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Men with Multiple Sclerosis: A Study of a
Mutual Self-help Support Group.

A Thesis presented in partial fulfilment
of the requirements for a
Master of Arts Degree in Social Anthropology at
Massey University, Albany Campus.

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Abstract

Multiple sclerosis is a condition that affects about twice as many women as men. I am a man with multiple sclerosis (an insider in this work) and my aim within this thesis is to relate the stories of our involvement within the support group environment. For the purpose of examining the individual and group process, I have found it useful to adopt a combination of narrative and feminist post modernist methods for understanding our ways of knowing and systems of helping. I was influenced by women of colour who argue about patriarchy and post colonialism to guide my thinking about the oppression of people with difference. The guiding principles of my study are inclusion, participation and emancipation. Inclusion occurred through involving the entire group in the research process. Active participation ensured that the theory presented in this study was grounded in the experiences of the individuals. Emancipation was achieved through presenting the voices of participants and working to provide better conditions for those concerned.

This is an in-depth study of eight men who meet on a regular basis to share our interests, and life stories. We are people who are searching, surviving, succeeding and/or failing in our daily tasks. We are guys who are rational thinking human-beings and are just trying to be “normal” and included in our community.

This thesis examines the process of surrendering power and the ways in which this causes the alienation of this group of individuals by our wider society. It looks at the social

constructions of our disability, the fears, the chaos, dependency, our identity, and/or our visibility. Then we look at our “seizing the moment”, through the process of reclaiming some of that power and control for ourselves through the benefit of mutual social support using camaraderie; the genuine need to help and care for each other and to be concerned. It is evident how our struggles and problems are not that dissimilar from other groups, for example, the emancipation of women and the plight of indigenous peoples. The discipline of social anthropology, being located within the humanities, provides an ideal base for studying the interconnections between oppressed groups.

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Dedications

Firstly to my Mum and Dad.

Secondly to one of us that never made it, Steven Wear, we miss your cheerfulness, your stories and your wit. Multiple sclerosis didn't kill you, but it helped and your time came in your 30s. You never suffered from MS, you were a person with it, fortunately you knew that we only suffer the boars who thought your multiple sclerosis was pervasive in those early days.

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Chapter 1

Introduction

It was a Friday morning when I joined the "Motivation Group" for what was to be one of life's little enjoyable episodes. It was here that I was to find out that other guys were having similar experiences to myself. Just being in the company of others who shared the experience of multiple sclerosis was enough; we didn't have to bleat about our own problems, we understood. It was here that I came to realise the value of gaining knowledge from more experienced members of that group. That helped me to adjust more easily to society's demands. They showed me how to access the vital resources that would make my life more comfortable. It was this process of guided participation in the support group environment that now forms the basis of this thesis.

I wish to explain at the beginning of this thesis that I am part of the research process, an insider. I begin with my relationship with multiple sclerosis, my fears, my tribulations, my successes, my failures and this disclosure of myself. The outcomes expected from this transparency of self aid this project as it identifies me firmly in the centre of the study and helps build the relationship between me as the researcher and the research. This aids the process of eliciting rich, authentic information and allows the joint participants of this study to share their own lived experiences. This procedure not only gives validation to my own experiences, but it is truly emancipatory for all the participants as it gives us a platform for an expression of our concerns. It may be that this study is therapeutic, for I realised that we are not sufferers of multiple sclerosis, we live with it and it at times impedes our life choices, but it does not consume our whole being.

Christmas time of 1979 was a momentous period in my life. I had just turned 28, I was married on December 29th, and my partner had her birthday on the 31st. All seemed well. But in hindsight I remember some minor back pains. I put those down to boredom and standing around in the Farmers Building on shopping expeditions.

Nearly a year later I was working for a real estate agent in Sydney. I was office bound. I had a series of headaches, severe but not alarming. Again I dismissed these, attributing them to my being indoors, probably a result of the fluorescent lighting, and took some paracetamols. Only weeks later, I tried to take a photograph and noticed I had a problem with the vision in my right eye. The next day I made an appointment to see an optician for an eye test and he informed me that I had a lazy eye. He scheduled an appointment with an ophthalmologist across the road for later that day, and a thorough inspection showed that my right optic nerve had dried up. Whilst there, a further referral was made for me to see a neurologist the next day. At the end of the week I was admitted as an inpatient to Royal Prince Alfred Hospital.

By now I was a trifle alarmed. I felt well, I had started a new job. But suddenly, for the first time in my life, I was ensconced in hospital, and all I had was a lazy eye. I remembered my school days when children wore a patch of sticking plaster over one eye to retrain the other lazy eye. Within a week, from only having an insignificant eye problem that I thought could be corrected with glasses, I was amazingly bewildered.

I may have appeared to be a little distracted in those few days at work. I remember chatting with one of my tenants whose husband was Chinese born and educated in Western medicine, and was a qualified doctor acting as a general practitioner (GP) and

was also a traditional acupuncturist. She said I could contact him at any time and gave me his business card. It was his influence that conditioned me to explore alternative therapies, not to just believe that the dominant Western medical practices knew the answers to wellness. I learnt from him to question those who represented the social or institutional power bases in medicine.

The Hospital Induction Ceremony

The ritual of admission to hospital was significant, and reminds me of similar experiences of being initiated into any fraternity or brotherhood, such as that of Freemasonry or initiation into other esoteric schools. At 4.30pm on a Sunday night, the process started. I was issued with a unique credit card for use on every item or service within the institution. This was swiped, as if I was at a restaurant paying for the meal. I was given a number and divested of all my worldly possessions, stripped of my clothing and forced to wear pyjamas for confinement to bed, and then to go through the rigmarole of a physical examination by the inducting registrar. During this my wife was ordered out of the cubicle, so the doctor could be alone with me. I think that was part of the rationale in those days of the doctor exercising their power over the patient as a method of making them comply with their commands, a sort of front that they were superior to us mere mortals. I didn't know what I was doing. I was now in a liminal world¹, I answered a few questions, had my examination and then the doctor pulled the curtains back, and now I formed a part of their world.

During my hospitalisation, I was invited to join a conversation between my wife and a fellow “incarceratee” regarding his dreadful experiences of having a lumbar puncture, along with barbaric tests involved within many of the antiquated neurological tests. Some

¹Turner (1967) refers to this as a period of betwixt and between worlds, a period in the margin, or on the threshold between two states.

of these, I feared, I might expect in this ward. My wife and I came to the conclusion that I should refuse to have a lumbar puncture. She left the hospital to go home and spend our first night apart in over three years. That evening I rang my newly found GP, the husband of the tenant I had met, to explain some of my fears and the dread of the lumbar puncture. He said, "Michael, you are free to refuse any treatment, if you don't want that test, put your foot down firmly and refuse it".

That night was uncomfortable. The ward was a large Victorian dormitory with subdued lighting and, a nurses' station from which the nurse could keep an eye on all the patients. It had parallels with the way (Foucault 1980) describes Jeremy Bentham's ideology of the Panopticon. I couldn't do a thing without the nurse's gaze, even going to the toilet was observed under the sheets by reaching for either a bottle or pan. There was no better process for bonding with my neighbouring patients as they had been through the same ritualistic abuse that I had been suffering. We ate, slept, and drank together, forming a kind of *communitas*². A few days after the battery of tests, I told the neurologist that I would refuse to have the lumbar puncture. He intimated to me that without the lumbar puncture the only conclusive evidence was the optic neuritis. In the back of my mind I thought it was his anger with my refusal to co operate in having the lumbar puncture that prevented him from telling me more. The day after, I was discharged.

I had an eight hour consultation with my Chinese GP. He spent more quality time with me in that day than the four days I had in hospital with all those tests. He told me that I had to realise that I may have multiple sclerosis. I had heard of it. I knew people who had the condition but none of them on a personal basis, but I had read that multiple sclerosis was a degenerative chronic medical problem. I had watched Marcus Welby MD in the

²Turner (1967) describes *communitas* as a shared feeling with fellows in a liminal state that causes a sort of bonding or camaraderie between the sharers.

early 60s, a TV series set around a family health practice, and remembered one program devoted to multiple sclerosis. The story line showed a patient who couldn't get out of the bath one day, had a little bit of numbness, and then ended up in a wheelchair.

For the next three nights I didn't sleep. I couldn't switch off and relax. Here I was, only a problem with one eye, and the next week my future blotted. I thought I was fire proof. I was in a new job. We were in a new country living on Sydney Harbour and I looked healthy. I never displayed signs of being unhealthy.

But something had changed. No longer did my career seem that important to me. I was now conscious of looking for the triggers or signs of what I knew might be multiple sclerosis. In this reflexive process which consumed much of my spare time, I was confused about whether I was becoming a hypochondriac or a manic depressive, or was I simply going mad. But deep down, did I really want to know, was I in denial? Sometimes I wanted to know and sometimes I didn't.

Minor things were happening which would turn out to be significant, yet they were not discussed with medical staff at the hospital. These developments included clumsiness, falling over in the park a couple of times, thinking I may have a problem reading an eye test at the police station. But all of these were minor incidents and could be attributed to other causes. Nevertheless something was sinister. I was detached from it. I didn't want it to be a problem. I was in denial.

I maintained a daily regime of going to my GP for acupuncture Monday to Friday for two months, which required at least two hours out of the office. These daily rituals were

impacting on my workload. I hadn't been in the job long, and I was devising new systems to make the office run more smoothly in my absence. Other members were required to cover for me when I was out. But the situation became untenable, and besides, my GP's requirements for changing my lifestyle were what I considered unreasonable. He required major life style changes, including resting more, drinking less and generally behaving like a monk. I stopped going to him. I wanted to continue to enjoy the excessive life style that the Sydney-siders seemed to me to epitomise. It was not to last.

Several months later, I had a major exacerbation relating to my multiple sclerosis. I was out walking the dog, ran out of energy and thought, "How the hell do I get home?". In the next few weeks I lost feeling in the bottom of my feet, and I felt I was walking around on egg shells. But these incidents were hidden, known only to me, and could only be felt and seen by me, so I kept that information to myself. I thought the signs might go away and never sought the help of the medical profession. Besides I had been told by the clairvoyants that I didn't have any long-term health problems. So really the messages I had been getting from others were only reinforcing my denial of my true health status.

But there was an underlying problem and I needed to know. I had discussed with my wife that it was better that only family should know about this Damocles that lurked in my background. We came back to New Zealand for a long weekend and told my parents. They too chose not to believe and thought I was making it up.

I started going to another doctor. I sought out clairvoyants for readings and surrounded myself with people who indicated my long term health was not going to be a problem. But deep down I knew differently and long term plans in Australia without universal

health cover were not going to feature in my life.

I had been to England before where I met my wife, Lesley, and we went back there in March 84. I secured a position with the company I had worked for before. Somehow all the salesmen seemed much younger, more virile, energetic, and able to devote long hours to their work. I had to prove I was still good. I was able to increase my knowledge of the area that I didn't know. I read once that luck comes easiest to those who are prepared for it, and in the first two weeks I sold more houses than all the other six salesmen combined.

I continued to mask the signs of my health condition. I even convinced the sales director that it may be a good idea to have the sales team go for a run each morning before work, which could act as a bonding exercise and help motivate the staff. I suggested this, knowing full well that I would not be able to partake in the activities. Fortunately he could not get enough interest from other staff members and I was never required to perform. But nevertheless because I had suggested the run, it may have been part of the bravado, it may take the heat off me if I had to decline in something that was physically too demanding. When the office manager asked me one day why I limped, I said I fell out of a tree as a child and dented my hip. On another occasion when one of the staff had a fit, an indication of his brain tumour, I asked why he didn't declare to the management that he had a health problem. All of these things were adopted strategies for concealment, to take the heat off myself.

I started to plan my working career for a less internally competitive company and applied for a few positions. I found a family firm close to home inside six months. In the meantime I knew deep down that I wanted to have conclusive proof about my health

status. I went to a local doctor, not alerting him to my multiple sclerosis, and he only thought my blood pressure was too high and prescribed medication. I explained that I had sensory problems so he referred me to a neurologist. After a series of extensive tests very similar to those in Sydney, I decided this time to have a lumbar puncture. Again a stay in hospital was necessary. This time I was a little wiser to hospital's power over the patient, so every night I went home after tea and came back before breakfast. This was conducted with the approval of the nursing staff. I didn't want to be in a ward of sick people. I didn't want to be seen as a young man in hospital at the height of the Aids crisis. I didn't want to be tarred with that brush. But in any case I was subjected to a variety of tests which included a lumbar puncture where an amount of fluid was extracted from my spinal column.

The usual practice in the Western medical profession was for the specialists to do the rounds of the wards trailing along with their trainee doctors and various members of their special team. When the neurologist conducted his rounds, on my final round, he informed me that the protein count in my cerebrospinal fluid showed that I had multiple sclerosis. I said I thought so. Somehow, it seemed a relief to be told conclusively. The main thing that concerned me was his saying that I was a spastic in front of his entourage. This was a term from my early childhood that denoted the biggest insult, especially when you were a child in the days of the polio epidemic.

Work and my need to conceal continued. Again the dented hip scenario was dragged out to appease my employer. I still had my reputation and ability and we did very well. If we were not the best real estate agents when I joined in the area, we certainly became so for the next 18 months. I was head hunted to join another family firm in Twickenham and duly went to them. Problems began to surface. I fell a couple of times in the High Street

up the road from the office. I devised strategies of parking the car as close to the office as possible and made sure that I did not have to walk long distances. As I managed the office, I was able to get others to perform required jobs, and what I felt to be “duck-shoving” could be put down to delegation of tasks. Then cognitive dysfunctional aspects started to arise and I could not keep staff (perhaps they got sick of doing more than their fair share of work). I had difficulty in multi-tasking or doing more than one thing at a time.

My wife was able to shield me from many of the blunders and was continually getting used to them. I didn't see them coming, and I thought basically I was OK. I do remember ringing up a multiple sclerosis society in England one day. A little old dear answered the phone and I reacted badly, thinking I would have no more to do with them. The problems continued. I was having more falls and breaking a few bones, our financial security had turned to custard with our financial losses in the property market. I still enjoyed success in sales and worked for a building company selling some expensive new houses backing Hampton Court Palace in the south of London.

We came back to New Zealand to live. I thought I was still a good salesman and had grown increasingly homesick. I located a real estate agency and applied for a job. For three months I didn't sell anything and decided to move to another company before I was asked to leave. I lasted there ten days before the principal came to me and said, “You conned me, you haven't got the ability to sell, I can not see you ever selling”. So I was fired. Finally, I had to address the fact of going onto a benefit to help us live and to pay the mortgage. It was at this point I needed to join the local multiple sclerosis society and get involved in living a life as a person with multiple sclerosis, a person not scared to tell the community I had a problem.

What is Multiple Sclerosis?

Multiple sclerosis is an incurable and debilitating neuro-spinal condition and the most prevalent neurological problem for young adults in the Western world. It affects only a small proportion of New Zealand's population, those people of Northern European ancestry. According to the Multiple Sclerosis Society of New Zealand (MSSNZ)³, there are approximately 2500 members of the society who currently have MS, and of those affected, approximately 70 percent are female.

Some observable symptoms can include "intention tremor" (difficulty in controlling movements), "scanned speech" (loss of control in speech), and loss of "muscle control" (fluctuating and jerky movements in the muscles) which generally result in adding to degrees of severe fatigue in its hosts. The following have been my concerns: major chronic fatigue, balance problems, loss of energy, bumping (walking in to door frames, misjudging placement of furniture, knocking items together--like chipping crockery), lower limb weakness, walking problems, locking knees so that you do not collapse and commonly called "stilted legs", perceptual problems as in judging distances. A "cantankerous sphincter" is a term referred to by Ginter (1978). This term relates to closure problems on a nervous bladder or an irritable bowel syndrome, and other problems such as aggression, pain, hypersensitivity. Cognitive problems include a reduction in rapid decision problem solving skills, multiple issue problem solving skills, long term planning, a lack of focus and some minor bi-polar psychological problems. Vision problems involve varying degrees of night blindness, double vision, permanent central vision blindness of one eye, partial blindness caused by plaques when fatigued, with the closing of eyes causing a loss of balance. Many of my friends with multiple sclerosis share these symptoms, but they are not pervasive or all encompassing. The

symptomatic problems are often intermittent and never happen all at once. But paying constant attention as to how they affect one's abilities to function as ordinary human beings is often problematic.

The public face of multiple sclerosis and how this study will benefit those of the multiple sclerosis movement.

My thesis documents the lived experience of men with multiple sclerosis. I show how the concepts of concealment and disclosure are linked to the perceptions of the managed self of the individual. The study examines the grieving process amongst individuals with multiple sclerosis to indicate that it is similar to that faced by others who are attempting to cope with a life threatening or chronic illness that affects their life style choices. The extent to which individuals become effective in coping with the condition depends on a complexity of factors including the availability of mutual social support, guidance to move through the grieving process, and the learning of strategies for adapting to the effects of the condition.

This thesis studies men's social responses to their illness through a process of direct participation by the researcher in a men's support group. Utilising a participatory action research model, I have worked collectively with the participants to examine ways in which the group functions to support its members and to guide them to cope more adequately with the effects of the condition. Both group and individual processes are examined through observation of actions and interpretation of information. The ultimate aim of this participatory research approach is to guide participants to develop knowledge and skills that will enable them to work effectively in order to improve their social relationships and coping strategies.

³Telephone conversation with Ruth Vincent, Information Officer MSSNZ January 1999.

The underlying theoretical perspective to be adopted for this study is the “communities of practice” framework advanced by (Lave and Wenger 1991). This proposes that particular communities of practice act as powerful mediums to accomplish real collaborative work through guiding participants from the periphery to the centre of the community. According to Lave (1991), learning takes place as a function of the activity, context and culture in which it occurs. Learning is thus “situated” within a definite social and cultural domain. Social interaction is a critical component of situated learning in that newcomers develop an identity within the community and acquire skills through collaborative interaction with established members. Learning in this context is usually not directly taught but is unintentional, occurring through active participation in working together with other people. These ideas are what Lave and Wenger (1991) refer to as the process of “legitimate peripheral participation”. Within the context of the multiple sclerosis support group, the “community of practice” framework holds promise as an anthropological perspective for understanding the conditions necessary to promote effective coping strategies amongst those who have multiple sclerosis, their carers, loved ones and members of the wider community. Such a perspective is in accord with best practice in anthropology which stress the creation of a reciprocity with participants so that something can be given back for the betterment of the community in which the research has taken place.

The importance of this study is that it will provide an in depth examination of social processes and collective actions that can be taken by a group of men with multiple sclerosis to gain greater understanding and coping skills with the potential to improve their quality of life.

The conclusion of my own research, confirmed by the Information Officer of the

MSSNZ, is that there is a lack of international literature written about men who are dealing with their multiple sclerosis and their need for social support. Support Groups that use an “apprenticeship model” for guided participation for both males and females include structures that combat fear of flying or dealing with addictions like Alcoholics Anonymous. This study compares and contrasts the experiences of other men’s support groups such as those described in Levine, Petrie, Gottardt, and Sevig (1990). These authors, in their book *Men and Eating Disorders*, promote plans for therapy and intervention and focus on mutual support groups in the United States. They state that the goal of self-help/support groups is to teach their members to provide themselves with the six major benefits of social support. Levine et. al., (1990: 188) have highlighted a plan for a working definition of social support that can be divided into six categories, these include:

1. *Emotional support.* The opportunity to share and express feelings, coupled with empathetic feedback concerning the authenticity and appropriateness of pressing emotional experiences.
2. *Esteem support.* The experience of being accepted and valued by people who are willing to listen reflectively and empathetically instead of judgementally.
3. *Informational support.* The opportunity to collaborate with people in order to gain information, advice, and guidance are (sic) potentially helpful in clarifying problems, generating options and developing workable solutions.
4. *Companionship.* Enjoyment of the friends which emerge in the course of pleasurable social activities.
5. *Motivational support.* The availability of encouragement and reassurance, offered in an atmosphere of hope. This enables the recipient to endure frustrations and to persist in the solution of long term problems.
6. *Status support.* Some mutual aid groups may produce positive changes in self-perception and social recognition by offering the individual a meaningful role and a valued identity

within the larger community.

The significance of my study will be that it will provide valuable information for all those involved in the multiple sclerosis movement. In particular:

- It documents the lived experiences of men with multiple sclerosis.
- It will help Multiple Sclerosis Societies better strategically and tactically plan to meet the needs of their membership.
- It will produce information that can be given back to the joint participants, thus fulfilling the researcher's part of the reciprocal relationship.
- It will provide a framework for networks of support.
- It will inform those who remain outside the Multiple Sclerosis Society, who have not disclosed their condition, but just require information so that they can make their own choices.
- No literature exists on men's experiences of multiple sclerosis in the support group environment. Therefore this thesis is a seminal piece of work.

Chapter 2

Methodology

Conceptual Framework and Aims

The purpose of this qualitative research project is to provide an in-depth study of the lives of men with multiple sclerosis to see how they cope with the continuing changes in facets of relationships within the general community and with those closest to them. This study seeks to be participatory and emancipatory in nature. The aim is to study the experiences and perceptions of men with multiple sclerosis, and in the process, to empower them to make adaptations that improve their quality of life. Specifically, I have: (1) explored the experiences of eight men with multiple sclerosis; (2) examined their personal coping strategies as individuals; and, (3) sought how they made use of the support group to which they belong to promote their own adjustment and independence.

The thesis draws upon two conceptual frameworks that are collaborative in form: (1) apprenticeship models and guided learning within a community of practice as described by Ryba, Selby and Kruger (1999) and, (2) *Pedagogy of the Oppressed* as advanced by Freire (1972) to illustrate how general apathy of the population aids the powerlessness and disenfranchisement of members of a minority community.

Early in the process of constructing my methodology I had been warned that a study of the members of my own group could be problematic. Namely, concerns were raised as to my personal power over the participants, (my own friends who were also members of the

North Shore Multiple Sclerosis Society) about the reliability and quantifiability of the research findings that would be forthcoming. After a lot of deliberation I decided to treat them as a reference group merely to act as my experts to assist me in devising appropriate questions for asking other groups of men with multiple sclerosis. I felt that this process may appear more of a collaborative venture. Thus the members of my men's group contributed to the developing or formalising of my research questions.

Prior to the beginning of the research, a facilitated meeting was set up where I could participate as an observer rather than have too much of an influence on this group of my peers. Many writers thank their colleagues and friends in the acknowledgement sections of books for their support and advice. Bishop (1996) says his research methods are created within a whanau of interest, a metaphoric whanau is where support, ideas and reflections came from his colleagues at the Education Department at Otago University. Like Bishop my intention was to seek advice and counsel from my peers.

It was decided following the meeting that a study of this group of my friends with multiple sclerosis would be a worthy study for a thesis after all. The facilitator of the meeting said afterwards, "You know your support group doesn't display any power hierarchies, you all regulate each other's behaviour, it is a psychologically safe environment. I do not see a problem using them as joint participants in the study". I decided to approach my supervisor with the view to changing my proposal to just using this group. The facilitated meeting was a useful if not a novel way of using my peers in discussing themes and topics for exploration to form the research parameters. As Heshusius (1994: 15) would say recognition of my peers was the core of a participatory mode of consciousness.

As discussed in chapter one, I am one of the group, and this exercise may be seen as transparent, collaborative, and in effect, emancipatory for all the participants including myself. Denzin (1997: 201) comments that ethnographic realists tend to write “from the inside out” and their stories become cultural texts. Insider research lends itself well to the study of the human sciences wherein people are observed in a holistic environment, which includes all of their physical, economic and social domains. The focus of traditional scientific research is preoccupied with the replication of testable, quantifiable experiments set out of people’s natural setting and possibly located in a laboratory.

The reliance on seeking information from individuals is gained from listening to the men’s experiences and this narrative research forms part of an eclectic paradigm of post-modern research methods. The stories are told, the researcher interprets these and tempers these against available theories and literature. Sometimes getting the confidence of the participants of the study takes time and the building of relationships has meant that the social anthropologist spends many months in the field to make sure that the information is accurate. In insider research the relationship is pre-existent and therefore the researcher is able to access raw data in the light of what he/she already knows.

This insider research approach to the study of the psychological and social effects of multiple sclerosis assumes that those affected are “active participants in the social interpretation of their world” (Ballard 1994: 293). The insider researcher observes people as sovereign individuals, worthy of respect. This view parallels a wider post-positivist feminist tradition which searches to find meaning from the experiences of people by looking for commonalties and differences to comment on. This is also the *raison d’etre* for study in social anthropology.

Insider research operates at a level that is truly compassionate for the members of the study group, and as Smith (1999) says, the researcher has an advantage that he/she does not have to waste time proving their credentials and identifying with the participant. They are more aware that information extracted in the course of the work is likely to be accurate. It may be more difficult for participants in the study to manage and pretend false displays of the self when they are in an informal and comfortable environment. But the researcher must display a responsible attitude, researchers are ethically bound by commitment and protocols of respect to their fellows especially when their relationship exists before the study, and is ongoing afterwards. In the present study, my relationship with the group is paramount regardless of what transpires from this research. (Smith 1999) informs us in her study that insiders are more than just researchers because they are located on the same critical plane as the researched. This is true in my case.

Reinharz (1992) alludes to the distinction between the researcher and the researched becoming less apparent because of the egalitarian nature of the relationship. The researcher abandons control and this process is complemented by an insider status. A dialogue between the parties is based on “natural openness, reciprocity, mutual disclosure and shared risk” and she further comments that other feminist action researchers call it “passionate or engaging scholarship” that is communal rather than hierarchical as a form of research (Reinharz 1992: 181).

Reinharz (1992: 185) further interprets Lather, another feminist action researcher, in saying: “The most effective emancipatory approaches are interactive interviews in which the researchers self-disclose...”. This research process is very much part of me, by identifying with the members of the group individually I am able to create an informal and comfortable atmosphere for the sharing of information. Both group and individual

processes are examined through observation of actions and interpretation of their behaviour. The ultimate aim of this participatory research approach is to guide participants to develop knowledge and skills that will enable them to work effectively in order to improve their social relationships and coping strategies. Thus, there is an explicit emancipatory agenda which involves all of us in the group.

Researchers in the positivist paradigm would dispute this research because of its informality; for them it is suspect and contestable. But insiders, mindful of their own subjectivity, process information within a constant reflexive modality in order to generate valid and useful information.

Participants

There are eight participants in this study, including myself, ranging in age from our early 30s to mid 50s. All of the participants lived in their own homes. One was interviewed in a rest home; his stay was for respite reasons, and he returned to his own home after a stay of less than two weeks. There were no formalities of selection of the participants, and all are members of the “boyz.R.us” multiple sclerosis support group and well known to the researcher.

The group members came from an upper socio-economic background, and all are, or have been, relatively high achievers. They were hard workers, ambitious and successful in their employment and business generating ventures. Many of the participants are well travelled and have a developed appreciation of the arts, and some have succeeded to high standards in their sporting endeavours.

