

**THE LIVED EXPERIENCES OF WOMEN SUFFERING FROM
MULTIPLE SCLEROSIS**

by

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Declaration

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I, Lynnette de Villiers, declare that **THE LIVED EXPERIENCES OF WOMEN SUFFERING FROM MULTIPLE SCLEROSIS** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

.....
SIGNATURE
(Mrs L de Villiers)

.....
Date

DEDICATION

*I dedicate this work to
Ernst, Danny, Alvaro, my mother
and all persons with Multiple Sclerosis.*

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I am immensely grateful to God for giving me the opportunity to complete this study.

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Abstract

The study investigated the lived experiences of women suffering from Multiple Sclerosis in Johannesburg and the East Rand. The study aimed at describing how these experiences affect their lives, and how these women cope after being diagnosed. A qualitative approach was utilised following an exploratory, descriptive, phenomenological, contextual research design. An in-depth literature study was conducted for information used as a basis for the study. Data collection included semi-structured interviews and a focus group. Data-analysis revealed a lack of understanding for the emotional, physical and social problems encountered. Recommendations proposed that the community be sensitised to the reality of MS and disabled persons, and that comprehensive support structures be put in place to attend to the needs of women suffering from Multiple Sclerosis.

Key terms

Women, Multiple Sclerosis, lived experiences, coping mechanisms, resilience, emotion, perception.

Chapter 1

Orientation

1.1	INTRODUCTION	1
1.2	BACKGROUND TO THE STUDY AND PROBLEM STATEMENT	2
1.3	AIM OF THE STUDY	7
1.4	RESEARCH QUESTIONS	7
1.5	RESEARCH OBJECTIVES	7
1.6	SIGNIFICANCE OF THE STUDY	9
1.7	ASSUMPTIONS	10
1.7.1	Theoretical-conceptual assumptions	10
1.7.2	Ontological assumptions	10
1.7.3	Methodological assumptions	12
1.8	RESEARCH DESIGN AND METHODOLOGY	12
1.8.1	Research design	13
1.8.2	Population and sample	13
1.8.2.1	Population	13
1.8.2.2	Sample	14
1.8.3	Data collection	14
1.8.4	Data analysis	15
1.8.5	Trustworthiness	15
1.9	ETHICAL CONSIDERATIONS	17
1.10	LIMITATIONS OF THE STUDY	17
1.11	OPERATIONAL DEFINITIONS	17
1.12	OUTLINE OF THE STUDY	22
1.13	CONCLUSION	23

Chapter 2

Literature review

2.1	INTRODUCTION	24
2.2	MULTIPLE SCLEROSIS	24
2.2.1	History of multiple sclerosis	27
2.2.2	Exploration of the term "multiple sclerosis"	27
2.2.3	Genetics of multiple sclerosis	28
2.2.4	Types of multiple sclerosis	33
2.2.5	Symptoms of multiple sclerosis	35
2.2.6	Diagnosis and causes	37
2.2.7	Treatment	45
2.2.7.1	Possible future and alternative treatment	45
2.2.7.2	Drugs used to treat multiple sclerosis	47
2.3	RESPONSES TO THE IMPACT OF MULTIPLE SCLEROSIS	50
2.3.1	Emotional responses	51
2.3.2	Responses to the impact of multiple sclerosis on the family	54
2.3.3	Social challenges to the impact of multiple sclerosis	56
2.4	SELF-CONCEPT	57
2.5	COPING RESPONSES	58
2.5.1	Resilience	58
2.5.2	Coping resources	60
2.6	CONCLUSION	60

Chapter 3

Research methodology and design

3.1	INTRODUCTION	61
3.2	RESEARCH DESIGN	61

Table of contents		Page
3.2.1	Selected design	61
3.2.2	Rationale for choice of design	61
3.2.3	Qualitative research	62
3.2.4	Phases of the research process	64
3.3	CONCEPTUAL PHASE	66
3.3.1	Background to the problem	66
3.3.2	Research questions and objectives	66
3.3.3	Literature review	67
3.3.4	Reflexivity	68
3.3.5	Bracketing	69
3.3.6	Intuiting	70
3.4	DESIGN AND PLANNING PHASE	71
3.4.1	Research design	71
3.4.2	Definition of terms	71
3.4.3	Data-collection techniques	73
3.4.4	Pre-exercise	74
3.4.5	Sampling design	75
3.4.5.1	Criteria for the selection of informants	76
3.4.5.2	Population	76
3.4.5.3	Sample	77
3.4.5.4	Sample size	77
3.6	EMPIRICAL PHASE	78
3.6.1	Interviews and field notes	79
3.6.2	Focus group	82
3.7	DATA ANALYSIS PHASE	83
3.7.1	The researcher's role in the data analysis	83
3.7.2	Data analysis	84
3.7.2.1	Transcribing the interviews	84
3.7.2.2	Organising data	84
3.7.2.3	Coding and categorising	85
3.8	TRUSWORTHINESS	85
3.8.1	Credibility	86
3.8.1.1	Prolonged engagement and experience	87
3.8.1.2	Member checking	87
3.8.1.3	Reflexivity	88
3.8.1.4	Interview technique	88

Table of contents		Page
3.8.2	Transferability	88
3.8.3	Dependability	89
3.8.4	Confirmability	89
3.9	ETHICAL CONSIDERATIONS	90
3.9.1	Beneficence	90
3.9.1.1	Freedom from harm	90
3.9.1.2	Freedom from exploitation	90
3.9.1.3	Benefit from research	91
3.9.2	Respect for human dignity	91
3.9.2.1	The right to self-determination	91
3.9.2.2	The right to full disclosure	92
3.9.3	The principle of justice	92
3.9.3.1	The right to fair treatment	92
3.9.3.2	The right to privacy	92
3.10	CONCLUSION	93

Chapter 4

Data analysis and findings

4.1	INTRODUCTION	94
4.2	BIOGRAPHICAL DATA	94
4.3	THEMES, CATEGORIES AND CODING SYSTEM	95
4.4	EMOTIONAL RESPONSES	96
4.4.1	Shock and denial	96
4.4.2	Fear and anxiety	97
4.4.3	Anger and frustration	98
4.4.4	Hopelessness and powerlessness	99
4.4.5	Guilt	100
4.4.6	Depressive mood	101
4.5	HEALTH-ILLNESS PERCEPTION	103
4.5.1	Causation and precipitating factors	103
4.5.2	Progression of the disease	104

Table of contents		Page
4.5.3	Experience of treatment regiment	105
4.5.4	Experience of information received	107
4.6	PHYSICAL CHALLENGES EXPERIENCED	108
4.6.1	Mobility challenges experienced	108
4.7	SOCIAL CHALLENGES EXPERIENCED	109
4.7.1	Role changes	110
4.7.2	Isolation	111
4.7.3	Perception of people's attitude	111
4.7.4	Self-concept	112
4.7.5	Types of symptoms	113
4.8	COPING RESPONSES AND RESILIENCE	114
4.8.1	Perceptions on improving quality of life	117
4.9	CONCLUSION	118

Chapter 5

Conclusions, limitations and recommendations

5.1	INTRODUCTION	119
5.2	SUMMARY OF THE STUDY	119
5.3	FINDINGS OF THE STUDY	120
5.3.1	Emotional responses	120
5.3.1.1	Conclusions	122
5.3.1.2	Recommendations	122
5.3.2	Health illness perception	122
5.3.2.1	Conclusions	123
5.3.2.2	Recommendations	123
5.3.3	Physical challenges	124
5.3.3.1	Conclusions	124
5.3.3.2	Recommendations	124

Table of contents		Page
5.3.4	Social challenges	125
5.3.4.1	Conclusions	126
5.3.4.2	Recommendations	127
5.3.5	Coping responses and resilience	127
5.3.5.1	Conclusions	128
5.3.5.2	Recommendations	128
5.4	RECOMMENDATION FOR FURTHER RESEARCH	128
5.5	STRENGTHS	129
5.6	LIMITATIONS	130
5.7	CONCLUSION	130
	BIBLIOGRAPHY	132
	ANNEXURES	

List of tables		Page
Table 1.1	Estimated multiple sclerosis sufferers in selected countries	2
Table 1.2	Worldwide estimations of multiple sclerosis sufferers	3
Table 1.3	Schematic representation of the research methodology	16
Table 2.1	Immune modulators	47
Table 2.2	Urine and bladder control	48
Table 2.3	Tremor control	49
Table 2.4	Other drugs	49
Table 3.1	Participants' biographical data	78
Table 3.2	Biographical data of the focus group	83
Table 3.3	Trustworthiness	85
Table 4.1	Participants' biographical data	95
Table 4.2	Shock and denial	97
Table 4.3	Fear and anxiety	98
Table 4.4	Anger and frustration	99
Table 4.5	Hopelessness and powerlessness	100
Table 4.6	Guilt	101
Table 4.7	Depressive mood and suicidal feelings	102
Table 4.8	Causation	104
Table 4.9	Progression of the disease	105
Table 4.10	Experience of treatment regiment	106
Table 4.11	Experience of information received	107
Table 4.12	Mobility challenges experienced	108
Table 4.13	Role changes	110
Table 4.14	Isolation	111
Table 4.15	Perception of people's attitude	112

List of tables	Page
Table 4.16 Perception of self-concept	113
Table 4.17 Coping responses and resilience	115
Table 4.18 Improving quality of life	117

List of figures	Page
Figure 1.1 World map of prevalence of multiple sclerosis	5
Figure 1.2 Map of Johannesburg and the East Rand	8
Figure 2.1 Incidence of multiple sclerosis in South Africa	26
Figure 2.2 The axon	29
Figure 2.3 Brain scan of a person with multiple sclerosis	30
Figure 2.4 A computer-digitised colour-enhanced magnetic resonance imaging scan	31
Figure 2.5 Prognosis of multiple sclerosis patients 10 to 20 years on	34
Figure 2.6 Types and courses of multiple sclerosis	36
Figure 2.7 Area of lumbar puncture	38
Figure 2.8 Lumbar puncture procedure	38
Figure 2.9 Magnetic resonance imaging of a normal brain	40
Figure 2.10 Magnetic resonance imaging of a brain with multiple sclerosis	41
Figure 2.11 Magnetic resonance imaging of spinal cord	43
Figure 2.12 Brain atrophy in multiple sclerosis	44
Figure 3.1 Phases of the research process	65
Figure 4.1 Symptoms commonly experienced	114

List of abbreviations

MS	Multiple sclerosis
HLA	Human leucocyte antigen
MHC	
RR	Relapsing-remitting
PP	Primary progressive
PR	Progressive relapsing
CSF	Cerebrospinal fluid
MRI	Magnetic resonance image
BVT	Bee venom therapy
Mg	Milligram
IV	Intravenous
q.i.d	Four times per day
TDS	Three times per day

List of annexures

- Annexure A Letters requesting permission from Gauteng Health Department to conduct research
Letter requesting permission from the Ethics Committee to conduct research
- Annexure B Letters from Gauteng Health Department granting permission to conduct research
Letter from the Ethics Committee granting permission to conduct research
- Annexure C Letter to participants
- Annexure D Agreement between participant and researcher
- Annexure E A personal reflection of the researcher's experience
- Annexure F Aide de memoire
- Annexure G Example of a transcription
- Annexure H Newspaper excerpts

CHAPTER 1

Orientation

1.1 INTRODUCTION

Multiple sclerosis (MS) is a chronic, progressive neurological condition which is unpredictable and for which there is no cure yet. An estimated 2 500 000 people worldwide are affected by MS (Van der Westhuizen 2001:14). MS is a quixotic illness, and each individual suffering from MS is faced with a different set of symptoms (Singer 2000:7).

