigmatised (too much meaning) or made invisible (too little meaning).

Disability, narrative and autobiography

Narrative research corroborates this balance of positive and negative -- that people do get on with normal lives but that it is not easy. Similar to the results of Thomas-Maclean (2004), narratives of spinal injury by Yoshida (1993) and Smith and Sparkes (2002) do not find transcendental stories, but complex, shifting stories of feeling the same but being different. Wright (1960: 36) pointed out the fundamental contradiction in being disabled, that although disabled people are different, they want to and are expected to act normal, and the difference "does matter, it matters a great deal." Although Yoshida (1993) introduces the useful concept of a dynamic, shifting pendulum for the contradictions
involved in adapting to spinal injury, she also loses some of the emotional meaning by concentrating on the process of identity reconstruction as a form of trajectory and career. When one of her informants, who had been injured for 12 years, says, "I think you have to continue to accept it every day", she argues that acceptance is "an ongoing dynamic event", rather than noting that the difference may never become ordinary and will always matter a great deal (Yoshida 1993: 232). Smith and Sparkes (2002) examine the coherence of spinal injury narratives and again the emotions are put aside in the analysis of how incoherence is dynamically made coherent. A restitution story is compared to a constantly shifting restitution and quest story, but the person telling the quest story says, "the body doesn't represent who I am"; implying that this may not be a quest story, but only appears so as this person had more options in moving on with his life (Smith and Sparkes 2002: 160). Skultans (1998b: 62) argues, in a study of Latvian narratives of Soviet occupation, that "history... has fragmented the experience of time, place and the self" and some "lament the lack of an internal connectedness". History, like the polio epidemics, fate, luck and the contingencies of life, may lead to illness, disability, and narratives that cannot be made coherent, as described by Mee (1999) in Chapter 1.

It is important that these shifting, incoherent-coherent stories have been highlighted, but the researcher, in tidying them up, has eliminated the uncomfortable emotions about identity. It has been people with disabilities, often academics, who have tried to explain in autobiographical writing, some of the contradictions and incoherence of living with chronic illness and disability (Zola 1982a, DiGiacomo 1987, Beisser 1989, Murphy 1990, Sacks 1991, Sparkes 1996, Greenhalgh 2001). They have been able to integrate discussions of disease and illness, body, thoughts and feelings. I will concentrate on three examples, Zola, Beisser, and Murphy, who wrote about living with long-term weakness and paralysis. Murphy and Beisser wrote about the experience of first finding out they were or would become quadriplegic. Murphy, an anthropologist, describes how he had no fear on hearing his diagnosis of a progressive spinal tumour, because he separated body, thought and feeling, so that the 'real' him was standing somewhere across the room. Afterwards, he could only conceive of one day at a time, while the past became a golden age, again making a separation. This change in the conception of time,
creating a futureless world and golden past, was also described by Beisser, a psychiatrist, who spent 18 months in an iron lung with polio when he was 25.

Without familiar sources of pleasure and meaning, there was no future. Those things I had been moving toward were gone; they had simply disappeared. The movement of time was blocked, making the present interminable, lifeless and dead. The past, however, was a different story. I spent my time reviewing it as a moment of glory, detailing its pleasures, and even its failures. (Beisser 1989: 5)

Beisser (1989: 8) found a way out of this lifeless time in the iron lung by learning to perceive differently -- "The doorways opening onto the corridor formed subtle geometric patterns according to the different ways the doors were ajar. I began to look carefully and wonder at the scene that only a few minutes before had depressed me so." This could be seen as a form of creative resistance (Becker et al 2000). He concluded that "My more important task was to integrate my past with things in my present: somehow to put together the many torn fragments of my life" (Beisser 1989: 12). Fragmentation, and the image of a past golden age, has also been found with emigrants, making them "more prone to see continuity and coherence (Myerhoff 1979: 34).

Murphy went on to research the social consequences of paraplegia and developed the concept of liminality, originally theorised in anthropology by van Gennep (1960) and Turner (1995), in relation to the paraplegics' in-between status of not being well or ill (Murphy et al 1988). The authors draw on Douglas' (2002) argument that the liminal person is not easily categorised, and therefore an anomaly and taboo. Comparing disabled people to other deviant groups, they conclude that there is more ambivalence about disabled people who inspire "fear and revulsion" but also need help and support (Murphy et al 1988:236). Disabled people seem closer to the liminal, who are isolated from others and tend to be invisible. In a cultural analysis of disability, Shakespeare (1994) continues to draw on Murphy, Turner and Douglas on liminality, ambiguity and anomaly as useful concepts in describing disability. Hughes (2002: 578) utilises the ideas of Douglas and Bauman to theorise the ambivalence and otherness of disabled people in postmodern times, noting that although "contingency and uncertainty are fast becoming a way of life", at the same time physical perfection becomes more and more highly valued. In empirical
disability studies, the concept of liminality and its incommunicable nature has been refined by Pinder (1995) in the case of fluctuating, invisible symptoms, and by Little et al (1999) for those who have recovered from cancer. Liminality has also been employed more widely, showing connections between the experience of disability and exile or emigration, in particular from Nazi Germany (Schlesinger 2004). Becker et al (2000) uses Murphy's concept of liminality for refugees with chronic illness, comparing the invisibility, blurring of boundaries and uncertainty.

In this liminal position themselves, both Beisser and Murphy describe the shifting back and forth from disabled to non-disabled, especially when involved in their work. Being severely disabled, neither experienced a liminal status between being normal and disabled, which was the situation of many who had recovered fairly well from polio, including Zola (1981, 1982b), a medical sociologist who had polio at the age of fifteen. Although he wore a leg and back brace, he did not consider himself disabled until later in life. People who had polio spanned both sides of the disability identity contradiction. Those who were most disabled began the drive for disability rights, taking on, to some extent, a disability identity (Gallagher 1998). Those who were less disabled saw themselves as normal, and often did not want any special treatment which might emphasise their disability (Mee 1999). Zola (1981: 358) fell into this second category until he began to acknowledge his disability in the 1980s, realising there had been costs, and that "One may accept and forget too much".

For Murphy (1990: 87), who became disabled as a mature adult, an understanding of his disability was relatively accessible but he felt forced into silence, saying "Nobody has ever asked me what it is like to be a paraplegic -- and now a quadriplegic". In trying to understand the inaccessible, Zola describes many of the contradictions resulting from the hidden anger and grief of disabled people, who are seen as victims if they complain and victims if they remain silent.

With little opportunity to confront our realities, we find ourselves thought of as distant because we refuse to acknowledge our big problems, or cry babies because we dwell
so much on the small ones. Yet this is the very trap we are forced into by a society which neither acknowledges our losses nor our need to express them. (Zola 1982b: 65)

Disabled people are silenced because there is no world for them. Their story is "fragmentary in structure and content" as they live "in the shadows of the external world" (Zola 1981: 358). These stories of long-term disability, lived out in the normal world but not part of it, are as untellable as Holocaust narratives (Hoffman 2004, Greenspan and Coles 1998, Rosenthal 1998). Hoffman (2004: 9-11) describes her parents' Holocaust communications:

The memories -- no, not memories but emanations -- of wartime experiences kept interrupting in flashes of imagery; in abrupt, fragmented phrases; in repetitious, broken refrains... The fragmentary phrases lodged themselves in my mind like shards, like the deadly needles I remember from certain fairy tales, which pricked your flesh and could never be extracted again.

Zola does not tell the positive story of disability because that is the story that has been told and retold with the implication that "if a Franklin Delano Roosevelt or a Wilma Rudolph could OVERCOME their handicap, so could and should all the disabled" (Zola 1981: 357). Having unleashed the hidden disability story, what has remained extremely difficult since then is to understand the delicate balance between the strengths and vulnerabilities of being disabled, which the current research will study in relation to newly developing PPS symptoms. None of these autobiographies were written by people who became disabled as young children, and very few studies on disabled children themselves, or adults looking back at childhood, have been conducted. In the next section I will examine a few studies that have included disability in childhood and some of the studies on PPS which look back to childhood polio.

Disability in childhood and polio studies

Studies of disability in children have found very fluid conceptions of what disability is, which, to some extent, reflects the wide range of problems included in the term 'disability', but also the messages children may receive from parents and teachers, such as
'everyone has problems' (Priestley et al 1999, Davis and Watson 2002). Priestley et al (1999) found that, for some children, the general concept of disability excluded their own problem, and some saw disability as only existing at certain times or in certain places. However, the children were unified by discrimination, being teased, bullied and stared at, experiences that do not seem to have changed in the past half-century. Davis and Watson (2002) demonstrate how children resist rigid disability identities as well as discriminatory attitudes towards them as disabled or as children. Mulderij (1996) conducted a phenomenological interview and observational study about disabled children's perceptions of their bodies and relationships with parents, friends and professionals. This subtle study questions the phenomenological emphasis on bodily unawareness being positive, and examines children's positive and negative feelings about their bodies. Connors and Stalker (2003), who interviewed children with disabilities about their families, found that children spontaneously mentioned medical and practical factors about their disability but not how they felt. The siblings of these children said that conversation about disability with parents was too difficult. As Davis (1963) demonstrated of the families of children who had polio, and Voysey (1975) of parents of disabled children, a story of life as normal is created, but this myth of normality may create confusion both at home, at school and with friends. In a recent autoethnographical study of a middle-aged non-disabled woman and her disabled sister, the main author (non-disabled) questions whether the silence between them in childhood about the disability had been a barrier in their relationship (Davis and Salkin 2005). The non-disabled sister is able to discuss her feelings in the interviews and e-mails of the research project, but the disabled sister does not, making clear that a barrier existed and has not been overcome.

Two studies that have examined the difficult balance between normality and difference are Thomas (1998) on disabled women's stories of childhood, and Fisher and Galler (1988) on disabled women's friendships. Thomas (1998: 92) shows examples of both good and bad experiences of childhood disability, including polio stories, and of the "fine line between too much or too little emphasis on 'being normal'", which could lead to disability not being acknowledged or discussed at all, sometimes because of parental guilt. Fisher and Galler (1988) combine an interview study of disabled women looking
back at friendships since childhood with their own experience of friendship between a non-disabled woman and a woman disabled by polio. Their friendship began in the 1950s at college but disability was not discussed until the late 1970s, several years after they had both joined the feminist movement. The most important theme across the study was the balance of autonomy and reciprocity, which often involved hiding the experience of disability and pain. Again it was mentioned that patterns were set by parents not to mention the emotions surrounding disability. Only one woman had had conversations with her parents from an early age about the meaning of disability for her. Thomas' chapter concentrates on disabled women looking back at their parents' attitudes, and Fisher and Galler on adult friendship, but neither links the adult and childhood life, which will be a focus of the current study. This has also been lacking in qualitative PPS studies, the subject of the next section.

Between the early 1960s and the late 1980s, polio was forgotten in social science and rehabilitation studies. Interest has been reawakened with new PPS deterioration, and studies have concentrated on the effect of rehabilitation values on PPS coping strategies (Young 1989, Scheer and Luborsky 1991, Westbrook 1991, Westbrook and McIlwain 1996, Thorén-Jönsson 2001, Harrison and Stuifbergen 2005), on vulnerabilities created by negative hospital experiences and discrimination in the past (Westbrook and McIlwain 1996, Thorén-Jönsson and Möller 1999, Wenneberg and Ahlström 2000), lack of understanding or recognition by the medical profession (Westbrook 1991), new coping strategies (Westbrook and McIlwain 1996, Thorén-Jönsson et al 1999), and ambivalence about dependence on respiratory technology (Kaufert and Locker 1990). Although all of these studies involve qualitative research, they are oriented towards health service practitioners and generalisable principles of practice. They tell the polio story of normalisation, working hard, and forgetting polio, but also suggest the fine balancing act sometimes needed in the adjustment to PPS symptoms, such as seeing help from others as supportive rather than "infringement" (Thorén-Jönsson 2001), and "balancing the freedoms and constraints imposed by life-support systems" (Kaufert and Locker 1990: 876). Scheer and Luborsky (1991: 1180) also suggest another fine balance implicit in the attitude (among those who had polio and others) that they are over-achievers, which
suggests that they were not expected to achieve; this concept functions "to separate disabled persons from others and socially categorise them as 'different'."

More recently, in a study of polio and PPS narratives, Schanke (2004) notes gender differences in the narratives in relation to the need for independence through work (men) and unmet emotional needs (women). Shared themes between genders included being both strong and empathetic, and PPS leading to personal growth. However, this study may not be typical, as a prerequisite to enter the study was that patients felt psychologically harmed by early polio treatment, and most had previously seen the author in her role as a PPS clinic psychologist. None of these studies has looked specifically at the effects of medical disbelief in PPS symptoms although in one study "many medical consultations resulted in the patients feeling upset, angry and devalued" (Westbrook 1991: 99). In the next section I will focus on the problem of disbelief for people who have contested illnesses and similar subjective symptoms to PPS.

2.4 Contested illnesses and the patient

Research into contested illnesses, such as repetitive strain injury (RSI), chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME), multiple chemical sensitivity (MCS), fibromyalgia (FM) and chronic pain, can be divided into studies that explore primarily the patient's experience or the interface between doctor and patient. In this section I will examine the major themes in research on the experience of these illnesses, and in the next chapter the focus will be on the doctor's understanding of contested illnesses (or medically unexplained symptoms) and the resulting relationship between doctor and patient. There is a great deal of interest in these illnesses in the social sciences because of their liminal status between mind and body, and one way to categorise this research is by the position of the researcher in relation to the central conflict between biomedical and psychosocial theories, or whether the illness is 'real' or not. The reality of symptoms may also be a problem when organic diseases begin with nonspecific, subjective symptoms, as in the studies of MS (Stewart and Sullivan 1982) and childhood cancer, in which Arksey and Sloper (1999: 492) argue that doctors were employing
Mishler's (1984) concept of the voice of medicine so that "respondents experienced problems in getting their lay voices heard and believed." It is also the case, as occurred in polio, that continuing subjective symptoms after a major illness has stabilised (for instance, after stroke, encephalitis or meningitis) or in conjunction with more objective symptoms in an organic disease (MS or Parkinson's disease) are ignored, trivialised or diagnosed as depression, and this is rarely researched in medicine or the social sciences (Röding et al 2003, Carlsson et al 2004). Rather than being contested illnesses, these are contested symptoms.

In order to understand the controversy surrounding contested illnesses, it is necessary first to note some of the problems defining 'disease' and 'illness'. The word 'disease' originally related to a lack of ease, discomfort, disturbance, distress, and then, more specifically, a bodily derangement. Disease encompassed a combination of bodily and mental discomfort. Illness was the more extreme word and was synonymous with evil (Oxford English Dictionary Online). Disease has come to take on the biological meaning and is related to an objective pathological entity. Illness, with its original connotation of evil and blame, is the subjective experience of symptoms or disease.

Radley (1994) describes the differences between disease, illness and sickness:
- disease is the pathological changes in the body
- illness is the experience of disease, the feelings relating to bodily changes and consequences of living with disease
- sickness is the status or role in society created by disease or illness.

Kirmayer (1988:59) moves further towards a social definition so that "Disease stands for the biological disorder, or, more accurately, the physician's biomedical interpretation of disorder, while illness represents the patient's personal experience of distress." By focusing on the biomedical interpretation of the doctor in contrast or conflict with the psychosocial or moral concerns of the patient, social research has widened this dichotomy, rather than including the patient's experience of body, symptoms and disease, and the doctor's everyday understanding. An example is Mishler's (1984) concept of the
voices of medicine and the lifeworld. Bury (1982: 179) has argued that "The identification of medical thought with disease and lay thought with illness in medical sociology seems to me oversimplified."

It is the overwhelming conclusion of studies of the experience of contested illnesses that because people have no organic diagnosis they are delegitimated and stigmatised, and their symptoms are trivialised (Hilbert 1984, Ware 1992, Garro 1994, Cooper 1997, Malterud 2000, Söderlund et al 2000, Åsbring 2001, Åsbring and Närvänänen 2002, Lillrank 2003, Dumit 2005). All of the above researchers are both neutral and empathetic, or believe the current psychosocial theories are unfair to the patients (Dumit 2005) or wrong (Malterud 2000, Söderlund et al 2000). Söderlund et al (2000: 166) argue that symptom experiences should be regarded as "valid sources of knowledge with the potential to challenge expert knowledge". At the other extreme are social scientists who favour the dominant psychiatric paradigm of medically unexplained symptoms and portray the symptoms as similar to everyday aches and pains (Banks and Prior 2001, Zavestoski et al 2004).

In anthropology, another position is often taken in relation to the patient's symptom description, in which the symptoms are not acknowledged as physical and bodily as understood by the patient, but transformed into a symbol of the social and used to construct a story of oppression (Kleinman 1992, Waitzkin and Magana 1997). Although Kleinman (1988: 45), a psychiatrist and anthropologist, has a sensitive understanding of chronic illness as "a kind of quiet heroism", he also "tends to paraphrase the patients' stories" and in the process filter them through the prism of psychiatric history taking", imposing a psychosocial narrative (Skultans 1998c: 226). For instance, Kleinman (1988: 119) argues that a woman with chronic fatigue "holds firmly to the idea that she has a basic deficit in energy", and, comparing her with another patient, "neither person has insight into the way her chronic illness expresses and helps resolve tensions in her life". DiGiacomo (1992) demonstrates the universality of the moral discourses of healing and blaming the patient, by comparing three opposing discourses -- biomedicine, popular self-help cancer theories and the medical anthropology "mindful body" (Scheperto-Hughes
2. Literature: the experience of chronic illness and disability

1987). Whereas Scheper-Hughes and Lock (1986: 140) conflate disease and unhappiness, and describe "symptoms as a cryptic language of distress", DiGiacomo (1992: 126) suggests that "reifying illness -- all illness, from depression to cancer -- as 'protest' or 'resistance' also recruits suffering into the service of an ideological agenda."

Besides the stigmatisation due to the disbelief in contested illnesses, a second cause of stigmatisation is the inability to keep up or keep active, which is so important in our society, and several studies found that this leads to shame and loss of confidence (Ware 1992, Åsbring and Närvänen 2002, Clarke and James 2003). However, another finding has been that there is resistance to the stigmatisation by attempting to prove the legitimacy of the symptoms (Ware 1992), carry on with as normal a life as possible (Åsbring and Närvänen 2002), or see oneself as a better person (Åsbring 2001, Clarke and James 2003). Two studies particularly concentrate on the narratives of strength that women with chronic pain tell, and the contradictions and balances involved in telling these stories. Richardson (2005) demonstrates how participants construct a story of strength, balancing their stoical ability to ignore their pain and live a normal life, with descriptions of their pain as severe and therefore 'real'. This paradoxical behaviour exacerbates the lack of understanding or disbelief by others (Wiener 1975). A similar paradox is described by Bauman (1991) about the overzealous and therefore unnatural efforts of German Jews to assimilate into German society, which could never be successful. Werner et al (2004) interpret women's positive stories of chronic pain as a struggle for dignity and a balancing act between being strong enough not to complain (and condemning those who do), but also being strong enough to complain when necessary. Although these studies are exploring the specific problem of contested chronic pain, they are important for the much wider paradox of being disabled in normal society, the subject of the current study of both living with polio disabilities, and later, the contested symptoms of PPS. The ambivalent position of patients struggling for dignity, who present themselves as strong and healthy, when they are weak and ill, blurs the boundaries of what is normal, and creates discomfort and disbelief (Douglas 2002).
2. Literature: the experience of chronic illness and disability

2.5 Conclusion

In this review so far, I have traced the development of interest in experiences of illness and disability and narratives of these experiences. Gradually, researchers have tried less to force stories into conceptual categories and more to work with complexity, ambivalence, incoherence and even silence (Poland and Pederson 1998, Wikan 2000, Charmaz 2002). A route into the ambivalent and silenced may be through biographical narrative and emotion, or the absence of emotion, felt by both researcher and researched, the place in between habitual everyday life and moments of crisis. Rosaldo (1989: 102) suggests that attention should be paid to "improvisation, muddling through, and contingent events". DiGiacomo (1987: 341) sees emotions, especially anger, as a research tool in that "disputes of any kind, like rituals, distil the essence from aspects of culture and social organisation". Another aspect of emotions often ignored in research is their complexity and the ambivalence this causes (Briggs 1987). Multiple emotions may be felt at the same time, which are difficult to disentangle and express. Riessman (2004: 20) has revised her earlier research into infertility, feeling that at the time she could not "imagine then how a despairing self could exist alongside a courageous self". The present research looks at biographical narratives, linking early experiences of recovery and becoming independent with later deterioration to investigate how people weave difficult and discordant events into their story.

People, who had polio in the epidemics half a century ago, are in a unique historical position. Having forgotten polio and been forgotten, in turn, by the medical profession, the new deterioration has forced some people to rethink their experiences. These narratives may be able to open the debate about the value of personal experience in understanding the ambivalence involved in long-term disability or illness, and how people attempt to create a balance between the world of disability and the normal world, where their illness story is rarely heard. Williams S. (2000) notes that the theory of chronic illness as 'biographical disruption' is often in a middle or later life model and
neglects both childhood illness and illness that is accepted stoically or seen as 'normal'. Silverman (1987: 159) suggests that "In some respects, however, the sociology of medicine has still to discover childhood." Polio stories encompass a range of childhood to adult illness, disruption to normality, stoicism to emotionality. The narratives of those who had polio at different ages and with different severity and recovery may highlight the complexities of the disease, the social consequences, and the reactions of doctors. The next chapter will explore doctor-patient relationships and the theories developed by PPS researchers in the face of symptoms about which there is little understanding and no objective tests.
3. Literature: the medical profession, contested illnesses and PPS research

...rather like Humpty Dumpty, medicine offers us little hope of putting it all back together again! (Williams S. 1996: 38)

3.1 Introduction

Much has been written in sociology about doctor-patient communication, lay views of symptoms, and the sometimes dehumanising aspects of the doctor-patient relationship (Mishler 1984, Kleinman 1988, Freund and McGuire 1995, Ong et al 1995, Mattingly and Lawlor 2000) -- but less has been written about reactions of doctors to the symptoms patients describe. The first section of this chapter will concentrate on the literature surrounding the acknowledgement of patient symptoms by the doctor in both well-established and contested illnesses, and theories about why doctors are uncomfortable with chronic or unexplained illnesses. The second section will focus on the interpretation of epidemiological research in contested illnesses, particularly on the controversies in PPS research and how doctors have developed theories about the subjective symptoms. Any conflict or misunderstanding between doctor and patient will have an impact on research, and may lie in interpretations of the disease or social factors. In cases where the disease is straightforward, where a diagnosis is made through a combination of the medical history and tests, the tension between doctor and patient may lie between the medical interpretation of the disease and the patient's social experience of illness. But often, the diagnosis or disease is not clear or well understood at first or ever, and then the tension is most likely to be between the disease and symptoms as conceived by the doctor and by the patient.

3.2 Doctors, patients and the biopsychosocial

When diseases are in question because there are no tests or visible signs, doctors resort to the biopsychosocial, which Armstrong (1987) understands as a medical tool used to manage patients with questionable diagnoses and retain the dominance of the medical model. Kirmayer (1988: 83) suggests that "the 'biopsychosocial approach' of
contemporary medical education will become just another technique for rationalising the patient as a system of medical facts". This then becomes a matter of morality and "The threat that unexplained or uncontrolled sickness presents to the authority of biomedicine is neutralised by making the patient accountable for the illness." In everyday life, people who are ill are also blamed if they cannot justify their behaviour (Douglas 1996). Patients often accept these psychologising 'victim-blaming' ideologies because they may gain some agency and hope through trying to change their attitudes, their lifestyle or by using alternative therapies (McClean 2005).

In the same way that doctors use the 'biopsychosocial' to continue separating medical facts from the psychosocial, social scientists also practice a medical-social dualism in their interpretations of doctor-patient interactions and patients' illness narratives. Mishler (1984) developed the categories 'voice of medicine' and 'voice of the lifeworld' as a move toward more respectful patient-centred doctor-patient encounters. In a critique of narrative analysis as giving unwarranted status to people's stories, Atkinson (1997: 333) criticises Mishler's implication "that the narrative mode of lifeworld is more authentic -- by virtue of its biographical warrant -- than the decontextualised discourse of biomedicine." I would argue that the two worlds cannot be separated for either doctor or patient, and that the patient does not bring a lifeworld, totally separate from medicine, to the doctor, he brings a description of symptoms in context, a fusion, not always coherent, of both worlds. As an example, Clark and Mishler (1992) compare a successful and unsuccessful clinical encounter, judged by how well the doctors encourage the patients to tell a lifeworld story of the development of their symptoms. What is not discussed is that in the less successful encounter, the patient has a myriad of confusing new diabetic complications, is upset, and does not have a simple coherent story. Future readings of this encounter interpret the patient's tears as being the result of the doctor's manner rather than the confusing symptoms (Riessman 1993). Katz and Shotter (1996) suggest listening to the poetics or emotion of the patient's statements to enhance understanding, but this may also cause physical symptoms and a matter-of-fact story (in this case a cough and TB) to be ignored.
Barry et al (2001), using Mishler's voices of medicine and the lifeworld, found that the same doctor used different approaches depending on whether problems were seen as psychological or physical. From the detailed examples given, it can be seen that the two worlds are inseparable, that symptoms are embedded in daily life, and that the emotional context of the encounter may also have a crucial effect, as in the case described by Taussig (1980) where a woman's pain is not acknowledged because she is not considered reliable by hospital staff. Latimer (1999) also describes the interrelationship of the two worlds in a study of older people in hospital, who keep quiet about themselves in order not to be seen as difficult, and therefore social rather than medical problems. Kleinman (1988: 17) says that doctors "find chronic illness messy and threatening", which may explain why the incoherent story of unpredictable, fluctuating symptoms may lead to doctors feeling discomfort, not listening, interrupting and even disliking the patient.

Research into doctors' negative feelings towards patients has shown that certain categories of patients are disliked, such as substance abusers, hostile patients, hypochondriacs and malingerers (Najman et al 1982, Gorlin and Zucker 1983). Qualitative studies of doctor's perceptions of CFS and unexplained symptoms have shown scepticism about the lack of objective tests, disbelief in the severity of symptoms, psychological attributions and negative judgements (Åsbring and Närvänén 2003, Wileman et al 2002). Observing doctors and nurses in an intensive care unit, Cassell (2004) found that doctors, nurses and herself, the anthropologist, all made moral judgements, disliking and withholding care from angry, violent patients. More often, doctors refused to hear details of patients' stories, in order to be able to treat them equally. The social story or lifeworld is not essential for people to treat each other as humans rather than objects, and the story may encourage reification of the person as a drunken driver or murderer.

**Doctors and certainty**

How do doctors come to understand the "messy and threatening" illnesses of patients and morally judge them? One solution, especially when tests are equivocal, is to resort to the
psychosocial (Kirmayer 1988). In order to understand how this is done, it is necessary to explore the narrower question of how doctors deal with the immense body of knowledge they need to acquire and then match to infinitely variable human individuals. Fox (1957) described an uncertainty in medical decision-making, especially when the diagnosis is not straightforward, leading to frustration and the doctor blaming himself or the patient. Atkinson (1984), concentrating on more straightforward diagnoses, suggests that doctors do not live in a constant crisis about the uncertainty of medical knowledge and their own understanding, but adopt a practical approach of simplifying complex problems and approaching diseases as puzzles to solve. This leads to "the 'certainty' of dogmatism and personal judgement" (Atkinson 1984: 954). Although Atkinson sees this certainty as becoming natural everyday thinking as described by Schutz (1970), not imbued with emotion and morality, this may only be true where patients fit neatly into medical categories. In order to reach the feeling of certainty needed to practise medicine, deeply felt beliefs must develop, and when symptoms fall outside these beliefs, emotions are stirred up and responsibility is handed back to the patient through psychosocial diagnoses (Salmon and Hall 2003). Wileman et al (2002: 181), in a qualitative study of 15 GPs, found that GPs felt inadequacy and resentment when patients with unexplained symptoms gained "authority by undermining the opinion of the doctor or lacking trust in the doctor's ability." Belief, morality, responsibility and emotion become integral to the doctor-patient relationship. Sacks describes the mental conflict that can occur with strong medical beliefs:

The forgetting of sleepy-sickness (encephalitis lethargica) and the forgetting of Tourette's have much in common. Both disorders were extraordinary, and strange beyond belief -- at least, the beliefs of a contracted medicine. They could not be accommodated in the conventional frameworks of medicine, and therefore they were forgotten and mysteriously 'disappeared'. (Sacks 1987: 93)

The first difficulty, the first barrier, lies in one's own mind, in allowing oneself to encounter new ideas and then to bring them into full and stable consciousness, and to give them conceptual form, holding them in mind even if they do not fit, or contradict, one's existing concepts, beliefs, or categories. (Sacks 1997: 153)
Rigid beliefs, lack of knowledge, or misunderstanding the patient, may all lead to problems and mistakes. In studying medical mistakes, Mizrahi (1984) found that trainees went through a similar process of blaming themselves or the patient and various levels of distancing, denial and long-term ambiguous feelings "which have repercussions for ways in which novice physicians anticipate practising medicine and for their relationships with present and prospective patients." (Mizrahi 1984: 142) The next section will focus on how doctors deal with these ambiguous feelings and contested illnesses.

Contested illnesses, the medical profession and the social sciences

Research into contested illnesses such as RSI, chronic fatigue syndrome (CFS), chronic pain and fibromyalgia highlight how patients and doctors negotiate the physical-psychological divide in respect to subjective symptoms. The basic trust between doctor and patient is at stake if they do not agree on important issues. Bulow and Hydén (2003) and Garro (1994) demonstrate how patients with CFS and temporomandibular joint pain (TMJ) construct new illness theories (combining physical and psychological ideas) with other patients, health professionals or alternative therapists. In a subtle analysis, Horton-Salway (2002) interviewed GPs about their CFS patients and demonstrates how doctors construct a patient identity, using psychosocial information, as grounds for a diagnosis of physical or psychological illness, when there are no abnormal tests. In these cases the lifeworld of the patient has been listened to, but interpreted in different ways. To justify a physical illness, doctors showed how active the patient was before or during the illness. In patients who were given a psychological diagnosis, previous lifestyle was ignored or interpreted as inability to cope. Whether personality factors of doctor or patient influenced these interpretations could not be evaluated. Escher et al (2004) have found ICU doctors are unconsciously influenced by patients' personality traits and Raine et al (2004: 1356) have found "that where doctors find it difficult to make a satisfactory diagnosis or are influenced by negative encounters with patients, difficulties in management are likely to escalate". Most of the sociological research on contested illnesses has failed to address the influence of strong beliefs and emotions on the medical profession, patients and researchers in relation to contested illnesses.
3. Literature: the medical profession, contested illnesses and PPS research

In the grey area between supposedly physical or psychological symptoms, researchers also make choices between who to believe and who is 'right'. As DiGiacomo (1992) noted, it may sometimes be social scientists with chronic illnesses that begin the process of writing about them. Writing an autoethnography of her experience of being misdiagnosed as having fibromyalgia when she already had chronic pain from psoriatic arthritis, Greenhalgh (2001) demonstrates how a doctor misinterprets drug side-effects as fibromyalgia symptoms as a result of his strong beliefs. On the other hand, Kleinman (1988) interprets the symptoms of CFS as the expression of social tensions. Waitzkin and Magana (1997) suggest that certain symptoms, like headache in people who were tortured by blows to the head, are symbols of psychological trauma rather than the result of physical injury. Brown (1992, 2000) has studied and been sympathetic to lay epidemiology linking illness and the environment, both in relation to leukaemia clusters and Gulf War syndrome, but, without proof of organic disease, has come to accept the psychiatric interpretation of Gulf War syndrome (Zavestoski et al 2004 ). Mishler (1984: 184) describes the psychiatric approach as an extension of the biomedical model into a non-medical domain, which "often marks a lack of attentiveness to patients' lifeworlds and to experientially-grounded understandings of the problems." Malterud (2000), a GP, has used qualitative interviews with CFS patients to challenge the depression and somatisation orthodoxy, arguing that doctors are not accepting patients' symptom descriptions, which indicate more specific cognitive and neuromuscular problems than found in depressive illness or everyday life.

Research has noted some of the reasons for tensions between doctors and patients, centring on tolerance of uncertainty, resulting in doctors moving towards more scientifically based medicine, beyond the reach of the patient whose concerns are assumed to be philosophical and emotional. It is difficult to conceive of the doctor as having lay views and the patient as having a disease story. The same tensions exist in daily life between those who are ill, and the healthy, who also fear the uncertainty surrounding ill health and disability. Because of the emotions surrounding health and illness, it is difficult to both carry out and interpret research. Doctors, patients and
researchers may find certain subjects uncomfortable or may avoid them inadvertently (Lillrank 2002, Riessman 2004). These stories become silenced. The rest of this chapter will concentrate on how doctors describe, define, research and develop theories about subjective symptoms.

3.3 Contested illnesses and medical research

Most social science research on contested illnesses and the medical profession focuses on the conflict between doctor and patient or on the beliefs of different medical specialties about the 'reality' of an illness (Cooper 1997, Arksey 1998, Banks and Prior 2001, Zavestoski et al 2004). The medical arguments may be alluded to (Cooper 1997), and possibly described (Kroll-Smith 1997), but there are no in-depth examinations of the methodology and terminology used in survey and epidemiological research, and often only one side of the argument is referred to (Banks and Prior 2001, Zavestoski et al 2004). Medical researchers discuss their results and express their opinions in articles, which may be used as sources for understanding how medical arguments are framed and how anomalies are relegated to be 'forgotten' or redefined to fit existing categories (Douglas 1987, Sacks 1997).

Arksey (1998) suggests that the sociology of scientific knowledge theory has tended to separate the physical and social, only very slowly beginning to incorporate the physical component into explanations. The argument put forward by Arksey about the democratisation of lay knowledge is muddied when an attempt is made to define lay knowledge in medicine, as it includes three disparate modes of thinking: the patient's experience of symptoms, the patient's knowledge of the body and biology, and the patient's thinking about possible causation. The first of these, the patient's symptom experience, is integral to the medical encounter, and must be heard, and then interpreted. When the pathology is not clear, hearing is difficult and interpretation may differ between doctor and patient.
In contested illnesses such as Gulf War syndrome, CFS, multiple chemical sensitivity (MCS), and fibromyalgia, symptoms are often delegitimised by being described as magnified 'normal' symptoms (David and Wessely 1995). However, in controversies about contested illnesses, patients' descriptions of symptoms are an integral part of epidemiological studies and the understanding of the illness. It is lay people who often first describe a new illness through their symptoms (Brown 1995). Doctors may then accept or resist the proposed symptoms. For example, David and Wessely (1995) have analysed the Camelford 1988 water poisoning incident reports from a psychiatric perspective, concluding that the abnormal 'objective' evoked potential, memory and information processing tests were influenced by patients' anxiety and that the cause of symptoms was a misperception of common symptoms due to anxiety. The irony of this situation is that objective tests are rejected as not being objective enough, but the unproven subjective theory of anxiety-induced symptoms is accepted without criticism. Graveling et al (1999: 82) wrote a review of MCS criticising the assumption of psychological causes after other objective illnesses have been eliminated. "This is presumptuous when other plausible mechanisms require further exploration". It is this imbalance in arguments which will be explored in this chapter.

Controversy over subjective symptoms is also prevalent in organic diseases. For instance, in endometriosis, sleep apnoea and lupus, pain is expected to correlate with objective disease activity; otherwise, it is explained as depression (Whelan 2003, Bardwell et al 2003, Bruce et al 1999). In studies of long-term stroke sequelae, fatigue is found to be a serious but little explored problem, often interpreted as depression (Glader et al 2002, Carlsson et al 2004). Significant subjective symptoms after mild stroke are ignored because function has returned to normal (Röding et al 2003). Similarly, fatigue was not accepted as an after-effect of polio even at the time of the epidemics. In a one-year follow-up study of patients who recovered well, Young (1949: 269) found that "the outstanding response among these patients was the complaint of feeling tired" and "this fatigue is out of proportion to what might be expected in view of the muscle loss." He believed that "problems that had to do with adjustment within the family and toward work and society in general seemed to be very important", even though this sample had
recovered well, and research had shown that, even in mild cases, polio damage was often extensive subclinically in the spine and brain stem (Bodian 1949). In PPS research, an anomaly has been found that the original polio severity and the new weakness do not correlate with new muscle pain and fatigue, although initial polio weakness is a risk factor for PPS (Vasiliadis 2002, Schanke and Stanghelle 2001). This poses the question of how to understand PPS pain and fatigue and whether to accept that they relate to polio.

This problem can be approached by exploring the directions that have been taken within epidemiological research. In this part of the chapter, I propose to use PPS research to show the arguments researchers bring to controversial issues, and how methodology and interpretation are employed to promote different views of symptoms and whether they are related to polio or other factors. The next section will examine researchers' views on the controversy surrounding PPS, the contradictory evidence about risk factors for PPS, and then how three teams of researchers developed this risk factor research, arriving at quite different views of PPS and its symptoms, particularly muscle fatigue. The scepticism about PPS symptoms has impacted on patients, and this will be examined in Chapters 9 and 10. The chapter will conclude with a discussion of how doctors, who conduct clinical research on the understanding of a disease and its symptoms, deal with balancing uncertainties with the need for credibility and responsibility for themselves and their patients.

*Disease credibility: one disease and one pathology?*

In *Scientific American*, Halstead (1998a), a rehabilitation specialist who had polio and helped to instigate the first PPS conferences and research, brought together some of his thoughts about why there was scepticism about PPS. He felt that "polio came to be regarded as a static, nonprogressive neurological disorder." Older research into PPS, which was first mentioned in 1875 when polio was uncommon, had suggested a rare after-effect consisting of progressive muscle weakness, which had never been explained, and therefore was not accepted and was largely forgotten.
Because there was little in modern medical literature about delayed neurological changes in polio survivors, the initial response by many physicians was that the problems were not real. For a time they were dealing with a cluster of symptoms that had no name -- and without a name there was, in essence, no disease. (Halstead 1991 accessed online)

Dissonant ideas may be forgotten in order for a cognitive system to continue working (Douglas 1987). But when categories become necessary, for instance, due to patient pressure for symptoms to be acknowledged, the "response to ambiguity is generally to encourage clearer discrimination of differences." (Douglas 1999: 110) Strict categories are formulated in defining a new disease, and ideally doctors search for a single cause, a single pathology, and if possible a single cure (Williams 1991, Aronowitz 1998). For instance, the controversy over Gulf War syndrome has centred mainly over whether there is one illness, rather than whether soldiers had been harmed during their service (Ismail et al 1999, Coker et al 1999). In an interview with Gould (1995: 212) about PPS, Spencer, a retired UK polio physician who sees the symptoms as orthopaedic deterioration rather than nervous system deterioration, said, "It is a real thing but it is by no means a single condition and it is destructive to think of it as a single condition."

Perry (1988) has a different view of the scepticism of doctors towards PPS patients, based on the nature of muscle weakness and the validity of muscle testing.

...the overly generous functional interpretation of the manual muscle test grades exercised by most clinicians has complicated the post polio patients' ability to generate medical acceptance of their complaints. (Perry 1988 accessed online)

If patients say they feel weaker or cannot do an activity they previously could, the doctor expects to be able to calculate the difference through muscle testing. Problems with muscle testing are made more complicated by transient weakness caused by muscle fatigue, which is not well understood, may not relate directly to the weakness, and affects performance and perceived exertion but not instantaneous force (Nollet et al 1999). Due to the scepticism about the lack of explanation and tests for PPS symptoms, the first definitions and criteria were strict, as described in the Introduction. Naming PPS was
important in encouraging research, disseminating ideas and helping patients obtain a
diagnosis, but with or without a name, symptoms which are not understood are dismissed
or forgotten.

**PPS risk factors: more or less severity and recovery**

The first surveys of PPS symptoms and risk factors sought to clarify the new polio
deterioration, but the sample selection and emphasis on selected rather than population
studies have created as many ambiguities as they solved. In 1985, Halstead concluded,
from a survey of 539 self-selected people who had polio, that polio severity and older
polio age (> 10) were the most significant risk factors for developing PPS (Halstead and
Rossi 1985). These factors were refined by Klingman et al (1988) to include older polio
age, more severe polio, better recovery and higher activity levels (Table 3.1). In both of
these studies, the polio severity of the participants was high.

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<tr>
<td>More severe polio</td>
<td>More severe polio</td>
<td>Female sex</td>
<td>More severe polio</td>
<td>More severe polio</td>
</tr>
<tr>
<td>Older polio age &gt; 10</td>
<td>Older polio age</td>
<td>Longer time since polio</td>
<td>Female sex</td>
<td>Longer time since polio</td>
</tr>
<tr>
<td>Better recovery</td>
<td>Permanent impairment</td>
<td></td>
<td></td>
<td>Older age</td>
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<tr>
<td>Higher activity level</td>
<td></td>
<td></td>
<td>Greater present weakness</td>
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<td></td>
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<td></td>
<td>Recent weight gain</td>
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<td></td>
<td></td>
<td></td>
<td>Muscle pain</td>
<td>Joint pain</td>
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In 1992, an epidemiological study of PPS used a population-based cohort of 551 people
who had polio, with a wider range of disease severity than previous studies (½ with no
residual impairment) (Ramlow et al 1992). A questionnaire was devised to detect the
presence of new symptoms, particularly muscle weakness, muscle pain and fatigue. The
authors arrived at quite different risk factors: length of time since polio infection,
permanent residual impairment in mild-moderate cases (low recovery), and female sex
(Ramlow et al 1992). In both the Ramlow and Halstead studies, the symptoms of
weakness, pain and fatigue were described in terms of muscle fatigue -- "a marked change in level of energy and endurance" brought on by ordinary activities (Halstead et al 1985: 18) and "aching muscular pain associated with exertion and relieved by rest and heat" or "muscle weakness associated with decreased endurance and poor performance of specific jobs or activities" (Ramlow et al 1992: 771). However, the term muscle fatigue was not used in either survey. A year later, Lønnberg (1993) studied 3607 Danish polio survivors and found that female sex and polio severity were important risk factors, but that polio age was not a risk factor because there were not significant differences between the age groups (Table 3.1 and 3.2). However, the risk of PPS should have risen with polio age, as the risk rose with polio severity, and severity rose with polio age.

Table 3.2: Lønnberg (1993) Polio age as PPS risk factor

<table>
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<tr>
<th>Polio age (years)</th>
<th>PPS symptoms (%)</th>
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<tr>
<td>Below 5</td>
<td>48.9</td>
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<tr>
<td>5-9</td>
<td>44.3</td>
</tr>
<tr>
<td>10-14</td>
<td>47.7</td>
</tr>
<tr>
<td>Above 15</td>
<td>62.7</td>
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I would argue that the insignificance of the differences in risk between different polio ages was important, and showed a higher relative risk for those who were younger. If researchers had taken note of this anomaly, which implies some difference in polio between the ages, later anomalies about the symptoms may have been more understandable. The received wisdom or 'dominant epidemiological paradigm' (Zavestoski 2002) of PPS risk factors are older polio age and higher polio severity and recovery (Jubelt and Agre 2000), although there is the confounding factor found by Ramlow et al (1992) of milder cases with low recovery. Because of these anomalies, it was important in the current study to hear the stories of those who had polio at different ages and different severity.

Having concluded that more severe polio predisposed to PPS, it seemed logical for researchers to assume that those who had had more severe polio would experience more
of the three main PPS symptoms: weakness, fatigue and pain. The pain is sometimes described as "overuse of weak muscles" (Jubelt and Agre 2000). However, Willén and Grimby (1998), in a study on pain, physical activity and disability in PPS, found that muscle weakness did not correlate with daily pain, but that there was a close relationship between pain, physical activity and those who were using muscles maximally to walk. Something other than 'objective' weakness was, therefore, causing some people to be using all their muscle power in order to walk. In another study of disability and function, Nollet et al (1999) compared a PPS and non-PPS group and found very little difference in strength tests but large differences in physical performance tests. They conclude that "continuous repetitive muscle activity is more disturbed than instantaneous maximal force, and that fatigue, being the major complaint reported by the PPS patients, in fact signifies reduced muscle strength." (Nollet et al 1999: 141)

Although muscle fatigue or decreased endurance was known to be a crucial component of PPS from the early research (Maynard 1985, Cosgrove 1987), the concept was not specifically used in most patient surveys (Halstead and Rossi 1985, Ramlow 1992). Cosgrove (1987) found that decreased endurance was the most common symptom (153 out of 154 patients) after weakness, the defining symptom. There had been scepticism about fatigability after the initial illness at the time of the epidemics (Young 1949), even though it was found to be a significant symptom in a follow-up of nonparalytic polio patients, in which, surprisingly it was found that 38.6% had muscle weakness and 42.7% of those had increased fatigability (Moskowitz and Kaplan 1953). In the next section I will demonstrate how three research teams have recently approached the study of subjective symptoms in attempting to make sense of contradictory evidence. The McGill team has examined PPS risk factors and, more particularly, muscle and joint pain in relation to fatigue and weakness. The Bergen team concentrated on defining PPS and exploring the relationship of paralytic and nonparalytic polio. The Oslo team has studied fatigue in relation to other physical and psychosocial problems. Like the qualitative and narrative PPS studies, much of this research was followed during the current project.
Three PPS research teams: McGill, Bergen and Oslo

McGill, Montréal

An early study from the neurology department at McGill University showed that no electromyographic test or muscle biopsy could distinguish between patients with stable polio (no progressive weakness) or PPS because both had evidence of early denervation and ongoing motor unit remodelling (Cashman et al 1987). PPS was defined by muscular weakness, and other symptoms mentioned were atrophy and fatigue. The McGill team subsequently became interested in linking the instability of the motor unit, sometimes found on testing, with patients' descriptions of muscle fatigability. They hypothesised that there might be a neuromuscular junction defect similar to myasthenia gravis, which is well understood and treatable (Trojan and Cashman 1995). They cite Berlly's (1991) study of PPS fatigue to suggest that muscle fatigability is more specific to PPS than general fatigue. Berlly found that only 15% of those with PPS found exercise helpful for fatigue, while 70% of controls found it helpful. Some patients studied by the McGill team did have neuromuscular junction defects, and pyridostigmine, a drug used in myasthenia gravis, was helpful for some patients, but a large trial was not successful (Trojan et al 1999).

The team also conducted a study of risk factors to test the results of previous work and found that older age, longer time since polio, greater weakness at acute polio, greater weakness at present, recent weight gain, and muscle and joint pain were significant risk factors for PPS (Trojan et al 1994). As there is little understanding of PPS muscle and joint pain, the McGill team set up a study of risk factors for the two types of pain (Vasiliadis et al 2002). The results were considered "intriguing". The risk factors for muscle and joint pain were not the same, suggesting different pathophysiology. The risks for joint pain were "as expected" -- greater weakness at acute polio and lower current strength. Other factors were female gender, younger age at polio, younger age at interview and lower general health score. For muscle pain, the risks were female gender,
increased duration of general fatigue and lower general health score. Almost significant was duration of muscle fatigue. Also tested was pain perception (SF-36 bodily pain scale) and significant variables, among others, were female gender, younger age at polio, increased weakness at acute polio, increased duration of muscle fatigue, and decreased general health score. They conclude that although motor unit loss (weakness) is associated with joint pain, it is not associated with muscle pain, which must be caused by a different pathology. Two significant findings, fatigue in relation to muscle pain, and younger polio age were not discussed. In a review article on PPS, Trojan and Cashman (2005: 12) suggest that "Interestingly, weakness at the time of acute poliomyelitis and current isometric strength were not predictive of muscle pain, indicating that the extent of motor neuron loss may not be important in the genesis of muscle pain."

Bergen, Norway

Rather than studying the risk factors related to a polio patient developing PPS symptoms, a neurology team from Bergen, Norway, contacting patients from the 1950-1954 polio epidemic hospital records in Bergen, compared the risk of getting PPS symptoms in three groups: a paralytic polio group, a nonparalytic group and controls, as the symptoms are common in the general population (Rekand et al 2000). They conclude that both nonparalytic and paralytic polio patients have an elevated risk of developing PPS symptoms compared with non-polio controls (odds ratios were 2.36 for nonparalytic and 7.19 for paralytic patients to develop muscular pain). Nonparalytic patients had relatively high odds ratios for joint pain and respiratory distress. Paralytic patients were most likely to develop fatigue (OR 11.06), weakness and both joint and muscle pain. The authors theorise that PPS symptoms in nonparalytic patients are the result of subclinical motor neuron damage.

This study was followed by an in-depth follow-up study of nonparalytic patients (Rekand et al 2002). Thirty-nine out of 47 patients responded to a questionnaire and 25 reported new symptoms. Twenty were included in the study, but nine were diagnosed with other possible causes for the symptoms (nerve entrapments, arthritis, rheumatic conditions or
sleep apnoea). Of the 11 remaining patients, three had abnormal findings on examination or electrophysiological tests. The explanation for normal tests in eight patients was that the motor neuron damage might be very scattered. Interestingly, these eight patients had a larger number of symptoms, predominantly muscle pain, than the three with abnormal tests. Case histories of the three (all female) with abnormal tests show that the one with the most abnormal tests was the eldest when she had polio (14 years) and her only symptom was weakness. The other two were younger when they had polio and they reported weakness, pain in arms and legs, and fatigue (polio at two years) and weakness and pain in legs (polio at six years). These cases have been described because they correlate with the results of the McGill pain study findings that younger polio age is a risk factor for PPS pain.

Very few studies have included nonparalytic polio patients, but all have found evidence of PPS symptoms (Nee et al 1995, Ramlow et al 1992). There have been two studies of people who did not know they had polio but had typical EMG abnormalities (Petajan and Currey 1987 (abstract), Halstead and Silver 2000). Another study examined patients who had come to a PPS clinic with typical symptoms and history of mild polio, but were found to have no abnormalities on testing (Bromberg and Waring 1991). More extensive, sophisticated testing was conducted on 17 patients, and the authors concluded that they could not have had polio. The authors had no explanation for the weakness, breathing problems, fatigue, and pain the patients experienced, or why several had not been able to participate in sports since childhood. A study by Nee et al (1995) traced twins (one of whom had had paralytic polio) who had been studied originally in 1951 and asked both of them about new symptoms -- 71% of the polio-affected twins and 42% of the exposed siblings had PPS symptoms. Two muscle biopsies of non-affected twins were abnormal. EMGs were conducted but the results were not published. This was small but convincing evidence that nonparalytic polio could lead to PPS symptoms. The Bergen team had moved on by presenting the results of tests on a group of nonparalytic patients.

A more recent study by the Bergen team aimed to define PPS and the causes of loss of health and function of the polio patients being admitted to their postpolio clinic (Farbu et
al 2003). Only patients with abnormal EMGs were selected. The main symptoms reported were pain (84%), weakness (79%) and fatigue (57%). Fatigue was defined as "unusual or extensive tiredness, not as of muscular fatigue with decreased endurance." Fatigue was associated with sleep disorders, not with muscle weakness. Pain was most commonly located in clinically nonparalytic muscles (57%) compared to paralytic muscles (48%), in a pattern distinct from the expected overuse of a limb compensating for another weak limb. This finding is anomalous if it is expected that more severe weakness leads to more severe PPS symptoms in general, but is congruent with the findings of the McGill team. The Bergen team adopted a strict PPS definition necessitating "new muscular weakness including objective findings such as weakening of tendon reflexes and new muscle atrophy", which meant that only 26% of patients met the criteria. Another 53% had loss of function due to less specific symptoms such as fatigue and pain, mainly in the nonparalytic muscles. Unlike the studies by Kidd et al (1997) and Windbank (1996), the authors did not feel that other diagnoses such as arthritis or fibromyalgia explained the muscle pain. Also, in contrast to Ramlow (1992) and Lonnberg (1993), more men than women (41% versus 11%) were diagnosed with PPS, suggesting that men may have more objective weakness than women, who have more pain from widespread milder damage.

Moving from an open-ended study of a total population of paralytic and nonparalytic patients admitted to their hospital in the 1950s epidemics, the team had narrowed their focus to patients with objective signs of new weakness. Having shown in their first study that, even in nonparalytic patients, subclinical damage could lead to PPS symptoms, in this study clinical paralysis is not sufficient to classify the appropriate symptoms as PPS without objective evidence. Most of the patients in this study have been eliminated from a diagnosis of PPS. Many of these patients fit into the category beginning to be formulated by some of the McGill team's risk factors for pain -- women who had polio at a younger age and have had longer periods of fatigue and muscle fatigue.

Both of these teams are in neurology departments, although the McGill team is led by a physiatrist (rehabilitation specialist), and their thinking is based on objective signs and
electrophysiological tests. They are investigating the same aspects of PPS and arriving at similar results but their attitudes are different. The McGill team have always proposed that there might be two lesions in the motor unit, a dysfunction of terminal axons and a proposed neuromuscular junction defect. They are open to both general and muscular fatigue, and different causes for joint and muscle pain. They have linked the joint pain to motor neuron loss, and are uncertain about the links between muscle pain and fatigue. The Norwegian team eliminated muscle fatigue from their study at the outset. Although they originally included nonparalytic polio in their study and accepted the symptoms in nonparalytic patients as related to subclinical polio damage, they then formulated a strict definition for PPS because it is a clinical diagnosis and "most symptoms reported by polio patients are non-specific and common in an ageing population" (Farbu et al 2003: 411). As a result of the strict definition and the elimination of muscle fatigue, the symptom which may separate PPS from common complaints (Berly 1991), they were left with the majority of cases unexplained. The McGill team has focused on research in understanding PPS from the beginning and this may motivate some of their thinking. The Norwegian team seems more concerned about credibility, a major problem in diseases where there is no test, as explained by Halstead:

Until a definite test is available, post-polio syndrome will remain a diagnostic challenge that probably will become more difficult in coming years...as interest and knowledge about post-polio syndrome continue to grow and expand, polio survivors (and those who mistakenly believe they had polio) will become more sophisticated in matching their symptoms—either consciously or unconsciously—with those described in the medical literature. If this becomes a widespread phenomenon, it could decrease the credibility of the diagnosis of post-polio syndrome... (Halstead 1991 accessed online)

For patients who may have a predominance of muscle fatigue over weakness, these different attitudes may make the difference between whether their symptoms are acknowledged or not, and whether they get a diagnosis or not. Another common problem for patients is whether the general fatigue is accepted by doctors as related to polio or dismissed as psychological. This is similar to the delegitimation found by chronic fatigue syndrome, fibromyalgia and chronic pain patients (Ware 1992, Cooper 1997, Hilbert
1984). The next team to be discussed has, over the course of several studies, changed their attitudes to PPS fatigue, from a physical fatigue to depression.

The Oslo team

The Norwegian Polio Study 1994 carried out by the Sunnaas Rehabilitation Hospital near Oslo, involved a nationwide survey of 1449 people who had polio. Questions in the survey covered severity of polio, new symptoms, psychosocial situation and experiences of the healthcare system. This survey divided new problems with fatigue into general fatigue (57%) and fatigue during exercise (80%). The figure of 57% for general fatigue is the same percentage found by the Bergen team, suggesting consistent symptoms in similar populations. The only more prevalent symptom was weakness (85%). Interestingly, only 17% were satisfied with the healthcare system in relation to polio (Wekre et al 1998). At the same time, polio patients at the rehabilitation hospital were being followed from their initial visit for 3-5 years to evaluate the first programme (Stanghelle and Festvåg 1997, Schanke 1997). One study investigated new symptoms, pulmonary function and work capacity, and found significant deterioration in spite of the interventions (Stanghelle and Festvåg 1997). In this study, general fatigue was not separated from muscular fatigue, and the authors concluded that as depression scores were not above average, "depression is probably no significant reason for the fatigue" (Stanghelle and Festvåg 1997: 507). The team's next studies began to concentrate more exclusively on various aspects of fatigue.

One study examined psychosocial aspects of coping with new postpolio symptoms (Schanke 1997). Depression and anxiety scores were within normal range, though they did positively correlate with fatigue. Test results suggested that fatigue might affect mental function, and it was hypothesised that this could be caused by polio brain stem damage, hypoventilation, stress or physical exhaustion. A second study on psychosocial experiences used the Norwegian Polio Study survey, especially answers to the question 'I think I have been psychologically harmed by the treatment received at the time I contracted polio' (Schanke et al 1999: 516). The authors confirmed their hypothesis that
longer hospitalisation and perceived lack of support influenced later psychosocial well-being. The group who felt harmed currently experience more anxiety and depression, pain, fatigue, concentration and sleep problems. No causal connection could be made between early experiences, and later psychological problems and physical PPS symptoms, but a connection is implied by grouping the psychological and physical symptoms together. Left out of the discussion were other significant results: the group that felt harmed were younger when they had polio, had more severe initial polio and more surgery. Currently, they have more widespread new weakness and more used wheelchairs. Factoring in the severity of the initial polio and PPS deterioration, there could be multiple interpretations of the study results.

Fatigue is admittedly a very complex concept but it is often made far more complex by linking it to depression in studies where the depression scale includes fatigue or statements that could relate to physical symptoms (Liechty 1995, Berlyl 1991). Berlyl (1991) has clearly shown differences between PPS fatigue and fatigue in the general population. As an example of the confusion that may arise in research examining links between fatigue, depression and illness severity, is a study of obstructive sleep apnoea (common in postpolio patients), where sleepiness is a major symptom, defined as the physiological need for sleep (Bardwell et al 2003). Patients also experience fatigue, which the researchers defined psychologically as "weariness, inertia and low energy level" rather than the physical result of lack of sleep. The scale used in the study was designed to measure psychological distress. Fatigue scores correlated with depression scores and not with the disease severity measured by oxygen saturation levels. Disease severity was not measured by levels of sleepiness, for which there are objective tests and which may have had more relevance to fatigue. Having admitted that the study could not determine direction of causality, the authors conclude that because the correlation with disease severity was low, fatigue is most likely caused by depression. The bias in this study, resulting in the choice of tests and direction of causality expected, seems to be inherent in medical thinking that the most objective tests should be chosen and the most subjective symptom is likely to be psychological.
The Oslo team next conducted a survey specifically on fatigue with 276 members of the Oslo polio support group, compared with a recent Norwegian population fatigue study (Schanke and Stanghelle 2001). Mental fatigue in people who had polio was not significantly different from the general population and the researchers concluded that physical fatigue was the major problem in polio, and that this fatigue was "primarily due to their physical health with both polio-related problems and comorbidity." (Schanke and Stanghelle 2001: 251). In a follow-up to this study, 15 patients, with either mild or severe fatigue and no comorbidities underwent extensive psychological and physiological testing. One comorbidity of the Norwegian fatigue survey was low back pain, a common problem in polio, which eliminated 49% of polio patients. The only differences noted in the fatigue comparison were that the severe group had fewer years since polio and had elevated SCL-90-R scores on the obsessive-compulsive behaviour, depression and anxiety scores. They therefore conclude "that attention should be given to assess psychological distress and depression when fatigue is reported among polio survivors." (Schanke et al 2002: 139) One significant result not mentioned was that the severe group had more pain. They were also younger, more often female, were more likely to be on disability benefits and had had more widespread polio. It has also been found that chronic pain patients have the same pattern of scores on the SCL-90-R, and scores returned to normal if the pain could be treated (Wallis et al 1997). The higher score on the obsessive-compulsive behaviour component in patients with pain was felt to be due to the concentration and care needed in daily activities when dealing with pain.