Procedure

Initially, I spoke to my men's multiple sclerosis group asking if they would like to become my expert advisors in my study of men in multiple sclerosis support groups in New Zealand. I invited fellow group members to a meeting, asked for permission to bring a facilitator so that I could be just one of the group. I explained my concern that some people may see me exerting power over them because I was president of the North Shore Multiple Sclerosis Society and they were all members of the society. The members of the group said that they did not see me as having any power over them, and saw me as an equal, and that they felt in no way obligated to be in our study. All of the group were happy to be involved and share their experiences.

I knew from my professional contacts within the multiple sclerosis movement that information about the men's support group environment was an area that needed a greater depth of study. I noted that there was a lack of international and local literature and found a desperate need to find out more information as to their needs so that the Society could better plan to service their membership. The initial facilitated meeting was set up to explore whether my group saw the need for this sort of study, was it worthwhile, feasible, and what benefits it would have for other men with multiple sclerosis. I sought permission from the members of the group for permission to have one of my colleagues from Massey University come along and facilitate a meeting. Every member of this group at the meeting gave permission.

It was decided at the meeting that a study of this group would be a worthy study for a thesis. The whole meeting was tape recorded with the permission of the group members and transcribed by myself as data for a potential thesis. The members were informed that all of our conversations were private and our taped discussions were confidential to the group. After I had transcribed the tape, I took the hard copy to one of the group meetings

and offered it to the members to peruse and informed them that if they would like a copy I would give them one. In the event, no one requested a copy. The tape recording was conducted in a coffee lounge, a public place, and at this stage nothing was formalised for any potential research project. The transcription was difficult because of all the background noise and the lack of privacy. I decided that somewhere more private should be sought if there were to be further recordings.

The study of individuals in my own geographical area made for easier access to the participants, and this would keep down the costs of any research project. An application was made to Massey University's Human Ethics Committee. This was granted and application MUAHEC 99/052 was approved.

Once approval for the study was granted, each member of the group was posted an information sheet and invitation to partake (see Appendix 1). The letter confirmed the outline of the study, stating that it would be partial fulfilment of my master's degree. I also gave a statement of commitment not to compromise my dual role as a member of the group and the researcher of this study. The information sheet with the consent form and a stamped addressed envelope were posted to the prospective participants so that they didn't feel coerced or personally pressured into signing. The information sheet stated that if they wished to become a participant in this joint project, they were required to return a signed consent form. All of the members of the group became participants and duly returned the consent forms (see Appendix 2).

After the consent forms had been returned signed, the next stage was to interview the group members individually. The interviews were unstructured and informal in line with participatory action research. The participants chose a time and place convenient to

themselves. Most elected to be interviewed at their own homes, one was conducted at a nursing home, another came to me and we conducted it at my home. I asked to be interviewed by one of the group and we conducted that interview at his home. This meant I was as much a “subject” within the research as any of my fellow group members.

The interviews consisted of the participants telling their life histories, and as the interviewer I would say something like, “Tell me about when you were diagnosed and how you felt at the time?”. For the first interviewee I said, “Tell me about yourself for about ten minutes,” and he talked for about one hour. Another participant said, “This is the easiest interview I have ever given,” and he had been interviewed most of his adult life within his profession. This valuable anthropological technique is similar to other field researchers finding ways of knowing and Myerhoff has perfected this in dealing with older people. Kaminski discusses the merits as:

When one takes a very long, careful life history of another person, complex exchanges occur between subject and object. Inventions and distortions emerge; neither party remains the same. A new creation is constituted when two points of view are engaged in examining one life. The new creation has its own integrity but should not be mistaken for the spontaneous, unframed-as-lived person who existed before the interview began. This could be called an “ethno-person,” the third person is born by virtue of the collusion between the interlocutor and subject. (Kaminski. 1991: 10)

The meetings were tape-recorded and I transcribed the conversations. Each transcription consumed between 18 and 25 pages of single spacing typescript for each interview.

Although I edited those transcriptions for my spelling and grammar problems, the tapes were in otherwise “pure” form: this was to become my raw data.

All of the transcriptions were sent back to the participants for their approval as to

accuracy and if they felt they needed to change any of the dialogue they could. The transcripts included my personal letter of thanks for their involvement so far.

The next stage of the research process was to synthesise the groupings of themes that came out of the individual interviews. A focus group interview was conducted with all the members of the group after all individual interviews had been transcribed and returned. The focus group meeting explored at greater depth the issues raised at the facilitated meeting, these were able to be more refined by the group members. Issues around concealment and exposure emerged as the back-bone of this study as will be borne out in an analysis of the data chapters of this thesis. I had provided lunch (a small part of my commitment to our reciprocal relationship), they gave their time, so I went to a lot of trouble preparing the meal. We met in a meeting room/lounge in a central position so that the participants who did not drive could gain easy access. In any event not a lot of new data was gained out of this process but as mentioned by various members of the group, the reflexive nature and self-disclosure in front of their peers was empowering for many individual members. Many of the topics had been discussed in the personal interviews but seldom at the support group meetings held on a monthly basis.

Analysis

The qualitative data in the study was collected through a three-interview process. Themes that arose out of the discussions at the initial facilitated meeting were further explored in the personal unstructured interviews, and later revisited in the focus group meeting. A manual method has been used to evaluate and analyse the themes that have emerged, and these themes became the subjects of different thesis chapters. Some members of the participant group have over the period of the research kept me informed of issues that they have reflected on and felt were pertinent to the study. These notes

include medical reports and curriculum vitae and are filed in my journal for reference when necessary. The data produced showed that although the group members had a common malady to bind them as a unit, their individual responses to each condition showed that they were people first, and their multiple sclerosis was a secondary issue.

Chapter 3

Literature Review and Theoretical Perspectives

Birds of Feather Flock Together (Anon.)⁴

Part 1

The benefits of being in the company of others who have shared similar lived experiences somehow makes it easier to survive. One develops a deep understanding of how the other person feels, a sense of bonding ensues from this recognised commonality, and because a sense of trust naturally builds up between the members of a group they usually share in *communitas*. Support groups are generally small groups of people who have formed an alliance and seek mutual benefits. In this chapter I will show that there has been a lack of literature on men and the social effects of multiple sclerosis. This is mainly caused by historical reasons: 1, the idea that men should need the support of self help groups only dates back to the 1960/70 period⁵; and 2, one of the first multiple sclerosis societies was set up in United States the mid fifties and the New Zealand Society was formed in 1967.

Support or Self Help

There are two types of support groups. Firstly, there are those that are focused on self-help and are consciousness-raising, these tend to be membership driven, are peer led and are informal. Secondly, there are those which generally have arisen through mental

⁴Quotations from the Brewers Dictionary of Parables and Fables does not attribute this saying to any person in particular, just gives a definition of the saying.

health problems, are focused on therapy and are generally facilitated by health professionals, and are very structured (Stein 1982: 273).

Kauth (1992: 3) has said that support groups grew out of the women's movement and these were mainly focused on "consciousness-raising" groups for women in their plight to liberate themselves within a patriarchal society. He also says that some remarkable men's groups soon followed as they saw that liberation from the traditional roles were possible for everyone. The importance of finding mutual support from groups helps those seeking answers to their concerns and problems that eventually may lead to their regaining personal autonomy.

Allen (1993: 227) is instrumental in the American men's movement and says there are two general kinds of men's groups. He refers to these types of support groups as being generally leaderless and designed to give a forum for discussion, and labels them "support" as in or akin to "consciousness raising". He also alludes to both the self-help and facilitated group as being therapeutic in nature.

Self-help groups according to Kauth (1992: 3) "began as offshoots of therapy groups and quasi-religious movements". They were established as small, mutual, self-help groups that consisted of the more experienced members of the group guiding newcomers. This enabled the more experienced members to integrate the newcomers into the group by teaching them how to help themselves through the gaining of skills and knowledge. To this extent Levine et. al., (1990) speak of the close relationship between mental health and social support and make clear the social maladaptiveness, role inefficiency and alienation of the members of the groups.

⁵Kauth, (1992: 3), Stein, (1982 :276), Biddulph (1995: 177).

In her discussion of self-help groups, Rogoff (1990: 549) uses the metaphor of apprenticeship models which use guided participation where newcomers learn from the more experienced members of the group. This is also called peripheral participation (Rogoff 1990). In guided peripheral participation the newcomers to the group learn to become the skilled masters over a period of time by the gaining of knowledge. They in turn then become the trainers of initiates to the group, and it is vital that the groups remained controlled by those who have had the lived experience of that condition. Such a notable and effective self-help group mentioned by Lave (1990: 73) and Kauth (1992: 3) is Alcoholics Anonymous where new members to the group learn from reformed alcoholics. Knowledge is gained by the new members in a process of constructing and reforming their own identities spending time in the company of more experienced participants. They learn through the sharing of life stories that will eventually lead to sobriety.

Raeburn (1999) a community based support service on the North Shore of Auckland, published a brochure saying that self help and development groups vary from Parenting Support, Survivors of Abuse, Women's Support, Men's Support, and Older Adults' Support. These support groups are for people involved in novel or different situations, and those that are in unhappy situations or are in crisis situations. These groups may be therapeutic and/or consciousness raising.

Stein (1982: 294) comments on women's support groups as showing characteristics that help the women to bond together through positive affiliation with each other. The women may also internalise a sense of identity as women. The support groups may help them to adopt a more egalitarian relationship with men and they may lead to a greater awareness

of sexism. This tends to help the women to change rigid gender-role definitions of themselves. Stein also states that the raising and self-building of positive attitudes by women within their own support groups are similar goals to those of men seeking outcomes from their support groups.

Reason for support groups

The literature generally outlines the reasons for and highlights the benefits of the value of seeking social support by becoming members of groups. Spiegel, Bloom, Kramer, and Gottheil (1989) reported a 10 year follow up of 89 women with breast cancer, some of whom had taken part in a support group designed to boost their self-confidence, help them to express emotions and to teach them self-hypnosis. Women who had taken part in the study had lived on average about twice as long as women who had not.

Unell (1987) conducted an extensive study for the Nottingham Local Authority regarding the uses of support groups in their area. She stated that self-help support groups contribute to the well-being of those who take part in them. These groups fill an important need within society in terms of providing information and support to its membership. The beneficial effects of the group are that members become more self-sufficient and the council recognises the contribution made by self-help groups. Unell (1987: 3) says, "Groups have been formed around chronic illnesses and disabilities, transient but traumatic life crisis (such as bereavement), socially stigmatised behaviour (such as illegal drug-taking) and problems of social isolation".

In her MA thesis Rowsell (1996) reported the experiences of 11 people and their relationship to their cancer. Her study group found that social support was vital for their sense of self-worth. Rowsell (1996: 47) comments, "The role of acknowledgement and

the support of others in a more general sense, is in reconnecting the sufferer to life, living and humanity in general". The 11 members who had cancer shared their experiences with others that had cancer and found that it was beneficial to their own psychological recovery of their condition. Rowsell (1996: 51) further says, "Often there was a feeling that only those who had been through a similar experience could really understand the magnitude of the personal crisis that was being experienced".

Support for People with Multiple Sclerosis

Miles (1979), a British sociologist, conducted research on the effects of social interactions as to whether people with multiple sclerosis mixed with either able-bodied people or members of their own disabled community, and related the patterns to self esteem. Her study was of 22 married couples where one of the partners was a person with multiple sclerosis. Her investigation was carried out both on those people that wished to continue in isolation without recognising any multiple sclerosis society and on those that did seek out a society. She found a significant proportion of the participants became members of the Multiple Sclerosis Society, and of those the majority were active in regular social activities in the society. These people perceived it was important for the members of the group to be with others who understood the problems and feelings they experienced.

An interesting study into social support was that of Maybury and Brewin (1984) who found that a number of factors were thought to influence the psychological adjustment to multiple sclerosis. They found that both knowledge and demographic characteristics had little to do with adjustment to the condition. It was social support that helped to reduce stress associated with multiple sclerosis. Reducing stress was important for their participants' self-concept. The study found that there is a positive correlation between

people with multiple sclerosis, their self-esteem and their interactions with able-bodied people.

Another study that confirmed the efficacy of social support was that of McNett (1987) an associate professor of nursing studies in Indiana who conducted a study of 50 functionally disabled Americans and found that there were significant relationships between the availability of social support and coping effectiveness. She says some theorists report that the use of social support may have a negative impact on members because these people could lose out on some benefits of personal problem solving skills. Her study has suggested that social support enhanced the effective coping of people with disabilities for their continued integration in, or reintegration, into the community.

Unlike McNett (1987) who discusses both the potential positive and negative effects of social support, Wineman discusses only the benefits. Wineman (1990), also an associate professor in nursing studies in America, analyses the relationship between social support and adaptation to multiple sclerosis, functional disability and perceived uncertainty. She concludes that belonging to a social network promotes a sense of purpose and well being. Wineman looks more in-depth at the benefits of social support and comments on Durkheim (1951) who theorised that being a member of a social group fostered a sense of meaningfulness in life and, alternatively, not being in a group engenders a sense of despair. Wineman (1990: 295) also says that many writers "provide evidence for a direct, positive relationship between social support and psychological well-being".

Women with multiple sclerosis approximately outnumber men two to one, they are the dominant force by numbers within the Multiple Sclerosis Society. Most of the health professionals with an interest in multiple sclerosis, with the exception of medical

specialists, are females, and the field officers in all the New Zealand local societies and employees at head office are females ⁶ with the exception of one. Perry (1994: 7) says that reliable sex estimates show that more women than men are affected with multiple sclerosis. Many men are conditioned into believing that it is weak to be sick, and they are conditioned by Western society and the “puritan work ethic” that their identity is tied to their work. Allen (1993) quotes a Professor in Psychiatry at Mount Sinai Medical School in California as saying that many men felt shame when they had physical symptoms (Allen 1993: 20).

According to Vincent (1995), The MSSNZ was founded in 1968 by well meaning but patronising people who did things for people with multiple sclerosis. Not until the mid 1980s did they realise that people with multiple sclerosis wanted to do things for people with multiple sclerosis and be involved with the decision making process. It was at this time the most important committee within the multiple sclerosis movement started: The People with Multiple Sclerosis Standing Committee. This committee saw its role in the facilitation of support group networks through such mediums as: workshops, teleconferences, Education Fund, National Advocacy, and sought to make changes for its membership through arranging achievement awards, changing the language, and understanding the resistance to change. Vincent (1995: 27) said, “The overall objective of the Committee [Persons with Multiple Sclerosis Standing Committee] was to monitor, advise and motivate other Standing Committees within the National Society to develop, educate and deliver the right support and information to all those with multiple sclerosis, their personal support networks, all health professionals and the general public”.

A more recent avenue for support has been provided through technological developments.

⁶29 May 2000 Private conversation with Field Officer of the North Shore Multiple Sclerosis Society.

A unisex support group called Jooly's Joint (Howell 2000) is Internet based and administered from the UK. This is specifically devoted to all people whose lives are affected by multiple sclerosis. The volunteer administrator is Julie Howell a woman with multiple sclerosis and a manager for information technology for the Royal Blind Foundation. This service is partially funded by the Multiple Sclerosis Society of Great Britain and Northern Ireland and a number of disability information organisations. It has 10,000 members and their services are used at least 4000 times per month. Support groups, facilitated by this organisation, involve people with multiple sclerosis, their carers, families and friends in a number of different countries. These include pen pals, support boards, chat groups, people new to multiple sclerosis, teenagers of people with multiple sclerosis, people with multiple sclerosis currently in the work environment and email groups.

Current Local Literature

Wright-St Clair (1996) a New Zealand researcher, has stated there is a lack of knowledge about and understanding of the demands of living with multiple sclerosis. She comments that research has mostly focused within the biomedical quantitative boundaries, i.e. neurological, pharmacological, and epidemiological aspects of finding a cause and cure for the condition. Although she refers to a growing body of psychological and sociological literature, this relates mainly to the quantitative research into the chronic illness experience. Wright-St Clair's research, carried out in the Auckland area, examined women and their relationship to the illness experience and provided suggestions for changing the education of health professionals.

Two unpublished masters theses focusing on multiple sclerosis were written in 1999.

Jopson (1999) concentrated on the greater Auckland area and examined aspects of

adjustment to multiple sclerosis; 77% of her study sample consisted of women and their experiences dominated her report. This study was predominantly a quantitative research project and focused on ways health professionals might be able to offer a better service. One of the influences on this researcher was her close family connection with a person with multiple sclerosis. But on the whole the research was for, rather than with, people with multiple sclerosis and within the power relationship of professional and patient. Hight (1999) however studied women with multiple sclerosis as a person with the condition (she has been a vice-president of the Wellington Multiple Sclerosis Society). Her qualitative research for an MA in Social Work concentrated on a small group and aimed at finding better ways of meeting women's needs. The findings are significant in that the researcher indicated that she learnt more from her participants about the social constructions of the illness than from the medical profession and its literature.

Men and support groups

According to Biddulph (1995) our society socialises girls to accept help from older women e.g. mothers and their networks, and they grow up knowing that group support has long been part of the repertoire of female readjustment to many of life's conditions. Boys on the other hand seem to be brought up in isolation from older male contact and mainly learn from their peers. This isolation is significant, boys learn to become self-sufficient and in turn come to believe that individuality is necessary for their survival.

Bill Kauth was instrumental in forming many support groups in the United States, many of which were not necessarily gender specific but the rationale is the same. He says, "That was the purpose of our group: to support and help one another in learning new ways to be--socially, personally, professionally, and in relation to one another" (Kauth 1992: x). He has been seen as one of the leading lights in the formation of many of the

men's support groups, and his book *The Circle of Men* is the original manual for men's support groups. Kauth (1992: ix) saw that historically, men as hunter-gatherers and farmers spent many hours with their fathers. By being in their company they were taught how to become men. The elders would initiate and induct young males into the community of men, but these rites of passage altered with the evolution of modernity and urban living following the industrial revolution. This saw that increased technology took the workforce (predominately male) away from the home. Everingham (1995: 2) says, "When men separate from women and begin to talk in matters close to our heart, the tone changes. We let go of trying to be sensitive, reasonable "nice guys," our language gets course and powerful... We speak to men in a masculine tone". Stein (1982) notes the important ways in which men's groups might help their members. Accordingly men have met for millennia in all male groups to perform certain functions which have excluded women. He illustrates a few professions, which historically included all-male membership as the armed services or religious orders. These serve to maintain gender definitions of both feminine and masculine roles in all our cultures. Stein (1982) explains that there are several types of men's groups which help individual members explore ways of enacting the masculine gender role. These include support, political action, consciousness raising, discussion, educational, and psychotherapy groups.

Men join groups for a number of reasons but mainly the outcomes that are expected are the belief in the need for men as a group to change their behaviours, belief systems, and affective experiences. Stein (1982: 282) says:

Men's groups may lead to the greater understanding of special problems for men such as male diseases, an excessive need to achieve, reactions to divorce, and difficulties in presenting... The opportunity to hear about other men's experiences in these areas may be especially helpful to men in two ways. First,

some stress for individual men in the areas may be alleviated merely by learning that other men experience similar concerns. Second some men's groups may attempt to alter the male experience in these areas...by focusing the entire group's area of concern to men.

Significantly Stein (1982: 278) also said that the very nature of men's groups never adhered to the scientific notions of documentation in relation to their experiences and followed more the feminist approaches in looking at experiences holistically rather than fragmentally. One contribution to the literature on men's support groups is that of Levine et. al., (1990) which looks at professionally led support groups for males with eating disorders. The authors have noted that experienced health professionals believe the goals of therapy should include:

(1) restoration and maintenance of set point weight; (2) development of normal eating patterns; (3) overcoming pathological attitudes about the body, the self and relationships; (4) strengthening coping skills; and (5) helping the individual discover and use social resources which can facilitate both recovery and future development. (Levine et. al., 990: 187)

Although the condition of eating disorders is curable, Levine's conclusions are useful for men with multiple sclerosis in that they illustrate ways of maintaining and improving men's psychological well being. Like eating disorders, multiple sclerosis is often considered to be a women's problem.

Despite the lack of literature on men and multiple sclerosis support groups, there is a whole plethora of men's groups. Interactions in men's support groups are not necessarily face to face contacts, there is Internet support available for men's needs. A few examples include:

- an American based support group called The Men's Center of Raleigh and Wake County; [Internet] <<http://www.mens-ctr.interpath.com/>> Assessed 14 Feb 2000, define a support group as a group of 5 to 10 men committed to sharing events in their lives. This support group is from the Raleigh and Wake County, a centre that concentrates on men's support, and publishes a newsletter.
- Us Too International Inc, a Men's support group for those affected by prostate cancer [Internet], <<http://www.ustoo.com/>>, Accessed 20 September 2000. This support group offers fellowship, peer counselling, education and treatment options and advocacy.
- Plep, LCSW of The Northern California Men's Center Men's Quest International 2000, [Internet], <<http://www.mensgroups.com/>>, Accessed 11 November 2000. This is a practitioner offering facilitated support or counselling for men to resolve problems, express feelings from friendships and understand and improve relationships with women.
- Men for Change, [Internet] <<http://www.chebucto.ns.ca/CommunitySupport/Men4Change/index.htm>>, Accessed 11 November 2000. Men for Change is a profeminist men's group based in Halifax, Nova Scotia dedicated towards promoting positive masculinity and ending sexism and violence. About healthy relations

Part 2

In the second portion of this chapter I show the different ways that people and illnesses are presented within literature. I will show some of the discourses that form frameworks for the understanding of medical conditions and contrast them with those which seek a holistic way of understanding people. I look at discourses by comparing and contrasting

the role of participants involved in the research. This is done firstly by examining the model predominantly used by the medical and psychological professions which tends to concentrate on objectifying the disease of multiple sclerosis; and secondly by reviewing the writings of those interested in the social consequences of illness and non medical concepts of the illness experience.

Dominant Medical Models and Psychological Discourses

A dominant discourse, according to Wright-St Clair (1996), on multiple sclerosis centres on the medical model which is also known as biomedicine or Western medicine. So far, this understanding of multiple sclerosis is incomplete and the major foci of the medical model are set specifically around the physiological aspects of disease and the searching for both a cause and a cure. Perry (1994), for example, has noted that multiple sclerosis is categorised as a neurological disease and could also be described as vascular, metabolic, endocrine or a genetic disorder.

The medical profession's major focus is on the clinical, objective measurement of patients with multiple sclerosis and observing the deterioration and disabling effects of the disease. The biomedical studies of multiple sclerosis reviewed below show an emphasis which presents patients as objects, the use of drug intervention, and the use of positivist ideologies of rationalisation, placebo tests, and controlled experimentation. These are all traits of hard, testable and verifiable scientific practices. These studies, which although in the long run benefit people with multiple sclerosis from the scientific knowledge derived, help the medical profession and the drug companies foremost. They add to the symbolic capital of the professional rather than the so-called "patient". The ultimate well-being and concerns of the person with multiple sclerosis and his/her functioning at all societal levels are not the subject of focus of the medical profession. This viewpoint was

confirmed in Hight (1999) as mentioned earlier. Couser (1997: 21), encapsulates this view:

In fact, the dual basis of medical-professional authority, esoteric knowledge and humanitarian intent, are sometimes at odds. Indeed, the crux of the problem of medical discourse may lie in the nature of its relation to the discourse of science: the claim to expertise rests on the prestige of science, but the scientific tendency to objectify and quantify human experience may obstruct the profession's humanitarian intent. One need not want to undermine the authority of physicians to be uneasy with many aspects of medical discourse, such as its tendency to infantilize patients, reify illness, and medicalize experience.

The medical discourse concentrates not on the experiences of people with multiple sclerosis but on the physiological effects of disease. Studies have focused on, for example: (1) identifying the disease (McCarthy 1999; Wunsch 1999; Kappos 1999; Moeri, Raduc, Schoetzau, Schweikert, Barkhof, Miller, Guttman, Weiner and Gasperini 1999); (2) mapping the trajectory of the condition (Langworthy 1948; Grant 1989; Brown, Harris, McDonald, Patterson and Trimble 1989); (3) studying the effects of environmental changes (Warren 1982, Greenhill and Warren 1982; Rudge 1999) (4) experiential drug programmes (Mohr, Likosky, Dwyer, Van Der Wende, Boudewyne and Goodkin 1999; Compston, Kaser, Deisenhammer, Berger and Tilg 1999; Napier 1999); (5) clinical and psychiatric tests to find relationships between stress and physical illness (Druss and Douglas 1988; Gilchrist and Creed 1994; Murell, Kenealy, Beaumont and Lintern 1999; Shroehie, Kuempfel, and Sonntag 1999); and (6) checking and analysing the work of other health professionals (Carter, McKenna, MacLeod, and Green 1998; Richardson, Robinson and Robinson 1999; Vickrey, Edmonds, Shatlin, Shapiro, Delrahim, Belin, Ellison and Myer 1999).

The medical profession's scientific model is a valuable and necessary part of the understanding of the disease process, but it is only part of it. Christensen (1995: 144) draws a distinction between disease and illness. She says "disease refers to the biophysical condition" which is the focus of the medical profession whereas "illness refers to how the sick person and members of the family or wider social network perceive, live with, and respond to the symptoms and disability". The role of medicine is primarily on the health and well-being of society, but it sometimes depersonalises the patients/clients/customers with an emphasis on testing in the hospital setting. This is so that aspects of disease and handicap can be separated, commodified and repackaged similar to any experiment in a laboratory situation. This disconnection is part of the "hard science" philosophy, whereas social anthropology and nursing studies look at entire lived experiences, taking into account people's social, emotional and spiritual well-being making up the whole person. Couser (1997) shows how patients in the medical system are moved from a position of being unique and considered as individuals, to merely being used in the quantifying of objectivity. People who are ill and disabled are moved from being a source of personal testimony to that of the source of bodily specimens. Wendell (1996) agrees that both impairment and disability cannot be explained biomedically because they both take into account biological and social aspects of the person with a disability. Impairment is a personal functional restriction of any person who is not able to perform in the usual way, whereas disability is said to be in the eye of the other and relates to society's restrictive practices on that individual.

Wendell (1996: 71) indicates that just as doctors and specialists use the medical model of disability, other health professionals such as health psychologists and researchers also employ the medical model. On the whole they tend to universalise people's experiences of illness and disability. This probably is because they are trying to fit these experiences

into “hard” scientific descriptions. There are exceptions to the rule but this Western scientific model of generalisation and universalisation is a very linear way of studying phenomena.

There is also a vast amount of literature written within the psychological paradigm which relates to the psychological well being and the manifestations of psychosomatic symptoms of people with stressful life conditions. As with the medical model, discussed above, this tends to focus on quantitative research and the language of exclusion by referring to the research subjects as patients i.e. the objects of the research.

It is significant that this research primarily benefits the practitioners, and as in the medical model adds to their symbolic capital. This could eventually benefit the person with multiple sclerosis but it may not. The practitioners get to know more about that “patient’s” body than they know themselves. Knowledge gained can be used as a commodity that can be traded in other ways, the patient may feel that they have little option and are committed to a power relationship.