With its variable disease course and wide array of symptoms, MS presents each individual with ongoing challenges. As the disease progresses, these challenges are increased and intensified. Almost three times more women than men are diagnosed with MS. Women's perceptions of themselves, their roles and how others accept them as well as their everyday life are drastically affected by MS. Therefore the reactions of those around them can cause perceptual changes of their roles and changes in coping responses. The diagnosis and progression of the disease can elicit a wide range of responses from women because each one perceives the impact of the disease differently. MS has an impact not only on the woman, but also on her family, loved ones, and friends. The disease can disrupt the whole family, if the perceptions of the person suffering from it are not understood or taken into consideration.

MS poses a threat to women's independence and perception of competence and femininity as well as their coping mechanisms. Table 1.1 represents statistics of the estimated MS sufferers in various countries.

Table 1.1 Estimated multiple sclerosis sufferers in selected countries

COUNTRIES	NUMBER OF PEOPLE	SOURCE
America	400 000	National MS Society brochures (2003)
France	60 000	MS Society New Zealand (2003)
United Kingdom	85 000	Graham (2000:3)
New Zealand	3 000	MS Society New Zealand (2003)
South Africa	10 000	Phillips (2002:95)
Zimbabwe	5	MS Society Zimbabwe (2003)
Canada	50 000	MS Society Canada (2003)

The figures in table 1.1 were obtained from the various MS societies and information brochures. People suffering from MS include all races and ages, and both genders. From table 1.1 it is clear that colder areas like America, France, Canada and the United Kingdom have a higher prevalence of MS. The figure given for Zimbabwe is not a true reflection as those were only the persons who belonged to the MS society in Zimbabwe. Estimations for other African countries could not be found as MS societies could not be traced.

1.2 BACKGROUND TO THE STUDY AND PROBLEM STATEMENT

The researcher found that although literature is available on MS, little is known about how it affects women's lived experiences of their roles, life, health and coping mechanisms.

MS is a disease of the Central Nervous System (CNS), consisting of the brain and the spinal cord. The symptoms may include disruptions in sensory function, motor function, cognition and emotional status. It is a demyelinating disease of the CNS that is well known but poorly understood by the medical and nursing community as well as the general public (Miller 1997:294).

The disease starts between the ages of twenty and forty, is more common in women by 3:1 and affects whites more than other races (Yanofsky 2000:6). According to the International Multiple Sclerosis Federation, MS already affects an estimated 2 500 000 people worldwide (Van der Westhuizen 2001:14). Halper and Holland (1997:1) estimate that in the United States between 250 000 and 350 000 people are afflicted with MS. The South African National Multiple Sclerosis Society is aware of between 3 000 and 5 000 South African sufferers (Van der Westhuizen

2001:14), while Phillips (2002:95) estimates that up to 10 000 people in South Africa suffer from MS. The difference in estimations could be due to the fact that MS is not a notifiable disease in terms of article 45 of the Health Act, 63 of 1977 and some people do not know that they are suffering from the disease as it is often misdiagnosed or confused with other diseases.

Table 1.2 represents mainly estimates by national societies and extrapolations of survey data for regions within the countries. This serves to indicate the overall distribution of the disease and emphasise the importance of having knowledge of a disease that affects over one million people worldwide (Jones 2002).

Table 1.2 Worldwide estimations of multiple sclerosis sufferers

COUNTRY	NUMBER OF PEOPLE WITH MS	PREVALANCE (P w MS PER 100 000)
Argentina	5 000	13,6
Australia	12 000	63,8
Austria	7 000	86,4
Belgium	8 900	87,5
Brazil	7 000	4,0
Bulgaria	3 200	39,3
Canada	35 000	111,0
Cyprus	350	46,7
Czech Republic	10 000	97,1
Denmark	6 000	112,0
Estonia	725	51,0
Finland	5 000	98,0
France	50 000	84,9
Germany	110 000	99,0
Greece	5 000	46,7
Hong Kong	50	0,88
Hungary	6 000	65,0
Iceland	285	105,1
Ireland	4 500	125,0
Israel	4 500	80,4
Italy	50 000	88,2
Japan	5 000	4,0
Libya	290	5,9
Luxembourg	400	94,1
Mexico	8 000	8,1
Netherlands	15 000	94,9
New Zealand	3 000	81,3
Norway	3 800	86,4
Poland	30 000	77,1
Portugal	5 000	50,5
Romania	7 500	33,4
South Africa	1 500	3,5
Spain	30 000	76,7

COUNTRY	NUMBER OF PEOPLE WITH MS	PREVALANCE (P w MS PER 100 000)
Sweden	12 000	134,8
Taiwan	175	0,8
Turkey	30 000	46,4
UK	85 000	143,8
USA	250 000	91,7
Zimbabwe	50	0,45

(Jones 2002:10)

From table 1.2 it is evident that the more temperate countries and regions north of the 40 degree latitude have a higher prevalence of MS, such as the United Kingdom with the highest prevalence of 143,8 persons with MS per 100 000 of the population, Sweden with 134,8, Ireland with 125,0 and Iceland with 105,1. These countries are also all in the northern hemisphere. The countries with the lowest prevalence of persons with MS per 100 000 are all in the southern hemisphere and include Zimbabwe with 0,45 people with MS per 100 000, Taiwan with 0,8, Hong Kong with 0,88 and South Africa with 3,5 (Jones 2002:11). The same pattern of prevalence can be seen on the world map of prevalence in figure 1.1 below.

From figure 1.1 it is clear that the highest prevalence is in the northern hemisphere and more so above the 40 degree latitude, but below the 40 degree latitude the prevalence in New Zealand is also higher (Jones 2002:14).

According to Fraser, Clemmons and Bennett (2002:15), most people with MS will live a normal life span although increasing levels of symptomatology may cause increasing vocational and independent living impairment. As women became more career oriented, their roles and responsibilities within their home and community have escalated. MS imposes alterations in lifestyles and changed perceptions of a woman's body image and roles which, in turn, might cause perceptions of insecurity. MS affects many aspects of living, family, and intimate relationships, vocational status, finances, self-esteem, mood, morale and sense of personal control. Balch (1999:6) points out that people who are actively involved and believe they have some control in life situations are healthier than people who are passive and believe they are helpless victims.

Figure 1.1

World map of prevalence of multiple sclerosis

Jones (2002:14)

The diagnosis of MS can influence a woman's ability to deal with its impact on herself as well as her family life. According to Hattingh (2001:186) and Strümpfer (1999), this crisis brings with it the opportunity to develop new ways of coping and resilience. Halper and Holland (1997:22) indicate that research on a particular disease is usually assumed as aimed at understanding the basic disease process and then developing therapeutic agents. MS affects not only the individual woman but also family life and the community.

In order to better understand this phenomenon, research needs to be done on the woman suffering from MS, her lived experiences, and her perceptions of her roles, independence and competence. Preconceptions about disabilities and common fallacies about MS can affect employment, family life and the community structure. Halper and Holland (1997:23) state that the focus of research into MS should be aimed at understanding the disease process and that the "whole person" is the subject of modern research. People with any type of disability face social and physical barriers. Newly diagnosed MS sufferers are often reluctant to tell others because of fear of their response. Living with MS can affect how people see themselves and how they relate to others. Therefore this study focuses on the lived experiences of women suffering from MS and their resilience.

In a qualitative study of the lived experiences of relapsing remitting MS, Miller (1997:294-304) found that persons with MS rely on hopeful attitudes projected by others. Balch (1999:2) emphasises that people with MS are not responsible for developing the disease but are responsible for the way they react to it. Furthermore, people who live well with MS focus on current talents and abilities. Balch (1999:32) argues that emotional adaptation to MS includes accepting that MS has become part of one's life. Halper and Holland (1997:25-80), Graham (2000:9-11) and Balch (1999:1-8) describe good health practices and problems that may arise. Halper and Holland (1997:127-130) discuss women's issues in MS. Although these authors discuss psychosocial implications, the researcher found little information on the perceptions of women and how they cope. There is a paucity of research on women's perceptions of and issues in MS. The lived experiences of women suffering from MS are not anticipated or taken into account, thereby leading to problems in coping. This problem made the researcher aware of the need to explore and understand the lived experiences of women suffering from MS.

1.3 AIM OF THE STUDY

The aim of the study is to describe the lived experiences of women suffering from MS in Johannesburg and the East Rand (see figure 1.2 below for map), and how these experiences affect their lives.

The area in which the study was done is demarcated on the map. For reasons of confidentiality of the participants, the specific towns cannot be identified.

1.4 RESEARCH QUESTIONS

The following questions guided this study:

- What are the lived experiences of women suffering from MS in Johannesburg and the East Rand?
- What is the impact of MS on the individual?
- What emotional, physical and social challenges and barriers do women suffering from MS face?
- How can resilience be enhanced to affect women suffering from MS positively?
- How does MS affect family life?

1.5 RESEARCH OBJECTIVES

The following objectives were formulated to guide the researcher. In the study the researcher aimed to

- explore and describe the lived experiences of women suffering from MS
- explore and describe the impact of MS on the participants
- identify and explore the emotional, physical and social challenges and barriers experienced by the women suffering from MS
- explore the resilience of the participants suffering from MS and provide guidelines to enhance resilience to cope with their changed lives
- determine how the participants perceive the influence of MS on their family life

Figure 1.2
Map of Johannesburg and the East Rand
(Southern Africa places 2003:1)

1.6 SIGNIFICANCE OF THE STUDY

There is a need to increase awareness and knowledge of the phenomenon amongst people who work with MS sufferers. It is envisaged that this study will help to acknowledge and understand the experiences and perceptions of women suffering from MS. The significance of the study lies in understanding how MS affects women's lives, how they perceive its impact on their lives and how they cope after being diagnosed. It is important for nurses and caregivers working with persons suffering from MS to anticipate these perceptions, as this can enhance cooperation in the treatment regimen. The information obtained might serve as a framework for assessment and management by referral sources. Research results can help to influence perceptions of women coping with MS in a more positive manner.