Why had this rehabilitation team changed their view from their early hospital follow-up, where they concluded that depression was not the reason for fatigue (Stanghelle and Festvåg 1997)? In the 2002 study, comparing mild and severe fatigue, a group of physical tests of lung function, maximal exercise capacity, perceived exertion, strength test, ADL and mobility indices showed only one significant difference -- perceived exertion (Schanke et al 2002). The authors cite research of higher depression levels in people with PPS, fibromyalgia and chronic fatigue syndrome and recommendations of psychotherapy and psychopharmacological interventions, which they suggest may be beneficial for "polio survivors experiencing fatigue without physical or medical problems" as "our
study does not support the general notion that perceived fatigue in polio survivors corresponds to physical function and test results." (Schanke et al 2002: 139-140) This conclusion disregards the study of Nollet et al (1999) showing that although the strength of two groups may be the same, the performance may be quite different, and the caveat by Perry et al (1988) that manual muscle testing is of limited value in polio patients.

In the Norwegian Polio Study 1994 survey, fatigue had been divided into general fatigue and fatigue during exercise, with the second being most common (Wekre et al 1998). In the 5-year follow-up studies and the Norwegian Polio Study of early experiences and psychosocial well-being, only the term 'fatigue' is used (Schanke 1997, Stanghelle and Festvåg 1997, Schanke et al 1999). In the same team's survey specifically targeting fatigue, a patients' description of fatigue is given as "an increasing loss of strength during exercise, such as overwhelming exhaustion, or flu-like aching accompanied by a marked change in the level of energy, endurance and sometimes mental alertness" (Schanke and Stanghelle 2001: 244). This is the muscle fatigue described by Berly (1991) as being quite distinct from the fatigue experienced by controls, as it was felt as a heaviness in the muscles and was made worse, not better, by exercise. In the Schanke et al (2002) study, this physical fatigue is redefined as psychological, as there were no objective differences in physical tests between the mild and severe fatigue groups. The patients' view of fatigue is no longer accepted as there are no tests for this kind of muscle fatigue.

Credibility, uncertainty and understanding

Each of these three teams has set out to increase the understanding of postpolio syndrome and how it affects people. Each has meticulously delved into different controversial aspects of PPS including muscle fatigue, pain, fatigue and nonparalytic polio, and then reached a level where understanding became difficult and tests were lacking. It is at this point that discomfort with conflicting data often leads to stricter categories and elimination of a group of people from the diagnosis (Douglas 1999, Crawford 1994). The McGill team did not propose a hypothesis for the muscle pain which did not correlate with weakness. The Bergen team used a strict PPS definition to maintain credibility and
eliminate people with muscle fatigue and pain who did not meet objective criteria for muscle weakness. The Oslo team redefined physical fatigue as psychological because objective muscle weakness differences were not found. They have not found explanations for the pain and physical fatigue, but they have maintained the narrow definition of PPS as new objective muscle weakness resulting from the disintegration of enlarged motor units caused by viral destruction of motor neurons. They have each found the same, anomalous group of people, mostly women, often younger when they had polio, with widespread original weakness and new muscle fatigue, fatigue and muscle pain. With the strict definition, many patients are left without a diagnosis, acknowledgement, explanation or advice.

In order to understand why these PPS clinician-researchers are not addressing the conflicting data about PPS muscle fatigue and pain, I will approach these cases from two angles -- the research on the need for certainty and credibility, and the responsibility towards patients. Social research on contested illnesses has concentrated on the patient's experiences and the doctor-patient relationship, not on doctors' role in research and how and why definitions and paradigms are formed. As discussed earlier in the chapter, doctors are trained for certainty, which sometimes leads to dogmatism (Atkinson 1984), but must also deal with uncertainty when diagnoses are not straightforward (Fox 1957). When tests are normal and there is an uncomfortable conflict between pathology and medical history, the biopsychosocial approach is used to blame the patient and leave the authority of biomedical theory untouched (Armstrong 1987, Kirmayer 1988). Salmon and Hall (2003) suggest that medical practice is influenced by a combination of scientific understanding and the needs of doctors. What may appear to be the medical profession expanding into more and more psychosocial and everyday problems may also be a way of distancing from and escaping responsibility for these problems by defining them as psychosocial.

An example of the discomfort clinicians feel about possible inconclusive tests is a study by Halstead and Silver (2000) of four PPS patients who had never had a diagnosis of polio but did have abnormal EMG tests in all four limbs. Although the EMG may miss
the abnormal muscles in mild cases, Halstead and Silver insist that they are necessary for a diagnosis. The patients in this study were given extensive testing "that made us comfortable in making a diagnosis of PPS" (Halstead and Silver 2000: 18). More recently, Sandberg and Stalberg (2004) demonstrate that a small number of patients with a history of paralytic polio (some with sequelae such as weakness, atrophy, scoliosis, pain and fatigue) may have normal EMG tests. Their reasoning for these results was that tests are only abnormal when 30-40% of neurons are lost, neurons might have been affected but not killed, metabolic changes may have caused the symptoms, or there may have been central nervous system involvement.

Even without abnormal objective tests, doctors are more comfortable with certain types of symptoms. In a study of GPs' perceptions of chronic fatigue syndrome and irritable bowel syndrome, it was found that doctors pejoratively stereotyped and blamed the chronic fatigue patients because the lack of a precise location for the symptoms made it difficult to conceptualise a pathological mechanism (Raine et al 2004). Other studies have found that GPs vary between physical and psychological explanations in different patients with CFS, depending on whether the patient is seen as previously active and positive or not (Horton-Salway 2002), or shift in using physical or psychological approaches in the same consultation, trying to minimise frustration and feelings of powerlessness (Woivalin et al 2004). In hospital neurology departments, up to one quarter of patients are thought to have non-organic symptoms, and studies have attempted to clarify, through detailed psychiatric testing, those whose symptoms are considered psychiatric and those who remain undiagnosed, but such detailed testing is not done outside research (Creed et al 1990).

The certainty that is needed in order to make decisions that may or may not harm another person leads to doctors' strong beliefs about objective tests and signs, in order to feel comfortable, for themselves and in the eyes of their profession, about giving a diagnosis, advice or prescriptions (Atkinson 1984). Then the question arises of whether the data match the strong beliefs or lead to surprising anomalies, which might then be ignored.
"Good science inevitably embodies a tension between the empiricism of concrete data and the rationalism of deeply held convictions." (Kaptchuk 2003: 1453)

The conflict between certainty and uncertainty in medical training and the biomedical model leads to the separation of contested illnesses or subjective symptoms into psychosocial categories, and the consequent dismissal of patients with these symptoms from medical responsibility. Research may begin open-mindedly but will then be channelled in ways that uphold definitions supported by objective tests.

3.4 Conclusion

Postpolio researchers are entrenched in historical perspectives of polio as a disease of motor neuron death, rarely factoring in the widespread damage and ongoing complex adaptations made by the nervous system. Patients that do not fit into the strict biomedical category are relegated to the psychosocial categories of anxiety and depression, without necessarily fulfilling any criteria. Doctors create a balance between strict objective tests and their comfort with the blurred edges of the categories. Intuitive judgements may need to be made about whether the patient is believed, and whether the patient is seen as stoically coping or amplifying everyday aches and pains. It is sometimes possible to solve these conflicts by listening to patients' descriptions of symptoms in context, as was done by Berlly (1991) in his study on general and muscle fatigue.

Patients are integral to disease and the social construction of a diagnosis, especially when symptoms are subjective. Feinstein (1967) emphasised the importance of careful listening to patients' symptoms descriptions in order to account for the complexities of illness beyond the reach of laboratory test results. Brown (1995: 44) argues that "Lay people are often central to the discovery of diseases and conditions. People are often most aware, via direct experience, of problems which might not routinely come to medical attention". But he also cautions that "Professional factors can include discovery as well as resistance to discovery." In all of these research studies, there has been resistance to understanding postpolio muscle fatigue and fatigue because the pathology is not understood. To include these symptoms, it may be necessary to situate the different aspects of muscle fatigue.
(transient weakness, aching, heaviness, exhaustion) in the context of activity over time -- what someone was doing and what happened next.

Sometimes when I'm with a patient who is having trouble getting across to me what he wants to say, I tell him to stop describing the pain, and just tell me where he was when the pain came on, and what he was doing. When the pain knocked on your door, interrupting your life, what were you doing? (William Carlos Williams quoted in Coles 1989: 105)

It is important to bring symptoms within their context into the formation of a diagnosis because the disease definition is no more than an interpretation or medical story (Hunter 1991). Several studies conducted before PPS was named or defined had more insight into the importance of fatigability as a cause of weakness than later studies, because no story had yet been formed (Anderson et al 1972, Hayward and Seaton 1979). The medical story is usually based on statistics, but statistics are not free from stories, either (Kaufert and O'Neill 1993, Newman 2003). Certain statistics are focused on rather than others, and lines must be drawn between normal and abnormal, leading to over or under-diagnosis or treatment. For instance, in a controversy about safety seats for infants in aeroplanes after a couple of high publicity crashes, it was realised that higher infant plane fares might force more parents to travel by car, causing more infant deaths in car crashes. These deaths, however, would be less noticed than those due to plane crashes. "The infants who die in these car crashes do not crash and die statistically; they really crash -- they really die" (Bishai 2003: 953). Two stories needed to be heard, but the second story was not obvious, like the story of muscle fatigability. Evidence has shown how difficult it is to elicit abnormalities on EMG testing on the less affected limbs of polio patients (Hayward and Seaton 1979, Bromberg et al 1996) and the deficiencies of the manual muscle testing (Perry et al 1988), but these methods continue to be used to guide doctors on diagnosing and treating postpolio symptoms rather than listening to the 'real' patient with 'real' pain. Without the correct abnormalities on tests, these patients do not count, although this may include 53% of polio patients at a clinic (Farbu et al 2003).
4. Research design

Loss, mourning, the longing for memory, the desire to enter into the world around you and having no idea how to do it, the fear of observing too coldly or too distractedly or too raggedly, the rage of cowardice, the insight that is always arriving late, as defiant hindsight, a sense of the utter uselessness of writing anything and yet the burning desire to write something, are the stopping places along the way. (Behar 1996: 3)

4.1 Introduction

The original impetus for my research was a personal interest in postpolio research and what I perceived as a lack of fit between patients' symptom descriptions and those in the medical research. The aim of the current study was to explore how polio and its after-effects, and later PPS symptoms, affected people's lives. In my MSc postpolio survey, some respondents wrote that they had never seen themselves as disabled or polio had not been talked about in their childhood, and this has been reflected in the literature (Scheer and Luborsky 1991). This study questions the prevalence of this experience of silence and how, if it was so, people learned to live with it. A related aim of the research was to examine the experiences people had with the medical profession and how this related to PPS research. The study involves two approaches to living with a long-term chronic illness: looking at the life story after polio and more specifically how the symptoms and disability have affected and merged into that story. The life story and illness-disease story are inseparable, but need to be teased apart momentarily in order to devise the best methods to study them. Multiple methods (epidemiology, survey and in-depth interviews) have previously been found useful in a study of the long-term effects of polio (Kaufert and Kaufert 1984). Lerum (2001) suggests that a "layered account" of narrative, theory and statistics can be used as a form of triangulation. Two methods were used to facilitate answering the research questions, a survey and in-depth interviews, with the major emphasis being on the use of narrative in the interviews. The interviews included other material from the interviewees such as diaries, stories and photographs. Background information was acquired from two e-mail lists (Postpolio Medicine, PPM and Lincolnshire Postpolio Network, PNLincs), support group newsletters and visits to support groups. Medical knowledge about polio and doctors' attitudes towards PPS
developed through in-depth study of medical research articles compiled through Medline, and a small survey sent to 20 neurologists and rehabilitation specialists.

A survey method was chosen in order to obtain background information about the initial polio and PPS symptoms, and provide a varied sampling frame. The main approach was qualitative as the research questions centred on meanings rather than quantifiable events or facts (Silverman 2000). Narrative became a particular focus because it is "a fundamental human way of giving meaning to experience" (Mattingly and Garro 2000: 1) and is appropriate for what were often lifelong, biographical stories. Narrative analysis focuses on what stories are told and why they are told in a certain way (Riessman 1993), and I was interested in cultural prescriptions about the kinds of illness and disability stories (and lives) that are expected, and possible resistance to these stories (and lives) (Frank 1997a). Narratives are often used to explain the unexpected, from change in everyday occurrences to major disruptions such as serious illness (Becker 1997).

On one level, there were two reasons why I wanted to concentrate on narrative rather than any other form of semi-structured or unstructured interview. Two of my research questions were whether the initial young adult and child polio stories differed and why there seemed to be a lack of fit between patients' and doctors' stories of the symptoms and disease. Biographical narrative could therefore be a way into understanding both the patterns of how polio affected social lives and the pattern of symptoms over a lifetime. On a deeper level, there was a question about the effects of living with a forgotten epidemic disease, forgotten both socially and medically. The effects of polio on those who had been affected, which had often never been thought about or discussed, caused deep emotions, and stories of everyday life are a way into emotion and meaning. It is the everyday routines and their disruptions which may be focused on during a difficult time and are then talked about. This chapter describes how these methods were planned and used.
4.2 Survey

A survey was carried out primarily to generate a sampling frame for in-depth biographical interviews. The survey made it possible to access a wide range of people who had had polio and varied in age, the age that they had had polio (polio age), gender, illness severity and PPS symptoms. This sample was self-selected and would probably not (judging from experiences talking to people, reading support group newsletters and PPS e-mails) have included some people who do not want to talk about polio or PPS, do not believe in PPS or who are wary of research motives, especially in relation to disabled people. Others may have felt their story was too ordinary or not the kind of story they were comfortable telling or anyone would want to hear. The study was advertised through the British Polio Fellowship (BPF), the sole UK polio support group, founded in 1939. The BPF is split between the long-term members, who are older, generally more severely affected and less interested in PPS, and newer, younger members who have joined more recently because of PPS problems. Most local BPF groups are social groups dating from the 1950s, but a few recent groups have emerged which focus on PPS. The organisation itself has a chequered history in relation to scepticism about PPS. However, several people in the survey also mentioned reservations about PPS, indicating a range of attitudes. Polio and its after-effects are very variable, and a large sample was needed to encompass the range of initial and later symptoms. There have been contradictory research results about PPS symptoms, especially gender effects, and no research has specifically pinpointed the effect of the age people had polio. The survey has been able to explore some general differences in symptoms between these groups.

The survey related to that used in the MSc, which was influenced by other postpolio research surveys and by symptom descriptions from postpolio e-mail groups and support group newsletters. The MSc survey had been conducted in 2000 with 90 people who answered an advertisement placed in the British Polio Fellowship (BPF) Bulletin. Questions had been asked about the initial polio paralysis and weakness, pain during the stable years and new postpolio symptoms. There had been some unexpected differences in postpolio symptoms between different polio age groups and between men and women.
PPS research has occasionally shown some gender differences in risk of PPS (Ramlow et al. 1991) and symptoms (Lonneberg 1993), but the polio age has never been considered a factor until a recent study on pain (Vasiliadis et al. 2002). A limitation of a self-selected survey is that it might attract people with more severe symptoms, but results are similar to the above studies which were population studies or random selection from a clinic. A wide range of severity of both polio (including nonparalytic) and PPS were recruited.

In the new survey, additional questions were asked about severity of the original weakness and the major PPS symptoms, weakness, muscle fatigue, pain and fatigue. Open-ended questions were asked about fatigue and muscle fatigue and there was an empty space for comments at the end (Appendix 1 letter and survey). In the MSc survey a chart was used to show in which parts of the body people had weakness, muscle fatigue and pain. In the current survey, this was divided into three sections (mild = 1, moderate = 2, severe = 3) to indicate severity. A score could then be calculated for extent and severity of the symptoms to provide a rough estimate for the different age and gender groups. It was important to get an idea of the severity of the original weakness and later symptoms, as there was such a large variation, and I found that if there was only one category, mild symptoms would not be mentioned (Appendix 2 criteria used for symptom categories).

Advertisements about the project and survey were placed in the BPF Bulletin and on the Lincolnshire Postpolio Network (LPN) e-mail discussion group. The Lincolnshire Postpolio Network is an independent PPS support group which is both local and international, through its internationally known website of PPS information and medical research articles. Having a diagnosis of PPS was not a requirement to take part in the survey. Cardiff and London postpolio groups, recently started local BPF groups, were also contacted. The list of respondents from the MSc was combined with those who answered the new advertisements. The survey was sent out in the spring of 2002. A letter was sent with the survey briefly describing the survey, the possibility of a future interview about the experience of living with polio and PPS and confidentiality concerning name and address for future contact if they were interested in any future
4. Research design

follow-up, which most were (Appendix 1). I also mentioned that I had PPS. A pilot study was conducted by initially sending questionnaires to the first 20 people from the MSc list of respondents. A few subtle changes in wording or order followed. In all, 223 questionnaires were sent out and 170 people replied, a 77% response rate. There were 101 women and 59 men in the group that were analysed on SPSS (several questionnaires were sent later). The average age of respondents was 63, and the average polio age was 8. The age range was from 44-88, and the polio age range was from a few weeks to 36 years (results in Appendix 4 and 5).

A small survey was sent to a group of hospital consultants to ascertain whether they had heard of PPS, how they defined it, the symptoms, and the cause of the symptoms (Appendix 3). This was undertaken because the knowledge and attitude of hospital consultants in the UK about PPS is unknown and could be influenced by the limited and sceptical UK research (Kidd et al 1997, Howard 2003), or more varied research from the US and Scandinavia (Grimby et al 1998, Jubelt and Agre 2000). Doctors were chosen either randomly from hospital websites or from the British Polio Fellowship list of interested consultants, and 20 letters were sent out. Nine letters were sent to BPF consultants and six replied. Eight letters were sent to other consultants and four replied. An additional three individual letters were sent to three PPS specialists, who had written about PPS, and they all replied (results in Appendix 4).

4.3 Interviews

Interview sample

Interview participants were chosen from the survey by a combination of geographic proximity to my home and the University, and to acquire a wide variation of respondents by gender, polio age, polio severity and PPS severity, criteria used in recent PPS risk factor research (Trojan et al 1994, Vasiliadis et al 2002). The large sample from the survey made it possible to find more people who lived within 50 miles initially. As women and those who had polio at a young age (0-5) were most common in the survey,
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these would also predominate in the interviews. These groups are underrepresented in polio autobiographies and have caused controversy in the medical research as discussed in Chapter 3 (see Appendix 6 for factors influencing sample choice).

Thirty-one people were interviewed, 20 women and 11 men. Their ages ranged from 47 to 88, and their polio ages from 5 months to 25 years. The proportion of men to women was similar to the survey. A lower proportion of people who had polio as teenagers or older were interviewed, partly due to geographical chance, and partly because PPS had impinged later and less on their lives, especially in the case of men. Twenty-six of the interviewees had been hospitalised with their initial polio. Four had not been hospitalised --- three who had had nonparalytic polio and one who lived in South Africa --- and one who had polio in 1915 was not sure. Of those who were not hospitalised initially, the ones who had paralytic polio were later hospitalised for surgery. Two of those initially hospitalised spent several months in iron lungs.

Pilot work: Three pilot interviews were conducted with those who lived nearest to me, which helped to plan the form of the interview and certain questions about childhood and disability. These interviews were included in the final study.

Sample selection: The initial interviewees, after the pilot, were mainly chosen for their proximity. When there was a choice among those who lived further away, consideration was given to factors such as gender, polio and PPS severity, and polio age, and the comments on the questionnaire, in order to get a large diversity of experiences. Another geographic consideration was whether there was a cluster of people in one area where I could spend several days, as I did in London and Suffolk. This was necessary due to the fatigue I experience from travelling. The people interviewed were of several nationalities (Australia, South Africa, US) and came from a wide variety of backgrounds. Two described their father's rise from a working-class background to a middle-class life, and another four described their rise through education from a working-class childhood to professional life. Because of their disabilities, however minor, only two did manual work, both eventually moving into business. Of the 31 people interviewed, 11 had
degrees, three of them from working-class families, one of whom was from the US. Of those 11, two obtained their degrees some years after leaving school. The others either left education at 14 or 16, or continued towards non-degree professions such as nursing, teaching and accountancy (Appendix 8 interviewee details).

As a BPF postpolio group had recently started near the University, I contacted them, went to several meetings, handed out surveys, and interviewed 6 people from the group. One of these six people was housebound and did not take part in the survey but was interviewed together with another member who asked me to include her friend. I was contacted by another BPF postpolio group in London, went to one of their meetings and later interviewed three people. One interviewee did not belong to the BPF or any support group and was told about the study by his ex-GP, who saw the study mentioned on a narrative health research e-mail list. Two other people who belonged to the BPF were contacted by me: one who had nonparalytic polio and contributed a letter to the BPF Bulletin, and another who was featured in a local newspaper article given to me by another survey respondent. In three interviews, other members of the family took part. One daughter took part in the entire interview, and one husband and one wife came in part way through. In many of the other interviews I met and talked to partners. At academic conferences or seminars I also met three children of people who had polio, who described different polio legacies. Meeting many people who had polio and their relations, as well as reading many polio stories in newsletters, autobiographies (Le Comte 1958, Marshall 1989, Beisser 1989, Gallagher 1998, Mee 1999), and belonging to two PPS e-mail lists, generated background information and helped validate the findings in that similar themes were recurrent. Notes were taken about polio stories heard at support group meetings or conferences.

Six interviews were conducted by telephone, either because people were very busy or lived too far away, which Sturges and Hanrahan (2004) found comparable to face-to-face interviews. I had met two of these people previously. I wanted to interview the others for specific reasons: one was the only one in the survey who had completely recovered, one had been in an iron lung as a child (I had interviewed one adult who had been in an iron
lungs), one was an age (8) which was not well represented, and one had told me an interesting story on the telephone about her father's attitude to disability. Although I did not see these four people, their interviews were comparable to the others in that they were used extensively and were valuable in the study analysis. In a study of a sensitive subject, phobias, Davidson (2005) found telephone interviews were preferred as being potentially less anxiety-provoking, and yielded comparable results to other interviews.

An additional interview was written through e-mails with someone who I did later meet. This occurred because he had sent other written material about his life and theories about PPS with the survey. After several e-mails back and forth about the neurological basis of PPS, he began to write about his life, which I compiled as an interview transcript. The 31 interviews included 24 face-to-face interviews, 6 telephone interviews and one e-mail interview.

**Interview design**

I planned to undertake informal semi-structured interviews, in order to encourage the trust needed to feel comfortable and tell a story possibly never told before. In sensitive interviews such as this, trust develops between interviewee and researcher through a mutual experience of humanity and emotion (Lillrank 2002, Ellis and Berger 2003, Rosenthal 2003). That I had PPS and understood some of the symptoms made this easier, as has been found in other studies where illness or disability experiences were shared (Lipson 2001, Tregaskis 2004, Landsman 2005). Informality, in this case, meant not asking set questions but relating questions to the story being told to facilitate the flow of a narrative and give the interviewee some control (Chase 2003). Trust was initiated by having a discussion, if they wanted, about polio, PPS and the background of the research on the telephone when I rang to ask if they would take part in the interview. Notes were written afterwards about these conversations which informed the interview guide. Only one woman did not want to be interviewed and this was because she decided she was uncomfortable discussing her life, which involved leaving Austria for England just before World War II, three years after she had polio at age six. Everyone else said they felt comfortable about doing the interview and talking about their polio memories.
I explained about the form of the interview, anonymity (names would be changed) and
the use of a tape recorder or mini-disc recorder, and arrangements were made for the
interview. I also made clear that the interview could be stopped at any time, that I would
be interested in any thoughts or questions they might have after the interview, and that I
would be in contact again with the transcript for their approval. I visited most people at
their homes, but three, who lived relatively close, chose to come to my house, and one
came to the place where I was staying to do distant interviews. Later I did visit the home
of one of these people informally. Although interviews in people's homes and face-to-
face interviews add information from lifestyle and body language, the lack of these did
not seem to detract from the interview. People may be more or less comfortable on the
telephone or outside their home. Some may have wanted to know more about me. I
telephoned people again just before the interview to check that they were still happy
about doing the interview. I constructed a written interview guide of basic points to be
covered, and specific points that may have arisen for each person from the survey, stories
written on the survey or telephone conversations (see Appendix 7). The guide was
generally referred to towards the end of the interview to see if everything had been
covered.

Most interviews began with the initial polio story, as that was often a dramatic story to
tell. I introduced the interview by saying I was interested in how their lives had been
affected by polio and PPS and suggested we begin at the beginning with when they had
polio or their life at that time. In a few cases I began with their present life and PPS
symptoms because they had begun talking about it. If they were very young when they
had polio, I would ask about their first memories and what they had been told about
having polio. People talked about whether memories were clear, vague or missing, and
whether they remembered images, emotions, sensations, tastes or smells. I wanted to let
people first tell their story, choosing important events themselves, and this happened in
many cases. Some people needed some direction, as they thought that only medical
considerations were relevant to a polio story. Other people felt their story was so ordinary
that there was nothing to tell. The interview remained fairly unstructured, in that
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specifically worded questions were not used. There was general guidance to carry on with the story beyond the polio treatment phase to explore how polio affected later life, school, family and jobs. If the subject was not mentioned, I would ask if people had felt disabled or if other people knew they had had polio. If the story stalled, questions focused on everyday occurrences and incidents which might encourage narrative.

As polio had been so well hidden, these were often emotional interviews, but people generally seemed comfortable and interested in remembering, thinking about, and constructing their story. A few people became momentarily sad mentioning their parents or a hospital experience. I told everyone that they should feel free to stop any time, or not talk about something they felt uncomfortable with. Silence or avoidance of topics may be important to the interview, not simply failure to elicit information. Poland and Pederson (1998) suggest that silence may have many different meanings such as resistance, representation of the untellable, or reflection of the taken for granted. Within the interview, the authors suggest silences may be exacerbated by cultural differences or similarities between the researcher and the respondent. Several people did not talk about certain aspects of their lives, and others sent me stories, photographs or diaries that they felt might clarify times that were difficult. Where relevant, the stories and diaries were coded and included in the analysis. Photographs have been used in the analysis where it is felt that they clarify a story and written consent was obtained wherever possible to use these photographs. Becker (1997: 14) suggests that people sometimes use photographs and scrapbooks because "narrative cannot completely capture the expression of emotion". Schlesinger (2004: 55), writing about narrative and exile, argues that "photographs may also connect memories... and are central to how we constitute our family identities."

After the interview, we usually chatted to unwind, sometimes turning the tape back on if something interesting came up. The interviews generally lasted between one and two hours.

I initially planned on doing one interview per person for logistic reasons to do with travelling and because I wanted a wide enough sample to cover different ages and polio severity, which might not have been possible with multiple interviews. However, I
remained open to future interviews if needed and did use other means of follow-up, such as e-mail and telephone, with most people shortly after the interview. After the interviews had been transcribed, I sent, by post or e-mail, a copy to those who had said they were interested in receiving a copy, and asked if they were happy with it and whether they wanted to add or subtract anything. I also sought clarification of some questions I may have had from the interview. A transcript was sent to all except one woman, who said she did not want one. I had telephone or e-mail response with all but three people, who did not reply to the e-mailed transcript, and had seemed ambivalent about the interview. I have remained in informal contact with 10 people, through a local support group (4), e-mails (2), telephone (3) and occasional visits (1). Two people did add important points to their story in a future telephone conversation and this was recorded afterwards as notes. These contacts were informal but gave valuable information about the continuity and flexibility of the interviewees in other settings, other interactions and outside the story told at one moment in time.

Narrative, ambivalence and emotion

These polio stories had often been hidden for half a century, overshadowed by cultural stories of achievement and 'triumph over adversity' (Westbrook 1996, Bruno and Frick 1991). When a story has been hidden for so long it may be told in a matter-of-fact, emotionless manner (Bar-on and Gilad 1994). Paradoxically, matter-of-fact accounts of trauma may be very emotional to hear. Narratives may also be about avoiding meaning or presenting the discordant as normal (Craib 2000). Similarly, in interviews, for whatever reason, some people cannot or do not want to tell stories, especially if the emotions are forgotten or too difficult. A researcher may wish to construct a life story with an interviewee as a changing, fluid creation (Good 1994, Mattingly and Garro 2000), but find the person has a rigid story they are reluctant to change. Rosenthal (1993) interviewed a former Nazi who had a well-constructed story minimising his choice in his past behaviour. McKevitt (2000) found that some of the people he interviewed had no story at all, being totally isolated, silenced people. More relevant to this study, Järvinen (2000) selected less successful interviews of alcoholics to demonstrate the value of
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interviews that do not conform to cultural expectations of justifying behaviour considered negative. An interpretive approach allows one to be open to all these ambiguities and accept them, not pressuring people to tell stories they do not want to tell.

If we foster the illusion that we understand when we do not or that we have found meaningful, coherent lives where none exist, then we engage in a cultural practice that is just as repressive as the most repressive of political regimes. (Denzin 1987: 83)

Accepting that people may avoid difficult aspects of stories, the dilemma arises of how sensitive the subject is, whether one should probe further, or whether probing would be intrusive. Each situation needs to be evaluated individually, at the moment. Although Lillrank (2002) found she could use her own emotional reactions to the unexpressed emotion of the interviewee to help keep the interview going, and in the interpretation, others have found their emotional reactions and judgements more problematical (Young and Lee 1996). Barnard (2005) explores these difficult issues in the highly sensitive area of the effects of parental drug use on the well-being of children, where judgements of harm need to be made and where research can also cause harm to the individual or the group. She distinguishes between probing in the interview and the later probing of analysis, the fallibility inherent in research and the balance needed in deciding how far one should go. I learned from doing the interviews that one has to use a range of interview styles to accommodate people's differences in what they think an interview is, and how they think about their life. I may have wanted to ask a single question and allow a life story to emerge, and then initiate a natural conversation to resolve further points, but in reality I found I was doing something far more complex in order to encourage different people to talk about their lives. It seemed best to follow what the person needed to tell the story.

In retrospect, I did interview people who were ambivalent about telling their stories but they wanted to be helpful and did not like saying no. I rang one woman for an interview because she was the only person who had completely recovered from polio to the point that she went jogging every day. I had some trouble contacting her as she was never at home and she said she did not really have time for an interview. I said I could come to
her house any time for just an hour or so, but she was resistant. Finally, as a last chance, I mentioned a telephone interview, and suddenly she changed her tone and we arranged a time for the next week. When I rang, I wondered whether she would be there, but surprisingly, she sounded pleased and said she had arrived home half an hour earlier and made a cup of coffee ready for the interview. I wondered whether she had felt she did not have a story to tell, or whether she preferred the informality of a telephone interview.

Another woman rang me about my questionnaire because she realised I lived only a few miles from her house. She was in her sixties, lived alone, and spoke angrily about how she would not 'give in' to her fatigue and weakness, and she would carry on doing everything in her house and garden. She went on and on, and I began picturing people who had always been in wheelchairs, and some of the people I had been talking to who hated giving up their jobs, their gardens, travelling and countless other things they loved doing. I thought of myself, and finally, I interrupted, quietly, "You know, some people don't have any choice." There was silence. Then very quietly, very movingly, she said, "I know." With hardly a pause, she continued in her angry voice saying that she was not going to give in, that she would not let it get her. I sent her the questionnaire but I did not expect a reply and I did not get one. I felt that my comment signalled to her that an interview might cross into difficult territory for her, and it was up to her to take up the challenge or not. I felt like I was chasing shadows and another shadow had faded from sight.

Several people who were interviewed feature less in the study as they said they had not thought much about the past or did not want to dwell on the subject, but in some cases these stories were interesting in their brevity and in the one or two illuminating stories they contained. A few others did not want to talk about several aspects of their lives, but appear in sections where their story is relevant. Several interviews felt like chasing shadows in that I had a brief interlude of meeting and talking to someone but then they disappeared, and I felt that that was what they wanted. For instance, two men said they enjoyed telling their story, but they would forget they had told it by the next day. When I contacted one of them about the transcript, he said he had forgotten. As in Järvinen's
It was apparent from having open-ended questions in the survey, written stories and diaries, and interviews that some people are better able to describe symptoms and how they feel in writing, when they are alone with time to think, than in an interview. One man sent me a diary he had kept for two years about his medical experiences with PPS, which uses bold type, capitals and lists, which juxtaposed endless fruitless appointments resulting in inappropriate advice, to express, organise or control his feelings. In the interview, when asked how he felt about the lack of knowledge about polio, he only said he understood why polio was forgotten. One other person sent a diary from when she was in hospital as a teenager, two sent me stories they had previously written about having polio, and one sent a book he had written and privately published about his missionary family, which included his polio story. Another sent me a fable about a disabled child that she wrote about six months after the interview for a writing class. Two people showed me historical books with photographs of the rehabilitation hospitals they had been in, another showed me childhood photographs during the interview, and two more sent me childhood photographs afterwards. Possibly because polio had been so long ago, because it is now seen as history, because they had been young, or found it difficult to discuss, people looked for other means to explain their experience. Becker (1997) found that people sometimes used photographs or artwork to add to a difficult, distant story. Having learned to 'be positive', several people found it difficult to criticise, complain, talk about symptoms or say anything negative in an interview, after having spoken spontaneously or written about negative feelings previously. The need some people feel to use different communicative forms beyond the interview suggests a tension between different cultural and personal stories, and how acceptable they are felt to be.
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The position of the researcher

The researcher also has emotions about the interviews and people interviewed, which are important both during the interview and as part of the analysis (Lillrank 2002). In almost all of the interviews I felt a great deal -- with the person and for the person and their life. I did not come away from any of the interviews with negative feelings because each person told stories about balance, however fragile, between their strength and vulnerability, their independence and interdependence. I understood but did feel uncomfortable in one or two interviews when someone judged other unknown ill or disabled people to be 'giving in'. I did not want to judge others for being judgemental or for any other reason. This has been a hidden problem in both interviewing and analysis, which recently has been aired, but there are no easy answers, especially when harm is being done to others (Barnard 2005, Hoskins and Stoltz 2005). Another potential problem in researching sensitive subjects is the reaction of other academics. I found that the subject of ill children being treated as objects, silenced, or harmed by ostensibly good intentions was particularly sensitive, and could lead to anger in academic discussions. People who had had difficult childhoods themselves seem to become more understanding and sympathetic or more stoical and defensive.

If the interview is seen as a mutual construction (Gubrium and Holstein 2003, Ellis and Berger 2003), the question of how much the interviewer needs to understand the interviewee's situation becomes more important and relevant. In medical sociology sensitive work has been done by sociologists with illnesses or disabilities (Zola 1982a, Murphy 1990, Frank 1997a). Lipson (2001) describes what she calls 'peer research' in a study of a contested illness which she also has, multiple chemical sensitivity. Some of the benefits she found included ease of recruitment, trust and ability to observe subtle nuances. Zola (1982a) studied a Dutch disability community partially as an outsider, since he had recovered enough from polio to be able to ignore his disability and deny its existence. His study became an enlightening experience about his own ambivalence about disability.
In short, even though people with disabilities have long been writing about their lives, to a marked degree certain aspects of those lives have been inaccessible even to themselves. I fear that remains true to a larger extent than anyone with a disability (including myself) is aware of or willing to admit. (Zola 1988: 7)

In this study of polio and PPS, I am also a partial outsider as I did not have the experience of an acute illness and hospitalisation, or remaining visible disability. On the other hand, I have always experienced muscle fatigability, and more recently the inability to walk more than a few metres without becoming weaker. I also understand the confusion of having lifelong symptoms that were never understood. I think that I gained some trust in that I am disabled and understand the symptoms, but caused doubt for some people because I do not have the usual polio orthopaedic problems. Several people interviewed said they would not discuss their symptoms with someone who had not experienced and therefore could not understand their pain and fatigue. Like many who had polio, I do not think of myself as disabled (Scheer and Luborsky 1991, Halstead 1998b) and therefore I inhabit a space both inside and outside the category of disability, creating an interesting point for observation. I have also never concurred with the common portrayal of the wheelchair as a tragic symbol, because of my own childhood experiences of wheelchair-users (see Appendix 10).

A short autobiography/ethnography has been incorporated into the analysis where it was felt it might aid understanding as "autobiographical or introspective material in the service of a sociological analysis" (DeVault 1997: 218). Greenhalgh (2001: 53) argues that autoethnography is not self-obsessive because "the central narrative is not the unfolding of a life but the development of an argument" and is developed within an analytic structure. In this study, the word 'autobiography' has been used for accounts that consist mainly of past memories, and 'autoethnography' for recent accounts or retrospective analysis. In each chapter, I attempt to ask myself questions as if I were interviewing myself. Although I interviewed two people who, like me, did not know for many years that they had had polio, and others who did not understand their fatigue, or thought that pain was normal, I had a slightly different viewpoint in that I questioned why a society had developed that was often impossible for supposedly ordinary people to take part in. Why did so many activities and jobs involve standing, when standing was so
When I fell off a ski lift, and slid down the mountain because my arms became too weak to continue gripping it, I wondered why something so impractical and dangerous had been invented. Then I puzzled over why only I had fallen off. One can find everyday excuses for tiredness but not weakness, and I veered between thinking I was wrong or society was wrong, suggesting ways to understand how children and adults attempt to understand or ignore the liminal space between normal and abnormal.

The polio story has mainly been told by men who had polio as teenagers and adults (Zola 1983, Gallagher 1998, Mee 1999). The more confused stories of those who were children have rarely been written because these are particularly difficult stories to know, remember and tell. Postpolio syndrome has never been written about by patients in any extensive way. This study concentrates more on the often untold and unresearched children’s stories of polio and PPS, as they are the largest group, but also important is the comparison with those who were older, and the differences between the stories of men and women.

Analysis

When talking about their lives, people lie sometimes, forget a lot, exaggerate, become confused, and get things wrong. Yet they are revealing truths. These truths don’t reveal the past ‘as it actually was’, aspiring to a standard of objectivity. They give us instead the truths of their experiences... (Personal Narratives Group 1989 cited in Riessman 1993: 22)

Writing about narrative analysis, Riessman (1993) emphasises that narratives are interpretive, whether explicitly or implicitly, but they are also confused, ambiguous and thus open to multiple interpretations by the researcher and interviewee. This is especially true of traumatic experiences which are always difficult to speak about, and "because they are essential meaning-making structures, narratives must be preserved, not fractured, by investigators, who must respect respondents' ways of constructing meaning" (Riessman 1993: 4). On the other hand, they are, to some extent, realities as well and this must also be respected. Skultans (1998a: 26) argues that "Clearly, narrators select and organise memories. But equally the substance of those memories is rooted in past
experience, as population statistics, dismembered families and disfigured landscapes
 testified." Using some of Riessman's ideas, the interviews were studied as each was
 completed, in order to inform future interviews, looking first at the biographical narrative
 as a whole (what kind of life was being presented and why, how did this person see
 themselves and others) and then at individual themes and stories within stories,
 particularly those that stood out as meaningful to the person or myself. These are the
 'epiphanies', significant events or turning points described by Denzin (1987). Categories
 and themes were formulated by looking more closely at the content. At this point, the
 techniques of qualitative analysis, and more particularly, narrative analysis, are never
 fully described, nor is there a clarification of the role of the researcher's emotional
 argues that "fantasies, intuition, interpretations, and reflections do play a crucial role in
 the formation of politically relevant knowledge".

 I also followed Lieblich et al (1998), who describe a similar method of narrative analysis
 to Denzin's use of epiphanies, a holistic-content perspective, which involves searching
 initially for patterns in the whole story, including contradictions and disharmony. Then
 they formulate specific themes, distinguished by the detail and repetition of the subject.
 The beginnings and endings, transitions and contexts of the theme in each story are
 studied. Lieblich et al (1998: 76) also discuss interpretive level from an extreme
 phenomenological stance of "respecting the explicit narrative as is", to an extreme
 theoretical position of doubt in which there is a search "for silences, gaps, contradictions,
 symbols, and other clues to the underlying or implicit contents".

 Josselson (2004: 23) merges these two extremes in a "hermeneutics of faith and
 suspicion", which involves a shifting position of openness to multiple levels of "what is
 said and what is not said." I have adhered to this in-between position, in which people do
 sometimes hide, unconsciously forget, exaggerate, become muddled or come upon areas
 of their lives that they do not understand or have never thought about. Subjects are not
 "data to be discovered or alternatively, constructed" (Mauthner and Doucet 2003: 424),
 but something more indeterminate and complex, with stable and changing aspects. I also
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followed Wikan (1992) who highlights important 'resonant' parts of the transcript and compares within and between interviews, searching for a sense of the paradoxical and difficult. Using studies of state-authorised torturers as examples, Frank (2004: 438) suggests that, through acknowledging the constructed nature of the narrative and the conflicting horror and humanity, qualitative studies "seek not to explain but to deepen complexity. Their contribution is to give complexity an articulate form". Complexity is clearly apparent in these studies of prisoners, but is also a part of illness narratives and less explicitly in everyday life. Ideas of the paradoxical and complex became increasingly important in the analysis of the current study.

The interviews were transcribed by other people, for disability reasons, but each tape was then closely listened to and corrected. Most of the transcripts were transcribed by one person who became familiar with the medical terminology and stories. Transcriptions were as accurate as possible, including indications where there was laughter, sighs, pauses, loud or quiet speech, or special emphasis. Quotations from the transcripts were edited slightly by removing repetition. Every stage of the study was affected to some extent by my disability, from difficulties travelling to difficulties with writing by hand for any length of time. This necessitated the use of voice recognition software which created some limitations in using other complex software. The transcripts were initially coded with concrete categories, and conceptual themes were developed from the language and ideas people used in the interviews. Both codes and more general themes were written in the margins of transcripts. Then, for each interviewee, a short synopsis about their life was written (see Appendix 9), which was combined on one page with a list of important themes and stories. Each person was thus kept intact, allowing contradictions and complexities to remain apparent. To aid the comparison of interviewees, another list was compiled of each person with their ages, polio age, and other details such as time in hospital, job, marriage, children, retirement and problems with doctors. The themes were mainly developed and clarified through writing -- a diary of thoughts, conference presentations (see Appendix 11) and the thesis chapters, which began very early in the interviews and in qualitative research may be part of the analysis (Evans 2000).
An ethical dilemma for qualitative research involving sensitive, personal subjects, as in this study, is the effect the findings and analysis may have on the participants if the results are sent back to them or reports are written for an organisation or support group that co-operated with the research. Barnard (2005) suggests harm may be minimised by better communication about the research to participants initially, being non-judgemental, and describing continuums rather than discrete categories in the analysis. The interpretation of the reader may also affect a study and its participants. The writing about this study attempts to avoid discrete categories and accepts each respondent's definition of terms. Unfortunately, it is impossible for participants to predict how they will feel seeing their words or story in print, as happened to one participant in my survey, who had taken part in another research project, and found it unbearable to look at a chapter which included a short synopsis of her childhood story.

Whole stories were examined first in order to see overall structural patterns and links that were being made between the childhood polio and later life (Bury 2001, Riessman 1993). Rather like Mandlebrot patterns, complexity could be seen both at the level of the whole story and smaller stories or embedded themes. Nussbaum (1990: 7) argues that form and content cannot be separated and "any style makes a statement". Each story was unique but was also permeated with the social and historical story of disability and polio in particular. The cultural polio story, especially among this group of people who recovered quite well, was almost always a story of cure, independence and being normal. This was expressed through repeated phrases such as "I was always treated the same", "I wanted to do everything myself", "I had to achieve more than others", "I never wanted to be helped", and by emphasising career stories. Personal stories were more often implicit. There were some differences in the kind of stories told between those who had polio at different ages, genders, and the severity of the polio and PPS. The youngest children had to rely on their parents' stories to some extent and were often not clear about their past or their present symptoms.

A series of everyday codes was devised including the initial polio, recovery and rehabilitation, surgery, disability, parents, siblings, school, friends, work, marriage,
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children, social life, sport, exercise, PPS symptoms, and doctors. Within these codes were questions of how positive or negative people's experiences were. Notes were made if people had mixed or contradictory feelings at different places in the interview. Another level of more abstract categories was formulated, related to the meanings and emotions people attached to polio, recovery and getting on with life with a disability. These led to more general, conceptual themes. The codes were written on the transcripts using interviewees' words or phrases, and stories about these ideas or feelings within the larger narrative were marked. By coding on the transcript, it was easier to check the context of any story or quotation being referred to. A few interviews consisted predominantly of one or two themes or stories woven throughout, about discrimination at school, relationship with a parent, or a series of hospitalisations. By mainly keeping the stories as a whole, the importance of these major themes remained clear. Sometimes, by comparing two or three people who seemed to have a common thread in their story, an important but possibly subtle theme would emerge. Interviews which might initially have been seen as less successful, in which the person said they had no story or polio had never been a problem often turned out to be very important in creating new understanding. The conceptual themes were divided into those related to the public image of strength and recovery, and a private, more complex image, Goffman's (1990b) social and felt identities. Each theme could best be conceptualised as a continuum, such as stoicism/mixed emotions, independence/interdependence, and they could generally be subsumed under one major theme, which was the tension between normality and difference. Having noted in my MSc survey that many people commented about not feeling disabled (Goffman 1990b), this study sought to trace the effects of the paradox of disability, described by Wright (1960), that disabled people are different but are expected to live as normal.

4.4 Conclusion

Lerum (2001) suggests that although objectivity is usually linked to emotional detachment and subjectivity to emotional involvement, the opposite may be true. Postmodern relativity may create abstractions and distance emotions, while emotional
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understanding, coupled with comparisons on individual and structural levels, may help create a more objective analysis (Lerum 2001). Behar (1996: 12-13) describes incorporating the personal into science or ethnography as "stretching the limits of objectivity" which is only successful if "one is able to draw deeper connections between one's personal experience and the subject under study." This study has adhered to the idea of the subjective and emotional but also objective format, combining closeness and distance within the interview, and comparing interviews within and between each other, and with other empirical and theoretical research on polio, other illnesses, traumatic experiences, and illness autobiographies.
5. Childhood: polio stories, memories and silence

We follow a narrative suspensefully, always reminded of the fragility of events, for things might have turned out differently. (Mattingly 2000: 205)

5.1 Introduction

The paralysis of polio often came on within hours of feeling unwell, although it may have been preceded by a few days of 'flu'. The acute illness would be over within a few weeks. In contrast, the recovery often carried on for years, involving strenuous physiotherapy and possibly surgery. Most of the respondents in this study were children or teenagers when they had polio (17 were five years old or less, and only four were between 20-25 years old), so the polio stories are considered as childhood stories. The two chapters on childhood centre around the stories of the initial polio illness and recovery, almost universally stories about having a normal life and 'getting on with it', interspersed with small, sometimes matter-of-factly told, stories of confusion, ambivalence and not being listened to in hospital or at home. These may not be coherent or comfortable stories, but then, they are stories of lives that were, in one moment, fragmented into before and after paralysis. Bury (1988: 90) describes the "strong cultural emphasis on achievement, action and success in contemporary society and the essentially ambiguous situation this creates for those 'failing' through illness or other misfortune." Due to this emphasis on achievement, polio was rarely, if ever, mentioned after the illness, and stories of being normal and not thinking about it were told. These two excerpts from the interviews exemplify how ingrained were the ideas of normality and the silence this necessitated:

Michael (54, polio at 2): School friends, they remind me of what I was like at school. 'Never thought of you as a polio even with your legs in iron, never ever, it didn't stop you from doing anything. Just a normal school guy...you were one of the toughest boys in the whole of the school."

Nick (72, polio at 2): Polio as a subject was not discussed and I never asked.
The childhood chapters follow a circular path from the initial memories and stories of being in hospital with acute polio, to some of the difficult feelings about these stories, and then the effects for children of going back to hospital for surgery to counteract the problems of remaining weakness and growing with polio damage. The main theme of these childhood polio stories is learning to be independent and putting aside thoughts and emotions to do with polio. This leads to the socially expected 'restitution story' (Frank 1997a). The story of being normal and 'positive' is a story of not showing emotion, becoming strong and taking responsibility for one's recovery (Salmon and Hall 2003). This first chapter about childhood will explore the early polio stories as told now, and how complex feelings about independence and being different are represented.

5.2 Polio stories

How people who had polio came to understand themselves and their disability began with their experience of polio, the impressions they received from family and others, or the stories that they were told. Many people grew up with a message about strength and independence, often powerful and emotional, from doctors, family, friends or school, that remained with them, as a voice in the background, such as 'getting on with it' and being 'no different from anybody else'.

Ken (63, polio at 9 months): I can remember at that, that was a definite stipulation on my mother and father's part that I was not to be... pandered to or... yeah, just let him get on with it.

Jane (66, polio at 11): You just get on, you just, I don't know anyone that didn't just get on with it...

Mark (49, polio at 5): it came from everywhere really. It came from the doctor saying you've got to push as hard as you can and my father saying you've got to push as hard as you can. And of course the school would be saying to everybody, 'If you want to achieve you have to maximise effort.' So it was part of what I grew up with as a way of life... I'm a real ladder climber... I am competitive and I think the polio has made me more competitive (very quiet).
Ken says that he was "very grateful" that his parents insisted he "wasn't to be helped up" or "treated any differently from anybody else", and Jane said, "it's much easier just to accept and get on with things." However, Mark, by lowering his voice to a near whisper, seems to indicate ambivalence about the pressure to be independent and later said, "I desperately want to win." In this chapter, I will describe various ways that many of those who had polio seem to have been silenced for much of their lives, in order to become independent, by stories they were told or not told, by whether and how they were listened to and by feelings they picked up. These stories are told in retrospect, in middle age, after the onset of PPS symptoms and several people said that a few years earlier the story would have been different, more stoical, more about 'getting on with it' and polio being forgotten in the past. It is difficult to untangle how much people may have changed through having to acknowledge new symptoms or because society has become more open to emotional personal stories (Atkinson and Silverman 1997), although this openness is highly circumscribed (Furedi 2004), especially in the case of chronic illness (King et al 2002). Stories of overcoming, recovery or transformation are still preferred. In the first section of the chapter, several small stories within stories about the initial polio which stood out as containing important and often contradictory lifelong themes of strength, weakness, independence and dependence, will be explored.

Stories within stories

Small stories within stories about the initial polio often encapsulated the integrated physical, emotional and social repercussions of a serious illness. The five stories in this section were felt as striking to me and it is mainly their emotional content, whether explicit or implicit, that singles them out as important for the narrative as a whole (Lillrank 2002, Lieblich et al 1998). Small emotional stories embedded within an often stoical narrative exemplify the "struggles between interpreter frameworks" described by Järvinen (2000: 389). These stories within stories are what Denzin (1987) has termed 'epiphanies' and Riessman (1990: 1196) describes as inserted emotional stories that "are reserved for quintessential moments". Seidman (1998) suggests that particularly meaningful interview excerpts include conflict (both within and between people), hopes
expressed or fulfilled, frustrations and resolutions. Radley (2005: 261) adds that in writing about illness narratives, this "revelatory aspect" must be preserved to show what "mattered to them at that time, and still does." The following small stories are about overcoming vulnerability, paralysis and powerlessness, both the physical and social effects, and attempting to hide any remnants of weakness and vulnerability. They were told by people of varying ages and encompass different points in their polio experience (see Appendix 8 and 9 for a list and descriptions of respondents). Most were told early in the interview, but one was slipped in towards the end. Two people (Beth, polio at 21 years and Allen, polio at 9) remembered having polio very clearly, but Alex (polio at 18 months) had no memories and was told his story by family, Barbara (polio at 4) had only a few fragmented memories and very few family stories, and Polly (polio at 8), who had clear childhood memories, remembered little about several months in two hospitals because, as she put it, "as far as I'm aware nothing happened to me".

Barbara's story, which seemed to express vulnerability or fragility, slipped out without even a change in tone of voice. Barbara, who had recovered well with only a slight limp and felt that polio had not affected her life, described being turned over for a lumbar puncture when she first entered hospital:

Barbara (58, polio at 4): And I think the reason I remember it is because the doll I had, which was my aunt's, fell out of bed...and it broke, and the nurse promised to mend it and she didn't.

Barbara later said that she became a nurse as "repayment" for all that was done for her, although in the story the nurse does not fulfil her promise. The story remained in her memory but was not explained in the interview, possibly because the dominant theme of her narrative was gratefulness for her excellent recovery and how "fortunate" she had been. Sometime after the interview she thought again about the story of the doll and whether polio had affected her life, which is described in Chapter 7.

Polly caught polio on the ship from England to Australia in 1958 and was in a Home for Crippled Children for two years after some months in other hospitals. When I asked her
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how she finally left this place she described as just "concrete rooms" like a Romanian orphanage, she told a story of her family house burning down while she was home for a visit.

Polly (53, polio at 8): Well, what happened when I finally got out, um when I finally, was that our house burnt down. My grandmother was living in Brisbane and my grandmother, I think, we're kind of jacks of all trades really and she set up doing the catering for the golf course, the way of earning some living and being independent and while we were out visiting her one day, when we got back, our house had burnt down (laughter), so um I was there...there was this house and it was just gone, everything and my mother had had a grand piano for her engagement present, which she had taken out to Australia in the pig truck and so I just remember going back and there were the ashes and all the, all the strings were laid out in beautiful neat rows, you know.

Although the main theme of Polly's life story combines the stories of polio and strong independent women like her grandmother, mother and herself, which is discussed later, this little story is most strikingly about the remembered image of the piano strings in the ashes which seems to be symbolic of permanence or order (the metal strings 'in beautiful neat rows') and fragility, chance or loss (the destroyed house), reminiscent of the broken doll. Later, Polly talked about polio creating "extreme vulnerability combined with extreme strength". In the sometimes fragmentary manner of these stories, the burning of the house did not directly relate to how she left the Home for Crippled Children. When she came home for weekends, she used to run away to avoid returning, and eventually "they just kind of gave up".

Another story demonstrating the strength as well as the vulnerability that resulted from having polio is a story of a snake told to Alex, who lived in South Africa.

Alex (47, polio at 18 months): And she (his nanny) screamed and I saw the snake coming towards me and she ran to grab me...and she got away from the snake and somebody tended to the snake, I don't know the details. But apparently that, later that day I started crawling and sometime later I started trying to stand up. I did it all by myself, it was probably the shock of the snake, I don't know.
The story combines the fear communicated by the nanny, and his understanding of the importance of both the physical need to be able to move and social need for independence, expressed by his saying, "I did it all by myself." Alex was brought up on an Afrikaans farm and was not taken to hospital or to any rehabilitation. He described his family saying, "if I'm going to walk, I will walk". One incident, like the snake, might be a turning point, an important individual episode that has a huge influence, or may be chosen, as one of many, to illustrate the ideology of strength and independence.

Beth, who had polio at 21 and remained quite severely affected, told a story of vulnerability and dependence at the end of the interview, when her husband came into the room and mentioned how old-fashioned the hospital had been, even for 1949.

Beth (74, polio at 21): Well they’ve pulled it down since. But there was a big fire in the corner, there was no f-, no guard or anything in front of it. I had a lady called Vera with me and she died. She left a little girl of three, and she and I shared this ward. We had this big fire there, they used to…put the coal on at night and leave it, there wasn’t a hearth…no guard at all. And um the nurses used to be away down the corridor, in another room. And one was preparing her trousseau for getting married and they didn’t come to see very often. And I was terrified of fire. Lying in bed, helpless-

This story combines physical and emotional vulnerability, paralysis and fear, and links Vera’s death and her own possible death. She went on to say "it's given me a fear of fire". At the end of the interview she described recently buying a new lower bed because she could not get up herself at night, as in hospital, and she said, "I didn't like it when I couldn't do that." These four stories are all about vulnerability, although the stories by Alex and Polly also suggest the strength that is often described as a reaction to the vulnerability. The final story in this section shows how some people, in their polio stories, made a break between life before and after polio, the time of physical strength and the time of vulnerability.

If people had been old enough, I asked about their lives before polio, and as has been found in Holocaust stories (Rosenthal 1998), for some people, it was a difficult story to tell. Rosenthal (1998: 26) found that Holocaust survivors could not find connections between life before and after the war and would say one statement like "We were a happy
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family." Similarly, Joanna, who was initially completely paralysed by polio at 11, said little more than "I have a few memories of being active and what it was like to run".

Karpf (1997: 139) describes this bisection in the lives of her parents, Holocaust survivors, and the possible need for distance to mend the division:

I was horribly aware that their lives have been bisected, but whereas they always seemed to accept the bisection and fully inhabit the second half, I was in some way always trying to recover the former half, for which I felt an enormous sense of loss. (Karpf 1997: 139)

Murphy (1990: 27) also described a disconnection and his pre-wheelchair past became "a golden age". Becker (1997: 37) found that generally the disruption of illness causes "two separate realities", before and after. Beth focused idyllically on walking 30 miles along the coastal path on Sundays. Two men described running through fields on a hot spring or summer day just before they became ill. One of these men, Allen, clearly remembered the days before he developed polio.

Allen (55, polio at 9): Good Friday, me and a group of my friends, we'd been birds nesting across the marshes. We ran and ran and ran and ran and walked and went miles for these days across the marshes looking for skylark and meadow pipits' nests and all this sort of stuff. Just having a wonderful time, as nine year olds could. And then came Good Friday and I was sent round to the baker's to get the hot cross buns, I went into the baker's and I went very woozy. My head began to spin, you know, and I went back out and sat down on the seat, on the step.

Allen seems to be emphasising the importance of this story by the repetition "ran and ran and ran and walked and went miles" and its image of free movement. He carries on to tell a positive story of never having a problem with polio and his paralysed leg, and that "it's just enhanced me", but the idyllic spring day seems to add another layer of earlier freedom. Possibly similar to Beth, who said polio had not changed her, she had been "very out-going and active" and still had "lovely dreams" and "happy memories" of walking, Allen also has been able to keep the time before polio meaningful and present. Allen said very little about his time in hospital and avoided any mention of dependence. When he returned home from hospital after 12 weeks and needed a wheelchair
temporarily he said, "None of these things lasted very long because I didn't want them to." In other cases, like Joanna, where little is said about the time before polio, there may be a more severe 'biographical disruption' (Bury 1982), the earlier life may have become meaningless, and the time afterwards may be devoid of the idea of running. The problem of disrupted identity will be explored further in later chapters.

These small stories within stories demonstrate a way in which narrative is used to create thematic structure, in this case about independence and dependence, in biographical stories (Becker 1997). The next section will discuss the situation in which interviewees felt there was a polio story but also a dichotomy between their parents’ story and their story, so that their memories or feelings were silenced. This division may have been one reason for the fragmentary quality of some stories, the ambiguity about identity and being disabled, and the split between pre-polio and later memories.