Research within the field of psychology is concerned with: (1) improvement in clinician service (Jopson 1999; Schroeder and Costa 1984); (2) the study of disease states (Evers and Karnilowicz 1996; Demaree 1999; Deluca, Gaudino and Diamond 1999; Landro 1999; Sletvold and Celcius 1999); (3) patient’s self-esteem and social support (Landro 1999; O’Brien 1993; Arnett, Higginson, Voss, Bender, Wurst and Yippin 1999; Barak Lampl, Sarova-Pinchas, and Anchrion 1999; Schwartz 1999) (4) helping patients cope with the psychosocial effects of multiple sclerosis (Paris 1997; Clayton 1999; Diener 1984; Brooks and Matson 1982); (5) analysis of social relationships (Maybury and Brewin 1984; Pakenham 1999) (6) the study of depression and the creation of

measurements or assessment scales, (McIvor, Riklan and Reznikoff 1984; Zakzanis and Provinciali 1999, Ceravolo, Bartolini, Louglio, and Danni 1999; (Pfenning. 1999), Van der Ploeg, Cohne, Polman, Lankhorst and Vleugels 1999).

Non medical discourses

Unlike the literature discussed above which employs a quantitative methodology, the following reviews studies employing qualitative methodologies. These studies tend to look at more holistic ways of studying multiple sclerosis from a health professional's point of view. Although not focusing specially on people with multiple sclerosis, Morse and Johnson (1991) highlight the value of stories of illness with a series of studies carried out in the nursing profession in Canada. The preface indicates that usually social science graduate students use hard science "laboratory" methods in the work environment.

However this work moves away from looking at the medical model of generalising all life experiences to studying a broader understanding of the illness experience through looking at human development. Morse and Johnson discuss five research projects and stress the significance of qualitative research methods. These projects consisted of different illness experiences ranging from recovery from heart attacks, to husbands' experiences of their wives' chemotherapy. All of these studies used the grounded theory approach to establish validity. The editors develop an illness constellation model to overcome current illness theory, and look at the role of the family and the value of reciprocity in all relationships.

McLaughlin and Zeeberg (1993), using the methodology developed by Glaser and Strauss (1967) compared and contrasted self-initiated, self-care practices of 51 Danish and 35 American people with multiple sclerosis. The purpose of the study was to determine strategies employed by people with multiple sclerosis to function as individuals without taking biomedical treatments. The researchers developed a self-care behaviour inventory

using grounded theory methods to research the participants of the study. The results were centred around coping strategies featuring self-care used in fatigue, weakness of limbs, depression, changes in living environment, loneliness, backache, changes in diet, changes in employment, bowel and bladder and vision problems: the common problem areas for people with multiple sclerosis.

The studies of McLaughlan and Zeeberg have been followed by an influential academic report presented by (Dyck 1998) a geographer involved in rehabilitation studies. Dyck conducted a Canadian study of 21 women with multiple sclerosis who were involved in the workforce. Her study revealed strategies employed by women for their continued acceptance from others considered physically able. Dyck says that women with multiple sclerosis maintain a “cloak of invisibility” which they consider is important in retaining higher levels of self-worth. The aim is to try to keep vestiges of “normality” for as long as possible. Dyck (1998: 116) noted: “Non-disclosure and the concealment or management of symptoms were common strategies employed by women to manage this ‘secret knowledge’ and defer its meanings, as they negotiated both their ability to work and the threat to their able identity”.

A different, yet informative study was that of Stewart and Sullivan (1982) which involved 60 American individuals with multiple sclerosis and was centred on looking at: (1) the conflict and diversity that occurred in the professional and lay definitions of multiple sclerosis; (2) the doctor-patient relationship; and (3) people with multiple sclerosis taking a more active role in their therapy. The study concluded that the medical profession had a significant power relationship over the diagnosis, such as the control of information and at what time to inform people of the condition.

Although these studies attempt a more holistic approach to the study of people with multiple sclerosis and the explanations of the participants are inclusive, they are written by “outsiders”. Nevertheless, the studies are grounded in the experiences of the individuals and help to form a bridge from the hard sciences to the soft sciences in line with (Peacock 1986) as outlined in his anthropological work *The anthropological lens: harsh light soft focus*.

This paradigm shift from hard to soft science is best illustrated when looked at in relation to what post-colonial studies and feminists discuss in looking at ways of knowing and interpreting for others. An advocate of “insider research” and subjectivity is Anzaldua (1990) who describes her own concerns as an ethnic feminist in America and discusses issues of the dominant feminist ideologies as affecting coloured women’s lived experiences. She says that telling our personal experiences and our world-views within a social reality validates us as human beings. The objectifying of lived experiences is disparaged by Heshusius (1994) a professor of education in Canada who presented a paper in which she observes a shift from the practical concerns of objectivity and impartiality to a more managed form of subjectivity, a shift in paradigms from empiricist or Newtonian thought to a new way of thinking. Heshusius (1994) says that “before the scientific revolution the act of knowing has always been understood as a form of participation and enchantment”. She refers to an awareness of a deeper level of consciousness in the form of a participation between the knower and the known. This can best be described as telling stories that help the reader to identify with the experiences of the teller.

These important works lead to the understanding that life experiences can not be measured in the laboratories of the hard scientists in which empiricist studies

depersonalise individuals. It is necessary to tell the stories, to share the lived experiences, for we socially construct our lived experiences through hearing what others say about their experiences. This contributes to human development and gives us a sense of increased personal power and a feeling of importance.

Another highly influential feminist is Wendell (1996), a philosopher, who has myalgic encephalomyelitis (commonly known as “chronic fatigue syndrome” in this country). She gives credence to her powerful and highly developed conceptual base for connecting the issues between the experiences of illness to feminist theory and the literature on disability. This ground-breaking book critiques the way that society stigmatises people with differences, she criticises the cognitive and social authority of medicine and rationally discusses the ideology of disabilitism. The book is very empowering and inspirational, it is an important study made all the more powerful by the fact that she comes from the perspective of a “lived in” condition, she is an insider. Wendell explains that we should be seen as individuals and not as a group of subjects in a category.

The following section is also about qualitative research, narrative descriptions, story telling, and respecting diverse realities of people. These reflect the ethnographical realist perspective of this thesis. The narratives reveal the experiences of individual authors.

Personal narratives

There is also a plethora of popular autobiographical literature written by people with multiple sclerosis and many of these are important to give personal perspectives of having this condition. Mythen (1990) presents a serious book in a light hearted manner. The author has multiple sclerosis and this interesting book is illustrated with cartoons, which are the traits of his profession. This Canadian book is well presented and punctuated with

his lived experiences, it is subtitled “Meeting the challenge of multiple sclerosis” and is kept in many regional Multiple Sclerosis Society libraries to give to members to read.

Another recent popular book is that of Mackie (1999) a British air steward who relates stories of her development of the symptoms of multiple sclerosis and the development of her condition. The subtitle is “Learning to live with multiple sclerosis”. The book explains her social relationships and is uplifting, a source of encouragement for others who have the condition, and assurance “that life for them is not over”. Although these autobiographical accounts are valuable they add very little to the theoretical base of this thesis. However, they confirm that individual experiences can provide insight into living with a chronic condition. Academic writers who have multiple sclerosis have contributed to our theoretical understanding of the lived experience and their writings are reviewed below.

Ginter (1978) presents what he calls “An autobiographical primer of multiple sclerosis”. Although his book was written over 20 years ago it has many pertinent reflections on the condition. Ginter was a prominent educationalist and was an associate professor at the University of Chicago when he developed signs of his multiple sclerosis. He was diagnosed in 1962 although the medical practitioner withheld the information from him for over 10 years. This valuable and informative book was written so that others may benefit from his experiences. This empowering text gives legitimisation to symptoms that I thought were too embarrassing to share. Importantly, the book reminds us of the changes in the patriarchal nature of the medical profession who interpreted the experiences for their patients in the past. Ginter also devotes some time to the explanation of the value of social support discussion groups that he joined in his area.

Another valuable source is Burnfield (1985) who reports a personal exploration of multiple sclerosis. Burnfield is a leading British member of the international multiple sclerosis movement. He is a qualified medical practitioner practising as a psychiatrist. The work gives a balanced view from the individual's perspective of the illness experience and gives a synopsis of the disease condition. Burnfield further extrapolates many of the social issues that may affect people with multiple sclerosis, such as dealing with health professionals, family, and the wider society. Although written 15 years ago this book covers these concerns which arise even today. A most poignant part of this book is the postscript where he feels that his experiences make him a better doctor.

Another recent book is that of Loader (1996), A British academic, who gives a personal narrative of her multiple sclerosis. Her interesting account of the procedures that she endured in the hospital shows similarities with other people who are diagnosed with multiple sclerosis. Her stories and the social construction of her illness are empowering, her resilience and the tenacity of her spirit are uplifting. Although much of her book is given over to biomedically unrecognised treatment, her stories of her illness experience are powerful.

I have sought not only literature relating to people with multiple sclerosis and the following are influential academics who give their own renditions of the experiences within the disability and illness field. A seminal study by an eminent anthropologist was that of Murphy (1987). Murphy relates many of his own experiences of a serious chronic illness which eventually led to paralysis. At the time of publication he said that no other anthropologist had written a book on the experiences of illness. This is significant literature because it is personally helps me to relate to the experiences of the struggles that he surmounted, feelings of connectedness and the empowerment of being able to identify

with some aspects of the author.

This is very similar to another academic in a related discipline who presents a more contemporary finding in a book called "*The Wounded Storyteller*". Frank (1995), a professor of sociology at the University of Calgary in Canada, is informed by his own serious and chronic illnesses. This book is about people telling personal stories of illness which not only gives a voice to the body, it helps them to relate to others facing similar experiences and empowers the listener who may also have an illness. According to Frank, one of the social aspects is that stories of illness are not made up by the storyteller in isolation, they are constructed and the telling is moulded and internalised by rhetorical expectations of that person. This book is inspiring and empowering for those who have illness. It shows that the ill person can become actively involved in describing and taking responsibility for their illness, rather than being a passive patient awaiting medical practitioners to assume control, interpret and speak for that individual.

Another illuminating book written by an American academic with her own chronic illness, is that of Register (1987) The book contains many experiences of life threatening conditions including multiple sclerosis. This literature draws on her own lived experiences of another incurable condition, lupus, and provides an in-depth understanding of most social issues that affect those who are chronically ill. She examines how healthy people react to those who are ill and gives guidance on the various sources of social support.

Similar to that of Burnfield mentioned earlier was Bessier (1989) who illustrates his experience of illness. He was a competitive athlete in America qualifying to become a medical practitioner when he contracted polio in his early twenties. The story of his

illness experiences have some similarity to the experiences of multiple sclerosis as the majority develop signs of their condition in their mid twenties. This is a powerful and well written book dealing with many issues such as spontaneity, issues of social adaptation and accommodations, and re-integration back into society. This is not an academic book but the experiences of illness help to develop a clearer understanding of the phenomenon of illness.

A study by Neilson (1995) examines the experiences of New Zealand women with congenital disabilities. This masters thesis used life history gathering techniques and focused on nine Pakeha women and concentrated on looking at success in relative and achievable terms. Her work relied on Foucault's theory of discourse analysis. This is a valuable source of New Zealand research although specifically is about feminist issues and it raises issues of the disempowerment of a minority group.

To finish this section, I present book a by Couser (1997) which is set in America and is primarily concerned with illness narratives. Although the author does not have a serious illness he says that prolonged, serious, or chronic illnesses and disabilities may ultimately yield more complex and multidimensional narratives than acute illnesses; as they may lead more to autobiography rather than autopathography. He also looks at the structures that illness stories use, and seeks to find how the storytellers draw on, revise, or expand the existing range of life-writing conventions in order to represent previously under represented conditions.

Conclusion

The first section of the literature review examined the beneficial nature of the support group environment, which was followed by literature on men's groups, and involved the

multiple sclerosis community. The second part of the chapter covered separate discourses and centred on the rationality behind those ways of knowing, the medical profession's focus on objectifying and rationalising the physiological aspects of the disease processes of multiple sclerosis. Other literature has highlighted the change towards looking at the subjective nature of study. This has mainly been the feminist analysis of disability issues and the study of post-colonialisms whether it is looking at ethnic studies in relation to dominant Anglo-American feminist discourses or medical hegemony of practitioners over their patients. The final portion described phenomenological aspects of the lived experiences of illness including multiple sclerosis to show that illness experiences could never be learnt in isolation; they are socially constructed.

The literature review reveals a shift towards a study of the subjective and personal lived experiences from the objective nature of looking at impairment, disability and handicap across the disease spectrum and used predominantly by the medical and health professionals. Wendell (1996) notes when relating to the false universalisation of disability that problems arise out of the medical model of disability where "Doctors, researchers, and rehabilitation specialists tend to uniniversalize the experience of a given disease or disability because they are trying to fit people's experiences into "scientific" description of disease or disability". The World Health Organisation (WHO) produced a classification used by Perry (1994) to describe these as:

Impairment is defined as any loss or abnormality of psychological, physiological or anatomical structure or function. Disability refers to any restrictions or inability to perform normal activities. Handicap is defined as social, economic, environmental and cultural disadvantages that arise from impairments or disabilities which prevent a person fulfilling normal social roles.

So disease is seen as a physical characteristic and illness along with sickness are social constructions. Issues arise here about the naming and labelling of these conditions, illness is a personal description and may be chronic but sickness is usually a short term complaint. There are relationships of power to do with who gets to label, name and describe these conditions. But illness and disability are not the same and unlike people who are ill, those with disabilities are not universally incapacitated although being disabled can cause health problems which lead to illness. And the effects of being ill can be disabling.

Chapter Four

The Joint Participants

Stereotypes of disabled people as dependent, morally depraved, superhumanly heroic, asexual, and/or pitiful are still the most common cultural portrayals of people with disabilities.

Wendell (1996: 43)

The joint participants in this research are all rational thinking individuals and I have devoted a chapter to introducing them. I was profoundly affected by a scene in the film *The Elephant Man* where the lead John Merrick was being pursued by a crowd seeking a glimpse of the “strange creature”, and then when he was cornered, his yelling, “I am a man”. I empathised with him, and in some small way, although I do not wish to essentialise his experience, I felt if my condition was disclosed without permission, I may suffer similar frustrations in dealing with my own society.

The emphasis of this study is not primarily the condition of multiple sclerosis, it is about people. This group is not homogenous by nature, but we do share some similar experiences and as a group we are drawn together for camaraderie. We use the group as a platform for dealing with some issues, but there are other issues that would not be appropriate to discuss in this group setting. We are individuals and people first and we do not live in each other's pockets. The group survives only if the relationships are reciprocal, there must be give and take from all of the members. There are protocols that are followed, although these are unwritten and not spoken about, the group members do not transgress these and if they do they only do it once. Examples

of these would include not eating in front of each other and not discussing personal sexual performances either past or present.

This is important to members since many people with disabilities are hidden, they are relegated to the realms of the home and the private sphere. It is important to be seen in public. The benefits to them are; firstly, it is good for their own self-esteem, and secondly it helps the others (able-bodied people) to lessen the fear of becoming disabled. You can see that we are human-beings, we are part of society. The members of the group and joint participants in this study are as follows:

Jack

Jack is 48 and has known about his multiple sclerosis for about 20 years. Although diagnosed in 1982, his symptoms were evident for a few years before with summer time exacerbations of fatigue causing dropped foot and vision problems, falling up steps and dropping items became a more frequent occurrence. By the time of his admittance to hospital in 1982 he had been married for 7 years. The marriage ended in divorce two years ago when he and his wife went to America.

Prior to the diagnosis of multiple sclerosis, Jack maintained a hectic social schedule. He was an athlete who enjoyed skiing and he worked as a company accountant for a well-known North Shore car business. Slowly his health started to fail and he needed a safer working environment. He sought sympathetic employment and replaced the more mentally and physically strenuous positions that he held. His final employment

was at a company where his boss was understanding of his needs. This person had first hand knowledge and was keenly aware of the physical limitations of a disability unconscious society as his son also had a chronic life condition.

I was managing three petrol station workshops doing the accounts work. At that point it was OK, from time to time to work the forecourt, and like washing windscreens. One minute you have got hold of the squeegee brush and the next minute you have poked it through the window into someone's face, because you have missed the windscreen. And it was really embarrassing and you can't explain things to people. You are falling all over the place, particularly in the summers.

When I first met Jack he was pretty well ambulant but used to walk with the aid of a stick. He has since lost the strength in his legs and is totally reliant on a motorised disability scooter. This is his sole means of transportation and when he wishes to travel further afield he gets a mobility taxi that can carry him in his scooter. He owns his own house in a central North Shore location where he can access many services by riding his scooter to them.

Jack's positive attitude has helped him to relate to his failing health. He now shares his house with a partner who also has multiple sclerosis. He maintains a regular regime of physiotherapy at a local university campus where he has treatment and he assists the institution by acting as a research participant. Since being diagnosed with multiple sclerosis, Jack has been a committee member of the Multiple Sclerosis Society. He continues to be a respected senior member holding the position of past-president and is currently the newsletter editor.

James

When I first met James in 1992 he had been diagnosed as having multiple sclerosis a year or two before. At that stage he was going through a period of transition and readjustment to living by himself.

James was launched into the world of multiple sclerosis when he was diagnosed at 44. He had noticed a problem when he could not maintain the stamina needed for lifting heavy weights. Concerned about his poorer performance, James went to see his general practitioner who did not know what the problem was and referred him on to a specialist. His life was turned upside down and this traumatic life event saw him hospitalised within a day of being assessed by a neurologist. Within two weeks of his hospitalisation, his analytical mind deduced that he had multiple sclerosis. By the time he returned home the letter was waiting from his neurologist confirming that this was, in fact, his diagnosis.

Before being admitted to hospital following what turned out to be a major exacerbation of multiple sclerosis, James had been a dynamic and robust athlete and a successful chief executive officer working in the printing industry. However, when he was released from hospital he was in poor shape; he could not walk to his letterbox without the aid of two walking sticks.

James had been married for nearly ten years but the marriage was destined not to last and about a year later he and his wife separated and eventually divorced.

So it came as no surprise when she said she was leaving. I knew it would eventually happen. You know, being sick of course, the days of my usefulness are being diminished very rapidly.

James bought out his wife's share of the property and now lives by himself.

James' tenacious spirit and the "will to live" have driven him to rebuild, sustain and maintain his body through planned and strenuous physical exercise so that he can walk without any aids whatsoever. His stamina, although not as good as it was, can last long enough on his good days to enable him to walk for a few kilometres. This is vastly different from before diagnosis when he used to jog 10.5 kilometres every two days, lift weights as a competition weight-lifter and, for a hobby, partake in deep-sea skin diving.

One of the problems that he lives with is that his eyesight is not good enough for him to drive a motor vehicle and he relies on his friends or a taxi to get about. His poor eyesight has made his world a much smaller place to live in. He says it confines his existence.

James is now very much in control of his life. He has maintained his interest in business and is involved in several, including one importing and retailing marine chandlery.

Des

Des is 37 and a family man living with his partner and two young boys, one a pre-schooler. He is the only member of the group with a young family. He has been diagnosed with MS for a relatively short time. He joined the group in the later half of 1999 and, by that stage, had been noticing symptoms of multiple sclerosis for about two years. He drives a car and has only recently given up his full time business activities, although he does design work. He receives an invalid benefit, but this is a stop gap measure until he is able to resume full time activities.

Des is a craftsman by trade and operated for many years as a self employed manufacturing jeweller, a business that required many hours of diligent work. But he worked long hours, about 80 hours a week and this had an effect on his health for he noticed his stamina and fatigue were the most affected.

You are getting home and you are getting more and more tired, and you think back and you think yeah, that last month of work all I was doing was getting home. When I got there I was doing nothing. I was going down hill and you think. The point where you reluctantly give up the work. You think, damn, I just fell off the cliff. Well you didn't, you went down hill and it started a week ago.

Des takes responsibility for his life and illness. He particularly likes one of the local multiple sclerosis groups as the focus does not centre on his multiple sclerosis. It is just a get together of similar guys, and Takapuna is convenient for him. He has been to other support groups but dismisses them for a number of reasons.

I think when you go to those meetings and you have a couple of ladies saying, "How are you getting on, and would you like a cup of tea?" and thinking you are accentuating my disability. That is not what I need. I don't want a shoulder to cry on. I want a crutch to lean on. I don't want sympathy.

Des is committee member of the regional Multiple Sclerosis Society.

George

George is aged 51 and holds a PhD. He is an articulate speaker, a talented artist and he had spent most of adult working life in either Australia or Europe. He has travelled widely. George is a classical musician who plays the violin and spent many years either conducting orchestras or composing music. He now lives in a very large property owned by his family and shares with his father and other relatives. George has been divorced for some time now.

George started to experience related health difficulties when in his late 30s and then in 1992 he noticed numbness in his hands. It was not until his forties that he had intermittent eyesight and multiple sclerosis was confirmed with an MRI scan in 1997. Around the time of his diagnosis he was given steroids for his optic neuritis which meant his resistance to infectious diseases was significantly lowered and he caught a double bout of pneumonia.

George does not look as if he is moderately physically impaired and appears quite agile although he uses a walking stick from time to time. He drives his own car and

travels great distances visiting his many friends around Auckland. He confirms that he is a social butterfly.

But dexterity, good eyesight, and extreme concentration are fundamental for him to complete any classical musical piece. He says he can still play the violin as well as he always has, but his body is unreliable and he will not give public recitals. He does give impromptu performances occasionally.

He says:

That is why I can not take engagements. If I take an engagement I have to take a private one not a professional one. Because of my lack of co-ordination, there are some days where I am shaking a bit and somedays my co-ordination is OK. As you know that is the first thing that struck Jacqueline Du Pre many years ago. She had to stop playing as well, the cello as you know, which was an incredible tragedy in her life. I tried not to become bitter at the time, but I almost thought that God is almost testing me, the only thing that is significant in the last couple of years is my belief in God. Especially since losing my mother, because I just know, now I know and I have that sort of faith.

George has become more altruistic and selfless. He wants to offer his talents to others and one way he does this is by playing impromptu recitals to groups who are less fortunate than himself. He says he tries to “Positivise” every situation. He is a committee member of the regional Multiple Sclerosis Society and is the representative on their national council.

Harry

Harry is 31 and the youngest member of the group. He gave up driving in February 1999 because of vision problems. He is a member of the group who attends only a few meetings as he has a problem with his back muscles and is unable to sit up. He is unable to attend in either a wheelchair or disability scooter. Harry is now bedridden. The personal interview was conducted when he was in respite care at an Auckland nursing home that had hospital facilities for a grade 5 person. Grade 5 is 24 hour nursing support for patients who are effectively tetraplegics. This is the most comprehensive care without being in a public hospital. The North Shore's nursing homes are limited in the extreme, the only beds at the time of writing this thesis are in the Auckland area on the southern side of the harbour bridge. Harry keeps his mind active by reading and watches television from a remote controlled bed.

Harry was diagnosed with multiple sclerosis in 1995 about the time of the Rugby World Cup. The initial symptom was a sore neck and he was treated unsuccessfully at the physiotherapist. His doctor made a referral for Harry to see a neurologist. He was diagnosed with the aid of a MRI scan and submitted to a lumbar puncture. This was not painful and he had no ill effects as a consequence.

Before he noticed problems of multiple sclerosis Harry played rugby and judo. He was a truck driver and worked long hours 55 to 60 hours per week, but it just got too difficult for him. After he was diagnosed he went to the Auckland Technical Institute and retrained for computers and his old firm offered him a position back in their office taking telephone orders and putting data into the computer. But by early 1999 the

firm asked him to leave.

Yeah they did eventually say, "We are going to have to let you go, because your memory is getting worse and you are slurring a bit more". I said fine, I said no problem, you have done more than enough for me.

Maurice

Maurice was physically active as a young man and started in his early working life as a merchant seaman broadening his experiences by leaving school and going to sea at the age of sixteen. Now 51, he is the only member of the group who does not have multiple sclerosis. His condition is allied to multiple sclerosis in the fact that it is hidden; it is invisible to the general public and it can be concealed from them and he has had osteoporosis over 10 years now. Maurice is a member of the group, by association more than anything, as he was the catalyst from which the "motivation group" started off. About a year ago James mentioned he had seen Maurice in the street after not seeing him for a number of years and asked if was appropriate to invite him our local multiple sclerosis support group. He was invited to come along and is now a participant in the group. He is an active member of the multiple sclerosis society at both regional and national levels.

Maurice lives by himself in a self-contained apartment and he was until recently in a long term relationship for more than six years. Like the rest of us, his illness is socially constructed and he comments that initially the medical profession was not looking for what he was diagnosed with. This was because he was an active male in

his early 40s, and the majority of newly diagnosed people with his condition are female and in their 60s. Maurice can look forward to the constant companionship of pain and, like multiple sclerosis, osteoporosis is degenerative and progressive.

It is like your MS, you learn to live with it. Initially when they first diagnosed me, I went into a complete spin. I didn't want to talk to anybody, I just sat here and I brooded and that went on for a long time. I was a really miserable sod. Why me? What have I done? I have always had good health. I have been "Jack the Lad", I have been "fireproof" and all this thing. And now they tell me that I have got this!

Maurice's accent on life is now of service to his fellows, he says he is so busy he has not got time to think about his own condition. He enjoys being in the political limelight and is an active senior member of one of the local political parties.

Ronald

Ronald is aged 57 and is the oldest member of the group. He was only told of his multiple sclerosis about six years ago.

Before being diagnosed with multiple sclerosis he had been a self employed successful businessman, an entrepreneur and innovator with an astute business mind. With such entrepreneurship, he purchased land in central Albany when it was the place you passed through on the way from the North Shore to the Hibiscus Coast and north. But things started to go wrong. His intellect became cloudy and wrong business decisions were made. Others noticed the deterioration probably before he

did and his health started to fade. Ronald says:

I was doing very well for a long time you know. Virtually I could sit down and figure out things and I wouldn't make a mistake. All of a sudden I started making mistakes, huge mistakes...I lived on twenty acres up there and I used to run here and run there, and I got up one day and went to run across and I just couldn't move my legs.

Ronald has been married for 36 years, has grandchildren, and he is predominantly house bound. He does not drive because of vision problems, and has difficulty moving around. Ronald would benefit from having a disability scooter for out of doors, but doesn't qualify for one from wheelchair services as he is not a beneficiary. His world is now extremely small. He used to enjoy driving, and says that his friends and acquaintances can not believe he does not drive.

Although still walking, he has great difficulty with mobility. He has the classic multiple sclerosis signs such as dropped foot, laboured walking gate, is slow and has perceptual difficulties. He falls a lot and finds walking fatiguing. His wheelchair is used when he goes out with his wife and has to cover long distances, but this is not suitable at home as they live on a steep property with steps at both the front and rear of the house.

The main focus of his health regime centres on acupuncture. His Doctor is Chinese and qualified as a biomedical general practitioner and is proficient in acupuncture. Ronald has regular acupuncture treatments and supplements his diet with evening primrose oil.

Chapter 5

Lived Experiences

Where are we headed?

The next three chapters are devoted to the presentation of “data” obtained from participant observation, personal reflections, conversations and interviews. These were used to examine issues around the experiences of the individual participants who collectively form the “boyz.R.us” group. Each member gave unstructured life histories of their experiences and these in turn were used to develop different themes for this study. Recognising the extent and complexity of information gathered, I decided to present this in three separate chapters, each of which represents a major dimension of the study. It needs to be kept in mind, however, that the three chapters are not mutually exclusive and were developed in unison.