Research findings can be useful to

- Newly diagnosed persons suffering from MS to give them a better understanding of what to expect as the disease progress.
- Women struggling to cope with MS, to help them understand their feelings and enhance coping mechanisms, as well as to help their families.
- Physiotherapists, nurses, physicians and other health care workers involved with treating persons suffering from MS, to help them to anticipate and understand the perceptions of persons with the disease in order to deliver a better service.
- Primary caregivers and significant others of the person suffering from MS, to enable them to cope better with the situation and to understand the person suffering from MS better.
- Results will provide authorities, such as the government and institutions, with insight into the needs of those suffering from MS, to provide more comprehensive support and services.
- The results can strengthen the current services provided for those suffering from MS and reaffirm the need for support services to deal with the issues surrounding the condition.

1.7 ASSUMPTIONS

Assumptions are basic principles or statements that are accepted as being true on the basis of logic or reason, without proof or verification, even though these statements have not been scientifically tested (Brink 1999:30; Burns & Grove 1997:48; Polit & Hungler 1997:451).

1.7.1 Theoretical-conceptual assumptions

Theoretical-conceptual assumptions have to do with how researchers perceive where they stand in relation to reality (De Vos 2000:240). Epistemological assumptions are the relationship between the researcher and that which is being studied (Polit & Hungler 1997:11). The researcher interacts with the participants and is thus being subjective (De Vos 2000:242; Polit & Hungler 1997:13). In this study the theoretical-conceptual assumptions are:

- The participants are women suffering from MS who have their own unique lived experiences. Developing perceptions of the disease is a dynamic process.
- The participants might not experience the same feelings or experiences every day. There are internal and external elements that will influence these perceptions and feelings.
- The researcher assumes that she knows little of the phenomenon but wishes to find out more (Seamon 2000:14).
- Interpretations of the lived experiences of the women suffering from MS are the key to understand the phenomenon.
- Findings are the creation of the interactive process (Polit & Hungler 1997:13).
- A diagnosis of MS has an impact on women and affects their resilience.
- The lived experiences of women suffering from MS are unfamiliar territory that the researcher attempts to explore. The researcher must discover meaning out of these perceptions.

1.7.2 Ontological assumptions

Ontological assumptions have to do with the nature of reality. Reality is not a fixed entity but a construction of the individuals participating in the research (Polit & Hungler 1997:12). According

to De Vos (2000:242), ontological assumptions are made to understand reality by discovering meanings that people in a specific setting attach to it. Reality is complex, can be understood and interpreted but not be controlled. It is assumed that only those who experience it personally can know the reality of living with MS.

Women suffering from MS are not passive beings, but are responding to reality in what they perceive as the only way. The reality of living with MS can only be understood by uncovering the meanings the women attach to it. These perceptions can be interpreted but not controlled. Human experience and consciousness necessarily involve some aspect of the world as their object, which, reciprocally, provides the context for the meaning of experience and consciousness (Seamon 2000:7). The reality in this study will be the life-world of women with MS. The life-world is the place of daily living activities, for example the home and the workplace, that includes the routine, unusual, mundane and surprising elements of everyday life (Seamon 2000:7).

The mind and body interact in powerful ways that affect a person's health. Social and psychological stress can trigger or aggravate a wide variety of diseases, such as high blood pressure, and possibly MS. However, the relative importance of psychological factors varies widely among different people with the same disorder. Emotions can affect certain body functions, such as heart rate, blood pressure, sweating, sleep patterns, stomach acid secretion, and bowel movements, but other relationships are less obvious. For example, the pathways and mechanisms by which the brain and immune system interact are only beginning to be identified. It is remarkable that the mind (brain) can alter the activity of white blood cells and thus an immune response, because white blood cells travel through the body in blood or lymph vessels and are not attached to nerves. Nevertheless, research has shown that the brain does communicate with the white blood cells. For example, depression may suppress the immune system, making a depressed person more susceptible to infections, such as those by the viruses that cause the common cold and worsening of the symptoms of MS. Stress can cause physical symptoms even though no physical disease may be present, because the body responds physiologically to emotional stress (Beers 2004:1). The mind-body interaction is a two-way street. Not only can psychological factors contribute to the onset or aggravation of a wide variety of physical disorders, but also physical diseases can affect a person's thinking or mood. People with life-

threatening, recurring, or chronic physical disorders, such as MS, commonly become depressed. The depression may worsen the effects of the physical disease and add to a person's misery. A possible link between the mind, body, and risk of death suggests that people who are pessimistic, that is, people who interpret bad events as permanent and pervasive, are more likely to feel relatively helpless and depressed than those who are relatively optimistic. Feelings of helplessness and hopelessness have been associated with illness, and pessimistic people are more often in poor health and prone to depression. A pessimistic outlook on life events have been linked in one study with a 19% increased risk of death (Beers 2004:2).

1.7.3 Methodological assumptions

Polit and Hungler (1997:13) describe methodological assumptions as the way in which knowledge is obtained. This study assumes that a qualitative research methodology with inductive processes will serve the inquiry best as well as the following:

- Variables are normally distributed in the population.
- Only an interactive process between researcher and participants can obtain information on which to base an interpretation.
- During the interaction between researcher and participant the subjective world of the participant will be uncovered.
- Interviews will be best for interaction and to obtain narrative descriptions of the perceptions of women suffering from MS.

1.8 RESEARCH DESIGN AND METHODOLOGY

Chapter 3 describes the research design, population and sampling, data collection and analysis, and ethical considerations in detail. Qualitative research is based on the premise that individuals are best placed to describe situations and feelings in their own words (Holloway & Wheeler 2001:12).

1.8.1 Research design

The researcher chose a non-experimental research design, based on a qualitative research approach that is exploratory, descriptive and contextual. The aim was to interpret the social reality and describe the lived experiences of the participants (Holloway & Wheeler 2001:3) (see chapter 3, sections 3.4.1.1, 3.4.1.2, 3.4.1.3 and 3.4.1.4).

The study is phenomenological as the purpose is to uncover the meaning of the phenomenon through the description of the lived experiences of the individuals (De Poy & Gitlin 1998:82). Phenomenology differs from other forms of inquiry in that phenomenologists believe that the meaning can be understood only by those who experience it (De Poy & Gitlin 1998:113). In this study the subjects are women suffering from MS and their situations or interactions.

1.8.2 Population and sample

The population and sample are described below.

1.8.2.1 Population

Burns and Grove (1997:790) describe the population as all the elements (individuals, events, objects, or substances) that meet the sample criteria for inclusion in a study. In this study, the population is women suffering from MS living in Johannesburg and the East Rand. The following criteria were set for participation in this study:

- The participants had to be able to communicate, comprehend and express themselves in the English or Afrikaans language to be able to be interviewed.
- The participants had to be women diagnosed with MS.
- Due to the researcher's geographical restraints, the participants had to live in Johannesburg and the East Rand.

The population is discussed in more detail in chapter 3, section 3.4.4.2.

1.8.2.2 Sample

Before data collection the researcher conducted interviews with three individuals (who were not part of the population) to enhance practical experience with interviews and focus groups. This was done to ensure reflexivity, bracketing and intuiting during the study (see chapter 3, section 3.4.3).

A sample is a subset of the elements of the population that is selected for a study (Burns & Grove 1997:794). In this study, the sample elements were women suffering from MS living in Johannesburg and the East Rand. These elements were named participants as this expresses the collaboration between the researcher and the researched (De Poy & Gitlin 1998:159; Holloway & Wheeler 2001:129).

A list of names, addresses and telephone numbers of women with MS in the specified area was obtained from the MS Society in Triomf, Johannesburg. The researcher contacted these women by telephone to ascertain whether they would be willing to participate in the study. This was non-probability, purposive sampling to select information-rich informants for the study (see chapter 3, section 3.4.4.3).

In this study, the sample consisted of eight women who were interviewed. The interviews were tape-recorded with the consent of the participants. A focus group was held and persons who attended the support group meeting were invited to take part in a focus group discussion. Four women suffering from MS took part as well as support persons. This interview was also tape-recorded with permission (see chapter 3, section 3.5.2). The researcher's study leader supervised the interviews and the focus group.

1.8.3 Data collection

Interviews use personal contact and interaction between interviewer and the participant (Collins, Du Plooy, Grobbelaar, Puttergill, Terre Blance, Van Eeden, Van Rensburg, Wigstone 2000:176). Individual interviews were conducted in the participants' homes. The interviews lasted between forty and eighty minutes and were tape-recorded. The interviews were open-ended and semi-

structured to provide participants the opportunity to explain their experiences and perceptions of the phenomenon (see chapter 3, section 3.5.2)) Reflexivity, bracketing, and intuiting were continuously reviewed to prevent bias of the researcher (De Poy & Gitlin 1998:230; Holloway & Wheeler 2001:173). Reflexivity, bracketing and intuiting and their application are discussed fully in chapter 3, sections 3.3.4, 3.3.5 and 3.3.6.

The interview was accompanied by an aide memoir of topics to be covered. The aide memoir served as a guide to ensure that similar types of data were obtained (Holloway & Wheeler 2001:82). Probing, prompting and summarising were used to obtain responses from the participants and to allow them to talk freely about their lived experiences (see annexure F for the Aide de memoire).

A focus group was used to discover how the women think and feel and to explore and stimulate ideas based on shared perceptions (Holloway & Wheeler 2001:111) (see chapter 3, section 3.5.2 for details).

1.8.4 Data analysis

Data analysis involves “breaking up” the data into manageable themes, patterns, trends and relationships (Mouton 2001:108). The researcher tape-recorded and transcribed the verbatim data of the interviews and focus group (see annexure G for an example of a transcription of an interview) and took field notes. The QSR NUD*IST (Non-numerical Unstructured Data Indexing Searching and Theorising) Power Version 4.0, a computer program for qualitative data analysis was used for this purpose. The data were first labelled for organising. The researcher used reflexivity, bracketing and intuiting to exclude preconceptions of the phenomenon in order to enter the participants’ world with an open mind.

1.8.5 Trustworthiness

The goal in a qualitative study is to accurately represent participants’ experience. The four components of trustworthiness are credibility, transferability, dependability and conformability (Lincoln & Guba 1985:290). These components were implemented in the study to establish

trustworthiness. To establish rigour, Lincoln and Guba's (1985) model of trustworthiness was used to guide the research process (see chapter 3, section 3.7). Table 1.3 represents the research methodology schematically.