Parent's stories not children's stories

Even if polio was not talked about afterwards, there was often an early story told by parents to children, although sometimes even this was lacking. Polio often brought parents and children very close together, but some children did not feel anyone wanted to know their story. This section describes how two people, Jonathan and Jennie, who particularly described this situation, talked about their story and their mothers' stories. This is followed by stories about the difficulties some people saw their fathers having acknowledging disability, creating, in the case of Lauren, a father's story, which is the major theme of her interview. Both Jonathan and Jennie, who were five when they had polio and might have been more aware of having a story, however precarious, than younger children, describe the experience of listening to their mother's problems and anxieties about their illness, and felt that no one listened to their viewpoint.

Jonathan (52, polio at 5): I think what happens is you get a kind of story, a family story and a family role and then a, a part of that, a part of my role was to kind of get on. I suppose like a lot of disab- er polio people you know. Yes I did have a disability but I had to make the most of it, you know. And get on as though I was no different from anybody else. And the stories were around the difficulties of things like getting
physiotherapy after I left hospital. And more the kind of struggle about getting what
the basic things I needed. But they were less to do with you know when I said I
thought about it, later on, there's a kind of denial from the parents. My mother was, in
particular denial really around the fact that I probably would have had to have a spinal
fusion later on, you know, or that I was affected in any major way, that would make
me that much different from other people.

Jonathan, who spent two years in hospital, describes his mother's stories as concentrating
on his physical needs but also denying the extent of his disability, expecting him to "get
on as though I was no different". He concludes by saying that this denial meant that no
one had to admit that he was "that much different from other people" and implies that
therefore no one had to consider what that might mean for him. Jennie, who spent 8
months in hospital, and told a confused story about what happened, suggests that her
memories were both different from and distorted by her mother.

Jennie (57, polio at 5): I have thought about this a lot and one of the things I've worked
on is what I remember versus what I've been told. I sort of had taken on my mother's
memories but actually I have written about mine and thought about mine... So and
there's lots of things she doesn't quite remember as I do so and also, I don't talk to her
and I could ask her some more things but I did try once a few years ago, with my
parents. I just remembered something differently from them and they got so defensive.
Erm my husband couldn't believe it, so I think there's a lot of guilt there with them ...
so it's best left alone really, I suppose. As far as they're concerned.

She says that she has "taken on" her mother's memories, but also that they remember
things differently. Jonathan focuses more on the acknowledgement of the physical extent
of his disability and Jennie felt that she had to "listen to my mother" rather then be
listened to, possibly because of her mother's guilt.

According to the accounts told, fathers often found it more difficult than mothers to
accept the idea of a disabled child, and became quite involved with treatment and
fostering independence. Lauren, who is 57 and had polio at 18 months, described how
her father went against medical advice for a caliper and found a doctor who was willing
to work with him, using exercise. She told how she was brought up with her father's
story of her recovery to a normal life, "he was forever pushing me" and when she saw a
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film of herself walking with a pronounced limp at her wedding, "I literally ripped up the cine film." On the other hand, she also said "my dad took me everywhere, he was a brilliant father... there was encouragement all the time". Lauren crawled until she was five, and her father made her leather boots with steel caps and leather pads for her trousers. After the interview she sent a photograph of her holding onto the garden fence wearing the shoes and trousers, illustrating with concrete evidence her "brilliant father" (Figure 5.1).

Unlike Lauren, Beth had been 21 and had an idea of herself before having polio which she gradually merged with her disability, but she felt her father never came to terms with her disability and told the story of him wanting her to run for a bus and "it didn't seem to register that I couldn't do that any more." Nick, who was interviewed through e-mails, wrote that he was an only child due to the polio and had been very close to both his parents. After he had written much of his story, I mentioned a polio autobiography (Mee 1999) to him, which included a moving description of the father, who kept a pre-polio photograph of his son, in full football gear, in his wallet for the rest of his life. Mee concludes that his father felt regret and disappointment. After reading the autobiography, Nick told the following story:
Nick: After he (his father) died I had the task of going through all his smaller personal effects, one thing slightly upset me. In his wallet were something I have never ever carried -- photos of what are termed loved ones... There was just one picture of me -- very worn, dog-eared, indeed. A small boy in a sun hat, in a tennis court, was delivering a volley stroke into the empty air.

Afterwards, he wrote that his father "must have been carrying and concealing his own hurt...and thinking how different things might have been yet never once letting on to me". His awareness of the air as "empty" seems more meaningful in relation to how things "might have been" and how Nick could never be a competitive tennis player like his father. Nick then explained that his father did get very involved in activities Nick was interested in, such as competing in model aircraft competitions.

To understand the background of these emotional family stories, it is necessary to think first about how parents feel about having a child who is seriously and possibly fatally ill. Lillrank (2002: 114) writes about the parents of children with cancer: "Despite my professional experience I was emotionally unprepared for the interviewees' depth and immersion of nonverbally communicated extreme emotional pain." In an e-mail support group study of parents of disabled children, parents write of tragedy and guilt (Avery 1999). Children first learn about themselves through their parents and, to some extent, painful feelings about illness or disability are communicated (Harris and Wideman 1988). Kelly and Field (1996: 245) argue that the infant has no sense of self and "is a social object invested with meaning by others". The degree to which polio and any mention of disability, or the feelings engendered, was hidden would affect how the child felt, and this was handled differently in every family (Schneider and Conrad 1980). As Helen, who had polio at 4, commented, "it must impinge on you very early in life that there are very sort of negative associations around disability." However, people did not blame parents, who often became particularly close to their children and did everything they could to help them, as will be seen in numerous examples, such as Matthew's mother who refused to leave the hospital, and Lauren and Nick's fathers, who spent so much time with them.

Sometimes those who had polio did remain with ambivalent feelings about their parents, because of the difficult contradiction that love and care do not preclude harm, which will be discussed further in the next chapter. Lauren said, "I had probably the best parents I
could have had, although in later years there are things that perhaps needed to have been different."

Thomas (1998: 89) emphasises the two ends of the parental spectrum in relation to disabled children, those who were "allies in a difficult and sometimes hostile world, or as people who had to be resisted, often at great personal cost." In many more cases, parents fell in-between, sometimes allies, sometimes overly protective, sometimes finding any difference difficult to accept. As one woman who had polio said (Gould 1995: 284), "There might have been some families or parents that were stronger themselves. My parents had some problems, and I think the fact that they were caught up in their own problems made it more difficult for them to see beyond those to what I needed as a child." The result was that many children, like French (1993) and her description of adults worrying about rainbows, felt they must not add to their parents' worries, which catapulted them even more strongly into independence.

Practical stories and emotional stories

In this section, some of the differences in early polio memories between those who were teenagers or young adults and those who were children will be explored. Those who were older clearly remember having polio, and although many did not remember any emotions, they were aware of the emotional impact of polio on their families. Emotions may not have been felt at the time because some were too ill, but it was also noted at the time of the epidemics that polio patients, even more than patients with other serious diseases, seemed less concerned and more convinced that they would be fine in a few days (Holland and Coles 1957, Young 1949). Millward and Kelly (2003: 165) note that "disturbances in self invoked by the experience of the body" have not been elucidated in chronic illness literature. Some of those who were young children remember emotion, some do not, and a few had no memories and no story. Generally, they remained confused about how they had felt or continued to feel. Afterwards, most said that their parents concentrated on practical matters only, not how their child felt. First I will explore the early emotional experiences of the most affected of the young adults, Beth
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and Wendy. Beth described how, at 21, she was not concerned about her polio diagnosis. "I was just numb and it didn't mean anything to me. Because I thought, 'Oh, I shall be all right.'" Later she said:

Beth: But oh yes, the shock of having it I think came years afterwards. And it suddenly hit me that perhaps I would never be ... physically a hundred percent. I think you ... for a time you think oh yes I'm going to get over this. I'm going to be n- back to normal.

This slow realisation might be protective and allow people to carry on as best they can. Wendy, who had polio at age 20 and was put into an iron lung, said:

Wendy (62, polio at 20): I could see the faces of my family, parents I suppose, out through a glass door and of course what I saw was the worry on their faces. I wasn't worried-

Wendy said that her parents' worry "worried me" but generally feelings were "pretty inaccessible in those days. Not only fear but certainly any thought of the future" and "one of my ways of coping" was to learn "intellectually" about polio and muscle physiology. She describes that she "even went to an autopsy in the hospital". Beth and Wendy talk about emotions and fears of the future being hidden but also known to be hidden. Beth knew that she felt "numb", and Wendy recognised her parents' worry.

In some of those who were children, feelings seemed to be more deeply hidden. Jane, who had polio at 11, told her polio story in a very matter-of-fact manner, explaining later that people didn't make a fuss having lived through the war.

Jane: I said to my mother, 'I, I don't want to go to the party, I don't feel very well, I've got a terrible headache.' And she knew I was, there was something wrong then, because if I missed dancing that was a tragedy, and I went to bed, and, that was it for 2½ years.

Jane refers to missing dancing as a 'tragedy', which, as a child, it may have seemed to be, but the starkness of saying "that was it for 2½ years" might indicate ambivalence about
acknowledging the more significant tragedy that she would never dance again. There could be multiple interpretations or different levels of interpretation for this very small description of a major event. This could be what Craib (2000) describes as avoiding meaning or presenting the discordant as normal, or she may not have seen it in terms of tragedy but as "random misfortune" (DiGiacomo 1992: 126).

Jonathan commented that "in a way it's harder for adults because they know" and similarly, it would have been very difficult for parents, but children often did not understand the possible finality of their paralysis. Mark, who had polio at five felt that as children they just assumed they would get better.

Mark: I think you take it...you're too young to be scared. It it's just, it's part of what happens and because you're right at the learning point of life you've got nothing to refer back to and say 'This is bad news.'...you just believe that it's going to get better. That something or somebody, your father or your mother or people they trust will make it better. It'll go away, erm and that's I think my own memory of it at the time.

Skultans (1998a) similarly found that people who had hidden, as children, with their families in the forest in Latvia during the war, remembered not feeling any fear. For Mark, it was just another illness, and it was not until he was a few years older that he says he began to notice some differences. On the other hand, some very young children remember a feeling of being alone, especially as several weeks were spent in isolation only seeing parents through a window. Matthew, who is 47, described remembering, at 18 months, a dreadful feeling of seeing his mother through a glass window, a feeling he still experiences of "being yanked away." Nick described "endless tears and crying and just the feeling of desertion because my parents, I believed, would not take me home from hospital". Michael said he remembers, at age two, an image of the ward blinds being pulled down for the night, "I was distressed at night being on my own, perhaps, being left, you know ..." Sarah, who is 50, said that she remembered nothing of being in hospital with polio at age two until a memory returned to her, during a counselling course, of being in a hospital bed, crying, strapped down to stop her limbs twisting. The
image upset her for several weeks and she wrote in a letter before the interview that "the child in me was still crying".

Many of those who were children mentioned that parents talked about practical problems but the child's emotional story was ignored. Helen, whose grandmother collapsed and died of a stroke when she heard that Helen and her brother had polio, never felt that she was able to be herself. She said, "I think my role in life really was to be the good little girl" and "I don't think I really had any idea of the kind of person I was." This was said after she described the very emotional effect the polio, and the death of her grandmother, had on her mother, of which she was deeply aware.

Helen (52, polio at 4): So she was always very very anxious and very worried about everything and I think this, erm certainly impacted on me. And I was very aware of that and I shouldn’t do anything to upset her or set her off, you know, or anything like that.

It is important to remember that polio was not the only disruption in the lives of the respondents or their families. There were other illnesses and deaths in some of the families. Besides the death of her grandmother, Helen's father died when she was a teenager and her brother who had mild polio died of MS when she was in her twenties. Matthew had a younger brother who was severely disabled by an accident, Alex had a younger brother with kidney disease and Elizabeth, who had fairly mild polio when she was 25, had parents who died in India when she was very young.

Matthew, whose mother insisted on staying in the hospital against the rules, and Mark, whose eyes became tearful when I asked how his parents reacted to his illness, were aware, like Helen, of their parents' feelings, but others who were young did not indicate this awareness. Michael said that only practical matters were discussed, and otherwise he was expected to carry on as normal, which encouraged him to be extremely independent.

Michael: No, well my mother and father treated as if it was something that was past now and you just got on with you know the way you walk and your shoes, the way
they wear, wear out very quickly because of the way you just wear part of the shoe. Er in the sole of the shoe anyway. And my mother and father just got on with-

In some of those who were less than three years old like Nick, Deborah, Lauren and Sarah, with parents concentrating mainly on practical matters, the children knew almost nothing about their early story. Nick said he "never discussed anything beyond the mechanical contraptions". Looking back, Nick commented that his "painful hospital experiences" had been "erased." He had written in his questionnaire that he had been in hospital with polio for three months, but over the time of his e-mail correspondence, he talked to an older cousin who said he had spent most of two years in several hospitals. Sarah's parents knew she tired easily from polio but never told her, leaving her to feel "something was wrong with me". Ian and Sue, who had nonparalytic polio, also lacked stories and understanding of their symptoms, and their families tended to be dismissive and disparaging. Ian said his tiredness and other people's reactions to it gave him "hang-ups and a lot of self consciousness and failure" and Sue said that her "energy just gave out" after an illness at age nine and "I couldn't ever make anybody understand what I meant."

Autobiography

I do not remember being two years old (1950). I do remember maybe a year later my mother rubbing my leg in bed at night because it ached and I couldn't get to sleep. I remember being at the doctor's when I was about four and having my left knee reflex tapped and thinking that it was wrong for my leg to jump. My stories are my own because I was only told that I had hurt my leg and it had stopped growing properly, and it was never mentioned again. I assume it was considered past and buried. That was how my parents' families had dealt with their pasts in Russia. There were no stories and no photographs of my grandmother from age 13 until after she had had five children and had immigrated to the US (Appendix 10). There is only one photograph after my second birthday, showing my thinner left leg (Figure 5.2), until I was three when my father bought a movie camera, as if to begin a new reckoning of our lives. Like the stories of nonparalytic polio, I had no story and no understanding of my weakness or fatigue. My thoughts give some insight into how small children think about differences in themselves that neither they nor anyone else ever mentions. When I was about four, I first doubted the story of my leg but never thought to ask any questions. My father was showing me how to eat properly with a knife and fork, and I found it very difficult to lift the fork to my mouth with my left hand. I didn't seem to know how to find my mouth and my arm felt shaky. Nick, who had had one paralysed
arm which later regained strength with physiotherapy, described the same feeling using a fork. I decided to use the fork in my right hand and came to the conclusion that the way people ate was strange but also that whatever had happened to my leg had affected my left arm as well. When I was six, I joined a gymnastics class after school and when we started doing handstands I found my left arm always buckled under me and I finally injured the arm and left the class. Again, I wondered about my mother's story.

Figure 5.2 Ruth 1950

5.3 Vivid memories

Several of those who were children did remember having polio very vividly; especially those who spent a year or two in hospital, and two of these stories were predominantly about lack of care and the integral nature of physical and emotional vulnerability (Jonathan and Joanna). The isolation from family, and sometimes the uncaring treatment, may have helped consolidate memories. Jonathan, who was only five when he had polio, felt "that maybe traumatic incidents keeps a sense of your own identity" because he had "a continuous memory of what happened to me, who I met, doctors, events that happened, how my parents' felt, continuous really..." Jonathan had spent two years in three very different hospitals -- a fever hospital where he was in an iron lung, a rehabilitation hospital where he "was absolutely terrified", and a second rehabilitation hospital where he remembered being happy. His story contrasts happier periods where he remembers mostly practical details and the usual interests of children, with the time when
he remembers mainly fear. Before the interview, he sent a story he had written about the first two hospitals, complex impressions that might have been difficult to express in an interview. About the second hospital he wrote:

Jonathan (written story): The constant fear of doing something wrong but never knowing what was wrong, or right, a fear that eventually became transformed into a constant anxiety, highlighted by moments of terror. I can still feel to this day, almost every moment of my life, some part of that anxiety... the clearest memory is of holding on, holding onto myself. A sense of place, not person. The metal bedstead, the corporation style gloss paint, the lights, the tiles at the back of my bed, the coldness of the bathroom.

In the interview he mentions not remembering what it feels like to be paralysed, nor does he remember what it was like not to be able to dress or feed himself, which was a problem for quite some time. Although he remembers his initial physiotherapy as extremely painful, he does not "remember the pain but I remember it being painful." Like Beth's story of the coal fire and Alex's of the snake, his story brings together the complexity of both the physical and emotional vulnerability, remembering the fear of powerlessness in relation to the nurses, but not the physical feeling of pain or the powerlessness of paralysis. His parents did remove him from this second hospital, against medical advice, because he became so withdrawn. Cockburn (2005: 59) describes a similar experience in hospital of children being treated as things, and he eventually stopped speaking, recalling "a soothing sense of withdrawal from the world around me." Because Jonathan remained with weakness in both arms, his story continued to be one of physical and emotional vulnerability, as he was unable to physically defend himself or reach out to people.

Joanna, who was 11, is the only one who said that she remembers a constant, pervasive fear, in contrast with Jonathan's varied experiences. This fear has remained with her throughout her life. Thomas (1998: 94) also found that long hospital stays and lack of information to children could leave women with "lasting fears (for example, of separation) and a strong sense of insecurity." Because of "people not explaining", Joanna said "there's always that fear of what are they going to do to me next", and she avoided
doctors and even having children for many years. In the interview, she described remembering being totally paralysed, alone in a room, being told there was a bell she could push for help, except she could not reach the bell as her arms were paralysed. She then remembers being with two other girls, one who became a lifelong friend, and the other who was connected to a life-support system.

Joanna (58, polio at 11): ...this thing going up and down and hitting and puffing and hitting and puffing and banging, so all night long we had the noise of her support systems going and oxygen cylinders running throughout the night and I was absolutely petrified, I thought that was what was going to happen to me...and then they moved us into the ward next door which had lots of children in it, and then some time during my stay on that ward there was this big bang from next door and that was this girl's life-support system going and she died.

Joanna did not appear to have the support from home that many others did, and there is no sense of strength in her story until she returned to school seven months later, described in Chapter 6. She describes the lack of support in the first days of her paralysis, before she was taken to hospital.

Joanna: ... before I became completely paralysed I remember getting out of bed and collapsing on the floor, my legs wouldn't stand my weight and I banged on the floor and my mother came up the stairs and, sort of, laughed...as if she didn't know what had happened...

Joanna said "I don't think she'd even called the doctor...and I would have thought, having a child paralysed in bed, that she would have got the doctor sooner." Later in the interview, she commented:

Joanna: I've never discussed any of this with my mother. I think it would upset her too much so I don't, I don't know how she feels about it all, whether she's carried a big burden of guilt all her life, I don't know.

Jane told a very different and matter-of-fact story of over two years in hospital with polio at age 11. When asked how her parents felt about her having polio she said:
Jane: I don’t think they ever thought about it. I honestly don, they certainly never said anything to me, they just accepted me as I was, and if I could do something I could. They never ever made a...fuss...ever.... People didn’t in those days; we’d lived all during the war.

On one level, her story is full of stoical commonsense and ‘getting on with it’, but it was also important for her that "they just accepted me as I was". Similarly she says that the hospital became home, because it was a place where polio was normal and accepted.

Jane: You see the, the psychology of all this was, was totally different in those days. You were ill, if you were lucky you got better and nobody made a fuss about it. It was, you just got on with it... They told you what to do and they... It was a very cheerful atmosphere and I, I didn’t...want to go home. I mean after two and a half, two years four months it’s your home... Everybody was in the same boat. So there was no point in moaning. You looked down the ward and saw somebody in an iron lung and thanked your lucky stars that you weren’t in one. I mean it was as simple as that.

One important phrase is "Everybody was in the same boat." Sacks (1991) described entering the outside world, after several months of paralysis, and finding that no one could understand his experience. Greenspan and Coles (1998) identify an unresolvable contradiction for Holocaust survivors, in the same historical period as those who had polio, that they wanted to tell their stories but also did not, because they knew that such a different experience could not be understood. Kirmayer (2002: 736) suggests that this lack of understanding leads others to turn away, which is "the most basic violence."

Experiencing severe illness and paralysis, and remaining different and separate, created a similar conflict which never left the lives of those who had polio. Jonathan commented that "nobody quite understands unless they are disabled themselves".

5.4 Conclusion

In this chapter, the meaning of polio memories, parental polio stories, and the lack of stories are explored. The themes of children's stories being dominated by the parental story, the practical story and the story of not being treated as human in hospital, all re-enforced the idea that feelings about polio and disability were not to be spoken about.
Kirmayer (2002: 730), writing on the predicament of refugees, suggests that "the fragmentation of narrative then comes... from the absence of others in the social world, willing to help to weave memory and experience into a coherent story", which may help explain why these stories were difficult to tell. Children who had polio often have a confused, composite story from their memory and about their parents' memories and emotions, combining the distinction Hoffman (2004) makes between Holocaust survivors' stories being written from memory and their children writing about memory. Gordon and Paci (1997) argue that the silence around illness is a protective mechanism for the family, or a wider social group, from the experience of suffering. The ill person both protects and is protected. That the ill person supports others and protects them from suffering has been found by Murphy (1990) and Little et al (1998), and has been found in the children of Holocaust survivors (Karpf 1996, Rosenthal 1998).

The paralysis itself, hospital treatment and attitudes of parents all played important roles in the stories people told and how they came to see themselves and any remaining disability, which will be explored more in further chapters. Although, at the time, there was often a stoical silence about polio unless it was necessary to discuss practical matters, many of the stories told now about the initial illness are about vulnerability or merge both physical and emotional vulnerability and the strength to carry on, thus creating the scene for ambivalence about disability. The silence had been quite complete. Although several women said they were very close to their mothers, only Clare, who had polio at 3, of all the interviewees, said that earlier in her life she could talk to her mother about how she felt, for instance, about being in hospital.

One importance sociologically of these stories is how the cultural story of strength and 'triumph over adversity' is brought in, even from the very first days, especially by men. Jack, who was 17 when he had polio, and knew the story of Douglas Bader, said, "I felt it was up to me and I was going to battle this thing right from the beginning." This self-sufficiency was also apparent during recovery in very young children, even toddlers, as will be seen in the next chapter. Instead of Frank's quest or restitution stories, the polio story is an 'ambivalent restitution' story of recovery and strength suffused with hidden
5. Childhood: polio stories, memories and silence

doubts and confusion. The next chapter on childhood examines stories of the process, throughout the school years, of recovery and learning to understand and ignore the results of having polio, and creating a liminal world within normal society. The ability to 'pass' led to paradoxes, because society does not accept the complex and contradictory. Disabled people are pressured to and want to live as normal although being different (Wright 1960), resulting in considering themselves normal when others may not (Goffman 1990b). They are also thought of as weak and dependent when actually being pressured to be and becoming strong (Salmon and Hall 2003, Little et al 1998), but treated as strong when they may need help, understanding or acknowledgement (Wiener 1975). While society tells stories of heroes and victims, these paradoxes may lead to untold stories or stories that are more ambivalent than the restitution story. The merging and separating of "sense of self and the physical body" (Millward and Kelly 2003: 165) continues throughout the recovery period. The chapter ends returning to the often damaging hospital experiences for the surgery that many children had at intervals throughout their school years.
6. Childhood: recovery, ambivalence and being normal

What was I to do? First of all, I would not talk about it; I would not even allow myself to think about it. I would carry on just as if I had never had polio, just as though I was not using a wheelchair. I did not want to know, did not even like disabled people. (Gallagher 1998: 246)

6.1 Introduction

This chapter on recovery follows the process of becoming independent, and both discovering and putting aside the after-effects of polio. Although everyone was motivated to work hard to recover and forget polio, it was not easy and there were reminders, such as discrimination or the more subtle feeling that there was too much pressure to do everything. This led to a certain amount of anger, resentment or resistance. Finding a place in the normal world became a necessary but difficult balancing act. The end of the chapter returns to later hospital treatment and the major effects this had on some children. Most people recovered from acute polio within a few weeks. They then often began a long period of physiotherapy and rehabilitation, sometimes moving to a rehabilitation hospital and then outpatient physiotherapy or home exercises. Children also usually underwent several operations particularly on ankles or feet. Spinal surgery often had to wait until the teenage years. During this time of recovery and rehabilitation, there was endless encouragement to work hard and not give up, and to consider oneself lucky to have survived. This quotation from an interview with a woman, who had polio as a child, confronts the paradox, and confusion for children, in quantifying or comparing experiences.

Every time I'd go back to Sister Kenny (hospital) for a check-up, the doctors would look at me and look at my mother and say, 'She is such a lucky girl'... I didn't know what to do with that except to feel grateful, but I remember feeling angry: So what's lucky about what happened to me? (Register 1987: 109)

Even those who were very young children incorporated the work ethic message and said it was they who wanted to do everything themselves. This was expressed by Alex, in his story of the snake, and by Michael and Nick below. Only one woman, Polly, who had
polio when she was 8, made the point about her lack of care in hospital, that "if I got up it was because I decided I was going to get up." Differences between the narratives of men and women in relation to emotions, independence and interdependence will be discussed later in the chapter and in Chapter 8.

Michael: ...she (his mother) said...'you got on and just picked yourself up...' She wanted to pick me up but I said, 'No, I'll get myself, got to get myself'.

Nick: With celluloid splints I stood and fell, and began to get about by myself again. I required enormous effort and determination and I refused all help. I had to do everything for myself, I still have to now.

On the other hand, it was hard, as shown in the quotation below by Nick, and it would have been easy to give up, both physically and emotionally.

Nick: If you had met me before PPS I would have claimed polio had not been a problem -- I would not have been telling a lie consciously, but I would have been concealing quite a lot, not wanting to appear weak or suffering from some form of self-pity... I never let on that one lad Jimmy something or other had once lost control when we were in RNOH (Royal National Orthopaedic Hospital) together and, trying to walk, had clung on to me and just cried and sobbed his heart out -- it was the most embarrassing moment I experienced as a youth -- largely because seeing him like that made me want to give way to -- but I fought it off... I still have those memories of all those medics and adults telling me I had to be 'a brave little chap' when really I just wanted to scream with rage and anger.

Many people told positive stories of how well they coped with polio and its effects, but now they also want to say that it was not easy. This came out quite forcefully in some interviews but in others it was slipped in surreptitiously during the interview, or in an e-mail, written story or a telephone conversation. Edith had talked to me with great passion at a support group meeting about the lack of polio treatment during the war, and when I telephoned to arrange an interview, she had mentioned that there might have been too much of the attitude of 'getting on with it'. But during the interview her view changed.

Edith (68, polio at 8): But she (elder sister) thinks that you shouldn't keep on talking about things because you, you must get on with it. And I think that's probably the
same, the same attitude that I've got, basically... I can talk about it to most of my friends but then find, if you keep on talking about things, that's all you ever talk to them about. And they only see you as, as an ill person or unwell person. Whereas you know, don't bother, they think you're normal.

There is a common all or nothing attitude that one either talks or keeps silent and one is either seen as ill or normal. On the other hand, Edith saw the cost saying, "in some ways, it makes you harder." The next section of the chapter will examine some of the ways people negotiated the contradictions and confusions of being normal but different during their school years. They had to find a place among other people and learn to understand and sometimes resist what they considered unfair treatment and being categorised as different. The chapter is dominated by those who were children when they had polio, because they made up a large percentage of the interviewees, and they had some of the longest recoveries and often numerous operations.

6.2 Recovery, normality and difference

Comparing and motivation

As people started to recover from the initial illness, they began to try to understand their new position in the world. Making comparisons with others worse off, "somebody in an iron lung" (Jane), was an important way for many people to begin forming their identity as normal, to motivate and feel better about themselves and understand the relativity of their situation. Frank (2002: 100) suggests that "nurses and physicians cue patients to deny their own experience when they compare one patient's suffering to that of someone who is 'much worse off'", that it devalues experience, that "cancer is no small thing". Most people who had polio seemed very happy to make a little less of an experience that was no small thing. Wendy, affected in both arms and legs, was not stable enough to walk by herself for several years, but eventually she only visibly had a limp, similar to someone who "just had a blister on their heel". Lauren, who had operations when she was seven, thirteen and sixteen, said:
6. Childhood: recovery, ambivalence and being normal

Lauren (57, polio at 14 months): …there's a lot worse than you, get on with it because I've been amongst people that are worse than me, but there are times where you just wonder why…it really made such an impression on me, that you wake up and suddenly this little friend that you've known for three months has gone and all you get told is that they've gone to sleep and, and the brittle bones...I can still hear the screams.

Saying "I can still hear the screams", Lauren makes it clear that this positioning has remained in her mind since childhood. She questions what happened to her but then carries on. Paralysis is a big thing but the death of a child is bigger. Jack saw people worse off than himself as a moral issue, saying, "I just felt that she could have got out of the wheelchair and made more of an effort". Positioning was carried on throughout life, wherever inequalities were met, such as at work and with other disabled people, and will be discussed in later chapters. As Myerhoff (1979: 142) found in a study of elderly Jewish immigrants to the US, it was necessary to "avoid the devastating consequences of judging themselves in the terms used by people who disdain them". Disability needed redefining, but it was not always easy to find downward comparisons, as many people were given the prognosis that they would never walk again, even though they all did. This statement was engraved in many minds causing anger and a desire to disprove it, which created great motivation to recover and be normal.

Allen: - the point was a doctor told me I would never walk again... No one, no one tells me that. No one tells me I'm never going to do something again and I fight against it straight away. Yeah I was told I'd never walk again.

Matthew (47, polio at 18 months): They said, "He won't walk again", never walk, and my mum said, "He will, you know", and my dad said that she was determined that I would get walking almost straightaway, you know.

Allen was nine when he had polio and felt responsibility for recovering, whereas Matthew was only 18 months and heard stories from his parents.

The motivation from medical or public negative reactions was coupled with the opposite message from parents, that polio was over and the child could now do anything. Both messages created a strong impetus to recover and see everything in terms of all or
nothing, being normal or giving up completely (Craib 1994). Having lived with the story of the snake as his impetus to recovery, Alex also told several negative stories from his childhood that were "a refrain coming back all the time". In one story, when he was about five, he was in a bank queue with his mother, and he heard two women talking about him, saying, "What a pity that such a good-looking youngster is going to become a burden on society." Individual comments like this could have repercussions throughout life. In another story he described a teacher in a careers lesson saying, "Take Alexander, he is going to be an absolute bum, he is going to literally get into the gutters." Alex described that "there was this cripple inference again... and I said, 'if you ever imply that again I will flatten you.' In front of everybody." Later in the interview, he said, "this absolute aggression that I felt at times, was focused into my career" and "I just didn't like stopping."

Bauman (1995: 112) argues that people are educated "in such a way that they want to do what they must do", and that they conform in order to alleviate uncertainty and feelings of inferiority. Several people mentioned that they could have done otherwise but they wanted to be working every moment, did not want to have holidays, did not want to talk about polio. Mark and Sarah described teenage experiences that pushed them into this all or nothing need to achieve and win.

Mark: I was in the CCF when I was at school, the cadet force, but you always end up walking miles and they'd all...walk off, then they'd stop, waiting for me to catch up. I mean the moment I caught up I would think 'Good, now I could do with some of this sitting down' was 'Oh come on. We've been hanging around here for sort of two minutes.' And I'm sure that some of the competitiveness comes from that. It's that I'm just...if you're not at the front there's a danger you're at the back. So if you're not actually leading you could be being left behind.

Sarah (51, polio at 2) (about hill walking): ...all I remember is I would be exhausted afterwards. I made sure I would get up there first (laughs). And I was going to be back down first. And that was part of my coping strategy. I was as good as everybody else. If not better than...than they were going to be.
Sarah laughs as she describes needing to be first and Mark jokingly tells his story, doing the voices, and saying "We've been hanging around here for sort of two minutes", but it was Mark who "desperately" wanted to win, and Sarah who was "so scared of failing."

Sport was very important for many of the men and a few women as a way to achieve and feel normal. For disabled people, sport and leisure activities seem to be suffused with ambiguity, because they are both an escape from the everyday, as they are generally (Robinson 2004, Lewis 2004), plus they are the achievement of the ordinary. Mark described his scuba-diving and a holiday white-water rafting in Turkey, repeating twice that he was "desperate that we were not going to be the last canoe in". Michael mentions feeling driven to try many available sports and become as proficient as possible.

Michael: At school I used to play in goal because you couldn't run but you could play goalkeeper, used to play cricket, do boxing, badminton, swimming...the swimming and lifesaving and you know, it wasn't just doing normal things that for some reason I was quite driven to want to achieve a bit more than that... I could cycle, I could, I'd go 50 miles on me bike."

Michael cycled 50 miles, while Ken spoke about cycling 100 miles every Sunday and family holidays cycling in Ireland and Holland. Working hard to achieve as much as possible, there were bound to be 'sticky' moments (Davis 1964) when disability moved into the foreground and the next section will look at some of these moments.

**Ambivalence, liminality and shifting**

Alex, with two full-length calipers and a back brace while he was at school, had no doubts about his difference, made more obvious by people's reactions, but for most of the interviewees there was some confusion over whether they were normal and what that meant. Allen had one totally paralysed leg with a full-length caliper, but contrary to Alex's experience, he lived in a close community where several children had had polio in the same epidemic, and felt his leg "was never a problem".
Allen: People see me, see me limp along to them and then, I engage in conversation and they remember me because of the engaging conversation.

Although Allen says later that his limp is a "useful tool", by developing a knack for "engaging conversation", he is actually not using the limp but using conversation to deflect from the limp, as it is the conversation he wants people to remember. This riddle emphasises the liminality that people found themselves in as they grew up. Murphy et al (1988) describe disabled people as being in a liminal position between healthy and ill, but for children, this liminal space was between disability and normality and was the result of trying to live the paradox of being different among normal people. In this section, I will explore how people shifted in, out and between the worlds of disability and normality, and the subject will be continued in Chapter 8 in a section on friendship in adulthood, as this ambivalence and feeling of liminality is mainly, though not always, felt in relationships outside the family.

Children with a less obvious disability, or one that developed gradually, were sometimes confused about whether they were disabled, especially if no one talked about it. Almost everyone, whatever age they had polio, went to some lengths to avoid mentioning polio all their lives. They were aware, on some level, of their limp and limitations, but often never spoke of them and thought others did not notice. Sometimes the awareness of polio shifted in and out of consciousness as described by Beisser (1979: 1029), who remained quadriplegic after polio and would shift from healthy professional to quadriplegic when a patient would sometimes ask him, "How do you bear spending your life in a wheelchair?" Jennie, who had recovered very well except for a limp, illustrates this shifting.

Jennie: I hated it if anyone else asked me about it, if anybody mentioned it... I hated it. I really did. I really, because I really thought nobody noticed and nobody knew.

Although Jennie "thought nobody noticed and nobody knew" she still "went to great lengths to hide it." She described letting people go first on stairs so they would not watch her limp from behind, an example of impression management (Goffman 1990a), which she carried out at the same time as holding in her mind that "nobody knew". Both visible
and functional differences could be manipulated in subtle, often unconscious, ways. Matthew did not manage an impression for others so much as trick himself into believing he could walk longer distances.

Matthew: I would go down the bus stop, walked down to the bus stop which was a walkable distance, get on the bus and get off in town and I convinced myself that I'd walked the whole way... I'd tell my parents I walked down town.

For most people, there was no management, only silence, not questioning and ignoring what they knew. Lauren had particularly ambivalent feelings about her limp, as her father had been determined to cure her polio, discovering regimes which included salt water baths, olive oil massage, faith healers, exercise, and surgery. She described:

Lauren: When it did hit me was when I actually saw myself in a cine film walking and until that point I had no idea that my limp was so pronounced and it was that point on where a lot of my self-confidence took a great big jolt... I just couldn't believe the person walking towards me, you know, as I'm watching a cine film, was me... that was my first feeling that the family had been overprotective and closeted me and I can't describe how I felt, all I can describe is I, I literally ripped up the cine film.

Lauren remembered hating a girl in the fifth year "for the rest of my life", who told her she walked "like a duck... but, of course, she was the one that was trying to let me know what I did look like now." This message had stayed with her as an insult, only much later seen as a warning of how others saw her. Sarah, whose parents did not talk to her about her lack of stamina or her limp, said she had a feeling "that there was something wrong" and "people wouldn't accept me." She described:

Sarah: There's a strange sort of dichotomy between people thinking that you're different but not actually saying anything to you. That nothing is said... You're not going to be sure about what they think at all.

Sarah shifted between seeing herself as normal because no one told her otherwise, and feeling that no one would accept her because she was different. She only found out recently that her parents had been aware that she tired easily from having polio.
Sarah: I remember something my husband said, a couple of years ago... when I was saying that I hadn't thought about... how polio impacts on your body. And er and all this getting tired and everything and all the symptoms that we now have, and he said that before he married me, my father took him aside and gave him a pep talk ... on how he was going to have to look after me because I got tired very easily. But at that time I was 23, I didn't think I got tired very easily. I just thought there was something wrong with me. No one talked, no one told me that it was anything to do with the polio ... and I was stupid enough not to realise it had anything to do with the polio.

As no one had told her this story, she spent much of her life believing she was "mentally and emotionally fragile" because doctors told her she was depressed, on the basis of her becoming exhausted from standing all day teaching. There may be a link between her parents' silence and her doctor diagnosing fatigue as depression. Doctors knew very little about polio after-effects, especially after the development of the vaccine. Even during the polio epidemics, Young (1949: 269) was sceptical about fatigue after polio, writing that "this fatigue is out of proportion to what might be expected in view of the muscle loss". Depression may be easier to understand for both doctors and the public because of general discomfort with subjective symptoms and their difficult boundaries (Douglas 2002). Without straightforward objective tests, the medical profession, even when professing to merge the physical and emotional, remains more comfortable using psychological and moral statements such as "individuals choose to take advantage of the role" (Wade and Halligan 2004: 1401). The lack of understanding of symptoms increased the need for people like Sarah to normalise.

Another way to identify as normal, and minimise shifting, is to redefine categories. Becker (1997: 4) suggests that "restoring order to life necessitates reworking understandings of the self and the world, redefining the disruption and life itself." Either the definition of normality is enlarged (Watson 2002) or incongruent information is dismissed (Douglas 1999). Writing about AIDS, Crawford (1994: 1347) suggests the importance of "how individuals meaningfully shape their identities, what boundaries they draw and thus what meanings are expelled as not belonging to the self". Allen described his caliper as "never a problem, it's part of, it's me... I never saw myself as disabled, no, I was just a guy with caliper." Ken described being disabled not as his 3-inch leg length
difference but "sort of 9 or 12, 12 inches difference", like the disabled orthotic technicians he knew. Nick saw himself as normal because it was his normality, although he was aware others thought differently.

Nick: I had never been aware of being free of the effects of polio, so in that sense I accepted my situation as one normal option. The problem is mostly the way other people react to you.

Matthew assumed that the pain in his life and the discriminatory way he was treated were normal. Discussing long, painful treatments in hospital, he said, "I didn't know what was normal and what wasn't, I think that's what confused me quite a lot." Later, as a teenager, someone suggested he buy handmade boots as his feet were so painful.

Matthew: I couldn't believe how comfortable your feet could be. Again, it was something I expected, that that's what everybody had to put up with really.

Whereas, for Matthew there was confusion about attitudes, functioning (walking to town) and pain, often women were ambivalent about their physical appearance. It was difficult to redefine what was physically visible. Deborah, who had an obvious paralysed arm, was confused because her mother said that there was nothing wrong with her. Thus, looking in the mirror created ambivalence and she said, "I hate looking in the mirror". Mirrors were equally problematic for Helen, who had spinal curvature.

Helen: When you are disabled, you have an image of yourself in your brain somewhere, which is how you would be if you were normal... When I was a teenager I had an image of myself and if I saw myself in a mirror I got a tremendous shock because that wasn't me.

They shifted from the world without disability to one, suddenly, where they were confronted with it. For women, buying clothes or comparing the way they looked with other women could be uncomfortable because they did not fit with who they felt themselves to be, as Edith described.
Edith: In *myself* you always think, you've got an idea of the *type* of person you are and the *type* of clothes you would wear but you can't do it and so, you end up, sort of, being something that you're not, it's not really *you* and how you would *really* like to go out.

The problem of "being something that you're not" will be discussed further in a section on identity in Chapter 8. Helen, who, because of "denial and repression" is still learning who she is, introduced the idea of not being "one thing or the other". She used an image from *The Jewel in the Crown* of an Indian brought up in Britain who is no longer accepted in India. She felt it might be easier to be more disabled and have it acknowledged. Helen did not "think of myself as disabled, and I didn't like anybody...referring to my disability." Her friends at school were able-bodied and "I identified myself with them."

Helen: So it's almost as though you can hold two different sets of beliefs at the same time...it's almost as though you don't connect one thing with the other. You know you've had polio and you know it has affected you. But on the other hand you don't think of yourself as anyway disabled. I mean it's a bit like that everybody knows that they're going to get old and eventually they're going to die. They accept that on an intellectual level but they don't accept it on an emotional level.

For disabled people, the emotions of everyday life often cannot be contemplated in a complete, embodied way. Six months after the interview, Helen wrote a fable about a crippled girl "abandoned" to a convent, where she "must not trust anyone" and her "feelings are of no importance". Disabled people must never let on that disability is a problem or even that they are disabled. By blindly carrying on, they can create a myth that they are normal. Murphy (1990: 123) argues that the problem and fascination of the interaction between able-bodied and disabled people is that the little white lies of ordinary interaction are compounded by "a big lie -- that the physical deficiency makes no difference."

For those who did not even know their story, understanding themselves and interaction with others was much more complicated than just living a lie, because they were not sure of the lie. Like Sarah, those who had supposed nonparalytic polio, mostly undiagnosed,
did not understand or know about their fatigue and stamina problems. Often they had no story at all, because their illnesses had not been seen as serious, and they were considered lazy or stupid. Sue, who had several months of walking difficulties after a fairly severe undiagnosed illness when she was 9, which left her with a weakened left side, was criticised for being lazy and teased for clumsiness. During the illness she remembered "my dad carrying me up and down stairs to bed, because I was brought down to be in the sitting-room, on the settee, so my mum wouldn't have so much running up and down to do." Ian had severe fatigue and pain all his life, seriously affecting his walking ability and job choices. His family had considered his problems psychological and it was not until he was in his 50s that he had neurophysiological tests that showed he had had polio. Most people still did not believe him. I also had no story and was confused, but did not mention my weakness or pain to other people. Somewhere I had picked up the idea that it would not be believed or would be considered unimportant.

**Autobiography**

1958: I was 10 years old and going to an English school in Rome. We were outside running relay races in PE, jumping up and down, screaming and shouting. Suddenly, the girl in front of me fell for no obvious reason and couldn’t get up. We shouted for her to get up. She had broken her leg, and some time later we were told she had a bone disease and her family had returned to England where she could get better treatment. The thought flashed through my mind that maybe something like that would happen to me. Then I wondered why I was thinking that, because my leg hadn’t bothered me for several years. But deep down somewhere I felt there was something wrong. The photograph below (Figure 6.1) shows me and three other girls at school, wearing what we probably wore for PE. Possibly the girl on the right was the one who broke her leg. The photograph makes a strange story (a makeshift school in Rome for foreigners after the war, a bone disease), ordinary -- four friends at school. The next year our English teacher asked us to write our own obituaries. I remember thinking that maybe people die from a disease that attacks a part of the body previously damaged by illness. I thought that I would die from a disease in a body system like the blood, bones or muscles, something that I thought might cause weakness. In my mind were probably my friend with the bone disease and a cousin who had died the year before of Hodgkin’s disease (see Appendix 10). And so children slowly develop their theories of illness.

I began to have pain in my muscles when I was 11 and was taking part in more sports. I found it painful to hold a tennis racket, and all my limbs ached after swimming one
length of a pool. My legs began to hurt at school in the afternoons, when I was about 14, probably from sitting for long periods on wooden chairs. I would keep shifting my position and putting my legs up on the seat in front of me. When the pain became very uncomfortable, I told my mother. She ignored me for two years then finally took me to an orthopaedic specialist who x-rayed my curved spine and seemed puzzled by the pain. I have no idea what the doctor was told or whether I spoke to him. My mother never mentioned my leg pain again.

The next section will explore several examples of what was felt as unfair treatment and the reactions and attempts to resist this treatment. Ironically, sometimes unfairness resulted from successful 'passing', as too much might be asked of the person, but more often, no matter how normal behaviour was, someone would disparagingly point out the difference. In other cases, unfairness was to do with dehumanising treatment in hospital.

Resistance: too normal or too different

On the subject of whether she was always aware of polio, Jane said, "It was hard" and then told a story of having to carry trays of coffee up several flights of stairs at work. She did not feel she could admit to not being able to do it. "Well, you don't, do you?" The subject of what was right or fair was a complex one, as people wanted to be treated the same as anyone else and wanted to hide any disability, a paradox noted by Wiener (1975). What was previously discussed as motivation to recover and be normal, can also be seen as motivation to disprove stereotypes and resistance to being treated as disabled,
different or less than anyone else (Becker 1997, Watson 2002). Resistance, in this study, is widely defined not only as opposition but also as "creative and transformative" (Becker et al 2000: 140). These situations arose in school, in hospital, at work and at home. People were treated as different, as objects, or as normal, but rarely as themselves. Matthew and Alex, mentioned earlier, were particularly influenced by the way teachers discriminated against them at school.

Matthew: Primary school, the first school up near Chester was terrible, I hated that. I was hauled, first day at school I remember, I was hauled to the front and, um, put in front of the teacher with this lad who was, had Downs Syndrome and it was a little village school and she said, "I'll have you cripples here", like that, and I remember her saying that, I didn't know, and this lad, he was very nice, you know, quite friendly with him but it was just like, you know, we were completely ostracised by the rest of the group, you know, and it was not happy at all.

I asked Matthew whether he was able to tell his mother about how he was treated at school and he said, "No, no, it was difficult. I just... you just sort of get on with it... I think at the time I was shutting down and shutting off a lot of it and just getting on with it, you know." I interpret this to mean that the situation and feeling of unhappiness were difficult, whereas shutting off was probably much easier and automatic at the time. The discrimination carried on in secondary school, where Matthew felt he was being punished for being disabled by being made to write lines or essays while the others did PE. In another instance, the headmaster was a bully.

Matthew: At Turnpike School, and again um, I thought, you know, this was normal (laughs), this is what happened to you if you were, if you're a cripple, you got punished, you know, and it took me ages to cotton on that this wasn't right and stand up and say, hang on a minute, you know, what's going on here

Matthew: The Head Teacher saw me walking down this corridor and he shouted, "Pick up your feet, Smith", like that, and I turned round to him and I just said, you know, and he was a bully as blokes go, so I said, "But, you know, I've had polio, I can't, this is the best I can do" and then he came running at me and he was, he just rugby tackled me and, but this lad saw it and I got up and just said, "I'll have your job for that", you know.
In Matthew's first story, he is only five and cannot understand why he is being ostracised. By the next story, in secondary school, he describes beginning to think that he was not being treated fairly and in the third story, he is taking some action. Through his father's efforts, the headmaster was eventually dismissed. The reaction of these teachers to disability echoes Douglas' (2002: 129) argument that "Here are people living in the interstices of the power structure, felt to be a threat to those with better defined status. Since they are credited with dangerous, uncontrollable powers, an excuse is given for suppressing them." She suggests that strength and power is not an either-or situation, but a struggle about difference. Other teachers, however, used subtle ways to help children get around the school and found sports they could take part in. Occasionally, unfair treatment in favour of the disabled child could have an equally devastating effect, as this accentuated the disability.

Nick: What hurt the most when I was at the Strand School was not being caned! ...we were all marched in to see the head. He caned the other boys and remarked in front of them that he couldn't cane a 'sick' disabled boy and that I would have to write 500 lines.

Another aspect of being treated unfairly was being treated as nothing, as an object, in hospital. Helen and Polly particularly felt they had not been treated as human beings.

Helen: ...nobody ever told me anything, because you were only a child and you didn't count.

Polly: ...there's not a lot of what I told you where you could think that anybody recognised that there was a living, feeling human being on the receiving end of things... The nurses would fly around... and smooth your covers so you looked neat for when the doctors came around... so there was that element of it that I was just furious, infuriated by this hypocrisy really

For Polly, who was in hospital for a spinal fusion as a teenager, understanding the treatment of patients as hypocritical made her angry but also gave her ideas for using this anger in a future career helping people.
For men, fighting or confrontation was one way to prove their normality and achieve a certain level of fairness. In Alex's case, there was also the fear concerning his own instability standing.

Alex: There's one thing I hate, don't stand behind me, don't push me, don't bang me, whatever. I have this sense of this is my space and don't hurt me. And he (another student) walked past me, and he whacked me and I thought he wouldn't dare... and I can recall, I still do not know how I got up so quickly because I was slow getting up, normally, and I got up and I had the chair and I hit him with the chair, with the library chair... Bop, it was lights out, and the teacher was hysterical.

Nick: I think I was a rather determined pushy little kid, a tad aggressive even, but at the same time a bit scared inside of other boys physicality... I got into fights on several occasions... I'd strike out if someone made a crack about my being a cripple.

Whereas Alex expresses pure aggression, Nick remembers the underlying fear as well. In Jonathan's situation of having significant arm weakness and being unable to stand up for himself physically, fear and self-protection become dominant.

Jonathan: When I left hospital, physically quite vulnerable, and going to private schools and mainstream schools, you have to look after yourself and one of the ways you look after yourself is not get anybody to beat me up. Which may mean being nonconfrontational; those skills are not useful when you move in to certain other types of life, where you need to be a little bit more assertive, stand up for yourself.

Several men showed their ambivalence and fear about attempting to use physical force, but, at the same time, they learned a certain amount of assertiveness. Later, in adulthood, they used a more conciliatory approach and suppressed anger, probably for reasons that are explained by Jonathan's more individual situation. Their vulnerability, both physical and social, meant that they needed to learn to judge situations carefully and not aggravate people. Briggs (1971) describes a situation of suppressing anger and judging subtle emotions in a very small community of Canadian Inuit in harsh conditions, which has certain similarities to the isolated position of the disabled person. For the Inuit, although independence and self-reliance are crucial, interdependence is also necessary for survival, as it was in the early stages of polio, and continues to be for many disabled people.
Throughout this study, it seemed that women found suppressing emotion more difficult, and they showed more anger than men. Expressing anger may be seen as loss of control, but alternatively as resistance or assertion of autonomy (Myerhoff 1979). When I asked Michael, who had gone to the local newspaper with his PPS story, whether he had been annoyed with the lack of medical knowledge about polio and the bad advice on exercise he had been given, he said, "it wasn't annoy, I thought, I can understand why people feel it's not an issue any longer." Women were more likely to express anger, often about people not accepting situations that they had had to accept when they were younger, especially about how children are treated. Jane said that, after the war, people didn't make "a fuss — ever... we'd seen terrible things around us, and, this striving for a perfect world and perfect people, is just full of frustrations." Cynthia, who received little treatment for her paralysed legs except months in plaster casts, commented:

Cynthia (84, polio at 18): ...the least thing and they've got to give them trauma counselling these days -- we didn't have any trauma counselling and at 18, everything to be taken away from you like that, there couldn't have been anything more traumatic than that, could there, really?

Barbara expresses strong feelings about women having children without thinking of a child's needs, whereas Polly becomes equally irate about children, especially disabled children, being wrapped in cotton wool.

Barbara: So, it would be nice to be married but... you know, that's the way the cookie crumbles and we all have to take it whatever way it comes... these (single) women that want babies... I don't approve of that at all... they don't know what they're letting the children in for, do they? All this donor stuff and goodness knows it's gone too far... I mean, I would have liked children but you don't go out and just get children, they're not a commodity, are they?

Polly: ...there was a culture of cosseting children who had things wrong with them... and I just want to say, "Look, for God's sake, what do you think is going to happen to them at 16 or 18? They're going to come back into this world with the rest of us, they want a job, you need a job to get your self-esteem in our society, you're just disabling them further".
Comparing these comments from Barbara and Polly emphasises the uneasy balance between lack of care and overprotecting children. One of the difficulties with parents fostering extreme independence, which was seen as caring, is that if too extreme this caring could be construed as the opposite. More strikingly, the Inuit use quite harsh behaviour called 'benevolent aggression' towards children who have been very ill, which involves a complex emotion of both protecting a child but also neglecting it enough to foster independence (Briggs 1987). Bauman (1995: 161) argues that as individual liberty and ambivalent situations increase in society "the more occasions there are for cruelty masquerading as care and violence that thinks of itself as kindness."

Resistance about parental treatment was rare. There was generally deep loyalty to parents and most people interviewed felt that their parents had done the best they could and had had to perform a complex act of protection and encouraging independence. The men who told the most stoical stories felt particularly grateful that their parents had treated them the same as anyone else, but a few others, mainly women, felt that possibly this had gone too far and resented the lack of acknowledgement of their disability. They were glad that fostering independence had helped them become strong, but it could also lead to confusion about any difference, and cause them to ignore problems and become so independent as to have difficulties relating to others. In a study of women's narratives of growing up with disability, Thomas (1998: 92) wrote: "There is, perhaps, a fine line between too much or too little emphasis on 'being normal'." Ken and Jennie demonstrate opposing reactions to being treated the same as anyone else.

Ken: I wasn't to be treated any differently from anybody else and I was very grateful for it.

Jennie: She told me very recently that when I was outside playing and I fell over, you know playing with the others and she wanted to rush out and pick me up but my father said 'No no no, she must pick herself up.' Which is ok, which is fine but actually I think there was a bit I feel there was a bit too much of me doing everything... When I was at the grammar school, there was a bus strike one day, so my father got himself on his bike, got me on my bike and we cycled all the way across the city and it was very uphill downhill. And this leg, my left leg got very very tired, and I did resent that...
And of course, when I got to school, nobody else had really made the effort to get there… so, there again, you know, why can't my father be like everybody else, why did he have to make me do this?

Jennie described resenting, at the time, what she saw as her father's extreme work ethic where she had to do more than other children when she was less strong. This strategy may also be counterproductive in that trying desperately hard to be normal seems to lead to differences, as Bauman (1998) described in relation to German Jews attempting to assimilate into German society and becoming too German. Once a natural rhythm of living is disturbed, the sense of how far to go in restoring it seems to become lost. Lauren also said she found it difficult at the time that her father could not accept her limitations and pushed her further.

Lauren: …my dad used, I used to have to do what everybody else did and I used to get tired and he would not tolerate that. He was forever pushing me, um, so I just sort of gritted my teeth and got on with it. I was aware of that.

Nick was the only man who recently began to doubt the wisdom of silence, ignoring and hiding.

Nick: I think once I was truly mobile when I was seven, I put all my painful hospital experiences out of my mind, thought I had erased them for good, and got on with life as if the past had not happened. If my parents, doctors, and others had any failings it was that they let me get away with this deceit.

Reactions to unfair behaviour had repercussions throughout people's lives and will be brought up again in later chapters. It affected the jobs that people decided to do, their attitudes to working with people, and later their attitudes to doctors about PPS. On the other hand, some people tended to think more personally about problems with other people, and blamed themselves. The guilt and shame caused by blaming themselves was mentioned more often by women, even those who also saw fault in others, like Jennie and Lauren.
Jennie (e-mail): I think that because I was treated as completely 'normal' and the emotions around the polio experience were kept hidden (by others and so by me), that I grew up to be very hard on myself. I have blamed myself for all sorts of (perceived) failures. I had a lack of self-esteem. I felt inferior at times and I felt ashamed that the whole polio thing had happened to me. I was very quiet in a lot of situations. I often felt I had nothing worth saying as a result of not being listened to.

Sarah was the only woman who remembered being physically bullied and she emphasised that she felt that there was something wrong with her and she feared failure. Nevertheless, there was ambivalence and she was "determined I was going to be the same as everyone else". Nick quotes Hamlet that "the fault lies in ourselves". The next section explores the repeated surgery undergone by many of those who were children when they had polio, as these were often times when they felt they were treated unfairly and some learned to take more control in difficult situations.

6.3 Surgery and more surgery: difficult stories

Stories of surgery did not often play a big part in the interviews, although surgery did sometimes play a decisive role in the lives of those who were children when they had polio. Seventeen interviewees had surgery, out of 25 who were under 12 years old when they had polio. A story of surgery was occasionally slipped in at the end of the interview or on the telephone. Even if the surgery was successful and time in hospital was short, there was sometimes anger about not being told what was going to happen or being treated badly by staff, although Deborah, who had surgery throughout her childhood, became attached to her surgeon and several nurses. More often, many months were spent in hospital with few visits, and the surgery was not very successful. Matthew describes some of his surgery as "outright abuse, experiments, questionable" and lacking in informed consent. His experiences led to a lifelong desire to help change the way children are treated. This section examines several stories told about surgery and what these stories might indicate about the effects of these hospitalisations on later life. The first two examples (Clare and Daniel) show how some surgery stories by those who were younger when they had polio were told minimally, possibly because they are such difficult stories. Then the meaning of three stories told by those who had surgery in their
teenage years will be explored. Jonathan barely mentioned his spinal fusion, Joanna's spinal fusion was a major episode in her polio story, and Alex described both surgery and refusing surgery. Like the stories of resistance, these stories are complex and often developed over the time of several surgeries, so I will concentrate on a few stories in more depth.

Clare, who had two operations in primary school and then missed much of secondary school because of pain and surgery for leg ulcers, barely mentioned the initial surgery, but did mention her disappointment, as did Lauren, who did not describe her early surgery at all.

Clare (66, polio at 3): I can remember being very disappointed because when they removed the plaster and what have you, my limb still wasn't straight. The foot wasn't straight and I'd convinced myself, you know, that after all this I was going to have a straight limb, a straight foot. But it didn't happen...

Lauren: Again, in my head must be the little girl that thought she was going to have these operations and come out and be fine.

For her major leg operation at age 10, Clare described being in hospital for six months with visiting times only on bank holidays, Christmas and Easter and "parents would come and they would stand on the pavement and hope to see you at the window just to have a wave, you know. That was the hardest part." More negative aspects of this story came out later after another interviewee lent me a history of the local rehabilitation hospital in which Clare had written a story about nurses threatening to strap children down in bed because "we had waved to our families". She did not realise the story had ever been published. After seeing the story she told me on the telephone about the surgeon who had neglected an infection in her leg after the operation. In the interview she had described how, two years after the operation, a surgeon advised an amputation, which she, at age 12, wanted because the pain of the ulcers was so severe, but her parents "were absolutely horrified". She continued "which I can understand, I mean I would probably have felt the same if it were my child." She did not have the amputation until she was in her forties. She described her parents' reaction as understandable, but possibly the story of the
surgeon's meaningless neglect was more difficult to tell. Another story she did not tell until later was about a private patient in the ward with the other children who was allowed parental visits and better food. About the lack of visiting in hospital, she said, "that was very, very difficult and totally wrong."

Daniel (65, polio at 18 months), who recovered very well, told a positive story of a supportive family and community, and did not mention his period of three months, age 9, in hospital for a leg operation until the end of the interview. He described the ward filled with crying younger children as the evening approached. The nurses would come by pulling the blinds down, one after the other, and he showed me, in the air, saying "blind down, each window, blind down" in preparation for the long night. He said, "and the kids, one or two of the kids, oh my God." He was upset at first but "quickly got over it". At the end of the story he said, as he often said, "so no problem really." Gallagher (1998: 57), who was 20 when he had polio and had more understanding of his situation, discovered that any emotion surrounding his paralysis could not be expressed to his family or hospital staff.