This chapter covers issues of discovery in which the participants tell their stories of when they were diagnosed with their condition. We describe our feelings around the time of our initiation into this world of becoming “different” from what is considered “normal” or ordinary. This examines the processes of transition and then explores the world of being considered an “other” looking at the societal fears and perceptions of negative stereotypes. The members of the group explain ways that they do or do not cope and adjust to these perceptions about their lives. It describes the development of

their strategies for survival and wishes to be included in society.

Every person's experience with multiple sclerosis is different and even in this small group of eight there are dissimilarities. The major factors that we share in common are that we are male, have multiple sclerosis, are Pakeha, and have lived on the North Shore of Auckland for a number of years. There are probably many more similarities, but there are also many differences. Some of us work and many of us are committed to relationships that bind our responsibilities to performing certain tasks.

Newly diagnosed

The condition called multiple sclerosis has symptoms in most of our cases that developed from what we thought were minor and insignificant problems. As the condition developed, these problems began to impact seriously on our lives and well-being. In my case, I thought I needed spectacles and went to the optician. Des thought he had a pinched nerve and went to a chiropractor. Harry had a sore neck and went to the physiotherapist. Jack started tripping up stairs. James could not hold a heavy weight and thought it was muscular, George had a smoky eye, and Ronald had difficulty running. The exception was Maurice who had severe pain that required hospitalisation due to a condition related to multiple sclerosis (experiential rather than physiological⁷). Our conditions crept up on us and took us by surprise with what appeared to be fairly minor and easily explained symptoms that steadily became more and more significant. These minor problems turned into what later became diagnosed as multiple sclerosis.

In the beginning stages, many of us were ignorant about what was happening and the effects of our condition. As multiple sclerosis is difficult to diagnose, people with the condition are often not informed about the true intentions of the medical examinations. Many of us began with the idea that our problems were relatively minor and could be fixed through medical intervention. These misconceptions are illustrated by the experiences of one participant who started by paraphrasing what his doctor told him:

He said: " I am going to set you up with an MRI scan. It could be that you have an inflammation in the spine". I believed this could be entirely logical. I was aware of a bit of an inflammation in the spine as my wife had one. (Des)

So what was it like to be told that you have a debilitating condition that may be progressive? Most of us did not really know what multiple sclerosis was, although some of us did know in the back of our minds that it was some dreaded disease.

I had never ever heard of it before. I was 28 or 29. I mean you are too busy having a good time, aren't you. We were just into our second house, renovating. The thing that really frightened me was when I was up a willow tree with a chain saw, I couldn't hold it any longer. So it is not only the Willow Tree that nearly got topped, it was me as well. (Jack)

We are unique individuals and do not have the same experiences. As a result, we handle different situations in different ways.

I was also keeping it a secret from my family, except for one brother, and

⁷ Maurice is more a member by default, his condition, osteoporosis is perceived as a "woman's" problem as is multiple sclerosis.

then I had to go in for an MRI scan, went to the neurologist two or three times, then the diagnosis was MS. I was unbelievably shocked. Part of the reason why I had double pneumonia was because of the effects of prednisone which reduced my strength, my immunity. It was so incredibly fast moving. It came at me with a rush... well I was very, very distressed.

(George)

The loss of health may be understood along the lines that Kubler-Ross (1969) illustrated in her stages of grieving, where different phases in a process of dealing with life's issues may be challenged or accommodated by the participants of this study. Her five points in the process included denial, anger, bargaining, depression and acceptance. But the complex nature of dealing with any life threatening condition may see these processes arise in a person's life at various times in their lives. It is complex and human nature is not static, and moods can swing from one to the other and go back and forth.

Yeah, there was anger, there was depression the whole gambit, the whole bit, I went right through the card, then, as I said earlier, gradually I came out of that with Sally the Disabilities Co-ordinator and various other people. I think it may have been Sally, or somebody said to me, when they first sent me back home from North Shore Hospital, they knew I lived on my own... they shouldn't have done that.

(Maurice)

Or in the case of another participant it was necessary to concern themselves about other issues as a release from thinking about his multiple sclerosis.

When I was diagnosed I had a classic feeling of "why me?" I had a sick dog.

(George)

One of the newly diagnosed participants showed classic denial of his condition and

preferred not to think about it.

I have never felt any sorrow in my relationship to MS, in my plight as a result. I have felt some serious sorrow about a bad job, that I am stuck at because I can't just quit, and things like that. I guess I have different thought patterns to most, and this is where I wonder how much. You have to be very careful that your psychopathic thoughts aren't inflicted on yourself too much, i.e. I worry, should I worry about the fact that I have MS? Everybody seems to say, everybody is saying, oh I know when you hear the news, you just think, oh no, why me? At the same time, at the coffee group, James said, the first thing is you think of was why me, and the amount of people who have told me that, so many people, and every single time. I actually get a little angry at that. No, the thought never entered my head. It just never did. (Des)

We are all individuals and our responses differ, some of us are too busy just trying to survive and do not concern ourselves with what might or might not be the consequences for the future. Maybe he did not think, "why me?" When he was preparing to hear the medical professional's diagnosis of his condition.

I received a phone message from my GP on my answer-phone, asking me to ring him. I rang him back, he said, "I have got your MRI results here. Well, the results aren't good. Can you come in this afternoon and perhaps bring your wife. Yep, to which we did so, which gave me an hour and a half to wonder what it might be. During that hour and a half, I was surprised at how I felt and thought... Just about everybody I spoke to said that that hour and a half must have been horrible. Oh you must have been thinking the worst. (Des)

Ironically other people imagine the wait for diagnosis as being worse than the person with the condition does. Another participant did not accept being kept in ignorance of

what to expect and decided to take matters into his own hands whilst still being diagnosed, and found out for himself.

I went to the Medical School Library at Auckland Hospital, and in conjunction with some nurses at three o'clock in the morning to six am looking to see what I had. And I couldn't really understand what I was reading, but I came to the conclusion that I had multiple sclerosis.

(James)

One participant told me of a dilemma he faced subsequent to his diagnosis. (To maintain confidentiality, I have not printed his pseudonym here). He said:

Very early on in the piece, I was having difficulty sleeping and my doctor prescribed sleeping tablets. One night sitting here I just had reached a stage where I thought I had had enough, I don't want to carry on, I am out of here and I took the whole bottle and then went to bed. I slept for thirty six hours and I woke up again.

Most participants experienced what Kubler-Ross (1969) refers to as the bargaining stage in which they revisited their own philosophical or religious beliefs. Some of us might see the diagnosis interpreted in a religious paradigm. This is illustrated by the following participant's description:

I tried not to become bitter at the time, but I almost thought that God is almost testing me. The only thing that is significant in the last couple of years is my belief in God. Especially since losing my mother, because I just know, now I know and I have that sort of faith. (George)

Other writers such as Burnfield (1985: 62) have stated that 'Once we have been diagnosed as having MS, we must live with a disease which is humiliating and

depressing. We have to cope with a loss of health and security, as well as changed roles in family and at work, which may be devastating to our self respect'. But sometimes we just shut the problem out, we are in denial and by avoiding it, it may go away. It was another member of the group that spoke of being extremely optimistic and acknowledged his denial of the condition.

But you have to think along those lines, and this sort of gives you something to work to, because I have a hell of a problem accepting I have got something wrong with me. (Ronald)

Having to deal with any problem is different for each of us as we have our own ways of coping or not coping. My denial started as soon as I had heard the word "multiple sclerosis." In the early stages, I would try not to link any health-related issues to my condition.

Yeah exactly, and then I had to figure out how I was to get home, as I was out walking. I didn't have a walking stick, I didn't have a walking stick for five years after that. I never went to the Doctor about this, you know, I didn't know it was an exacerbation. I thought it might have been related to MS and then for the next week, when I used to walk up to the supermarket, from where the office was, it was like walking on egg shells, it was difficult, there was no feeling in my feet. (Michael)

Burnfield (1985: 51) comments that a lot of people with multiple sclerosis find it impossible to believe that their condition is incurable and he indicates that it may be a usual response for us to find a balance between giving up and fighting against the inevitable. He parallels many of Kubler-Ross's phases and the responses of dealing with changing emotions relating to multiple sclerosis. He also says that people with multiple sclerosis often speak of the relief in knowing that their condition has been diagnosed. Wright St Clair (1996) comments that many of the women participants in

her study also confirmed this. In my case, some three years later, the balancing between the denial and the need to know led me to seek further information.

He [the neurologist] said your tests have come back and the protein level in spinal fluid indicates that you have got multiple sclerosis. I said I thought I might have it, it was a sort of relief to know, because I only had this young Chinese doctor tell me, "Well you have got multiple sclerosis", and everyone else told me I didn't. The clairvoyants I had gone to, said "there would be no problem with my health and I was good as gold", I could still walk, so it didn't appreciably affect me too much. (Michael)

Liminality

The shock of being told that you are ill or disabled is somewhat like transiting to another world. One minute you are well and the next minute you are ill. Describing the process of liminality, Turner (1967) explains that the individual moves from one state to another and that the symbolism is convoluted and modelled on human biology. Van Gennep (1960) defines it in rites of passage as the first phase of separation or as Frank (1991: 9) describes when he found out that he had a heart attack: "I was lost in the sense of sudden and profound change. In the moment of what I call a different person". This is very similar to the experiences of the participants in this study who had been diagnosed with multiple sclerosis but did not know the real extent of their condition. The transition from having good health to having bad health may have been immediate or have happened over a period of time. But nevertheless, being told was often shocking for members of the study. Our experiences as children of hearing about others who were ill, also helped us to construct our own ideas of what it was like to be ill. One of the participants described what it was like when he was told of his condition in hospital:

...about early afternoon, about one o'clockish, they swarm into the room draw the curtains around you and they are all standing there with their clipboards and they say you have got multiple sclerosis. I had never heard of it, (could never say it), and are there any questions? And if you don't know the term, they sort of say don't change your life, nothing may happen, go on and act normally, and if you have any question go and see your GP. (Jack)

Jack's description of the experience of being in hospital was very similar to others including myself. He goes on to explain:

Well, no one is saying anything to you, you are being put through this whole raft of tests and I have never been sick in my life. I have never been in a hospital before, and all of a sudden you are in there for three days and not allowed to get out of bed basically. You know, it is peeing in bottles and you have never had to do that in your life before and you don't feel unwell. But the diagnosis, it is the way they throw it at you at the end of the three days. (Jack)

The problem is often that you still think you are as good as you once were, and the process of knowing that your health has now gone, may take some time to come to grips with. Many men with illness still respond to the "man's box" image that they have to work, work, work. They carry on with their work as before for fear that they may be considered bludgers. A tenuous relationship forms with their partners who are conditioned also to believe that men must work.

How we deal with the liminal state differs amongst individuals, but the uncertainty is certainly an integral part of the experience of that state:

I was actually in quite a lot of turmoil when I lost this eye, I was frightened of course. I was sent by my GP into Auckland Hospital and was given this prednisone, quartisone, 1000 milligrams in the morning, straight into the vein, took an hour and a half, and in the evening as well. And I had to go backwards and forwards. Someone had to drive me because I was in such a distressed state. (George)

Once we have transited through one world to another, to that of a person with an impairment, our acquaintances and some friends start to give us a wide berth.

As one member of the group said:

I lost all the fair weather friends, the ones that you couldn't go skiing with any more, and the apreski and have a good time. (Jack)

But then the genuine friends start missing your company and you start to feel that you are affecting their enjoyment so you stop going to functions because you do not want to be a problem. As Jack indicates:

But then I became aware that they were coming down off the mountain earlier, because they couldn't handle the fact that I was there on my own. (Jack)

Perceptions of negative stereotypes

A common problem that we have all faced is that our acquaintances and other people generally have a poor perception of us. I will develop this conversation a lot more in the next chapter, but people who knew us before we were diagnosed tend to avoid contact. They probably do this because it reminds them of their own mortality, and perhaps because they are embarrassed about not knowing how to broach the topic of

our condition. It may be the fear that they can not cope with the situation and for some misguided reason consider that multiple sclerosis could be contagious or that it is all pervasive and consumes our very being. People make a point of avoiding you. One of the newer members that has recently joined the group, but is not a participant in this study, said that people used to cross the street to avoid him. Another participant commented:

You can soon sense when others are uncomfortable with your condition, so you would stop. Getting back to my skiing mates, I would go away with them, but I couldn't walk in snow any more, it was really difficult. (Jack)

A common theme in the interviews was the difficulty that participants had in seeing what might happen to themselves in the future. Once they have seen the “other world of MS”, they stop wanting to be reminded of what might happen to themselves and therefore they often engage in avoidance. This avoidance response can sometimes continue for a period of years. But at some stage, they start seeking out others with the same condition. They seek solace in the company of others with shared experiences and eventually and collectively feel a sense of communitas. Other researchers have noted the benefits of mutual support groups and social support in general. This developing sense of affiliation with a community can sometimes have an adverse effect, of it at least initially. As one participant said:

What I put it down to, is like the MS Society has their meetings and what have you, and I've found that when I went to them, and there was young people there and they were severely handicapped, and in wheelchairs and that sort of thing, it just blew me away. I thought, God the things that they have got and it really used to knock me. So I just never went, I thought the easiest thing was to talk about it to someone, and they said just don't go.

(Ronald)

Although this was Ronald's initial response becoming involved in the "boyz.R.us" group has helped him to feel relaxed in the company of others with visible signs of difference.

A common concern expressed by participants (myself included) was that illness is considered by others to be a sign of weakness and that we become self-conscious and perceive that others may well be looking at us as being different. All through our lives we are conditioned not to stare at people with impediments - our parents say to us as children, "Don't stare at them" - whereas in actual fact they really mean do not stare at them as it might bring embarrassment on me. Jack comments on observations that he has made:

I suppose the worst time of being conscious of people looking at you was prior to accepting that I had needed to use a cane. Then once I had a cane, which was a symbol of my disability, it didn't worry me, but prior to that you could almost see they were thinking that he was drunk. And that really hurt.

(Jack)

The perception of a negative stereotype influences the way we react and conceal our problems. As James explains:

I was carrying some chain out one day for a customer, and I fell over and lost my balance. He said, "What's wrong?" I said I got wounded in Vietnam, I got shrapnel and there is still some stuck in the cerebellum and it affects my balance, I knew he couldn't handle the fact that I had MS. I could tell, that's the sort of guy he was. And he immediately thought oh, a war hero, so he looked upon me in a different light.

(James)

There is a hierarchy of disabilities evident in the minds of people. Apparently, persons with disabilities are perceived by society in general to have more validity if they are wounded in war in the service of their country, than if they have a neurological condition, intellectual or psychiatric disability. As one New Zealand theorist in disability studies, Cahill (1991: 11) states, "There is a hierarchy of disability -- some disabilities are more acceptable than others, e.g. psychiatric disabilities are stigmatised more than hearing disabilities. These different combinations also have an effect on self esteem".

But when I asked James why he came to the above conclusion, he never considered a hierarchy of disabilities as such. He just concluded that he was a better judge of character than most others, saying:

For some people, and I can actually sort them out, I am almost always right, in the people I can sort out, who I am going to tell the truth and who I am going to fabricate, the story theme. (James)

When challenged on this view point he just said: "That is how other people can perceive us".

Unfortunately there are many occasions when we cannot be involved in particular activities through one reason or another owing to our condition. By withdrawing, it may be construed that we do not like the activity or the person that we are with. Often this misunderstanding is due to a lack of communication between people with and without disabilities. This is illustrated by Jack's comments about his former partner. Part of her enjoyment was being with him

and if they were apart she was not enjoying herself. They had gone to Disney World near their home in Florida where she enjoyed riding the exhibits.

And coming whizzing past me sitting in my wheelchair and I didn't understand that, I know I didn't understand that, because I would say 'do the rides, I enjoy seeing you enjoying yourself', but she wasn't enjoying herself. But these are the things we didn't talk about. (Jack)

Another member of this study related episodes of other people finding conversation with him difficult. He became aware that he was saying "silly things". He was informed by his wife later that he said something that was not well received in the group he was having a conversation with. One participant said:

Yeah, they definitely do, but of course sometimes my wife will relate what has been said, and other times she just ignores it. (Ronald)

Even our "loved ones", our parents and partners, tend to believe that our multiple sclerosis is pervasive and that we can not think and do things for ourselves. We should act as if we are helpless.

I decided to exercise, even though my wife at the time and her father said "No don't exercise". I still did it any way. (James)

Multiple sclerosis is often a progressive and debilitating condition and there are many young people with multiple sclerosis living in nursing homes. When it came to considering the long term implications of possible institutionalisation some of the members coped in different ways.

Yeah, but I try not to, it actually worries me, because I just see people sitting around these old people's homes, and you walk into the lounge and they are all sitting there and they look up at you as you come in, and they are not with it.

(Ronald)

When relating my own arrangements as being in a complex built for retired people the next participant never seemed concerned.

It doesn't really matter, I can see the reason for you doing what you did because one, it will not be a foreign environment. It will be a familiar one and you will already know your way around.

(James)

Another participant considered his long-term arrangements and was quite philosophical about the outcomes.

I wouldn't have a problem going into a rest home, I would find a situation in my orbit, you know. You don't know what is in the future. In twenty years time you might come into a special little place that I might build maybe with my mother's money, let's say. It works like this, with medical people around, who knows, close by and you might be one of my friends and maybe able to put some money into it as well. I have a lot of friends like this, a lot of friends. So don't sort of think of things like that, we made a deal with my mother and my father, they are not going into rest homes. The same for my mother's sake and my father; he is not going into a rest home.

(George)

Adjustment and coping

Those of us with multiple sclerosis cope with our condition in different ways. We develop strategies over time by trial and error. Sometimes we have disclosed our condition and have received bad reactions from other people. I asked a participant

how his relationships changed over time. He was very much like me in that he hasn't told people that he has multiple sclerosis.

I'd rather not ... with complications people look at me and think, oh no not really. (George)

But we learn just to cope with life and carry on about our business and consider it an inconvenience. Another participant said:

I fall over sometimes. You can see all the scars on my legs. It happens quite often, but I don't worry about it, I get up and just keep on going, that's all you can do. You can't dwell on it, and think woe is me, I just get up. I went walking on Tuesday, I usually walk to the vegetable shop, but I should have stopped and rested and sat in the bus stop for ten minutes, but I didn't, I just kept going, and I didn't quite make it and fell over and broke three eggs on the way back. (laughter) (James)

Another of the participants thought that people with multiple sclerosis had an amazing resilience and developed a keener sense of humour. He said:

I try to make a humorous situation out of something that could be quite catastrophic in my life, but I am going to make a positive thing in my own mind out of it, out of any sort of disability or ability I might have, whether it is a wheelchair, whether it is not being able to move and not being able to put myself on the toilet. Which in actual fact if it does happen, I would still be smiling, and I would still be joking. I think it is so unimportant that if some other human being has to put me on the lavatory or has to wash me in the bed, because I can't move, if that happens to me. (George)

Another person said he would devise a plan for withdrawal from society as a means of coping with situations if things got a little hectic. It is often difficult if friends call and want to get you included in an activity. Sometimes it is easier to simply make an

excuse not to accompany them. Often it is a matter of not embarrassing yourself or them. As Register (1987: 60) has explained, it is all part of an etiquette for people who are ill to minimise the illness by withdrawing.

If someone says, how about this or that and I say, no I am busy, or make any excuse to get out of it. (Ronald)

For dealing with cognitive problems, this participant devised different strategies to help him cope with memory problems.

Yeah, you have to work things out. One thing is to write things down, and make sure you do write them down, then you think, bugger, I'll remember that, but you don't, and that doesn't help. So you are better off writing things down. (Ronald)

Another member of the group would try a positive mental attitude as a means of coping with difficult situations. This was evident at the time of the death of his mother and a favourite pet.

I once tried to positivise every situation that happens. For instance my hound who I adored and he adored me. At least he went to eight. It might have been five or six. Do you understand what I mean? With my mother, I make that into a positive thing. She was such a magnificent, marvellous woman and that I was able to help her to have another few years of life, and this is what my family believes...we were very close. She actually went to seventy five, she hadn't walked for twenty years. So when I say positivise, it is my word actually, I make a positive thing out of everything that has happened, that happens to the world in fact. (George)

In line with this "positiveness", another strategy George uses is compartmentalising

each day. Motivational experts say this may be a way we use to deal with stress. As George says:

I have always been fascinated by time anyway, that is why it is part of my philosophy, it always has been, "Make each day a complete life," said Albert Schweitzer. Especially since I had my pneumonia, I try to enjoy every minute of every hour of every day. (George)

On this theme of time, Ronald has this to say about the changes in his life.

Time and Motion become different things. Sometimes you think, I have been doing this thing for ten minutes or quarter of an hour, whereas in reality you have only been doing it for ten seconds or something like that. (Ronald)

Often our loved ones would try strategies to speed up our diminishing speed and our failing health, thinking that they may help. (This line of reasoning is discussed in the next section.) But this may be misinterpreted and resented by the person with multiple sclerosis as they fear they are being controlled and manipulated. As one participant says:

My wife is trying to get me a wheelchair and all that sort of thing, but I am determined to do what I can for myself for as long as I can. I have just noticed the way people go down hill when they find it a bit difficult walking so they get a wheelchair and they never ever walk again, and you know yourself and I know myself, that if you have a few days when you don't do much walking, well, you pay for it don't you? It takes a long time for you to get fit again. That will be about right, wouldn't it. (Ronald)

But eventually, at some stage, we rationalise it out and realise that we need help and

do not struggle against the inevitable.

Yeah, you know, like, everyone is having to do things for us, or they don't get done, so they are more sympathetic I guess and they understand the problems we are having. You know I have gone beyond the fatigue levels as being the major problem and I'm into the physical problems now. So I have gone through the various stages, I mean...you get to the point where you have to start using a cane to get around safely, and all of a sudden it is a whole new ball game because people are giving you room to move about, providing they see your cane in a crowd situation, instead of jostling you.

(Jack)

In dealing with the progressive nature of multiple sclerosis, there is always the need to evaluate a continuing worsening reliability of the body and the fear that we will eventually lose control of our own lives, so we start increasing our professional support networks to take the strain away from our families. Jack says:

To a degree, I've found the St Johns medical alarm has taken a lot of the stress and worry off my family. Because they were happy that I was moving into here, and being self sufficient, but they worried about me on my own as I was at that stage. So once I got a medical alarm, well it empowered me actually and it took the stress off them and since I have had to use it a number of times it has taken the worry off me. Because I know help is at hand.

(Jack)

But sometimes it is not enough to devise a coping strategy and all we can do is rest and make sure that we do not over-exert ourselves.

And so I am thinking, my main problem at the moment is stamina and fatigue, I just can't seem to sustain any level of exertion, I certainly think a

degree of that exhaustion just comes quite simply from walking around with legs that are only half working, so the other half of the work that is needed to walk has to come from somewhere, so the energy is drained from something else. (Des)

Problems of Inclusion

Society has this poor perception of people with disability and hence that of people with multiple sclerosis. Again I will discuss this in detail later, but conditioning of the population is historical. According to Bynoe, Oliver, and Barnes (1991: 11), there was a deep-rooted fear of the unknown and most illness and disability were dreaded. This has been translated in the industrialised world, where illness and disability are seen as disorder and a possible pollutant to the workforce. This idea of fear is continued in society by usually unfounded prejudices to keep people of difference in “their place”. As Kippax, Tillet, Crawford and Cregan (1991: 3) have explained, “Prejudice confirms and underscores the status quo, it protects ‘self’ by scapegoating ‘other’... They further go on to say that “lack of control” augments inappropriate fear and suspicion. The participants use methods for inclusion in different ways; they try not to alienate their acquaintances.

I try to use no one. I try not to sponge off people. A number of people in my life and in your life too, they can be sponging on your emotions. You know they have got problems and they talk to you about them. But my friends, I can just talk to them and it is not sympathy that I am looking for it is just understanding. And I have got a lot of good friends, I am very fortunate, I am very lucky. Do you know what I mean, I have a good family. I have got so many plusses going for me, I refuse to be depressed for instance. (George)

But sometimes it is not just people that we have a personal relationship with

who make it difficult for us. The public are generally ignorant and frequently thoughtlessly selfish. I had such an experience when attending the “Hero Parade” a couple of years ago when I took my scooter and the crowd just milled around and blocked my view. Jack said:

But what I hate is anything like, I can remember a few years ago, going to the Ellerslie Flower Show and you are in your scooter and you are trying to get up to the displays and to the little walls to have a look or whatever and people would basically walk across your scooter. (Jack)

When chatting to another participant, I asked how he felt when he could not do a full day’s work, and for a number of reasons, such as fatigue, he is stuck at home.

You are not a house-father because you have got no kids. They are all grown up, but you are stuck to the home. You are really restricted there. How do you feel about that? (Michael)

“It is by far the easiest way to go, you know”. (Ronald)

But there is frustration at self-imposed isolation. In the case of Ronald, if it gets too difficult. He tends to withdraw.

Some of our personal relationships do not survive. It may be that the fear of our condition is of concern to our friends and they decide to move on. George described his own experience of the loss of a relationship:

But in actual fact she told me in hospital, she was going off skiing to Japan and she came..., she came to see me in North Shore Hospital. She came when I had been there about three weeks and she thought it would be best.

It wasn't because I had pneumonia but she thought it best that we keep it just as friends. So I haven't seen her since. She met another man and is anxious to get remarried to someone who she really understands and who speaks her language... oh one of the things she couldn't really understand is my lifestyle... it is all a bit too sort of over the top. (George)

Sometimes we have no option but to withdraw from the mainstream, especially if our health has failed us. This was the case for Harry who had to make his own decision to stop driving:

Yeah in that sense, I was the one that stopped driving, mostly it was vision problems, and I decided I am not going to drive. (Harry)

But isolation can be caused by the environment and by institutional prejudices. For example, the local council and central government laws allow new developments to be constructed with little regard for the convenience of people with mobility problems. Jack describes a conversation he had with the mayor of North Shore City and the problems of inclusion in the new Albany Megacentre.

It is not worth it, I said, You try going out there and parking outside anywhere. It is hard work and then you go into that shop and then come back and get into your car and drive into the next carpark and go through the same. (Jack)

On Reflection

Our memories are the past experiences locked in our minds, and multiple sclerosis does more than anything else to restrict our range of experience. Those memories play over and over in our minds and we remember very poignantly how we were versus who we are now. It was Bessier (1989: 22) who said that, "My head is the

repository of the past”.

Many of the participants were internationally mobile and often had business commitments overseas prior to their multiple sclerosis. James relates:

My life used to be a rather large expanse... it covered the world; I could go anywhere in the world and now it has confined me just to a small area, say within a car or taxi distance away from home. (James)

This highlights a problem noticed by Dyck (1995) who studied women with multiple sclerosis and work. She said, “The majority of women were found to experience shrinking social and geographical worlds which rendered their lives increasingly hidden from view as patterns of social interaction changed and use of public space diminished” (Dyck 1995: 307). One of my participants was a globe-trotter and a professional musician who needed to rely on excellent eyesight in subdued lighting. But his health was prematurely ageing his life. He did not understand at that stage he had multiple sclerosis.