Table 1.3 Schematic representation of the research methodology

RESEARCH OBJECTIVE	DATA COLLECTION	DATA ANALYSIS	SOURCES SAMPLE
Phase 1 <i>Conceptualising and planning</i> Background Research questions and objectives Identification of the site	Literature review	Analysis of: <ul style="list-style-type: none"> • Reflexivity • Bracketing • Intuiting 	Interpretative analysis Labelling Organising QSR NUD*IST computer program
Phase 2 <i>Conducting the study</i> Research design Data collection Instrument Trial sampling Trustworthiness Ethical considerations	Literature review	Analysis of: <ul style="list-style-type: none"> • Reflexivity • Bracketing • Intuiting 	Primary and secondary resources, national and international Non-probability purposive sample with three individuals in pre-exercise
Phase 3 <i>Disseminating findings</i> Data collection Analysis Interpretation	Semi-structured interviews Focus group Field notes Literature review	Interpretative analysis Labelling Organising QSR NUD*IST computer program	Non-probability purposive sample of eight participants for the interviews and four participants for the focus group Primary and secondary resources, international and national

(Adapted from Polit, Beck and Hungler 2001:43-45)

This table is discussed in detail and in systematic order in chapter 3, section 3.2.5. Reflexivity, bracketing and intuiting are discussed in sections 3.3.4, 3.3.5 and 3.3.6. Sources were obtained from the University of South Africa (Unisa) library, the MS Society and the Internet.

1.9 ETHICAL CONSIDERATIONS

Ethical considerations were implemented to prevent ethical dilemmas. Permission was obtained from the Gauteng Health Department to conduct the study (see annexures A and B for letters requesting and obtaining permission from Gauteng Health Department and Ethics Committee). Ethical principles pertinent to the study were consent, protection of human rights, right to privacy, and scientific honesty. These considerations are discussed in detail in chapter 3, section 3.8.

1.10 LIMITATIONS OF THE STUDY

Acknowledging limitations empowers the reader to appreciate what constraints were imposed on the study (Vithal & Jansen 2002:35). Possible participant effect, researcher's bias, data collection and analysis, limited resources, and methodological and theoretical limitations are discussed in chapter 5.

1.11 OPERATIONAL DEFINITIONS

The following definitions are used in this study:

(1) Live experience

Wehmeier (2001:693) defines *live* as “to be alive and to spend your life in a particular way”.

Rooney (2001:843) defines *live* as “to remain alive or to continue living”.

Rooney (2001:503) defines *experience* as “involvement in something over time, active involvement in an activity or exposure to events or people over a period of time, leading to an increase in knowledge and skill”.

Wehmeier (2001:406) defines *experience* as “events or activities that have happened that influence thinking and behaviour, to have and be aware of a particular emotion or physical feeling”.

Brink (1999:7) describes *experience* as “a representation of familiar and functional sources of knowledge”.

Boyd (1993:85) states that *experience* refers to *living* through a situation, event, or circumstance in time, which can only be known reflectively and can be recalled.

Lived experience in this study refers to the individuals living through feelings, emotions, perceptions, events and personal reactions to events and people’s reactions while coping with MS.

(2) Women

Wehmeier (2001:1373) defines a *woman* as “an adult female human being with qualities typical of a woman”.

In this study, *women* refer to female persons suffering from MS, living in Johannesburg and the East Rand in South Africa.

(3) Multiple sclerosis

Wehmeier (2001:770) defines *MS* as “a disease of the central nervous system that is characterised by deterioration over a period of time with loss of feeling and loss of control of movement and speech”.

Halper and Holland (1997:3) state that *MS* is “a disease of the central nervous system in which the myelin sheath surrounding certain nerve fibres becomes damaged”.

Yanofsky (2000:17) describes *MS* as “a disease causing scattered scarring and inflammation in the white matter of the central nervous system”.

The National Multiple Sclerosis Society (2004:1) defines MS as “a chronic, unpredictable disease of the central nervous system”.

For the purpose of this study, *MS* is defined as “a chronic, incurable, and disabling disease that greatly impacts the lives of women diagnosed with the disease, as well as the lives of their families”.

(4) Perception

Zimmerman (2001:70236.htm) defines *perception* as “the quality, state, or capability of being affected by something external”.

Wehmeier (2001:864) defines *perception* as “an idea, a belief or an image you have as a result of how you see or understand”.

“Perception refers to the process of selection, organisation and interpretation of a stimulus, which was received from the environment” (Louw & Edwards 1997:121).

In this study, *perception* refers to how the women suffering from MS interpret their disease and problems that arise and society’s attitude towards them, as well as the family’s feelings about their condition.

(5) Coping

Wehmeier (2001:257) defines *coping* as “dealing successfully with something difficult”.

According to Smeltzer and Bare (2000:74), *coping* consists of “the cognitive and behavioural efforts made to manage the specific external or internal demands that tax a person’s resources. *Coping* can be emotional focussed or problem focussed.”

“Coping is a problem-solving process that draws on cognition, judgement, memory, and defence mechanisms. Coping is an adaptation strategy” (Thelan, Urden, Lough & Stacy 1998:78).

For the purpose of this study, *coping* refers to the attempts of women with MS to alleviate and remove stress while adapting to their changed lives.

(6) Emotion

Wehmeier (2001:379) defines *emotion* as “the part of a person’s character that consists of feelings”. In addition, Rooney (2001:469) adds that *emotion* is “a strong feeling about somebody or something”.

According to Stevenson and Haberman (1998:177), “a person is responsible for his/her *emotions*; there are ways in which they choose to react to the world”.

In this study, *emotions* refer to the feelings, responses and reactions to events of women suffering from MS.

(7) Attitude

Colman (1999:100) describes *attitudes* as “the favourable or unfavourable feelings, thoughts, and behavioural dispositions that people have toward other people, objects and abstract ideas”.

Louw and Edwards (1997:750) describe *attitude* as “a strong belief or feeling toward a person, object, idea or event and consists of three parts: cognitive (thoughts or beliefs) affective (evaluations or emotions) and conative (motives or intentions)”.

In this study, *attitude* refers to the thoughts or beliefs, evaluations or emotions and motives or intentions that the women suffering from MS experience.

(8) Society

Kruger (1997:66) describes *society* as “a fairly large number of people living in the same territory relatively independent of people outside their area and participating in a common culture”.

Rooney (2001:1375) defines *society* as “the sum of social relationships among groups of humans”.

For the purpose of this study, *society* refers to all the people with whom the women suffering from MS come into contact.

(9) Family

Rooney (2001:516) defines *family* as “a group of people who are closely related by birth, marriage or adoption”.

“*Family* refers to whoever is identified as primary-level intimates or dependents, be they legal relatives or purely chosen” (Fraser, Clemmons & Bennett 2002:83).

In this study, *family* refers to close relatives and significant others in the life of the women suffering from MS.

(10) Multiple Sclerosis Society

The *Multiple Sclerosis Society* is a society that offers counselling, education, social and recreational activities, information and referral, equipment, assistance and more to people with MS, their families, friends and caregivers.

(11) Resilience

Wehmeier (2001:1000) defines *resilience* as “the ability of people to feel better quickly after an unpleasant event”.

Rooney (2001:1235) defines *resilience* as “to be able to recover quickly from setbacks”.

“*Resilience* is the process of adapting well in the face of adversity, trauma, tragedy, threats and even significant sources of stress” (Camas-Dias, Luthers & Maddi 2002:1).

In this study, *resilience* refers to the ability of women suffering from MS to adapt well or “bounce back” after the initial shock of diagnosis.

(12) Relapse

Wehmeier (2001:988) defines a *relapse* as “to go back into a previous condition or into a worse state after making an improvement”.

Rooney (2001:1224) defines a *relapse* as “to become ill again after seeming to have made a recovery”.

“*Relapse*: (Attack, exacerbation) A clinical worsening in a disease marked by re-emergence of symptoms” (Yanofsky 2000:18).

In this study, a *relapse* refers to a clinical worsening after being better and the opposite of a remission, which is a temporary improvement in a disease.

1.12 OUTLINE OF THE STUDY

This chapter introduced the study. The background to the problem, problem statement, research questions, purpose of the study, objectives, importance of the study, research design and methodology, and terminology were discussed.

Chapter 2 describes the literature review conducted by the researcher in order to obtain background, knowledge and clarification about the problem under study. How MS affects the perceptions of women is also discussed.

Chapter 3 outlines the research design and methodology, including the population, sampling, and data collection and analysis. The ethical considerations and measures to provide trustworthiness are also discussed.

Chapter 4 presents the findings of the study.

Chapter 5 discusses the conclusions, strengths and limitations of the study and makes recommendations based on the study and for future research.

1.13 CONCLUSION

This chapter described the background to the study and explained its significance and purpose, and defined terms used in the study. Chapter 2 deals with the literature review.

CHAPTER 2

Literature review

2.1 INTRODUCTION

Chapter 1 discussed the problem, the significance, aim and purpose of the study, the research design and questions, defined terminology and outlined the study. This chapter discusses the literature review conducted by the researcher on MS in terms of prevalence, symptoms and treatment. In MS there is a body-mind interaction, which cannot be separated. The physical progression also causes psychological changes. The literature covered people's reaction to MS in their lives, their resilience, their lived experiences, as well as how their self-concept and perceptions are developed and influenced.

2.2 MULTIPLE SCLEROSIS

MS is one of the most common demyelinating disorders affecting the central nervous system (CNS) and a neurological cause of long-term disability (Fraser et al 2002:1; Haslett, Chilvers, Hunter & Boon 1999:983). MS is a chronic, degenerative progressive disease of the CNS characterised by the occurrence of small patches of demyelination in the brain and spinal cord. The inflammatory and demyelinating lesions result in impaired transmission of nerve impulses (Rieckman 2001:5; Smeltzer & Bare 2000:1718). Each person is affected differently. It affects young adults in the prime of life between the ages of 20 and 40 (Fraser et al 2002:3; Halper & Holland 1997:1; Phillips 2002:97; Smeltzer & Bare 2000:17, 18; Van der Westhuizen 2001:14). However, Fraser et al (2002:3) point out that people of any age may be vulnerable to this condition. According to Phillips (2002:97), although it is rare in children, there has recently been an increase in the number children affected, which could be due to the advancement of technology for diagnosis. The frequency of the onset of MS later in life drops abruptly after the age of 45 years (Bauer & Hanefeld 1993:56; Coyle & Halper 2001:3). The reasons for this are still unclear as the researcher found no relevant literature on this question.