If I showed even a fraction of the depth of my feelings, they would abandon me; they would leave the room... But, so far as I was concerned, so far as the real me was concerned, it did not matter -- none of it mattered. It was all over. I had retreated into a private place, deep within me... I would not, I could not take such hurt and rejection again. I would not allow myself to feel it.

Some of the women who spent months in hospital were able to form more relationships with other girls and nurses than men, allowing them to express more feeling. Daniel's story is quite minimal, but it affected me, and, in the next chapter, I will explore how his experience, in tandem with his story of a very supportive family, may have impacted on his later life. For Riessman (2004: 4) "the investigator's emotions constitute a fertile field for disciplined study and, further, their examination can generate knowledge about the 'substantive story'."

Those who had surgery as teenagers generally had detailed stories of spinal fusions, but Jonathan barely talked about his spinal fusion at 17. He was in hospital six months and
on his back for nine months. He had previously missed two years of secondary school because of the pain of his scoliosis, and the operation was tremendously successful in stopping the pain. That these three years were so briefly mentioned may reflect the story at beginning of the interview about his parents' denying how seriously he had been affected and that he would need a spinal fusion in the future. On the other hand, Jonathan said that "doctors always talked to me like an adult" from his first hospitalisation at age five, so he may not have had the anger about being disregarded by medical staff that others felt. Even in his telling about his early experience of polio and being in an iron lung, Jonathan describes a human and respectful relationship.

Jonathan: Dr Michaels came up and explained, I was in the iron lung, and he said, 'Look, we might have to do a tracheostomy.' And explained what that was, which I know is a pretty scary thing to say to a 5-year old. He said, 'Well, we might not. If you remain calm --

Jonathan also talked about becoming very close to his father during the years he was not at school. His father took him to outpatient appointments, business dinners and "we'd spend days together." Jonathan's overall story, like his initial experience of good and bad hospitals, is a complex mix of the positive and negative, which may have led to him not telling the expected negative hospital story.

In contrast to Frank's (1997a) argument that chaos stories cannot be told, Joanna, who experienced the most fear since polio at 11 years, was able to talk openly about her fear of being paralysed initially and in hospital for a spinal fusion four years later. Her fear was "of being helpless and people doing things and I can't stop them" and "people not explaining". When she went back to school after polio, she walked with a crutch "to keep people away from me, and so they didn't bump into me... I didn't need it but, psychologically I needed this crutch as a support, to keep me safe." It was not until she arrived at the hospital for the spinal fusion that she was told she would be there for six months -- "I didn't have a clue and then my mother went home... I was sort of abandoned." In a diary, which she kept every day during the hospital stay, she only
recorded mundane everyday experiences, except for the first few days when she was very upset.

Joanna (diary): Saturday 20 August (4th day in hospital) -- Mum came and I cried for one hour, she won't take me home. I want to go home. Bed at 10 p.m.

Tuesday 23 August -- Carol came in. Had card from Auntie Phyllis. Played Monopoly. Had my plaster jacket (body cast from neck to hips). I cried.

Gallagher (1998: 26) wrote about his experience in an iron lung: "The mind does not know how to cope with finalities of such scale and size; it continues to deal with the daily and mundane: the term paper due on Monday, the dance on Saturday night." Joanna concentrated on making friends, daily activities and the discomforts of being in a cast, not the surgery or its outcome, and this may have been her way of gaining some control and seeing herself as ordinary. She may have preserved the diary all these years as a testimony. Joanna also sent a photograph of herself wearing a Milwaukee brace after her spinal fusion, saying she wanted to show what the brace was like (Figure 6.2).

In the photograph, her head is forced high and, in contrast to her story, she looks strong and defiant. Possibly there is another side to her story of fear, one in which "I've always
been a bit of an outsider, and I think that was partly shaped by circumstances and polio because I learnt to cope on my own and not to rely on other people, not to have people as a group… and not using other people for support."

At 15, Alex had had reconstruction surgery on a previously painless foot, which led to ten years of intermittent extreme pain. He said, "there was no question, it was, just you do it. That was a major mistake and I seriously, I know it's crying over spilt milk, but I wish my parents said no." He described in some detail the infection after the operation, a second operation and then the removal of the cast.

Alex: Well, let me tell you when the plaster cast came off and that foot went back into natural position, it was ooooh, it was one of the most incredible, intense moments of pain. So every time they tried to touch that foot, and obviously the metatarsals hadn't mended properly yet, it was like scraping. It was very intense.

Two years later, he was booked in for a back operation, but this time he spoke to the surgeon.

Alex: I was adamant that nobody was going to make decisions about me, and this extremely good orthopaedic surgeon but very rude, well, he was just so damned rude... I said to him, 'What exactly are you going to do?' And he told me what he was going to do in the lower back because I had severe pain in my lower back, sometimes a kerbstone was like a mountain. I would gently shuffle to find a place one could actually get up and not hurt, that kerbstone would hurt, getting up onto it... I said to him, 'What are the risks?'... And he said, 'The risks are that you, we're going to try and fix this you could end up in a wheelchair.'...but then when he said to me, 'You're going to be in wheelchair roughly 34 anyway', that's when I decided I'll take my chances. I can remember thinking, 'These Godlike creatures, I don't trust you any more. You've messed around on a number of occasions and every time it hurt and brought no benefit. Now I made my own assessment, the risk of things going wrong was too high.

Similar to both Matthew's and Alex's gradual understanding of discrimination at school, Alex gained more and more control with each operation as he came to understand the level of trust he felt and his ability to weigh up the risks for himself. The stories of surgery bring together two themes in this chapter -- children being treated as objects and
resistance to this treatment. The first stories told by those who were younger children, still in primary school, are difficult stories of not being told what was happening and not being listened to. The stories of those who were teenagers are about gradually learning to take some control for themselves.

6.4 Conclusion

In the beginning of Chapter 5, several stories about the initial polio and vulnerability in the narratives of people who had tried to concentrate on their strengths were highlighted. Ambivalent stories of confusion, silence, liminality, discrimination and unfairness, and finally the beginnings of resistance followed. The resistance was about the behaviour of other people towards them -- the interviewees did not ask why they got polio, but they asked why they had been treated "as if they didn't count" (Helen). The emotions were hidden, unknowingly, often with some cost, as was made clear in Jennie's e-mail quoted earlier. Barbara, who told the story of the broken doll, told another story about children's needs, even simple needs like rest, being recognised.

Barbara: I missed the first year of school, I was upset that when I went to school, the year earlier than mine, they had little camp beds in the school, for four year olds... and in the afternoon they had a little sleep. Of course because I'd missed that year I was then in the other class and I didn't have that. And I always used to think, 'Oh I wish I'd had that.' That was the only memory I have of wishing I'd had something that everybody else had.

This example of treating children as if they do count and do have needs holds the key to what was often lacking because people find childhood illness so difficult. The childhood stories in these interviews bring together two major themes of living with polio, which are inseparable physically and socially -- the physical and emotional vulnerability, and the resistance to their weakness and how they were treated. The two themes exemplify both lack of control and control, and the stories similarly form a balance between expressing and controlling emotion.
The stories varied according to the age that people had polio. Those who were younger when they had polio had specific experiences due to their age, relating to sometimes not knowing their story, not understanding what had happened or what was being done to them, not having any choices, and not being listened to. However, the stories of people who were older are often similarly confused. People who had polio often ask whether it was easier to have had polio as a very young child and not known anything else but also not have understanding, or as an adult who had known a normal life and would understand. Jonathan had commented that "in a way it's harder for adults because they know". The situations were different but neither was easy. It was probably easier for those who recovered completely and harder for those who became seriously disabled, but it was also difficult for those left in a nearly recovered liminal position, as explained by Helen. Another aspect which became evident through the survey is that women and younger children had more widespread damage than was obvious and have had more complex later symptoms which doctors often dismiss (Appendices 4 and 5, Benjamin and Taylor 1951, Weinstein 1957, Ramlow et al 1992, Lonnberg 1993).

The next chapter will carry these same themes into adulthood, where independence predominates, concentrating on how the tension between strength, vulnerability, ambivalence and resistance to discrimination influenced people's work, family and other relationships. I will look at how people felt these earlier experiences influenced their adult lives and how they came to live life 'as normal'. In a few cases, recovery was excellent, but for most, polio did not go away, either physically or socially. Having been away from home at a young age and having to work hard at recovering and finding a place in the world, many of the people I interviewed became very independent and responsible quite early in childhood. Alex and Polly mention their feeling of responsibility for their younger siblings although neither was the eldest in the family.

Alex: As I grew up, there was also a *sense* that, nobody gave it to me, but there was a sense of 'I have to look after my two younger brothers.' That's *another* refrain throughout... if there were decisions to be made in the absence of my parents, I made those decisions. So I rather *strongly* put myself into a position of *control*.
Polly (after her father died when she was 14): I was at the head of the family, I was seen to be a competent child who was getting on... whereas, the smaller ones, they needed looking after.

Independence and control, which were necessary parts of being normal, became major factors in the next stage of people's lives. It was not until PPS forced many people to stop and look at their lives again that a few felt the costs, the anger and sadness, and wondered what it had all been about.

Matthew: No but it's like you, it's not a good analogy really but, you know, when you think about and when you hear about what went on in the concentration camps and you're just shocked at, these people co-operated with this mass slaughter, you know, it's and then, and they say, what do you do, you know, what could you do, you had to do it, you had to get on with it

As people had learnt such control, both physical and emotional, they could go out into the world and no one, including doctors, understood their experience and therefore no one, including themselves, spoke about their difficulties and even polio itself. This may have led to some of the scepticism and lack of understanding about PPS among doctors and other people that continues now. This control and lack of understanding from others led to the ambivalent restitution stories people told.

Ian Dury: I don't wave it about. Roger Daltry said to me, when the Kilburns supported the Who: 'Cor, if I had a bad leg I'd fucking wave it about.' I said, 'No you wouldn't, Roger, you'd leave it alone'. (Gould 1995: 252)
7. Middle years: work, independence and interdependence

7.1 Introduction

I'm not sure that I could be where I am (largely happy in my work and life) if I had not been able to regard certain elements of my life as something alien to me, to be overcome, to be put behind me. But it did have a cost of... how much of my experience and adaptational processes had distanced me from myself and the phenomena I wanted to understand. (Zola 1983: 198)

In the previous chapter it became clear that there was rarely an evolving polio story told and retold among family members. The past was put aside so that children could get on with normal lives, as has been found in other qualitative studies of polio and PPS (Thorén-Jönsson and Möller 1999). Although many people who had polio would say they had had an ordinary childhood in a close family, they also often had several hospitalisations, which disrupted home life and education. After these experiences, how did they feel about moving out into the world, embarking on jobs, relationships and creating their own families? As independence had been a major goal for themselves, their parents and their physiotherapists, this remained a major factor in their lives. Williams and Wood (1988: 131) argue that "The particular ethics informed by injunctions to self-reliance, independence and so on are prominent components of western individualism", but for people with chronic illnesses and disabilities the need for autonomy and control may become even more important, as they are seen as different, dependent and in need of a cure (Zola 1993).

Bauman (1998) argues that modern society seeks order and the elimination of ambivalence and contingency, characteristics personified in the 'stranger', those whose lives are uncontrolled, unstable and outside the norm. Douglas (2002) describes those outside social categories as anomalies, people who cause discomfort to others. Failure to conform to categorisations of normality and independence risks opprobrium and stigma (Goffman 1990b). It also risks blame, as illness and morality are closely linked (Kirmayer 1988, Rosenberg 1992, Conrad 1994, Galvin 2002). Even if a disease is not blameworthy, a person may be blamed for not working hard to recover, for 'giving in', or for not behaving appropriately, as the good patient or the good disabled person (Williams
and Wood 1988). The strength of these social controls leads to a polarisation between success or failure, triumph or tragedy (Bury 1991).

As a result of the difficult recovery from polio, independence, both for rehabilitation staff and individuals, first and foremost related to physical ability. Secondly, it was about independence to work and become "productive members of society" (Wilson 2005: 70). This often led to an extreme work ethic involving a feeling that one must keep achieving and never slow down or stop (Scheer and Luborsky 1991). More paradoxical was the position of interrelationships, an integral part of normal life but in conflict with the impossible ideal of independence. In reality, "we are all so inextricably bound together that our autonomy requires our dependence" or interdependence (Williams 1991: 522). Autonomy, as distinct from independence, often refers to the ability to make decisions about action, rather than completing the action, allowing for interdependence (Cardol et al 2002). The concept of autonomy is complicated further by adding Nussbaum's (2001: 372) idea of an "uneasy balance" between self-sufficiency and contingency, contrasting stability and risk. Rosaldo (1989: 102) describes the ambivalent position between order and chaos as "the less explored realm of 'nonorder'... improvisation, muddling through, and contingent events." Although strict categories are attempted, there are always boundaries and grey areas, and however much chaos is feared, rigid order is equally intolerable.

The first chapter on the middle years will focus on work and its meanings in relation to independence and interdependence, and the second chapter on relationships and families. In order to achieve normal lives, of work and family, incredible strengths were developed, and polio had to be put aside, only to shift into focus when necessary. Themes that emerged from narratives of work were the importance of work itself, feeling natural in work, the role of luck in contrast to the need for control, and a complex concept of 'helping', both wanting to help others and wanting to have been helped. In contrast to the distant and symbolic childhood polio stories of the previous chapter, the accounts about work tended towards explanation or description rather than stories, as work was well-remembered and distilled from a longer, more recent time period.
As background to the stories of work and careers, it is interesting to note that in a survey of 1710 people who had polio, conducted through the British Polio Fellowship by the Office of Health Economics (Lee 1965), it was found that 84% of the men and 70% of the single women were employed. Among married women, 25% were employed. In the general public, the figures were 95%, 92% and 32%, not greatly different. In contrast to this, every one of the 31 people interviewed in the current study worked after they left school and only 2 women did not work after having children, and this was because of their more severe disability. The majority of the interviewees span the generation born from the 1930s to the 1950s, now aged from late forties to late sixties, so some differences in attitudes to employment, especially for women, might be expected. There was a difference in the kinds of stories told, in that more of the older people concentrated on the positive and 'getting on with it'. They were also more likely to say that people did not analyse or think about things as much as is done today. Even though almost no person thought of themselves as disabled, some did think about jobs they felt they could or could not do. One generational difference was that some of the older women were channelled into office work as their only alternative, and this sometimes led to resentment. Career choice was sometimes restricted because of disrupted education or the physical inability to do certain jobs. There was more choice for the younger women but many still felt they were limited to nursing, teaching, social work or secretarial work. Several people tried various jobs before finding something they felt comfortable with. A few others changed careers midway. It was important to many people that they find something they could do naturally, which brought a feeling of achievement, pride, autonomy and control.

Most of the interviews centred on work as a major theme, and the feeling of being comfortable in their work was crucial to many stories. In contrast to the important theme of control, many people spoke of finding work they loved through chance, often work that involved helping or managing people. Although work was an integral part of being independent, it was also often important that it involved people and interdependence. Helping others could enhance autonomy and was also morally important to some people.
because they felt they had not been helped or cared for as children, for instance, while in hospital. Several people did a second degree in psychology or trained in psychotherapy after an earlier career. It may, of course, be that those who had worked with people were more likely to volunteer for research. Murphy (1990: 153) found that many disabled people became psychologists, social workers and speech therapists, where "their frailty is a strength". For varying reasons sometimes related to polio, others were not able to do what they wanted, or were glad to have found any work. The people interviewed did a wide range of jobs: teacher (7), office worker/accounts/secretary (7), nurse/health visitor (2), social worker (2), accountant (2), business (2), civil servant (2), psychologist (2), doctor/medical research, engineer, charity administrator, mechanic, caterer. The rewards from working with people were various and complex, and I will examine several who had helping jobs, such as psychology, special needs teaching, nursing or social work (Polly, Jonathan, Barbara, Matthew and Jennie), and one who worked in business management (Alex). The themes explored are autonomy, independence, fate, risk, helping others, interdependence, and feeling natural.

7.2 Autonomy, contingency and helping others

Visotsky et al (1961) studied the coping behaviour of 81 severely affected polio patients in a respiratory centre, and one of their conclusions was that previous difficult experiences in childhood, if resolved, could provide strength for dealing with the current polio experience. This was the view of Polly who became an educational psychologist and had always been very independent -- at age seven she had a tooth pulled out "on my own and I had to go on two buses".

Polly: Modern children don't have a lot of the tough learning experiences we had, that when troubles come along, they actually don't have the resilience and emotional resourcefulness to cope with it...it's like a vaccination, you learn to deal with trouble in bits and gradually get terribly resourceful and resilient.
She described her interest in psychology as growing from her experiences in the children's home, school and hospital and not being treated like a "living, feeling human being".

Polly: I was always very interested in psychology and, kind of philosophy and right and wrong... I had definite views about what is right and wrong and I think I was always more of a psychologist but I didn't actually know that psychology existed, I thought I wanted to help people the way most girls do.

She explains that her interest in helping people was actually different from "most girls" because being in hospital had developed a strong moral feeling of "right and wrong" and the polio creates a vulnerability that "gives you empathy with other people ". Fate is woven throughout her somewhat confused narrative, from her house burning down leading in a roundabout way to her refusal to return to the children's home, to a chance meeting in Morocco leading to her enrolling on a psychology degree. As will be discussed later, several women told confused stories in which it was difficult to understand when or where major life events had taken place. Polly described the conversation in Morocco, but it did not seem clear what degree she had done:

Polly: Then someone I met in Morocco said, 'Oh, they've got places in the Department in Nottingham, go and roll up and you could probably enrol on a psychology as a minor and then transfer', so I did that, term had started... I went and signed up and lo and behold I did well and then they let me transfer to the major degree and I did botany and zoology.

However, her narrative is clearly structured by the continuity of family and polio influence. Polly felt that polio was "the most formative experience of my life", and that it led to "extreme vulnerability combined with extreme strength", which helped her learn to cope with so many difficult experiences. She summed up "I just think, 'Why have I worked so bloody hard, you know, why have I put up with so much?', and that, I think, that's the polio legacy." Although part of her would have liked to have been able to take things more slowly, to have worked part-time and spent more time with her children, another part felt driven to work. This was the side of her who felt natural being a psychologist and helping children avoid some of the experiences she had had. "Once I
found psychology, I knew that was me, I've always been very in love with my profession... I'm a natural really". The other side of her was the one who felt inferior and had to prove she was normal and in control, the one who "would have choked" rather than use the "polio word". The work ethic was also part of her upbringing and integral to the way she described both her mother and grandmother, "we're kind of Jack of all trades... way of earning some living and being independent". However, she also saw the need for children to have "a balance between what they can cope with and exposing them to challenge".

Jonathan remained more disabled than Polly and told a story of a more precarious strength. He had been left with spinal curvature, breathing problems and arm weakness, which literally made reaching out to people difficult, and he learned that he had "to help people with their problem with it". Unlike Polly, Jonathan's strength was in explaining his weakness rather than hiding it, but this was not easy, and lack of understanding and the inability to get help formed the continuity of his story from the beginning. After being a graphic designer for some years, he trained as a psychotherapist and psychologist, which he described as an early interest.

Jonathan: I also had an interest in psychology from art school; I did educational design at art school. So in a way I got into it by interest and I used to joke at art school, I said, 'Oh, I'll either do philosophy or psychology when I'm 60.' So it's a luxury.

Again, this was a pleasure; something he felt was natural because he had always been an "observer", studying other people in order to make them more comfortable with himself. Murphy (1990: 92) also noted that "as the price for normal relations, they (disabled people) must comfort others about their own condition". It was also fate, in that Jonathan had taken on a graphic design job for a psychiatrist, who did not have the money to pay him and asked if he would like to take part in a course on sex therapy instead. Possibly when lives are so dependent on "planning, being careful", grabbing at a chance occurrence is one element of freedom. Also, as polio had been such a chance occurrence, it might have seemed natural that fate should play a part in their lives.
Whereas Jonathan said he felt he became particularly independent from being away from home and treated as an adult even at age five, when he was in the iron lung, Polly became competent and independent because she had always had to be responsible for herself. Besides having a tooth extracted on her own at age seven, after having polio she went alone into the city centre to have physiotherapy twice a week. Polly's empathy is mainly with tough people who have had difficult experiences like herself, while Jonathan's experiences have led to more understanding of the outsider who avoids confrontation. Paradoxically, although Polly's children also have a tough, working mother, she said that her grown daughters "need lots of support from mum". Jonathan, who still has young children, seems protective of them and concerned to carefully explain his disability. He thought polio had made him "self-reliant" but also less able to stand up for himself because of his physical vulnerability. Both Polly and Jonathan, who had very difficult experiences in hospital, struggle with the ambivalence of troubles creating strength and vulnerability, of protecting and creating strength in their own children and the people they work with. On looking back at her research, Riessman (2004: 20) was able to see more contradictions and complexity, and could finally imagine "how a despairing self could exist alongside a courageous self", which comes across in this study. Barbara's story of her feelings about how children are treated, her nursing vocation and any links to polio is particularly interesting in that her thoughts seemed to evolve during the interview and afterwards.

Barbara, who considered herself "very fortunate" compared to other children who had polio, became an orthopaedic nurse and then a community midwife, a choice she explained as "repayment" for all that the nurses had done for her. She had told the stories of the broken doll which the nurse had promised to fix but had not, and the camp beds she had missed, hinting at wishing some things had been different. Talking on the telephone to Barbara two years after the interview, she told me another forgotten doll story she had heard from her sister in the interim. The two doll stories were almost identical. Barbara had scarlet fever when she was nine, and while waiting for the ambulance, her mother had rushed upstairs to get a doll belonging to her sister to give Barbara, promising to
replace it. She never replaced it, and the contaminated doll was confiscated by the hospital.

Barbara explained how guilty she felt that her sister had always remembered this story and had not had a happy life, and that she felt guilty about the earlier doll which had belonged to her aunt, who was only a few years older than herself. She also felt very strongly how important it was to keep promises made to children. Telling this story, I felt she was re-entering the experience of children taking on responsibility for events beyond their control, and how adults rarely have understanding of how deeply children are affected by both small and large events. In her experience, this lack of understanding of children leads to a lack of care through ignorance and broken promises. Like Jonathan, Barbara's experience was at a young age, and both feel the need for more protectiveness towards young children. The camp beds may have been an indication of adults understanding the needs of four-year-olds, something Barbara had missed. Several of the people who went on to help children or other people in their careers, told stories of a connection between their childhood polio and their career, wanting to fill the gap in understanding and need they had experienced. However, Barbara did not explicitly make the connection between her anger about women's attitudes about children now, and her experiences in hospital. She suggests that her own lack of children was chance and that she had always had a premonition that she would not marry (see Chapter 6 and 8).

In a study of disabled mothers, Prilleltensky (2004), who has muscular dystrophy, describes her own experience of falling on a slippery, snowy path and being unable to get up, while her four-year old son tries to help and is unable to. The reader becomes witness to his helplessness and guilt, but, looking back 13 years, his mother concentrates on his compassion and helpfulness. This description of the child of a disabled mother is similar to the story of disabled children, a heightened experience compared to 'normal', of finding a balance between helplessness and helpfulness, vulnerability and strength. I will next explore the stories of Matthew and Jennie, who both weave together stories connecting childhood and career, of feeling that they had not always received the care they needed as children and wanting to help vulnerable children.
Matthew started working in a children's home a couple of years after leaving school with no qualifications, because a friend suggested they work together. Fate intervened in his career and he also relates a visit to a palm reader who "was adamant that I would end up in a mental hospital and I think, because of that, I've always striven to understand my anguish." Fate was particularly relevant to Matthew's story, because he had been taken to the doctor for a polio vaccination shortly before he caught polio, but had had a cold and was not given the vaccination. He also felt "it'd be easy to go under with it all, you know, you could quite easily accept fate and go down with the ship." Fate weaves together the polio, the mental anguish and the career helping children and himself. As he said, "when you're helping them, you never get over it, but, you know, it's the same thing I've done... is that you find a way to live with it, so it isn't quite as painful". The first job in a children's home began a lifetime of social work with children, eventually leading to an MA in therapeutic child care. Like Polly, Matthew wanted to work with disadvantaged children because of his bad experiences in hospitals and at school. He mentioned identifying as a "wounded helper", but at the same time, did not identify as disabled. When a doctor suggested he apply for the new mobility allowance in the 1970s, he said, "No, that's for people who are really disabled, isn't it?", and the doctor replied, "'Yeah, I'm afraid you are really disabled.'" Defining disability sometimes became a very fine art, suggesting what Crawford (1994: 1347) calls the "politics about identity and difference, about the boundaries of personhood which distinguish legitimate from non-legitimate identities, and about the meanings upon which identities are constructed, managed, and reworked."

Like Barbara, Jennie's story evolved through and after the interview, although since PPS forced her to retire, she had been trying to make connections between polio and her later life. Whereas, after the interview Barbara tried to discover feelings that would explain her few fragments of memory, Jennie, throughout the interview, searched for memories that explained her feelings. Jennie became a primary school teacher and, by chance, found herself teaching several special needs children, and decided it was something she wanted to do full-time.
Jennie: And I was sitting there at the end of the table, one of these children one side and one the other, everybody else getting on nicely and really helping these two and I thought 'I'm really enjoying this helping these children with their special needs'.

She told a story of a disabled child she taught, whose mother was not really helping him but assuaging her own guilt.

Jennie: There was one mother with a child with cerebral palsy ... who felt so guilty. She spent all her time building a, writing letters, finding out about it and building up a massive file so that when he was older ... she could see ... he would be able to see that she'd done everything she could...the fact that she let him get so overweight that you really, we couldn’t do his exercises with him any more and ... he really went downhill, she didn’t see was important. But she just had to show him that she did all she could ... to help him with his problem. Except that she wasn’t doing it the right way.

When talking about her parents' visits when she was first in hospital with polio, aged five, Jennie mentioned "resentment that they couldn't do the right thing". She described one example when she was moved to a larger ward.

Jennie: ...they'd moved me from the isolation into a ward... and my father, he was worried that, my mother says now, he was worried that I would think they didn't know I would, sorry I'm not put, I would think they didn't know where I was and that's why they hadn't come to see me... so my father came and peeped through the window, and waved to me. And the nurse came and said, 'Look through the window, there's somebody there.' I now think that didn't help because I must have thought, 'Why is my father out there waving to me and he won't come in and see me.' But...I'm not sure that was the best thing to do from my point of view. But anyway it was very, very sweet of him.

Jennie knows that her father was doing the nicest thing he could have done, but she is trying to be faithful to her feelings. She mentioned another story about her parents bringing Christmas presents the wrong day, on Christmas Eve, so she had none on Christmas Day. She described other resentments about her parents not making allowances for her weakness, such as when her father made her cycle to school during the bus strike, but she seems to be searching for the right story about "not doing the right thing". It was
not until after the interview, in an e-mail, that Jennie connected her stories with the story of the disabled boy, which explained the resentment as a feeling that there was not enough listening and understanding her needs, the delicate balance Polly described of supporting and challenging. During the interview, Jennie tried to minimise the effects of polio, explaining her resentment by saying "there are lots of other things, nothing to do with polio" and "the change of school, the disruption, upset me more than the whole polio thing."

Jennie (e-mail): I suddenly see the links between all this and the boy with cerebral palsy that I talked about. I wondered why I had talked about him and his mother so much. His mother spent all her time putting her case, her point of view, without listening to, or doing what was best for him. As I saw it my mother did the same thing...In my role as a support teacher for children with special needs, I saw myself as helping them to fulfil their potential, (I feel I did not achieve my potential) and making allowances for them, (as I would have liked allowances to have been made for me). Overall I saw myself as 'being there for them'. I would have liked someone to have been 'there for me'. All this needed negotiation with other teachers who did not like allowances to be made and children to get too much attention! I was not able to say this to you in the interview as I had not connected these things then. They were things that were in my mind and things that I was aware of but it is such a slow process putting these things together so that they make sense... Even now I don't think I can grasp the devastating effect that polio has had on me.

'Helping others' was a common refrain in this study, to the point of many people saying they would take part in the interview in order to help me, not because of their interest. It is a complex concept, involving interdependence and incorporating both helping and being helped, in the same way that so much of this study, and so much about illness and disability, is about the tensions of strength and weakness. Briggs (1971) shows a complexity of helping among the Inuit, which involves both (strong) healthy adults helping (weak) children and ill people, but also (weak) women helping (strong) men, in order, it is suggested by one Eskimo, to guarantee help in return, although people describe it as what they want to do (Bauman 1995). Myerhoff (1979: 145), in a discussion of feelings of worth in marginalised poor, elderly Jewish immigrants, describes the complexities of how "One's honour was enhanced by giving and correspondingly diminished by receiving". A fine balance needed to be created because everyone, at some time, would be in a position of giving and receiving. Those who had polio found
themselves in a similar situation of wanting to prove their strength by helping or being in control of others, but possibly also knowing that they may need or may have needed help in the past. Helping others because one was not helped in the past may relate to a desire to keep the cycle of interdependence going. In many cases, the understanding of how the interviewees had felt about their childhood and their job did not become apparent until they had to make changes because of postpolio symptoms, or after telling a story in the interview as Jennie did.

As a result of their need to show they were 'normal', most of the people interviewed found asking for help impossible or nearly impossible, a finding in other qualitative polio and PPS studies (Thorén-Jönsson 1999, 2001). Their parents insisted that they were not "to be helped up" (Ken), which led to a tremendous sense of independence, drive, control and self-reliance, and an inability to ask for help. Wendy, who continued to have substantial arm weakness, could not bear to apply for the disabled parking badge she was entitled to and "I'd just pay the tickets because I didn't want anyone to think I was disabled... it just took years to really acknowledge that to myself." Years later, when she finally had to ask for help at a petrol station, the attendant said, "'Well, you don't look disabled.'" This experience accentuated the risks people took in disclosing weakness. Several others, like Wendy, recognised more physical and emotional vulnerability earlier on, often because they had more widespread weakness after polio. Joanna said "every step I've taken in my life, every literal step with my legs is a possible fall" and "I've still got that shame, mainly because of my back". Jonathan, who was more open about his disability, still found it difficult asking for help, feeling from childhood that "if you're not relying on yourself and sorting it out yourself, then you're kind of failing in some way." Those who found work helping people or working as a team with people were able to feel they were sorting things out.

Although work is a sign, for most people, of adult independence, an integral part of most work is dealing with other people, or interdependence. Working with people, managing people, and teaching people were important aspects of work for many of those interviewed. Like many of the others, Alex linked his childhood with his career and was
determined to be successful in order to disprove the teacher who said he would end up in the gutter. However, he also spoke with satisfaction about learning to work with people in business. Like Matthew, he was not afraid to speak his mind, and had several other parallels in his life to Matthew, including bullying by teachers and multiple unsuccessful ankle operations. He described feeling very independent and needed to be in control since childhood, as mentioned earlier. He was left very unstable in walking, so physical control was also essential. In order to feel in control, the work needed to flow smoothly and come naturally, often in contrast to the ability to walk. On Alex's way to becoming very well-off, he realised how "intuitive" business was, how "easy" it was once you got things going. This created a new freedom not experienced before.

Alex: We tackled this thing and it was the most amazing time of my life... And I recall all of that time there was no such thing as polio in my life.

He said that "this absolute aggression that I felt at times was focused into my career" but at the same time he loved the excitement and he never stopped, never went on holiday. He also described having pain every morning, and sometimes excruciating spasms, but he worked 17 hours a day and forgot the pain. Real control also involved being able to take risks. Alex moved from sales into computers and then the management of huge multinational companies, which he knew nothing about but "I took the chance...it just happened." He learned that factories consist of people.

Alex: So it wasn't my job to take people along with me, I could just have had the attitude most have. I took people along, I had little meetings. 'What's your problem, fears?' And people started trusting me and that was key. And the lesson I learned there is never speak before you have earned the right to speak.

Two important aspects of work that felt natural were that polio could be shifted out of the picture, and that energy and emotions such as anger could be controlled and turned into working positively with people. However, for various reasons, not everyone was able to obtain challenging work, and in the next section several examples, in which lack of encouragement or physical symptoms hindered career choice, will be explored (Helen, Joanna, Ian, Sarah and Sue).
7. Middle years: work, independence and interdependence

7.3 Difficulties with work, physical and social

Several of those interviewed, especially women who had had polio when young, came through their polio experience with less confidence than the others, and they saw this as affecting their careers and leading to less fulfilling work. They may have been more visibly disabled or their parents were more protective and less encouraging. Those who were in their sixties had less choice, but women in their fifties, mostly born after the war, had a few more options. Helen, who worked as a librarian and secretary, belongs to the younger group, who generally were most encouraged, but feels she was not pushed to do as much as she could have.

Helen: I don't know whether I really thought it through because I don't think I really had any idea of the kind of person I was. I mean, I think I lacked confidence through the whole of my life. But it's always been, it's always made life very difficult for me, my lack of confidence. And certainly when I was a teenager I didn't have a clue what I wanted to do until one of my teachers suggested, completely out of the blue and without any particular evidence to back it up, that she thought I would make a good librarian...I think she perhaps thought, 'Oh well, that's a nice quiet little job for Helen, and perhaps she'll find it manageable whereas perhaps she couldn't manage anything else'.

Helen "didn't think of myself as being one thing or another", which may have made it difficult for her to visualise herself in a job or in a future. She envisaged taking the teacher's suggestion as a "way out of having to make a decision for myself". Helen was the only one who felt cynical about the work ethic and this may have been because she did not find more challenging work.

Helen: ...although I suppose in some ways I was quite ambitious, there was a little voice in my head that said to me on occasions that really it's not all that important, you know. It doesn't really matter. And it's not worth killing yourself for... And I thought 'What are all these silly people rushing about going to meetings for? What difference is it going to make in the end anyway?'... I think sometimes you just have to have the strength to stand back and not get on that particular ride, or something.
She missed the paradox that others found, of being totally there in an easy flow, and able to forget themselves, especially their disabled selves, as described earlier by Beisser (1979). Joanna was also in the younger group of women, but had not been encouraged academically by her parents and, having missed two years of school through polio and a spinal operation, may have lost confidence and the impetus that comes with being part of a group that continues in education together.

Joanna: It wasn't what I wanted to do, shorthand and typing, I felt I wanted to go into social work...I did temping work in the local hospital for a few months, for a social worker, and I felt I could manage that kind of work if I'd had a better education.

For several people, their careers were limited by strength or fatigue. Clare "really wanted to be a physiotherapist", having had physiotherapy after several operations, but her surgeon said it was too physical for her and she should learn typing, leaving her with the frustration of not being able to do something that interested her. Another problem with work was lack of stamina, which could lead to fatigue or pain. These symptoms were ignored or treated as psychological in the polio research (Young 1949), which concentrated on the weakness, and only one PPS study explored fatigue and neuromuscular symptoms during the stable period. The authors found that 58% of the sample had fatigue, muscle twitching or pain in the 1970s and that this was the highest risk factor for PPS (Ivanyi et al 1999, Appendix 5). I will describe three participants, Ian, Sarah and Sue, whose work lives were seriously affected by fatigue and stamina problems.

Ian, who did not know he had had polio until he had tests when he was 54, and could never walk more than half a mile due to pain, discovered, after several jobs, that he needed a sedentary job, working alone, because of concentration problems. Eventually he found work he enjoyed as a farm accountant. He suggested that there were many, probably interconnected, reasons for his unhappy childhood and lack of education. His schooling had been disrupted by evacuation during the war. His other siblings had been sent to relations but he had been "shoved off" with others from his school where the education was inadequate, "three or four hundred kids, all in one great big church hall".
When he returned, he found it difficult to concentrate, and he left school at 14 with no qualifications and worked in a garage his father owned. He found the standing painful and exhausting. Several years later, during national service, when it became obvious he could not do the training, he was given a job as librarian, and he realised for the first time that he had no pain or concentration problems, sitting in a quiet atmosphere. He described this as his first realisation that he might be able to find work that he could do comfortably. As with all people, the compatibility of person and job is all important, but those who could become totally involved benefited in being able both to forget their disability and find the 'natural attitude' (Schutz 1970) other people have in movement which they did not.

Sarah's story of fatigue and stamina problems, which her family knew about but did not discuss with her, described in Chapter 6, had some similarities with Sue's story. Sue had had nonparalytic polio when she was nine, which had not been diagnosed, and had been left with slight weakness and fatigue. Both Sarah and Sue became part-time music teachers. Sue also kept animals (pigs, goats, ducks, geese and chickens) and Sarah helped on the farm her husband managed. They also both told complex stories in which the chronology was never quite clear, and both mentioned substantial mental fatigue. Sarah had had polio at two, spent six months in hospital, wore a caliper until she was 10, and later had two operations and needed orthopaedic shoes. Planning to study mathematics at university, Sarah took a music course for fun and ended up studying music, as it felt so natural. Doing harmony in class one day, she said, "And I could just do it. And I had never experienced something where I could just do it." Both Sarah and Sue went on to do degrees some years after their original training and did some full-time work after their divorces, but found they could not keep it up. Sarah worked full-time for a year doing research in clinical audit including working in the evenings which became too tiring. She next taught psychology part-time and when given the job full-time, found it too exhausting and reduced the hours again. Soon after, she began working on a PhD. Both women then began having problems with PPS symptoms, which will be explored more in Chapter 9.
Like Sarah and Sue, I always had stamina problems and never believed I would be able to have children and do a full-time job. After going to school in Italy (from the age of 10), I studied biology and art history in the US (BA 1969), and then studied art in the UK (Dip.AD 1973). In 1969 my mother was diagnosed with terminal cancer and I looked after her in New York and then Italy (see Appendix 10). This influenced my decision to go to England, as I would be able to return more easily to help her. She died in 1972. Throughout my life I had puzzling problems with weak muscles, trying to do ordinary things and finding that little or nothing happened or I had pain -- rowing a boat, sanding wood, hammering nails, painting walls, chopping or sawing wood, carrying children. I married in 1970 and had two sons, in 1973 and 1977. Like Barbara, I have strong feelings about attitudes towards children. I think they should be treated with respect, somewhere between the treatment, I suppose, of kittens and geniuses. As soon as they show interest, very small children should be given real physical challenges, such as real tools, because that is when they learn both the coordination to avoid danger and the understanding of their limitations. In the 1980s I worked as an artist (ceramics and drawing) and did some part-time art teaching. In the mid-1980s, my muscles gradually started becoming weaker, after a bout of whooping cough in 1982 when I was 34. In the late 1980s, I began to do volunteer work in art therapy, which interested me, especially working with children, as I could no longer do the lifting involved in making or teaching ceramics. By 1991, I could no longer negotiate the distances or steps at the art therapy unit. After several back injuries, my walking distance diminished from several hundred yards without pain to about 50 yards.

Below are three drawings which may show something of myself and what I wanted to express, the hesitant lines slipping between life and thoughts or dreams, and who we are, like Oliver Sacks' shadowy people on the border of personhood (Figures 7.1-7.3). The first drawing, of my mother sleeping, is possibly about her absence at many times in my life when she was actually present, and the importance of the bowl as a marker of the moment she knew she had only a few weeks to live (see Appendix 10). However, I enjoyed doing the drawing and seeing it over the years, whether or not it tamed the experience. The drawing of the psychiatric patient may also be about absence and presence, and hands were chosen as the most expressive part of one's own body easily visible, which can be opened or closed, relaxed or tense, can give or take, create or destroy. Like stories, what you draw and how you draw it both tell something about who you are, who you think you are, and who you want to be.
7.4 Conclusion

The silence about polio, the lack of understanding of how children were affected, and their treatment by others, led to great strengths, but also to the cost mentioned by Zola (1983: 198) at the beginning of the chapter, that "much of my experience and adaptational processes had distanced me from myself". The stories people told often had continuity from childhood to adulthood in which the strengths developed through working hard to recover and dealing with conflicting attitudes from others, led to motivation to find work they felt comfortable with. Many chose work which involved interdependence, helping others or working in teams, creating a position of control, belonging, and sometimes a means to prevent others having some of the negative early experiences they had had. The need to adapt, physically and socially, often led to an ability to think creatively and persevere until solutions were found.
In long-term illness and disability, the initial disruption and chaos eventually moves into an ambivalent situation which may include different levels of muddling through, creative adapting and even order. An uneasy balance will be found between autonomy and contingency, independence and dependence, favouring the more acceptable autonomy and independence. Good (1992) found that although chronic pain is often thought to be causally associated with stress at work, work can also be a haven from pain and an area of control and achievement in life. In contrast to the emphasis on control, Good also found a paradoxical theme of fate in the successful career, as in this study, so that an aspect of uncertainty remains. Important in Good's study and this research is the separation or bracketing of different aspects of life, work and home or work and disability. By helping or managing others, the separation or categorisation of work as different from disability could be strengthened and clarified as the person was in a position of control.

The next chapter on the middle years will explore how these strengths and the resulting cost of forgetting polio affected how the respondents saw themselves and their relationships in adulthood. It is, however, impossible to know the relative effect of different events or situations in a person's life, such as historical events, poverty or other illnesses in the child or family. In this study, many people did make connections themselves and others were more tentative. Attitudes about the effect of polio went from one extreme to the other -- two men said polio had not been a problem and one woman said "my world had ended" (Cynthia), but almost everyone said that it had had a momentous effect. Alice, who completely recovered from polio at 12, said that polio had not affected her, and then continued:

Alice: they (people who had polio that she met in rehabilitation) are a breed, there's no doubt they are an indomitable sort of person... fiercely independent... don't you dare pity me attitude, I'm all right, I can cope... maybe I'm, you know, a bit like that too.
8. Middle years: identity and relationships

8.1 Introduction

I find it constantly amazing that after all these years on crutches, they still don't seem natural to me; my inner sense of what is normal is still what it was when I was fourteen... And I am still followed always by my shadow self, the boy who was overcome by polio, undone by it, enraged by it, exhausted by it, who wants to give up... And there are still days when I have to talk him into going on, sometimes several times a day. (Mee 1999: 216)

From the time of rehabilitation, the main focus on independence, for those who recovered relatively well from polio, was in relation to education and work. But independence and 'being normal' also meant friendship and family (Wilson 2005). The long recovery from polio often led to close relationships between parents and child but also tensions around the silence about polio and the independence that was the objective of the recovery. This chapter describes some of these tensions and the compromises people found in forming a workable 'normal' life for themselves. At the deepest level, polio and recovery from polio affected how people saw themselves, and very often led to feelings of ambivalence and liminality.

...for many people, most of the time their body and mind together is their self, or more accurately perhaps their sense of self is inextricably bound to their physical body. (Millward and Kelly 2003)

The self "arises as the product of continual introspective debate" hinging on the individual's private world and social environment (Millward and Kelly 2003: 162). We have a sense of a constant self related to bodily continuity and a changing self in relation to a changing physical and social environment. Whereas self relates to individual perceptions, identity relates to social perceptions of the individual (Millward and Kelly 2003), although the two can probably not be divided. The body, biology and disease also cannot be separated from either the self or identity, as the self is affected by the discomfort of symptoms and others are affected by and make judgements about descriptions or visible expressions of symptoms. Williams S. (1996: 42) suggests that:
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...a focus upon narratives of embodiment in the context of disease and disorder may serve as an important conceptual bridge between a phenomenological approach to embodiment, and broader considerations of the socially constructed nature of illness and the cultural transcripts of sickness.

This chapter will begin with how the interviewees in this study saw themselves, personally, physically and socially, how they understood the social message of independence and 'being normal', and how they saw their relationships with partners, children, siblings and friends. It will end with an exploration of the feelings surrounding the paradox of disability, the use of humour, and feelings of anger, sadness and shame.

8.2 Self and identity: "the real me"

In their autobiographies, Beisser (1989) and Gallagher (1998), initially totally paralysed by polio when they were 25 and 20, describe the self as remaining the same, although a paradoxical, shifting separation and integration seems to have occurred between the disabled body and non-disabled self. Beisser describes himself as "the same person" while totally paralysed in an iron lung, and Gallagher meditates on how he remained, inside, a non-disabled person even after 40 years of paraplegia.

For the entire first year and a half, I lay flat on my back in an iron lung... The person I had known myself to be was quite suddenly trapped in an alien body -- one which did not perform automatically on command, or indeed even perform at all... In spite of all this, I paradoxically continued to think of myself as the same person I had been.

(Geisser 1989: 4, 20)

Strange as it may be, I am both disabled and able-bodied at the same time. It might be expected that -- over time -- the inner ghost of the able-bodied me would fade as -- over time -- I learn to live with my disability. On the routine level of daily living, this is the case. But at a deeper and more important level, this is not the case. Over the years, my self image remains that of a non-disabled person, the ghost inside, while the frail and paralysed person -- my real and daily person -- I seem to treat as an aberration, an inconvenience in my progress through life. (Gallagher 1998: 3)
Murphy (1990: 81), on the other hand, having become paralysed in middle age, feels he has lost part of his self, although he also says, "Hey, it's the same old me inside this body!".

I had also lost a part of myself. It was not just that people acted differently toward me, which they did, but rather that I felt differently toward myself. I had changed in my own mind, in my self-image, and in the basic conditions of my existence. It left me feeling alone and isolated, despite strong support from family and friends; moreover, it was a change for the worse, a diminution of everything I used to be.

Medical sociology has neglected the area of embodiment and illness in children and the effects illness may have on later conceptions of self (Williams S. 2000, Lawton 2003). For those who had polio as children or young adults, there was no sense of a loss of self, but varied conceptions about "the real me" at various times in their lives. Some were interested in whether polio had caused them to be different from what they might have been. Jennie commented, "I possibly would have been the same anyway". Others wondered "was it better to have it as a baby and grow up with it... but I've got happy memories of 21 years of being able-bodied and really active" (Beth). I will first explore the conception of self as related to the body and disability, which was expressed in various ways by Joanna, Lauren, Jonathan, Helen and Alex.

Joanna saw herself, like Gallagher, as not disabled, and said, "people never really got to know me, because there's this ghastly thing in the way." She seemed to separate herself from her body which had always caused her shame. Lauren, who had been a baby when she had polio, had been brought up to believe she was normal and she now said she was really the small child who was disabled but had not been allowed to be. She "was made better because of polio", someone who achieved more than she might have and was a "happy, bubbly person" but it was not "how I really felt." Lauren expresses an ambivalence that concentrates on her body, which is herself, and which she feels she was separated from. Jonathan, who is more seriously disabled, was aware of his body and said he had become "an outsider", "an observer" and "I knew I was always disabled". Jonathan wrote a story of his memory of the day he became ill with polio, a day in which he went to the circus and the clown gave him a picture of himself. He writes that "this
8. Middle years: identity and relationships

memory of the circus is mine... the clowns are my memory... Why is it important? I'm not sure, but possession of one's identity can be so bound up in the disability itself, that the need to grasp what and who one is, independent of the events that caused or coincided with such a fundamental change seems important." Possibly it was important to him that the clown, an outsider like himself, had given him a picture, a form of identity, at the moment when his identity was changing forever. He wrote, "That was the time when I parted from the body and life that would have been mine."

Like Jonathan, Helen had spinal curvature and missed several years of school. She felt that she didn't have "any idea of the kind of person I was." When talking about school friends, she brings together the personal and social, saying that she couldn't talk about her polio experiences "because not only would I have been embarrassed about it, I would have felt that they would have been embarrassed about it too." She also had a visual image in her mind that she was not disabled which made looking in the mirror a shock, as it did for Deborah who had a paralysed arm (Chapter 5). Helen described that intellectually "you are quite well aware of the effects it has had on your body" but not emotionally. Emotions are a physical expression of the body, but, for Helen, may be cut off from the body itself, except in specific situations like the mirror. In her fable about a crippled girl abandoned to a convent (Chapter 6), Helen writes about caged birds, "I liked to see them flying free." At the end of the story, the girl escapes from the convent and, accompanied by a bird, does "seem to float away." Helen appears to be trying to bring together the whole disabled person, and reconcile the damaged body with the mind and emotions, which have been separated by the "negative associations around disability". Freedom from the stereotypes which negate, and in doing so, emphasise differences will reappear as a theme in the next chapter. Ignatieff (1999), in questioning how neighbours, such as Bosnians and Serbs or Germans and Jews, can come to hate and kill each other, concludes that assimilation of difference can be more threatening than explicit difference.

Alex, who was 18 months when he had polio, said that in his adult years, when he became very involved in his work, "there was no such thing as polio in my life", yet, when there was reference to it, he did not seem as ambivalent as many others. He was
over six-foot tall and had "a strange walk" but he was "so dynamic, it's almost aggressive" that people often did not notice his walk, and months after meeting him would ask if he had hurt his leg. He described the kind of conversation that would follow: "Didn't you notice, I mean this obvious limp.' And then the reaction was 'Oh, I'm sorry.' 'No, don't be sorry. It's okay.' And I had to explain that this is just *me*". Alex seems to have become strong and assertive from his childhood experiences, enabling him to put polio aside, not for shame, but in order to do what interested him. His body is "me", similar to Allen in the next section, who was also able to remain present with the idea of polio.

I will turn now to explore the accounts of several respondents (Beth, Wendy and Allen) who saw themselves more as an integral whole, but also told subtly ambivalent stories. Most of the previous group were under five when they had polio and this group were older. Wendy and Beth were 20 and 21 when they had polio and said they had not changed, although Beth, discussed earlier, described herself as previously very active and always walking. Beth seems to have kept an image emotionally in her mind of her physical self before polio. Wendy, who was at college and just becoming independent when she got polio, described changes in her outlook to do with her need to show she could be independent. However, her idea of self must have included a basic, unchanging core self, unrelated to her physical body, because she said she had only changed "how I was outside and how I looked to other people." She then described the shifting that has been and still is a constant in her life — "the hardest thing to do is to become more conscious. *All* through the years, I mean even *now*, I go along, you know, *not* thinking about it but than something will hit me over the head." Even more than Gallagher and Mee, Wendy is able to remain unconscious of the effects polio had on mundane, daily activities, which have become natural for her, and only becomes conscious of disability when something unusual occurs.

Allen, who told a positive story of polio as "never a problem", described a continuous self which oscillated with a multilayered, ambivalent self that was both the same and changed. His first comment about himself after being left with a paralysed leg at age nine
was "What you see is what you get now and that's what you got then. I've always been bright and cheerful... most of the time anyhow." Then he commented, "But of course, anything that is a major impact on your life helps form you... having to overcome something like this, of course you do fight... to be as good as you can." It was Allen who ambiguously saw his limp as "a very useful tool", but then said, like Alex, that it was his "engaging conversation" that would be remembered (Chapter 6). He told a story about meeting an old school-friend who told him what their teacher had said about his return to school after polio.

Allen: ...she told me that our form tutor said, 'Well, Allen's coming back to school in September. You have to treat him a little bit differently be- no, you won't treat him differently because he is actually our same Allen, but he can't get around as well.' Well, Jane told me that, I mean, I didn't know about this, but Jane said that when I got back to school, she wouldn't have known there was any difference.

The idea of being different but not different is the paradox disabled people are left with. About the physical effects of polio, his caliper and paralysed leg, Allen said, "it's part of, it's me."

A somewhat different self developed in those who had symptoms, like fatigue or stamina problems, which they did not understand. Sarah did not make a division between disabled and not disabled because her narrative of confusion about what others thought led to her thinking "there was something wrong with me." Like several others who were under three when they had polio (Alex, Michael and Nick), she had seen polio as past and not part of her adult life, and she therefore did not connect her fatigue to the polio. Her stamina problems became part of herself and were defined, first by doctors and then by herself, as being "emotionally fragile". The limp, that caused her to feel that "people wouldn't accept me", made walking and standing physically more difficult, but also may have caused doctors to see her as depressed. Similar assumptions were made about those who had nonparalytic polio, such as Sue and Ian, who became tired easily or had trouble concentrating, and were told they were stupid, depressed or lazy. They had no conception of visible or objective symptoms, or an illness or disability that they could
Bracket off (Williams S. 1996), and Ian described a feeling of "self consciousness" and "failure" until he received a polio diagnosis in his fifties.

Murphy (1990: 81) suggests that disabled people say they are "the same old me inside" in order to protect their identity, and "for preserving that inner sense of who one is". Murphy himself also said he had "lost a part of myself" and although he developed the concept of liminality in relation to disability, he used it to explain the isolation of disabled people rather than the shifting perceptions of self found in the current study. He describes why there is discomfort between disabled and able-bodied people, the lie "that the physical deficiency makes no difference" (123), but this also creates discomfort and a need to protect the self. Frank (2002: 68) says that "To live among others is to make deals", but deals are also necessary to live with oneself. Possibly because in many cases polio initially paralysed much of the body, people talked in terms of the self, which may have seemed particularly threatened, rather than identity. Identity was explained through the whole narrative, as "identity is a life story" (Blaxter 2004: 170), and the next section will focus on interrelationships and how people saw themselves as part of society.

8.3 Identity, independence and interdependence

Independence and remaining single

Many people who had polio did not see themselves as disabled in order to be able to take part fully in society. But they were different and needed to make deals with themselves and others in order to perceive themselves and be perceived as 'normal'. Although relationships were not the main focus of most of the narratives, it was probably the most complex subject and most often the cause of liminality and shifting between disabled and non-disabled self. Most of the people interviewed worked full-time for many years as described in the last chapter and only two women, who were more disabled, chose to have children knowing they would not be able to work afterwards. Besides working, most wanted an ordinary family life. Twenty-three of the participants married and twenty had children. Eight remained single. In this section I will describe four people (Nick, Wendy, Barbara and Daniel) who felt that their families had been quite protective and they later
lived alone. Nick and Wendy tell stories that link the polio with their later relationships, but Barbara and Daniel do not. For those who lived alone, friends were very important, and this will be explored later in the chapter.

Nick and Wendy both described a conflict between their need for autonomy and relationships. Nick, who became an engineer and astronomer, wrote that his mother fought hard for his education so that he could be financially independent, but she discouraged him from relationships, feeling he would only be hurt. Nick felt "that others might think of me as a kind of freak" (as he described one woman saying to him), that close relationships "led to the weakness of dependence" and that he does not "need or really deserve" support. Kelly and Field (1996) suggest that we develop a sense of self from very early interactions, and Schneider and Conrad (1980: 36) emphasise that, in the case of epilepsy, stigma is learned mainly from parents and "Family silence about epilepsy can itself be a lesson in stigma." Nick wrote that his large extended family saw him, as a child, as "damaged" and did not expect much from him, and "polio as a subject was not discussed". This led to always "fighting to be in control of my life and emotions... I refused all help, I had to do everything for myself, I still have to now."

Wendy had very severe polio at age 20, leaving her with instability walking and arm weakness, which prevented the use of a walking stick, making falls dangerous. She described working very hard towards her physical independence, which broadened to a wider concept of personal autonomy. She went back to college a year after having polio and needed a friend (and later her sister) to walk with her to protect her from falls, open doors and help her in the bathroom. By the time she left college she was able to manage on her own. She had several boyfriends in this time and later one long-term relationship for six years but she said, "none of them worked, I think probably, my personality, I think, I worked so hard to get so independent I couldn't let myself get into a..." She became too emotional to finish the sentence. Like Nick, she saw relationships as dependence. This view came partly as a rebellion against her mother's attitude that "a woman had to have a man around the house to do everything." She described her parents as not being able to conceive of her living alone, so Wendy set out to prove she could.
She also decided to move to England, saying it was "fate or fortune" that she managed to find an accessible ground floor flat on her first weekend, or she could not have stayed. Her story is one of living on the edge, physically and socially, of possible dependence or a sudden fall.

In Barbara's case, the reasons behind her narrative of striking independence were less explicit. She mentioned an "overprotective mother" and a "sheltered life" but said that polio had had no effects except a minimal limp that no one noticed. She never married and had a premonition that she would never marry because she had had a recurring "dream of, like getting married, but I never saw the face of the man", although "I would like to have married and had four children, four daughters, of course". For the past ten years she has been living with a man, but still describes herself as single and independent, "we were neighbours... we just sort of, you know, got together". She had told the childhood stories of the broken doll and the little camp beds, but these had only slipped between the lines of a story of fierce independence, which related, to some extent, to her upbringing.

Barbara: ...as long as I can manage on my, you know, I mean, I've been brought up that way. I mean, my mother never got anything for me. She never got any assistance in any, you know, taxis or anything. She always paid her own way to take me to hospital although it was three times a week... but they were brought up that you didn't ask for charity... And so we've been brought up to sort of, you know, try hard to be, you know, work and be normal.

Instead of focusing on polio, Barbara suggests that it was the war-time culture of proud working-class people that dictated an ethic of hard work and financial independence.

Daniel had polio as a baby and also recovered very well, with only a slight limp. His story is quite different from the others in that, although he lived alone for much of his life, he does not tell a story of independence. He described coming from a close, protective family, like Nick and Wendy. He became ill while the whole extended family was on holiday in a rented cottage by the sea, and his parents rushed him back to town on a bus. He had a different experience from most of the others in that he felt well supported
not only by his parents but by a local clinic, his school, friends, work colleagues and even the doctors he later met about PPS. He had polio in 1938 and felt the war years brought people together. The clinic he went to as a child was next to his primary school and he described it as "so natural, the right thing, the close association was so easy". He was never instilled with the need to fight, push or overachieve from family, school or doctors. He referred to his parents as "very protective" and then said "they didn't stop me doing things by any means, when I say protective, supportive I should say". He described the clinic and two nurses that he knew much of his life.

Daniel: My mother always came to the clinic with me, you see. I hardly ever went on my own. Even when I was grown up, she was always there. So that she used to get on with these two nurses so marvellously well that I mean, well, there were people doing the same thing. We weren't any different to that extent. They were, the whole group was very supportive.

Daniel said he enjoyed the challenge of his work in accountancy and computer systems, but possibly because his family were so supportive and his hospital experience at age 9 was so isolating, he never wanted to move beyond his family for relationships. He has a twin brother, who also did not marry, and they have lived together since Daniel began to have PPS symptoms. I asked if his brother had always felt protective towards him, and he said that they were close "And people accept us for that... so that, again, no one sort of said anything, 'what's the matter with you two? Why are you two always together?"

Although their relationship might have seemed strange in other circumstances, it was considered natural, but whether this was because they were twins or because of the polio is not clear. Possibly he is not sure or he wants this point to remain ambiguous. There is no one interpretation in a complex situation such as this, but the story Daniel tells is that the life he has chosen is the best one for him and this feels right and makes sense to the listener or reader. Unlike Nick, Barbara and Wendy, Daniel did not see his life in terms of independence or dependence, but as an ordinary life. Like Barbara who saw herself as "fortunate" in recovering so well, Daniel described himself as "one of the lucky ones" and did not have "any regrets".
It is important to keep in mind the interaction between the physical and social situations in these stories. Although Nick was two when he had polio and Wendy was 20, both were quite severely affected and had long periods of rehabilitation. Nick remained with one paralysed leg and Wendy with significant arm weakness. The weakness and long rehabilitation probably affected their need for independence. Barbara and Daniel recovered very well. Barbara was brought up with a strong work ethic, whereas Daniel felt less pressure to achieve. He lived independently but may not have felt the need to be independent from others, and may also not have needed a close relationship beyond his family. A delicate balance was needed between having worked too hard for independence or not hard enough. The next section will focus on those who did marry, those who divorced, and relationships with children.

