

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.

**MULTIPLE CHOICE? THE EXPERIENCES OF
WOMEN WITH MULTIPLE SCLEROSIS:
OPPRESSION, OPTIONS, OPPORTUNITIES.**

A thesis presented in partial fulfilment of the requirements for the degree of
Master of Social Work
at Massey University, Palmerston North, New Zealand.

Susan (Sioux) Elisabeth Natasha Green

2001

DEDICATION

This thesis is dedicated to the memory of

Maureen Elenor Walsh

27 October 1943 - 08 October 2000

and

Andrew Leslie Cantwell

22 November 1955 - 19 December 2000

and

Mike John Deane

31 May 1955 - 05 January 2001

in recognition of their friendship and support
for the completion of this work.

ABSTRACT

This thesis examines the ways in which women with Multiple Sclerosis (MS) experience disability as their disease progresses over time. Underpinning my analysis of the process of becoming disabled is a critique of the ways in which a combination of patriarchal discourse and the medicalisation of disability result in the social construction of disability. This study contends that such a construction can exclude and oppress women with MS, reducing their choices in life.

Additionally, this research examined whether or not the alternative discourses of feminism and the social model of disability offered women with MS options for politicising their experiences and opportunities for empowerment and emancipation.

Seven women participated in in-depth interviews. Additional information was obtained from documentation provided by six of the participants. Finally, one male was interviewed and provided documentation about his recently deceased wife's experiences of MS which was presented as a case study separate to the main body of the data.

Themes which emerged from the data suggested that the greater the number of oppressive variables present in a participant's life, the higher her risk of social oppression and exclusion appeared to be. Counterbalancing this, the greater her access to appropriate assistance, alternative discourses and strategies of resistance, the more she seemed enabled to resist disability as social oppression.

Emerging themes around the political issues of oppressive and inadequate welfare assistance, fragmented and uncoordinated health and care systems and poorly actioned employment and human rights policy are discussed; as is the civil rights issue of the underfunding, non-subsidisation and capped budgets for medical treatment of people with Multiple Sclerosis which promotes exclusion and dependency.

The aim of this thesis is to highlight these themes, to offer alternative discourses of the social model of disability and feminist theory as options for empowerment, and to politicise the experiences of this group of women. In so doing, the aim of this thesis is also to inform professionals and policy makers of the very real need to promote a politics of difference and inclusion, rather than oppression and exclusion for women with Multiple Sclerosis.

ACKNOWLEDGEMENTS

There are a number of people to whom I am greatly indebted for their support, encouragement and practical assistance over the past year as I have worked towards completing this thesis.

First and foremost, my heartfelt thanks to the seven women and one man who participated in this study. Without your generosity in sharing your time and your experiences of Multiple Sclerosis, this thesis could not have been completed. I consider myself honoured to have heard about your experiences with the disease we share, and I hope that as an outcome of this work, not only can others learn about the experience of the disease, but that steps will be taken to continue to strive towards agitating for positive change for all who live daily with MS.

To my thesis supervisors, Mary Ann Baskerville and Dr. Mary Nash, I have appreciated immensely your ongoing support and encouragement during this study, as well as the ways in which you have critiqued and challenged me over the past year. Many thanks for your guidance and direction in enabling me to complete this work.

My thanks to the Massey University Disabilities Co-ordinator for her assistance in providing funding for a typist to transcribe the recorded data; and to Dianne Keane for her very professional completion of this task.

A number of people have provided an 'enabling environment' without which I would not have been able to complete this study. Firstly, the support of my workplace, and particularly my manager, Lyn Davis and the team within which I work. Many thanks for your support of the numerous absences during the past year which have allowed me to complete and present this study. My thanks particularly to team members Emily Hohapata who lent me her car to complete my interviews, and to Dr. Yvonne Van den Worm and Dr. Sharon Houghton who provided encouragement, critique and support throughout the year, and particularly during the last weeks of completing and presenting this thesis.

To friends and family who supported me at every possible level during the year, I will always be indebted. I would particularly like to acknowledge and thank Chris Duffy and Anita Smith for opening their homes to me on regular occasions in order that I have places to work free from interruptions, and who have continually offered encouragement, support and the occasional shoulder to cry on. My heartfelt thanks for everything you've done for me this year.

To my mum, Sandra Green, who has supported me through the past five years of this degree, and the rollercoaster ride of the past three years of living with Multiple Sclerosis, words can not ever express enough how much your help, love and support has meant to me. Thank you.

CONTENTS

	Page
PART ONE: THE RESEARCH	
Chapter One: Introduction	1
Chapter Two: In From the Margins: Theories of Disability	13
Chapter Three: Research Methodology and Design	39
PART TWO: OPPRESSION? DATA RESULTS & DISCUSSION	
Chapter Four: What is Multiple Sclerosis?	64
Chapter Five: Foucault, Medicalisation and Multiple Sclerosis	82
Chapter Six: Oppression? The Social Model of Disability and Multiple Sclerosis	107
Chapter Seven: Oppression? Feminism, Disability and Multiple Sclerosis	138
Chapter Eight: In From the Margins: Lived Realities of Disability	168
Chapter Nine: Public Policy, Private Pain	179
PART THREE: OPTIONS? OPPORTUNITIES?	
Chapter Ten: Multiple Choice? Conclusions and Recommendations	194
PART FOUR: REFERENCE MATERIAL	
Appendix One: Massey University Ethics Protocol	211
Appendix Two: Interview Format for Participants	228
Appendix Three: Copy of Personal Narrative sent to Participants	231
Appendix Four: Glossary of Medical Terms	248
References	253

LIST OF ILLUSTRATIONS

	Page
Figure 4.1: Multiple Sclerosis Symptoms (Past and Permanent) Experienced by Participants.	77
Figure 5.1: Participant References to Negative Experiences of Power, Subject/Object Position and Internalised Discourse.	92
Figure 5.2: Participant References to Positive Experiences of or Resistance to Power, Subject/Object Position and Internalised Discourse.	92
Figure 6.1: Participant References to the Experience of Powerlessness or Worthlessness and the Experience of Disabling Constraints as Social Oppression.	114
Figure 6.2: Participant References to the Experience of Empowerment or Being Valued and the Experience of Enabling Assistance as Social Emancipation.	115
Figure 6.3: Participant References to the Experience of Powerlessness or Worthlessness at Different Societal Levels.	115
Figure 6.4: Participant References to the Experience of Empowerment or Being Valued at Different Societal Levels.	116
Figure 6.5: Social Oppression Theory: Participant use of Strategies, Resistance and a Politics of Change.	116
Figure 7.1: Participant References to the Experience of Invisibility / Not Being Heard and to the Experience of Hiding Impairment.	151
Figure 7.2: Participant References to Strategies or Resistance to Experiences of Invisibility and Hiding Impairment.	151
Figure 7.3: Participant References to Positive and Negative Experiences Relating to the Concepts of Time, Work and Productivity.	152
Figure 7.4: Participant References, Positive and Negative, Relating to the Dependence-Independence Dichotomy.	152

	Page
Figure 8.1: Total Number of References to Negative Experiences: Foucault and Medicalisation, The Social Oppression Model and Feminist Theory.	173
Figure 8.2: Total Number of References to Positive Experiences: Foucault and Medicalisation, The Social Oppression Model and Feminist Theory.	173
Figure 8.3: Total Number of Responses to Negative and Positive Experiences and References to the Impact of Multiple Sclerosis.	174