According to Phillips (2002:97), Van der Westhuizen (2001:14) and Yanofsky (2000:6), the disease affects women more than men and whites more than other races. Halper and Holland (1997:1) state the ratio between women and men as 3:1 and that MS appears to have a higher prevalence in Caucasians than other racial groups. Halper (2001:4) mentions that MS affects mostly Caucasians and that it is unusual for people in Africa to be diagnosed. The researcher found no statistics on race prevalence in any of the sources or on the Internet. MS is very rare amongst indigenous black South Africans. According to Dean, Bhigjee, Bill, Fritz, Chikanza, Thomas, Levy and Saffer (1994:1014-1019), the first record of a black person with MS was in 1987. To date, eight black South Africans have been diagnosed (Modi, Mochan, Modi & Saffer 2001:500-505). Figure 2.1 illustrates the incidence of MS in South Africa graphically. From figure 2.1 it is clear that the highest incidence is amongst immigrants between 20 and 30 years of age. There is also a higher incidence among white English-speaking South Africans than South African-born African-speaking persons (La Porte 2001:9). Migratory effects are evident in South Africa. Moreover, individuals had to migrate before age 15 to see the rates go down (La Porte 2001:9). Graham (2000:7) suggests that people who migrate to areas with temperate climates after the age of about 15 retain the likelihood of developing MS corresponding to their country of origin, rather than the increased likelihood associated with temperate climates. MS appears to be a disease of temperate rather than tropical climates in genetically predisposed individuals (Van der Westhuizen 2001:14). The researcher found no literature on why South Africans who did not or whose parents did not migrate developed MS.

More than 70% of individuals with MS are women. An unidentified neurologist in the Biogen Information Series (1999a:7) indicates that MS affects women more than men by 3:2 and occurs mostly in European countries. Graham (2000:3) also gives the same ratio of women to men (3:2). Smeltzer and Bare (2000:1718) state that MS is more common in people in the northern temperate climate zones, affecting twice as many women as men. According to Halper (2001:4), this could be due to the fact that most autoimmune diseases are more common in women and MS is thought to be linked to an autoimmune disease (Halper 2001:4).

Figure 2.1

Incidence of multiple sclerosis in South Africa

Y axis: annual incidence (1/ 100 000), X axis: age

(La Porte 2001:9)

2.2.1 History of multiple sclerosis

There are few early reports of patients who could have suffered from MS. According to Rolak (2003:4), St Lidwina of Schiedam (1380-1433), a Dutch nun, may have been the first reported MS patient. From the age of sixteen, she developed intermittent pain, weakness of the legs, and visual loss, symptoms typical of MS. She died at the age of 53. The first written record of MS appears in the diary of Sir August D'Este (1794-1848), an illegitimate grandson of King George III of England. It began at age twenty-eight. His diary describes his 22 years living with the disease. In 1822 he wrote of symptoms he experienced such as blurred vision, not being able to write, progressive weakness, numbness, spasms, and difficulty in walking, and bladder problems. In 1844, he was confined to a wheelchair (Rolak 2003:2). In 1883 Sir Carswell made an illustration of a strange spinal cord he had seen during an autopsy, with scattered spots of hardened and discoloured tissue. The only clinical details of the case were given as a paralysed patient (Rolak 2003:3). According to Goetz (1999:1678) and Rolak (2003:3), MS was only properly identified in 1868 by Jean Charcot, who gave a detailed description of the disease.

2.2.2 Exploration of the term "multiple sclerosis"

MS is a disease of the CNS that is made up of: the brain, spinal cord and nerve fibres. The nerve cells in the brain, spinal cord and nerve fibres are surrounded by the myelin sheath in order to convey messages. Messages are sent along axons with an electrical code. Inflammation in the myelin causes damage to the myelin sheath (Biogen Information Series 1999a:7; Halper & Holland 1997:3; Yanofsky 2000:3). When the myelin is affected, impulses travel over the axon very slowly or not at all, as there is an electrical disturbance (Yanofsky 2000:3). Figure 2.2 below shows the difference between a healthy axon and a damaged axon in MS as well as how the myelin becomes damaged in MS, resulting in a disturbed transfer of nerve impulses along the axons (Biogen Information Series 1999b:9).

MS is classified as an autoimmune disease, as people with MS produce inflammatory reactions against their own nervous system (Biogen Information Series 1999b:13; Halper

2001:4). According to Yanofsky (2000:3), the immune system seems to attack and destroy the myelin. Certain types of lymphocytes, T-cells, engulf and digest the myelin, but do not attack the nerve cells or axons. These immune cells are usually active in the presence of bacterial or viral invaders (Baranzini, Oksenberg & Hauser 2002:201-210; Rieckman 2001:5; Yanofsky 2000:3). The patches of inflammation are called lesions and after the inflammation subsides, a scar is left which is called a plaque; from thence the word "sclerosis" (Frankel 1997:3; Graham 2000:3; Haslett et.al 1999:983). Figure 2.3 below illustrates a scan showing the brain of a person with MS. On this scan the four white spots visible are plaques.

A magnetic resonance imaging is also a type of scan used to diagnose MS. Figure 2.4 illustrates a computer-digitised and colour-enhanced magnetic resonance imaging (MRI) scan of an affected brain. MS plaques can clearly be seen as the palest areas on this colour enhanced MRI.

When the myelin is destroyed the messages are not transmitted effectively, causing slow and uncoordinated movement, altered sensations as well as other symptoms. As the damage to the myelin sheath occurs at several different places, the person can experience a wide variety of symptoms. It is not always possible to tell in what stage of MS a person is, it is based on clinical observation and examination, with documentation of gradual deterioration and loss of neurological function (Coyle & Halper 2001:18). One of the hallmarks of MS is its unpredictability from person to person and within a given individual over time, although women have a better prognosis than men (Halper & Holland 1997:4). The researcher could find no literature to explain or support this statement of prognosis.

2.2.3 Genetics of multiple sclerosis

It is likely that MS susceptibility is under the control of several genes encoded both within and outside the major histocompatibility complex (MHC) (Sadovnick 1994:194-203). The genetic component (of MS etiology) is believed to result from the action of several genes of moderate effect, but although these genetic components are present in MS, there is a lack of obvious and homogeneous mode of transmission (Baranzini et al 2002:201-203).

Figure 2.2

The axon

(Biogen Informaiton Series1999a:9)

Figure 2.3 Brain scan of a person with MS
(Discovery Health 2003:1)

Figure 2.4 A computer-digitised colour-enhanced magnetic resonance imaging scan
(Abrahams 2001:93)

Human leukocyte antigen (HLA) is a substance located on the surface of white blood cells. Leukocyte is the name for a white blood cell, while antigen refers to a genetic marker. This substance plays an important role in the body's immune response. There are four types of human leukocyte antigens: HLA-A, HLA-B, HLA-C, and HLA-D. Certain HLA types have been linked to diseases, such as rheumatoid arthritis, MS, serum lupus erythematosus, and other autoimmune disorders. By themselves, however, none of the HLA types are considered definitive. Because the clinical significance of many of the marker antigens has not yet been well defined, definitive diagnosis of disease is obtained by the use of more specific tests (Smith 2004:1). The HLA-DR-2 halotype is a set of alleles, an alternative form of a gene that can occupy a particular place on a chromosome of a group of closely linked genes, which are usually inherited as a unit (Smith 2004:2).

The HLA-DR-2 halotype within the MHC on chromosome 6, which carries one of the most important regions in our genome for fighting disease, has been linked to over one hundred diseases, including many autoimmune diseases, such as MS and type 1-diabetes (Ruder 2003:1). Chromosome 6 is the strongest genetic effect identified in MS, and has consistently demonstrated both linkage and association in family. MHC genes appear to influence primary susceptibility (Baranzini et al 2002:201-210). Discovery Health (2003:1) confirms this by stating that except for a single area in chromosome 6, no other genes or chromosomes appear to be involved in MS. A strong genetic component in MS pathogenesis is indicated by the relatively high recurrence risk in family members of affected individuals in the same ethnic population (Baranzini et al 2002:201-210). About 20% of people with MS have a relative also diagnosed with the disease (Coyle & Halper 2001:5). When a parent has MS, the biological children are thirty to fifty times more likely to develop MS than the rest of the population. The risk depends on which of the relatives have MS and how close the relation is (Discovery Health 2003:1). Although this suggests a genetic role for MS, it is clear that MS is not an inherited disease. MS involves more than just genes and includes environmental factors and the immune system (Coyle & Halper 2001:5-8).

2.2.4 Types of multiple sclerosis and prognosis

The disease follows a characteristic relapsing and remitting course. Recovering from each episode of demyelination (referred to as a relapse) is usually incomplete and a progressive clinical deterioration ensues, although the progress of the disease is variable (Underwood 1996:855). Recovery from an MS relapse is never guaranteed. People tend to make a complete recovery after early relapses but incomplete recovery after later relapses. Most people with MS (85%) start out with a relapsing form of the disease (Coyle & Halper 2001:10). MS can result in considerable disability but does not significantly reduce life expectancy, and is neither fatal nor contagious. The average lifespan of a person with MS is generally not substantially decreased; it is two years less on average (Halper 2001:4). With the improved treatment for complications, such as lung and bladder infections, the life expectancy for persons diagnosed with MS is only slightly reduced. The earlier in life onset occurs, the slower disability progresses (Rolak 2003:3). As a result, persons with MS have to cope with normal age-related changes in their life and health as well as having to manage with disability related to MS. Disability after five years correlates well with disability after fifteen years. Two out of three MS patients with low disability after five years will not markedly deteriorate during the following ten years (Finlayson 2002:3). Figure 2.5 below represents the prognosis of disability. According to figure 2.5, 25% of persons suffering from MS will not be disabled after ten to twenty years, whereas 35% will be disabled. An international survey in 1996 by Lublin and Reingold (cited in Halper 2001:1-3) to standardise the terminology used to describe the clinical course of MS led to the four major classifications of the disease:

- *Relapsing-remitting* MS has clearly defined relapses followed by periods characterised by a lack of disease progression and by stabilisation between attacks.
- *Secondary progressive* MS has an initial relapsing-remitting course followed by progression with or without occasional relapses, minor remissions, and plateaus.
- *Primary progressive* disease is demonstrated by a nearly continuous worsening disease course that may be interrupted by occasional plateaus and temporary minor improvements.
- *Progressive-relapsing* MS is progressive disease from the outset with clear acute relapses with or without recovery.