And then in my forties I used to have intermittent eyesight. Funny, oh you just need glasses perhaps but it never got really bad and I had superb vision... really perfect vision in both eyes. So I thought I would never need glasses, and then I started having lapses in my speech and putting words in the wrong order. I denied that by saying, I know all this in retrospect you see, you are used to speaking in a German language where the words are around another way, and then I had moments for five or so minutes where I couldn't speak properly. (George)

Another of the group remembers the days when he was agile and a dynamic businessman but things changed.

Virtually, when I think back, it was not being able to run any longer. I lived on 20 acres up there, and I used to run here and run there. And I got up one day and I went to run across and I just couldn't move my legs. It was about the time I was having a few hassles with the place up there, and I was thinking of selling it and doing all of that sort of thing. I just put it all down to that. (Ronald)

Even his doctor reminded him of his sharp intellect before his condition manifested itself.

There was a multitude, and as my doctor has picked it up, it was he, I have been going to him for years, whenever any one has mentioned business interview or like that, he said you just changed tone, you were so sharp. Yeah she noticed that, when we had Albany, when we had the land out there, I was doing very well for a long time, you know. Virtually I could sit down and figure out things, and I wouldn't make a mistake. All of a sudden I started making mistakes, huge mistakes. (Ronald)

But he also remembered that issues were not being dealt with well and mistakes started to be made that affected his livelihood. Now he is totally dependent on his wife earning a living.

I had it for a few years before I was diagnosed, you look back at some of the mistakes you were making and the different pressures you couldn't handle, and you realise you have had it for a lot longer. (Ronald)

Jack too reflected on the days before he was diagnosed and then realised some of the problems he had been having in the past.

Well, one of the things, once you had been diagnosed, you look back on things that happened and say, Oh that must have been a symptom of my MS. Prior to being diagnosed and we were trying for kids, my wife would

go out for these sort of things they do on women. I had a sperm count done and my count was high, but not very motile, they weren't moving very much. Once I was diagnosed, I look back and I thought... (Jack)

One of the younger members of the group was also a keen sportsman and loved the outdoor life and worked long hours.

Yeah I used to play rugby, judo and I was a concrete layer and a concrete truck driver by that stage which I had to stop. (Harry)

The work was very physical and his doctor advised him the hours were going to be unacceptably long.

The concrete sealing is, yeah that's what I done since I left school, and I used to work 55 to 60 hours per week and my doctor said, "No no you can't do that". "Why I said". "Because it is too long". But I said "That's normal". "No its not Harry". "It is to every one I know". He said, "That will have to stop". (Harry)

Reflection on drunks

Part and parcel of having multiple sclerosis are the sensory problems and the difficulty in walking. All of the participants had concerns with their bodily appearance and the general view that they appeared inebriated. An explanation is warranted here as to the feelings of the members, some reflections and coping strategies that members of the group use. Men are culturally constructed to be in control of their bodies, the work ethic is part of their identity and to be, or to appear to be drunk, contravenes both of these expected norms that our society places on us.

I remember going during the day to Speaker's Corner, a bar on the North Shore, a few

years ago. I was with my father and he did not want to park the car immediately outside the bar (which would have made things easier for me). He was concerned that other people would see him. To him parking outside the establishment somehow made his action of going for a drink more public. And another time he was horrified that I did not take my stick into the bar as I would appear drunk to others. Perhaps such a reaction dates back to that colonial cultural cringe and self-responsibility, where you had to stable your horse and only the drunks would hitch their horses to the posts outside!

More recently, I have adopted strategies in response to what I think is expected. I now always take my stick into the bar even if I am having one of my better days and my balance is good. I drink mainly lemonades, the staff know me, and if I order a beer I will make sure it is a slow pouring one and they may bring it over to the table. I make sure that when I go to the bar to order two drinks I have my stick with me and the chances are if they are not busy they may bring the drinks to the table. The conditioning of the bar staff has been a drawn out process. I have been conscious that the newer staff do not appear to think of people with mobility problems.

Most people I know with multiple sclerosis (myself included) have major problems in this environment. They have tremors which make carrying drinks cumbersome, or they have varying degrees of unsteadiness in walking with weakness in limbs which are often unpredictable. Hence, the stick is necessary as the walking gait is laboured and balance is often haywire. Carrying just two drinks can create a high cognitive loading, and make co-ordination physically very demanding.

As part of an ongoing educative process for others, I deliberately walk slowly and make sure that I spill a little too much of whatever is in the glass. Personally I do not enjoy going to any bar for a drink because of the difficulties I experience. I become self-conscious that every one thinks I am drunk before they even recognise that I have a problem. But I go to be with my friends and it is important that I am out there being seen and I enjoy their company. I drive many kilometres to have just a few lemonades. We devise euphemisms like we are “going for exercises” which shield us from society’s disdain for the appearance of a lack of self-control.

One of the participants in his earlier days could conceal that he had been drinking and never lost control, got drunk or disclosed that he had been to the pub.

When I was younger, I always considered I could drink my share. I used to go to the pub for a couple of hours and my wife wouldn't even notice that I had had a drink. (Ronald)

But owing to his failing health, others started to notice his lack of co-ordination and assumed that he was drunk. He went on to say:

Funnily enough, I was thinking this morning about John, “the crazy butcher”. I used to run into him, because I have known him for years, and I saw him at a function once in Auckland. He rang me up the next day, “God you were bloody pissed”, and I said, “Bullshit, I had a couple of glasses of wine”. He said I was tanked and at that stage I hadn't even been diagnosed. He thought that...he thought I was drunk, but I sure as hell wasn't. (Ronald)

Another of the group found that he was also concerned that people considered he had a drinking problem in the early days.

I suppose the worst time of being conscious of people looking at you was prior to accepting that I had needed to use a cane. Then once I had a cane, which was a symbol of my disability, it didn't worry me, but prior to that you could almost see they were thinking that he was drunk. And that really hurt. (Jack)

Because of his apprehension about the public's perception of his losing control of his body, one of the participants went to the trouble of joining the organisation that promoted "Medic Alert". James carried a card and disability symbol hoping that it would allay fears from others if he was to ask for assistance. It read, "Any speech impediment or unsteady gait shown by the bearer is due to a medical condition. Do not confuse symptoms with intoxication and kindly render any assistance necessary". This was probably for his own peace of mind. At this stage he does not use a stick and he tries not to use walking aids. But just after he was diagnosed, it was different.

I felt drunk while I was driving, I couldn't see properly and I wondered what was wrong. So, when I... I actually got two walking sticks made, out of stainless steel and I was using them, and I was shaking like mad and I had intention tremor really bad so I thought I really would have to do something about that. (James)

So he started to exercise and built up his body so that he could walk without walking sticks but was always conscious of appearing drunk and seldom walked in the late afternoon or in the evening.

In the morning it is fine because you wouldn't be pissed in the morning, but at night time you could be a drunk. (James)

He related an incident when he fell over whilst out doing some shopping and people came rushing to give him assistance.

It was about 9.15 in the morning, and a lot of people stopped to help me and they wouldn't have done that in the afternoon. (James)

Men with multiple sclerosis seem extremely self-conscious about their appearance of drunkenness, a “state of disorder” in an ordered society. On the whole Jack would rather not have been seen. One night we went to a bar in Newmarket to fund-raise for the Multiple Sclerosis Society. We had only been drinking soft drinks. Outside in the poor lighting and difficult camber in the footpath, he fell over but quickly rose to his feet hoping no one had seen him.

Yet he is now more philosophical and now he is permanently in a disability scooter in public and accepts the inevitable treatment from others.

So I never got angry at people that had that look about them towards me because you thought that... It is a natural response. Once I got a cane, and once I progressed into a wheelchair and then from a wheelchair to a scooter, now I don't give a toss. I am so visible... there is obviously something wrong with me. (Jack)

The fear of appearing drunk was commented on by every one of the participants. They also identified it as a sign of disorder and deviancy.

Sometimes I don't know whether, in fact I had a strange feeling...in fact I had it there sitting at that table, in that sort of chair I don't like. I feel that I am going to fall off it. But in actual fact I am not and I know that, so it is mind over matter. What I am actually often feeling is that there is no sort of central point, I don't know whether I am standing up or standing on my

head. The best way to describe it is like having a hang over. Do you understand that? Have you ever had a hang over? (George)

The lived experiences described above are a small rendition of concerns that were highlighted by the participants, and they indicated the issues that were of most concern to them. The illustrations of their personal histories allowed them to determine the pace and content of their stories.

This chapter covered topics of concern for the participants beginning with their diagnosis of the condition, followed by their transition into the world-ness or the liminality state. Our perceptions of other people's negative stereotypes of our condition also affected how we acted in response. I then discussed our adjustment to multiple sclerosis and some personal coping strategies. The final portion dealt with problems of seeking inclusion in the wider community and reflections on disorder and the appearance deviancy and drunkenness.

Chapter 6

Power and Control

The records of an athlete are a source for admiration, those of a cripple, a subject for pity.

(Bessier 1989: 80)

Laying the Ground

Men's identity is firmly entrenched in their physical appearance of self control and mastery of their environment. Issues and concerns relating to these subjects have dominated all aspects of the discussions I had with group members or individual participants in this study. This chapter considers the cultural constructions of disability, issues of power in relation to the medical establishment, the working or ex-working life of the participants, and relationship anxieties.

We live in a Western world that is patriarchal and capitalist. It favours youth, work, virility in the body, and is less tolerant of difference of those who do not conform or can not conform to the dominant society's expectations. Gershick & Miller (1998: 393) have noted that "For men with physical disabilities, being recognised as masculine by others is especially difficult, if not impossible to accomplish. Yet not

being recognised as masculine is untenable because in our culture, everyone is expected to display an appropriate gender identity”.

Are you man or mouse?

This cultural construction of men was a subject of many of the discussions in this research. All participants remembered their “perfect” bodies from before. Their physical stamina was important to this identity, and in days before the physical deterioration caused by multiple sclerosis, they recounted their physical exploits.

Apart from being a fit and competitive athlete, James always pursued outdoor life to the fullest. He spent many years on Great Barrier Island and I asked him if he personally had built the massive fireplace in a photograph that I saw at his present home. He explained:

Yes I did. It is about 11 feet wide outside and nine wide inside or so. It was a real big one. Took me six months to build that out of stone. You see the hearth is that concrete piece around the cross. (James)

Another participant recounted the days when his agility allowed him to play football.

I had always been a nippy, wiry, little bugger. When I did get into rugby at school, for example, which wasn't often, because I was small and so you could get hurt, and of course you are playing with bigger stronger kids that want to hurt you. But when I did get into it, if I was prepared to take the knocks, if I got into a good game, I was extremely hard to catch and extremely hard to keep hold of than the average kid because I was wiry and nippy. (Des)

The following member of the group described his days when strenuous exercise was essential for being a competitive sportsman, a state very different from today which sees him permanently bedridden.

I have lifted weights for years, as part of the judo, because the people I was fighting were always black belts. You know I thought I had better get something on my side because they would kill me. So I started with the weights and I have been doing that ever since... well...up until a couple of years ago of course. (Harry)

Another participant reported that a few years before his diagnosis he used to be quite a rambler.

Well I have been doing that increasingly in my late thirties, I can remember that happening. I used to run like a goat too. I used to love scrambling around hills and things like that. Igedi in Jerusalem is rather pretty. I was there for a few months in '82... conducting there actually. (George)

But unfortunately they are now only memories. Another participant reflected on the same theme of being fit:

Virtually, when I think back, it was not being able to run any longer. I lived on 20 acres up there, and I use to run here and run there. I got up one day and went to run but I just couldn't move my legs. It was about the time I was having a few hassles with the place, and I was thinking of selling it and doing all of that sort of thing. I just put it all down to that. (Ronald)

Another member of the group also reminisced about the days of yesteryear.

Since I was sixteen, I went to sea, I thought I was Jack the Lad. I thought I was fire proof, you know... nothing could hurt me, and then I ended up flat on my face and they were pumping my backside full of morphine and Jack the lad had really come down to earth. (Maurice)

Also, unfortunately, we have aged and whereas we expected to be at the peak of adulthood and enjoying the “dirty thirties” or the “naughty forties” we are already acting like old men. But we try to be resilient and attempt through exercise to reclaim some of that health. We discuss this briefly later in this chapter on alternatives to the medical model. But James remembered his days of coaching athletes and applied some of his knowledge to his own well-being. He said:

It felt weaker my left arm. The left side is the one the weakness usually comes out in them. So I thought that I am going to have to do something to try and increase the strength in my left side. It may work and it may not. So I tried it anyway, and it took two years before the muscles in my left arm were the same size as the ones in my right arm. And I only did that by doing chin ups and loading up my left side, so that it worked a little bit harder than the right side. It was harder with the left side than it was with the right side which was quite easy, seeing that the strength was there already. (James)

Another participant told a story about an exercise program that had been devised for him just after he had been diagnosed. The feelings of self-confidence that were engendered were hugely important when he could strut around the gym.

They tailored a program for me to work on the area where the vertebrae had collapsed, where the ligaments and muscles were pulled all out of

alignment I did benefit by that...Oh yeah, they have got big mirrors around the walls of these gyms and you are like that, and you are posing, and you can see your body starting to tone up, and mentally it is good for you, it really is. (Maurice)

In my own experience, self-confidence may not be bolstered and going to the gym worked against me. Although a little exercise is better than none, it was demoralising as I did not to see any appreciable changes.

But it has worked the opposite way for me, because we have a gym at the university, and I go in there and all these virile young women are in there. And here is an old fart, trying to have a go and only exercising for ten or fifteen minutes, whereas they are on the damn machines for an hour.

(Michael)

Exercises for individuals in this group were generally conducted in the home where it was private and only the participants could self-consciously observe their failing health. James had equipped out his garage so that he could do strenuous exercises and is in the process of acquiring an exercycle. Although I started going to Auckland University of Technology for treatment at the physiotherapy clinic, I was always conscious of others observing and picked times before the other people with impairments arrived. I have since purchased some equipment to use at home. When discussing activities with Ronald, he said he keeps busy around the home transiting up and down his steep garden. Jack is the only one in the group that goes out for physical exercises and does this with treatment at the physiotherapy clinic at the Auckland University of Technology.

Medical profession

The medical profession assumes an awful lot of power and control over the participants' lives. The medical model uses the scientific analytical methods where the disease is objectified and the patient becomes secondary. In this process the lived experience of "the patient" is not as important as the disease, and many "patients" are not referred to by name. For example, the MS patient may be referred to as a bed number or patient number. We need to keep in mind that this may be part of the ethics of the institution where names are better not used for reasons of confidentiality. But objectification was evident in my own admission to hospital for a car accident. When some of the trainee doctors became aware that a patient had multiple sclerosis, they flocked around in the emergency ward whilst I was waiting for treatment for broken bones. This treatment had nothing to do with my chronic illness condition and when a complaint was made I was probably labelled neurotic. In any case, I was not allowed out the next day until I had been visited by the chaplain and medical social worker.

Maurice had a painful condition and was asked to attend a pain clinic.

Because I wouldn't attend this group, they referred to me as psychotic, and I think they put it on my medical file. He's psychotic, whether in their wisdom they saw I was psychotic, I didn't see myself as psychotic, but you remember these things. (Maurice)

It is interesting that the neurologist who was responsible for discovering multiple sclerosis was able to interpret experiences of pain and reinterpret the condition as noted by Cousins. "Sometimes a pain may be a manifestation of 'conversion hysteria'... the name given by Jean Charcot to physical symptoms that have their

origins in emotional disturbances” (Cousins 1979: 91). Maurice was concerned that some in the medical profession viewed his condition in the same light.

I was having trouble sleeping anyway because of the pain, but I was absolutely stunned. They asked me about my family history of it, (osteoporosis)... is there any history of it in your mother, or her mother. I have got three sisters and none of them have got it. They are quite healthy. There is no family history of it, and they were just scratching their heads. {Maurice)

Men with multiple sclerosis, like those with osteoporosis, are in the minority amongst those with the condition. Because men with disability are mostly relegated to the domestic sphere away from the work-place it is therefore considered to be a “woman’s condition”. This is a misrepresentation, just as men can contract breast cancer and Levine et.al., (1990) allude to eating disorders as misreported as a “woman’s problem”.

Maurice went on to say.

When they finally diagnosed what it was, I remember clearly what they said. They said, you had us worried because we thought we were looking at bone cancer. I said, Don’t you dare say that. We finally nussed out what it is. The good news is that it is not going to kill you. The bad news is we can’t cure it. They told me about osteoporosis. (Maurice)

Insurances

Another form of power is exercised by making services expensive and restricting insurances to those earning good money before diagnosis. James said that he had good life insurance in place before he had health problems but the company only

offered a modest pay out when he contacted them. So he continued to keep the cover in place until his death. That way at least, his children will benefit. Jack had health insurance which remained in place until he left the country to reside in Florida. But company rules made his cover void and on his permanent return to New Zealand he found he was uninsurable. Another person with good insurance cover initially was Ronald. But as is the nature with some multiple sclerosis, observable signs may take longer than psychological signs and owing to his long term health deterioration compounded by difficulties with finances, he let his policies lapse and he is now in the “same boat” as the rest of us... uninsurably expensive.

Another problem of having multiple sclerosis is maintaining life insurance. When I was in the UK, I had severe difficulty in starting a new policy and was loaded somewhere between three and five times the normal premium. On the whole, the rest of us who discussed this topic had no cover, and in this respect, most of us have limited financial security for our old age.

One of the participants related his concerns regarding insurance as follows:

...you are looking at \$1500 to \$1700 for a basic policy for health, for a family for two adults and two children and there is no way in the world, on the money I was earning, I could facilitate that. Considering we are a family of people that barely go to the GP. If we get a cold we don't go running to the doctor. We are not people who get sick, so up till now it has been a massive saving to the extent where I would be quite happy to spend some money on myself. But the neurologist he referred me to basically asked for \$250 plus GST for the first session, so you could imagine what his hourly rate would be.

(Des)

I had been raised in a social welfare state and been used to free medical care in the hospital environment. Following along the lines of costs for health I dodged facing to pay as we had been brought up with the notion of “Keynesian” economics and national welfareism. This is where we had been used to the state looking after us from the “cradle to the grave” (Williams 1989).

I didn't go back to the neurologist you know. He put me in as a disadvantaged patient, to get me into the hospital. We had always been used to the national health, in New Zealand and the UK. But in Australia it was quite different, you had to pay for your healthcare. And when I had to go back to the specialist, he wanted \$35 for the consultation, I thought, bugger that, I won't go back, never paid the bill. (Michael)

An issue of control is still evident in the health services where the restricting of information is not client-centred when you are still within publicly assisted health care. As Des found out:

So I rang up, and asked: Where are the MRI results at the North Shore Hospital? The nurse I spoke to said it would take a week to come through and there was no way that they could do anything about speeding it up. I told them that I had lost the ability to walk, thank you very much and I wanted the status from being an outpatient stepped up, unless they wanted me to become an inpatient. I am thinking, I want it sped up; I want to know what is going on, I want to get on finding what this is and fixing it, otherwise you are going to find me in your A&E (accident and emergency department). (Des)

This is still an unclear issue as and even when one of the participants who paid for private healthcare still did not consider he was kept informed enough by health professionals. Insurance like most of the institutions in the Western world uses an adversarial methodology of working out the odds. He said:

I came to the conclusion that I had multiple sclerosis. I asked Doctor Neil ... (if I ever found the guy, he would have to lower his trousers to clean his teeth). I asked him a direct question: Do I have multiple sclerosis and he said no. If he didn't want to commit himself, he could have said why don't you ask your specialist. (James)

But the hospital has its own set of procedures and rules in which every one has to comply for the smooth running of the institution. All those in medical establishments are socially constructed as well. This is part of the coercive nature of the institution for arranging order in its inmates. (Foucault 1967)

I get back to the bed and there is a string of doctors around the bed and the neurologist and he was about to castigate me and he said: Didn't they tell you to stay in your bed. I said I didn't expect you here at eight o'clock in the morning, (Michael)

This view according to Turner, saw power as being closely associated with Foucault's fascination with discipline, namely that power exists through disciplinary practices as produced by particular individuals, and institutions such as hospitals. (Turner 1997: xii)

Foucault wrote on many aspects of institutional power and I have shown above where power has been exercised over members of this study when they were hospitalised. Following along this theme, power is also exercised over the body where the medical profession through technology can observe and gaze at it. They make interpretations with only a minor input from the "patient". The following participant said:

Yeah lumbar puncture, drawing pins in the head, optical tests, speech tests and the usual. Can you walk or stand with your eyes closed and then they scrape you up off the floor. I guess I was lucky because I had to only wait two years before I was diagnosed. The most traumatic thing of it all was

that you were in the neuro. ward around people with obvious problems and you are feeling quite normal except these strange things are happening to you. You are sort of sequestered in there and it is the first frightening thing that ever happens to you. (Jack)

My experience was similar and I was also disempowered by the confusion of being at the mercy of “the profession”. Feelings about lack of control in the hospital and being exposed negatively affected my self-esteem.

I went to the doctor and the first thing he said was: You have got high blood pressure. He put me on medication for that and made an appointment for me to go and see a neurologist. The neurologist arranged a series of tests, at a number of different hospitals, from Royal University Hospital to Westminster Hospital. Everything was piecemeal because I wasn't a private patient, and then I was admitted to Queen Mary's Hospital in Roehampton, and had the series of electro encephalographs. I had three of these bloody things and then they said: You are going to have a lumbar puncture. (Michael)

Maurice's involvement with the medical establishment was also similar in that the “medical gaze” according to Armstrong (1994: 24) was used to objectify the body as an extension of medical surveillance.

I got up and had a couple of pain killers, went back to bed and the pain just got worse and worse. It wasn't till they examined me the following morning, when they x-rayed and found that a couple of vertebrae had collapsed in the back, and were completely mystified why it had happened. (Maurice)

But sometimes the testing raised concerns in us that perhaps contracting multiple sclerosis may have been our fault. Sometimes it is inefficiencies within the hospital

system that have adverse effects on the adjustment of people with MS and other conditions. This is well illustrated by James' story:

So I came home, they had already given me prednisone. They started me on 1600 units a day, then they said it was not working and they would have to increase this to 1900 which they did and it still wasn't working so they moved it up to 2400 and one of the guys said: If you give him any more you will probably kill him. That's after one of the guys said we are going to have to go and give him some more, I came home. (James)

James also had definite ideas on believing that practitioners using the medical model had a controlling influence on people with multiple sclerosis. He saw that they always talked to the "patient" as if their condition followed a progressive course of deterioration of their bodies. He also saw that the MS Societies have adopted this line of reasoning.

This is something you are going to need, and this is the medical model, they actually say. This is your walking stick and you will eventually go in a wheelchair. They should be looking at the problems from the other direction and saying, why do you need this, because you haven't got enough strength in your legs.... (James)

He also says that he can understand why some people will not join our society.

They have a perception that the MS Society is in with the medical model. That's reality. That is where it rears its ugly head again, in the medical model... (James)

But not all the participants followed his line of thought and when he was asked what he thought of physiotherapy he said.

I think it is bullshit, it is good for our soft tissue and rejuvenating and getting it to work, but a lot people seem to rely on physiotherapy as the fix it for MS and it is not. You have to do some real resistance exercise work to actually get muscles working again, as well as physiotherapy. It is a "feel good" type, not a fix it. (James)

We do not always agree on each others methods for medical interventions and tend to follow our own prescribed paths. This particular group of people were able to advance their understanding and did not hold James's opinions of exercising as being crucial to prolonging fitness. In actual fact exercise is pertinent to all people. The participants were able to think about other alternatives and used different practices.

Many patients who cannot be helped significantly by scientific Western medicine, and those who feel abandoned by it because their conditions are considered incurable, seek attention and relief from alternative practitioners. (Wendell 1996: 97)

Burnfield (1985) devoted a portion of a chapter on treatment, to quackery, saying that people with multiple sclerosis find it impossible to believe that the condition is incurable. This is an unkind assumption and people with the condition may just be using methods of treatment not recognised by the British Medical Association. After all it was not that long ago the rubbished acupuncture as a treatment for other conditions. Others like Loader, because of her feeling of abandonment by the medical profession, turned her aggression into something positive and developed what she has called "a breakthrough in treatment of the condition" (Loader 1996). Her breakthrough may have some merits but at this stage it receives scant regard from the

medical profession until proven by their methods. Loaders supposed “miracle cure” works for some people but not all. Although she has no medical background and her concoction of biomedical drugs and vitamin supplements is undergoing testing by the medical establishment.

It is not that we are looking for alternatives, but perhaps we are seeking additions to the medical model that may work for us individually. All systems of healing have positive and negative aspects. Western medicine is highly developed and technologically superior to others in the production of sophisticated drugs, advanced surgical procedures and the ability to deal with trauma. But the participants of this study exercised their right to complement their care from whatever source they wished. These include acupuncture, vitamin supplements, food supplements such as evening primrose oil, strenuous exercises, diets and faith healing.

Not all of us are against the medical model. But there are other traditions and ways of knowing and some of the group used these and got definite benefits. One of the participants went to a medical practitioner who was Chinese and also used acupuncture and their traditional healing methods. He said:

There is something in Chinese medicine, I went to my practitioner and he said: What is wrong with you, and I said that I hurt my ankle so he had a look and pushed it around with his thumbs, how he does and he said I'll sort that out and gave me some acupuncture to my shoulder and said that should fix it and bugger me, I was even better before I left the surgery. Where he is good too, with the acupuncture, he says he is able to bypass the nervous system and he can do it, by going right to the spot, whereas there is nothing else you can do. And also he doesn't like modern drugs.

He doesn't like giving aspros or any thing like that. He will say: You go home and sit down for ten minutes and you will feel a lot better, but he won't give you any pills. (Ronald)

On another occasion he related:

I cut my leg across there with a chain saw once, I was out the back and I must of slipped and wacked myself with the chain-saw. I can't remember whether I drove down to my acupunturist or someone drove me down and patched my leg up, and put some stitches in. He said: This powder I am putting on is not part of the New Zealand medicine. It is imported, but I think it will help. He put this stuff like flour on my leg. Well my leg cleared up, and it looked as though nothing had happened there. It was all better even before I got the stitches out. They come up with some amazing things. (Ronald)

He felt comfortable that his care was in good hands and they had developed a long relationship of thirty years as doctor/patient, a relationship that had been built up by his offering holistic methods using other forms of therapy which encompassed the maintenance of both the mind and the body. In my case I also use acupuncture and in the past 20 years I have maintained relationships with four Chinese medical practitioners as a patient.

I believe that he did some good, this Chinese doctor, because he put me on a series of mega vitamins, you know vitamin A and C and D and fish oil and stuff like that, which may well have helped. I don't take any biomedicine whatsoever, but I do see my acupuncturist once a week. The last time I asked him what he was doing on top of the head and the back and all that sort of stuff, he said I am building up your organs now to deal with things, and he wants to get me walking for an hour in the mornings

and evenings. I didn't go for a walk last night because it was raining, but the thing is to build up the stamina. This is important. (Michael)

But traditional Chinese medicine uses other forms of healing as well as acupuncture which is applied by various methods including touch, the use of herbs, and the application of heat. One of the other participants who interviewed me had this to say about his supplementary diagnosis outside the rubric of Western medicine.