Marriage, divorce, and children

Marriage and divorce

Most people in these interviews chose to concentrate on their careers, possibly because this seemed the biggest challenge or sign of their independence, so most information about families came from small stories and impressions. I felt there were many long and close marriages and families. For instance, Michael comes from a family of six children, all of whom are married and have children, and his parents live nearby, as do his children and grandchildren. He and his wife look after his grandchildren two days a week. He said, "We, sort of, get on as a family." I met several husbands and wives at interviews and support group meetings, and three family members took part in the interviews, including one daughter. Of the 31 people interviewed, 23 had married (20 had children) and of those, four were divorced (one had had another partner for 10 years) and one had divorced and remarried. This number of divorces may be ordinary for a group of people of this historical time and age range, but it is interesting that the four who divorced were women in their 50s, and three had had polio at two years or younger. These three, Sarah, Deborah and Lauren, had been told very little about their initial polio and had been brought up to feel that they were normal and could do anything. The fourth was Sue, who had undiagnosed nonparalytic polio at 9, and was also confused about her story and
expected to be normal, although she was left with weakness and lack of stamina. About her family, she said, "I couldn't ever make anybody understand what I meant." All four women told narratives of becoming strong and independent, and only Sarah recognised her confusion about being "bolshy" and also having "a huge fear of failure". Deborah divorced quite early and did not mention her husband, but Lauren and Sarah described men who seemed to have been attracted to and needed both their strengths and weaknesses. Both told stories, centring on family, of gradually coming to understand and then learn to be a self they felt more comfortable with. Examining the cracks in unsuccessful marriages might lead the way to understanding lasting marriages, which seem too ordinary to be stories.

Sarah described her husband as focused totally on his career, "He would just get angry. This is his life... Everything had to be tailored to him and his life." Before they married, Sarah had discussed with her husband that "I had a problem accepting that people actually did like me", and very quietly she described him saying about her leg, "it didn't bother him at all." But she later said that even when they first met, "he didn't understand... the physical tiredness and the sheer lack of energy", which led to tensions in the marriage from the beginning. She said that in the early 1990s he "felt very threatened" when she began a full-time MA, and also started having ankle pain. She was given a new caliper and describes its squeak, which accentuated the hidden problems of the disability, the marriage, and the new freedom of not caring "what people think".

Sarah: And they said that I'd got osteoarthritis. And that was why this was happening, so I started wearing a caliper, and I would walk the dogs round the village wearing shorts and a caliper, and think 'I don't care what people think, any more'. You know, 'cos I was becoming this bolsky feminist anyway and David hated it. It squeaked and every time it squeaked I could see him looking at me. And he hated that squeak. He said that squeak really got on his, on his nerves (laughs) when it squeaked.

Sarah's laugh seems to be one of triumph and freedom, symbolised by the powerful squeak. Humour, as in the paradox of a powerful squeak, used as a means of gaining control and freedom will be discussed later in the chapter.
Lauren's story of her divorce is a detective story in which she pieces together clues from her childhood polio story, particularly in relation to her father. She explained that her marriage began to go wrong when she started having severe ankle pain, and problems continuing working full-time and being "the perfect mother, wonderwoman". She had explained, that seeing the cine film of her wedding, when she was 20, it "hit me... I had no idea that my limp was so pronounced and it was that point on where a lot of my self-confidence took a great big jolt." From then on she felt "some daemon or something driving me, that I had to prove myself all time", "I didn't think I was good enough". She described her father as wanting "me to be normal" and "forever pushing me".

The turning point in her story was a brief breakdown in the 1980s, after three years of undiagnosed severe ankle pain, and the gradual dissolving of her marriage. She described that because "all my life I've played normal... they weren't there for me, my friends, nobody...nobody could understand the breakdown". Her husband said that "I was putting it all on, I was a good actress." Her father refused to visit her or let her mother visit. Her story gradually builds up to an understanding of her father, his "vanity", "selfishness" and having "a problem with me being a cripple", but at the same time she says "I had probably the best parents I could have had, although in later years there are things that perhaps needed to have been different." Although she shows her father in a more and more negative light as the story progresses, she cannot let go of her ambivalent loyalty to him. Doctors eventually found a broken chip of bone in the ankle that had been reconstructed when she was a child. She said she began to see that her husband, her father and even the psychiatrist she saw wanted her to return to being the good actress she had been, the "happy, bubbly person that the world expected."

For both Sarah and Lauren, although they lived 'normal' lives, polio formed the structure of their divorce narratives. Their disabilities seem to have been accepted by their partners but only because of their strengths, and there was no leeway for these dynamics to change. When PPS problems began, in both cases a painful ankle, the delicate balance began to shift. Both Sarah's and Lauren's stories revolve around their marriages, their divorces and the effects of stories their fathers never told them about polio. Sarah's father
had told her husband, but not her, about her easy fatigability and Lauren's father had forbidden the family telling Lauren her polio story because of his guilt when she fell from a carry-cot into a gutter of water. She was told after he died. These two stories indicate some of the complex tensions inherent in the told and untold polio stories, the shame, guilt and discomfort about disability. Lauren and Sarah both gradually felt uncomfortable with the good disabled person they were expected to be, and slowly tried to free themselves, which will be explored further in the next chapter.

The women who were older when they had polio became equally independent, but had more understanding of their past and were possibly better at communicating this, even unconsciously, because the husbands I met seemed sensitive to them as complex people with strengths and vulnerabilities. This allowed some of these women to express their anger more openly. I met more husbands of the older women, both at home and support group meetings, and they seemed more involved and interested in PPS and their wives' problems, but this may have been because they were retired and had time. None of the older group was divorced, and this may partly have been because of different values in that age group. Women in the younger group were brought up with greater equality between the sexes, and greater sense of independence within marriage, whereas in the older group there seemed to be a more comfortable interdependence. The younger women had less support and more often expressed complex feelings, such as confusion, loss or sadness, about the past. The men, whatever age they had polio, had more support from their wives, because generally women expect to take on a more caring and emotional role.

Murphy (1990) suggests that it may be easier for men to suppress emotions as they are taught to do this from an early age, but that as society expects more emotional expression, this becomes more difficult. This might explain why there were more ambivalent and emotional stories from the younger people, both men and women, although they also experience more complex PPS symptoms. On the other hand, men are expected and taught to be more independent than women, so being disabled could be even more of a problem if not totally denied, and many men did say that "there was no such thing as
polio in my life" (Alex) for many years. An added difficulty for women is becoming independent against the expectation for disabled people and women to be dependent, especially before the 1960s. As discussed in Chapter 6, women expressed more emotion in the interviews than men, including anger. Although marriage involves difficult balances between the able-bodied and disabled partners, children seem to cause less problems and this will be explored in the rest of this section.

**Children**

No one in the interviews mentioned a problem with any of their children, and most spoke very movingly of them. Michael proudly showed me photographs of himself and his son around age 20, saying how striking the resemblance was. All the parents had fostered independence in their children, most now being adults living some distance away. But there was also a hint of some protectiveness. Jonathan, with young children, said he did "tend to be very concerned about my children's health" and Polly said that her grown daughters "need lots of support from mum". It sometimes seemed that the bond and loyalty formed between the child with polio and their parents was being recreated with the children. And the children who were now grown up often felt protective of their parent. Deborah's daughter came to her flat to take part in the interview, expressing great indignation about her mother's experiences at work and with doctors.

Whereas relationships with parents had sometimes been difficult and ambivalent because of the emotions around polio, having children could sometimes create easy, natural relationships. Jane and Jonathan pointed out that their children (and grandchildren) were perfectly natural with disability, implying that it was not inevitable that disability causes discomfort. Just as some people could become so involved in their work that they forgot their disability, with their children it could also be forgotten.

Jane: I remember, I was walking back one day, shopping, and the younger daughter was about ... two and a half, three, and I had we were walking along with a neighbour and I heard ... the woman I was talking to (whispers) say 'Now you mustn't do that, that's naughty.' And I looked down to see (laughs) my little two year old limping down the road (laughs.) And she was obviously copying me. Yeah, she did it quite
unconsciously, that was the way you walked (laughs)... Now I’ve got the great-granddaughter who’s five and the granddaughter who’s four, they are so natural with that walker of mine, and they take it all for granted, (laughs) it’s absolutely wonderful. I think ‘oh dear they’ll, they’ll hate it when they see me … struggling around with these things.’ But they don’t, they just accept it, it’s lovely.

Jonathan: And the other one (his son, 9), we were in Spain, this villa my family has in Spain, and he said, he’s always wanting me to do a video of him showing people round the villa, so he’s had like an estate agent’s tour, I took this on the, video machine and we came in and he says ‘And this is my mum and dad’s bedroom.’ And he walks over to my machine and he says ‘Now my daddy had polio which means he can’t breathe properly at night, so he has a breathing machine and this is it.’ And just moves on to something else, so yeah, oh it’s not really an issue for them.

Both Jane and Jonathan speak with wonder that "they just accept it" and "it's not really an issue for them". This is their proof that disability need not cause discomfort and problems in others. Writing about her experiences in the 1930s, Hathaway (2000: 117), who had spinal tuberculosis, described her nieces and nephews.

They unlocked a lifelong barrier in me, and so they made me feel more at home and more at ease in their world than I had ever felt in the world of grownups, where this problem had been excluded from every conversation or, if by some awkward accident it did protrude above the surface, was met with dreadful embarrassment and a quick changing of the subject.

For a disabled woman, having children is not straightforward, partly because no one can predict whether there will be extra problems in childbirth. Jennie mentioned worries about polio affecting childbirth as one reason she might not have had children. Joanna, who refused for many years to see doctors after her hospital experiences, finally had a daughter in her mid-thirties. The birth was long and very painful, she found it difficult to hold a baby with her weak arms, and she had great fears that she wasn't "a good enough mother". She said, "I loved her desperately" but "I felt it was just too much for me."

Beth, who was left with considerable weakness and could not manage everything when her children were young, had help from her mother. Most of the women interviewed did not mention the time when their children were very young, possibly because they wanted to emphasise that it was a normal time for them. Clare, who had so many problems with
osteomyelitis, said, about the five years when her children were young, "that was my best
time... I don't know what was magic about it, but certainly those were the least
problematic years."

Although many expressed a comfort and naturalness with children, several mentioned,
when asked, that their children did not know the polio story they were telling in the
interview. Jane said, "she knows I was in hospital but I mean, there was no point in
going into all the details. If they wanted to know anything they would ask, anyway, they
just accept what is." I also asked Jack if his children knew the polio story that he wrote in
his family biography, and he said, "no, no, it was new to them." Polly suggested the
practical consideration that, "they're very different ages my children so it's not a matter
that you ever, kind of, sit them all down and tell them. I think they know bits..." but she
also added, "I don't think anybody is really particularly interested". So, often, the silence
permeates through to the next generation and creates the situation described by Wiener
(1975: 100) that people "who are presenting a normal image to the world are nevertheless
perplexed when they are not taken seriously by others". Polly explained, "you don't want
to play the polio card... I do want good relationships with them later on and I'm not going
to turn into a whinge", so there is a fine line between explaining and complaining.
However, there is also a fine line between a parent being unable to tell the polio story to
the next generation, and children then not understanding and not knowing how to ask
questions. The next section will move beyond the immediate family, to siblings and to
social life outside the family, where silence could create normality or identity problems.

**Siblings, friends and positioning**

**Siblings**

Many people, in telling their polio story, would have talked solely about themselves,
possibly mentioning their parents or partner. This section will explore beyond parents to
siblings, and beyond partners and children to friends. I asked people about their siblings
because an illness affects the whole family, and our relationships with siblings must
colour our future relationships with contemporaries outside the family. Stories of
wonderful and terrible relationships followed, many of which were thought to be related to polio. Alex and Polly said they had felt responsible for their siblings, as mentioned earlier. Polly and her sisters had been through difficult times and instead of bringing them together, she said they felt that she had "had it easy". Allen mentioned his younger sister who has not spoken to him in about 20 years, which the family think might have to do with the attention he received when he had polio. Deborah mentioned a younger sister who has had psychiatric treatment and believes "that a lot of her problems are to do with me." Matthew said he got on with both his brothers, one of whom is disabled from a childhood accident. He described his other brother as having an uncontrollable temper and mentioned the family theory about this.

Matthew: My dad's theory is that, because mum was preoccupied with us two, she neglected him a bit, really, in terms of his emotional development and so he'd just fly off the handle and she, she'd get angry and wouldn't have reasoned with him, the way she would have reasoned with us.

Sarah came from a family of five children and had the misfortune to come home from hospital after polio on the same day that her newborn sister arrived home.

Sarah: I hated that child, I hated her from the word go. And I remember coming home and feeling...I did not like this person. She was as if she was my replacement.

It was not until the end of the interview that Sarah began to talk about her later relationship with her younger sister. She recalled that her sister had been called "clumsy", which suggests a strange reversal of circumstances.

Sarah: She felt I was getting all the love, she says now it was because of the polio...I have a lot of memories of Anne being very tearful, she was a whiny child and I don't think she got the attention that she needed...Anne was not a happy child. I remember times when we were actually quite cruel to her... When James (youngest brother) was little he would have the pram when we went out for these long walks, and Anne would have to walk, and I can remember her moaning about having to walk.
At the beginning of the interview, Sarah had mentioned the family walks when saying that she had been encouraged to do everything. "We'd walk several miles and I would walk too, I mean, with the baby (her sister, Anne) as well, then we shared the pram occasionally, but I would walk a long way." She has no memories of getting tired or wanting to stop, possibly because she was being encouraged to see her disability as "past". At the end of the interview, she described how the story of "clumsiness" has passed down through the generations. At a recent family wedding, one of Sarah's great nieces knocked over a glass of wine and Sarah's eldest sister said, "You know, of course, she is the clumsy one."

Sarah: And Anne, my sister, got up and flounced out into the kitchen. And the child's mother got up and flounced out into the kitchen and apparently in the kitchen they both talked about what it was like to be the clumsy one. And it's gone through and it's now in my great niece.

The problem was that no one could say that Sarah was the clumsy one, so they have to go on tormenting each generation and hiding the disability story. On the other hand, Lauren has always felt close to her brother and sisters, and Rebecca, who had polio in 1915 and remained single, has been close to her brother and sister and their children all her life. Daniel, who lives with his twin brother, is also very close to his other brothers and their children. Similar to the delicate balance between treating a child as normal or different, it seems that there was a delicate balance with siblings, who might lose attention, receive negative attention or feel protective.

Friends

An integral part of being normal and hiding any disability, was keeping a silence with friends about polio, necessitating the shifting back and forth between being aware and unaware of any disability. This was generally an uncomfortable subject to talk about and led to ambiguous stories, as everyone prefers to feel they can be open with friends. In a study of people with chronic illnesses, Register (1987) concluded that only those who had never talked about their illnesses since childhood (polio and epilepsy) had difficulty talking about friends. Fisher and Galler (1988) found that older disabled women "veered
away from the topic of friendships with women", while others said they would not mention disability in order not to burden friends. Several people in this study, especially those who had polio when older, and those with a more obvious disability, said they were comfortable talking to people about polio, though Wendy put it this way: "I would talk about what I could and couldn't do. I wouldn't talk necessarily about how I felt about it." Many others "wouldn't have talked about (polio), wouldn't have said unless they asked me" (Sarah). A common refrain in many stories was that "really people don't understand" (Clare). A second refrain was that no one wants to understand, which means that polio must remain outside the relationship.

Thus, gradually the lesson was learned that no one, including myself, really wanted to hear the mundane details of being sick or handicapped, neither the triumphs nor the hardships. (Zola 1981: 359)

Edith: If you break a bone people can cope with you for a month saying, 'How are you?' But you know, with long-term things people can't cope because they don't understand and they're not interested generally, are they? Not in a nasty way, but people just don't know what things are and what you're going through.

Jonathan, who said that "nobody quite understands unless they are disabled themselves", also tried to explain this as a lack of empathy. Bauman (1998: 58) suggests that the stranger or stigmatised person is not an unclassified person who may be classified in the future, but "unclassifiable", part of a world without a key.

Jonathan: When I talk to people who are black, for instance, if they're the only black person in the group, it's very difficult to get, although people understand it might be different, there's nobody there to really empathise. Because it's a kind of different experience.

Cole (2004), writing about spinal injury narratives and using some of the phenomenological ideas of Toombs (1993), describes empathy as trying to imagine yourself as the other person in their shoes, rather than putting yourself in someone else's shoes. Toombs sees narrative and imagination as crucial in creating this empathetic understanding. However, this discounts the strong cultural stories which have already
moulded the imagination of the ill person who needs to imagine a new life after becoming ill. In Cole's (2004) stories of people who felt they had exciting, creative lives with spinal injury, there were gaps and silences about pain, practicalities, personal relationships and sex, which some of the angrier quadriplegics saw as barriers to a better life. Not mentioning polio at all to friends could be a barrier but there were indications that this was not always so.

When I asked Jane if she had ever told a friend about having had polio, she said "No" very quietly. She continued: "They just accept you as you are. They don't need to know really, do they?" Peggy also did not tell friends that she had had polio. She no longer had visible effects, but became very tired by evening. Trying to explain the situation, she said:

Peggy (68, polio at 14): My close friend, Shirley, had always known that there was a reason why I didn't accept late night engagements. We were never invited to their very popular, exclusive New Year parties... I never worried about that. But she must have realised that there was a reason for it but I didn't.

Jane, in her quiet voice, seemed to be saying that maybe it would have been more comfortable to have been able to say something, but in Peggy's example there is some indication of unspoken understanding and her own shifting understanding of why she did not accept invitations. Discussing emotional understanding, Wikan (1992: 477) quotes from a newspaper interview with a Norwegian poet who had recently lost his daughter:

"How are you?" people ask. It can be a gentle way of approaching, a light brush across the cheek, words that wish to remove bandages gently so the wound will not start bleeding again. And I could have answered with long explanations, I could have told of all the rents in the fabric we call life, I could have told everything. But I answer: "Takk, bare bra -- fine, thank you." Each in our own way we know it so well. And it is good to have everyday trivialities to cover it with. (Wikan 1992: 477)

As in Peggy's story, a delicate balance is found in interpreting silence between people as understanding rather than its lack.
More examples, however, emphasise the difficulties some interviewees had with their own and other people's views about polio, emotions and friendship. All the single people in this study have very close friends and Nick explained another reason why friendship was difficult — the need to be independent and the fear of appearing weak or vulnerable, which precluded real closeness with others.

Nick: Friends are both important and difficult. The trouble is that I know that some of my friends have far greater feelings for me than I am willing to admit...I conclude it is a fear that if I let anyone get too close I may have to give all, as it were, admit that I still hurt inside, and am a priceless twit.

Instead of feeling, like Sarah, that people would not accept him, Nick also found it difficult when they did. Like Sarah, Jennie began to think that the silence about emotions in relation to polio may have caused her to feel inferior, rather than disability making emotions difficult, as Nick suggested. Jennie had written in an e-mail, quoted in Chapter 6, that because "the emotions around the polio experience were kept hidden... I grew up to be very hard on myself."

Paradoxically, although people felt their situation could not be understood by 'normal' people (discussed further in Chapter 9), many avoided disabled people in order not to identify with them and to perpetuate the pretence that their disability did not exist or was not noticed. This avoidance was also found by Fisher and Galler (1989) in their study of friendship in disabled women. In her first job after leaving school, Joanna worked in an office with another woman who had scoliosis, but neither of them ever spoke about it.

Joanna: Well, she might have had polio for all I know. I didn't want to be around disabled people for a long, long time because I was mirroring, I think, what I saw in myself. .. I didn't want to be with other disabled people because people would think I was disabled and I didn't want them to know I was.

Later, she said, "I did come out, as it were, and tell people, in my forties, I think, so I didn't have to hide, hide what I couldn't do." In an e-mail after her interview, Jennie wrote that there was something she was "almost too ashamed to write."
Jennie (e-mail): Just before this (reading about PPS in 1995) I had seen some people in wheelchairs collecting money for polio at a London tube station. I did not want anything to do with them, did not give them any money and walked straight past without properly looking at them. I just did not identify with them and they made me feel uncomfortable...I was shocked to be reminded.

Lauren had quite a different experience. In secondary school, she had a friend who had polio more severely than herself. She said that, looking back, "it was probably a little bit of an ego trip for me to have a friend like that." Later, when she began work, she said she preferred working with men as she "always felt uncomfortable, I always felt more disabled in a group of women... because I envy the shoes, I envy how they look." Lauren seems to identify more with disabled people, possibly since she saw herself in the wedding film. She described her discomfort with more disabled people as relating to her creating "the feeling of regret or sadness" that she felt with non-disabled women.

Because he felt uncomfortable in social situations, Nick found other roles to play. This often seemed to be one benefit of work, where there were more distinct roles which could also be used outside work as ways to manage people in everyday life.

Nick: I never found it possible to accept invitations or to participate in parties or social gatherings. Even later in life I still only attended functions where I was wanted as a sort of 'star turn' giving the keynote speech or something... Safety always lay in my ability to hold people at least at arms length! My social relations were and probably still are based on being a doer, a driving force, running and organising things, meetings and so on.

Later, when postpolio support groups began to be formed, some people might have found it easier to run the group or help out in some way rather than forming an equal relationship with the others, or identifying as someone needing help (see Chapter 9). All of these examples are about comparisons, categories and position, which began being conceptualised when people first saw someone worse off than themselves in hospital, and relate to physical appearance (Lauren, Joanna), function (Sarah, Peggy), equating physical weakness with inferiority or dependence (Nick, Wendy), or equating the silence
about emotions to inferiority (Jennie, Sarah). These examples are also about ambivalence, the shifting back and forth from knowing to not knowing that they are disabled, and putting themselves in a position that minimises their disability.

**Autoethnography**

Like Sarah and Lauren, my father also kept my story from me, through loyalty to my mother, but as I did recover well, the repercussions were not obvious until later. Although I did not have to try to appear 'normal' in contrast to disabled, my lack of story derived from similar cultural and family pressure to be 'normal'. Frank (2002a) describes the "densely storied world I grew up in" which reminded "everyone who we were -- and were not -- and why that identity was valuable", but that was not my world. So, who was I? Like Jennie, I wanted to make some connections. I desperately wanted my mother to tell me about her childhood and her Russian parents and their lives. She told me three stories.

Her first story took place in kindergarten. The teacher read a story about a grandfather clock and asked the class if anyone had a grandfather clock. My mother waved her hand and described her grandfather clock, and the teacher suggested the whole class visit her house. I can't remember exactly when my mother confessed that her family did not have a grandfather clock. Possibly it was when the whole class was crowding into her hallway. I remember realising that my mother had not changed. She had told me that when she first went to school she could not speak English and I imagine she was constantly reinventing herself in order to fit in. The grandfather clock was one attempt and her story that I had recovered was another. I knew I could not keep up with other people, I knew this was me, I knew people were valued for their energy and vitality, especially by my mother, and I decided I didn't agree with these values.

In the second story she was even younger, maybe four. She was sitting alone on the front porch of her house, unable to move because she had just had stitches in her knee. A runaway horse galloped down the street and she was terrified, thinking she would be trampled. She said that when she fell and cut her knee, her mother had smacked her, shouting, "Don't worry me like that." My mother added, "I would never do that to my child." Instead, she walked away, like when I had headaches for months after a concussion when I was 9 (Appendix 10). But she also tried to teach me not to be afraid.

The third story broke my heart. It was about a heavy, crocheted blanket that always lay at the foot of my mother's bed. She said that when she went to college in New York she lived at home and took the train into the city, about half an hour away. The story continued, that because she was the youngest of her mother's seven children (two
died in Russia and one brother drowned), her mother was all alone, so she took the 
train home every day for lunch and crocheted the blanket on the train. I picture her 
mother, who I never met, less than 5ft. tall, weathered and old in her fifties, always 
foreign, always strange, always worried, always sad, sitting on the front porch, 
remembering her lost children. My mother was possibly trying to tell me that we both 
would or would not repeat the pattern of generations.

In the next section I will examine how humour, never far from anger or sadness, was 
often used in social situations to bridge the gulf between normality and disability, and 
ease the discomfort caused by both the vulnerability, and the independence, strength and 
stoicism developed to hide the past and appear normal.

8.4 Resistance: humour and shame

Humour was an acceptable, visible face of the social side of independence, being normal 
and 'getting on with it', and several stories about social situations, friends and other 
relationships were told as funny stories. It was the other side of the hidden pain, anger 
and shame. In sociology, humour has mainly been seen as "both resistance and control 
mechanisms in social relations" (Powell and Paton 1988: xiii). Recently, more complex 
multidisciplinary analyses of humour have widened the concept to include many levels of 
paradox, reminiscent of the ambiguities inherent in disability and illness (Kelly and 
Dickinson 1997). Humour can "make unacceptable messages acceptable", and can both 
align and distance (Griffiths 1998: 875). Through humour, contradictions in society can 
be both maintained and challenged. Someone who laughs at others may also be laughing 
at himself, 'laughing with' not being easily separable from 'laughing at' (Lynch 2002). 
Douglas (1999) describes jokes as an attack on control, but successful humour is also the 
ultimate control of the ambiguous, spontaneous and uncontrolled. Cardeña (2003: 120), 
in a study of a marginal community in Mexico, conceptualises humour as encompassing a 
similar marginal status -- "the value of humour seems to reside in constructing alternative 
meaning systems that do not promote binary oppositions and logic, but rather affirm 
uncertainty and ambiguity as the centre of experience." Behaviour that could be 
described by the dominant group as 'irresponsible' or 'immature', might be described as 
'spontaneous' or 'spirited' by the marginal group, as the weakness (physical) of disabled
people maybe reinterpreted by them as strength (moral). This section mirrors the section in Chapter 6 on resistance, as humour became one adult form of gaining control without negating differences in social situations.

Along with his talk of harrowing work with abused children, Matthew was also quick with "hilarious" but painful stories. Several of the men used humour in this way. In one story, Matthew thought he was going with a friend up Mt Snowdon by the train and, instead, found himself on one of the more difficult tracks "screaming in agony". He was with a good friend from his social work course who seemed to know nothing about his polio. The final irony, which he described as "the funniest thing in the world" was that he had just been given the new mobility allowance by his GP, had collected it, and the cash in his jeans pocket "rubbed my thigh raw", his only injury. This obvious visible injury hides the pain and difficulty he had climbing the mountain, first with one stick and then two, "hauling myself up, really". The pain for the listener is not only in his legs but his inability to explain his disability. Throughout the story, there is a subtle balance, shifting between pain and triumph. Several men, like Allen quoted below, became humorous storytellers as it diverted attention from their disability by controlling conversations. Humour is also another part of being ordinary, so a humorous story by itself implies ordinary life rather than the 'tragedy' of disability.

Allen loved the control he found in teaching (Chapter 7) and he became a natural storyteller to enhance this control. He did not put polio aside so much as incorporate it into himself and use it positively. "I never saw myself as disabled, no, I was just a guy with a caliper...it's part of me." This was another instance of the art of defining disability, and he used this definition humorously to normalise his paralysed leg. Allen told a story about his early teaching and being asked by a child if he had a wooden leg.

Allen: 'No'... I said, 'I tell you what though, if you annoy me I shall take it off and throw it at you.' And that was the beginning of a legend that went on all the way through. I said, 'Do you want to find out?' 'Oh, no sir, oh no sir.'... And when I was finishing there, I mean I was teaching children of children that I taught...and they all came in and said, 'My dad, my uncle, my mum, my aunt all say if we annoy you you'll take your leg off and throw it at us. Is it true?'
Allen used his disability and humour to create a powerful position in his work, saying, "it's a great, it was a very useful tool... and I've never used it, you know, I never used the fact that I'm disabled, but it is, if you realise it, it is actually a very useful thing in some instances." Allen did not use his disability to obtain advantages, but used it as part of who he is.

Murphy (1990) brings together the prohibition of negative emotional expression for disabled people discussed by Zola (1982), and a cause for this, the discomfort and vulnerability of able-bodied people and their need for disabled people to be strong. Humour remains the only outlet for disabled people.

To make matters worse, as the price for normal relations, they must comfort others about their own condition. They cannot show fear, sorrow, depression, sexuality, or anger, for this disturbs the able-bodied. The unsound of limb are permitted only to laugh. (Murphy 1990: 92)

Women did not find it so easy to shut away their emotions, leaving a certain amount of anger, sadness and sometimes bitterness just beneath the surface. The simmering emotions may have made it more difficult for women to tell humorous stories and control the conversation. Rebecca, who is 88, and had polio as a baby, was the only woman who seemed to use humorous stories to avoid other emotions or to incorporate them into a less threatening web of mixed emotions.

Rebecca (88, polio 5 months): Funny things that make you laugh. Well, the last time, when I broke my leg, you know, when I was in Boots, I'd gone to get some films... I went in there, my sister thought it was hilarious, I'm lying on the floor and I thought, 'I'm not going without those films', so I called somebody passing by and I said, 'Will you get my films please, before we go.' She thought it was so funny that I bothered with the films and I was lying there with a broken --

Rebecca had asked if she could be interviewed with a friend, Cynthia, who was 84, had remained with paralysed legs after polio at age 18, and who spoke freely about her
bitterness and shame. Both women had worked all their lives but had not married or had children. Together, they explained the importance of humour for them.

Cynthia (84, polio at 18): (laughs). But you do get a laugh out of things actually.
Rebecca: Yes, you've got to haven't you?
Cynthia: Well I think I read somewhere that they say that, polios in particular, seem to, their sense of humour seems to increase, once they've got over the, you know the trauma?
Rebecca: Trauma?
Cynthia: Trauma, yes, of er having it. And I don't think we would survive if we didn't.
Rebecca: It's a great help.

While these humorous stories emphasise the weakness and shame of disability, they also show strength and resourcefulness. The power of humour is to bring together these contradictions simultaneously, a trick disabled people live with all the time.

It was rare that people talked about the other side of humour, shame, as shame is a hidden, untold emotion (Macdonald 1998). In a chapter called The hidden injuries of a slight limp', Kalekin-Fishman (2001: 148) wrote "each individual has something 'slight' and shameful and not worth talking about, but is the core of her being, a constant companion, the rude daily awakening." Joanna said, "I've still got that shame and mainly because of my back... It's always been this hiding." Another unspoken emotion is sadness, possibly because it sometimes signifies pity. Lauren mentioned "the feeling of regret or sadness" about her disability and Nick mentioned that he felt "a bit lost, empty and sad" about his inability to relate to people. Allen, who was always positive and saw polio as something to be overcome, said in an e-mail after the interview, about first being in hospital, "I feel a bit sad as I think of those moments", which was my feeling on hearing his story of running through the fields the day before he got polio. An emotion like sadness is not only expressed in words; it can surface through tone of voice, a story or a photograph. The stories of children alone in hospital are stories of sadness. A more common story is one of guilt, by parents and children, who often feel that family problems, such as illness or divorce, are their fault. Both Davis (1963) and Gould (1996)
describe instances where children felt they had become ill with polio because they had misbehaved. Levi (2001: 56-57) describes shame in Holocaust survivors as a "consciousness of having been diminished" and guilt as awareness "that we had not done anything, or not enough, against the system." Many of those who had polio were too young to understand or resist the early reactions that caused them shame or guilt.

Nick: I do not know why I have a sense of guilt about having had polio. All I know is that I do and can't shake it off. I have learned one other thing too, that in terms of body image I carry a form of self-loathing and contempt.

Nick brings together his unexplainable guilt and bodily shame. Lauren, who had weathered many emotional experiences, even more so with PPS, explains that she could never let people know "how I really felt" and "always felt I had to apologise for myself." Often memories of polio and forgotten feelings of anger, sadness or shame were revived when people deteriorated with PPS. This was particularly true with Nick and Lauren, and will be explored further in the next chapter. Shame was part of the basis for the silence about polio that lasted through these middle years and was also sometimes broken by the arrival of PPS. In his polio biography, Mee (1999: 92) blames a fear of failure in our culture for the shame people feel if they cannot be completely 'normal'.

It produced an entire subculture of denial and shame, where failure cannot be admitted, where those who cannot succeed must apologise and take the blame, where a vast network of institutions has been built to hide the millions who cannot pull themselves up by their boot straps.

As quoted earlier from Jonathan, "if you're not relying on yourself and sorting it out yourself, then you're kind of failing in some way." It is this spectre of failure and dependency that is behind the 'biographical disruption' of illness (Bury 1982).

8.5 Conclusion

By the time people had reached this middle part of their lives, they had found a balance, possibly uneasy, between independence and interdependence, autonomy and contingency.
Hiding polio, strength and pride was often found in interesting work, family and children.
Allen said polio was "not a problem... it just enhanced me", Mark felt that after polio "whatever happens I'm going to sort it", and to Lauren "my life was made better because of polio". Jane was realistic and pragmatic, "You were ill, if you were lucky you got better and nobody made a fuss about it, you just got on with it." But that did not mean there were no problems and everything was easy, and it is this conflict that led to the ambivalent restitution story.

Jane: They certainly didn't say, 'Oh, you'll be all right.' Because, apart from anything else, you weren't going to be all right. You were going to have to... deal with what you were left with.

What you had to deal with was both physical and social. In a study of stroke patients, Kaufman (1988: 349) describes the existential feelings of loss and fear due to "cultural understanding of individual autonomy, control and will". This chapter begins with the existential feeling of being someone, and moves on to the equally important being with someone, which involved both the physical (appearance and function), and the emotional (comfort or discomfort between people). For people who recovered well from polio, especially the younger children, negative messages about appearance and disability, even unspoken, produced mixed feelings of anger, sadness, guilt or shame and stories of resistance -- sometimes angry, sometimes humorous. This may have led to a search for freedom from disability stereotypes, which will be explored in the next chapter. Freedom was part of the search for autonomy as control of who you were and what you did, and often involved allowing fate and risk to be part of life. Interdependence, in both work and social life, is essential to independence and although there was a general feeling that "nobody quite understands" (Jonathan), there was also sometimes a feeling that "they know" (Michael).

While everyone was getting on with their lives, in the background for most people was some weakness, lack of stamina or pain. For some, this was only an inconvenience, but for a few, there were many operations, pain or fatigue. Several of these people were still able to put polio out of their mind, but fatigue or lack of stamina often had consequences
for confidence and ability to work and carry on with family life. Although sociologists have debated the meaning and effect of pain (Hilbert 1984, Bendelow and Williams 1995), similar studies on fatigue and stamina are lacking. When people are blamed for not fully taking part in life, it is often for the invisible problems of fatigue and lack of stamina. The next two chapters on PPS will delve further into the ambiguous meanings of these symptoms. I will describe how the house of cards, the precarious nervous system and facade of strength, collapsed and more modest houses were rebuilt. The stories that people tell now, whether clear and linear or more ambiguous, are dependent on their experiences of PPS. Many who would have told the typical 'triumph over adversity' story a few years ago tell a different story now.
9. Postpolio syndrome: connecting polio and new symptoms

9.1 Introduction

Suddenly, I remembered a recurring nightmare that has plagued me all my life. I am walking on my way home at night when an overwhelming sense of fatigue strikes my legs. I am forced to the ground, and I crawl through the darkness on my hands and knees -- and once my knees fail, flat on my belly -- until I reach my house. Then I drag myself up the stairs -- there are always stairs... -- and throw myself into bed. (Siebers 2002: 51)

Siebers (2002: 52), an English professor who had polio when he was two, wrote that although he did not realise it until PPS caused his legs to buckle under him, he was "always compensating for my disability, just like I was always dreaming that dream."

Zola (1973) analysed how people come to think of a bodily sensation as a symptom, and why they then choose to take that symptom to a doctor, although he ignored his own polio symptoms until he began to write about disability in the 1980s (Zola 1982). Similarly, most of the people in this study had ignored polio so well during their adult years that polio was the last thing they connected with the arrival of new weakness, fatigue or pain. As they had considered themselves normal for many years, new symptoms were initially slotted into normal explanations such as ageing, overwork, stress and tiredness. In the two chapters on PPS (Chapters 9 and 10), I will trace how people reconnected with their bodies, how they came to see their symptoms as polio-related, how their symptoms affected their lives, and how doctors reacted to their descriptions of their symptoms. The study comes full circle in two ways: people's stories often came round in a circle, linking current experiences and feelings back to early polio feelings; and there is a return to the discussion of polio and PPS research and how doctors conceptualise subjective symptoms, particularly muscle fatigability and fatigue, symptoms that occur in specific contexts over time.

In this chapter, I will set the scene by briefly describing the medical position on the two main PPS symptoms, muscle weakness and muscle fatigue, and give examples of the patient's descriptions of the major symptoms of PPS through the open questions in the questionnaire, the interviews and one diary. This will facilitate understanding the
9. Postpolio syndrome: connecting polio and new symptoms

remainder of the chapter, which explores how people made sense of PPS as they came to realise the new symptoms related to polio, and then how they dealt with explaining the symptoms to colleagues, family and friends, when adjustments in their lives needed to be made. Chapter 10 examines experiences of bringing polio back to doctors, possibly for the first time in many years, and concludes with an exploration of how people felt about PPS, which necessarily involved how they now perceived their feelings about polio and its aftermath.

9.2 The symptoms: "I cannot even think how to move at times."

Postpolio syndrome has recently been described as an increase in muscle weakness or muscle fatigue, atrophy, or general fatigue (Jubelt and Agre 2000). One early PPS study found that muscle fatigue was present in 99% of 154 cases (Cosgrove et al 1987). Notwithstanding the use of muscle fatigue in Jubelt and Agre's definition, muscle weakness has been used as the defining symptom in most studies, and muscle fatigue is considered part of general fatigue (Bouza et al 2005). Muscle pain is often considered a secondary symptom as PPS is a motor, not sensory, neuron disease (Trojan et al 1994). In the UK, there seems to be a particular disinterest in PPS fatigue, which was found in only 7% of a study of 239 patients (Kidd et al 1997)\(^1\), whereas, in a group of other

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\(^1\) This study was conducted by the Lane-Fox Respiratory Unit (Guy's and St Thomas' NHS Foundation Trust), one of only two PPS clinics in the UK. The unit was originally set up in the late 1960s by Geoffrey Spencer, an anaesthetist at St Thomas', interested in opening a respiratory unit for patients who were surviving intensive care but needed artificial respiration (Gould 1995). The Lane-Fox Unit does not actually use the term 'postpolio syndrome' but calls itself a postpolio clinic and the new weakness is called 'late postpolio functional deterioration'. They are sceptical about whether there is any new change in the nervous system, and consider the symptoms to be due to orthopaedic and neurological consequences of the initial polio. They published a retrospective study of Lane-Fox clinic patients, in which new weakness was explained as arthritic changes (Kidd et al 1997). This was conducted after The Lancet wrote a news article "Study casts doubt on postpolio syndrome" (McCarthy 1996) about a Mayo Clinic PPS study (Windebank et al 1996) which concluded that there was "no evidence of progressive neuromuscular failure" and patients were diagnosed with degenerative joint disease, fibromyalgia or other diseases. This contradicted previous US and Scandinavian research showing progressive weakness (Dalakas 1995b, Sonies and Dalakas 1995, Grimby et al 1994). In a recent review article, one of the Lane-Fox team wrote, "Some patients were referred because of the development of disability even though the initial polio left no residual sequelae, or the original diagnosis was equivocal. In my experience, these patients always have an alternative explanation for their symptoms, often a myopathy or a fatigue syndrome" (Howard 2003: 70). The Mayo Clinic team recently published a 15-year follow-up of their original study group and found significant decline in electrophysiological testing, number of motor units and upper body strength, which suggests some change in the nervous system, although no conclusions are drawn (Sorensen et al 2005). Similar changes had been shown in earlier research (McComas et al 1997, Grimby et al 1998).
studies, fatigue was present in between 44% and 89% of patients (Bouza et al 2005). The figure of 7% in the study by Kidd et al (1997) refers to patients who presented solely with fatigue. It is not mentioned in relation to patients with weakness or pain. It is very difficult to separate muscle weakness from muscle fatigue if the fatigue develops rapidly, and testing for muscle weakness itself is inaccurate in polio patients (Perry et al 1988, 1995). The objective test for weakness due to loss of motor neurons is the EMG, but in a few cases of paralytic polio and PPS this test is normal, demonstrating the complexities of the damage caused by polio (Sandberg and Stålberg 2004). The authors of this study hypothesise that the polio and PPS symptoms could relate to motor neuron dysfunction, metabolic changes or central motor pathway dysfunction.

For most people who have PPS, muscle weakness and muscle fatigue will often merge -- an arm that is becoming weaker will also tire more quickly and this may feel like an increase in weakness, increased aching, tiredness and lack of concentration. Sometimes the two will remain separate, in different limbs, the originally weaker limb becoming weaker while the stronger limb will tire more easily. These symptoms can be seen as existing on two levels: a macro-level, in which they may have existed since the initial polio or developed over months or years and are part of a biography, and a micro-level, of the moment, or in which they develop over hours, which relates more closely to the biological symptom meaning. Symptom descriptions which tend to the biological and grapple to translate bodily sensations into words may sometimes need to stand on their own to be understood. Radley (2005: 260) suggests that significant meaning about pain or suffering is conveyed by description -- "the evocation of a moment" and "the use of words to picture". Malterud and Bærheim (1999) wrote a paper titled *Peeing barbed wire* describing the precise listening needed to understand the variation and complexity of bodily symptoms, in this case urinary tract infection. It is particularly difficult to describe muscle fatigue and fatigue as they exist in a continuum, varying through the day and over a lifetime, and people who had polio were also taught from an early age to ignore symptoms and not complain in order to get on with life. In trying to be true to both the biographical and biological person, this section uses quotations from the questionnaires, interviews and one diary, of symptoms and symptom experiences,
9. Postpolio syndrome: connecting polio and new symptoms

separated from the whole stories, in order to group a range of symptoms together and clarify them for the reader. Most of these descriptions were not embedded in narratives, but developed from questioning. Several symptoms were described more eloquently in the questionnaire ("hot marshmallow") than in interviews and are therefore included below (Table 9.1).

<table>
<thead>
<tr>
<th>Table 9.1 Symptom descriptions</th>
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<tr>
<td><strong>Weakness and falling</strong></td>
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<td>Wendy: The turning point with the can't do things as when I couldn't get up off the floor, indoors the resolution to that is I have one of those alarm buttons. That's about 1990, probably. But that also means if I fall outdoors I'm completely dependent on someone picking me up. And that took some thinking through, because I can't put myself in a position where there are no people around.</td>
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| **Muscle fatigue**             |
| Helen: You know, so I was finding I was getting more tired, I was finding gradients more difficult, you know if I was walking uphill, that was more difficult. |

Sarah (questionnaire): It feels like being in slow motion -- I collide with walls as direction is lost. After a couple of days mild gardening, fatigue can last for days, as ankles and wrists feel like hot marshmallow, fasciculations increase. Brain fog more disturbing, cannot even think how to move at times. Once fell in supermarket, could not think how to get up again.

Michael (diary): Chronic fatigue develops in both legs after walking a few yards on my own and I am finding it increasingly difficult to maintain my balance unless the surface is completely level.

Michael: If I was tired and if I had got to a stage where fatigue was really creeping in, you do not need much of an uneven or an imbalance to your putting the weight down on that leg for you to completely give way altogether. You had to really concentrate on how you were going to apply that foot to the ground and how you were going to coordinate the next move with the body or the gait of the leg.

| **Interconnections of general, mental and muscle fatigue** |
| Jennie (questionnaire): Any physical or mental activity starts it (fatigue) off... My brain 'turns off'. It's as if something is not connecting. |

Sarah (questionnaire): I find it difficult to differentiate between general and muscle fatigue.

Alex (questionnaire): Fatigue is like hitting the wall mentally and physically.
9. Postpolio syndrome: connecting polio and new symptoms

Table 9.1 Symptom Descriptions (continued)

Helen (e-mail): I'm sure physical fatigue does make things worse (mental fatigue and concentration problems) but I find it quite difficult to sort out physical from mental fatigue because they are so interrelated when you think about it. I mean, even writing this involves a certain amount of physical as well as mental effort. And a task like driving -- both physical and mental.

Pain

Joanna (e-mail): My pain was permanent aching and burning in my shoulders down to my hands, any movement hurt, so even getting out of bed, dressing and washing was painful, let alone trying to get through the day.

Alex: my muscles went into spasm, sometimes I couldn't breathe, I don't know if you've ever had a spasm in your diaphragm, it hurts. There are very few things I can compare it to. You can't breathe properly, because every slight hurts.

Swallowing problems

Clare: I started then having the choking problems, spells of coughing which would then lead into choking...it got to the stage where I was afraid to go out...also my voice would suddenly disappear and it became very, a lot of hoarseness and very gravelly...I found that talking made my throat literally, the muscles, literally would ache so much that I would be unable to carry on a conversation...I went through the whole lot of tests and it was found that a third of the swallow muscles, muscles that control the swallowing action, were dead.

Breathing problems

Jonathan: Breathing has always been a little bit of a problem. I get, I would have got breathless, but it is a lot different now for me. Although strangely, my vital capacity is very little different from when I was 20. But it's quite low, one litre, 1.2 litres... But one of the things I noticed, I was having sleep apnoea. So I was stopping breathing and it was waking me up... Most people breathe involuntary, with involuntary muscles. So it's kind of a brain stem thing. And that probably was always so, but as my muscles have got slightly weaker, I think it just has kicked out when I go to sleep, I stop thinking about it... Walking has got less and less and now it's partly to do with breathing, yes. Breathing is more the issue.

Mental fatigue

Ian: If I get in a crowd of people, I find it an awful job to focus

Helen (e-mail): If I'm concentrating on doing one thing I completely forget that I also meant to do something else. If say I'm interrupted writing this by a ring at the doorbell, I'll go and deal with it, then I can forget all about what I was doing before. I certainly couldn't write this and listen to something on the radio at the same time.

Clare: That was two hours of continuous sort of talking and information that you tried to absorb and so on (chronic illness management course). And although I enjoyed it and found it very beneficial, I would come out of there and I would feel absolutely drained, physically and mentally...I'd been sat
down, whole body felt weak and my eyes just felt that I wanted to shut them for ever.

Matthew (questionnaire): I get to the point where my brain feels full and I can't cope or bear to hear or see anything else.

Sarah (questionnaire): Brain fog more disturbing, cannot even think how to move at times. Once fell in supermarket, could not think how to get up again.

These symptom descriptions may be seen as a window into the feeling and functioning of the body, and, to some extent, may create an image clarifying the sensations the respondents were trying to categorise as normal or abnormal, everyday aches or disease. Jonathan, who had had breathing problems all his life, talks for some time about his breathing problems, bringing in technical terms like his 1.2 litre vital capacity, without creating a clear idea of how he felt. On the other hand, short phrases or adjectives such as "gravelly" voice, "being in slow motion", "wrists like hot marshmallow", "cannot even think how to move", "you can't breathe properly, because every slight hurts", "absolutely drained" do create images of experiences beyond the everyday, experiences that made people stop and think. The phrase "cannot even think how to move" has been repeated because it emphasises the connections between physical and mental fatigue, mind and body, thinking and moving.

**Autobiography/ethnography**

I woke up one morning, towards the end of March, 1982, and knew that something was wrong. My legs felt light, as if they weren't there, I felt shaky on the stairs and my legs ached and began to feel heavy if I stood or walked more than a few hundred yards. I had had whooping cough in an epidemic two months before and I thought it must have affected me somehow. The funny feelings went away after 10 days or so, and came and went several times over the next two years, then settling down to more frequent episodes. I knew there was something wrong, but also I didn't know, because people had ignored my leg pains and weakness for so many years. It took about 10 years before I put my story together and discovered polio could be mild and this could
explain my childhood leg weakness, scoliosis and pain. Doctors I saw said there was no PPS or you couldn’t have PPS unless you had obvious paralysis and atrophy. From 1986 I began having injuries, first a slipped disc which led to a diagnosis of myasthenia gravis. Over the next five or six years I strained muscles in my back, had tennis elbow for a couple of years in both arms, and had a very painful trapped nerve in my right shoulder. Gradually, my walking ability diminished from around 2 miles to 20 yards, after which my legs would ache for at least a day, a day in which I sometimes could not bear to walk to the kitchen for a drink. A few times, when out shopping, my legs ached to the point where I had to sit down on the pavement or in a shop. My GP began to take me seriously after I told him a story about nearly being run over by a truck.

1987: Walking up a very straight road in central Bristol, I felt my legs stiffening and feeling like blocks of wood, having just done some shopping. As I began to cross the road, I saw a truck hurtling down the empty road, but it was far away, quite small in the distance. I expected to have crossed the road well before the truck had reached me. But my legs weren’t doing their normal thing. Suddenly the truck was almost upon me and I was just halfway across the road. I could see the surprise and then panic on the driver’s face as he realised I was walking with the speed of a snail. I tried to increase my pace to a stride, but my steps remained miniscule. In a panic, as a last resort I tried leaning forward as if I were diving into a swimming pool, and attempted to throw my body towards the curb, hoping my legs would follow. They did. Having reached safety, I turned back to see the truck swerving, nearly hitting a parked car and then straightening up.

1992: The mental fatigue, often directly related to muscle fatigue, was sometimes equally strange. The last time I walked into a Waterstones, I had only walked from the car into the shop, maybe 50 ft. when my legs began to ache, a horrible, heavy aching, and the names and authors of the two books I was looking for vanished from my mind. I sat down on a little stool and after about two minutes the name of one of the authors floated back into my mind. In order not to forget again once I stood up, I repeated the name over and over to myself until I found the book. Then I sat down on another stool to wait until the second author’s name reappeared.

In the next section, I will compare how two people who were younger when they had polio, Alex and Jennie, came to recognise their symptoms as PPS, with two who were older, Alice and Polly. I will concentrate on this small group because three of the stories are complex and took place over many years. The fourth is an example of a clearer story of recognising PPS, even though, or possibly because, it was the story of the one person, Alice, who completely recovered from polio. Polly is the only one who is dubious about the existence of PPS and would "like proof", as she feels that what people interpret as
PPS may only be everyday problems. As PPS begins 30 to 40 years after polio, it was those who had polio young and were still working and may have had children at home when symptoms began, who told the most detailed PPS stories as they could not easily change their lives. Differences between the two groups centred both on the symptoms themselves and the depth of their forgetting of polio itself.

9.3 Recognising the symptoms: "I never thought polio."

Almost all the people interviewed deteriorated slowly from their 40s or 50s, gradually feeling weaker or finding they tired more easily, and they often assumed at first that this was part of normal ageing. After a few years of gradual slowing down, the changes began to impinge on ordinary life and new explanations were needed. Several people blamed their pain on old injuries, stress, fibromyalgia or RSI. Daniel, who found the most support and understanding throughout his life, even with the doctors he saw about PPS, still called his arm pain RSI, possibly as a way of minimising its importance. Most people had taken in a message during their rehabilitation or recovery that they would "stay at that level, more or less, for the rest of my life" (Wendy), "I was on the up not going down" (Michael). Only one person, Mark, specifically said that "my biggest frustration is that nobody told me" because he would have "organised my life differently" and travelled more when he was younger. Several people, however, said they assumed that they would deteriorate. It seemed logical to them that if many normal people develop mobility problems with age, then it would be inevitable for those who already had mobility problems and added pressure on joints from weak muscles.

Allen, who had one paralysed leg, and Jack, who had had some pain and difficulties walking, expressed this idea, but had not expected the extent of PPS. Both clearly remembered having polio and had remained quite clear about it effects. Jack, who was older than many of the others, having polio at 17, had mainly progressive weakness in his legs, which forced him to give up primary school teaching at 50. Allen, who had polio at 9, also had to give up teaching at 50, but mainly because of overwhelming fatigue. A theme throughout this chapter will be the differences in postpolio symptoms between
those who were older and those who were younger when they had polio, although this has never been a focus of research and has only recently been noted (Vasiliadis 2002).

Michael noticed differences when he went to a local Polio Fellowship meeting where there were mostly older people. "They hadn't got postpolio... And they never had it (polio) as babes... They had it in the army, in their twenties, slightly different." Those who were younger when they had polio, like Alex (18 months) and Jennie (5), put it out of their minds for many years which added to their confusion about new symptoms. They also had more severe fatigue, including mental fatigue. Fatigue of all kinds was more difficult to recognise than weakness. Those who were somewhat older, like Alice (12) and Polly (8), read about PPS and "logged it" (Polly), "made a mental note" (Alice) for the future. Eventually, when people learned more about PPS, they looked back at their polio experience and reconsidered their past and, to some extent, their future.

When Alex was 17, he had been told by an orthopaedic surgeon, "'You're going to be in a wheelchair roughly 34 anyway.'" Alex said he ignored the doctor's prediction and gave up the back and leg braces he had been wearing. He had significant back pain at the time, which gradually diminished, but he remained with weakness, which he described: "Sometimes when I got tired I, you know, that hand in the pocket thing and push back, this leg, this knee does not lock back like most people would". Occasionally he had "massive spasms" or tendonitis and daily pain that he ignored.

Alex: There was no time for aches and pains -- I would have, almost every morning it would take ages for me to be able to walk properly. Taking the weight, because both feet would hurt.

New symptoms began in the late 1990s with "bizarre things happening like electric shocks" in his lower back and he was getting "terribly, terribly exhausted." He had a logical answer.

Alex: Logically I said, 'Well, I'm not surprised. You've been working for so many years so many ridiculous hours, you're tired...I never thought this was because of polio. It was always because I was on my feet for too long, logically...but I wouldn't
let myself go slow. I was on such a roll that I think, I think if I stopped all these things might catch up.

For some people, there was a fear that stopping the round of constant activity would in some way cause the pain to manifest itself more, possibly realising that activity distracts from pain. This may be another example of Bauman's (1995: 112) argument that people "want to do what they must do". In this case, keeping active not only fulfilled the social requirement for achievement, but also masked his symptoms, which, if he stopped, "might catch up". Alex then described how he started falling and feeling more exhausted and was eventually persuaded by his wife to see a friend who was an osteopath. This helped temporarily, but the falls continued.

Alex: At Beaconsfield station went up the stairs and, thank God, it was very busy, people right around me, very packed, and this leg just gave away and I fell backwards...and this was the first time I thought 'Now this is serious. Something's not quite right.' There's no warning, there's no aches and pains, yet I didn't do anything about it.

Alex continued to relate that, around this time, his osteopath went on a course and heard something about polio having effects years later. Alex said he immediately put the word 'polio' on the internet, found several web sites and realised "it's a project, I can learn about this". This was his way of working and getting control, which had not been possible before the connection was made with polio, leaving him unable to "do anything about it". After another fall, when he was nearly hit by a car, he began ringing up polio groups and went to see his GP. He described having muscle spasms at night, when relaxed, and "it was so bad that I actually, anyway gritting your teeth doesn't help, at some point, you scream". During the day, "by 11 I was just so intensely exhausted my brain went fuzzy, I couldn't possibly drive anywhere". In order to understand why he waited so long to recognise such severe pain, it is necessary to return to his descriptions of the pain he had as a teenager, and on and off for years afterwards, which he had incorporated into normal life. It is this very long process of remembering and forgetting chronic symptoms that makes a biographical narrative study appropriate for understanding chronic illness since childhood. The next example demonstrates a similar
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long-term, but more convoluted, process of remembering, in someone who had recovered to a level of excellent strength and stamina.

Jennie weaved a complex story of slowly developing problems from the 1980s, when she began to notice that she was getting flu more often and it was lasting longer. She then shifts back and forth between stresses at work, illnesses of her husband, increasing tiredness, and muscle injuries. Besides full time teaching, she was studying for a special needs diploma and beginning to find it hard to concentrate. She also practised archery after school and it was in relation to this that she told a more specific story about her developing stamina problems.

Jennie: So I'd take my stuff to school and stop off on the way and, you know, do some archery with everybody else. And I got that I was too tired to do this, after my day's work. I would go there and I thought just carrying the stuff from the car park to where we had to shoot was just too much. And then, I bought a new bow, which cost seven hundred pound, and it was the same, very similar to my other one, and I suddenly found I was struggling with it, I couldn't pull it back.. Um, and that was possibly the first time of it and that was, I don't, very early nineties. That was the first of it, but even then, I don't think I'd ever heard of the postpolio thing, so, and then, I carried on.

It was also through the archery that she noticed her performance deteriorating over time, as a tournament progressed, but she interpreted this as psychological, that she "didn't want to win, didn't want to be in the limelight, didn't want to be noticed", although she then added that she had wanted to win. She said she had to give up archery in 1992 because she began to have joint pains in her knees, neck and hip on the right side, and a frozen shoulder which carried on for two years. She could only get through the week if she collapsed and did nothing on weekends, so she had to give up any social life. During the interview, Jennie became confused about how she did eventually learn about PPS and she moved back and forth between her joint problems, fatigue, inability to concentrate on written work and stressful incidents.

After the interview she sent me an e-mail clarifying how the idea of polio resurfaced in her mind during this time. In 1994 she took part in a counselling course for her special needs teaching and it was the first time she "consciously thought of polio", as one of the
counsellors mentioned her special needs and "that was a completely new idea to me". She remembers reading something the editor of The Guardian wrote about having to slow down because childhood polio was affecting him more, and then watching a five-minute television slot about someone who had retired early because of polio effects. She wrote that "In a strange way it is as if it was gradually drawn to my attention" because at this time she rarely read newspapers or watched television. In the interview, she mentioned that the first time she saw a hospital consultant since 1962 was in 1994, because of swelling in her knees. This consultant said that polio had no late effects. In 1995, she read a review of The Summer Plague by Tony Gould, which mentions PPS. In 1998, she began having serious difficulties working all week. Her doctor thought she had chronic fatigue syndrome and she was given several months off work. It was suggested that she work four days a week, but she realised this was not a viable long-term solution and she started to think about early retirement. Perhaps more than the other interviewees, Jennie went through a process, even during the interview, of looking back and trying to piece together when symptoms might have started. Like the previous stories, Alice's story of developing PPS stretches over several years, but it has a linear quality the others lack, possibly because, having recovered so well from polio, she had not spent the intervening years shifting polio from focus.

Alice was 12 when she had a relatively mild case of polio from which she recovered completely, becoming an avid sports person. Of those interviewed, she was the one who could most easily have forgotten polio, but it still remained as a ghost. She never spoke about it, "I just didn't really want to go into it", but was able to make "a mental note" when she first read about postpolio syndrome, although, at that time she was jogging anywhere from three to nine miles every day. Sometime in the mid 1990s, she "found running was getting harder...going up hills was hard." She assumed it was age although she was only in her early fifties. Some time afterwards, "stairs were blinking hard work." Then she described getting exhausted more and more often, though she was still running and playing squash.
Alice: You know, it gradually, it all happened so slowly…. And gradually the realisation dawned that things were not right. And if I analysed what bits of me really hurt, it was the bits that had been most affected by polio.