Figure 2.5 Prognosis of multiple sclerosis patients 10 to 20 years on
(Yanosky 2000:8)

Phillips (2002:97) states that the most common form of the condition is relapsing-remitting MS (see figure 2.6, no1), in which sufferers have attacks with full-blown symptoms, such as spasticity, temporary blindness or tremors, followed by remissions. Relapsing-remitting MS accounts for about 55% of MS (Coyle & Halper 2001:9). A benign type is described in which sufferers can have one attack and be symptom free for the rest of their lives, or for up to fifteen years (Halper & Holland 1997:6; Phillips 2002:97). Malignant MS has a rapid progressive course leading to significant disability or death within a relatively short time after onset (Fraser et.al 2002:5; Halper & Holland 1997:6). This type of progressive MS accounts for about 5% of MS (Coyle & Halper 2001:9). The extent of the person's level of disability five years after diagnosis signifies the long-term picture of the disease (Halper & Holland 1997:4). Asymptomatic MS is based on autopsy studies and is estimated to make up 20% of MS (Coyle & Halper 2001:9). Figure 2.6 illustrates the different types and courses of MS.

Relapsing-remitting (RR) MS is characterised by clearly defined acute attacks with full recovery or with sequel and residual deficit upon recovery. Periods between relapses are characterised by lack of disease progression. Primary progressive (PP) MS is characterised by disease showing progression of disability from the onset, without plateaus or remissions or with occasional plateaus and temporary minor improvements. Secondary progressive MS begins with an initial RR course, followed by progression with or without continuing relapses. Progressive relapsing (PR) MS shows progression from the onset with subsequent relapses (Coyle & Halper 2001:10).

2.2.5 Symptoms of multiple sclerosis

All persons suffering from MS experience different degrees and combinations of symptoms. MS has a number of symptoms, almost none of which is specific (Van der Westhuizen 2001:14). Symptoms of MS vary greatly from individual to individual and the condition is often characterised by periodic remissions and exacerbations, sometimes separated by months or even years (Fraser et al 2002:1). Most frequent presenting symptoms are paresthesias in one or more extremities and visual disturbances.

Figure 2.6 Types and courses of multiple sclerosis
(Coyle and Harper 2001:10)

Primary symptoms in MS include weakness, fatigue, tremors, pain, bladder and bowel dysfunctions, difficulty in coordination, loss of balance, paralysis, spasticity, visual disturbances, speech difficulties, cognitive impairments, emotional changes and diminished sexual function (Biogen Information Series 1999a:17-21; Halper & Holland 1997:25-44; Halper 2001:9-12; Smeltzer & Bare 2000:1719).

Secondary symptoms are complications caused by the underlying impairments. These include falls, reduced activity of daily living, urinary tract infection, pneumonia, contracture deformities, depression and physical barriers in the environment, such as inability to climb steps or use of public toilets due to inaccessibility (Smeltzer & Bare 2000:1719).

Halper (2001:9) describes tertiary symptoms as psychosocial or vocational problems, such as inability to perform tasks as well as before due to difficulty in mobility, spasticity, fatigue or slurred speech. As the variability of scarring in the brain is so different, no two cases of MS experience the same symptoms although most sufferers experience some of the symptoms.

2.2.6 Diagnosis and causes

Diagnoses are done on the nature and course of the symptoms. There is no single test to diagnose MS (Singer 2000:12). In general, blood studies in persons suspected of having MS are used to rule out other conditions (Coyle & Halper 2001:15). Analysis of the cerebrospinal fluid (CSF) can be useful to support a diagnosis of MS. A lumbar puncture is used to test the CSF for inflammation specific for MS. Figure 2.7 illustrates where the CSF is taken from anatomically while figure 2.8 illustrates how CSF is tapped during a lumbar puncture.

A lumbar puncture is a sterile procedure performed by a physician and is carried out by inserting a needle into the lumbar subarachnoid space to withdraw CSF. The needle is inserted into the subarachnoid space between the third and fourth or fourth and fifth lumbar vertebrae (Smeltzer & Bare 2000:1630). In figure 2.8 **A** represents the needle while **B** represents the specimen bottle.

Figure 2.7 Area of lumbar puncture
(Abrahams 2001:91)

Figure 2.8 Lumbar puncture procedure
(Abrahams 2001:93)

A

B

Magnetic Resonance Imaging (MRI) is used to show defects in the white brain matter (Biogen Information Series 1999b:22). The MRI Scan uses a giant magnetic coil and radio frequency waves to receive pictures of the brain and nervous system without x-rays. It is an extremely sensitive test for MS but a positive test can occur in a number of other conditions. The MRI also shows that MS is often active even when there are no symptoms (Yanofsky 2000:4).

The Evoked Responses Test is a way to detect electrical signals as they go through the nervous system to see how fast these electrical signals travel. Because MS affects the white brain matter and slows conduction of electrical signals, there are abnormalities with MS (Yanofsky 2000:3). Evoked potentials are used to test certain nerve fibres for speed of transmission (Biogen Information Series 1999a:23). The grey matter is a part of the brain and spinal cord lying mostly over the surface and including the cerebral cortex, composed of cell bodies (as opposed to axon extensions). These cell bodies of neurons have a grey colour when a brain is fixed for examination. The white matter is also part of the brain and spinal cord containing large amounts of myelin that colour it white. It carries electrical impulses rather than initiating them. In the brain and spinal cord, white matter is broken up into cables carrying messages that are called tracts; white matter gets inflamed and then scarred in MS (Yanofsky 2000:3).

Figure 2.9 illustrates an MRI of a normal brain. The white and grey matter can be distinguished and no white spots (also referred to as plaques) can be seen.

Figure 2.10 represents an MRI of a brain with characteristic MS lesions.

Figure 2.9 Magnetic resonance imaging of a normal brain
(Yanosky 2000:19)

Figure 2.10 Magnetic resonance imaging scan of a brain with MS lesions
(Biogen Information Series 1999b:23)

Characteristic round to oval shaped MS lesions can be noticed (marked by arrows) around the butterfly shaped ventricular system (white).

Figure 2.11 depicts an MRI scan of the spinal cord with lesions. The spinal cord is shown as an oblong dark shape. In the spinal cord, some long-drawn MS lesions are clearly visible (in white). The plaque is encircled with white (Smeltzer & Bare 2000:1719).

Figure 2.12 illustrates brain atrophy in MS. On the left, a baseline scan shows a near-normal corpus callosum, a highly myelinated area that connects the left and right cerebral hemispheres. On the right, the same area two years later shows considerable dystrophy due to loss of myelin (Coyle & Halper 2001:21)

The cause of MS is unknown and therefore effective cures have not been found. Popular theories on the causes of MS are:

- MS is an autoimmune disorder or response to an environmental trigger.
- There is probably an infectious trigger or virus for the disease. A number of viruses are thought to trigger MS, such as Herpes virus 6, Rubella and Epstein-Barr virus (Singer 2000:9).
- There is a genetic susceptibility that may predispose certain individuals to the disease (see section 2.2.3).
- There is a circulating toxin in the CSF (Biogen Information Series 1999a:11-14; Graham 2000:6-7; Halper & Holland 1997:12; Underwood 1996:854).

Figure 2.11 Magnetic resonance imaging scan of the spinal cord

(Smeltzer & Bare 2000:1719)

Figure 2.12 Brain atrophy in MS
(Coyle & Harper 2001:21)

2.2.7 Treatment

There is no cure yet although there are a number of methods for treating the adverse symptoms of MS. Mostly symptoms are treated as they appear with specific drug treatments. An individualised, organised, and rational treatment programme is indicated to relieve the patient's symptoms and provide continuing support. Symptoms most frequently requiring intervention include spasticity, fatigue and bladder dysfunction (Smeltzer & Bare 2000:1720). Cortisone (for example, Solu-medrol) is mostly used for acute exacerbations (Fraser et al 2002:13).

2.2.7.1 Possible future and alternative treatment

- **Cannabis**

According to a report in *The Star* (2003:3), in the Netherlands cannabis (also referred to as marijuana or dagga) has recently been introduced as treatment with good effects and the Dutch government has given pharmacies permission to sell cannabis to MS sufferers. Cannabis has been reported to help alleviate many symptoms of MS, including spasticity, seizures, neuropathy and depression. The effects of cannabinoids have not been formally evaluated as treatment for spasticity, and the use of cannabinoids is illegal in many countries (Halper 2001:126). Cavanaugh (2002:1) states that studies in England and Spain have found that cannabis is a selective immuno-suppressant and protects the integrity of myelin. Researchers at the University of Plymouth in the United Kingdom at the Derriford Hospital in Plymouth are coordinating a cannabis in MS trail. The research is funded by the Medical Research Council of the United Kingdom and Solvay Pharmaceuticals from Berlin. This cannabis MS trail is conducted with 660 patients (Cannabinoids in Multiple Schlerosis Trail 2003:1).

- **Stem cells**

Stem cells are naturally occurring cells, which creates new life and new organs in the developing embryo (Purcell 2003:3). Stem cells have the potential to develop into any form of

human tissue, after birth. Stem cells can be introduced to specialised forms of cells, which can then repair human tissue, if the stem cells enter a zone of damaged tissue. Stem cells are harvested from human embryos or umbilical cord blood. Umbilical cord blood stem cells are not immuno-sensitised and work better in autoimmune disease therapy, and may have a greater ability to differentiate into a variety of adult tissues (Purcell 2003:3). Stem cell transplants have been done successfully in the treatment of

- most common childhood malignancies, such as leukaemia
- adult leukaemia and lymphoma
- genetic disorders
- repair of adult bone marrow accidentally damaged by chemotherapy (Purcell 2003:7-8)

The treatment of degenerative neural diseases such as Alzheimer's, Parkinson's and MS is being investigated. Research suggests that in the near future stem cells could be modified to replace lost cells in the brain and spinal cord that cause these diseases (Purcell 2003:8). Since 2000, about three hundred transplants have been performed mostly on children with different types of cancers (Purcell 2003:2). In MS, it is thought that complete immunosuppression followed by stem cell transplantation may allow for proliferation of less auto-reactive cells and therefore less MS activity (Halper 2001:33).

Burt (cited in Halper 2001:33) conducted a small study of three patients which demonstrated stabilisation and some improvement in neurological function following stem cell transplants. An 8% risk of death from the transplant procedure is projected for MS sufferers. Extensive research is required to realise the full potential of stem cells (Purcell 2003:2). This study was conducted at the Cryoclinic in the United Kingdom which is a private stem cell bank and is a company dedicated to the highly specialised storage of healthy human stem cells for future medical use (Purcell 2003:3). No transplants have been performed in South Africa, although the Cryoclinic has a branch in Durban, mainly to collect cells and send them for storage in the United Kingdom at an accredited laboratory (Purcell 2003:22).

- **Bee venom therapy**

The Georgetown University Medical Centre in Washington, DC conducted a study in 2000 to examine the safety and tolerance of honeybee venom extracts as a possible therapy for patients with progressive MS, with beneficial results. MS clients engaged in bee venom therapy (BVT) receive 25 to 30 honeybee stings per session and go for two sessions per week for one year. (MSAA's Bee Venom Therapy 2000:1). The beneficial results from the BVT were that the MS clients reported significant symptom relief through this alternative practice.

