Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

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

Michael John McCool

2000
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.
Acknowledgements

Firstly a big thank you to the guys and you have truly been joint participants in this study. The sharing of your experiences have been my guiding light, and now you can help others as you have helped me.

I would like to thank Dr. Kathryn Rountree my supervisor for her helpful advice, counsel and thoughtful guidance.

To Dr. Eleanor Rimoldi affectionately known to some of us students as “Mother Rimoldi”, thanks for being there, you have been my inspiration and created my love of social anthropology.

To Ken Ryba, my exercise partner, confidant and friend, without you I would have “thrown in the towel” many years ago. Your direction has been very comforting and the sharing of our lived experiences over many a rough lemonade has helped me more than you will ever realise. I value yours’ and Linda’s friendship immensely. Thank you to Cathie Collinson and Miriama Davies for helping in editing.

I have enjoyed being a student at Massey University and a special thanks to the administration for their support both financially and the acknowledgement that they thought this was a topic worthy of study. It would be remiss of me not to thank my student friends, our shared communion, our living and breathing of applied anthropology:- Jacqualine, Amanda, Margot, Lily, Miriama, and Linda.

I am indebted to the ASA/ANZ for a grant from the Kakano Fund towards the costs of the production of this thesis.

All the crowd in the multiple sclerosis movement, particularly, Trish Robertson, Ruth Vincent and Anne Bray for their help and compassionate encouragement.
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.
# Table of Contents

Title page

Abstract

Acknowledgements

<table>
<thead>
<tr>
<th>Chapters</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction</td>
</tr>
<tr>
<td>2</td>
<td>Methodology</td>
</tr>
<tr>
<td>3</td>
<td>Literature Review and Theoretical Perspectives</td>
</tr>
<tr>
<td>4</td>
<td>Joint Participants</td>
</tr>
<tr>
<td>5</td>
<td>Lived Experience</td>
</tr>
<tr>
<td>6</td>
<td>Power and Control</td>
</tr>
<tr>
<td>7</td>
<td>Support Group Environment</td>
</tr>
<tr>
<td>8</td>
<td>Discussion and Conclusion</td>
</tr>
</tbody>
</table>

Appendix 1  information sheet  173
Appendix 2  consent form  175
Appendix 3  letter accompanying transcripts  176

Bibliography  177