Alice's story is straightforward, like many of the stories of those who were over five when they had polio. Those who were younger have more mental fatigue and concentration problems and they also have problems in areas of the body which they did not think had been affected by polio (see Appendices 4 and 5). Even if Jennie had not put polio out of her mind, she may not have linked her shoulder and neck problems with polio because she felt her arms had completely recovered. Possibly Alice could contemplate the possibility of new polio symptoms more quickly because she had not worked so hard to keep polio hidden. She also has not needed to take early retirement, so new symptoms have been less of a threat to her way of life. Jennie, Alice and Alex's stories are told as a gradual unfolding process of discovering PPS, a process of connecting thoughts with bodily feelings. There is little mention of any fears, and anger is usually focused on the medical profession, which will be explored in the next chapter. A few people did describe the emotions they felt about PPS and this will also be discussed in Chapter 10. Polly, like Alice, is still working full-time, but unlike Alice, has mixed feelings about the existence of PPS.

Polly had polio when she was 8 and has hospital memories of an absence, "nothing actually happened… no stimulation and no care", and she described spinal fusion surgery as a teenager as "horrific for growing girls… corsets and braces". She refused to use the "polio word" for many years, but when one of her sisters read an article about the late effects of polio, she "logged it and I did a bit of enquiry at the time...so I have been thinking about it". She has had pain in her legs, increased curvature of her spine and weakening of her hands leading to two operations for carpal tunnel syndrome. She had a diagnosis of fibromyalgia for the muscle pain. She comments, "I mean, how can you say which of it is due to postpolio, sure, I've got all these diagnoses and I think I have got fibromyalgia and my legs hurt a lot". For complex reasons, Polly is as wary of the PPS word as she was of the polio word and prefers to think of her leg pain as fibromyalgia to keep it separate from polio and possibly think of it as temporary. She is still working full
time and does not want to slow down yet, which she feels is the "polio legacy". She explained that "I've never looked for an easy way out but I think I should have... I should have taken it easy right from the beginning but, you know, I've done the things I wanted", again echoing Bauman (1995).

Polly described her deterioration as natural. "I've naturally got wear and tear; I've naturally got a back that's giving out". She felt stress at work was a major factor, and later described her feelings about the dangers of defining ordinary occurrences as symptoms, "I don't want to start believing... some of these things are self-fulfilling, and it is that bit about giving into it... I kind of like proof somehow." At the same time as describing her deterioration as natural, she looks "for the examples of the 85 year-olds who have polio but are still going strong and got all their marbles in place." Polly lives with a message from her mother and grandmother that being independent meant working and "families with working parents are difficult", a difficulty that is ordinary, unlike polio which created a deeper conflict.

Polly: It's very easy to blame everything onto polio but I never ever blamed anything onto polio...we had a lot of stresses in our family, you know, and the last thing I've ever done is say, "Oh, it's because I had polio", in fact, it's rather the opposite with me.

She also described how the resilience of people who had polio was combined with "incredibly low expectations for yourself", so she feels she has to keep working in order to prove she is not taking the "easy way out" or giving in (Pollack 1993). In an e-mail message to an internet list (PPM) a woman said:

PPM e-mail: For nearly 50 years, polio was something I didn't talk about. When I was a kid, if I mentioned having had polio, I was looking for pity according to my brother. Now where in the deep recesses of the past did that come from? My mother was very supportive but polio was not really discussed in our home.

Blaming problems on polio or PPS was considered "looking for pity" and "looking for an easy way out" by those who had polio and others, necessitating silence. Reference to polio was a reference to weakness and became a moral problem. Blaming muscle pain on
stress at work, family stress or fibromyalgia could be seen as an acceptable way out; 'stress' being the ubiquitous cause of illness in recent times (Pollock 1993). For most people I interviewed, stress and ageing ceased to be useful or meaningful explanations as the symptoms worsened, and understanding PPS helped them lessen the symptoms.

Alex and Jennie, who had polio when young, had put polio out of their minds sufficiently well not to connect their symptoms with polio. Both also have mental fatigue, which caused problems with work. All of this group are similar ages, but whereas Alex (47) and Jennie (57) have retired early, Alice (57) and Polly (53) are still working full time. Neither Alice nor Polly has mental fatigue and Polly predominantly has new weakness and pain, rather than muscle fatigue. Being older when they had polio, both were more aware of polio in relation to their symptoms from an earlier stage and have been able to adapt how they work, although Polly had trouble with an employer. In the next section I will examine how people described the stage when they needed to explain their symptoms to others.

9.4 Needing help or helping

Having buried polio in the past, it was often difficult for people to recognise new symptoms as related to polio, and this caused confusion, silence and loss of control in their lives. Until people understood the implications of PPS, they hid the symptoms from themselves and, even afterwards, they sometimes hid them from others and tried to carry on as usual. Alice commented that "an awful of lot people still don't know I've got a problem." Rather than explaining his symptoms to people, Michael preferred to think that "they know". At some point, as shown in the previous section, they realised something was definitely wrong, and they wanted or needed to find out what it was. This generally involved having to explain their symptoms and ask for help at work, from doctors or from other people, which was almost always described as difficult. Thorén-Jönsson and Möller (1999: 79) have found that those who had polio avoid asking for help because of "a strong desire for independence", autonomy, and freedom, which meant "being free from other people's help." In this section I will explore how the interviewees explained
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PPS symptoms to others, asked for help and positioned themselves in relation to PPS, which some turned round into helping others, as had often been done with their work. This section forms a continuum with sections in Chapter 6 and Chapter 7 on comparing themselves with others worse off during the initial illness, positioning themselves as normal during recovery, and learning to work with and help others as adults.

Several interviewees are still working full time (Polly, Matthew and Alice) and have more or less accommodated PPS symptoms to their working day. Others managed to work until retirement age, but about half the people had to retire or work much reduced hours from about age 50. Several of these had to mention their new limitations to people at work or friends with whom they may never have discussed polio. If they were having problems at work, they may have been more pressured towards seeing doctors and obtaining a diagnosis, which would be another admission of needing help. This will be explored further in the next chapter. I will now discuss some of the problems people had mentioning PPS and symptoms at work or to friends and family. As the understanding of PPS by others was brought up in most interviews, this section will weave together the comments of a large number of respondents.

It was difficult for those who had never previously mentioned polio when they first needed to ask for help at work. Sarah had taken time off from her PhD because of her fatigue and someone at her university suggested that she have some investigations and find out what might be wrong. When I asked if anyone had thought her fatigue might relate to polio, she said, "She thought, no, no, she didn't think it was, well, she, I don't know if she knew that, about the polio." Polio had never been mentioned as it was "past", even though she had begun wearing a caliper again. When asked if the people he worked with knew why he limped, Michael said "they knew that, but they didn't know". Daniel was the only one who, although he never discussed having polio, found everyone at work "very supportive". Peggy and Jennie had also never mentioned polio to people at work and did not find it easy to break the silence. Peggy emphasises that polio had never "passed my lips."
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Peggy: Then, I went on a school trip to St. Malo. Now this was my swansong because I was nearing retirement, and on the school trip I had to say to the master in charge 'Look, I can't cope with that. I'm afraid I had polio in earlier years.' And that is the first time that had ever passed my lips. And that was 1994.

Jennie: I did tell the head teacher actually, I did say, "Look, you know, I really cannot go on school trips...I really am having a bit of trouble, I've got this thing called postpolio syndrome." I said, "But I'm fine, I can work, except I can't get up the stairs at the teacher centre so I'm not going to do any courses and I can't go on school trips." And it took a lot for me to talk to him about it. And then, later on, I don't know how much later, he reckoned I hadn't told him and that quite, sort of, upset me really.

It is difficult for people to express the effect of first getting up the courage to explain something that has been hidden for many years and then to have it forgotten. Hilbert (1984) describes how people do not understand or remember when people with chronic pain try to explain how the pain feels. In the case of disability, Zola (1981: 356) says that the stories are "difficult to tell as well as to hear." Throughout the interviews, there is a litany that "Well, they can't understand" (Edith) or as Clare said, "It's difficult to describe it to somebody who hasn't experienced it." Jonathan found that even someone who has experienced the limitations of disability temporarily cannot remember how it felt.

Jonathan (about his wife's pregnancy): She actually, in the last week, ended up in a wheelchair. Which was quite an interesting experience...and I said to her, "You know, you want to learn from this experience because that's what it's like... It was a nightmare for her, she hated it. But you know, people have short memories, I'm afraid. I occasionally bring it up...she remembers it happening but doesn't remember the kind of frustration of it or the feeling about it...

Jonathan makes clear that, for him, disability is both about other people's attitudes and the frustrations of the physical limitations. Another aspect of the lack of understanding and frustration is the invisible problem of increasing difficulties performing activities over time, or the increasing time it may take to perform activities. Zola (1982: 66) commented that "Just because an individual can do something physical does not mean that he should." Jonathan discussed this lack of understanding of his fatigability.
Jonathan: People don't quite understand. You know this fatigue thing. You know the fact that I could get up and make a cup of tea and cook for myself, but then I'd probably be too exhausted to eat it. But if you can do it, it's not like saying, "I've got no arms, I can't do it." But, and people just don't quite understand that.

Many of those interviewed would say that they want to do these things (Bauman 1995), and this is also part of the equation, because everyone wants to do what is normal and ordinary. However, they also may feel an obligation even when the activity becomes extremely difficult, and it may then be a matter of holding on to their identity, their sense of autonomy, and wanting to be respected (Williams 1993). This is a topic, discussed further in the next chapter, that people skirted around, possibly not wanting to face the implications of PPS.

People did not talk much about friends, but a few mentioned the effects of new symptoms on friendships. Jonathan mentioned that many friends have moved around the country or across the world, but also "my energy levels restrict my social life."

Jonathan: So I have my kids and a couple of close friends, and my family, I mean we still, I mean my family live, apart from my sister, we all live in London. We see each other quite a lot...I'm kind of shot by the end of the day really. I mean they do make an effort sometimes but yeah, it's not easy to do that. So, my circle of friends is, is limited if you like. One of my close friends actually had a kind, a kind of chronic fatigue so, there's some understanding there.

Lauren also mentioned the difficulties her friends had understanding her situation, possibly because she had always appeared so strong. When she had her breakdown, she commented about her lack of visitors in hospital, "Well, they weren't there for me, my friends, nobody...nobody could understand my breakdown." She also had trouble explaining when she was tired at work, and partially blamed herself, saying very quietly, "I want to be admired and I want people to say, 'Lauren does a good job.'" She described that one friend did understand the tiredness because she had had cancer and Lauren added, "she actually has apologised to me and said, 'I didn't realise what you were going through.'"
Nick suggests, in a story about letters he received from school friends after he was on television, another reason why communication and understanding can be difficult. He quoted one friend as writing, "I remember always being impressed by your unfailing good temper in spite of what looked to my teenage eyes to be massive physical problems. I guess we never talked about such matters, and wouldn't really have known how to."

Hoffman (2004: 93), discussing her inability for many years to mention the Holocaust with a good friend of the same background, wrote that "The lack of a wider framework for such matters would have made it hard to know how to talk about them; in fact, it rendered the broader subject nonexistent." The lasting effect of these silences creates circular stories that return to the original polio experience as the only time polio had some reality, which will be explored in the next chapter.

People who had polio at an older age found it less difficult to explain their limitations, especially after they started having PPS symptoms and polio had re-entered their lives. Peggy, who had found it so difficult to initially mention polio at work, had a positive and pragmatic approach a few years later, which she found worked with others.

Peggy: I don't talk about symptoms; I don't talk about problems because problems are there to be overcome. I encounter people in the dressing-room at swimming who want to help or they want to know and don't know how to ask. And I'm happy to talk and make it quite plain, I'm happy to explain to anyone.

When I asked if people understood when she explained about fatigue she simply answered, "Yes". Similarly, when I asked Wendy whether friends understood her limitations and fatigue she said, "Yes, absolutely". I asked if they ever seemed to forget and she said, "Well, but I say it the next time. Or if we're planning an outing, what I can do or not do". As I pushed the questioning, her answers became more ambivalent. She carried on to explain that her friends were getting older now and had their own limitations so they have "a bit more, sort of, understanding", which indicates it was not always perfectly straightforward in the past. It is difficult to pinpoint in this exchange what she thought about other people's understanding and what she wanted to believe. There were no stories in the interviews about friends' lack of understanding, only short interchanges.
Matthew was able to write more openly about his own ambivalence and other people's attitudes in the questionnaire than in the interview.

Matthew (questionnaire): Like with all medical reading there is often I think an element of me reading something about PPS and then thinking "well that happens to me" and it could be that I am a hypochondriac; certainly some people I know think that. I am aware that sometimes this could be the case but I am sure that a lot of it isn't. The worst of it is that I really feel I can't do the things I want to do any more with my young children...I am really hoping it is all a bad dream and that tomorrow I will wake up. I have found it very difficult to get people to understand that I might appear to be okay yesterday but today is different.

To counteract the difficulties of acknowledging PPS and new vulnerabilities to oneself, and then describing it to others and possibly not finding legitimation, several people put themselves in the position of helping others. This may have minimised their perception of needing help. The impulse to help others was strong in many people I interviewed, as mentioned earlier, both in their work and in relation to PPS. There may have been a combination of reasons, such as the benefit to self-esteem of helping others, feeling useful, and seeing oneself in the position of being stronger than those being helped.

Since having polio, people were always searching for a comfortable place among others who were different and were always comparing and finding their own strengths and achievements. Wendy, a psychotherapist, said, "I don't believe anyone escapes, in spite of how it looks on the outside" and told a story of a friend who has to leave a concert "if somebody unwraps a sweet paper... one could say that's a very small thing... but I wouldn't want to actually be in her shoes, to have my life limited by whether someone crinkles a sweet wrapper." She seems to suggest that in very difficult circumstances a small thing can become large, and implies that she would rather attempt to make a large thing slightly smaller. Myerhoff (1979) used the story of a meal she shared with the elderly, Jewish people she studied, in which everyone grabbed the best fruit leaving her the bruised apple to understand how sometimes, when life is extremely difficult, a little thing can assume great importance.

The bruised apple often served as a mnemonic for me, reminding me that however vital and joyous and angry the Center people were, however adept at asserting their independence, disguising their hurts, protecting their pride, they were deeply injured by their situation. (Myerhoff 1979: 189)
Disabled people, like all people in difficult circumstances, hover between the good and bad apple, trying to find a balance between giving and receiving.

In joining a PPS support group, people could either feel they were with equals, or distance themselves slightly from those who needed help by organising the group or being helpful in other ways. At his PPS management course, Michael found that he was "very fortunate, I mean, I'm the one that is holding the door or pushing them through". On the other hand, Mark, Nick and Allen saw support groups as sad or uncomfortable, and Daniel and Ken also did not want to take part in meetings. Polly ambivalently both doubted PPS and is active in the British Polio Fellowship and a local support group. Several others, like Wendy, Beth and Elizabeth, run local support groups, while Sarah works on a telephone helpline for a national postpolio support group, and Helen works on a local ME helpline, feeling that she understands fatigue. Beth, now unable to walk, also does voluntary work at a hospital, counselling patients. This chapter ends with two subtle and complex stories about finding a balance, one of helping others and the other of needing help.

Jack, who retired early from teaching at 50 because of increasing weakness in his legs, now uses a manual wheelchair and two long plastic braces to support his legs for the few steps he takes. He had recovered from polio at 17 with only a slight limp and had always had a positive and cheerful attitude. Now he minimises the effects of PPS by not "dwelling" on things, and redefining words to put a positive slant on his situation. He uses words that are usually seen as physical, such as 'stamina' and 'active', for mental activity. He is fit enough to push himself to the local shops and back, and looks younger than his age, possibly because of his height (6'5"). He attends the local PPS support group, but says he is "not a great one for meetings... I'm not a great one for discussing or dwelling on, you know, but if I feel I can help other people, okay". By seeing himself as helping others, he minimises the tremendous effects that PPS has had on him. I attended his support group meeting and afterwards met him outside the building smoking a cigarette. He said he needed a little smoke before returning to his ordinary life. Sitting in his wheelchair between the building and his car for a few minutes, his full engagement
with polio and PPS might just have had the time and space to slip into the background before he returned to 'normal' life. This small ritual helped him shift from a position of being disabled but strong (in that he could help others in the group) to one where he redefined himself as normal and active although in a wheelchair in the ordinary world.

Jonathan, who features so much in this chapter on the subject of people not understanding, told a narrative which centred around the theme of not being able to get the help he wanted, rather than helping others, even though he is (or because he is) a psychotherapist, who has worked with and helped disabled people both individually and in running a charity. Running through his story, which will be discussed again in the next chapter, is the paradox that "I look so much more disabled" (to people generally), but "I probably look relatively okay" (at a PPS clinic). He means that he does have visible spinal curvature and people always expected that he could do less than he actually could, but he can walk (unlike many who had polio), articulate, and has vague symptoms like fatigue, so that it has been difficult to get the help he needed from doctors or from others who could not see his arm weakness. He hovers precariously between these positions.

By presenting the articulate, self-reliant image he has mastered, it is difficult for doctors and others to understand his breathing and stamina problems, and need for help, a paradox described by Wiener (1975). But also, because he looks disabled, doctors over the years had dismissed his fatigue as depression or refused to investigate, saying "Well, what can you expect as a disabled person". This section has brought together the complex problems people found in first needing some help and understanding, and then reworking the situation so that they returned, as much as possible, to their original sense of independence and balance. This was much more difficult when fatigue and muscle fatigue were the predominant symptoms, as they are invisible and fluctuate with context and time.

9.5 Conclusion

This chapter has brought together some of the physical and social problems people had, with family, friends and work, as PPS slowly developed and finally forced them to
rethink and make changes in their lives. A descriptive list of symptoms at the beginning of the chapter was followed by several biographical stories of how the symptoms developed and were finally recognised as relating to polio, which had often not remained present in people's lives. They had particular difficulties explaining their PPS symptoms and asking for help after years of being independent and avoiding talking about polio. The chapter ended with examples of people helping others in the same or a worse situation in order to position themselves in a more positive way. By doing this, they brought together the three levels of narrative suggested by Bury (2001), the contingent, moral and core or cultural, all of which, in polio narratives, relate to the weakness and need to present themselves as strong, positive and successful. On the other hand, Jonathan had had polio and PPS problems for many years and saw the complexities and paradoxes of becoming independent and yet needing assistance. The next chapter on PPS will continue with the examination of how people explained their symptoms to doctors and some of the difficulties they described being understood and acknowledged. It will end with the meditations of several of the interviewees, who, on looking back, felt they had more understanding of their feelings about having polio and how polio and PPS might have affected their lives.
10. Postpolio syndrome: doctors, symptoms and looking back

I really don't think you ought to have this leg brace... This leg looks perfectly powerful. (Alex quoting neurology rehabilitation specialist)

This fatigue business though, that just doesn't wash. (Jennie quoting neurologist)

10.1 Introduction

Many of the respondents had been seeing their GPs over several years for muscle injuries, joint pain or fatigue, without either of them connecting these problems with polio. Even after the patient suggested the connection, the GP or, more often, the neurologist remained resistant to the idea of PPS. Zola (1973: 686) describes the complex weaving together of physical symptoms and social situations that bring people to doctors, but he also comments about the other side of the picture, when doctors and other health professionals reject or hold off difficult patients because they "may not understand what the patient is saying or... do not want to hear it." Sometimes the most upsetting thing for children and teenagers in hospital, during the acute polio or later surgery, was the lack of communication, and feeling that they were not treated as human beings. "Nobody ever told me anything, because you were only a child and you didn't count." (Helen) As polio had been forgotten by the medical profession after the vaccine, this lack of communication continued due to lack of knowledge (Halstead 1995, 1998b). Nick was sent for a series of neurophysiological tests for PPS and diabetic neuropathy, and he described the consultant's attitude:

Nick: ...as far as he was concerned polio, the infection, was over, that was it, and the idea of a related causal chain of events was a concept he could not grasp... his answer was to imply I was imagining the mobility loss was great or recent, and I really could not have had a sudden reduction so I could not possibly have led anything like a normal life in the past either.

Marinker (2000: 120) argues that learning to take a medical history "involves a careful training (rarely made conscious) in what to ignore, what not to hear, and above all what not to share." Sue, who had undiagnosed polio and obvious new weakness on one side,
said that one hospital neurology department "would not discuss polio at all... they were absolutely determined they weren't even going to look... they basically said I was barking mad." She later received a PPS diagnosis from an orthopaedic surgeon, who had treated polio patients abroad, and recognised a typical pattern of skeletal changes.

Very few GPs had heard of PPS and most people had no understanding of their symptoms until they read or heard about PPS. In the survey, 76% of participants introduced PPS to their GP, and of those interviewed, it was 77%. A similar situation has been noted with MS patients, who found doctors dismissive, often over several years, and had to do research themselves and were often relieved when they finally received a diagnosis (Stewart and Sullivan 1982). Doctors are also dismissive of those with contested illnesses and parents of children with nonspecific symptoms later diagnosed with cancer (Arksey and Sloper 1999). The interviewees who were older when they had polio (over 11 years of age) presented to doctors mainly with new weakness and often saw their deterioration as a general polio decline. The group who had polio as younger children had a more complex array of less specific symptoms, including substantial muscle fatigue, fatigue, mental fatigue and concentration problems, which made working difficult. This chapter will be an examination of the interactions between doctors and those with PPS symptoms, and an exploration of how people felt about PPS, their current life in relation to their past polio and a lifetime of living with the effects of polio.

10.2 Doctors and symptoms

In this section, I will discuss the experiences four people (Alex, Michael, Jennie and Helen) had with doctors when their main symptom was fatigue or muscle fatigue, symptoms which have caused controversies in the medical research as discussed earlier. Similar to the previous chapter on recognising symptoms, I will concentrate on a few stories, typical of those who were younger, because PPS often evolved in a circuitous way, producing longer narratives which need to be traced over time. These four particularly discussed their experiences with doctors because they wanted a diagnosis in
order to make decisions about early retirement. Alex and Michael, 18 months and two when they had polio, both told quite detailed stories of their muscle fatigue and falling.

Muscle fatigability

Alex described having several frightening falls, severe exhaustion and muscle spasms in his chest over some years before he heard of PPS through an osteopath he was seeing. He then read about it on the internet, saw his GP and was referred to a neurologist who "doesn't even know of PPS, he doesn't even know that there's a possibility of it." Alex had read about the Lane-Fox PPS clinic in London and had himself referred there. This clinic specialises in respiratory problems and sleep studies and patients report varying experiences there, depending on their problems and knowledge about PPS (see footnote Chapter 9). Some, like Michael, who had never met other polio patients and knew nothing about PPS, found it very helpful. Alex described not getting anywhere and that "they are pretending to be a centre of excellence for us and they're not.” He described one of the doctors there as having "the most condescending attitude towards the polios... he pats them, he literally pats them and sees them for 10 minutes and out they go." He said he began to think that "fundamentally, Lane-Fox's opinion, when I went there, was basically there's no such thing as PPS.” After this experience, he was referred to another neurologist who diagnosed PPS after conducting tests on him as an inpatient over 10 days, in order to exclude other diseases, as there is no test specifically for PPS. But this neurologist could not see him again as Alex was outside his area. Alex started using a brace on his weakest leg but then found his stronger leg was tiring and causing him to fall. In an e-mail to a postpolio list I also belong to, he described the orthopaedic specialist he saw about this falling problem.

Alex (e-mail): He made me lift my left offending leg once and declared it sufficiently strong. I told him it is the repetitive use that tires my leg very quickly. He would have none of that. The severe muscle spasms I have, he declared a non-polio issue. It has to be neurological. The fact that the neurologists found nothing after many tests is of no interest to him.
In the interview, he then described being referred to a local rehabilitation specialist for his pain and a neurophysiotherapist to look into his falling and back weakness. He felt that the physiotherapist understood why he was falling and did repetitive tests like watching him walk and climb stairs. He described her explanation that over time his leg buckled more and he was consciously locking the knee "and if I'm busy and I'm not thinking about it, that's when I fall". This thinking was new for him, and helpful in understanding why he was falling. She recommended full leg braces for both his legs and a back brace, but the neurology rehabilitation specialist disagreed about the leg and back braces and any medication he had been given for pain, as described in the quotation below. Alex had pulled together similar information from people in the postpolio internet group, the neurologist he had seen as an inpatient, and the physiotherapist, to form an idea of PPS which he brought to the rehabilitation specialist, whom he was seeing at the time of the interview. This was an immediate and emotional story.

Alex: (She said) 'Can you take off your braces' and I do this whole thing and it's this schlep and it's hot and I'm struggling and she doesn't care. Anyway so she says 'Lift, do da, da.' Yes I can do it, I'm not going to con her, I don't have to. She does it (muscle test) once, so she says 'I really don't think you ought to have this leg brace.' I said 'Yah.' She said 'This leg looks perfectly powerful.' I said 'Erm and when I walk ten steps and I fall, because I can't control the knee?' I have not had that woman respond to one single problem and question that I posed. ... She spent the best part of my time there bitching about the fact that I'm still on Zanaflex and amitryptiline. So 'Why don't you tell Dr A. that? Don't tell me that. His regime is that we don't mess with too many factors at once. That makes sense to me.' Anyway bottom line is she doesn't think I should have this brace erm so I said to her 'So what you're telling me Dr C. it's okay for me to fall five six times a day.' She won't answer me. 'And I'm afraid I'm not leaving here until you answer me'.

This interaction has been reproduced in such detail because it exemplifies the paradox for doctors concerning their belief that polio causes the obvious and visible weakness and atrophy that Alex has in one leg but not the transient weakness and pain of muscle fatigue, which Alex has in the other leg and his back, which had less paralysis originally. The overuse of weak and easily fatigued muscles is thought to lead to painful spasms (Silver 2001), which might be ameliorated by bracing, but this did not seem to be appreciated by the rehabilitation specialist, who did not connect pain and weakness.
In 1990, Michael began having problems with weakness, decreased endurance and pain, especially on stairs and slopes, and his GP recommended leg exercises which did not increase his strength. In 1994 he had a multi-tendon transfer operation on one foot to improve ankle stability. After three months in plaster and months of physiotherapy and working out in a gym there was no improvement. He then met a physiotherapist who had some understanding of polio.

Michael: She said she worked with polios in India and that was at the Town Football Club where she was a physio. And I was down there of an evening on the strengthening equipment that they used, the footballers were using, and it was recommended that I try the Town Football Club for leg strengthening because that’s what they were special machines for. And while I was putting myself through there, and she said ‘I’m not sure that you should be doing this because polio limbs are not recovering erm from all this exercise.’ And she said ‘And yours certainly won’t.’

He described his belief that exercise would strengthen his muscles.

Michael: I thought ‘Well, whatever it takes.’ And was I committed to that, my goodness me you saw me down that gym there and I was you know two hours three days a week which is quite a lot...I was believing that this was the way forward only er think my heart of hearts I know I’m hardly walking out of this gym after the exercise...And of course that was really over burn and they never recovered.

Michael described, both in the interview and in his diary, how he began to find out about PPS from the British Polio Fellowship and was then diagnosed at the Lane-Fox clinic. He was given a respiratory device for sleep apnoea and spent over a year trying to get a leg brace, which in the end was not helpful. While waiting for the brace, he had a fall which brought home to him how difficult PPS was becoming.

Michael (diary): Falling down in our garden was very traumatic for me; my right arm suffered a double fracture, resulting in my arm in plaster for five weeks. Unable to hold my walking stick, becoming dependent more than ever on my wife for help in order to get up and go out...I have no feeling or control when my legs collapsed to the ground and I am unable to get back up on to my feet without assistance from another person.
During that time, he retired from work because of his falling and exhaustion, and applied for the Disability Living Allowance (DLA), which he received until a doctor examined him and terminated the benefit. It was then reinstated by a review and appeal. Like Alex, Michael had always had one weak atrophied leg but it was his stronger leg which was now causing the falls and this had not been understood by the DLA doctor. When doctors pushed against the stronger leg and judged the strength to be normal, they began to puzzle over the falling or pain. If patients tried to explain how the weakness developed over time, they often felt they simply were not heard.

**Fatigue**

Everyone who had fatigue as a major new symptom also had substantial muscle fatigue, and Alex, for one, had both equally. It must be remembered, however, that although muscle fatigue increases with activity over time, it is itself a constant symptom. The effects may go away with rest, but the muscle fatigability remains. This is also true for general fatigue. Weakness is different in that it is constant in relation to activity and throughout the day although it may deteriorate as a disease progresses. Those who had to leave work because of fatigue generally experienced more severe fatigue which began earlier in the day and did not resolve with short rests. They also had mental fatigue which made it difficult to concentrate. Two women, Jennie and Helen, told narratives in which fatigue made it impossible for them to carry on working.

Jennie, who was very energetic and strong for many years after polio, first mentions problems of muscle fatigability in the early 90s during archery, pulling back the bow and carrying equipment, and this led to shoulder injuries and tiredness. The tiredness made it more difficult to deal with the usual stresses at school and she began to have problems with reports and written work.

Jennie: ...we had to have sort of case conferences at least once a term and I had to do a report for that. And I found it was getting more and more difficult, couldn't get my head round it... Like, before, because I've always been able to write, and I always
knew...you know what I wanted to write because I was observing the children and taking notes all the time, keeping records of everything. But, yes, it got actually harder and harder, to actually do it.

She began to work only four days, needing three days to recover, and then during a period of sick leave, she mentioned postpolio syndrome to her doctor and was referred to a neurologist. She had realised that she would need a diagnosis if she had to give up work.

Jennie: I was off sick, there was a six months waiting list for the hospital and I thought I can’t be off sick full pay for six months without ... telling anyone what’s going to happen so I actually did go private you know, see the same fellow who gave me the diagnosis, so then he said, 'The only thing is to change your life style'. But he also said to me, he said 'This fatigue business though, that just doesn’t wash.' So I thought 'You can say what you like as long as you sign to say that I can’t work any more.' You know I don’t care about anything. (laughs) So um I haven’t been back to see him since because I thought if somebody doesn’t accept all your symptoms, there’s no point.

If Jennie had only had new weakness she might have been able to wear a brace, but the muscle fatigue, leading to pain, injuries and fatigue, accumulates all day and cannot easily be worked around. Her objection to the neurologist's attitude of not accepting "all your symptoms" seems to be the manner in which he separated the fatigue as something less real and did not connect it with the constellation of muscle fatigue and pain.

Helen began the description of her new symptoms with difficulties walking up slopes, falling and feeling more tired. She said that, at the same time, "I wasn't concentrating so well and I was having problems at work, you know, I wasn't sort of dealing with work as well as I used to and I was getting a lot more stressed up about things." At an early point in their narratives of exhaustion, Jennie and Helen felt 'fluey'. Helen thought she had probably heard of postpolio syndrome around that time and she mentioned it to her GP, who had not heard of it but did look it up. Her GP felt there was nothing that could be done and Helen was not referred to anyone until she felt she could not work any longer. It was when someone at work said to her, "Well I would give you a lot more to do but I can tell you wouldn't be able to cope with it" that she felt demeaned, and also that it was
not fair on the others. She was on sick leave when she went to see a neurologist, whose attitude made her "terribly angry".

Helen: And he was so arrogant and dismissive of everything I told him that I couldn't, I couldn't possibly have postpolio syndrome because his definition of postpolio syndrome was what he called postpolio muscular atrophy, and I showed no sign of this. And fatigue was nothing to do with postpolio syndrome. The inference was I was a neurotic woman and I had psychological problems and I should take mood-enhancing drugs.

As in Jennie's case, the neurologist separated the fatigue from PPS, whereas Helen felt it was "quite difficult to sort out mental and physical fatigue because they are so interrelated when you think about it." The neurologist was rejecting both symptoms, believing only in the strictest definition of PPS as weakness with atrophy. None of the people who had polio as teenagers or older had as many problems with doctors as this group of younger people. There are some differences between the two groups. It is not only that those who were older developed PPS nearer retirement age, because Jack and Wendy (polio at 17 and 20) took early retirement at 50 and 57. One difference is the amount of fatigue in relation to weakness that the younger group had. Jack had very obvious leg weakness and needed two long calipers but felt mentally alert. Wendy had always had extensive weakness, so even low levels of new weakness could cause her substantial problems such as not being able to get up from a fall, but she felt her mind was hardly ever "fuzzy". Although Helen (polio at 4) had always had spinal problems, her leg weakness had not been obvious and it was her fatigue which was affecting her work most.

It was the mental fatigue that was bothering the younger people, and this was absent in most of the older ones. Mental fatigue would make it more difficult to describe symptoms and tell a coherent story to doctors, and fatigue is not easy to describe. In addition, those who had polio when they were five or younger had less clear stories of having polio originally and they had often more successfully forgotten polio. These difficulties, combined with the attitudes of doctors about subjective symptoms and the lack of understanding about polio, could create a difficult if not antagonistic situation.
Elizabeth, who is 70 and had polio at 25 soon after completing medical training, answered my question about why doctors had trouble with postpolio fatigue, saying, "I'm absolutely appalled at the way some doctors are treating them... It's powerlessness. They feel they can't do anything. And a doctor who can't do anything for a patient tends to get upset and defensive." Her answer is, however, only part of the story, as research has found that doctors do not feel the same about all subjective symptoms they cannot treat. They feel more comfortable with, for instance, more localised subjective symptoms that are more plausible pathologically (Raine et al 2004).

A similar problem of not defining fatigue, ignoring fatigue, or conflating mental and physical fatigue, occurs with other neurological diseases and research (Lou et al 2001, Carlsson et al 2004). A major theme of Jonathan's interview was the frustration he had felt with doctors throughout his life with his polio problems. He related this to his atypical polio which affected mainly his arms and breathing, meaning he looks "relatively okay", his ability to "articulate", and the medical incomprehension towards nonspecific symptoms so that "the kind of statement 'I feel unwell' doesn't mean anything to them". Jonathan sums up that "I'm not really quite sure of the support I want from them, but I do want a discussion about it. There doesn't seem to be a discussion." Wendy has had assessments with a "terrific" rehabilitation specialist in the US, where she was given "understanding... and acknowledgement... of this as a process that is happening", which she could not find in the UK.

**Autobiography**

Between 1985 and 1997 I saw four neurologists, who could easily have been the same person. I will describe my brief encounter with the fourth neurologist, recreating approximate dialogue, in order to answer my question of how my muscle fatigue was or was not addressed in the interaction. I will compare this with an examination by a Benefits Agency doctor, who was understanding of PPS and muscle fatigue.

1997: Dr L. looked down at my notes and said that as I had had a previous normal muscle biopsy, in 1987, he did not believe he would find any abnormalities on examination or through EMGs. "And, if I don't", he said, "then your problem must be psychiatric. Neurology and psychiatry, very close, you know, and if the tests are
normal, it must be psychiatric. Postpolio syndrome is just a fad." He then asked me to describe my symptoms and I started to say how I had felt when I walked down the street, and how long this had been going on, but he cut me off mid-sentence and said he had heard enough. I never had a chance to say that I had been seeing a physiotherapist at a rehabilitation hospital for a year trying to increase exercise or activity, but continually having increased pain, fatigue and muscle injuries. He then asked me to sit on the examining table and began to test my muscles, pushing against my arms and legs. When he pushed against my right leg I could sustain the pressure of his hand, but my left leg buckled after an instant and he nearly fell on top of me. Sounding annoyed, he said, "That's absolutely normal." I returned to my wheelchair across from his desk. He said that my examination had been completely normal, but he would put me on the waiting list for EMGs, although he was convinced they would be normal. "Which means your problem with your legs is psychiatric." I answered, "How does that explain the injuries I get in my back muscles from walking?" His face tensed, he stood up, shouted "Don't put me on the spot", came round the desk, grabbed the handles of my wheelchair, whisked me round, opened the door, and shoved me outside in the hallway. It was as if he had picked me up and thrown me outside the room.

Around the same time, I also saw a doctor who worked for the Benefits Agency. He worked in occupational health and told me he had taken the job with the Benefits Agency because he liked visiting disabled people in their homes as it helped him understand disability better. When I mentioned polio, he said he had been interested in postpolio syndrome for at least 10 years, and then began chatting about the history of polio in the 1800s. He could have gone on all day. I told him I probably had not had any paralysis, I had only been two and wasn't sure, and he did not seem surprised or doubtful. He meticulously tested my muscles and found differences no one else had ever found, weaker muscles in the undersides of my arms and legs. He listened, he understood, and he was a completely sympathetic person.

Two conceptions of PPS

When doctors separate fatigue from PPS (Schanke et al 2002), and patients see the interconnectedness of the physical and mental fatigue as a major part of PPS (see symptom list in Chapter 9), they are talking about conflicting diseases. The doctor conceptualises motor neuron death leading to weakness which does not vary throughout the day and a patient describes a situation of becoming weaker and falling after walking a certain distance, of legs aching and feeling tired the next day. The doctor conceptualises a disease in which a virus has one effect on the body, destroying motor neurons, and this results in one symptom, weakness, although research showed that polio also left damage
in the brain stem, autonomic nervous system and other tissues (Bodian 1949). The patient is describing the complexity found in the few early studies of polio damage.

In the small survey I undertook by writing to 20 hospital consultants in relevant specialties, the doctors who did not have a special interest in PPS generally had a narrow view of PPS as ageing-related weakness, and a majority of the interested doctors recognised more symptoms and more complex causality. Even among the three doctors contacted who had written on PPS, replies ranged from scepticism from one doctor, a central (brain) cause for muscle fatigue from a second doctor, and a complex theory of muscle fatigue as peripheral and central from the third. This doctor related the muscle fatigue to lower motor neurons being "metabolically incapable of supporting these large motor units" and probably "the sensory and motor input to the basal ganglia from the abnormally large motor units contribute in some way to the sensation of fatigue" (see Appendix 4). Mol (2002) suggests that the disease-illness distinction, where doctors describe disease, and patients and sociologists generally describe illness, is no longer viable, as you cannot separate the physical from the social. In some cases, the patient is describing an objective physical act like walking upstairs, and the doctor is describing a subjective opinion, belief or interpretation of test results and pathology.

A discrepancy in the symptom stories of doctor and patient may result in a lack of trust between doctor and patient, and inappropriate care or treatment. Greenhalgh (2001), an anthropologist, describes her illness experience with a doctor who constructed his own story of her story to fit his specialty, fibromyalgia, explaining drug side-effects as symptoms of fibromyalgia. In the case of PPS, if the doctor believes the only symptom is weakness, he will bracket off other symptoms like pain and fatigue, classifying them as orthopaedic or psychological, and not relevant to new nervous system deterioration. Kirmayer (1988) has described this medical use of the psychosocial as extending medical power, not to understand the patient more fully, but to dismiss the symptom as unimportant and caused by the patient. Latimer (1997) observes that hospital doctors divide elderly patients into medical or social cases, and once divided, they will only be seen as having problems relevant to the category they have been placed in. This is
similar to the PPS patient with muscle fatigability and pain who is classified as strong or 'nothing wrong'. Ken spent an hour and a half with a neurologist who then "promotes me as being a superbly fit physical person, you know what I mean. 'Get up, take up your bed and walk sort of thing, clear off, there's nothing wrong with you.'" These classifications matter, because treatment and advice are based on them. Several patients in this study were either given no advice about exercise, managing activity and braces, or advice that led to deterioration.

When sociologists and anthropologists enter the arena of contested illnesses and unexplained symptoms with cultural explanations of illness, they may also be depriving people of their disease story in preference to the illness story (Kleinman 1988, Good 1994, Waitzkin and Magana 1997). This may interfere with already complex problems in the grey area between over-medicalisation and under-medicalisation. Latimer (2000: 387) suggests that "it is dangerous...to over-emphasise the personal and social aspects of older people's health troubles." The decision over the importance of subjective symptoms is one that everyone needs to confront from the patient to his family and friends, doctors and researchers, and as evidence is lacking, belief, morality and emotion become involved. For example, Zavestoski et al (2002) describe Gulf War veterans as resisting the post-traumatic stress label "because such a label did not guarantee them the treatment they felt was needed." They also did not meet the post-traumatic stress criteria. Later, Zavestoski et al (2004: 172) suggest that "what may be needed is a model for understanding how any doctor and patient can work together to arrive at a diagnosis that is medically sound and consistent with the patient's experience of illness" and that this would be consistent with "the integration of psychiatric treatments into primary medical care". This conflict between the beliefs of doctor and patient, which Taussig (1980: 12) describes as "a strange 'alliance' in which one party avails itself of the other's private understandings in order to manipulate them all the more successfully", is at the heart of controversies over the 'reality' of muscle fatigue. Radley (2002: 702) has more recently suggested that "The important point is not the 'voice' itself, but who has the right (and the power) to articulate it."
Those who needed a PPS diagnosis for early retirement eventually found knowledgeable doctors, or at least doctors who were willing to give the diagnosis. At this point, they often had to confront radically changing their lives. The main approach to PPS treatment is pacing (balancing activity with rest), exercise, and avoiding fatigue and pain that last more than a short time, quite different strategies from the polio philosophy of pushing hard and ‘no pain, no gain’ (Halstead 1998b). Finding the correct balance of maximising activity or exercise, and minimising fatigue and pain is so difficult and so fraught with moral overtones, harking back to the initial polio and fear of ‘giving in’, that this is sometimes an emotive subject when PPS is first recognised. In this study, most people had reached a balance concerning activity and rest, however uneasy, which sometimes included a certain amount of regular exercise, often swimming (Helen, Jennie, Lauren, Peggy, Barbara, Alice, Mark, Allen), and the use of passive exercise machines (Nick, Peggy). In the interviews, feelings about PPS deterioration were often described in relation to the polio story as resurgent feelings connected with the original polio experience. Just as attitudes to disability tend to polarise disabled people into heroes or victims, emotions produced by the experience of chronic illness tend to be seen as transcendent or tragic, but polio narratives belie such simple dichotomies and classifications. The next section will focus on how the interviewees reconstructed or resurrected polio memories and complex feelings in relation to their feelings about PPS. Several narratives which seem to come round full circle, linking polio and recent stories will be explored.

10.3 Looking back

Sanguinity and bitterness

In a BBC radio programme commemorating 50 years since the Salk polio vaccine, Tony Gould, who wrote The Summer Plague, commented:

From my experience of writing a book about polio, and talking to many other polio survivors on both sides of the Atlantic, one of the things that struck me most forcibly
about all of us, really, was that we have a quite sanguine outlook on life and there is very little bitterness about the illness. *(Archive Hour BBC Radio 4, March 2004)*

Several people interviewed in this study have a very positive outlook on life, but more feel some anger, resentment, disappointment, sadness and loss as well, and often have not shown it until recently. Emotions were mixed and difficult to express. When Lauren saw herself walking, on film, she said, "I can't describe how I felt". In the interviews, the story of the developing PPS was usually told in a matter-of-fact way although there was sometimes confusion about when and where they had heard about PPS. Understanding PPS had often been a slow process over many years, coupled with specific incidents that had had a big impact, but this was a few years in the past and the emotional effect had faded or been put aside. It was sometimes in writing that more feelings came out.

Michael (diary 1999): It is a devastating blow after spending a lifetime trying to conquer the functional deficits left by the original illness to have to be dependent on others frequently throughout the day to attend to my bodily functions...my leg muscles are suffering from fatigue in minutes, I dread to think how I shall be able to manage steps, stairs and slopes with this leg brace without causing further injury to myself...Post polio syndrome has dominated my life throughout 1999. This loss of independence is very difficult for me to accept.

Nick (e-mail about school friends writing to him after he was on the TV programme *Tomorrow's world*): They made me realise that the separateness, the apartness, I felt sprang as much from within me as it did from without. I had failed to reach out and touch... I had never felt any resentment, at least that I was aware of, before. Now I was on an apparently un-reversible decline, and suddenly I felt I had held so many boys and people at arms length. This suddenly changed, and a vast feeling of anger, rage, resentment, sadness, and real loss, poured forth.

Jennie (e-mail): It is hard to change unless something catastrophic happens to you in life. I woke at four this morning and was trying to remember something I had felt when realising I had to change because of PPS. It was something to do with wondering what would be left of me if I had to change everything which was habitual and familiar to my way of life.

These three excerpts are all written in quite formal language, and through this language both Michael and Nick slip in forceful words or phrases about their emotions like
"devastating blow", "dread to think" and "rage". It is only Jennie who continues to dance around the subject of what has happened to her, remaining slightly subdued and ambivalent. She writes that it is "hard to change unless something catastrophic happens", and never states that something catastrophic has happened. But then she says "when realising I had to change" as if confirming something catastrophic has happened. Jennie's interview has a major theme of "trying to remember something I had felt", which permeates both her polio and PPS experiences and epitomises the liminal quality of having only a child's memory of the original catastrophic happening.

Polio and PPS are seen, in these examples, as causing a complex mix of rage, sadness, defeat, catastrophe and an inability "to reach out and touch" (Nick), because of the emphasis in society on normality, achievement and action. Zola (1981: 357) described the polarised images of the disabled, as tragedy or success, and within the success story he suggested there are two messages -- that even the disabled can have lives, and that "if a Franklin Delano Roosevelt or a Wilma Rudolph could OVERCOME their handicap, so could and should all the disabled. And if we fail, it's our problem, our personality, our weakness." In other words, the healthy world blames the disabled for remaining disabled (Pollock 1993, Radley 1993, Williams 1993). Zola (2000: 47) argued that action and overcoming are crucially important values in modern society to the extent that "'Doing nothing in a difficult situation' was interestingly enough an item diagnostic of neuroticism on a popular American psychological test." These messages were well learned by the people in this study, including the polarity that there was nothing between success and failure. For some, like Nick, polio had been and PPS was, once again, the image of "defeat". Lauren commented, "I'm now the cripple." She analysed what PPS meant to her.

Lauren: I just think that it's incredibly cruel actually that it should come back. You know, this is the awful thing, why, when you've achieved so much, why does your body let you down like this and I think that's been the hardest thing to accept. It's as if I've let myself down...I resent the late effects of polio coming in and taking it all away and I do resent it, and in that way, I suppose, I resent me. I can't describe it any other way and I'm angry about it.
Lauren sees PPS as she and her body failing herself, rather than as an understandable or inevitable wearing out that some others saw. Earlier she had said, "I feel quite sad that I've lost something. I think I permanently grieve but it's only that I've got a strong personality that gets me out of it." This leads to conflicting feelings of anger and resistance on the one hand, and sadness, grief and fear on the other. Especially for those who were younger when they had polio, like Lauren, the physical and social could not be separated. She had new limitations and she wanted to be able to explain, but no one had given her this option.

Lauren: I basically live my life not letting people know how I really felt. I've led my life being what I think people expect me to be... and I wanted, I want to stand in the middle of the road and scream, 'Why me?' But I haven't been able to. I've wanted to turn around and say to somebody, no, of course, I can't do that because -- but I've never done that ... I always felt that I had to apologise for myself, apologise for my clumsiness.

Similarly, Jonathan found both his physical lack of stamina frustrating as well as people's lack of understanding. Until his thirties, he could play one game of badminton "before not being able to lift the bat" and he continued, "I learned to outwit people rather than outplay them", but "I'm quite competitive, so it was frustrating not being able to do all I could do in my head." Nick also combines the physical effects of polio and other people's attitude of ignoring those effects, writing first that he had "never been able to shake off the effects of my first defeat -- that of being crippled by polio" and "I survived with a level of internal fury and anger and a degree of contempt for everything I could not do or control". He then describes that when he was 15, "I only cried once and it was the sense of difference, of loss, not anger or frustration... I honestly believe now we all felt abandoned, people just went through the motions in dealing with you saying everything would be all right". There was physical loss and the anger and frustration that followed, but equally there was the loss of being different, no longer being part of a community, and no one understanding. Possibly Jane was fortunate in never being told "you'll be all right". For many, there was confusion about being 'all right'. This led to people never being able to say, or sometimes even know, how they really felt or, as Helen said, she did not know "the kind of person" she was.
Letting go

Others were more positive from the beginning and saw polio, and eventually PPS, as a challenge. About polio, Jack said that "it was up to me and I was kind of battling this thing right from the beginning" and Allen commented about a doctor telling him he would never walk again, "No one tells me I'm never going to do something again." The attitude of polio as a challenge sometimes seemed to be resistance to stereotypes of disability as dependence rather than capitulating to pressure to normalise. For some people, with the advent of PPS, there was a new challenge of resistance to the pressure to normalise. It often took a long time but eventually some people felt free to recognise their PPS symptoms, talk about them, be disabled and meet other people with PPS. Gradually, identities and biographies changed. Jennie said, "I'm a different person now, I don't get uptight about these things" and Joanna said, "I let things go, things aren't so important now." Michael explained that "once I understood a little, I wanted to understand a lot more. I started to read up, get on the internet." Allen has taken up photography and writes for several magazines and says that "life is to be got on with". Bury (1991) argues that sociologists have focused too intently on problems, whereas illness and illness narratives are often about solving problems. In the case of polio, where the initial solution, striving endlessly for success, became a problem, then, that too, needed solving (Scheer and Luborsky 1991).

Several people were both relieved to find out about PPS after years of struggling at work, and also felt ready to give up work when they realised it was necessary. Those with increasing muscle fatigue and mental fatigue like Alex, Helen, Sarah and Jennie had little choice about giving up work. Helen and Jennie both said that they had worked long enough. Sarah had been going to a gym as a remedy for fatigue and had read the article in The Lancet dismissing PPS (McCarthy 1996), and she also thought, "'Yes, it's all in the mind'". But some time later she looked it up on the internet and "was astounded by what I read, I thought 'This is it, this is what's wrong with me, so it's not in my head at all'". This knowledge liberated her from the medical psychological theory which had caused
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her to blame herself, and allowed her to rest when fatigued. Several years earlier, when she had first been given a "squeaky" caliper for her newly weakened ankle, she had begun to experience a freedom from earlier stereotypes about whether she was the same as everyone else, as discussed in Chapter 8. She had become free from her husband who felt that "Everything had to be tailored to him", but with her understanding of PPS she moved beyond having to accept people who "didn't understand the physical bit, the physical tiredness and sheer lack of energy". Riessman (2002: 37) suggests that "Despite the power of cultural plots, we do not simply follow them in re-storying our lives over time. We interpret past experiences in composing lives in the present that adapt to, resist, and sometimes reach beyond the master narratives of dominant cultural institutions."

Several other interviewees spoke of new freedom and changed thinking about the achievement and success they had felt was so necessary. Alex told of his difficult decision to retire, as his work was his life, but he was in considerable pain and unable to concentrate, and eventually learned that he must "let go".

Alex: I just love being at home, I love having my grandchild with me often. Because you know those are things I couldn't do. The first few months, there's a resentment, I really wanted to continue work and how's it going to be without hard work because that was my crutch. It was my whole justification for having a life, and suddenly there was this thing, that I was so buggered that I, I just let go and I just let it happen. And now after all this two and a bit years, I'm actually sitting here saying there is a life beyond, beyond being on, you know, the rat race all the time. And I feel wonderful --

A few people had doubted an extreme work ethic, like Helen, who said, "I felt that there was life outside of work as well. It wasn't the be all and end all." as discussed in Chapter 7. Jennie also said that the emphasis on independence from childhood sometimes went too far and "there was a bit too much of me doing everything", which led many to the need to always be proving their worth. Le Comte (1958: 96), a Columbia professor who had polio as an adult, had the maturity to question the rehabilitation work ethic and "whether you ever walk again is up to you!" Hockenberry (1995: 332), the paraplegic war correspondent whose autobiography is a meditation on freedom, writes that when he was finally forbidden to do what he wanted, to enter Baghdad at the beginning of the Gulf
War, "I felt liberated for the first time in my life from this need to prove something." As explained by Helen, PPS was sometimes able to perform the kind of liberation that the lack of a visa did for Hockenberry.

Helen: I do have concerns, and I'm just wondering, you know, how I'm going to be able to cope in the future if I deteriorate. But, in a way, it's quite nice to say, "Well, look, I can't do that" and not have to feel guilty about it. Because there's a reason, you know. Not having to push myself so hard to be normal.

It is interesting that polio could never be "a reason". It was Lauren who understood that it was "the world" that expected her to be "this happy, bubbly person" and that "you're not allowed to change". Like Helen, Lauren has changed her attitudes but has come up against other people who rely on her remaining the same. Jennie wrote to a PPS e-mail list, which I was a member of, some time after the interview:

Jennie (e-mail): I think what so many of us have in common is wishing that there had been some recognition, some acknowledgement of our difficulties.

Circular stories

The sense of freedom or increased openness, even in the midst of the limitations brought on by PPS, came from understanding and rethinking earlier polio experiences and feelings and realising that there had been difficulties. This sometimes produced circular stories, where feelings about PPS mirror earlier experiences with polio. Other stories seemed circular because one theme linked the entire narrative as polio merged seamlessly into PPS. One theme like this was not being listened to or understood, as a child and later both by friends and the medical profession. In some stories, these themes linked polio with work, marriage or divorce, and other relationships. Three examples, Jonathan, Jennie and Sarah, will demonstrate how the narratives linked from polio to PPS, and from the beginning of the interview to the end.

Much of Jonathan's discussion of his frustration with both his physical limitations and the health service about "getting some proper help because you seem okay" echoes the first
Story he told about his mother's diary and her frustrations obtaining physiotherapy for him after he left hospital, at the same time as she was denying the seriousness of his disability and how it might affect him. Jonathan had explained that he had needed to learn to be non-confrontational as a child because he could not fight back, followed by learning to "help people over their problem" with his disability, and to plan carefully so he did not get into a situation where he could not cope. He said that being away from home when young you learn that "if you're not relying on yourself and sorting it out yourself then you're kind of failing in some way." The end result, he suggests, is that because he looks disabled but copes, doctors will veer from saying, "Oh well, what can you expect as a disabled person", to dismissing him because he is articulate and managing. He quoted his GP as saying, "I never really see you as disabled exactly" which he did not feel was "very helpful." About his family, and the families of other disabled people he has read about, he said, "There's a lot of lip service paid, but the actual practice, people don't want to help with the things that you want help with, they want to help with the things that they feel comfortable helping with." At the end of the interview, he discussed how difficult he had found it to run a small disability charity because he did not like confronting people who were not doing their job, and then mentioned how corrupt big charities were. They may have "an ultimate aim to help people" but they have no problem about squeezing out smaller charities, in the same way that people only help in the way they want to, echoing Jennie's theme that "they couldn't do the right thing". All through the interview, from his mother trying to get physiotherapy for him, is the theme of not getting help, not being listened to and not having his symptoms understood -- of being too disabled or not disabled enough, and, having learned to help others deal with his disability, and then counselling others about their disabilities, there is no help for him.

Jennie's narrative is centred more on her own childhood memories and her relationship with her parents. Throughout, there is the repeated theme of not being understood or listened to, both as a small child in hospital, and later when her mother only tells her own side of the polio story. This theme is returned to in the story of the little boy with cerebral palsy whose mother does not listen to him, and, later, the neurologist who does not acknowledge all her symptoms. Towards the end of the interview, she relates a long
story about her last day at work in early December and the following weeks. She worked for a few days in her husband's bookshop just before Christmas and came down with flu on Christmas Day, a flu that left her exhausted for several months. She described ringing her mother to say she could not come for Christmas and her mother ringing back to say, "Your dad and I are very upset. We think that if you don't want to come and see us you should say so, not pretend that you've got flu." Jennie explained that she did not know much about PPS at the time, although she had had a diagnosis, so had not been able to explain it well to her mother. After her prolonged flu, she bought a computer and read about PPS on the internet. She continued:

Jennie: I didn't really understand myself what was going on, but they were very unsupportive actually, my parents, then... my mum's okay now, except she doesn't give me much time to talk but that suits me. My mother, actually, is quite an ambassador. She's going to hospitals for various things... wherever she goes she tells them about postpolio syndrome.

She had explained earlier that it suited her not to say too much to her mother because her mother would often contradict Jennie's story. Just as she felt her mother had told everyone her own story of Jennie's polio, the theme is repeated with her mother telling everyone about PPS, but still not listening to Jennie. Jennie described that she has, more or less, learned to ignore her mother's refusal to accept her polio story, explaining earlier, "I think there's a lot of guilt there with them, so it's best left alone really, I suppose, as far as they're concerned."

In Sarah's narrative there is a distinct connection between beginning and ending, involving her family and no one talking to her about her disability. The interview began with Sarah's story of her father telling her husband, but not her, that she easily became tired because of polio, a story she had only recently heard. She had also mentioned the "strange sort of dichotomy between people thinking that you're different but not actually saying anything to you. That nothing is said." Her first polio memory is coming home from hospital, after six months, on the day her newborn sister was brought home, and feeling her sister was a replacement. At the end of the interview, she talked about the anger her younger sister feels now about never having received attention, but Sarah also
10. Postpolio syndrome: doctors, symptoms and looking back

tells a story of her sister being the replacement, in that her sister was called 'clumsy' instead of Sarah, which has passed down through the generations, one child or another being called 'clumsy', as described in Chapter 8. Sarah described her sister moaning about being tired on long family walks, when it was Sarah's tiredness that was not spoken about in the family. Sarah ended the interview not knowing what had happened on the walks, as she had not known about her fatigue at the beginning of the interview: "she wanted to be in the (younger brother's) pram. Now it could well be, I don't know, perhaps I was allowed turns, you know, I have no idea, whether I was or not, whether she did, I don't know."

These three stories mirror a finding in Gordon and Paci's (1997: 1445) Italian study of concealment and silence about cancer, that "protecting the social group from the threat of separation or openly confronting suffering may be the implicit priorities here", but that both the individual and the group "pay a high price for the nondisclosure, feeling isolated and abandoned". In both cases, the group encompasses multiple levels, from the family to the public and the medical profession. Although the cultural stories of terminal cancer in Italy and childhood polio are in some ways opposite, one aiming for less and the other for increased responsibility and independence, the ultimate aim of a "reconstruction of everyday life -- nothing must change, life must continue as normally as possible" is the same (Gordon and Paci 1997: 1443). There are benefits and losses in making the balances necessary to reconstruct normal life. The narratives told in this study point to a range of complex reactions to polio experiences, both from the disease itself and reactions from others, which have remained with many people -- the frustration, fears of dependence, sadness about losses, anger about not being respected as a child or not being able to get help, and confusion about lack of information, but also the strength, independence and close family relationships. Now with PPS, there is sometimes new anger and sadness, and also a measure of calm, understanding and, occasionally, liberation -- a mixture of both sanguinity and bitterness. It may be that this 'ambivalent restitution' story of independence, but also mixed emotions showing the strength and vulnerability, is an emerging cultural story of long-term chronic illness since childhood.
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10.4 Conclusion

The first section of this chapter links back to the literature on PPS research, and has demonstrated the difficulties some of those with polio have had with the medical profession as PPS began to seriously impinge on their lives. The second half of the chapter focuses on how people described their feelings about PPS and looked back to sometimes newly understood emotions about polio and their earlier lives. Some began to understand that having polio had been more difficult than they thought (Jennie, Nick), some had always felt polio had been a problem (Jonathan, Joanna) some continued to feel it had not been a problem (Allen, Daniel), but most explicitly or implicitly told a story of some difficulties, but also successes.