2.2.7.2 Drugs used to treat multiple sclerosis

Tables 2.1, 2.2, 2.3 and 2.4 below present examples of different drugs used in the treatment of MS. The generic names, the indications for prescribing the drugs, the areas on which the drugs work as well as the side-effects are given briefly. It is beyond the scope of this study to examine the drug treatment of the disease. It is important, however, to provide a drug list to indicate the drug regimes used by medical practitioners to treat the symptoms.

Table 2.1 Immune modulators

DRUG	GENERIC NAME	INDICATION	WORKS ON
Deltasone	Prednisone	Acute attack	Lymphocytes
Solumedrol	Methylprednisolone	Acute attack	Lymphocytes
Betaseron	Beta-Inter-Feron1b	Attack prevention, decrease "lesion burden"	Immune modulation
Avonex	Beta Interferon 1a	Attack prevention, decrease disability	Immune modulation
Copaxone	Copolymer 1, Glatiramer	Decrease disease activity	Possible allergic desensitization Affects certain immune cells

DRUG	DOSAGE	SIDE-EFFECTS	COMMENTS
Deltasone	60 Mg then decrease	Stomach acid, restlessness, immune suppression	Side effects minimal in short course
Solumedrol	1000 Mg I.V. for 5 days then decrease with Prednisone tablets	Same as above	Severe tiredness, diaphoresis for about a week
Betaseron	9.6 M. Units qid	Flu-like symptoms, depression	Possible decrease in MRI lesions, expand time between attacks
Avonex	30 Mg weekly I.M.	Same as Betaseron but less.	More like human protein
Copaxone	20 mg qid injection	Minimal effects	Rare panic spells

(Yanofsky 2000:20)

Table 2.2 Urine and bladder control

DRUG	GENERIC NAME	INDICATION	WORKS ON
Ditropan	Oxy-Butynin	Urge incontinence	Inhibits bladder contraction
Valium, Lioresal		Tight outflow	Decrease muscle tone
	Nitrofurantion, Trimethaprim, Sulfamethozazole, Vitamin C	Prevent infection	Bacteriostatic

DRUG	DOSAGE	SIDE-EFFECTS	COMMENTS
Ditropan	5 mg TDS	Urine retention, constipation	-
Valium	10 mg daily	Drowsiness, weakness	-
Lioresal	Up to 150 mg daily		
Nitrofurantion, Trimethaprim, Sulfamethozazole, Vitamin C		Allergy, resistant strains	-

(Yanofsky 2000:21)

Table 2.3 Tremor control

DRUG	GENERIC NAME	INDICATION	WORKS ON
INH	Isoniazid	Cerebellar tremor	
Inderal	Propranolol	Rapid rest tremor	Beta-adrenergic blocker
Mysoline	Primidone	Resting tremor and ataxia	Motor control

DRUG	DOSAGE	SIDE-EFFECTS
INH	300 mg/daily+ Vitamin B6	Anxiety, liver toxic
Inderal	Up to 240 mg/daily	Fatigue, decrease heart rate
Mysoline	50-1000mg/daily	Sedation, nausea

(Yanofsky 2000:22)

Table 2.4 Other drugs

DRUG	GENERIC NAME	INDICATION	WORKS ON
Tegretol	Carbamazepine	Spasm, sensory complaints	Electrical after-discharge
Epanutin	Phenyton	Same as Tegretol	Same as above
Symmetrel	Amantadine	Fatigue,	DOPA transmitter
Prozac	Fluoxetine	Fatigue, depression	Serotonin
	4-Aminopyridine	Fatigue	Potassium channels

DRUG	DOSAGE	SIDE-EFFECTS	COMMENTS
Tegretol	200-800 mg/daily	Ataxia	
Epanutin	100-400 mg/daily	Same as above	
Symmetrel	100-200 mg/daily	Agitation, hallucinations	
Prozac	20-60 mg/daily	Few side-effects	Decrease libido
4- Aminopyridine	5-10 mg TDS	Tingling sensations	Can cause epileptic seizures

(Yanofsky 2000:22)

These tables are not comprehensive and contain only examples of various drugs used in the management of MS as a detailed discussion is beyond the scope of this study.

- **Anti-spastic drugs**

Valium or diazepam are used for spasticity and work on the spinal neurons. The dose is 4 to 20 mg per day. Side-effects include drowsiness and weakness (Yanofsky 2000:21).

- **Disease-modifying therapy**

Five disease-modifying therapies have been shown to decrease MS disease activity and damage in trials in the United States of America (Coyle & Halper 2001:27). All current disease-modifying therapies affect the immune system, but each does so in different ways:

- Cytokine strategy : Interferon B-1b (Betaseron)
Interferon B-1a (Avonex, Rebif)
Interferon expands the time between attacks.
- T-cell strategy: Glatiramer acetate (Copaxone)
This strategy affects certain immune cells.
- Immunosuppression strategy: Mitoxantrone (Novantrone)
Novantrone suppresses the immune system and therefore prevents attacks (Coyle & Halper 2001:28).

In South Africa Avonex and Betaseron are available but very expensive (Singer 2000:38). According to *Die Beeld* (24 December 2003), most medical aid funds will view MS as a chronic disease in terms of new medication legislation, but will not pay for Interferon as from 1 January 2004. Future treatment of MS is likely to involve combination drugs, very similar to the manner in which cancer is treated. This will be necessary until a cure for MS is found (Coyle & Halper 2001:38).

2.3 RESPONSES TO THE IMPACT OF MULTIPLE SCLEROSIS

MS has an impact on every sphere of the diagnosed person. The condition has wide-ranging effects on women and those near to them. It is important to acknowledge these responses,

so that problems can be resolved or at least managed. The effects can last a lifetime and range from mild interruption of daily routines to complete disruption of everyday life.

2.3.1 Emotional responses

Emotional concerns impacting on women with MS include stress, uncertainty and unpredictability, denial and adaptation, grief and depression, anxiety, powerlessness and hopelessness.

- **Stress**

Stress is a multifaceted process that occurs in reaction to events or situations that disrupt or threaten to disrupt psychological or physical function. Stress is multifaceted because of the wide variety of human functions that are affected. There are emotional, cognitive and physical responses. Stress is a process because of the psychologically ongoing impact of the event or situation. Stress is a state produced by change in the environment that is perceived as challenging, threatening, or damaging to the person's dynamic balance or equilibrium. Challenges can be perceived as positive (eustress) or negative (distress).

Eustress is positive stress set off by a positive event in one's life, but still requires the body to adjust and return to a homeostatic state. Distress is stress caused by a negative event that can lead towards disease (Arniston & Matheson 2001:1). Challenges that people can cope with are invigorating, whereas challenges beyond their coping abilities tax biological systems and create distress, anxiety and depression. The reaction to stress varies from person to person; the desired goal is adaptation, or adjustment so that the person can regain equilibrium (Smeltzer & Bare 2000:72). Halper and Holland (1997:85) state that stress can precipitate the onset of an exacerbation, but the question of the MS-stress link remains controversial.

The reality is that MS itself is a source of stress causing emotional and psychological distress (Halper & Holland 1997:85; Fraser et.al 2002:100). Many stresses accompany MS as it disrupts a person's physical and social life. Stress can be divided into two types: major life

events and minor stress. Major life events require change on the part of the individual and/or family, such as losing one's job. Minor stress, like being in traffic, does not require life changes, but is emotionally taxing.

- **Uncertainty and unpredictability**

Uncertainty is one of the first stresses MS places on women. First, there is the uncertainty until the diagnosis has been confirmed. Having MS means living with uncertainty and adapting to changing situations. The person with MS wants to know the prognosis, but soon realises the course of MS is unpredictable. To build a sense of stability and security in the face of this uncertainty is an emotional challenge (Halper & Holland 1997:86).

- **Denial and adaptation**

After diagnosis, some sense of disbelief or denial is a normal reaction. This defence mechanism can initially allow the person and/or the family to postpone what may be perceived as overwhelmingly frightening (Biogen Information Series 1999a:13; Fraser et.al 2002:85). Acceptance means that the person with MS is able to recognise the existence of the condition and deal with the symptoms (Halper & Holland 1997:87; Fraser et.al 2002:88). Accepting MS can be a challenging process involving a great deal of personal growth. The first step is for sufferers to accept that they are suffering from MS, then tell other people and lastly to change their lifestyle and environment to make life easier (MS South Africa 2003:1). Adaptation is a constant, ongoing process that requires a change in structure, function, or behaviour so that the person is better suited to the changed environment or, in the case of MS, to better cope with the restraints it puts on him/her (Smeltzer & Bare 2000:73). According to Graham (2000:4), accepting MS is a challenge that has to be taken in stages.

- **Grief and depression**

Grief is a normal reaction to the types of changes that occur in MS. Grief is often focused on a specific event and generally time limited, while depression is more severe, pervasive, and persistent (Halper & Holland 1997:89). Grieving may include one of the following

manifestations: shock, denial, fear, sadness, anger, withdrawal, guilt, and acceptance (Fraser et al 2002:85). Depression is very common among people with MS as there is a great deal of loss involved. The uncertainty of the future and the perceived loss of a normal life cause most persons to feel depressed occasionally. MS can make it more difficult to cope with depression (Biogen Information Series 1999a:18). Phillips (2002:95) states that many MS sufferers undergo periods of depression because they have allowed the disease to overshadow all else.

MS affects each individual differently, maintaining a healthy mental outlook is crucial. In a study in Toronto, Crickmer (2000:2) found that 42% of the MS population suffered depression. Halper and Holland (1997:90) state that 50% of people with MS experience a major depressive episode some time during the course of their illness, which is also why the suicide rate among MS sufferers is high (Halper & Holland 1997:90). In a study of suicide among people with MS, Halper (2001:7) found that those who committed suicide were more likely to be male, unemployed, experiencing financial stress, more severely disabled, in a progressive phase of the disease, experiencing unendurable psychic pain, withdrawn, and isolated from a support network. Biogen Information Series 1999a:31) state that although a large percentage of people with MS suffer some degree of depression, it is important to know that it can be treated.

- **Anxiety**

Stuart and Laraia (1998:274) define anxiety as a diffuse apprehension that is vague and associated with feelings of uncertainty and helplessness. Colman (1999:104) points out that a common generalised anxiety disorder is not focused on any specific circumstances but related to everyday events or activities. This type of anxiety features regularly in women with MS because of the uncertainty about the future course of the disease and a sense of feeling out of control.