It is interesting what your acupuncturist told you, because I had been diagnosed already, but friends had been to an Iridologist/Naturapath and used iridology to diagnose what was going on with them. They said: Go and see him. Because I wasn't taking any prescribed drugs or anything. I went. I was in there for 45 minutes and he ended up with two sheets. He saw in my eyes what was wrong with me. After that was finished, he said: Well, technically I never tell anyone that there is anything that is wrong with them, except I'll do a letter to your GP saying what I have found, and would he like to clarify it. I said I know I have got MS, he said well that is what I was going to tell your GP. He said, but I don't call it multiple sclerosis. I don't give it any common name. What you have got is about 24 things that have either shut down, slowed down, inactive or are hyperactive. And he said sure they were... .. I am going to go through this list individually. (Jack)

But in answer to a question raised by James most of us adhere to the medical model in many respects.

Part of the medical model. This is because Jack has a lot of faith in it, but I don't. We are not all like that - some of us are different - you know that, I have always been a proponent of looking at this holistically, and acupuncture is all about energy. Well, we have neurological physiotherapy as well don't we? (Michael)

But neither Western or alternative practices were ideal for one of the participants and although he used the services of a general practitioner from time to time, he believed in the positive mental attitude approach to facing his concerns.

That's exactly right, you have to have an incentive that comes from within to do these things. It is no good someone saying to you, you know you should do this, because you never will. So you have to have an incentive from within to actually make your mind up about it. (James)

But he was also aware that for him it was necessary to exercise the right muscles to maintain strength and he manages to maintain relatively better health than most of the participants for this reason. Before his onset of multiple sclerosis symptoms he was a physical fitness instructor at the YMCA, and was able to analyse his own problems with his stamina and health.

I actually thought it was a muscular problem. I am having trouble with my back, my legs, and my arms. I had my left arm, it was only twelve inches around. That was the circumference, and the other one was fifteen. So I thought well there was a definite, it felt weaker my left arm. The left side is the one that males usually have weakness. I thought that I am going to have to do something to try and increase the strength in my left side. It may work and it may not. So I tried anyway. It took two years before the biceps muscle in my left arm and triceps muscles were the same size as the ones in my right arm. And I only did that by doing chin ups and loading up my left side so that it worked a little bit harder than the right side. The right side was quite easy, because the strength was there already but the left side was much weaker. (James)

But trying these different systems can be very demanding of a person who is required to make a living, and the early days of my having to deal with my condition when I

never disclosed my problem required too much time out of the office. Unless one is self-employed, as James still is, your employer starts to believe that you are loafing.

I felt perfectly OK when I went into hospital, I was bright as anything and I came out feeling ill. So I have always had this adverse reaction to hospitals, but I went to Anthony Chan for a series of months and I was having acupuncture for two hours a day, and I felt it was taking up too much time.

(Michael)

Work

“I believed in winning, losing was a sin, a crime, a failure”.

(Bessier 1989: 80)

The male identity is rooted in his work and being physically active. On the whole the male is culturally constructed to believe that the “work ethic” is the driving force in many men. This is confirmed by Everingham (1995), Stein (1982), Gershick & Miller (1998), Biddulph (1995) and it is Goodwin (1999: 47) who says “Work is central to the masculine experience and the very nature of men’s lives”. But work in the Western world revolves around systems of order and control and when one does not “measure up” on this front, society tends to marginalise those who do not conform to its expectations. Wendell agrees and states that these are often surreptitiously administered “...there are rules at work, but most of us are trying to ignore the existence of the rules, trying to pretend that things are ‘naturally’ and effortlessly the way they seem, not socially enforced” (Wendell 1996: 89).

The group on the whole could be described as workaholics although not all agreed with this term. Des said he never saw himself as a workaholic, but did 80 odd hours

per week at work before he was diagnosed, saying, “How hard am I working? I have to maintain a reasonable life for my wife and children, because welfare alone won’t do it. It is not unreasonable”. And before he was diagnosed, Harry’s capacity for work often meant long hours. When Maurice was diagnosed, he said, “I had a seven day operation, I had a dairy with my sister, yeah I was doing long hours”. When asked about dealing with a condition that precluded him to a certain extent from working full time in the workforce, and how he felt when they said, “You have got a condition that old ladies get”, he replied: “I was absolutely stunned”.

George said, “Once a workaholic always a workaholic,” and maintained a regime of still keeping busy visiting people and composing his opera. But with a forever failing body, he was also aware of his shortcomings, and as a professional musician one of his strategies was to withdraw from the formal public arena, to concentrate on other aspects such as composing music and giving charity performances where there was less pressure for perfection. He said:

That is why I can not take engagements. If I take an engagement I have to take a private one not a professional one. Because there are some days when my co-ordination is too hard, some days where I am shaking a bit and some days my co-ordination is gone, and as you know that is the first thing that struck. (George)

George also reported feeling a need to work in order to be considered a useful member of society:

Absolutely, I'll be doing some more conducting when things settle down. I have a position I can go to I can conduct even if I am still shaking, even if I have to sit down, I can conduct. It is not the end of my career - it is just going on further. I am also a composer. At the moment I am putting together an opera. And I will also do the production side of it so I will have to make sure and go around businesses for sponsorship, that is if I do it in Auckland, for example. I have all the people, the relevant people, my core lady in Paris for instance. She will do the libretto, and what is called the insinual. I have someone to do the painting. The subject is Vincent Van Gogh, some one that fascinates me. So anyway, I am writing an opera. I can write music still. I can still write. Somedays I have bad days writing, and I don't.

(George)

Realising that he would not be able to continue to function in his job, another participant used the strategy of changing from a manual job to becoming more office bound, thinking that this would solve some of his major physical problems.

I took about six months off because I was starting to get to the stage where I really didn't want to drive the truck. I went to do a computer course at the Auckland Institute of Technology, and got a certificate in computing and I rang and told my firm, "I've finished this course now". And one of them said, "Oh do you want to come back to work?" and I said "Yeah, why?". "Well we have just put a new computer system in. Would you like to come back to work?". I said; Yeah. The only thing was that I got transferred to the concrete plant, to the batching room, which I absolutely hated, not because of the job, but because it is inside. I absolutely hated it, being inside for any length of time, because I was spending 10 to 11 hours a day inside sitting there answering phones and putting all the info. on the computer.

(Harry)

Some employers made great concessions towards their existing staff so that they could remain in the workforce. If they knew it was multiple sclerosis, they were more amenable to the changing patterns of their condition.

Later on, when fatigue became a real problem, my new employer allowed me to design my own hours, so I took Fridays off so I could rest up on Friday and we could still have our weekend. (Jack)

After diagnosis some of us were having problems accepting that we had multiple sclerosis and wished to remain private. Our strategy for coping with this was to shift to a different employment situation or become self employed in order to disguise our illness. Some resorted to community work and most of the group have either served on the board of the multiple sclerosis society or have been involved in service to their community. Maurice sees himself being of service to the wider community as a form of using the skills that he has learnt in business to make him feel worthwhile.

In the run up to an election campaign it is so busy. There is so much going on, you really haven't had a lot of time to think about your own condition. It takes you over and even now there are things going on, as I say we have opened an office here and I go in there and help out in the office. So yeah, I would describe my attitude at present as very positive. I have not had a lot of time to dwell on my medical problems and I think that is a good thing, I really do. If you can sit here week in and week out and worry about your medical problems it is not a good thing.

(Maurice)

Rather than just fading away socially most of the group, no matter how impaired they are physically, have interests that involve contact with others in the social world.

They are thus showing that they can still retain and have some personal control in their lives. Maurice became a national board member of the Multiple Sclerosis Society of New Zealand as well as becoming a senior active member of a political party, a board member of the regional Multiple Sclerosis Society and a board member of the Assembly of People with Disability (DPA). Des is a family man, running a small business designing custom jewellery. Although he has the safeguard of drawing a benefit, he is on the local board of the multiple sclerosis society. Jack is secretary and a board member of a disability information organisation and a board member of the local Multiple Sclerosis Society. George is a board member of the Multiple Sclerosis Society, their regional representative at national level and president of the DPA, and is busy writing a musical score for an opera and runs a hectic life visiting and being a “social butterfly”. James used to be a board member of the Multiple Sclerosis Society but is busy with other commitments and needed to spend more time on his importing, retail, service businesses both locally and internationally. Ronald can no longer drive a vehicle and is unable to attend many of his past interests. He was previously the chairman of a local political party and was board member of the local Multiple Sclerosis Society. Harry is now a permanent resident in a nursing home.

Being a member in a social world can be difficult because it is designed for the “able-bodied” and when you have impairments there are always considerations to be made about how much to disclose. Disclosure is not always a fixed display for the participants and mostly the participants pick and choose whether to withdraw or include themselves in activities.

Visibility and Seclusion

...the body is idealized and objectified to a high degree; these cultural practices foster demands to control our bodies and to attempt to perfect them, which in turn create rejection, shame, and fear in relation to both failures to control the body and deviations from body ideals.

(Wendell 1996: 85)

The decision about whether to display their illness or to keep it private is often puzzling for the participants. The problem is that other people assume that our multiple sclerosis is pervasive, and they tend to discount the fact that we are fully functioning spiritual and emotional human beings. As Wendell points out, “Disability tends to be associated with tragic loss, weakness, passivity, dependency, helplessness, shame, and global incompetence” (Wendell 1996: 63). At the focus group meeting I related the story of felling a tree so that I could split it for firewood and place it in our garage. At a later stage my wife made a comment on this at a later stage saying that she thought my multiple sclerosis could be selective and that I determined when I was ill or not. She did not understand that it was more than that, I paced myself, I had plenty of time. A “normal” person would have completed the task in a day whereas I took over a week. Our garden was secluded so I didn’t have to worry about people observing my visible signs of physical weakness and my dishevelled appearance when stumbling all over the place. Relative to this, Des told the focus group meeting about being given a new aluminium scooter (not a disability scooter) to try out:

I can't wait to take this thing to a school and try it out... It is funny I know. I will have the ability to take it out for a spin. I won't push myself. The last thing I want to do is to go scooting past WINZ on it, because the

wrong person would say "This guy is supposed to have MS." People would say that about you. (Des)

This is sometimes problematic. The disabled person is supposed to follow an etiquette of looking and acting impaired and when they attempt physical jobs and complete them, they are considered to be superhumanly heroic. This can have adverse effects on the person with the condition; he or she becomes weary and tired of society's beliefs about any person with a problem. Perhaps there is a sense of being patronised.

James described how his neighbours thought of him as being unusually heroic because he accomplished a feat that they considered too difficult for him.

I get on well with my neighbours. They think I am marvellous because I stained this fence here, have you seen it, well I stained all of that right up to there. That is 70 metres x 1.6 metres of fence. It took me two hours even with resting. (James)

It was a matter of pacing himself, and he was able to accomplish that which even many able-bodied people could not.

I have got to think about it a little more carefully. It is like this fence down here. I only used my wire strainer in my left hand and it is only the second time I used my fencing gear in 20 years. Other than that, I haven't used it except for pulling the odd tree out. That is all. So I really had to think about which way I was going to do it. (James)

Disclosing their multiple sclerosis was different for each person in this study. Some decided to tell people upon diagnosis and some did not. One participant wanted to tell his landlord, significant before he started to develop confusing symptoms.

I am a tenant in his house and if I take a turn for the worse, then he may have to suddenly get the news and I don't really want to end up in the position of ringing up the landlord and saying: Oh look, we are really in some serious strife. You see I have got MS I was diagnosed about a year and a half ago and so on and so. So if I tell him now, from the confidential point of view, from an independent point of view, I am not asking for anything. (Des)

Another also disclosed to all his friends at the outset of his diagnosis.

I never disguised the fact. I used to tell people. In fact when I was diagnosed, much to my wife's horror, I arranged a party at home. There must have been fifty odd people there, for the purpose of telling all, in one place and at the same time, that I had MS and that this is why I can't ski any more, and why I don't do this or that anymore. My wife was horrified. She said: This is no cause for celebration. I said I just want this out in the open. I don't want people saying, why can't he do that, and have to go through it time and time again. (Jack)

But some of the participants were self-conscious and didn't always disclose to friends or to the public more generally and chose when they thought the time was right. Some times delaying the disclosure proved to be very unsatisfactory. In my opinion I think the public are generally fairly ignorant. If you pulled them up, they would be horrified to think that they had denied access. Jack said:

I find this even at the Auckland University of Technology physiotherapy department. The same problem. After I finished my session, I would go

out to the front of the building and someone who was waiting for another patient to finish their treatment had parked right across the ramp onto the driveway, making it easier for their person to get into the car regardless of the fact that no one can get out of the building. So they are helping someone with a disability, mindless of the fact that they are stopping everyone else getting into the building. But when you go back into the building and say "whose car is that out the front", they are horrified. But they don't think. (Jack)

The problem of disclosure can be a matter of personal judgement. However, there are times when events take over and you try to conceal and hope for the best that any display of lack of control occurred without anyone noticing.

Even when I fell over last year in Orewa, I fell over behind a car. I had my stick and I actually tripped on one of my laces, I was embarrassed and wanted to get up, hoped no one had seen me. When I have ridden my scooter at university, doing something quite simple like backing, there is no stability on a three-wheel scooter going backwards. If there is a camber there, you will go over. One day I was lying in the bushes. This was outside the principal's office. I wasn't hurt, and all I was interested in doing, was to get my scooter up and running without anyone seeing what I had done. (Michael)

James thought it was a perception that the public had of not wanting to embarrass the person with the problem.

I think they don't want to come out, if you are all right... It is not themselves, it is you they don't want to embarrass. I think if you get up and you are OK, there is no point in them going out, is there? (James)

The North Shore Multiple Sclerosis Society's patron spoke to hundreds of people at the time of the "Cary Loader Breakthrough"⁸ and they would not join any multiple sclerosis society, yet they had multiple sclerosis. James spoke to Graham Sinclair a celebrity from TV3 and a person who disclosed on television that he had multiple sclerosis and said he would never join one.

I asked him the reason, and he said to me that he didn't like being fed steroids. He was going to try and do it the natural way. (James)

Many people, especially men with minor symptoms of multiple sclerosis, do not want to disclose that they have a life altering condition. It is deemed a sign of weakness. By alerting significant others in their spheres, they run the risk of people jumping to conclusions and the person with multiple sclerosis may feel aggrieved. Rather than appearing weak they may be able to convince people that they are eccentric. One participant said:

I have always been abnormal. I'll tell you something else, I have always been told how eccentric I was, even within the family. It was an eccentric family, but I was always probably, definitely the most eccentric. And that is increasing the older I get. And as we get older we become more like ourselves than we ever were. We are just becoming ourselves over and over again, if you follow what I mean. You know I have got a huge ego and at the same time I am incredibly ambitious. You can see what I have done in that CV. I have achieved everything I wanted to achieve and I am still achieving. They just think that if anyone can deal with it, it's George. That would be their attitude. My friends think that I am amazing. I did tell you that I have this huge ego. It simply is a huge ego. But I am very mindful not to be tripping over it because part of my philosophy is to look at other people and you see all your faults in other people, even your friends. You are determined not to be like them. It is like you are trying to

⁸ North Shore's MSS patron was involved in fielding enquiries for research for his

make your dealings with other human beings as perfect as possible. It can never be perfect. (George)

Another participant was more philosophical about his need to hide his disabled identity and accepted that he had to display the symbols of his disability so that he may effect a kinder consideration from the general public.

I find in winter when I wear long trousers, I get more looks because people are trying to work out what is wrong with you and why are you using a scooter. In the summer when I am wearing shorts they can see my AFO, my orthotic. They possibly think I have broken my leg for some reason. I don't know. Jack)

Language, Labelling and Naming

The ideology that disability is negative is a problem that has been with our Western society for a very long time. Society has tended to shun people who are disabled and shut them up in medical institutions. Originally the lepersoriums housed lepers in Europe and eventually when that condition was cured they became according to Foucault (1967) the places to house people with intellectual disabilities. The idea of the disabled being morally weak and depraved lasted, one of the method used by people to maintain these ideas was through prejudice and discrimination. This thinking is line with other theorists would say that society perpetuates negative assumptions about people with disabilitism through a whole system of social controls. Cahill in New Zealand comments:

company on this “breakthrough”

The major media images of people with disabilities are two-fold: either the person is an embittered individual struggling against the world and against his/her disability or else the person is superhuman.

Cahill (1991: 9)

A report furnished in Australia said that discrimination was reinforced by the media:

Media have a powerful effect in the promotion of fear through the promotion of misinformation (however unwittingly), selective representation, the use of loaded language and stereotyping. Kippax et. al., (1991: 14)

In the past people with disability were isolated by our communities, But discrimination helps to make some people with disability feel uncomfortable when they can not keep up with the pace of "normal" individuals. When I asked one of the participants what happened when he came into contact with others, if their actions upset him, he just said:

I used to, now people tend to give me an extremely wide berth... you know it is really exaggerated. (Jack)

He then went on to relate about the concessions that are given to people with problems in the United States.

Whereas if you go to America, and go to somewhere like Disney World and you are using any sort of apparatus, they will take you straight to the head of the line, you and your party. Some of these lines that I have stood in have little signs that say: One and a half hours wait beyond this point. It is just a different attitude there, because they have dealt with it for longer, I guess. I think the awareness over there is far greater of disabilities although they call them handicapped. (Jack)

He found this was not the case in New Zealand when we chatted about the attitudes of institutions only giving the minimum of services for people with difficulties.

It is compliance without putting yourself out, isn't it? Well I think it is like that with the North Shore City Council. (Jack)

He related a serious incident when he challenged the authorities in Takapuna and soon got Council intervention.

They had disabled toilets. They have got the lift. You can go into each individual cinema and not have to transfer out of your wheelchair, but you couldn't get in the front door, because there was a step. Crazy... I sent an email via DINS to the council and it was at a meeting of the disability advisory group to the council that my email was brought up and one of the engineers walked around to the theatre to have a look while the meeting was in progress, and came back and said: 'This won't do. We will fix it' and they did. (Jack)

I complained to the university at the start of a new year that I was unable to ride my scooter from the lower campus to the upper campus. There were no council footpaths and the bus didn't have a hoist in it. The pathway had steps in it so I used to by-pass that by using the bridle path. But it was a problem because they had some cattle rustling one summer so they put a padlock on that gate. I knew they could put that right by giving me a key to the padlock. The site manager refused saying it was a health and safety issue. I said it is a human rights issue. I complained to the Human Rights Commission and they agreed. And that got the university's notice and some action. In the process, the Council became aware of access problems and speedily undertook (within one week) to construct pram ramps at the roundabout in front of the University campus.

At a function sometime ago, Jack queried the council's attitude towards this minimalist care in the community.

We had a Neighbourhood Watch meeting here a couple of months ago and the Mayor and Mayoress attended it. The mayor was espousing forth how Albany was the centre of the Shore. I said to him: Who is in control of the development of the Albany Basin, - the actual physical developers or the council? And he said: Why do you ask and I replied because it doesn't work. I won't go there because it is not accessible and he claimed that all the buildings have to comply. I said the buildings do comply individually, but you can't get from one building to the next one. You can't go to Farmers and then decide to go to Placemakers, because you can't get from one to the other so you have to leave Farmers, get into your car and then drive into Placemakers car-park and if you are lucky, get a carpark.
(Jack)

Caregiver responses

'Transient mood changes, irritability and anxiety are the rule rather than the exception in MS. Two thirds of patients experience these symptoms in the course of a year and a third of them will be severe enough to merit the diagnosis of major depression. A life time prevalence for this diagnosis ranges from 40-50%'.
(Ron & Feinstein 1992: 1)

People with multiple sclerosis are very difficult to live with. Often marriages dissolve and it is not always the fault of the loved ones. Most of the participants in this research were in a state of transition although some had developed long term relationships. Some time ago I remember a conversation I had with one of the partners of a man with multiple sclerosis not involved in this study. She said she no longer loved her husband after years of impairment and infirmity and he was incapable of loving her. Her love for him had been replaced with compassion and she

saw him in the light of a child that needed looking after. This sort of response was common for most of the participants of this study and it is not the fault of the “loved one”. The self-perception of men with multiple sclerosis is extremely complex. Living with the condition and going through the various phases of the grieving process makes us extremely difficult to live with. We need to be mindful that such processes will affect people with other major life conditions as well as those with multiple sclerosis. Maurice recounted what he felt after his diagnosis:

It is like your MS. You learn to live with it. Initially, when they diagnosed me, I went into a complete spin. I didn't want to talk to or see anybody, I just sat at home and brooded. That went on for a long time. I was a really miserable sod. I would ask: Why me, what have I done. I have always had good health, I have been Jack the Lad. I have been fireproof and now they tell me I have got this, I had it for a long time. Michael honestly, I was a really objectionable miserable sod. (Maurice)

Most of the group were or had been involved in serious relationships, one had moved back temporarily to live with his parents but this created problems of autonomy. Parents have different relationships with their children than partners have with each other. Parents are in a quandary, their love for their children is always a lifetime bond, whereas a partner's love is more conditional and they can walk away. In my personal interview I indicated my feelings and observations on this.

So all these things play on our mind and this, to a certain extent, is why I think a lot of relationships fail. The wives or partners leave. The loved ones don't quite know how we feel and try to mother us too much. Whereas we want our independence. We are trying to individuate. We are attempting to think of ourselves as we were. (Michael)

One of the participants explained that his interests were not centred on himself but on the care of his family.

Basically all our lives we do this. We do what is best for our family. We do what's best for our wives. We do what is best for our kids, but we never seem to do anything for our selves do we? When you think of it, we do very little for ourselves. If we buy a new car, it is because the family would like a new car. You have always got that at the back of your mind, but you actually don't do it for yourself. (Ronald)

Another member of the group saw his partner wanting their relationship to move on to a more solid footing. But he was mindful that the loss of his independence could mean relinquishing his principle of self determination.

There have been many times when my partner has nagged me to move in with her and every few months it flares up again, and we have a great big row about it. I have explained to her that my independence is important to me. It is important to be able to look after myself and do everything for myself. I said there may come a time when I can't do that any more. I will have to have someone living with me. A couple of times it has caused real ructions and I can understand that... We have been together six years now and I can see where she was at. She wants to make it a more permanent thing you know. I can see that quite clearly and I sympathise with her. On the other hand if you are living with somebody, the benefit is drastically altered. It is the old male thing about living off a woman..

(Maurice)

Another of the group had his own philosophy that may have turned out to be a “self-fulfilling prophecy”. He predicted a decline in his health and value to others and foresaw the need to change his marital arrangements.

With being sick of course the days of my usefulness are diminishing very rapidly. I was earning hundreds of grand a year, and now I am nothing at all...I knew that would eventually happen. My usefulness has come to an end. (James)

There was a feeling of helplessness amongst many of the group concerning their continuing ability to support their loved ones. Things had changed and they started discussing situations with their parents or friends because they too had difficulty dealing with the multiple sclerosis. In my case, I felt that my wife and her mother were now following their own agendas of excluding me from their lives.

I was completely shut out of any decision making. Discussions are made without your input. That is the most hurtful of all. (Michael)

Another participant felt devalued and commented that his wife used to control and deal with any situations that arose.

Some of the things she used to do was go out somewhere. If we were going to a shopping centre or anywhere at all, she would immediately take charge. I felt a second class citizen, even though I was paying for everything, and, of course, she would ask all the questions. (James)

These perceptions of disempowerment do not just result out of our own relationships. It is a common problem with society as a whole. The wider society is confused about how to act with people who have impairments. Perhaps it is a learned helplessness that we develop as a result of no longer having to make decisions for ourselves--an

over-reliance on our loved ones. When I initially filled in the forms for social welfare assistance, the case officer turned to my wife asking if I could sign my own name! Friends of mine in wheelchairs have told stories of the public not knowing how to deal with them appropriately. We tend to resent the disempowerment we receive from our own families even though we may have been instrumental in creating the confusion. One participant said:

You don't like it [dependence] but it happens, and there is nothing that you can do about it. They are trying to do their best but in fact they are not. The relationship with family and friends has definitely gone backwards and is more strained, because I am basically a different person and keep biting the hand that feeds me. (Ronald)

Summary

This chapter covers a plethora of topics relating to power and control and the cultural construction of men and societal norms that they should have disease free, “normal” bodies able to provide for their families through working. When this changed for my research participants, their self-esteem was severely affected. Then along with the multiple sclerosis diagnosis and power exerted by instruments of the establishment came power and control through the medical profession. But as shown the men were not complicit in accepting that they were helpless “pawns” in any of the power games and devised their own strategies in answer to the authorities. Mostly they sacrificed their “safety net” of security or were forced into reclaiming some control over their lives. Paramount here are issues of self determination which looked at dealings within personal and community relations.

Chapter 7

Value of Support

We need same sex friends because there are types of validation and acceptance that we receive only from our gender-mates. There is much about our experience as men that can only be shared with, and understood by, other men. There are stories we can tell only those who have wrestled in the dark with the same demons and been wounded by the same angels. Only men understand the secret fears that go with the territory of masculinity. (Keen cited In Kauth 1992: 2)

This study, along with numerous other studies, confirms the benefits of mutual self-help support groups. This chapter examines why men with multiple sclerosis have decided to share their life stories through the process of joining the “boyz.R.us” co-mutual peer-support group. This chapter shares how support group members have made adaptations and learned a range of skills that enable them to more effectively participate within the wider community. It also provides an in depth examination of the success of the “boyz.R.us” group, members’ methods of accessing resources, and finally , different strategies and methods for regaining semblances of normality. In the New Zealand Multiple Sclerosis Society, the only other region that has a male-only group is in the Wellington area. There are however field officers in other regions who have identified the need for more groups.

The “boyz.R.us” group is known within the local Multiple Sclerosis Society and the meeting place is advertised in their newsletter (it is circulated within New Zealand). Out of the 30 or so men with the North Shore Regional Society there are still only a small number that have joined our group. There are three other support groups on the North Shore who include participants that are male but they do not feel the need for a specific male focus. Members of the “boyz.R.us” group attend from time to time or have attended other support groups but have decided that their needs could not be met or did not like the style of the meeting. One of the participants said:

I think it has probably got a lot to do with the same reason that I have only been to one MS society meeting. I went then because there was going to be a speaker there, talking about Primrose Oil, and I wanted the information. I am sorry, but, although the field officer is a lovely lady, her mannerisms, not uncommon for people in situations like that, were a little patronising, and I don't think people like that. I think when you go to those meetings there is a tendency for people there to accentuate my disability. That is not what I need. I don't want a shoulder to cry on. I want a crutch to lean on. I want strength and support, and not sympathy.

(Des)

The idea of support is part of the rationale of the multiple sclerosis movement and professionals within the organisation. For example, the emphasis is upon field officers acquiring skills to facilitate support groups. As a researcher and member of the Society, I have attended a number of groups that have met in various people's houses over the years. The support groups had input from all of the field officers, in many cases only slight. The exception to this is the “boyz.R.us” group that has had virtually no involvement in the activities of the Society.