Those who were young children when they had polio often remembered less, had no chance to talk about their feelings, felt they had not been treated as thinking, feeling human beings, and put the experience quite firmly out of their minds. They also had a more complex array of symptoms, which took them much longer to recognise as related to polio. They had to explain their symptoms to people who may never have known they had polio. Asking for help was extremely difficult for everyone, forbidden by the ethic of independence (Thorén-Jönsson and Möller 1999). Those who were younger when they had polio had difficult consultations with doctors because of their more subjective symptoms. Those who were older often have more severe weakness, but this was more easily understood by friends, family and doctors. Many of the devices and strategies that people had learned in order to live with polio, the planning (of physical movement and social interaction), finding activities that felt natural, being positive, comparing themselves with others, and helping others, could be used to deal with PPS. This narrative reconstruction involved rethinking the feelings they connected with having polio and how polio may have influenced the way they have lived their lives. Now many say they are disabled, they are not hiding it and they ask for help, although it has been difficult.

None of these changes has been made easier by the lack of recognition by the medical profession and difficulty obtaining advice about PPS. If the medical profession had
accepted polio muscle fatigue earlier in the century, more people might have been warned of a possible deterioration or helped when it first began, but people in general, and doctors, in their education, have little place for symptoms that only exist in relation to time. Sullivan (1986: 348) suggests that we need a "subjective clinical inquiry", where the subjective is "the personal, the meaningful, the situated and especially, the concrete" and "both physician and patient have the capacity for interpretation." In this case, "the concrete" is the everyday experience of loss of muscle strength when walking, lifting, bending and generally living. This doctor-patient interpretation is not solely about illness but about disease; a patient describing when he falls is describing why he falls. This is why narrative is important in medicine and in any study of illness. Ironically, in 1972, *The Lancet* published an early PPS article about functional deterioration in patients who had had polio, in which the authors said, "This diminished level of motor ability may not be demonstrable by manual muscle testing -- a static evaluation that does not study function over time" (Anderson et al 1972: 1063). This was the only article on PPS in a general UK medical journal until Howard (2005) and Bridgens (2005) in the *British Medical Journal*.

The paradox of strength and vulnerability, in which people both hide and acknowledge disability from childhood, leads to a much more complex narrative than Frank (1997a) found in the stories of chronic illness in adults. These are not stories that can appropriately be judged in the way that Frank describes his 'quest' story, in which people learn from illness and bear witness, as a morally superior story. Frank admits that all stories are a combination of his three typologies, restitution (medical cure), chaos and quest, but ideally he sees a progression towards the quest narrative, the only story that is tellable. Polio stories integrally combine variations on these types, leading to a workable solution for each person. The overarching story is one of putting polio aside (ambivalent restitution), which involves a confusion about living with paradox, and sometimes becoming perceptive through being different and observing the self and others. The confusion is ambivalent but rarely chaos, and the perception is often everyday observation rather than a new spirituality. The ambivalence is caused by the insistence from others (and then themselves) to be normal (and therefore silent) and this leads to
confused, mixed emotions, pride in achievement, and anger and sadness about hidden differences. Putting polio aside, and the confusion this caused, enabled people to find strength, do fulfilling work and observe others from a different perspective. They did not need to clarify the confusion or create a coherent story before being able to do interesting work or help others. Any incoherence, however uncomfortable, may have helped their understanding of others. These are not easy stories to tell or hear, because, as argued by Skultans 1998b: 62), there is a "lack of an internal connectedness" and a "conflict between agency and authorship which finds expression in the ambivalence of the narrative 'I'." Narrative is not solely about creating coherence and meaning. In making connections between strands of experience, a deeper complexity may be discovered, combined with the realisation that there will always be disorder or nonorder (Rosaldo 1989).

Both the medical story and the story of those who had polio are about categories and their boundaries, the criteria that define a disease or being normal. The fluctuating, amorphous rules surrounding PPS and normality create fears of transgression leading to a black-and-white, all or nothing mentality. For society, disability must be kept as a clear category, as tragic or heroic, and PPS must be visible, through muscle atrophy, paralysis, scans or abnormal EMGs. Normality translates as high-achieving, energetic, and successful, and anything less is failure and 'giving in'. Hockenberry (1995: 262) found a less polarised attitude in the Middle East where a wheelchair does not stand out "as an explicitly separate experience from the mainstream" as it does in the US, but "is just another thing that can go wrong in a place where things go wrong all the time".
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And, let's face it, I've had a lot of practice at this sort of thing by now. I've come to see that sorrow and loss and regret and life and pleasure do not need to crowd one another out. (Mee 1999: 222)

11.1 Introduction

This study set out to examine two interrelated problems: the experiences of people who had polio and then developed PPS, and the controversies and scepticism about PPS and in PPS research. The experiences people had living with the after-effects of polio were told through their present experience of PPS and the scepticism or lack of knowledge they found in the medical profession. The medical and personal narratives can be seen as a series of interlocking circles, as, in both stories, the past informs the present, but the present also leads to an understanding of the past. The lack of polio research and follow-up after the vaccine created a silence and lack of knowledge which was mirrored in the silence families created around polio in order to feel there had been recovery and a cure. New postpolio symptoms were greeted with scepticism in the 1980s which reflected back to the earlier unfinished research and lack of interest in a forgotten disease, and stories of PPS now mirror the often untold polio stories both physically and emotionally.

Diseases and research are often forgotten when they are anomalous within current medical paradigms (Kuhn 1996, Douglas 1987, Sacks 1997). Diseases that are not cured, and leave symptoms or disabilities, are also anomalies within the cultural work ethic, where strength and achievement signify worth. This is the central paradox of chronic illness and disability, creating ambiguity about separateness from or place in society. Scientific findings which do not fit into accepted theories, and ill or disabled people who do not meet the standards of normality, cause discomfort for those who most need control and certainty (Wendell 1996). Doctors who are comfortable with uncertainty can acknowledge the complexities of subjective symptoms, and patients who can accept "the possibility of random misfortune" (DiGiacomo 1992: 126) are able to tell stories of "improvisation, muddling through, and contingent events" (Rosaldo 1989: 103). This chapter begins with a summary of the thesis chapters followed by a discussion of the
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major themes. It concludes with an examination of the limitations and possible future
directions of the research.

11.2 Summary of chapters

In the Introduction and Chapter 3 Literature: the medical profession, contested illnesses
and PPS research, the unresolved dilemmas concerning polio in the 1950s, which
influence current controversies about PPS, were presented. The preference for doctors to
see recovery and cure wherever possible, and minimise ongoing subjective symptoms, is
part of a cultural ideology of achievement, independence and overcoming adversity,
which was equally prevalent among the families of those who had polio, and the public
(Kaufert and Locker 1990, Pollock 1993). This ideology increases a sense of order and
minimises confusion, ambivalence and fears, but necessitates strict definitions and
'objective' tests. Chapter 2 Literature: the experience of chronic illness and disability
reviewed the social science literature on chronic illness and disability, focusing on the
uneasy disease-illness divide and how narrative may be used to bridge this divide.
Another focus was research on childhood illness. There is a gap in research on the long­
term consequences of childhood illness and the historical aspect this necessarily involves
(Lawton 2003). Chapter 4 Research design delineated the methods chosen for the study
and how the study was carried out.

The analysis of the polio and PPS narratives has been divided chronologically into three
groups, childhood, middle years and postpolio syndrome, each consisting of two chapters.
The two childhood chapters, 5 Childhood: polio stories, memories and silence and 6
Childhood: recovery, ambivalence and being normal, trace how narratives of childhood
memories portray the medical, family and public thinking that influenced how people
were treated in hospital and afterwards, and the ambivalence and silence surrounding
polio and disability. The story of the initial polio often brought together the strength and
'fight' needed to learn to walk again, and, often in little stories, the fear of vulnerability
and helplessness. Afterwards, during the long period when children had surgery and
gradually became stronger, polio was often hidden, leaving the person in a liminal
position, between disabled and able-bodied, and although the narratives were restitution stories of 'getting on with it', more accurately they were often ambivalent restitution stories, involving a confused struggle to be normal. Each person, in some way, said that they just wanted to be like everybody else. However, there was also a recurrent theme of resistance, especially to being treated as an object in hospital or differently at school, which led to strong feelings of right and wrong.

For both physical and social reasons, the experiences and stories of men and women, and those who had polio at different ages, varied. Those who were younger when polio started often had confused memories, and said they were not encouraged to talk about their experiences, and were not told stories by their parents. They were also deeply ambivalent about whether they were disabled and whether any pain or fatigue was different from other people's experiences. Children often felt guilty or ashamed that possibly it was their fault they had become ill (Gould 1995, Davis 1963), and "if you're not sorting it out yourself, then you're kind of failing in some way" (Jonathan). Their disabilities and symptoms changed over time, as they grew, and as surgeons tried to 'fix' them. As shown by the survey, although those who were younger generally had less paralysis and better recovery than those who were older, they had a relatively high level of neuromuscular symptoms and fatigue in the interim years after polio. Women also had more symptoms in the interim years, and, in this sample, more severe and widespread polio.

One experience that was common to everyone was the need to find a balance between normality and disability, which involved the visible or invisible weakness and other symptoms, the limitations created by the symptoms, and the reactions of others. Most people described finding a balance very close to leading a completely normal life, which is the subject of the chapters, 7 Middle years: work, independence and interdependence, and 8 Middle years: identity and relationships. They learned to ignore or hide any limitations, and shift only when necessary from the world of normality to the world of disability. The stories had a strong element of 'getting on with it' and stoicism. A balance and sense of independence was found through work they felt was natural for them, often
involving work with people or helping people. Independence was integrally related to interdependence as work often involves others and joining a community. The desire to help others may have stemmed from early polio experiences and continued the theme of resistance, as it involved helping others in ways in which they themselves had not been helped, changing attitudes towards children, understanding themselves and having a sense of achievement and control.

The second chapter, *8 Middle years: identity and relationships*, commences with respondents' varied ideas of self in relation to disability, from a constant self to complex, shifting selves, and moves from self to social identity in the family and then outside. Stories emphasised work, but families were very important, symbolising, like work, independence and, implicitly, interdependence, leading to the closeness they had often felt with their own families, and lacked in hospital. As people who have experienced helplessness often speak in terms of independence, "the manifest interdependency of individual and modern society which lies at the heart of everyday life is overlooked" (Williams and Wood 1988: 132). These stories were mostly positive but below the surface was the idea that "it was hard" and sometimes lives were marred by ongoing fatigue, pain or relationship problems, which often related to disability or the beginnings of PPS. Resistance to negative reactions sometimes influenced choice of work, and, on an everyday level, was expressed through humour and controlling conversation. Women, and those who were younger when they had polio, often told more complex and fragmentary stories of mixed emotions and disruption caused by earlier symptoms and PPS. Women also had the added complication of juggling work and children. Men more commonly told clear, linear stories of 'getting on with it' and polio being forgotten, which matched their experience of less widespread paralysis and less fatigue. Those who were most confused about both symptoms and experiences may be thought to have told 'unsuccessful' stories (Jarvinen 2000). These may also be seen as important stories in explaining the ambivalence of disability, especially where symptoms and disability fluctuated and changed over time.
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It was only with PPS and new limitations that the balance was forced to shift and people began to rethink their lives. The chapters 9 Postpolio syndrome: connecting polio and new symptoms and 10 Postpolio syndrome: doctors, symptoms and looking back is about the experience of PPS symptoms and rethinking polio and its influence throughout their lives in order to understand the symptoms and themselves. For some people, it was very emotional remembering polio, rehabilitation and surgery, and wondering how much polio had remained important in their lives. PPS brought new confusion for some people who did not connect fatigue and even new weakness with having had polio, because polio was in the past. Some also had to begin to think of themselves as disabled and leave work that had been very important to them. Although people told mainly positive stories of success before PPS and learning to manage PPS or even see it as a challenge, many people also wanted to say, sometimes only in small, slipped in stories, that it was not easy and they did now feel mixed emotions — anger, sadness, resentment or grief. Narratives are not only about finding order, but may also be about describing disorder. On the other hand, a few people felt a new freedom in being able to acknowledge their disability and limitations. This chapter also completes the circle back to Chapter 3 Literature: the medical profession, contested illnesses and PPS research, exploring the experiences people had with doctors and conflicts in understanding stamina problems and the meaning of fatigue. Alex summed up the problem of lack of understanding among consultants by describing the attitude of a neurophysiotherapist, "the lower down the chain, the closer people are to the real issues and they tend to know much, much more. Jane (the physio) had one look at me, 'Forget about EMGs', she said." Feinstein (1972: 423) argues that "our primary challenge is to assemble information that is meaningfully human, even if scientifically imperfect" because the patient needs acknowledgement of their symptoms and experience.

11.3 Themes and debates

*Stigma, liminality and independence*

The main theme of this study is the ambivalence surrounding chronic illness and disability and the balance people try to find between the strength and weakness, because
there is no way to get around "that there’re very sort of negative associations around disability" (Helen). The story of the ill or disabled person is about stigma, often subtle but nevertheless deeply meaningful, and the avoidance of stigma.

An unguarded glance, a momentary change in tone of voice, an ecological position taken or not taken, can drench a talk with judgemental significance. (Goffman 1967: 33)

To stigmatise is to treat as different and inferior, that is, to place in a category outside of the normal and everyday. The process of this categorising or stigmatising is the oppression described by disability theorists. In the case of different cultures, religions or ethnicities, these categories may be quite distinct, and there is the possibility to ignore or resist the stigma. For chronically ill and disabled people, especially those who have 'recovered', who live among the able-bodied, the category is grey, and they find themselves in a difficult, liminal place, always striving to re-enter the culture surrounding them which values strength and achievement. If a narrative is told, it may not be about finding meaning and order, but about complexity and disorder. The ambivalence surrounding chronic illness centres on the paradox that they remain ill or disabled but wish to and are pressured to live an ordinary life (Wright 1960). This paradox leads to the multi-levelled silence -- cultural, medical and personal -- and the moral pressure to be normal.

In a strong moral sense people with a chronic illness sometimes find that they are not allowed to be ill. (Williams and Wood 1988: 130)

Although ill people often blame themselves for any limitations they may have (Williams and Wood 1988), this is because, in subtle ways, society is blaming them, possibly not for becoming ill, but for not fighting hard enough, not recovering, not trying enough treatments, not being positive, or daring to complain. Blame is more severe for those without a diagnosis or with subjective or fluctuating symptoms (Hilbert 1984, Pinder 1995), but Douglas (1996) argues that all illness demands justification. For physicians,
an inability to cure undermines feelings of control, and results in blaming the patient (Malterud 2000). Kirmayer (1988: 80) analysed further:

> Blaming people for their ill fortune moralises events that might otherwise be viewed as the result of external malign forces or simply chance. Both chance and nonhuman evil are threats to the notion of a 'just' and morally ordered world. Thus, one function of blame is to support and enlarge a coherent moral order centred on rational human agency.

Frank (2002: 112) explained why even the ill person may endorse a self-blaming theory:

> Cancer personality theories will persist, because they have a payoff for everyone. On the one hand the ill person is accused, but on the other she is comforted. Perhaps by changing her personality she can recover; it is never too late.

Patients would rather blame themselves and avoid the greater fear, "the possibility of random misfortune" (DiGiacomo 1992: 126). The blame and pressure on ill people to be positive and not complain creates the liminal category they find themselves in, and the need to be stoically silent and driven to achieve success and independence. The medical profession is equally guilty in promoting the stoical 'fighting spirit' beyond its obvious uses, in order to absolve itself of responsibility (Salmon and Hall 2003). By expecting the ill to 'fight' and not complain, society creates a paradox for ill and disabled people of being seen as weak, vulnerable and "not quite human" (Goffman 1990b), while being pressured to be strong in order to appear normal in the normal world. Vulnerability is uncomfortable for able-bodied people, reminding them of their own vulnerability and potential for disorder in their lives (Fine and Asch 1988b).

Mary Douglas (2002) explains how we squeeze anomalous groups into rigid categories to create order and alleviate discomfort. By separating off disabled people or insisting on assimilation only if they conform, ordinary people can ignore their fears of illness (Stiker 2002). This has led to the dichotomy of disabled people being seen as either tragic or heroic. As a result, the ordinary accomplishments of disabled people cannot be seen as ordinary but are labelled as triumphs or tragedies, which stigmatise them as different.
Douglas (2002: 127) shows that marginalised groups, dwelling in the corners and "cracks of the walls and wainscoting", are also felt as threatening, that "the inarticulate, unstructured areas emanate unconscious powers which provoke others to demand that ambiguity be reduced." Crawford (1994) creates a different metaphor, seeing the ambiguous category of illness as a border region, which may seem threatening. He argues that "health' has become a primary means of signification by which borders are maintained, threats specified, and internal weaknesses shored up" (Crawford 1994: 1348). Using this metaphor it is easier to see that disabled people also exemplify order and strength which may cause fear in non-disabled people.

The mutual vulnerability of both disabled and able-bodied people has been pointed out many times in the literature (Fine and Asch 1988b, Frank 1997a, Brody 1997) but the mutual strengths have been ignored. Sociologists have focused mainly on the vulnerabilities and suffering of the chronically ill, feeling that these are hidden and denied (Frank 2001, Charmaz 1999), but the strength and vulnerability cannot be separated. An in-between, everyday space needs to be found between triumph or tragedy. Having made these two categories for disabled people, the hero and the victim, and having created the stories of triumph and tragedy, there is discomfort with both categories, for both strength and weakness in disabled people awaken feelings of vulnerability in those who are able-bodied. If able-bodied people see strength, they realise they do not have this strength, and if they see weakness, they are reminded of their own vulnerability. And if a disabled person manages to break free from these categories and remain in-between, this also creates discomfort, because there is no way to tell who is disabled and who is able-bodied.

A step towards freedom

The strength and ensuing independence is complex. New forms of learning, thinking and planning had to be developed. This learning could be conceived as similar to the moral education described by Nussbaum (1990: 44):
This experiential learning, in turn, requires the cultivation of perception and responsiveness; the ability to read a situation, singling out what is relevant for thought and action.

Independence included this heightened perception to deal with contingent events, resistance to unfairness and helping others through similar problems. It could involve taking risks and allowing fate to play a part in a life that allowed inconsistency and uncertainty a positive place (Kaufert and O'Neill 1993). The line between autonomy and dependence is very fine, hampered by both the need for interdependence, and to be like everyone else. Gallagher (1998: 187) suggests that "the handicapped person, if he is to be free, must have the right not only to compete and to succeed, but also to drop out, to fail."

Henrich and Kriegel (1961: 197), in an early compilation of stories by disabled people, argue that the independence of the disabled person in the able-bodied world may be a mirage.

All of this leads one to wonder what it is that the physically handicapped individual should adjust to. Is he, in his search for a life of his own, to latch onto the hole offered him by society, to make his bed in a flotsam of sensationalism, to play the clown to his own pathos? Or is he, rather, to try to equip himself with certain basic substitutes for what he has lost physically, to be his own man, who demands no other excuse for his existence? It is easy enough to nod one's affirmation to the latter, but the choice itself is not that easy. The former role, although it robs the handicapped individual of dignity, does guarantee him a modicum of satisfaction; he is accepted by others, is part of the group, is granted if not self-respect at least the right to exist. He is not, in short, overly embarrassing to others. This may not be a role to be envied, but it is a role. But if he demands the right to be his own man, if he insists on living according to his own definition of what is right or wrong for him, then he must run the risk of alienation. He must face the prospect of going it alone, and he must do so in a country that is not, despite what our magazines tell us, filled with admiration for the independent man.

The above statement seems as true now as 40 years ago. Writing about the role he assumed as heroic disabled war correspondent, Hockenberry (1995: 350) says, "In a life of breaking chains and surmounting obstacles I had only bound myself more tightly to the idea of fighting for my freedom."
A solution for the problem of stigma and difference in relation to disability and illness would be to enlarge the conception of normal (Pinder 1995, Little et al 1998), with a shift towards "greater legitimacy to everyday culture" (Featherstone 1992: 176). However, the difference must also be acknowledged and normalisation "recognised for what it is" (Stiker 2002: 146). There is a very tight grip in Western society on conceptions of the normal life, on the achievement, energy, fitness and attractiveness needed to be successful, even if there is a gesture towards acceptance of more fluid identities (Hughes 2002). Unfortunately, this is a Catch-22 situation, in which society's fear of illness and death leads to the need for strict categories about normality, and will not lessen unless people become more familiar with illness by allowing it a normal part in everyday life. What is needed is not Oprah-style outpourings of emotion, which only separate emotion from everyday life, as does silence or psychotherapy, but bringing previously unacceptable emotions, or the possibility of mixed emotions, back into everyday life. Kirmayer (1996: 192) argues that to be most effective, psychotherapy "must also support their efforts to be heard beyond the consulting room, in a local world."

The move towards seeing the normality of trauma or disruptive experiences is exemplified by Sontag's (2003: 113) comment on images of war: "We can't imagine how dreadful, and terrifying war is; and how normal it becomes." Children also find normality in the uncertainties of cancer treatment (Stewart 2003). About recovery after war, Summerfield (2002: 1107) argues that, "'Recovery' is not a discreet process: it happens in people's lives rather than in their psychologies. It is practical and unspectacular, and it is grounded in the resumption of the ordinary rhythms of everyday life". The dreadful and the mundane, like joy and sadness, occur simultaneously. For instance, it is difficult to conceive of happiness in a concentration camp, but in the story of his camp experiences, Frankl (1984: 84) describes "the most idyllic hours I had ever spent" being the middle of the night when he could "lie stretched out in front of the stove and roast a few pilfered potatoes in a fire made from stolen charcoal". Freedom involves moving towards a complexity that includes both sides of the continuum, in order to find a balance between burying and forgetting too much or too little. The pendulum is possibly
swinging back towards the middle with more complex views about how people react to and recover from disruptions in their lives.

**Narrative, memory and understanding**

In order to bridge the gap between the healthy and the ill, Toombs (1993) suggests we need imagination and empathetic listening. Nussbaum (1995: 5) describes how literature uses emotion to create empathy and understanding.

Because it summons powerful emotions, it disconcerts and puzzles. It inspires distrust of conventional pieties and exacts a frequently painful confrontation with one's own thoughts and intentions. One may be told many things about people in one's own society and yet keep that knowledge at a distance. Literary works that promote identification and emotional reaction cut through those self-protective stratagems, requiring us to see and to respond to many things that may be difficult to confront.

In everyday life, it is narrative and the emotions created through narrative that attempt to bridge the gap. Kirmayer (1996: 175) describes trauma narratives as having "differences in the culturally constructed landscape of memory". He compares the collective human catastrophe of the Holocaust with stories of child abuse. Even if Holocaust stories were not told, an internal dialogue could exist because it was a trauma experienced by a community, but isolated abuse victims have stories "where telling and even thinking are forbidden" (Kirmayer 1996: 189). In the case of polio, stories were rarely told, and knowledge was kept at a distance. The polio story has elements of both of these landscapes of memory -- the cultural and historical stories of both medicine overcoming the disease with the vaccine and patients overcoming paralysis, and the hidden personal stories of vulnerability. More recently, these stories have been complicated by therapeutic cultural stories such as the quest story. Kirmayer (1996: 186) argues that "even fragments can be read as a story if a larger narrative context is supplied" and that both personal and cultural stories are necessary and equally important:

The adamantine self can be critiqued as a fiction, as acultural, asocial, self-justifying -- but it is also the place from which the individual can take a stand against lies and the self-interested promotion and domination of others... Similarly, the transactional self
can be critiqued as a fiction born of collusion, false consciousness and conformity… But this is to deny the centrality of relationships with others from whom we receive basic sustenance" (Kirmayer 2002: 739)

Long-term chronic illness narratives merge memory with the public and private self, and involve the narrative reconstruction of biography, in which people "reconstitute and repair ruptures between body, self and world by linking and interpreting different aspects of biography in order to realign present and past and self and society" (Williams 1984: 197). For those who had polio when they were very young, this reconstruction may not be easy. If they had never been told their story, or ever told or even thought their story, any fragments of story they had were, like the stories of exiles, "beyond familiar genres… and ultimately made communication impossible" (Skultans 2004: 298). The discomfort caused by difference leads to this lack of communication and the need for control that keeps discomfort at bay.

The strict categories formed to allay discomfort lead to anomalies, discordant facts and forgetting, which maintain the sense of the category (Douglas 1987). Douglas (1995: 27) suggests that sometimes a gap in history is preferred, and that "It is usually wise to leave bygones to be bygones." The gap in history, like the forgotten epidemic, is a time that conflicts with the public memory, because society cannot conceive of the complex or in-between, the state between order and chaos. Stories are forced to become even more constricted. Although society has become more open to emotional stories, these are limited to appropriate emotions, times and places (Furedi 2004). Douglas (2002) argues that fear and hostility is created if opposing categories are combined. As in the case of disabled people, who are seen as both strong and weak, power is given and taken away. A balance is needed between too much and too little meaning, between needing order and accepting randomness, between disability and normality, and between responsibility and blame. Instead, people are left grappling for a story among fragments, as there is no collective story that has any meaning for them.
11. Conclusion and discussion

Disease and illness complexity

Disablement, particularly that relating to chronic illness, frustrates the project upon which medicine's prestige rests: that of finding discrete causes for particular diseases on which basis it can then propose specific therapeutic interventions. Medicine tends to rate diseases according to the extent to which it has mastery over them (Williams 1991: 519).

The anomalies in PPS research suggest a more complex disease than previously theorised. A new examination of subjective symptoms, both through medicine and the social sciences, is needed. This study has shifted between 'disease' -- the physical pathology, the medical and lay knowledge of the pathology, and the patient's experience of symptoms, and 'illness' -- the social experience of living with disease. The sociological conception of the lay view of illness has often combined lay theories about causation of the disease, experiences of living with the symptoms and social experiences, the "human experience of symptoms and suffering" (Kleinman 1988: 3). This has led to confusion about the expertise of the patient in relation to the medical profession, as the patient's experience of symptoms has always been crucial for the doctor and the diagnosis. Williams (2000: 137) argues that "lay perspectives did contain impressively sophisticated epidemiological models and medical 'histories'". When people who had polio returned to doctors with PPS symptoms, they were not understood any more than they had been as children, partly because polio had disappeared from medical knowledge and partly because it had never been fully understood originally. The public medical story of polio, for both doctors and the public, was a story of overcoming paralysis, not subjective symptoms, like fatigue and loss of stamina. The narrative of the symptom in the context of everyday life, a combination of the voices of medicine and the lifeworld, can give concrete meaning to the ephemeral nature of the subjective. Instead, people with subjective symptoms are strictly categorised as having an organic disease, and therefore becoming a tragic victim, sufferer, or hero; or having medically unexplained symptoms, suggesting malingering, lying, exaggerating, ageing, or depression. Both categories are outside normal life, and are not allowed to merge and join the ordinary and everyday.
This study has brought together medical and social research to demonstrate the complexity of polio and its aftermath, the paradoxes for both doctors and patients, and the way people succumbed to and resisted social stereotypes. Both doctors and patients combine the voices of medicine and lifeworld, exploring balances in the paradoxical situations they find themselves in. Doctors shift from certainty to uncertainty, judging their own beliefs, their colleagues' beliefs and the rationale of past medical paradigms about the meaning of subjective polio symptoms. Patients also puzzle over symptoms and lives. Everyone faces the dilemmas of needing independence and community, a measure of control and an openness to chance events, but these are much more accentuated for people who are disabled or chronically ill. Skultans (1999: 326) argues that "we will find that collective and individual memory are not so thoroughly interconnected ... but that they are involved in continual processes of coming together and moving apart over time." The collective polio, illness and disability stories of tragedy or heroism and of objective symptoms are a long way from individual experiences of feeling normal but different, dealing with fatigue or pain, and wanting to be ordinary. The collective stories of overcoming, whether stoical or emotional, may become too powerful, resulting in a need for more individual stories of early memories of broken dolls and blinds being pulled down, of not being understood, respected or cared for as human beings. Douglas (2002: 202) paraphrases William James that complete philosophies "must find some ultimate way of affirming that which has been rejected", and that sorrow, pain and death must be seen as having rational significance. Possibly the current cultural narrative of chronic illness is moving towards an 'ambivalent restitution' story which does merge the hero and victim and tells about ordinary lives of joy and sorrow.

11.4 Autoethnography

In the *Introduction*, I widened the subject of childhood illness and disability to other traumatic events, such as war, family deaths, and forced migration, because of puzzling resonances found in the literature. This literature and the interviews in this study reminded me of the silence around my own family's history of emigration from Russia. I also told fragments of my own illness narrative, and in concluding, I realise that these two stories do link up. The only way I can try to reconstruct the missing
parts of my story, before my memory, is to come from before and after that time with whatever information is available -- fragments of information from before that time, about my parents, their family histories and possible reasons for their silence, and later information from my own memory of my life and my illness narrative. I had to learn to ask questions I had never before conceived as questions. This became possible by thinking through the paradoxes of being disabled -- that people can know they are disabled but feel they are not, and that people could go through life not asking their parents about forgotten polio experiences. I had to learn how much these things do matter. I began to understand about the importance of people's biographies through the interviews. I could then think about how I had thought that the deaths of children in my parents' lives, my father's infant cousin who was shot by Russian border guards, my mother's two brothers who died in Russia, her brother who drowned, and her first child who died soon after birth, were just normal occurrences that did not have major effects. Reading the passage below from Ignatieff's *The Russian Album*, opened for me that these deaths matter and have always mattered, although Furedi (2004) argues that only recently has society become so emotional. Possibly, my mother's nameless brothers who died in Russia had no photographs because it mattered so much, and maybe that is why there was only one photograph of me between the ages of two and three.

"Her (his grandmother) memory must have marched her back again and again to that hotel bedroom in Eupatoria, to that empty cot. When the time finally came at the end of her life to put down what happened that summer of 1909, she did not write about it at all... Through all the waystations of the life to come, she kept just one little picture in a round silver frame on her night table: the smiling image of her dead child."  
(Ignatieff 1997: 85)

I then brought these ideas to stories of illness and disability in my life and tried to understand these silences and what I came to see as absences in my memories, of people becoming shadows and fading away when circumstances became difficult (see Appendix 10).

11.5 Conclusion: strengths, limitations and future research

Dealing with the difficult, emotional subject of the long-term effects of childhood illness, a subject often silenced and little researched, I did not expect easy, straightforward survey results or interviews. Nor did I expect the medical research to be anything but contradictory. However, people do tell stories, and the main strength of this study is that I was able to obtain, partly because of my own experiences, a wide range of stories from people who had had very varied experiences of long-term disability. Most narratives of
disability, in which the reader can empathise with someone who had paralysis or polio, have been autobiographies (Murphy 1990, Beisser 1989, Mee 1999). These are individual experiences, and it is rare to be able to compare the narratives of a wide range of men and women who had polio, and explore why so many said they never felt disabled and never wanted to mention the word 'polio'.

**Limitations of sample, time, and place**

A limitation of the study is that the sample was self-selected and obviously there are people who do not want to tell their stories at all, or do not want to take part in research and tell their stories to strangers. Some people who are interested in disability politics and the social model of disability do not think individual stories are helpful. People must protect themselves, and opening up the Pandora's box of past emotions may not seem a good idea. Research is intrusive, the analysis may not be comfortable for all respondents, and the future of the written analysis cannot be predicted (Barnard 2005, Hoskins and Stoltz 2005).

Although the respondents chose to take part in the study, there was still a feeling that I was only catching shadows -- that the ambivalence people felt meant that they would disconnect themselves from the interview and what they had said immediately afterwards. Sometimes minutes after something was said, the train of thought was lost and it was too late to go back. Some people had never thought and did not want to think about various aspects of their lives. When they received the transcripts, several men laughingly said they did not understand what they had been talking about. The shadow had already disappeared. But these are not necessarily weaknesses in that this fleeting interest is part of the past experience of having had polio. On the other hand, a few people did become interested in looking more closely at the past. Some were glad to finally tell their childhood story and carry on finding out and understanding more.

The interviews encompassed entire lives but were only able to capture them from one point in time. However, there were so many variations concerning when people had
11. Conclusion and discussion

polio, how old they were, how severely they were affected, and when they began to have PPS symptoms, that people were at many different points in their illness trajectory. Attending meetings, reading diaries and stories, and keeping in touch with interviewees over several years meant that the research also had a longitudinal element.

It may be seen as a limitation that there is no setting in which to observe people who had polio in a clinic or hospital, but they are rarely patients. The combination of seeing individual people in their homes with occasional visits to support group meetings may actually be a strength of the study in that people who had recovered well from polio were isolated from others for most of their lives, and only now, in the past few years, have a few small PPS groups begun to appear. Many people who had polio are resistant to the idea of PPS, reflecting the medical scepticism. This isolation from doctors and other people who had polio is an important part of their lives and story, and the stories of many disabled and chronically ill people. Atkinson (1997) argues that narratives are given a higher status in social research than warranted, but, in this case, there were few other options. It is also clear that many polio stories are still untold, and that the stories told in this study are incomplete, ambiguous, and could be interpreted in many ways.

Complexity and future research

Another strength and limitation of the study was the complexity of such long stories coupled with the paradoxical nature of being disabled, and the confusion caused by the silence about the past. Such complexity leads to more than the usual difficulties with multiple interpretations, and ethical questions about retelling these stories and how the respondents might be affected. It may be for this reason that there are very few studies of childhood illness seen from adulthood, leaving the field unexplored. A strength of this complexity is that it might lead to a deeper understanding of some of the paradoxes surrounding the experience of illness, and could suggest new directions for future research. Two basic directions in which related research could move are to widen the exploration of long-term illness experience, and to further the understanding of subjective symptoms and medical attitudes to symptoms. In relation to the medical profession, the
aim of this research would be to explore the divide between 'real' and psychosocial symptoms, a schism which accelerated with work such as that by Balint (1957) and Berger and Mohr's (1969) portrait of a doctor, although their intentions were different. One of Berger and Mohr's (1969: 109) messages was that the doctor is "the clerk of their records", even those that are hidden, but what if the doctor has not understood? The purpose of research which moves on from this study is to clarify the patient's experience of subjective symptoms and explore doctors' attitudes to the after-effects of illness so that the doctor might "listen more precisely, which in turn may enhance her competence in diagnosis and management of symptom-based conditions" (Malterud and Bærheim 1999: 52).

Relating to the first research direction, long-term illness experience, follow-up studies of the participants could widen the study by exploring their developing narratives and how memories may change in meaning over time. By combining this study with other biographical chronic illness studies, it may be possible to make some generalisations to other childhood illnesses with after-effects. This idea could be enlarged by researching more common illnesses with after-effects such as stroke, meningitis or spinal injury. Another direction for future research, which would also extend this research to the present time, would be a generational study of the effects of illness or its after-effects on people who had polio (or another illness or disability), their parents, siblings, and their children. Generational research could also be used to study the interface between disabled and able-bodied people, and be extended to partners and friends. Studying families could lead to work on the relationships between different life disruptions, such as other chronic illnesses or deaths in families, divorce or emigration.

The second direction for future research is through the medical story of PPS and controversies surrounding contested illnesses and could involve interviewing doctors about their choice of specialty and comfort with uncertainty and subjective symptoms. Doctors would be chosen from specialties with different levels of certainty, such as neurologists, orthopaedic surgeons and GPs, or doctors who have committed themselves to one side or another of a controversy. An exploration of patients' experiences with the
medical profession about the subjective after-effects of illnesses or disabilities such as spinal injury, stroke or meningitis could compare both medical attitudes to symptoms and different illnesses. For instance, if patients have symptoms which are considered psychosomatic, do they receive inferior care for new unrelated symptoms? These studies may help bridge the gap of understanding between doctor and patient which is not about lack of time but about careful listening and acknowledging symptom experiences.

These research ideas concentrate on certain groups of illnesses, because there is a lack of understanding concerning the subjective after-effects of illnesses or injuries that may be considered static or cured. Subjective symptoms generate a great deal of controversy in relation to work, disability benefits and the stigma and lack of legitimation experienced. Without understanding the more subtle aspects of the social discomfort about impairment and symptoms, and the physical problems people experience, it will be difficult to solve these controversies. This thesis has attempted to "give complexity an articulate form" (Frank 2004: 438) -- the complexity of the physical and social problems people face, and the solutions or balance they find in living with long-term chronic illness or disability.
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Appendix 1: Postpolio survey 2002

Dear

I am sending out this postpolio survey to anyone who took part in my previous postpolio questionnaire (winter 2000), contacted me about the results of that questionnaire, or answered my recent advertisement in the British Polio Fellowship Bulletin about my new research. This new study is part of a PhD in the School of Social Sciences at Cardiff University (Economic and Social Research Council funded), and will later include approximately 30 interviews about experiences of polio and postpolio syndrome (PPS). My interest in PPS (which I also have) is to clarify the symptoms and see if there are different symptom patterns in people of different ages and genders, and how these may have affected people's lives.

The survey is for anyone who has had polio, whether they have new symptoms or not. It does not matter whether you have had a diagnosis of PPS. One purpose of the survey is to see what symptoms and problems people feel relate to polio, regardless of medical definitions.

The survey looks at the initial polio, stable period and later symptoms, their severity and extent. The stable period refers to the period between recovery and the beginning of PPS. If anything is confusing or seems incomplete, feel free to comment in the margin or write your experience at the end or on a separate sheet of paper. Polio is so variable that it is impossible to cover all experiences. Check that you have answered all the relevant questions. For instance, if you have muscle pain, remember to also answer the question asking where you have pain (even if it is mild or occasional). If you received the questionnaire by email you can print it out and return it or fill it in on the computer.

Thank you very much for taking part in this study, which I hope may have some effect on the recognition and understanding of PPS. If you have any questions, feel free to contact me.

If you are willing to be contacted in the future for any follow-up or interviews, please write your details below. These details will remain confidential.

Yours sincerely,

Ruth Bridgens

name

telephone

e-mail

Please return questionnaire and cover letter to: Ruth Bridgens, 66 High St., Marshfield, Chippenham, Wilts SN14 8LP tel 01225 891216 email pb.rb@virgin.net
Postpolio survey 2002

This questionnaire is designed to find out more about postpolio symptoms and their severity. Please ☐ the appropriate boxes. In a few questions, a written response or number is required. Please feel free to write comments if anything is not clear or if you want to add categories.

Sex: Male ☐ Female ☐ In what year did you have polio? _______ How old were you when you had polio? _______

Initial polio and recovery
Did you have nonparalytic polio (no obvious weakness or paralysis during the initial illness)  yes ☐ no ☐

Indicate below the extent and severity of your weakness or paralysis during the initial polio, and at the time of maximum recovery. If you had nonparalytic polio, but felt mild weakness, especially during activity, tick the 'mild' column below.

<table>
<thead>
<tr>
<th></th>
<th>Initial Polio</th>
<th>Recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>right arm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>left arm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>right leg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>left leg</td>
<td></td>
<td></td>
</tr>
<tr>
<td>back</td>
<td></td>
<td></td>
</tr>
<tr>
<td>chest</td>
<td></td>
<td></td>
</tr>
<tr>
<td>abdomen</td>
<td></td>
<td></td>
</tr>
<tr>
<td>breathing</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Were you hospitalised during the initial polio?  yes ☐ no ☐ don't know ☐ If known, how long for? _______ months

Did you use mobility aids after recovery from the initial illness?  yes ☐ no ☐ If yes, tick the appropriate boxes.
wheelchair ☐ crutches ☐
calliper/s ☐ walking stick/s ☐
If you stopped using mobility aids at some stage, how old were you then? _______

Symptoms during stable period (the period between recovery and the beginning of PPS)
Did you have fatigue or concentration problems during the stable period?  yes ☐ no ☐ not sure ☐
Did you have muscle fatigue (increased weakness or aching after activity) during the stable period?  yes ☐ no ☐ not sure ☐
Did you have muscle pain during the stable period?  yes ☐ no ☐ not sure ☐

How physically active were you during the stable period? (tick one)
took part in strenuous sports or physical work ☐
gentle sport or moderate activity (gardening, housework) ☐
daily living activities only ☐

Current symptoms
What do you consider to be your new polio-related symptoms? _____________________________

New weakness
Weakness is a constant lack of strength, whereas muscle fatigue causes weakness or aching to increase over time
in affected muscles ☐ in unaffected muscles ☐

New fatigue
Do you have new or increased general fatigue?  yes ☐ no ☐ not sure ☐
Do you have new mental fatigue?  yes ☐ no ☐ not sure ☐
Is fatigue constant?  yes ☐ no ☐ not sure ☐
Do you sometimes get a fatigue that is totally draining, so that you feel you must stop whatever you are doing?  yes ☐ no ☐ not sure ☐
Is your fatigue caused by activity and relieved by rest? [yes □ no □ not sure □]
Do you have problems with concentration? [yes □ no □ not sure □]
Do you have problems with depression? [yes □ no □ not sure □]

Could you describe your fatigue, whether mental, physical or both? Continue on last page if required

On average, would you classify your fatigue as: mild □ moderate □ severe □

New muscle fatigue
Do you have new or increased muscle fatigue? [yes □ no □ not sure □] If yes, tick the appropriate boxes.
in affected muscles □
unaffected muscles □
Could you describe your muscle fatigue (how it feels and activities that cause it)? Continue on last page if required

New muscle pain
Do you have new or increased muscle pain (or aching)? [yes □ no □ not sure □] If yes, tick the appropriate boxes below.
in affected muscles □ in unaffected muscles □
mostly after activity □ constantly □
Do you take medication for muscle pain regularly? [yes □ no □]

Severity of symptoms
This refers to new differences in symptoms, even if the problem is only occasional.
Tick the appropriate boxes below to classify new muscle pain, muscle fatigue, and muscle weakness:

<table>
<thead>
<tr>
<th>Muscle Pain</th>
<th>Muscle Fatigue</th>
<th>Muscle Weakness</th>
</tr>
</thead>
<tbody>
<tr>
<td>neck</td>
<td></td>
<td></td>
</tr>
<tr>
<td>right arm or shoulder</td>
<td>□ □ □</td>
<td></td>
</tr>
<tr>
<td>left arm or shoulder</td>
<td>□ □ □</td>
<td></td>
</tr>
<tr>
<td>upper back</td>
<td>□ □ □</td>
<td></td>
</tr>
<tr>
<td>chest</td>
<td>□ □ □</td>
<td></td>
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<tr>
<td>abdomen</td>
<td>□ □ □</td>
<td></td>
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<tr>
<td>lower back</td>
<td>□ □ □</td>
<td></td>
</tr>
<tr>
<td>right leg</td>
<td>□ □ □</td>
<td></td>
</tr>
<tr>
<td>left leg</td>
<td>□ □ □</td>
<td></td>
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</tbody>
</table>

Other new or increased symptoms Please tick the appropriate boxes below.

<table>
<thead>
<tr>
<th>Tripping or falling</th>
<th>Disturbed sleep</th>
<th>Waking with headache</th>
<th>Breathing problems</th>
<th>Cold intolerance</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes □ no □ not sure □</td>
<td>yes □ no □ not sure □</td>
<td>yes □ no □ not sure □</td>
<td>yes □ no □ not sure □</td>
<td>yes □ no □ not sure □</td>
</tr>
</tbody>
</table>

Functioning
Do you use mobility aids now? [yes □ no □] If yes, tick the appropriate boxes below.

<table>
<thead>
<tr>
<th>Manual wheelchair</th>
<th>Crutches</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes □ no □</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Electric wheelchair</th>
<th>Walking stick/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes □ no □</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scooter</th>
<th>Calliper/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes □ no □</td>
<td></td>
</tr>
</tbody>
</table>

Does activity increase symptoms? [yes □ no □ not sure □] which symptoms

Does stress increase symptoms? [yes □ no □ not sure □] which symptoms
Are you working full-time? □  working part-time □  
retired □  retired due to disability □  
not working □

In which year (approximately) did your new symptoms first begin? ______
Did anything seem to trigger the beginning of new symptoms? ________________________________

If you took part in my previous BPF post-polio survey (January 2000), have your symptoms become more severe since then? yes □  no □  not sure □
Which symptoms? __________________________________________________________

Do you have any other chronic illnesses (such as asthma, diabetes, high blood pressure)? yes □  no □
Which ones? __________________________________________________________

Did you introduce PPS to your GP? yes □  no □
Does your GP accept that your new symptoms relate to polio or PPS? yes □  no □  don't know □
Do you feel that people (family, friends, acquaintances) accept and believe your symptoms? yes □  no □  don't know □

Use this space or another sheet if you would like to add additional comments about your polio experiences or PPS symptoms.

Thank you for taking part in this questionnaire.
Please return to: Ruth Bridgens, 66 High St, Marshfield, Chippenham, Wilts SN14 8LP or email pb.rb@virgin.net
Appendix 2: Survey categories and symptom criteria

**Polio weakness:** (initial illness and recovery): a chart was divided into 8 body areas with choice of mild/moderate/paralysis (summaries: calculation of totals i.e. if someone ticked mild weakness of right leg (1) and paralysis of left leg (3) the summary would be (4)

1. mild weakness
2. moderate
3. paralysis

**Initial polio severity and recovery level used summaries of weakness**

**Polio severity:**
- 0-6 mild polio
- 7-12 moderate polio
- 12- severe polio

**Polio recovery:** based on a subtraction of the recovery summary from the initial polio summary and how the person was affected (whether they needed crutches, braces or wheelchair)
- **Low:** use of mobility aids unless severe initial illness or very mild initial illness (severe with wheelchair, very mild with remaining weakness)
- **Moderate:** severe initial illness with calipers, moderate initial illness with aids for short period or no aids with paralysis, mild initial illness with remaining paralysis or weakness
- **High:** from no use of aids to normal

**PPS:** extent of pain, muscle fatigue, weakness
A chart was divided into 9 body areas with choice of mild/moderate/severe symptom of (summaries: calculation of totals)

1. mild
2. moderate
3. severe

**Number of symptoms (out of 10 common symptoms):**
1. weakness
2. draining fatigue
3. muscle fatigue
4. muscle pain
5. constant pain
6. joint pain
7. swallowing problems
8. sleep disturbance
9. breathing problems
10. cold intolerance
Appendix 3: Clinician survey letters

Dear Dr

As part of an ESRC funded PhD in medical sociology at Cardiff University in the School of Social Sciences, I am writing to doctors in different hospital specialties about their knowledge of the late effects of polio or postpolio syndrome. The PhD is concerned with patients' experiences of polio and postpolio syndrome and with how medical categories and definitions evolve. The study has involved a questionnaire about polio and postpolio symptoms, which was advertised in the British Polio Fellowship Bulletin, and 30 interviews with people who had polio at different ages and with different severity. As there are conflicting opinions about postpolio syndrome and whether there is progressive muscle weakness, I would be interested in your views.

Specifically, I would be extremely grateful if you could fill in the following. Your response will remain completely anonymous.

Do you have any knowledge of postpolio syndrome?
If you do, how would you define it?

What do you recognise as the symptoms?

What do you think are the causes of these symptoms?

Thank you.

Yours sincerely,

Ruth Bridgens
Dear Dr

As part of an ESRC funded PhD in medical sociology at Cardiff University in the School of Social Sciences, I am writing to doctors in different hospital specialties about their knowledge of the late effects of polio or postpolio syndrome. The PhD is concerned with patients' experiences of polio and postpolio syndrome and with how medical categories and definitions evolve. The study has involved a questionnaire about polio and postpolio symptoms, which was advertised in the British Polio Fellowship Bulletin, and 30 interviews with people who had polio at different ages and with different severity.

Having acquired your name from the British Polio Fellowship Bulletin, I am writing to ask about your understanding of the late effects of polio or 'postpolio syndrome'. Specifically, I would be extremely grateful if you could fill in the following. Your response will remain completely anonymous.

How do you define postpolio syndrome?

What do you recognise as the symptoms?

What do you think are the causes of these symptoms?

Thank you.

Yours sincerely,

Ruth Bridgens
Appendix 4: survey results

Postpolio survey (Spring 2002)

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
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<tbody>
<tr>
<td>Number of participants (SPSS analysis)</td>
<td>160</td>
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<tr>
<td>Men</td>
<td>37%</td>
</tr>
<tr>
<td>Women</td>
<td>63%</td>
</tr>
<tr>
<td>Polio year (mean)</td>
<td>1947</td>
</tr>
<tr>
<td>Polio age (range 1 month-36 years)</td>
<td>8.24</td>
</tr>
<tr>
<td>Age (44-88 years)</td>
<td>63</td>
</tr>
</tbody>
</table>

Polio severity and gender

In total, 170 people completed the survey, and 160 were analysed on SPSS. The demographic and polio details were similar to other similar PPS surveys (Cosgrove et al 1987, Trojan et al 1994). Post polio surveys, other than population surveys, often have a predominance of women in a similar proportion to the current study (Trojan et al 1994, Schanke 1997, Berlly 1991). In this survey, women had more severe polio than men, and more widespread weakness, with more having affected arms (see Appendix 2 for method of measuring the acute polio severity and recovery and symptom severity). More women were affected in every one of the eight body areas used in the survey, except for the right leg, in which men and women were equal (73% and 74%), and the differences were all in the most severe category, paralysis (rather than moderate or mild weakness). For instance, 31% of men were affected in the right arm and 51% of women. This broke down to 11.9% of men having a paralysed right arm (38% of total affected) and 35.6% of women (70% of total affected). In his study of 618 polio patients, Weinstein (1957) found that up to the age of 15, of those in the mild group (one leg paralysed), 70.2% were men, and 29.8% were women. In older people the percentages were reversed.

Symptoms during the stable period (between the initial polio and PPS)

After the initial polio, many patients were left with some residual paralysis and weakness, often very scattered. Less acknowledged were the remaining stamina problems, fatigue and muscle pain. Only one PPS study asked patients about symptoms other than weakness during the stable period, and 58% had either fatigue or other muscular symptoms (Ivanyi et al 1999). In the current survey, people were asked whether they had fatigue, muscle fatigue or muscle pain during the stable period, and 56% had at least one symptom. The most common of the three symptoms was muscle fatigue (48%). Looking at the group who had at least one symptom, there was little variation by polio severity (the most severe group had a slight increase), but there was a gender difference, 44% of men having had one of the symptoms during the stable period, and 63% of women.

Examining polio age, the youngest and eldest more often had symptoms (60% and 67%), while 48% of the middle age group (3-12 years) had symptoms.

Polio severity, polio age, recovery and PPS risk

In this study, polio was severer at higher ages, as is generally the case. The difference between initial severity and recovery was much greater with severe illness. Those with a
mild illness had much less recovery (mild polio 86.2% low recovery, severe polio 22.8% low recovery). There has been confusion over the relationship of recovery to PPS risk, Klingman et al (1988) finding high recovery an important risk factor in a group with relatively severe polio, and Ramlow et al (1992) finding residual impairment a risk factor in less severe cases (discussed in Chapter 3). As PPS was initially conceptualised as new weakness, research has not concentrated on whether gender or polio severity influenced the overall pattern of symptoms.

PPS symptoms

PPS symptoms were generally more severe in women. Women and those who were young when they had polio had more symptoms. Using a list of 10 major symptoms (see Appendix 2), men had a mean of 6.2 symptoms and women 7.5. In the different age groups, the youngest had 7.1, the middle group 6.6, and the eldest 5.6. These figures were affected by the low number of symptoms in men who were older when they had polio. Women who had severe polio had the most severe symptoms, while men who were severely affected had the same or less severity of symptoms than other groups. Those who had a mild illness, both men and women, often had more severe symptoms than the severely affected men.

Differences were mainly found in fatigue and pain. As most people had some fatigue, another category was added called ‘draining fatigue’, which was described as an occasional fatigue which made the person have to stop any activity. This occurred in 76% of men and 93% of women. In those who had polio as children (0-12 years), 91% experienced draining fatigue and in the older group, 74%, even though the older group had more severe polio. However, in the older group 50% of men and 91% of women replied positively to draining fatigue. In the youngest group (0-2 years), both sexes had at least 90% fatigue. A similar relationship existed with muscle pain: men (78%), women (92%); in the mild cases it is men (85%), women (100%). In the age groups it was: 0-2 years (96%), 3-12 years (83%), 13+ (74%).

There were also large discrepancies between some of the other symptoms, many of which are more systemic rather than local, and sometimes relate to polio brain stem or cranial nerve damage, such as swallowing problems, sleep disturbance, and cold intolerance. These were again more common in women and the younger polio age group. There were several symptoms that were different between polio age groups (children and adults) but not between the genders. These were mental fatigue, concentration problems, depression and joint pain, all higher in those who were children. When just the mild cases are looked at, the male and female differences remain. As all the cases in the mild group had less affected areas originally, it is all the more striking that in initially unaffected areas women have significantly more weakness (65% men and 84% women) and pain (54% and 78%), indicating that women had more widespread initial damage at all levels of polio severity.

In the total postpolio pain summary (severity and extent of pain, see Appendix 2 for explanation), the largest differences were between the sexes and between the polio ages in men, younger men having more pain. The summaries were also higher in those under
60 and in men who had polio after 1950. These men also had more postpolio weakness than men who had polio before 1950, although their severity and recovery from initial polio was similar. The interval between initial polio and PPS was similar in all groups except the year (date of polio) groups. The gap varied from 56 years (polio before 1940) to 37 years (polio after 1950). The muscle fatigue and weakness summaries did not differ much by polio age, but did differ substantially by sex and by severity of polio and sex (women with all levels of polio severity had higher muscle fatigue and weakness than men, with severe polio having the highest levels). However, I think it is significant that there is so little difference in all the PPS severity and extent summaries by polio age, because polio was more severe in those who were older. The weakness summary does rise with age and weakness is the symptom that defines more severe polio. Some research does indicate that pain does not correlate with weakness and is more common in less affected muscles (Farbu et al 2003), which is reflected in the summary. More research should focus on explaining the similarities of severity and extent of PPS symptoms in those of different ages and different polio severity in order to understand both polio and PPS.

Survey of doctors

As a way of validating the interviewees' experiences with doctors about PPS, and obtaining an indication of how hospital consultants in the UK define and understand PPS, I sent a letter to a selection of doctors asking how they defined PPS, what they recognised as symptoms and what they thought caused the symptoms (see Appendix 3). Consultants were chosen from the British Polio Fellowship list of interested consultants, or from hospital internet sites. Nine doctors were chosen from the BPF list, eight from hospital websites, and three doctors who run clinics that see PPS patients were written to individually, in relation to their work on PPS. The doctors from the BPF list consisted of 5 neurologists, 1 orthopaedic surgeon, 1 rehabilitation specialist, 1 neurology rehabilitation specialist and 1 homoeopathic consultant. Three neurologists, 1 rehabilitation specialist, 1 neurology rehabilitation specialist and the homoeopathic consultant replied (6/9 replied). The other doctors were 6 neurologists, one neurology rehabilitation specialist and one orthopaedic surgeon. Three neurologists and one neurology rehabilitation specialist replied (4/8 replied). The three consultants from PPS clinics replied. Two are respiratory physicians and one is a rehabilitation specialist.

The randomly chosen consultants had fairly similar replies to the questions, defining PPS as a progressive motor disability, or deterioration in function, with weakness as the only symptom. One doctor mentioned wasting and fasciculations as well. Causes for the deterioration were considered to be age-related neuronal death and damage. Consultants from the BPF list had more varied replies. Definitions related to neurological dysfunction years after having polio. Symptoms were quite varied, two mentioning only functional deterioration, others mentioning fatigue, pain, fasciculations, respiratory problems, joint disease, and nerve entrapments. One neurologist listed two forms of PPS, a rare progressive loss of motor neurons, and a chronic fatigue-like form including pain, spasms and poor concentration. Causes were also varied, most commonly age-related
changes combined with previously damaged motor neurons, accelerated ageing, and late effects of previous brain stem encephalitis.

The division between the two groups was instructive. The randomly chosen consultants had a more narrow view of the symptoms, recognising only muscle weakness, and the cause was often related to age. The BPF list consultants had a wide range of ideas about various symptoms, and separated ageing from the effects of early neuronal death and poorly functioning damaged neurons. Two of these doctors however, only mentioned orthopaedic problems or "a mix of musculoskeletal, neurological and respiratory pathology." Another two mentioned recent neuronal death, which is the other end of the spectrum from believing that symptoms are mainly orthopaedic and result only from the original damage.

In one letter to a consultant running a PPS clinic, I asked about previous research from the clinic which concluded that postpolio problems were mostly orthopaedic or arthritic, and whether views had changed since then. He answered, "I am well aware that there remain a group of patients for whom late functional deterioration is not so explainable and for some appears to be progressive. I am convinced that the syndrome exists (new muscle weakness, fatigue and myalgia) but it is obviously difficult when there is no diagnostic test and where emotional factors are so important." The second consultant, in rehabilitation, has conducted a local survey and spoken at PPS support group meetings, and I asked him how he explained muscle fatigability. He replied that he tested muscle strength before and after the patient walked around the hospital, and he believed that "the origins are mainly central, ie brain, rather than peripheral ie nerve or muscle". The third consultant had written an article about PPS, describing muscle fatigue as the most important symptom after weakness and I also asked him what he thought caused the muscle fatigue. He answered that he felt it was both peripheral, that "the lower motor neurons appear to become metabolically incapable of supporting these large motor units in the long term" and central, probably involving "the basal ganglia as both motor and sensory coordinators and while it is feasible that there may be direct damage to the basal ganglia during the acute infection, it is more likely that the sensory and motor input to the basal ganglia from the abnormally large motor units contribute in some way to the sensation of fatigue." This theory of constant back and forth communication between deteriorating muscle and brain (possibly damaged or not) leading to muscle fatigue seems to make sense of the complex descriptions people give of interrelated muscle, general and mental fatigue.
Appendix 5
Postpolio survey (2002)

Demographic details

<table>
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<tr>
<th>Number</th>
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<tbody>
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<td>Age (mean)</td>
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<tr>
<td>Polio age (mean)</td>
<td>8.24</td>
</tr>
<tr>
<td>Polio year (mean)</td>
<td>1947</td>
</tr>
</tbody>
</table>

Frequency of the initial polio weakness and PPS symptoms by gender and polio age

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total</th>
<th>Sex</th>
<th>Sex (mild polio)</th>
<th>Polio age (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>male</td>
<td>female</td>
<td>male</td>
<td>female</td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
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</table>

Initial polio weakness (% of sex or polio age group)

<table>
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<tr>
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<th>Female</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right arm</td>
<td>44</td>
<td>31</td>
<td>51</td>
<td>19</td>
<td>9</td>
<td>22</td>
<td>46</td>
<td>67</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left arm</td>
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<td>34</td>
<td>57</td>
<td>19</td>
<td>37</td>
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<td></td>
<td></td>
</tr>
<tr>
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<td>73</td>
<td>74</td>
<td>58</td>
<td>50</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Left leg</td>
<td>78</td>
<td>73</td>
<td>81</td>
<td>50</td>
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<td>84</td>
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<tr>
<td>Breathing</td>
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<td>9</td>
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</table>

Selected PPS symptoms (% of sex or polio age group)

<table>
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<tr>
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<th>Male</th>
<th>Female</th>
<th>Male</th>
<th>Female</th>
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<td>31</td>
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<td>77</td>
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<td>35</td>
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<td>38</td>
<td>78</td>
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<td>70</td>
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<td>46</td>
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<tr>
<td>Joint pain</td>
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<td>77</td>
<td>84</td>
<td>90</td>
<td>84</td>
<td>69</td>
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</tbody>
</table>

1 stress/symptoms = symptoms increase with stress
2 stable symptoms = muscle pain, muscle fatigue or fatigue during stable period before PPS

Extent of PPS pain, muscle fatigue and weakness (mean number of nine body areas)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Male</th>
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<th>Male</th>
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Appendix 6

Sample: place and date of interview and factors relevant to choice of respondents

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Totals

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<th>M = 11</th>
<th>&lt;6 years = 17</th>
<th>&lt;60 = 16</th>
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<td>F = 20</td>
<td>&gt;6 years = 14</td>
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Appendix 7

Interview guide: how have polio and PPS affected your life?