But there are protocols that must be observed when dealing with either mutual self-help groups or structured organisational support groups. It may be acceptable for a field officer to introduce a new member of the society to other support groups, but in the case of a mutual self-support group, permission from the members of the group is sought before an introduction is made. The formation of the “boyz.R.us” as a group was not developed from a suggestion of the field officers, but was instigated by the members themselves who eventually undertook to form the group. When a field officer with multiple sclerosis attended a “motivation” group meeting in the past, there was much confusion as to her motives for being there as, on one occasion, she admitted it was an ideal way of checking on the condition of her clients.

A problem in the Multiple Sclerosis Society is that men are in the minority, and some of us consider that we were doubly marginalised in the sense that we are statistically underrepresented and have what is often perceived as a “woman’s complaint”. A men’s group seemed an ideal platform for interaction with other men and also as an interface with the multiple sclerosis organisation, where we could deal with our issues of alienation within our own society and the wider community.

You don’t have to “spill your guts” in a men’s group - there isn’t any pressure. Perhaps for that very reason, though, you soon find yourself hoeing in - prompted by the similarities of your own experiences being shared with other men. You get practical tips for living and feel you can breathe more deeply, all at the same time! It adds to a sense of relaxation in your life.

(Biddulph 1995: 238)

Contact between members of this group extends beyond the group meetings which are held a couple of hours once a month. Many members interact with each other a couple of times or more each week. Telephone and email are the main means of keeping in touch, and many of the members are on the boards of different committees, whether it is within multiple sclerosis or on disability issues.

Support Groups

Support groups come and go. Their existence depends on whether the members are able to gain some benefit out of attending. As members of any group, they need to be able to attend at their own leisure remembering that, what may be good for some members of society may not fill a specific need in either themselves or others. One member of our group had no intention of joining another sort of support group in a pain clinic.

Referring back to that time, the last thing I wanted to do was sit in a room full of other people wanting to talk about their pain, and me having to talk about mine. I did not want to do that, I found that abhorrent. They went on and on to pressuring me that I should do it.

(Maurice)

I described to one participant what it was like for me to belong to the 'boyz.R.us' group by identifying my past involvement with the "motivation" group.

The camaraderie, it is all the blokes together. We can tell a few blue jokes together. I came along to that "motivation" group and the first person I met that I remember was James. He chewed my ear about multiple sclerosis. Another important member of the group was Steven, who hasn't survived unfortunately. He told me about all the avenues where I could go

and get grants for different things. He said that you should have a car, and told me how I would go about establishing my entitlement for a car. I said I am not that disabled yet, and I thought that was the wrong thing to say, but disablement can be a state of consciousness as well. (Michael)

The “motivation” group was a support group started in Takapuna by the Co-ordinator with Disability Information North Shore. This woman identified a gap where there was little social interaction amongst young to middle aged adults with physical or sensory impairments on the North Shore of Auckland. Another influential person in the early days, was the then Field Officer for the Multiple Sclerosis Society. She recommended that a few of the newly diagnosed and younger adults might like to attend. It was the Field Officer who suggested I attend a “motivation” group meeting as it may help me with my adjustment to living with multiple sclerosis. But the group evolved from being a facilitated group to a peer led support group. The “motivation” became self-directed and it was from this idea that the concept of the boyz.R.us group developed.

Both the Disabilities Co-ordinator and the Field Officer noted that other cohort groups of people with disabilities existed and they were well catered for by support or self-help groups. One of the major problems identified by these professionals was that the ages of individuals were important in the mix. An invitation went out to adults with disabilities and the Co-ordinator of Disability North Shore facilitated a couple of meetings, but allowed the group to dictate any avenue of activity the members wished to pursue. One of the participants had this to say about his recovery and regaining his self-esteem.

I will always have a respect for the Disabilities North Shore Co-ordinator, because she was part of digging me out of the hole I was in, and from that time onwards I have just gone up and up. The “motivation” group got me really motivated when the Richardson/Shiplely duo cut the benefits. I was on a benefit at the time. (Maurice)

The issue of “matching” people with multiple sclerosis has always been important to the field officers in the multiple sclerosis movement, as they are aware that most newly diagnosed individuals are plainly distressed at seeing people severely impaired and in wheelchairs. It has often been stated by the members of the “boyz.R.us” group that when dealing with their own mortality they have tended not to become involved with the multiple sclerosis organisation because of that reason. This is unfortunate and part of the reason for writing on this issue of the construction of disabilitism; even people with multiple sclerosis look too much at the aids and objectify the disease, forgetting that the person is more important than the condition.

What are the Benefits of Mutual Support for Men with Multiple Sclerosis?

An amusing incident arose out of a conversation in the group that highlights the values gained through social support. One of the “boyz.R.us” members made a flippant comment that one of the wonderful things of multiple sclerosis is that you could be completely drunk all of the time, and, jokingly, another group member said:

You could fall over half way through your first beer in the pub. They would say that is enough for you buddy! and you could then say. “No. “Hold on, I have got MS,” and they would say: Sorry, and from there, you could sit down and get drunk all night. (Des)

Then George said, “*there should be an MS card like an FBI card*”. Apart from the jocular intention of the comment, there was a serious side. Such a card does exist, as mentioned earlier. They also realised that their own experiences of the condition were somewhat universal to other members of the group. These form part of the three main goals for mutual social support mentioned by Levine et.al., (1990: 193): (a) companionship; (b) emotional and motivational support; and (c) self-esteem. These beneficial processes in mutual aid groups can be looked at in terms of satisfying the needs of the members through:

- 1 overcoming the effects of isolation and instillation of hope-groups consist of people at various stages of dealing with their condition.
- 2 universality-a belief that members are unique in their experiences.
- 3 imparting of information-participants learn a vast amount on a great variety of topics.
- 4 altruism-opportunity to receive for oneself through giving.
- 5 collective emotional experiences-authentic emotional expression, the “no bullshit” factor and being in a psychologically safe environment.
- 6 group cohesiveness and commitment to each other.

What do members expect to gain from contacts in the group?

One of the participants assumed that another member enjoyed coming to the group meeting because it satisfied a need that he saw was being met for himself. I suggested that perhaps he did not enjoy meeting at such a public place. Des commented:

Ah, but he does like it. That is why he is turning up...I think he is busy, too distracted. But I think he is benefiting at the same time, because one of the key things about having MS is staying busy. That will help you keep in better condition for dealing with the MS conditions. (Des)

Maurice said:

As I explained to them when I first got involved, I am in the same boat as you, I have a long term complaint or condition. If I can do anything to improve the quality of your life, the chances are that I will do so for my own quality of life at the same time.

I asked another participant what he saw was a major benefit from joining firstly, the “motivation” group, and secondly the “boyz.R.us” group. His comment was: “*Social interaction*”. I related that when we first met in the group setting, it was the fact of mixing with other people who had similar experiences that somehow helped to validate my own experiences. He commented:

Well, that is part of it. The other is that your world is a lot smaller now. You are in the same category as everyone else who is in the room. So you might as well join them. (James)

The “Motivation” group and transition to “boyz.R.us”

This section presents the “voices” of some participants who tell their stories of the shift from the motivation group to boyz.R.us.

I said to Maurice I have known you for along time now, and the ‘Motivation’ group was started for your benefit because it was a success in his terms, so he left. The

membership of the group had changed. He felt too many of the newer ones were “*Moaning minis*” (his words).

James has been reasonably involved with the local Multiple Sclerosis Society and used to walk to the office which was a couple of kilometres away. He joined as a member not long after diagnosis and has been twice a committee member.

I decided to join the MS Society about two days after I was diagnosed in the hospital. (James)

The benefits of mutual support helped in the motivation of one of the participants.

So if I can, I will. So yeah that was another part of me getting more motivated. It really was a combination of things. The gym was part of it as was the “motivation” group. Gradually I came out of the depression I was in, and thought: Right, make the most of it and get on with your life. You are never going to be quite what you used to be, but, you still have a role to play. (Maurice)

The next participant was a member of the “motivation” group before he went abroad to live. Shortly after his permanent return to New Zealand I met him for a coffee in Takapuna. We devised a plan to meet on a regular basis and agreed to invite some of our old friends from the now defunct “motivation” group. He is now in another long-term relationship and met his partner at a “motivation” group meeting after his marriage dissolved.

My wife lived with MS for sixteen years, before she hit the wall. It was a shock to me. For two or three years after I wondered what would have

happened if she had said: I want out of this because I can't handle what is coming up in the future. I don't know what is going to happen. I would of said: OK. But I have MS for 23 years and I'm going to be all right. It is too much. (Jack)

Boyz.R.us

People who join mutual aid groups get the benefits of social support. These benefits vary however according to the needs of the individual members of a particular group. Maurice was one of the influential members of the “motivation” group. He was one of the first to leave because his situation changed. I asked him why he came to the “boyz.R.us” group and his comment was the same as the newer members, “*I still enjoy it*”. In turn he asked me what I got out of it and I replied:

You don't even have to explain because, everyone knows. Sometimes we talk about our condition or problems, but that is not the focus. It is to go along and have a few cups of coffee and a few laughs but especially because we are there with others who know what it is like.

Another participant felt relieved that the interaction with others in the group also validated his experiences. He said:

It is amazing what you have mentioned in our talk. You said you have had things that were wrong with you, and I have never heard that before. And I thought it was just me ... (Ronald)

I replied, “Yeah I know. You thought you were going mad”. And then Ronald said “*I thought I was the only one with those sort of problems*”. The members of the boyz.R.us group felt comfortable with each other, although their past experiences were individual to them, somehow the similarities bound them together with feelings

of solidarity. "I can understand how you feel, because I have been there", a participatory mode of consciousness so to speak. Another participant said following this but reframed it as:

I love going to that, because I go there, because there isn't anyone there, saying oh, come in, how have you been and things like that. It is just the guys, sit down, we don't say oh and how have you been getting on with your MS since we last met. That is not what it is about! It is living with MS and understanding and feeling that as a person, you are no less of a person than anyone else because you have MS, and you will now sit down and have a coffee and conversation with people who don't think we are any less.

(Des)

Another participant saw it more simplistically and enjoyed just being accepted and included as a person with multiple sclerosis. He said:

It is actually I enjoy coming to it.

(Harry)

One group member mentioned his liking for particular individuals, but it must be remembered we are not homogeneous group. Some of the participants had personal likes and dislikes for different members of the group, and most of the time we either tolerated each other or we chose not to attend. On the whole the group got on very well.

Part of the validation of our experiences meant that newcomers did not have to contend with changes in their health in isolation.

At a recent meeting I heard Jack speak for the first time, and it just made me think of when he could walk, and when he was still driving and he still had MS, because he had the card to put up on the dash. There was a discussion over that, and again, it just made me it was a good reminder that I haven't forgotten, that it is possible that I could end up there. (Des)

We have developed a rapport in the group, and an important feature of our group members is that they think of the interests of their peers.

I think everybody has benefited by it... I think for Des, particularly, because he is in the early stages, it has given him the opportunity to talk it through with other guys. (Maurice)

But he indicated that it was the informality that attracted him to both the "motivation" and the "boyz.R.us groups.

It is a get together which isn't a formal meeting, and I attend enough formal meetings, and this is a get together. You sit there and bounce things off each other. (Maurice)

An increased network of people with Multiple Sclerosis allows men in the group to share and gives them a sense of belonging. This promotes self-identity with the group and helps to create feelings that you are not on your own, and serves to kindly and gently build the esteem of group members.

The building up of the self esteem is important was mentioned by James:

That's exactly right, you have to have an incentive that comes from within to do these things, it is no good someone saying to you, "You know you

should do this”, because you never will. So you have to have an incentive from within to actually make your mind up about it.

By identifying our stories with one another, we realise that we are not on our own and that this is self-validating. This shared experience was probably the success of the “motivation” group. As a researcher and a group member, I believe the motivation groups were good for our development, even though we all went our separate ways. There was still something missing by way of fraternity, and that was the motivation for some of us to get back together as “boyz.R.us”. It has grown from there. It may not be for everyone; occasionally others have come but decided that this group was not for them.

Whakawhanuanga and the Internet!

Another great support vehicle is the internet which gives international access to other groups. Some years ago I was researching for an annotated bibliography. The topic was: “Where the computer culture meets the culture of people with disabilities”. One of the uniform resource locators was Jooly’s Joint. I contacted the administrator in England because she had disclosed her background as a person with multiple sclerosis and had lived in an area I had worked in. I passed this information on to Jack as he was born in England also. He decided to explore the options available in her vast empire of contacts. Jack was invited by a magazine associated with Jooly’s Joint to submit some short stories about his life for publication on the internet. This was validating, not only for Jack in telling his stories, but also for the people reading them, as they were able to identify with some of his concerns and frustrations. The submission of his stories was so successful that he was asked to send more stories that were published on-line!

Apprenticeship

The guided learning process (the idea of the apprenticeship model) can work in reverse where the so called newcomer to the group has specific skills that are of benefit to other members of the group. For example, Des had designed a small clip for a walking stick for clipping it to belts and handbags when temporarily not walking. It was James who commented, *“You know this idea of Des’s? I made this thing to put on there”*. He had made a clip for his own walking stick. Never-the-less, the apprenticeship model is a worthwhile way of newcomers learning from the more experienced members of any group. As Ryba, Selby & Kruger, (1999) have explained: The new members of the group learn from the established members of the group by: (1) becoming active in getting information and practising what they have learnt; (2) communicating their desires for they seldom learn alone; (3) carrying out cognitive processes jointly; and (4) seeking guidance from more skilled people and collaborating with others.

This guided process works for the members of the group by their following helpful hints that have been of benefit to the sharers of the information. For example, I asked one participant who had optic neuritis, how he coped with the variability of his vision and how he managed the various corrective lenses that he required:

I have got a pair here, I have got a pair there, and I have got some high powered ones down there, and I have got several pairs there and I have got some in the garage and some in my bag, they are all over the place. (James)

I was having difficulties with my own vision especially when severely fatigued but have now adopted this strategy for myself. I currently have five pairs of glasses at arms length at home. This has enabled me to continue with my studies without taking time off for lengthy recuperation.

The importance of finding mutual support from groups helps those seeking answers to their concerns and problems that eventually may lead to their regaining personal autonomy. (Kauth 1992: 3)

The benefit of using this model, whether we are conscious of it or not, is that it helps the members of the group to adjust to dealing with different phases of Kubler-Ross's model of the grieving process. These different states are never static and seldom resolve to a satisfactory conclusion, as each moment can be challenging and pose a different set of problems. Multiple Sclerosis is a complex condition, and in defining the different moods, it can be seen that the individual deals with more than one at a time. Just the slightest trigger may propel the person into another phase of having to cope with compounding emotional problems. Sharing experiences of how they dealt with their own grief helped members of the group help each other in the process by having to actively think through similar scenarios and reinterpret them for others' benefit. Through having to confront an issue and seeing how others have dealt with it, the group members provide a structure that serves to scaffold the problem solving capabilities of the individual (Ryba, Selby, & Kruger, 1999). In the process of collectively building these skills, members develop abilities and strategies for maximising their own independence.

Access to resources

The participants in this study develop the skills mentioned earlier in line with practical action research as denoted by Schmuck (1997) who described how that students learnt by adopting apprenticeship models of practice. This consisted of combining the process of seeking information, reflecting and thinking about it so they may be able to use it to their own advantage. Although Schmuck devised this “overarching rationale to justify the role of action research within the arena of academic research” (Schmuck 1997: vi) this is easily transposed into the support group environment. The members of the group can learn through discussing their own concerns and problems with each other and by listening to how others have coped with similar issues, they then reflect on those discussions. The members in turn rationalise them out and adapt them for use in solving their own concerns.

Steven Wear in the days of the “motivation” group told stories of how he accessed the resources from DSW⁹, and from that was learnt the technique of how to ask for the entitlements. This information coupled with the field officer referral from the multiple sclerosis society, one is able to present a lucid argument to the authorities where interpretation is left to a minimum by the case officer and the options left are then procedural. A number of other issues can be countered when dealing with that department: being friendly, pleasant and interested is another strategy to use effectively in an atmosphere that is often challenging to the staff.

The idea of support for people with multiple sclerosis has been highlighted by many authors including Dyck who says, “Financial situation and social support from friends

⁹ The Department of Social Welfare (DSW) have gone through a metamorphosis in New Zealand, changing their name several times to the department of Income Support

and family are important in mediating the lived experience of chronic illness, while access to practical knowledge concerning the management of both the economic and social aspect of the disabling consequences of MS of social dimension of variation". (Dyck 1995: 318)

Ageing Process

When discussing and sharing the nature of their health status, two of the participants were advised by their medical practitioners that problems they had recently been experiencing were more related to the ageing process than to Multiple Sclerosis. Perhaps as people with multiple sclerosis, we become more conscious of our health and tend to mentally note changes. However, many of the group were aware of age related weaknesses that are not necessarily a result of our condition. One of the participants said:

What shouldn't be forgotten is that no matter how old we are now, we are all getting older... As my doctor pointed out to me recently, "You have got to remember that certain things happen as you get older. You know, you are middle-aged now, even if you feel like a teenager". (George)

Another followed by saying

I went to my GP not so long ago because I couldn't read at night any more. I asked can you check to see this not an MS thing. He checked my eyesight from on the wall chart and said, "Jack you have got to remember you are getting older son. We all have to have reading glasses when we get to your age". (Jack)

(Income Support), then to Work and Income New Zealand (WINZ) and now they are the Department of Work and Income.

Even Des, who is one of the younger members of the group said, "*I suppose the one thing you have got to watch, is blaming MS for everything*". The participants in this study were mindful that in relation to their own health concerns, they may not rely on anyone but themselves and therefore took responsibility for self care. The members of the group had initiated programs for exercise whether or not they needed assistance to perform the tasks from external sources. Most were reasonably philosophical about institutionalisation, but planned for this as a last resort. They are relatively independent and are able-bodied at this stage. They have learned from the other members how to access professional support services from the community without having to lose their complete autonomy.

There is one exception as mentioned earlier. Harry has not been well and now resides permanently in a hospitalised situation where he has 24 hour medical care. I visited him recently and took the tape of the focus group interview for him to hear because he was not well enough to attend. In any event he was not interested in listening to it, but his spirits were high. He was watching television at the time and still occupied himself with an abundance of reading materials. Harry's plight was more severe than any of the other group members and being placed in an institution such as a rest home meant that he always had to appear to comply with their rules and regulations.

Other participants were very aware they wished their condition to remain invisible and craved to be regarded ordinary. They reminisced about their pre-illness condition and often considered they were emotionally strong enough to offer advice to others:

I would say to depression, not to someone who is generally depressed, I would say get on with it, there are people who are much worse off, who are getting on with it and I don't mean in the old fashioned way where they used to put people down. Probably a lot of MS people, who were undiagnosed in the early days, would say come on get on with it because they were so bloody tired, too fatigued to do something. People would say you are just being too lazy. I used to have an incredible amount of physical energy, I certainly have a lot of mental energy, incredible energy. It is almost bursting out Michael and that is why I like working and doing things and keeping up my social register if you like. (George)

But they were also aware that mutual support was reciprocal and they got benefits both by giving and receiving.

As I said to them as I first got involved, I said I am in the same boat as you, I have a long term complaint, a condition. If I can do anything to improve the quality of your life, the chances are that I will do so for my own quality of life at the same time, so I am in there boots and all.

(Maurice)

The sharing of their life stories legitimized the experiences and this, in turn, empowered and motivated members of the group. The support group environment is important to people in all situations and even in the university we surround ourselves with mini support group of friends. Even the disabilities group, in the same way as other mutual support groups, uses a mentoring system, which is really a different way of saying we are adopting the "apprenticeship model". I was fortunate enough to be able to speak to new students with disabilities before they started the academic year. I related this story when interviewed by Jack.

There are a lot of able-bodied people that are disabled, you know when I look at university I was there and Ross is a guy who has got Multiple Sclerosis, only a young fellow, and all these people were along there, thinking of going to university and they all have physical, sensory or intellectual impairments. I said to all of them, there are a lot of people who don't make the grade at university. Not because they have got disabilities, but because they don't have the will to succeed and I said that is the important thing. You are going to have to want to do it. You know it is not going to be easy, life is never easy, and you have got to be there. You have got to want to complete the job. And you have the support of people in this disabilities committee that have made it. They will help you to devise the strategies to show you the way through. (Michael)

Summary

The value of support was a subject of much discussion by the participants. It was evident from the range of experiences that there was much information exchange and sharing of strategies that were empowering for the group members. The ideology behind the success to the support group environment is strengthened by theories devised by researchers about “communities of Practice”. Most of us use our personal models and develop ideas without any true intention of thinking “why does this work so well for us”? The members of the group do not theorise why support works. They generally just like being there and it helps them to build their self-esteem. It is great to see your mates. Wineman (1990: 299) said that the “Supportive network interactions may function to confirm the individual’s sense of integration within the network, thereby providing reassurance of one’s value as a person”.

Chapter eight

Discussion and Conclusions

A good critical emancipatory standpoint text is one that is local, multivocal, collaborative, naturalistically grounded in the worlds of the lived experience, and is organised by a critical, interpretive theory.

(Denzin 1997)

With the above view in mind, I will undertake in this chapter to draw together the main findings of my research in order to formulate the conclusions and implications for further study and development of co-mutual support groups.

The analysis presented in this thesis is based on my own life experiences together with the voices of the “boyz.R.us” group. By comparing my own experiences with those of the research participants, I have sought to triangulate the results through analysis of the main themes emerging from the interviews and anecdotal data. The narrative approach to “insider research” that I have adopted is in keeping with the work of Roseneil (1991) and Smith (1999). Both of these writers advocate the importance of verifying the data through interaction and checking back with participants. This was achieved in the present study by working collaboratively with participants through the sharing of information and checking of data. Following the advice of Ballard (1995), I undertook, as a researcher, to create reciprocity with my comrades through exchanging stories and learning through collegial interactions (fuelled by many long blacks and flat whites of course).

Recognising that the information presented here is based on my own experiences together with the “boyz.R.us” colleagues, the opinions in this thesis should not be taken as all-encompassing statements, such as: “This is how all people with multiple sclerosis act”. My friends and participants are a small group and our experiences of learning to cope with our conditions have been affected by each other’s situations. I have tried not to influence the group, but in reality, I believe that I have. This study is mine -- the topic was my choice. The study was never set in concrete, and, in fact, the more I have read, the more my thoughts have evolved.

If only one point comes out of this thesis, it is that we are dynamic and capable people in our own right. We are NOT desperate disabled sufferers. We are sexual, emotional, and spiritual beings who are “disabled” by the environment in which we operate and the perceptions of society as disability is a social construct. Cahill illustrates this with a quote from one of his participants:

We are not victims /the disabled/cripples/handicapped/the physically challenged. I am not partially blind. I am partially sighted. We are people with disabilities who deserve the dignity of our ‘peopleness’ and the opportunity to participate with freedom and power. (Mathew)

(Cahill 1991: 30)

We are complex individuals who continually strive and develop strategies for survival in what is frequently a “hostile world”.

Increasingly, attention is being directed at providing support for people with

disabilities within the community environments where this is needed. Moreover, there is recognition that the people themselves can have a strong mediating effect on the adjustment and survival of individuals with disabilities. This is evident, for example, in how the “boyz.R.us” group support one another. Increasingly, recognition has been given within society to create conditions that will enable individuals to take responsibility for themselves. It is evident that the medical establishment is evolving in this regard, and placing increasing importance on prevention and community based support through both formal and informal channels. There is a need however, to recognise and legitimate the important role of informal peer support. The challenge now is for formal helping agencies and services to shift their thinking from “caring for” to “working with” people with MS so that they are better equipped to support themselves.

Me and M' Mates

This thesis is full of me and I make no apology for my inclusion. As Anthony Cohen, an anthropologist, has said, “Examining and reflecting on the self is not an alternative to addressing ‘society’ or social relations: they are mutually implicated” (Cohen 1994: x). His comments are also pertinent to the description of my self and the support group environment. Wendell (1996), a feminist philosopher with a disability, stressed the importance of dealing with issues of alienation. As indicated in this thesis, co-mutual support groups can have a valuable role to play in overcoming alienation through promoting collaborative and interdependent relationships. Recent “insider” research by Hight (1999), a person with multiple sclerosis, indicated that her female participants learnt more from each other about how to deal with their condition than from medical professionals. Relating this to my own study, it is

evident that co-mutual support for men with MS is an important strategy for assisting them to function autonomously within the community.

I have adopted many approaches from the feminist “basket” of methodological tools in my study on men with multiple sclerosis. Research into any group as an insider can be fraught with many problems. There is the camp of hard scientific researchers who think that this form of study is suspect. By being so close to the study, it is impossible for the researcher to remain “objective” in the traditional experimental sense. However, human beings are complex and relationships can not be observed satisfactorily in a laboratory situation. As Heshusius (1996) explains, we should move on from the focus on self and see objectivity and subjectivity as sharing the same alienated mode of consciousness. As a researcher, I place value on my own subjective experiences as well as the subjective realities of the people and environments around me. It is through sharing our subjective experiences, that the group has been able to devise coping strategies that enable participants to function more effectively within the community.

Reflections on my Collaborative Research Process

My aim in this study was to work collaboratively with my friends and colleagues to answer the research questions. In effect the participants selected the questions which were jointly decided in the collaborative method of enquiry and devised through differing modes of discussion starting with our facilitated meeting.

This collaboration was achieved by working closely with the group and presenting the voices of each participant. Rather than treating the participants as “subjects” in an

experiment, I sought to actively involve them as co-researchers in the process. Through our regular meetings, I was able to check my data with them and also get their views on the interpretation and presentation of information in the thesis.

I used several approaches to ensure that there was authentic and active involvement of the participants. These included:

Personal Descriptions of the Participants

I have described the joint participants in this study starting with a short vignette on the individuals with further exposure given in the lived experience chapter of this work.

Inclusion of Participants Own Stories

The data chapters have presented many stories to illustrate the participants own experiences and how these relate to my situation as a person with multiple sclerosis.

Personal Communications With Participants

Contact was maintained via phone calls, emails, coffee meetings etc. Because of the regularity of our contact this allowed more reflection for the participants on issues. Some of them gave or sent career resumes, references and written medical comments they received when diagnosed. This regular contact rather than just having a glimpse at the lives of the research participants acted as a form of unstructured longitudinal study.

Personal Auditing of Transcripts

I asked each person to check the transcript of the interview for accuracy and meaning. As it was, the information was mostly correct, by allowing them the opportunity of confirmation and correction of points in the transcriptions. This process gave them

dignity and power through being able to check and respond to my perception of them.

Focus Group

This involved discussion of themes and common issues. The group discussed these jointly in the initial facilitated meeting, expanded on them in their personal interviews, and verified the importance of these in the focus group interview. In essence no new ground was covered in this meeting but it allowed the participants to continue to share some personal experiences in front of their colleagues. This process was empowering for the participants.

The above methods enabled me to create what Bishop (1996) refers to as a reciprocity between the researcher and the participants.

Achieving Interdependence Through Guided Apprenticeships

Co-mutual support groups provide more than practical assistance and social interaction. They offer a means through which individuals can develop their identity and explore themselves through sharing information and developing new understandings about who they are in relation to one another.

It is through interdependence—people helping and supporting one another—that the group members are able to function more effectively in society. The sharing of information, learning through observing one another and giving information, this all helps them in turn to understand how to survive – the focus is not on themselves but through giving to one another, they get something back in return.

- The members develop their own understanding through talking about each others

problems.

- By listening to other members of the mutual self-help support group, individuals may be able to see that their problems are not just personal to themselves but these are shared experiences.
- They are better able to make adaptations for change, and develop knowledge and necessary skills for inclusion in society as a result of sharing ideas.
- They also learn from others strategies for managing concealment and disclosure to their maximum personal advantage.
- By knowing what is happening, the individuals in the group can take responsibility for themselves and their illness. By operating in this non-patronising environment they learn to develop skills of understanding. As one of the participants said, he wanted “a crutch to lean on, not a shoulder to cry on”.

The development of interdependence in the ways described above, show how anthropological studies can be applied to analyse the formation of “apprenticeships” for learning. Lave (1988) drew upon experiences in other cultures--Craft apprenticeship in West Africa and apprenticeship among Yucatec Mayan midwives--to illustrate that there are highly valued forms of knowledgeable skill in these cultures for which learning is structured in apprentice-like forms. “Guided participation” in communities of practice is highly relevant also to many other forms of socially organised activity that have become accepted within western society as sites of

learning. This includes the formation of co-mutual support groups such as “boyz.R.us”. Such groups convey a set of values and beliefs that guide their practices and influence induction of the novice into the expert membership of the group (e.g. strategies for maximising income support).

Although there are obvious differences between apprenticeships within different occupations and social contexts, there are some common principles of interactive learning that apply to all groups. Justification for the value of an interactive apprenticeship model has been provided by Rogoff (1990) who makes the following points:

1. Apprentices are active in gathering information and practising skills as they participate in skilled activities. Group members are active in observing and participating in the activities of those around them and they are motivated to participate more centrally.
2. The learning of apprentices is structured by practices developed by their predecessors to meet societally valued goals. This aspect of apprenticeship provides a parallel with the importance of recognising that participants' cognitive development involves learning to use the intellectual tools of their group to implement co-mutually valued activities and goals.
3. Apprentices are assisted in their learning by communication and involvement with more skilled people (i.e., experts) and more advanced apprentices, who help determine how to divide the activity into sub-goals that the novice can begin to attain, as well as to provide pointers on how to handle the tools and skills required.
4. Apprentices seldom learn alone. In addition to being involved with more skilled practitioners, apprentices often learn in a community of fellow novices

(such as fellow graduate students, classmates, siblings). Interaction with and observation of other novices provides challenge, support, collaborative solving of problems, and models of learning in progress.

Gender Roles and Social Constructions of Disability

It is mostly people with impairments who are relegated to the domestic setting. As Wendell (1996: 40) said:

When public and private worlds are split, women (and children) have often been relegated to the private, and so have the disabled, the sick and the old.

The chances are more likely the social interactions of men with multiple sclerosis are shared with others in that setting like women, the aged and children. As fatigue is a predominant feature of the participants' lives, they mostly spent time around their own homes. Often their self-imposed isolation is necessary for their regrouping of strength, but never the less, most regretted the implications given that the domestic realm may be seen as "the women's zone".

Men felt that their interests were different from the topics discussed by women. Stein (1982: 288) says men's groups display some traits that reflect the nature of the masculine gender role, for example, independence, aggressiveness, and self-centredness, whereas they tended not to display emotions and are less nurturing than women. Most of the research centred on the positive aspects and familial traits were confined to power and control issues. Whereas Hight (1999: 58-59) discussed sexual matters in her study of women with MS, this was never a topic raised in the

“boyz.R.us” research.

Meetings for men’s groups need to be conducted away from the domestic setting. At this stage, as men’s identity has been conditioned around being at work, it followed that the success of the “boyz.R.us” group was that it met in a public place. It was important to the members that they met in an environment where they could feel at ease with each other. But as already mentioned, not all men see the need for this “male bonding” and many others chose to go to groups that have both men and women. Interestingly, Wright-St Clair (1996: 174) indicates “there is strong evidence that the experience of chronic illness is gendered” when calling for more studies into men’s lives.

The Idea of An Alienated Consciousness

A key question concerns whose right it is to describe our experiences. Traditionally, most of the studies of multiple sclerosis have centred around the medical model. This model stresses the importance of interpretations based on empirical data concerning the condition of patients. Such research has a place, and testing in a scientific manner may be appropriate when studying aspects of the disease. In contrast to the medical model, however, the idea of participatory consciousness focuses on “sharing” the space of the person. It is about empathy and understanding and about being on the same wavelength. Such ways of thinking about research and service development are challenging however to established organisations such as the Multiple Sclerosis Society who continue to be influenced in their thinking by the medical model.

The dominance and influence of the medical model was reinforced by modernist colonial thinking.

“Colonisation was central to the achievement of modernist medicine”.

Frank (1995: 10)

To follow the rationale of the above statement, Heshusius (1992: 5) says:

As many have documented, the birth of alienated consciousness by creating the idea of a split, a distance between the knower and the known, can be located in the historical matrix of overlapping ideologies of patriarchy, capitalism, Marxism and colonialism. The idea of an alienated consciousness emerges for social, political and theological reasons as much as scientific/technological ones. It legitimised domination and a hierarchical concept of order, rather than an order of participation that implies relatedness, equality, care and a full somatic presence.

Others such as Kauth (1992: 3) writing about the “halcyon” days in the 1960s stated that:

It was the experience of “higher consciousness” that millions of people wanted without drugs! Millions succeeded through forms of meditation... and group processes.

Bishop (1996: 235) says that

The very act of participation, was knowing. Participation was direct, somatic (bodily) physical, spiritual and emotional involvement.

In summary, it is evident that medical science and empirical researchers have not

looked holistically at the condition of the individual with MS. By their very nature they seek to deconstruct and understand aspects of the person in ways that are alienated without regard for context or for the environment in which they operate. In contrast, the model for participatory consciousness provides a legitimate way of valuing and using the subjective experience as a basic unit of measurement within the whole ecology in which the individual with multiple sclerosis operates. Such a dynamic view of the interconnectivity between self and society has been provided by Cohen (1994).

Cultural Construction of Disability

A closer examination is required into the cultural construction of disability, dependency and denial of access to resources. As Wendell (1996: 63) states

“Disability tends to be associated with tragic loss, weakness, passivity, dependency, helplessness, shame and global incompetence”.

Also a number of authors have noted that the experience of having invisible conditions like multiple sclerosis creates problems that place these people at risk in an “able-bodied” environment. Dyck (1995) and Wright-St. Clair (1996) are feminist researchers that describe the tactics and discuss issues relating to the social construction of disability as it affects mainly women. But men are also affected when they do not “measure-up” to what is expected of them. This concern was well illustrated by the self accounts of the men in this study.

Many of these “women’s” issues also affect men. They too use tactics of concealment for living in this world of the “able-bodied”. In the exploratory discussion that

initiated this research the participants were keen to see the questioning develop to cover these issues of power.

My not being allowed out of hospital after my car accident in 1993 concerned me. At the time I thought this was amusing, but on reflection this episode annoyed me and today I would consider it an affront, and an infringement of my civil liberties. This appeared to me to be a display of the coercive power of the hospital, the bastion of the medical establishment. This infringement was evident also in the experience of another participant who went against the advice of a medical practitioner to attend a “pain clinic”, and thus became labelled as “neurotic”! Foucault’s ideas of looking at the power relationships of the hospital setting are described by Turner (1997: xii) as:

Foucault provided a description of what one might call ‘the institutions of normative coercion’ such as law, religion and medicine.

Negative Stereotypes

Some members of our group do not like the term “illness”. They consider they are not ill and that we do not have disabilities. Rather, it is the environment that disables us and the labelling of our supposed disability by members in society as being defective and not “normal”. Most people tend to think it is the problem of the “disabled” and not theirs. We are different! We have problems or difficulties that functionally impair our performances. But these difficulties mean that we are forced to live within a world of illness and impairment only part of the time. Mostly, we have learned to cope with our condition the hard way. We have not been brought up with a reference book on how to behave as “people with multiple sclerosis” as the condition does not manifest itself until adulthood.

We try to be “normal”. Reclaiming and maintaining our independence can be problematic. We endeavour to retain at least some of our independence. We do everything that we used to do. Part of the problem is that even our “loved ones” are confused. Some of the time, we are able to manage things that they consider amazing and some of the time we are so fatigued that we appear to be “bludgers”. We confuse them. We get concerned when others start speaking for us, then start speaking over us and determining how we should act. This happens throughout our relationships with others. We resent it. Our “loved ones” mean to help us and it is well meaning, but in our own confusion we tend to “bite the hand” that feeds us. It could be that some people with multiple sclerosis are embarrassed about not knowing how to act. Sometimes they employ strategies aimed at keeping their “loved ones” at arm’s-length.

Invisibility is Problematic

There is more than one issue involved here. Many of the participants had a desire to remain private and closeted. Self-disclosure or exposure was at stake. Who defines who is impaired and to what degree the impairment severely affects the life-style of the individual? It may be that the person with the impairment wants to remain quiet about their condition. If we cope and look “normal” then our problems are forgotten by others. It is not only society in general, but our loved ones and even health professionals who misinterpret and underestimate our needs. Do we really understand the services that are available to us?

A Paradigm Shift

Over the past twenty years or so, world economies have seen movement away from a protective and collectivist setting, a pervasive monopolistic base with nationalism prevailing and a lack of choice (Turner 1997). Currently, the global economy has been freed and along with this has developed a consumer driven free spending global society and of lack of national barriers. (Reforms in the ways that Health Funding has been administered have been driven with the “New Right” economic patterns.) This has produced a dramatic change in the ways that the provision of services in health care are administered by the Health Department. Gone are the days of providing unlimited general care to all of society. Today, targeted, needs-based, and eligibility-determined services are offered in the most restricted and limited form possible. The ideology of individualism has been somewhat high-jacked by successive governments world-wide, but if the truth be known, the targeting of health care has meant that people with multiple sclerosis have better attention today than they did previously. With the shift to individual responsibility there has also been a change from a formal care-giving situation towards the person with the condition taking more responsibility for their own illness or condition.

This present study, conducted within a post-modernist framework, has investigated the ways that the support group environment has responded to these changes. The individuals in the study have taken responsibility for themselves. Co-mutual support groups use methods of teaching the members how to best survive in this society. This is a difficult time of transition as we have seen the Western world move away from the waste of blanket care for people with multiple sclerosis to individualistic care and attention.

It is not being advocated that people with multiple sclerosis can be totally independent, the condition in most cases is debilitating and the problems of fatigue are not easily answered. But the idea of interdependence can be searched more fully and this could be a subject for investigation by the Persons with Multiple Sclerosis and the Carers Committee at the Multiple Sclerosis Society.

Primarily the Multiple Sclerosis Society is a support organisation for its membership and should increase its concentration on the social aspects of supporting people with multiple sclerosis within the community.

Social Models of Adaptation

Critical theory offers a number of models that can increase our understanding of what is happening to us. Schmuck (1997) has described a spiral of learning, reflection, and then action. Hight (1999) researched women's experiences with multiple sclerosis using a similar model with intervention being given by a social worker. Some other theorists have devised models for helping professionals categorise the progression through the different phases or stages from acceptance to denial of their conditions. Barnes discusses Anspash's (1979: 8) "four dimensional" model for 'Stratagems of Disability Management'. These four dimensions summarised below describe levels of acceptance of the different stages for people with disabilities and how they react to society:

- 'normalizer' - the individual is 'labelled disabled' and accepts at any price, society's estimation of their ability and in turn behaves or acts accordingly to what that society expects of them.
- 'disassociation' - Although accepting that society has a cultural interpretation of their disability, the person with the condition is unwilling or unable, to accept it,

but does nothing about it. This usually results in lower self-perceptions.

- 'retreatism' - The person who is disabled rejects the wider cultural views of them and withdraws from all social activity.
- 'political activist' - is a person with a condition who asserts that they are superior and does not seek claims of acceptance from the wider community, which they see as artificial.

(Barnes 1990: 8)

Gershick & Miller (1998) use a model that they term the "Analytic Induction Approach", which when describing men with disabilities is not dissimilar to the former.

- Reformulation - A belief in shaping their masculinity along the lines of their own strengths, perceptions and abilities.
- Reliance - men rely on the hegemonic masculinity standards, and learn to accept the others' point of view
- Rejection - men have a belief that the dominant society's attitudes are wrong, the person is foremost and the disability is secondary, "disability rights".

A well known framework for understanding the grieving process was developed by Kubler-Ross (1969). All of these models may be useful for theoretically understanding people, but it remains to be seen who stands to benefit from application of the intervention methods. Primarily, it may be the professional who benefits from developing a service.

Others differ on the delivery of providing systems of teaching these "coping" skills. The moods of the men in this study can not satisfactorily be described in any of these models. They do not see themselves permanently attaining any particular stage or phase in either acceptance or denial and see themselves rather as being on a

continuum and remaining in a fluid state.

As Schwartz and Sendor (1999) have explained:

We found that peer supporters reported a greater benefit in quality-of-life outcomes than those they helped... Indeed the supporters remarked a change in themselves of becoming more outer-directed, and this shift changed the way they thought of themselves and enhanced their perception of quality of life.

Schwartz and Sendor have indicated that social support is not enough, the benefits come in the quality and effect of the reciprocal relationships developed by the members in any group. These plans of analysing and understanding people have already been illustrated and the method of implementation needs to be administered by the individuals through co-mutual support groups under the auspices of the Multiple Sclerosis Society and in particular the Persons with Multiple Sclerosis and the Carers Committee. Skills need to be taught to people with multiple sclerosis. This includes for example, how to manage disclosure to others; firstly to their "loved ones" and secondly to the wider public. The development of skills within the MS support group community of practice, will serve to enhance the identity and hence the self-esteem of members. The formation of identity and the resulting gains in self-esteem will, in turn, equip individuals to achieve their maximum potential of development.

The potential of the participants in this study is that each one could become capable of mentoring other people with life threatening and life altering conditions. This could have significant positive impact on the building of self worth amongst individuals who might otherwise be devalued. What is often not recognised, is that the work

experience of these particular support group participants is considerable. There are energies that the members of the group may offer to the community of all people not just the so-called “disabled”. They would be able to demonstrate within mainstream society that people with multiple sclerosis are not necessarily “has beens” but that they are “can be’s”.

Difficulties with the study

In the initial stages of my planning to do this research, I received some mixed messages from some reasonably influential researchers in the fields of disability studies. I had conversations with or reviewed papers they had written (e.g. Roseneil, 1991). The more negative comments were:

- (1) that a study of my friends would produce biased information subject to ridicule and harsh scrutiny as not being verifiable;
- (2) Another said that I would jeopardise my relationships with my friends as I will be the sole beneficiary of the symbolic capital of this thesis.

In truth I have not had any problems with the participants. This thesis is their thesis and they are happy to share their stories in the hope that other people who read their comments and life histories will feel empowered in the same way as they are empowered hearing others’ stories. One of the participants who has a PhD commented that his interview was the easiest he had ever given.

Caregiver Problems

A problem arose when “loved ones” took the opportunity of reading two of the

transcripts sent back to the participants for checking. I had sent a letter to the participants with their transcripts advising them of the confidential nature of our discussions (appendix 3). The reason for the letter was to reassure participants that I would not divulge the information under their own names. Also, as a researcher, I disclosed my personal information to them as I did not think that it would have been read by a third party. I received two phone calls, in relatively close succession, from “loved ones” expressing concern that participants had disclosed negative information about them. I assumed that the calls were intended by them to attempt to manage my perception of them. One of the people said she had taken legal advice and threatened to remove any references to her whatsoever. She also said that my interviewing skills were suspect and I led the participants too much. It was never my intention to expose the caregiver and I have not referred to her anywhere in this thesis. These expressions of concern were unfortunate as I had properly followed ethical procedures of informed consent and confidentiality throughout the entire study, including the use of pseudonyms so that participants could not be identified. It is inevitable however in a study of this kind that dependence on family members and caregivers may render participants susceptible to censure and control by others.

Techniques that I employed to keep the interview “on the boil” so to speak consisted of treating the interview in a conversational style using narrative methods that identified myself with the participants. I accomplished this by relating much of my own personal history in order to help them feel at ease. This technique was well received by the group. We already had a relationship because we used to meet for coffees in Takapuna. The “loved ones” concerns were unfounded and the information that was read into the conversations by them was not the focus of my enquiry and was

only the means of discussing feelings of disempowerment for my participants. The effect was to confirm other members of the group, and not intended to alienate the “loved ones”.

One of the unfortunate effects of having multiple sclerosis is that the person with the condition is constantly battling with the effects of the grieving process that is ongoing and will remain with them all their lives. This can make the participants moody and suffer mild bouts of bipolarism, making them unpredictable and extremely difficult to live with. These psychological factors are often the reason that the marriages of many people with multiple sclerosis dissolve. These breakdowns are not necessarily the fault of the “loved ones”. Rather, it is frequently the case that they have had enough. They can not take it, have not got the strength to go on. They know that the relationship is doomed to fail as the person with multiple sclerosis is in a constant state of tension trying to cope with their own problems and trying to regain some of the power that they had in the past. I see my own self in the experiences of the participants in this study.

Strengths of the Study

This thesis has sought to achieve some clarification of issues which are of interest to the joint participants in this work. The participants have generated the research data and the study has been highly collaborative. The theories presented here are holistically grounded in the experiences of the individuals. This research is an intimate portrayal of men’s lived experience. A feature of the study is that it has been carried out by an “inside researcher” who is in a position to sensitively interpret information provided by the participants. The research is emancipatory in nature and

the techniques that have been used have enabled a naturalistic form of enquiry within the everyday environment of the research participants. The only imposition that the researcher made was to spend more time than usual on a one-to-one basis with some of the participants in order to conduct the individual taped interviews. This form of “insider research” has been used to advantage by producing information that is subject to verification through triangulation of the participants lived experiences with the researcher’s own experiences and discussing the results against relevant literature and previous research. Another feature of the study is that it was carried out in a comprehensive way over a period of more than one year. The advantage of this long time period was that on going individual and group discussions could be held with participants to check the interpretations and to confirm that the researcher was properly representing the views of those concerned. As previous researchers have noted, the limited time involved in the conduct of their studies was too short to enable the extent of contact and consultation that they would have hoped to achieve (Wright-St Clair ,1996; Rowsell, 1996).

An important finding of the study was that the members had devised their own methods of raising their level of consciousness and developed a self-healing practice that adopted altruism by forming reciprocal relationships with their peers. These links involved guided participation by using an apprenticeship model to help each other understand the true nature of service to their fellows and eventually the wider society. It is through the process of giving to others that the participants in this study were able to receive and benefit from support! I am not purporting to take a religious stand here, but many of the participants said that they had faith, what ever they conceived that to be. It is my hope that the collaborative and naturalistic nature of the present

study meets the recommendations of Denzin (1997) concerning a good critical emancipatory standpoint text. As far as possible, I have tried to present the voices of the participants in order to document their lived experiences as men with multiple sclerosis.

Implications for Further Research

There need to be more studies on the relationship between levels of interdependence, independence and dependence. As this study has shown, co-mutual support can have the effect of enabling individuals to function at a more effective level of independence as a result of the interdependent community to which they belong. Without this interdependent support, men with multiple sclerosis could possibly be more dependent on others than they need to be. A related point is that co-mutual support can allay or reduce the need for formal kinds of counselling and therapy aimed at dealing with grieving and adjustment difficulties. Many people with multiple sclerosis lead dysfunctional lives where they never seem able to attain a satisfactory level of independence and eventually sink into the depths of total dependence on others in order to function as human beings.

During the course of this research, I have not been able to locate any studies specifically about MS men's support groups. I am sure there are other successful co-mutual groups for men with multiple sclerosis but these appear not to have been documented. There need to be more studies carried out by "insider researchers" on the lived experiences of people with multiple sclerosis. These also need to come from the families because stories are empowering for both the teller and the receiver. Strength comes from hearing how others have strived to raise their own level of consciousness

and understanding about how to adjust to life with multiple sclerosis.

There is a need to understand the processes of alienation, and the tools that are used to keep people with multiple sclerosis excluded from partaking in employment and many aspects of community life. In particular, it is important to study the processes of discrimination against persons with conditions such as MS and the effects that this has on all aspects of their life.

Limitations of the Research

Studies of the “loved ones” role need to be explored since they are often excluded. Without this input of families and friends, people with the condition would not be able to survive. Perhaps studies need to be focused on the different roles and the many dynamic relationships that significant others have with people who have multiple sclerosis. Families and friends of persons with multiple sclerosis also need support and advice on how to contribute most effectively to the life of the person with MS. There needs to be a lot more non-academic literature written on the subject. I would have liked to have focussed more on other people’s relationships and their experiences of coping with life- altering and life-threatening conditions.

Stories of the lived experiences of others are empowering for the “loved ones”. They face problems that others experience in similar positions. More needs to be written on children’s experiences and the stories of parents, spouses and partners. There is a particular need to document the views of parents of adults with multiple sclerosis and also the feelings of partners and spouses as they face the reality of the effects of living with a person who has multiple sclerosis. As it now stands, many family members

and friends are locked into a nether world just trying to survive. As explained before, very little is known about the feelings and responses of family members and friends who have supported individuals with multiple sclerosis.

A final comment

It is time now to move from studies of support and service provision, to studies concerned with processes of interdependence that seek to maximise the potential of the individual with MS to function independently and fully within a regularly organised society. Practitioners and researchers in the medical profession are continuously finding new treatments for easing the hardships that face those with multiple sclerosis. To date, they do not have a cure for multiple sclerosis and so we are all “lifers” and here for the long haul. This study has shown that as thinking human beings, we can better help ourselves by helping others. One of the best ways to do this is through being participants in co-mutual peer support groups.

He (sic) who is on the Path exists not for himself, but for others; he has forgotten himself, in order that he may serve them. (Alcyone)

Appendix (1)

SCHOOL OF GLOBAL STUDIES

Information Sheet

Date

Men with Multiple Sclerosis: Our Stories.

Dear..... Researcher: Michael McCool

Howdy friend. As you know, I am the president of the North Shore Multiple Sclerosis Society, and a student of anthropology at Massey University. This research contributes towards my Masters thesis, and is the study of men with MS and their life stories within the group environment. I intend to show how we deal with our condition, and describe how we action coping strategies for survival in relationships at both a personal level and at a broader societal level.

This is a personal statement of commitment not to compromise my dual role as a person with multiple sclerosis who is a member of your support group, and the researcher of this study. You may withdraw from this study at any time, until one calendar month after you have received the final transcripts of your personal and focus group interviews. This should be early in the new-year. If you do withdraw or decline to participate, I do not think this will cause any animosity between us as this study is a sideline issue and your membership of this group is paramount.

Please accept this as a personal invitation to participate in this research project. I value any assistance you can offer. In accordance with the University's code of ethical practice, I would like to say that, you should feel under no duress in any way with the giving of information. Your rights as participants in this type of research are such that you would have the right:

- to decline to participate;
- to refuse to answer any particular question;
- to withdraw from the study at any time;
- to ask questions about the study at any time during participation;
- to provide information on the understanding that your name will not be used unless you give permission to the researcher;
- to be given access to a summary of the findings of the study when it is concluded;
- to have access to your MS Field Officer , who may be able to assist in dealing with unresolved issues of grief and loss, or if more appropriate, refer participants to an experienced third party.

You have already agreed to participate in an exploratory group discussion, and I welcome your input in personal one-on-one interviews which will take one or two hours of your time. At another time, we will meet for a final debriefing or focus group interview, of one to two hours. I would like to tape-record our interviews, you have the right to ask for the machine to be switched off at any time. A transcript will be

sent to you for acceptance or alteration. Remember this is your information and your cultural property. I would like to assure you of the utmost integrity of this study. The university is concerned and requires me to inform you, that issues and information that I will be privy to, may not normally be in the course of friendship. Any of our conversations remain confidential, and information and tapes will be kept under lock and will be used only for the purpose of the research. Your name is changed so that you can not be identified, within the group.

My supervisor is: Dr Kathryn Rountree
 (09) 443 9690
 Department of Global Studies
 Social Anthropology Section
 Massey University Albany Campus
 Private Bag 102904
 North Shore Mail Centre
 AUCKLAND

If you would like to be part of this study, Massey University's policy means that I must obtain your consent. Please read, sign the attached form and return it to me.

I would like to thank you for reading this letter and please feel free to contact me at any time. A copy of the final research report will be given to the group.

Yours sincerely

Michael McCool

My daytime telephone is (09) 443 9700 ext. 9767

Appendix (2)

Consent Form

Date _____

Men with Multiple Sclerosis: Our Stories.

Researcher

Michael McCool

I have been given an explanation and read the information on this research project, which I understand. I also understand I am at liberty to ask other questions, and that I am able to leave this project at anytime I so wish without giving a reason. I can ask for the return of tape recorded conversations at the conclusion of the study.

My information is given in strict confidence. This information will only be used for this research project, and publication will protect my right to privacy through the use of pseudonyms. After the report is published the information will be publicly available.

I agree to interviews being tape recorded, and understand that I have the right to ask the machine to be turned off at any time.

I understand there is no financial reward for my information and agree to take part in this research.

Signed _____

Name _____ Date _____

Appendix (3)

Michael McCool 9/488 Hibiscus Coast Hwy. OREWA
phone/fax (09) 426 0508

Friday 24 March 2000

Howdy Guys

Well I have finally transcribed all of our conversations and enclose for you the copy of your own personal interview. Be aware that this is between you and me only, it is not intended that I will just put it into a thesis. This is for you to look at, please excuse the grammar and spelling mistakes but I would appreciate you editing it if you like. My supervisor may look at them, but I would like your permission for my own personal support, my writing tutor to look at them with me for content and for her to help me with analysing and final production of the thesis. Please ring me in the week and let me know if this is not satisfactory for my tutor to look over the transcripts. I will take it that if I do not hear from you it is OK. She is a Psychologist and is covered by a code of practice that requires her confidentiality on any of my business, I have confidence in her.

I may use parts of our conversation in my thesis to confirm my own thoughts and you will probably see your comments but these will be attributed to another name (our nom-de-plume to protect you).

We still have one more process to go through and that is the focus group interview, where we all talk and discuss our areas of interest, very similar to that one at Peppers with Ken. But it is too noisy up there and I was thinking of holding it at the Richardson Centre in few months time, but I will see you before hand and confirm a date.

I have started writing up my work and the first chapter was submitted to my supervisor which came back with the comment, 'Michael this is great! Fix up the editing carefully, and it will do as it is without further work'. The rest of the chapters, I should expect to be as good. Remember this will be for all of us as we are joint participants in this study.

See you at Peppers next month if not sooner.

Regards

Michael

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