Before the interview starts the purpose of the research project will be described and anonymity will be discussed.

_Could you tell me about your life and how it has been affected by polio and postpolio symptoms?_  
For those who remember, start with asking them if they could tell me something about themselves before they had polio.

1. Initial polio

**Hospital stay:** how you felt (physically, emotionally), family feelings and staff attitudes  
*How did your family treat you (react to polio, disability)?? Memories, stories?*

**Treatment:** recovery, length of time in hospital, physiotherapy and exercise, disability, remaining symptoms (how you felt and others), energy?  
Did you feel you would recover completely (through exercise or operations) and when did you realise you wouldn't? What about your parents?  
*Did you think of yourself as disabled?  
Were you encouraged to ignore discomfort (was there any) and do everything?  
After you recovered from polio, were you able to talk about it to anyone? (Parents, family, friends, doctors)*

2. Stable period: parents attitude, friends, denial by yourself and others  
concentration problems, things you couldn't do, tiredness, symptoms

**School/job/family:** how choices made, was disability factor in choices, others behaviour  
did you feel disabled, ignore pain, talk about polio, problems with energy, stamina, attitudes to exercise, work ethic

3. PPS symptoms: did you recognise them as symptoms at first, reactions of others, did a certain incident make you realise your weakness (or whatever) was more than the old polio, what brings the symptoms on or makes them worse, can you describe the symptoms, experiences with medical profession, effect of earlier illness, can you talk about the symptoms with anyone

**less easily described symptoms:** sleep, stamina, concentration, fatigue (mental, general)
### Appendix 8

#### Interviewee details

<table>
<thead>
<tr>
<th>Name</th>
<th>Birth</th>
<th>Polio year</th>
<th>Polio age</th>
<th>Survey age</th>
<th>Marital status</th>
<th>Children</th>
<th>Education</th>
<th>Occupation</th>
<th>Work status</th>
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<td>Nurse/midwife</td>
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<td>Walking stick/caliper</td>
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</tr>
<tr>
<td>Beth</td>
<td>1928</td>
<td>1949</td>
<td>21</td>
<td>74</td>
<td>2 legs (p), 1 arm (p), back, other (w)</td>
<td>Same</td>
<td>Weakness, pain, stamina</td>
<td>Electric wheelchair/calipers</td>
<td></td>
</tr>
<tr>
<td>Clare</td>
<td>1937</td>
<td>1940</td>
<td>3</td>
<td>65</td>
<td>1 leg (paralysis), 1 leg (weak)</td>
<td>Same</td>
<td>All severe</td>
<td>Crutches/wheelchair</td>
<td></td>
</tr>
<tr>
<td>Cynthia</td>
<td>1918</td>
<td>1937</td>
<td>18</td>
<td>84</td>
<td>2 legs (paralysis)</td>
<td>Same</td>
<td>Severe weakness</td>
<td>Wheelchair/calipers</td>
<td></td>
</tr>
<tr>
<td>Daniel</td>
<td>1937</td>
<td>1938</td>
<td>18 months</td>
<td>65</td>
<td>1 leg (paralysis)</td>
<td>1 leg (weak)</td>
<td>Mild PPS</td>
<td>Walking stick</td>
<td></td>
</tr>
<tr>
<td>Deborah</td>
<td>1948</td>
<td>1949</td>
<td>18 months</td>
<td>54</td>
<td>1 arm (paralysis)</td>
<td>1 arm (paralysis)</td>
<td>Pain, weakness</td>
<td>Crutches/wheelchair</td>
<td></td>
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<tr>
<td>Edith</td>
<td>1935</td>
<td>1943</td>
<td>8</td>
<td>68</td>
<td>1 leg (paralysis)</td>
<td>1 leg (weak)</td>
<td>Fatigue, stamina</td>
<td>Walking sticks/scooter</td>
<td></td>
</tr>
<tr>
<td>Elizabeth</td>
<td>1932</td>
<td>1957</td>
<td>25</td>
<td>70</td>
<td>Scattered weakness</td>
<td>Mild scattered weakness</td>
<td>Weakness, stamina</td>
<td>Walking stick/scooter</td>
<td></td>
</tr>
<tr>
<td>Helen</td>
<td>1950</td>
<td>1954</td>
<td>4</td>
<td>52</td>
<td>2 legs (p), back, other (w)</td>
<td>Same, improved</td>
<td>Fatigue</td>
<td>Walking stick</td>
<td></td>
</tr>
<tr>
<td>Jan</td>
<td>1930</td>
<td>1938</td>
<td>8</td>
<td>73</td>
<td>Nonparalytic</td>
<td>Mild weak legs</td>
<td>Fatigue, stamina</td>
<td>Walking stick/scooter</td>
<td></td>
</tr>
<tr>
<td>Jack</td>
<td>1937</td>
<td>1954</td>
<td>17</td>
<td>66</td>
<td>2 legs (p), 2 arms, other (w)</td>
<td>2 legs (weak)</td>
<td>Leg weakness, fatigue</td>
<td>Walking sticks/calipers (indoors)</td>
<td></td>
</tr>
<tr>
<td>Jane</td>
<td>1936</td>
<td>1947</td>
<td>11</td>
<td>66</td>
<td>2 legs (p), back (w)</td>
<td>Same, improved</td>
<td>Weakness</td>
<td>Walker</td>
<td></td>
</tr>
<tr>
<td>Jennie</td>
<td>1945</td>
<td>1950</td>
<td>5</td>
<td>57</td>
<td>Total paralysis</td>
<td>2 legs, back (weak)</td>
<td>Fatigue, weakness, stamina</td>
<td>Walking stick/ wheel chair</td>
<td></td>
</tr>
<tr>
<td>Joanna</td>
<td>1945</td>
<td>1956</td>
<td>11</td>
<td>58</td>
<td>Total paralysis</td>
<td>1 leg, 1 arm (p), back (w)</td>
<td>All severe</td>
<td>Crutches/electric wheelchair (indoors)</td>
<td></td>
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<tr>
<td>Jonathan</td>
<td>1951</td>
<td>1956</td>
<td>5</td>
<td>52</td>
<td>Total paralysis, iron lung</td>
<td>2 arms, back (w)</td>
<td>All, breathing</td>
<td>Occasional wheelchair</td>
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<tr>
<td>Ken</td>
<td>1939</td>
<td>1940</td>
<td>9 months</td>
<td>63</td>
<td>2 legs (paralysis)</td>
<td>1 leg (weak)</td>
<td>All</td>
<td>Walking stick</td>
<td></td>
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<tr>
<td>Lauren</td>
<td>1946</td>
<td>1947</td>
<td>14 months</td>
<td>57</td>
<td>2 legs (p), back, other (w)</td>
<td>2 legs, other (weak)</td>
<td>All moderate</td>
<td>Walking sticks/scooter/wheelchair</td>
<td></td>
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<tr>
<td>Mark</td>
<td>1953</td>
<td>1958</td>
<td>5</td>
<td>49</td>
<td>1 leg (paralysis)</td>
<td>1 leg (weak)</td>
<td>Weakness (mild PPS)</td>
<td>Crutches</td>
<td></td>
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<tr>
<td>Matthew</td>
<td>1956</td>
<td>1958</td>
<td>18 months</td>
<td>47</td>
<td>2 legs (p), other (w)</td>
<td>2 legs (weak)</td>
<td>Pain, breathing</td>
<td>Crutches</td>
<td></td>
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<tr>
<td>Michael</td>
<td>1948</td>
<td>1950</td>
<td>2</td>
<td>54</td>
<td>Right side paralysis, other (w)</td>
<td>Scattered weakness</td>
<td>Fatigue, weakness, stamina</td>
<td>Crutches/caliper</td>
<td></td>
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<tr>
<td>Nick</td>
<td>1931</td>
<td>1933</td>
<td>2</td>
<td>72</td>
<td>2 legs, 1 arm (paralysis)</td>
<td>1 leg (paralysis)</td>
<td>Pain, weakness</td>
<td>Crutches/caliper</td>
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<tr>
<td>Pat</td>
<td>1935</td>
<td>1939</td>
<td>4</td>
<td>67</td>
<td>Nonparalytic</td>
<td>1 leg (weak)</td>
<td>Fatigue, pain</td>
<td>Walking stick</td>
<td></td>
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<tr>
<td>Peggy</td>
<td>1934</td>
<td>1948</td>
<td>14</td>
<td>68</td>
<td>1 arm, 1 leg (p), other (w)</td>
<td>1 arm, leg, other (weak)</td>
<td>Fatigue, weakness</td>
<td>Crutches/electric wheelchair/caliper</td>
<td></td>
</tr>
<tr>
<td>Polly</td>
<td>1950</td>
<td>1958</td>
<td>8</td>
<td>53</td>
<td>1 leg, 1 arm, back (p), other (w)</td>
<td>Back, other (weak)</td>
<td>Pain, stamia, weakness</td>
<td>Electric wheelchair</td>
<td></td>
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<tr>
<td>Rebecca</td>
<td>1915</td>
<td>1915</td>
<td>5 months</td>
<td>88</td>
<td>1 leg (paralysis)</td>
<td>Same</td>
<td>Fatigue</td>
<td>Walking stick/caliper/walker</td>
<td></td>
</tr>
<tr>
<td>Sarah</td>
<td>1952</td>
<td>1954</td>
<td>2</td>
<td>50</td>
<td>1 leg (p), other (w)</td>
<td>1 leg (weak)</td>
<td>Fatigue, stamia</td>
<td>Crutches/electric wheelchair/caliper</td>
<td></td>
</tr>
<tr>
<td>Sue</td>
<td>1950</td>
<td>1959</td>
<td>9</td>
<td>53</td>
<td>Nonparalytic</td>
<td>Weak left side</td>
<td>All severe</td>
<td>Crutches/scooter</td>
<td></td>
</tr>
<tr>
<td>Wendy</td>
<td>1940</td>
<td>1960</td>
<td>20</td>
<td>62</td>
<td>Total paralysis, iron lung</td>
<td>2 arms, other (weak)</td>
<td>Leg weakness, stamia</td>
<td>Electric wheelchair</td>
<td></td>
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Appendix 9: interviewees

Alex: 47, polio at 18 months, 1957, cared for at home, a farm in South Africa, began having operations at 4 and family moved to Cape Town, wore 2 leg braces and back brace until 17, has three brothers
Alex described having good memories of his family life but not of the attitude of his teachers. He also had several unsuccessful operations leaving him with more pain than he had had previously. He left school at 16 and worked first for a photographer and then in retail. He married and had two children. His career went very well, he moved into computer systems in multinational companies, and came to England in 1990. In 1998 he began falling and having extreme muscle pain and fatigue. He acquired an electric wheelchair so he could carry on working but was forced to retire in 2000. It was not until 2004 that he was able to get an adequate enough wheelchair assessment so that he had proper back support which has relieved his muscle spasms.

Alice: 57, polio at 12, in hospital for one month, had temporary paralysis of right leg with weakness in back, left leg and left arm, an only child
Alice was discharged early from hospital because her mother, a nurse, took charge of physiotherapy at home and she also went to a physiotherapist 3 times/week. This continued for three years and recovery was total, though back problems continued for several more years. She described a very busy, active life taking part in many sports, swimming, squash, jogging. She married, did office work and had two children. Since having children she has worked full-time for a volunteer agency and become a magistrate.

Allen: 55, polio at 9, 1957, in hospital for three months, both legs paralysed, one leg remained paralysed and he uses a full-length calliper, his brother (18 months) had polio mildly, has one brother and one sister
Allen tells a positive story that having polio led to him being encouraged to be more academic and he became a teacher, which he loved. He feels his paralysis was not a problem partly because he came from a small working-class community where there had been an epidemic, and everyone was very accepting. His first marriage did not work out, but he remarried and has two stepdaughters. He had to retire at 50 because of fatigue, but is involved in many hobbies.

Barbara: 58, polio at 4, 1948, in hospital about one month, paralysis both legs, left with one calliper until 11, had one operation and left with only very slight limp, eldest of four children
Barbara missed her first year of school (because it was difficult getting to physiotherapy by bus from her village) and never felt she learned to read properly or felt comfortable reading. She felt this was the only problem caused by polio. She became a nurse and eventually a community midwife. She retired at 50 because of contract changes involving hospital shifts, which would be difficult for her with the low birthing positions used currently. Shortly afterwards she began having problems with fatigue but she does exercises and can do most things. She never married but has lived with a man for the past 10 years.

Beth: 74, polio at 21, 1949, in hospital nine months, paralysis of legs, right arm, back and abdomen, left hospital with calliper and walking sticks and was never able to walk far, has one brother
Beth had been working as a medical secretary and had just applied to begin nursing training when she got polio. When she first became ill she went to her boyfriend's house to stay, and they married after she recovered. Her mother helped her look after her two children. She feels polio has not changed who she really is, although she described herself before polio as someone who had loved walking for 20 or 30 miles. She said it took her many years to realise that the polio would never go away. Beth was never able to work. Her postpolio problems, mainly new weakness and pain, began in 1985.

Clare, 65, polio at 3, 1940, right leg paralysis, left leg weak, legs put in plaster, no physiotherapy, used one calliper until aged 12, only child
Clare was an only child but described very supportive parents and a close extended family. She had several operations on her right leg and foot, and after an operation when she was 10 her leg became infected. At 11 she began to have ulcers on her foot which became chronically infected, necessitating many operations, until she had an amputation at aged 49. She married at 23, had two children and stayed home to look after
them. She always tired quite easily and had severe pain from the ulcers. A few years after the amputation she began to experience her first PPS symptoms, at first choking problems and more severe fatigue.

Cynthia: 84, polio at 18, 1937, in hospital 11 months with legs in plaster, paralysed from waist down, her legs remained paralysed and she used two full-length calipers and crutches, her father died when she was 17, had one brother. Cynthia had begun working for the civil service six months before she had polio. She described knowledge of polio at that time as very confused especially for older people. Her legs were put in casts and there was no physiotherapy afterwards to strengthen the muscles. Her employer was very encouraging and helped her back to work, and she worked for the civil service until retirement. She lived with her mother, and after her mother died, her brother lived with her. After an accident four years previously for which she was not given physiotherapy, she became much weaker and now can no longer walk and needs help with personal care from social services. She is quite bitter about the lack of help she has had from social services after years of independence, which mirrors the recurring story from her youth of the lack of proper physiotherapy.

Daniel: 65, polio at 18 months, 1938, in hospital three months, neck down paralysis, placed in iron lung, one half calliper until 12, operation on foot at 9, slight limp, has a twin brother and two older brothers. Daniel feels that polio was no problem, possibly because his family and community were very supportive. He also felt that people were particularly supportive of each other during the war. He attended an excellent clinic next to his school where he could always get help. He was never teased at school. He went to a grammar school and then became an accountant. He began to have PPS problems in his forties and moved to a flat with his twin brother, who had, like Daniel, not married. He retired early at 55.

Deborah: 54, polio at 18 months, unknown time in hospital, left arm paralysis, many operations and splint on left arm until age 13, her parents didn’t talk about polio so she is not sure when she had polio or what hospital she was in, her mother died when Deborah was 20, has two sisters. Deborah was brought up believing there was nothing wrong with her, although her arm is paralysed and she had many operations throughout her childhood at Great Ormond Street. She said she still feels she cannot accept she is disabled. When she thinks of childhood memories, she thinks of being in hospital. About the operations, she said she just accepted it. She married young but divorced her husband after about five years and brought up her two daughters alone. PPS symptoms, mainly arm and neck pain, caused many problems with her job with the Metropolitan police, and she is very angry about how they treated her.

Edith: 68, polio at 8, 1943, in hospital 5 months, part of which in a rehabilitation hospital with very little treatment or use of calipers, no physiotherapy offered when she returned home, mainly one leg affected, the youngest of four children, two sisters and one brother. Edith’s mother took her away from the rehabilitation hospital as she was just left in bed with no treatment. At home she learned to walk again by herself. Later she had several operations on her feet. She went to grammar school but left at 16 to look after her mother who had had a stroke. Both her parents died by the time she was 20. She married at 21 and had two children. She did office work, ran a B&B and then moved into catering. Her PPS problems have been complicated by other medical problems in the past few years.

Elizabeth: 70, polio at 25, 1957, in hospital four months, weakness of left leg, both shoulders, back, chest and abdomen, left hospital with mild weakness of left leg, shoulders and abdomen, her parents died in India when she was very young and she spent her childhood in boarding schools and with relations. Elizabeth had recently qualified as a doctor, married and was pregnant, when she became ill with polio. She had a relatively mild case and was treated well in the isolation wing of the maternity unit of University College Hospital. After six weeks she was transferred to a rehabilitation hospital. She recovered well, had a baby girl, and later two sons. When her children were at school, she worked as a locum GP and then went into medical research, mostly working part-time until retirement. She felt she did tire more easily than normal. She began having slowly increasing leg weakness in her mid-fifties, which became more severe after her retirement.
**Helen**: 52, polio at 4, 1954, in hospital three months, paralysis of both legs, back and abdomen, left hospital walking but had wheelchair for a time, began to have spinal curvature around age 7 and had operations from age 10 to 12 and missed several years of school, two older brothers had very mild polio and one died later of MS, her father died when she was 14. Helen's grandmother died of a stroke when she heard her grandchildren had polio, and Helen always felt she shouldn't cause her mother any additional problems. After missing 2 years of school Helen was sent to a small private secondary school. She went to university, worked for several years in different parts of the country as a librarian and then returned to live with her mother. Her PPS symptoms began about 1995 but because the main symptom was fatigue, both physical and mental, she felt doctors did not accept her symptoms. She took early retirement because of fatigue.

**Ian**: 73, polio at 7 or 8, around 1938, did not know he had polio until tests were done in the 1980s, has two brothers and one sister. Ian described an unhappy childhood, due to unexplained leg pain, fatigue and concentration problems. His situation was made worse by evacuation during the war to a place where the education system could not cope with the influx of children. After returning home, he had problems school and left at 14. Any job that involved walking or standing was very painful and eventually he found a sedentary job where he could work alone, doing accounts, which suited him best. He married and had two children. He went to doctors many times about the pain and fatigue, but tests were not done until 1985, when he was told he had had polio and should rest more. The diagnosis was a tremendous relief, except he finds that most people do not believe him.

**Jack**: 66, polio at 17 in Kenya, in hospital three months, both legs paralysed, both arms weak, left hospital of his own accord, refusing calipers, he was just able to walk with sticks but gradually recovered to quite good fitness though could never run and legs hurt when overused, has two brothers, one sister died in her forties. Jack has always had a very positive attitude and saw his polio recovery as a challenge. He came back to England for university after having polio, but felt weaker in the cold weather and returned to Kenya after his degree, having obtained a job in Customs and Excise. In his late twenties, he returned to England to qualify as a teacher, married and had two children. By his mid-forties he began to have trouble standing and took early retirement at 50. He now can only walk a few steps with two full calipers and walking sticks, and uses a wheelchair.

**Jane**: 66, polio at 11, 1947, in hospital 28 months, waist down paralysis, left hospital with a walking stick which she used until she was 15, has one sister. Jane felt her parents accepted her as she was and they chose to put polio behind them, never talking about it. She just got on with her life. She went to a grammar school but felt, having missed so much school, she was never able to catch up. She had various office jobs, married and had two children. She carried on working until her retirement. Her postpolio problem has been a gradual weakening since the late 80s, when she was travelling a lot looking after her elderly parents. Now her walking is very unstable and she uses a walker and has a scooter.

**Jennie**: 57, polio at 5, 1950, in hospital for eight months, completely paralysed for a short time, left hospital with one caliper which she discarded at 9 or 10, has two younger brothers. Jennie felt that no one had really listened to her and that she had had to listen to her mother's problems. When Jennie was 15 her parents started to run a children's home. Her education was disrupted by moving to a new school and an operation, culminating in her leaving school at 16. She had had a good recovery from polio, remaining with only a slight limp, and had energy and stamina. She did various residential care jobs, took exams at night school and eventually did teacher training. She married, and taught special needs children. Postpolio symptoms started with several muscle injuries and fatigue in the early 90s but she did not connect it with polio until the late 90s. She took early retirement in 1998 because of extreme fatigue.

**Joanna**: 58, polio at 11, 1956, 3 months in isolation hospital, then 4 months in a rehabilitation hospital, remained with leg weakness and a paralysed shoulder, used a crutch for several years, then at 15 spent 7 months in hospital for a spinal fusion, and wore a brace afterwards for 6 months, has one brother.
Joanna said she felt afraid and helpless totally paralysed in hospital where no one explained what was being done. She assumed that she would die, as another child had. She has remained fearful since then. She was not encouraged academically and became a secretary, but has also been interested in music, singing and theatre. She married in her twenties and has one daughter. She began having PPS problems in her forties, but these became severe in her mid-fifties with new leg weakness, falling and severe ankle pain.

Jonathan: 52, polio at 5, 1956, 2 years in hospital, was in an iron lung several months, upper body more affected and he was left with am weakness, spinal curvature and breathing problems, has three siblings. Jonathan's parents had him removed, against advice, from one rehabilitation hospital which had a very strict regime. When he returned to school 2 years later, he was still unable to eat by himself or dress himself but he gradually recovered. Jonathan felt his mother was never able to face the severity of his disability and concentrated on things like physiotherapy arrangements. He missed 2 years of secondary school due to extreme back pain, which was alleviated by a spinal fusion at 17. He then went to art school, became a graphic designer for 10 years, and gradually moved into psychology and psychotherapy. Since his early twenties he has had difficulties with balance and fatigue caused by nerve damage from an ear infection, which exacerbates the fatigue from his breathing deficiency and muscle weakness, which have also gradually deteriorated. He married when he was in his thirties and has two young children.

Ken: 63, polio at nine months, 1940, three months in hospital, wore a calliper until he was 16, had three operations as a child, has three siblings. Although he had a pronounced limp, Ken described being very active and did a physical job as a mechanic, working with heavy vehicles. He totally ignored any disability and felt he was the same as anyone else. He married, had three children, took part in various sports and long cycling holidays. In his late twenties he started having leg pain, and eventually had to turn to less physical work. He had many falls, breaking bones several times, had back problems and further ankle surgery. He retired in the mid-1990s because of fatigue and the need for a seventh operation on one ankle.

Lauren: 57, polio at 14 months, 1947, 10 weeks in hospital misdiagnosed as dysentery, paralysis in both legs, has three siblings. Lauren's father brought her home from hospital against medical advice and refused advice that she use a caliper. He found a consultant and a nurse who devised an exercise programme for her. She crawled until she was 5 and then had operations at 7 and 13 to improve her walking. Lauren talked about her father's determination to help her 'be normal' and she worked hard to be this normal person. In her thirties, she began to have severe ankle pain which was not diagnosed. She was working full time and bringing up three children alone much of the time as her husband was working abroad. After 3 years of this pain, her husband left and she had a brief breakdown. The ankle pain was finally diagnosed as a broken chip of bone and she had both ankles reconstructed. PPS problems began in the late 1990s and she is angry and sad that after working so hard to become normal, she now feels disabled.

Mark: 49, polio at 5, 1958, in hospital three months, right leg paralysis, left hospital with no calipers, had several operations in childhood and has a limp, has one brother and one sister. Mark said he gradually realised he was different as he grew and especially after an operation at 10. He was bullied at a local comprehensive and was sent to a boarding school near relations. At university, he started studying engineering but then changed to accountancy. He is very interested in motor racing, and he and his wife travel all over the world doing various sports such as scuba-diving. His PPS is much less than many others. He cannot walk as far and deals with it by increasing his exercise, swimming and going to the gym.

Matthew: 47, polio at 18 months, 1958, in hospital 2-3 months, wore calipers until he was 13, has two brothers. Matthew had a very close relationship with his mother and describes remembering a feeling of being 'yanked away' when he was taken to hospital. He had been due to have the vaccination weeks before he got polio but had a cold. He had many operations from age 6 and experienced extreme pain in one ankle throughout his life. He had several experiences of harsh hospital regimes and discrimination by teachers at school. He left school without qualifications, worked for the civil service clerical for 2 years, and then
began a career in social work, working with children with learning difficulties and children in care. He is married to a special needs teacher and has 4 children.

**Michael:** 54, polio at 2, 1950, in hospital six months, paralysis of right side with other weakness, calliper until 7, has five brothers and sisters

Michael described his mother teaching him to be independent and forget the past. He recovered except for a limp and did manual jobs, such as building and crane driving, after leaving school. He then studied for further qualifications in business and became a manager of his own company. He married and had three children. He began to experience new weakness in his forties, and had an operation on his foot which did not help. He was told to exercise his legs quite hard after the operation, which led to further deterioration. He began to fall and seriously fractured his arm. Eventually he heard about PPS from a physiotherapist who had worked in India. He took early retirement in 1999.

**Nick:** 72, polio at 2, 1933, in hospital three months followed by another 18 months rehabilitation, paralysed left leg and weakness in right arm and leg, has always used one full-length calliper and orthopaedic shoes, an only child

Nick felt his father encouraged him but his mother was overprotective, although she fought for him to go to ordinary schools. He was very successful in several careers, becoming an engineer and astronomer. However, he described feeling inferior underneath, and avoided social life unless he found a special role for himself, like organising events. Until a fall in 1989, which led to the beginnings of PPS, he would have said polio had not been a problem, but realising he could no longer fight back to his previous strength, he began to feel his early anger and guilt. He used poetry to try to understand these feelings. He spent nearly a year in hospital in 2003, breaking his leg twice, but carries on whenever possible with his astronomy.

**Pat:** 67, nonparalytic polio at about age 4, 1939, polio diagnosed at age 11 because of one flat foot, stiff ankle and slightly thinner leg, has one brother

Pat described polio as not a problem in childhood, except that she was not good at games. She became a nurse and worked in Africa for a couple of years. When she was 28, she began to notice her legs tiring more easily and she also had lower backaches. She eventually became a health visitor. In 1984 she started having severe leg pain, but no one believed she had had polio. Finally, in the late 90's, an orthopaedic surgeon noticed her thinner leg and asked if she had had polio. She managed to carry on working until she reached retirement age.

**Peggy:** 68, polio at 14, 1948, in hospital 12 months, paralysis of right arm, left leg and abdomen, left hospital with calliper, arm splint and corset until 16, had no lasting visible effects from polio but less stamina, one weak arm and leg and pain from standing, her mother became blind quite young, has one brother

Peggy came from a working-class family in Melbourne. She said her greatest passion was the piano, which she did relearn after polio. She became a teacher, at first finding the standing very difficult, but then found she could manage in small country schools. She married an English teacher, had three children and then came to England, teaching until retirement. She began falling in 1992 and now has considerable new weakness, muscle fatigue and pain. She goes swimming several mornings each week and has a passive exercise machine.

**Polly:** 53, polio at 8, 1958, acquired polio on the ship from England to Australia, in hospital in Sydney and Brisbane about six months, and then 18 months in a home for crippled children, she remained with a limp and spinal curvature, has four sisters

When she was 12, Polly's family returned to England and at 14 she spent six months in hospital having a spinal fusion. Her memories of childhood are about not being cared for in hospital, being very independent, having to go to physiotherapy appointments on her own, and her mother working very hard to make ends meet. Her father died when she was about 15 and she felt she became the responsible member of the family. She studied biology and psychology at university and became an educational psychologist, married and had three children. Although she has some new postpolio problems she is still working full time and recently obtained a PhD.
Rebecca: 88, polio at 5 months, 1915, paralysis of one leg, two operations on her leg, she has always used a caliper except for a short time after the second operation, has one sister and one brother. Polio was rare in 1915 and the doctor did not believe Rebecca's leg was paralysed, so her mother found a specialist herself. She went to a small private school and left at 14 to look after her mother, who had heart disease. Her mother died in 1950 when Rebecca was 36. She said she never conceived of working but a friend found her a job in the civil service. She passed several levels of exams, and worked in the Inland Revenue until she retired. She has a very supportive family and has not had much trouble with PPS symptoms except choking and swallowing problems.

Sarah: 50, polio at 2, 1954 hospital six months, right leg paralysis, other weakness, left hospital with one caliper until age 11, had three operations, has one much older brother and sister and a younger brother and sister, her mother died when Sarah was 21. Sarah described feeling confused about her disability as no one mentioned it. She decided to study mathematics at university but changed her mind to music and went to a teacher training college in Aberdeen. She had always tired easily and found standing in classrooms all day exhausting but when she saw doctors, they assumed she was depressed. She married soon after college, lived on a farm, and had two sons. She returned to education, doing an Open University psychology degree, and an MA in women's studies. She left her husband at this time and taught sixth form psychology, but only had the stamina for part-time work. She then did a PhD on stress in teachers, which was interrupted for several months by severe PPS fatigue.

Sue: 53, nonparalytic polio at 9, 1959, left sided weakness, has one brother. Sue had an undiagnosed illness for several months and remembered her father carrying her up and down the stairs to bed. She remained with mild left sided weakness, tired easily, was clumsy and fell often. She felt no one was interested or understood. She tried various jobs after leaving school and then settled on teaching music as well as having a smallholding. She had married, but left her husband in the 1980s and returned to education to do a degree in music and literature. By this time she was having severe problems with thyroid and postpolio symptoms and was not able to return to work.

Wendy: 62, polio at 20, 1960, in hospital seven months, completely paralysed and in an iron lung for a short time, left hospital with arm weakness, a wheelchair and calipers but discarded them a year later, has one younger sister. Wendy came from a working-class family in California. She had been living at home, attending college and planning to be a teacher when she got polio. When she returned to college a year later she needed a friend with her for stability and to open doors as her arms remained weak. At this time she changed her study to social work. She did an MA and became a social worker at a residential school for disturbed teenagers. Ten years after she had polio she came to England and obtained a job as a social worker in family therapy and later trained as a psychotherapist. She lives alone, feeling the need for independence. Postpolio symptoms started around 1995 with wrist pain and increasing weakness. She took early retirement at 57 but continues part-time work as a psychotherapist.
Appendix 10: Autobiography/ethnography

Biographical fragments of a Russian family (1905-2005)

I was horribly aware that their lives have been bisected, but whereas they always seemed to accept the bisection and fully inhabit the second half, I was in some way always trying to recover the former half, for which I felt an enormous sense of loss. (Karpf 1997: 139)

Just as in the moment of flight exiles must grab the treasures that will become their belongings on the road into exile, so they must choose the past they will carry with them, what version they will tell, what version they will believe. From being an unconsidered inheritance, the past becomes their invention, their story. (Ignatieff 1997: 8)

The question I wanted to answer for myself during this study was why my parents, if they knew I had had polio, kept quiet about it, and kept quiet about so much else of their lives. And could my own questioning answer other more general questions? Researching other lives and other polio stories opened up new questions to ask about these silences. When nothing is said, it is impossible to know what questions to ask. And whatever is not spoken about is important. I needed to be able to formulate questions about what my parents knew about me and also about their own pasts. If they had never been told anything about their own pasts, it may not have been easy for them to understand the importance of telling me about mine. And if I could ask questions about their pasts, I might be able to understand why their families had been silent, and why this may have caused them to be silent. I will never know whether, like in the quotation above by Karpf (1997), my parents did accept having no past, or, like me, felt a constant gnawing gap.

My aunt, Sara

My questioning began with my first interview. Helen, who was 53 and had taken early retirement from her job as a university secretary, lived with her mother. Her father had died when she was a teenager and one of her brothers had died when he was in his early thirties. She seemed to want to tell her story without telling very much about herself. She reminded me of a second cousin of mine, M., who was slightly younger than me, and lived with her parents outside New York. She was the granddaughter of my aunt Sara, my mother's eldest sister, who had been born in Russia and came to New York when she was five. M. and I had had an e-mail correspondence since the 9/11 disaster, which she had been caught up in, and she also did not say much about herself. I wondered if I could understand Helen better if I understood M. better. Or the other way around. M. had once visited me when she was in her thirties and I remember her saying that she had not been strong enough to get away from the family. I had never thought beyond her explanation, but now I had a bit more family information, coupled with thoughts about Helen. I wasn't even sure how old M. was. I emailed and found out she was five years younger than me. I began to write down some dates relating to people in her family, and our intersecting families. Just seeing the dates, pencilled numbers on a scrap of paper, began to generate questions.

I knew nothing about my mother's family except that when I was little and asked my mother where they came from, she told me her parents were from Lithuania, and that my other grandparents were from Russia. She told me nothing about their lives except that her mother had come from a fairly well-off family of seven children and my grandparents had also had seven children, five of whom had been born in Russia but two had died when young, one a small baby and the other somewhat older. She did not know their names. She thought they might have been boys.

Galia

In the 1960s I had a Scottish school friend whose Romanian father turned out to be a cousin of my mother's and he gave us a memoir in German by my grandmother's sister, my great-aunt, Galia, who had immigrated to New York with an older sister in the 1890s and later lived in Romania and London. She had had three children, two daughters and a disabled son. My mother read the book but said nothing about it and I did not know where the family was from until my cousin M. translated the book in the 1990s. Then I found out
that Galia never mentioned my grandmother in her book. She doesn’t mention that she returned to Russia to give my grandmother away at her wedding in the late 1890s, or whether she contacted my grandmother when she lived in New York in the 1920s. She does describe in detail getting help from a scrap dealer and his wife who lived near my grandparents. She describes them as kind but living a somewhat squalid existence in a very rough part of town. They have the same name as my grandfather’s sister, which made me think my grandparents might have come down in the world from their middle-class Russian life.

Through her book, I discovered that the sisters were born near Minsk, and a few details of Galia’s childhood, such as outings picking berries and mushrooms in the forest, and reading Darwin in her father’s library when she was 12. Although an Orthodox Jew who had drawn up a family tree traced back through generations of rabbis to a famous 17th century rabbinical scholar, Galia describes her father as an atheist.

**Emigration 1906: Aron, Michel and Sara**

Also in the 1990s, my cousin B., (M.’s mother) sent me a few old photographs, a copy of my grandfather’s Russian passport from Minsk and his naturalisation form to become a US citizen. My mother had already been dead for 20 years by then. I had never seen photographs of my grandparents from when they were young. Strangely, there is a photograph of my grandmother with her parents when she was 13 and another of my great-grandmother with two young children, but no photographs of my grandmother from the age of 13 until she was in her thirties, with three children and living in the US. This was a well-off family who had photos taken for years. The lack of photographs during that period after my grandmother was 13 may have related to the death of her parents shortly afterwards, but why were there no photos of her early marriage and first children? Mirroring this lack of photographs, is the lack of photographs of myself from the age of two to three, and the lack of dates on my family’s photographs after my second birthday. There is one photograph of me sitting on our swing with a thin left leg (Figure 5.2). In the passport, I saw the original names and ages of the three children, my mother’s brothers and sister, who came from Russia in 1906, Aron (7), Sara (5) and Michel (1). From the naturalisation form I discovered that their last residence in Russia was Kiev, where there had been a pogrom against the Jews towards the end of 1905.

![Aron, my grandmother, Michel and Sara c.1908](image)

**Three generations: Sara, her daughters and granddaughter**

Having found out how old M. was, I began to calculate other dates I remembered that related to her family and I was reminded of a mysterious two-week trip my parents made to New York when I was six years old. I never knew why they went. Now, as I did some calculations about M.’s childhood, I thought about her aunt, Marion, who had died of Hodgkin’s disease when she was 30. I was 10 at the time, and M. was five. I knew that Marion had been ill for four years, that I was six when she became ill but had never thought that my parents might have returned to New York to see her and her mother, my aunt Sara. M. would have only been a baby then. Shortly after Marion died, Sara, who was diabetic, also died. She was 57. I wrote to M. and asked her a few things about her childhood. I knew that her mother had looked after Marion’s children a great deal and they had come to live with her after their mother died. M. wrote:
My father talks about some things from his childhood but I know that some things are difficult and he avoids it, particularly his younger brother who died as an adolescent the same year that my father's father died. When he talks about this, it is usually in the context of his trying to get into college and it was noted that his grades slipped in his junior year of high school. He was under a lot of stress that year with the 2 deaths in the family and my grandmother being very dependent on him.

Which brings me to your question about my own childhood. I think because my father's was troubled my parents were determined to give me a carefree childhood. They never discussed anything serious in front of the children.

They perfected whispering to a point that all I could hear was their lips "flapping" and the whistling of their breath. To me that was the tip-off that something serious was being discussed.

I was moved by the way she used her father's story of two deaths in his family to speak of the two unspeakable deaths of her aunt and grandmother, when she was young, the deaths she only knew by the flapping lips. Writing about those two unspeakable deaths, I am reminded of the two other unspeakable deaths in the family.

Two missing brothers

Reading the email from M., I went back to the passport and calculated when my aunt Sara and two uncles had been born (Aron 1899, Sara 1901, Michel 1905). Aron had become Archie in the US, and his daughter had once told me, in the 1990s, that her father, whom I had always found quite frightening on the few occasions I had met him, had had nightmares all his life of Cossacks riding by with Jewish babies on their swords. Once my uncle had stayed at our house for a few days when I was 12 and I asked him if he still spoke Russian; he stormed out of the room slamming the door. Now I thought again about the year 1905, when he was six years old, the pogroms and the two children without names. My mother had said she did not know what they had died from and I had never thought more about it. What was not known was not known. My mother had always said that the family had come from Russia with all their furniture and things which made it sound like a planned, happily anticipated, event. My cousin, B., also said she had heard the story about the furniture but added that she didn't believe it. The information about the furniture had thrown me off track. Now I wondered whether they had had to leave in a hurry or had lost their home. I wondered about the two brothers, one being a tiny baby and one an older baby. And I thought about the gap of several years between Sara and her brother Michel (Milton), who drowned when he was 23. At the time of the pogrom in October 1905, Sara would have been about four and her brother Milton may not have been born. She could have had two other brothers of 18 months and nine months, the two that died. Had either of them been killed by the Cossacks? Is that what the oldest son (Aron, Archie) saw? Or was it terrifying enough to see any child being stabbed? Where was he when he saw these things? Out in the street? In their house? Were houses burnt down? Was it feet away or further? When I first heard the story about the Cossacks I imagined Archie seeing them far down a street, far in the distance somewhere. Now, as the story became clearer, the horses and soldiers became closer and closer. What would it have been like for Archie and Sara to lose two brothers, their home and then, within months, travel from Minsk to Liverpool and then take a ship to New York? What had they been like before and after leaving Russia? Why had I never thought of these questions? The lack of knowledge seemed to close down questioning which was opened by interviewing other people who had also sometimes spent their lives avoiding questions.

Escapes

I know two other stories about escaping from Russia from my other grandmother's family, which might throw some light on my mother's family. My father told me one a few years before he died. He found it very difficult to tell. His mother's family had escaped from Russia, also in 1906, by running across the Polish border near their home in Brest-Litovsk. They went singly for safety. His aunt went with her three small children. (I've just noticed the similarity with my mother's family who left Russia the same year with three young children. Did my parents know about these similarities when they married?) One was a baby
strapped to her back. The other two she held by the hand. As they ran through the woods, soldiers shot at
them. When she finally arrived at a town, she found the baby had been shot and killed, which had saved
her life. A story my father couldn’t bare to tell and never told me was about a female cousin he was close
to whom my mother was so jealous of she wouldn’t let my father see her. I wonder if this cousin was the
one who ran through the woods. I never met or knew the names of any but my father’s immediate family.

I heard the other story from my father’s mother. I was 14 and hadn’t seen my grandmother in several years.
I wasn’t even sure how well she spoke English because she and my mother always chattered in Yiddish
leaving me to get bored. But my mother had gone off to do something in another room, leaving me alone
with my grandmother. There was dead silence. She didn’t say a word to me, so suddenly I just asked,
“What was it like, living in Russia?” She began by saying how wonderful life was under Tsar Nicholas and
then started telling me how she had escaped from Russia alone, at age 14. So we were both 14 at that
moment. She had a passport and tickets to take a train to Marseilles from wherever she crossed the border
into Poland. She was supposed to meet an aunt in Marseilles and take a ship to New York. She got to
Marseilles but never found the aunt. She went by herself on the ship to New York. She only told me the
bare facts before my mother came back into the room. The effect that story had on me was to think of it
whenever I was in a difficult situation and imagine how much more difficult that journey had been for her.
I liked to believe I’d inherited whatever had helped her along. It was only years later that I began to think
about what hadn’t been told in that story – that she had been a poor girl who wasn’t educated, couldn’t read
and probably only spoke Yiddish. She had probably never been away from her family or her little village.
How long did it take her to get from Russia to New York and had she been able to speak to anyone, to get
food and places to stay? Then I imagine the embarkation at Ellis Island in New York, the crowds of
people, immigrants from every country and strict immigration officials. How did she ever find her
relations? And another question that grew from doing research and thinking about who tells stories to
whom – had my grandmother told this story to the rest of the family? Only now I realise that I may never
have mentioned what she told me, and no one else in the family, especially my father, ever said anything
about my grandmother’s childhood or emigration.

Silence, absence and disability

Now I was able to think of M. again, slightly differently. When she was five, her mother, B., was dealing
with the death of her sister and her mother and looking after her own three small children and her sister’s
two children, then ten and six. I compared this with her grandmother, Sara, who, at the same age, was
dealing with two lost brothers, a lost home, a new country and a new language. None of Sara’s past was
ever talked about. When I asked B. if her mother had ever talked about leaving Russia, she wrote that she
wouldn’t have remembered as she was only three.” I answered, “She was five.” Sara had been very
protective of her children, keeping them home from school with the slightest cold, walking with them to
school until they were 14, and not letting them use the cooker. What was she so worried about? M. didn’t
say much about her childhood except to mention a pervasive power of superstition in the background which
she assumed I had shared although I hadn’t. Like Helen, whose grandmother had died of a stroke when she
heard that Helen and her brother had polio, M. had probably had to be a good girl and not upset her mother.
Being a good girl meant being quiet. These were lessons passed on and on through the generations.

My mother tried not to hide as much as had been hidden from her. She tried to talk more about the deaths
in her family, her 23-year-old brother when she was 13 (of whom there are no photographs beyond the age
of about three), and her mother, who died the year before her own first son died. But she never said how
she felt. I thought her story of deaths was normal. I never thought sadly about her brothers who died in
Russia or her first child until I read this passage in Ignatieff’s The Russian Album, whose family was
contemporaneous with my family. No one would admit, in those days, that emigration, illness or deaths,
even of children, were hard.

_Her (his grandmother) memory must have marched her back again and again to that hotel bedroom in
Eupatoria, to that empty cot. When the time finally came at the end of her life to put down what happened
that summer of 1909, she did not write about it at all... Through all the waystations of the life to come, she
kept just one little picture in a round silver frame on her night table: the smiling image of her dead child.
(Ignatieff 1997: 85)
Possibly to counteract the told and untold stories of deaths and emigration, my mother needed to believe she now had a perfect family or wanted us to be "carefree" as M. put it. She talked several times to me about disability although she never mentioned that her first child might have lived and been disabled. And she never mentioned what had happened to me except to say it was thought I had hurt my leg when I was two, it had stopped growing at one point and hurt for many months. My mother told one other story about the summer when I was two about my first visit to my mother's father in New York. She said we went by aeroplane and I screamed so much at the noise of the aeroplane, that we waited and took a smaller plane. Then I threw up on plane and the first sight my grandfather had of me was wrapped up in an aeroplane blanket. I never thought this story made much sense. I remembered the story when I was reading an early polio conference book because on the same page were a list of early polio symptoms, fever, headache and vomiting, and the picture of an iron lung, which looks like a section from an aeroplane and was notoriously noisy. Maybe I had actually become ill on the journey, which might explain why I cried so much, and why I was wrapped in a blanket. My grandfather died a year later.

Years later, my father told me that my mother had lied about early stories of my childhood, but he refused to say anything further. Later still, I realised those were the only stories I had been told. I am reminded of Hockenberry's (1995) autobiography about being a paraplegic war correspondent, throughout which he weaves stories of two disabled relations, his grandfather who lost an arm in an accident, and an uncle, his mother's brother, who was hidden away in an institution when he was eight and never visited, having become brain-damaged from a metabolic condition, PKU. In both cases, there was terrible shame and suffering for family members. About his mother's memories of her brother being sent away, he wrote:

> From the upper floors of the patient wards, eleven-year-old Nancy recalls the pale, blank faces staring down at her as she walked to and from her parents' car. For much of her life she has had nightmares about those faces. In the worst of those nightmares the face of her brother appeared in one of the windows, looking down, looking for his older sister. "I always thought he must have wondered what had happened to us" (Hockenberry 1995: 341)

His story of paraplegia seems bound up with the stories of his grandfather and uncle and his family's attitudes, silence and sadness as mine has been bound up with my families' past. My mother never mentioned that Galia had had a son who was disabled, due to an accident with a runaway horse when she was pregnant. She only mentions his son a few times in her memoir and no one knows what became of him. He could read and write, was musical and had a good memory, but for some reason could not live with people. She was forced to put him in institution when he was 18 because she had no home.

My mother did talk about her own three-year illness after her first son died, in which she had had a ruptured bladder, peritonitis and septicaemia and spent most of the first year in hospital as there were no antibiotics. Ironically, during this time, around 1942, my father was transferred from his job as a chemist working for a whisky company in New York, to their factory in Indiana, where they were going to work on the new production of penicillin for the army. My mother liked to tell a heroic story of my father stealing some penicillin and saving her life when she was dying of peritonitis in hospital in New York. I never realised that the timing was wrong. There was no penicillin while she was in hospital in New York. She was taken by ambulance to their new home in Indiana but had already recovered partially. Later my father told me that he had not saved my mother but had stolen penicillin for the wife of the obstetrician who delivered my brother in 1945, before penicillin was generally available. My mother blamed my father for the death of their baby as he had been away on a business trip and had not returned home until the last day of the three-day labour. However, years after my mother died my father gave me a tiny spiral notebook in which she had written the story of the birth and said she had not told my father she had gone into hospital. She had wanted it to be a surprise. My mother did not recover completely until two years after they moved to Indiana. She had also been told she would never have any more children. As soon as she was better, she arranged to adopt a baby boy, but then found herself pregnant.

The first experience of disability my mother told me about was a supply teaching job she did for a friend soon after she qualified as a teacher. The children were mentally handicapped. She said they couldn't pronounce her name and they broke her heart. Shortly afterwards, she retrained as a social worker. She
once mentioned, out of the blue, that she didn't think my father could cope with having a disabled child.

Did she mean herself? The first time I think I heard of polio I was about four. My mother told me that the
woman who sometimes looked after me was leaving because she had a little daughter in Florida living with
her grandmother, and the daughter had polio. I was horrified to hear that this little girl was separated from
her mother, especially when she was ill. I don't remember any fear of polio in the summers where we lived.
I remember waiting hours on long, hot queues at the swimming pool and wondering why so many people
were there when everyone was told to avoid crowded places, especially swimming pools. Once, my mother
invited a woman she had just met, whose son had recently had polio, to our house for the afternoon. I
remember the two of us standing in the back garden, and I was trying to think how I could ask what it felt
like having a paralysed arm. I kept thinking of different ways to ask, and then thought it might seem rude,
so I tried to think of a different way. In the end, I didn't say anything.

When I was eight we moved back to the New York area, first to a rented house in Connecticut and then to
New Jersey. Shortly after this move, I was playing hide and seek with some children outside my house
when I ran into another girl and was thrown into the road where I lay unconscious. When I woke up I saw
a crowd of people around me and heard the girl I had bumped into running across the grass to my house
shouting for my mother. I knew I must get up immediately so my mother wouldn't think I had been run
over by a car. I stood up and the world spun around me. Strangely, my mother does not actually exist in
this memory. I remember being at the doctor's office where he said I must spend the night in hospital for
observation. I remember the hospital stay in great detail, being told I mustn't get out of the bed, the two
comics I was given to read, the little girls who had had tonsillectomies and were crying for their mothers,
needing to pee and no nurse appearing for hours -- but I do not remember my mother coming out of the
house, taking me to the doctor or the hospital or collecting me. Thinking about this now I wonder if this
shadowy absence is because of what happened a few months later. In the weeks that followed the
concussion, my head would hurt each morning. Usually the headache quickly went away but sometimes it
stayed all day. I never mentioned it to anyone. About three months later, after having a headache all day at
school, I came home and lay down on my bed. My mother came into my room and asked if I was ill. I
explained about the headaches and she walked out of the room. I don't remember thinking anything at the
time, but I remembered it when I had children.

Two years after moving to New York, we moved to Italy. My father had worked in several European
countries on and off over the years on antibiotics development and was offered a job with an Italian
pharmaceutical company. I probably had a strange life there on my own a lot, but it was a special, magical
place to be. So many smells bring back Italy -- roasting coffee and chestnuts, wood smoke, garlic and
rosemary, bread baking, hot pine needles. When I started secondary school I made a new friend, E., whose
mother had had polio a couple of years earlier, when she was about 40. She had four daughters, the
youngest only four. Her legs and one arm were completely paralysed and I remember her mostly sitting
stretched out on a chaise lounge talking on the telephone or in her wheelchair at the dining table. She was
very tall, very beautiful, very aristocratic, very charming. E. and I remained friends until we went to
college. One summer I went with her family to the beach several times -- the parents, the four daughters,
the Labrador, me, the sandwiches and the wheelchair all piled into the car. For me, they were perfect days
at the beach. The only time I felt there might be another side to my friend's mother's life was once walking
down the hallway in their apartment and seeing into the parents' bedroom -- the bed was unmade and I
suddenly realised that she couldn't do ordinary everyday things like that, but I would never have thought
that when I was with her.

Cancer

While I was growing up, no one in my family had been ill for any length of time until my mother was
diagnosed with cancer in 1969, when I was 20, a month before I was to graduate from college. In many
ways, this was the turning point in my life. I never returned to the US after that spring. My mother came
to Boston a few weeks before my graduation because she wasn't well. She was admitted to Brigham and
Women's Hospital in Boston, and was bluntly told she had a 50-50 chance of having terminal cancer. She
packed her bag and left in a panic and when I rang the hospital they had no idea where she had gone. The
next day she rang me from her sister's (her elder sister Margaret, also born in the US) in New York to say
she would be having an operation at the Memorial Sloan-Kettering Hospital in New York in a couple of
days time. My father was in Italy without a passport so I, having never been in a hospital except the one night with a concussion, was suddenly thrown in at the deep end at this huge machine of a cancer hospital. A few days later it was I who told my mother her cancer was terminal. My mother's sister and my brother had been at the hospital during her operation but somehow they mysteriously dissolved or faded away when the surgeon came to talk to us. He took me into his office and said, pointing to a graph in a book, "Your mother's insides were the biggest mess I've ever seen in 15 years of operating in the biggest cancer hospital in the world. She has a .01% chance of living three years." The surgeon had told her that if he felt he could remove the cancer he would leave a tube in her abdomen. The minute I left his office, a nurse grabbed my elbow and propelled me into the recovery room explaining that my mother was just coming round from the anaesthetic. I assumed she would be feeling groggy and would just be happy to be alive. Instead she immediately asked me if the tube was there. What could I say? I burst out crying. I spent the next month at the hospital, travelling into New York each day from a family friend's in New Jersey. It was a beautiful spring, walking across Manhattan every day. I went back to college for a couple of days to hand in my final papers and went to my graduation by myself.

My mother had had some extremely painful hospital experiences when her first child had died and she refused to have any treatment or anything done unless I was there. She was afraid to have blood transfusions unless I was there to disperse air bubbles, and she wouldn't go to radiotherapy without me because she thought they might forget to switch off the machine. I sat and timed the treatment for her, watching people with brain tumours lying, looking dead, in beds, with felt tip pen marks all over their heads. My mother who was afraid of nothing. In the next bed to her was a girl my age who had bone cancer and was having her leg amputated at the hip. She told me she had had pain for five years but no one had diagnosed it. I had never spoken to anyone about my legs continuing to hurt for the past six years.

At the hospital, I took my lunch onto a roof terrace, a roast beef sandwich, a Danish pastry and a cappuccino from machines in the hallway. Every day a nurse pushed a bed out onto the roof in which was a young man who had no body below his rib cage. There was a bar above the bed for him to reach up and move himself. Every day I tried to think of something to say to the nurse or him and everyday none of us said anything. I would start to open my mouth but then be afraid nothing would come out, or maybe he would look away and it would be impossible.

One day, walking down the hallway a woman called to me from a ward, saying, "What time is it?" I looked at my watch and said "Six." She said, "Morning or evening?" I pointed to the beautiful pink sky outside and said, "Look at the sunset" and then realised it could have been sunrise. Then she explained that she had just woken from surgery. It didn't cross my mind what was coming next. She looked at me and said, "I don't know if they have removed my breast or not, could you have a look at my bandages for me? I can't reach." I couldn't believe she had been left alone like that. She was a youngish woman, early forties maybe. I said I didn't know what the bandages might mean, although I had seen quite a few by then, having helped all the women in my mother's ward adjust their bandages. She said, "Just look." I looked, and the bandages seemed enormous. I said there was quite a wide bandage. Then we both just sat there thinking what that might mean.

I arrived at the hospital every day at 12 o'clock when visiting hours started. I never came a minute late. One day a nurse met me in the hall outside the ward and said, "Thank goodness you come every day -- your mother cries all morning and then at 11: 30 she stops crying, she washes her face, she brushes her hair, she puts on make-up, because she knows you're coming. It would be terrible if you didn't show up."

I took my mother back to Italy that summer, she recovered and had quite a good two years and 11 months. I went to England to study art, and decided I would stay. I felt free for the first time. In February 1972, my mother rang me and said she had an infection and I must come home immediately. I went the next day. She didn't have an infection but the doctor didn't want to say she had reached the end of the road. She knew. On the aeroplane I was sitting next to a very proper Englishwoman who turned to me and said, "Isn't February a beautiful time of year to be going to Rome." I answered, "It would be except I'm going to look after my mother who is dying." The woman turned away and didn't say another word for the next two hours. My mother had a wonderful doctor, a hospital oncologist, who helped her die at home with "no tubes" as she put it. He came every morning of those last four weeks before he went to work and put in a
drip and discussed any problems from the day before. My job was to change to a second intravenous bottle and then remove the needle. Each morning, early, I went to the pharmacy across the street and bought the bottles. One morning, my mother commented, "Every morning when I wake up, for about a minute or two, I feel fine and I imagine it has all been a dream and I can just go into the kitchen and make myself a cup of coffee. Then the pain begins again." After we finished with the bottles, for the first two weeks or so, we had some good times, chatting, reading, watching TV, doing normal things. Then one morning I came into her room and she was staring at her hands which were frighteningly white. I felt her fear. Possibly it was on that day that she commented, "This is worse for you than it is for me." After that she slowly became confused. The ring of the telephone frightened her.

The last sentence my mother said to me was "You're not as bad as I thought you were". Then, about a week before she died, she became silent. At first I thought she was dozing. But as the day went by and she didn't answer me I became frightened and thought possibly she couldn't speak and would never speak again. I have no memory of anyone else in the house that day. At last, just before I went to sleep, I went over and sat down on the floor beside her bed. Holding her hand, I cried and asked her why she wouldn't answer me. In a perfectly clear, ordinary voice, she said, "There's nothing more to say." The next day, she seemed to be drifting away as if she was in a dream, and would occasionally say things like, "I've been very ill haven't I? I'm too young to die. How old am I? What day is it? I don't want to go to school. I have no hands. I have no legs." Then she slipped into a coma for a couple of days. I hoped she was dreaming of her childhood and her mother.

The day after she died I went out for a walk and as I passed the pharmacy, the pharmacist rushed outside and grabbed my shoulder saying, "I'm so sorry about your mother." It was the nicest thing anyone did. I asked him how he knew. He said, "You didn't come for the intravenous bottles this morning." What I remember most about that time was the absence, the ghostlike absence of my father, my brother and any other family. I suppose, like the strength people developed recovering from polio, I felt that I could survive anything life might in the future throw at me. The only person who was there, and she came each day, was the wife of another cancer patient who died at that time. She remained a friend of the family for years.

When I got back to England it was 10 years before I spoke to anyone about my mother. I was in a car with two friends. We were coming home from a night out seeing On Golden Pond, leaving our children with their fathers. One of the friends' father had died of cancer when she was two and she suddenly asked what it was like when my mother died. It was dark and she couldn't see that my hands were shaking. One story I told was about the last day my mother ate anything, a moment when she must have realised she only had a few weeks to live. I was alone with her in the house and she suddenly threw up a bowlful of blood and I thought it might never stop. The next day the doctor told her he could put a tube into her stomach but she had decided "no tubes". For several years after she died, I would sometimes see the image of the blood before I fell asleep. Some years later both those friends died of cancer, the second friend having moved in with the husband of the first friend while she was dying. I had lost touch with both of them but I wonder if my story had remained with them. Until doing this research I would have said that my experience with my mother at the end of her life was ordinary. Silences are about forcing people to think nothing unusual has happened. Thinking about the memories of the interviewees made it possible to break through the silence and normality to the complexity underneath. And beginning to understand the complexity of my family story fed back to and added depth to the equally complex polio stories.

Slowly, I begin to realise that I am writing not just about silence, but about absence, disappearance and the way people fade away from memories like shadows. At first I was writing about family members I didn't know, who were never given names and were barely mentioned, people there were no photographs of. And then I found myself writing about my own memories and noticing how people who were there, in body if not mind, were not there in the memory. Some people are cut out of the family story because of illness, death, or some other trauma, but in other cases people absent themselves or are made absent by others even if they are there. They may become shadows, slipping into the corners of the room, possibly hiding feelings so no memory is made of their presence. Looking again at what I wrote I realise even my mother is absent in many ways. Possibly these absences create silence by communicating that this is something that must be forgotten or ignored.
Appendix 11: conferences and publications

Conferences

2005 (27-29 June) SPA Annual Conference -- Well-being and Social Justice, University of Bath
"No triumph, no tragedy": childhood illness, stigma and blame

2005 (5 April) Narrative, memory and knowledge, University of Huddersfield
The broken doll: looking for memories and making sense of memories

2004 (16-18 September) BSA Medical Sociology Group Conference, York
Sanguinity or bitterness? Narratives of polio and postpolio syndrome

2004 (3-5 June) Communication, Medicine and Ethics Conference, University of Linkoping, Sweden
Doctors and the invisible: "This leg looks perfectly powerful."

2004 (3 April) Narrative, memory and everyday life, University of Huddersfield
Walking and work: narratives of polio and postpolio syndrome

2003 (26-28 June) Communication, Medicine and Ethics Conference, University of Cardiff
Silenced voices: understanding postpolio syndrome through illness narratives

2002 (29 November) Connections 2002, University of Bristol
Silenced voices: understanding postpolio syndrome through illness narratives

Publications