- **Powerlessness and hopelessness**

Powerlessness is people's perception that their own actions will not significantly affect an outcome. Unrelieved powerlessness may result in hopelessness. Thelan et al (1998:71) state

that a person's level of powerlessness depends on their perceived control of the situation. Hopelessness is a subjective state in which an individual sees little or no alternatives available (Thelan et al 1998:73). Halper and Holland (1997:189) point out that a woman's degree of hopelessness is related to the perception and duration of her powerlessness. Empowering hope in persons with MS is a prime aspect of caring. Hope is a multidimensional and dynamic process that enables coping. Empowering hope is much needed, as there is a high incidence of depression in the MS population. Feelings of hopelessness and powerlessness pose a significant threat to a woman's independence and perception of competence (Morgante 2000:3). A variety of underlying characteristics can contribute to the woman with MS hopefulness or lack thereof. Hope exists in women with MS and they rely on the hopeful attitudes of those around them (Morgante 2000:8).

2.3.2 Responses to the impact of multiple sclerosis on the family

MS can impact a few to possibly all aspects of personal and interpersonal functioning. It affects the individuals as well as those around them, who can be family, colleagues, and friends. Fraser et al (2002:83) describe family as whoever is identified as primary level intimates or dependants, whether legal relatives or purely chosen. As mentioned earlier, strong emotional responses may alter the family's coping with MS. Each exacerbation presents a risk for a crisis reaction for the family. Within each family there are different coping styles (Biogen Information Series 1999a:24; Fraser et.al 2002:83; Halper & Holland 1997:99).

- **Roles**

There can be significant role changes in a family with a member with MS. A woman who has previously managed most of the domestic work may require more assistance from family members. Her husband or teenage child may suddenly be required to assist with household chores and with her personal care. These role changes within the family cause stress and can become problematic (Biogen Information Series 1999a:24; Frankel 1997:14; Fraser et al 2002:92; Halper & Holland 1997:101).

- **Guilt**

The family might experience guilt because they still find pleasure in the things the person with MS can no longer do, while the family member with MS feels guilty about being unable to fulfil her former roles. Other family members may be resentful about the changes that are acquired and then feel guilty about their resentment. Guilt is thus a common feeling amongst family members (Biogen Information Series 1999a:29).

- **Family communication**

Family communication patterns are complex even under the best of circumstances. To communicate their private fears and concerns about MS can then be complicated as the family members each have different communication needs and styles. Open communication about feelings and experiences is very important in the family with MS (Biogen Information Series 1999a:28-29; Halper & Holland 1997:103). According to Phillips (2002:97), MS is a lonely disease because sufferers find it increasingly difficult to relate to able-bodied people and anything that reduces their sense of isolation is a good thing.

Facing that there are real limitations to how much anyone can do, and not to overdo things, is a step towards helping the person with MS feel loved, valued and as independent as possible. It is important to allow the person with MS to do things that they still feel able to do. Wollin, Dale, Spencer and Walsh (2000:11) describe the promotion of independence and self-determination as the greatest service possible to individuals with MS. Family members must learn to incorporate MS into their individual and communal lives without sacrificing themselves, family life or interests and activities (Halper & Holland 1997:99). All human beings need loving relationships. MS can change the relationships with family and friends, but these are the ones who support the person with MS (Graham 2000:6). Socializing may be more difficult than it was, but it is an important source of emotional well-being.

- **Sexuality**

Sexuality and intimate relationships are an important part of life and well-being. These aspects can be of great pleasure, but can also cause worry (Foley 2000:2). The presence of a physical illness such as MS has the potential to complicate sexual development and the way a woman expresses her own sexuality. Women with MS may experience decreased libido, decreased vaginal lubrication, decreased frequency and/or intensity of orgasm, and altered sensation, and desire (Foley & Sanders 1997:4; Foley 2000:5). Another aspect that may hamper a woman's sexuality can be her altered perception of being feminine, because she cannot move as well as before, has bladder problems and because of not being able to dress as femininely as before.

Foley and Sanders (1997:6) refer to McCabe's 1996 findings regarding sexual concerns that 79,6% of women suffering from MS have sexual problems. The London MS Society's 1997 symptom management survey found that 25% of the people suffering from MS said that sexual difficulties had a major impact on their quality of life (Foley 2000:3). The effects of MS and the physical changes occurring in women with MS can alter the way they perceive themselves as sexual beings (Foley & Sanders 1997:7). While reports of the incidence and prevalence of sexual dysfunction in MS vary considerably, the consensus is that most men and women with MS experience sexual changes (Halper & Holland 1997:110).

2.3.3 Social challenges to the impact of multiple sclerosis

Social challenges can result from physical, vocational and emotional changes. Women suffering from MS face longstanding substantial barriers, which may include the physical environment and the attitudes of society (Halper & Holland 1997:130). Women suffering from MS must be assisted to develop a wellness perspective. Desirable outcomes are a positive self-concept, having preclusive relationships, managing barriers and maintaining optimal health and physical functioning. Wellness is an approach to living, and means making a decision to be the best you can be (Balch 1999:1).

Society discriminates against people who are "different" or have disabilities. Friends and co-workers sometimes pull away from or are pushed away by the person suffering from MS

(Fraser et al 2002:94). Those newly diagnosed are often reluctant to tell others of the diagnosis for fear of their response (Halper & Holland 1997:155). Community people include health professionals, family, friends, colleagues and support groups that can have an impact on the person suffering from MS. Wellness is dependent on interaction with other people. People suffering from MS are dependent on those around them for support and to overcome social barriers and isolation.

2.4 SELF-CONCEPT

Thelan et al (1998:78) state that a person's perception of self, environment and relationships with others is derived through the senses of vision, hearing, touch and smell. Perception is the sensory experience interpreted with reference to its presumed external stimulus, object or event after information processing and interpretation of the sensory information have taken place (Colman 1999:85). The self-concept refers to people's view of themselves, an image that has developed over years (Smeltzer & Bare 2000:56). The self-concept comprises attitudes about oneself, perceptions of personal abilities, body image and identity and a general sense of worth. A person's sense of self-worth, self-confidence and self-roles in the family and society are all dimensions of the self-concept. Although the self-concept is relatively stable, it can be modified. It influences how a person reacts to and manages problems every day.

A person's self-concept can very easily be threatened by changes in physical function or appearance or either threats to health (Smeltzer & Bare 2000:56). Changes in a person's self-concept may involve any or all of the abovementioned interrelated components, depend on multiple factors, including value of self-worth, interpersonal relationships, past experiences and achievements, failure and health status. People's self-concept is what they believe about themselves (Thelan et al 1998:63-67). Body image is the mental picture people have of their body, is based on perceptions and includes their attitudes and feelings about their body in appearance, health, performance, ability and gender-related concepts (Thelan et al 1998:68). Stevenson and Haberman (1998:158) quote Freud's saying that individual well-being depends on a harmonious relationship among the various parts of the mind and between the person and the external social world in which they live.

As MS affects the health and performance ability of the woman's body it can cause body image disturbance. Self-esteem is the measurement of person's worth. Self-esteem develops as a part of the self-concept through the reflected appraisals of significant others (Thelan et al 1998:69). The response society makes to women's physical attributes is a product of cultural and sociological conditions. Females are judged by a standard of physical beauty, thus a woman has to equate her self-worth with her attractiveness (Thelan et al 1998:69).

MS can rob a person of perspective and diminish their world of possibility. This may lead to low self-esteem, which is a feeling of incompetence, decreased self-worth, powerlessness, helplessness and depression. Self-esteem develops from four factors:

- the amount of acceptance and love from significant others
- past successes and social position
- past reactions to elevating situations
- commitment to values and aspirations for oneself (Thelan et al 1998:70)

2.5 COPING RESPONSES

Every person responds differently to MS therefore coping responses also differ. When coming to terms with the diagnosis of MS, people must accept that MS has become a part of life.

2.5.1 Resilience

Rooney (2001:1235) defines resilience as to be able to recover quickly from setbacks. Searle (2000:401) describes resilience as "the ability to overcome handicaps and barriers ... resilience is a crucial factor in growth and development and the achievement of a constructive power base". Women suffering from MS have many handicaps and barriers to overcome. People have the ability to receive, encode and process data of emotional experiences that enhance their ability to comfort themselves when stressed (Crickmer 2000:1). This author also states further that to talk openly about and understand the range and severity of MS symptoms makes a person cope more effectively and enhances resilience.

People with disabilities have to be resilient and “bounce back” in the face of social and physical barriers, and be able to understand that health and wellness exist within the experience of disability (Oschwald & Powers 2001:3). Women suffering from MS-related disabilities should promote and maintain their health and wellness on a daily basis. A wellness lifestyle requires attention to the body, the mind, and the spirit. This requires understanding and accepting that everything a person does to their body, thinks with their mind and believes with their heart has an impact on their state of health. In order to maintain a wellness mind, the world must be seen in a positive light. By focusing on current talents and abilities and not dwelling on what used to be, living well with MS can be achieved (Balch 1999:8). To operate efficiently the body requires fitness and nutrition, therefore a person has to be committed to a fitness programme and eat a balanced diet. To maintain a wellness spirit, a person must adopt a positive attitude and strive to be happy. Resilience can be seen as a philosophy in which a person takes responsibility for the positive development of the mind, body and spirit (Balch 1999:8).

Resilience is an element of hope. Morgante (2000:3) states that the presence of hope in a person with MS can provide the energy necessary to promote health and wellness. Hope plays an important role in health and is indispensable to coping. Morgante (2000:4) refers to Kubler-Ross, who found that hope for a cure or remission supported people and helped them to cope during times of difficulty. In a family coping with MS, the person affected with MS cannot always bounce back from a stressful life event as before MS. The emotional response is more intense and longer lasting than family members can remember their loved one experiencing (Crickmer 2000:2). Some people find something positive in having MS, which can be seen as resilience.

Hattingh (2001:387) is of the opinion that resilience can be learned, which, in turn, increases the resources available to reconstruct life circumstances and resources. Learning resilience strengthens the positive, resourceful aspects of functioning and does not merely help individuals to deal with negative aspects (Stümpfer 1999:14). Resilience is an essential ingredient to adapt successfully to a changed life. Resilience is the ability to bounce back from defeat by resetting goals (*Nursing Update* 2004:51). According to Hattingh (2001:387),

resilience is a dynamic characteristic and a resilient person is likely to experience change, stress adversity or life situations as challenges that can be dealt with rather than a crisis. This view is supported by Stümpfer (1999:20).

2.5.2 Coping resources

Women's health depends on their ability to cope and the support of resources they can utilise. These resources can be internal, such as self-esteem, or external, such as environment. These internal and external resources are interchangeable. There are many coping strategies, but a person coping well has a strong sense of coherence (Antonovsky 1993:57). According to the Biogen Information Series (1999a:32-38), ways of coping include the following:

- Look for opportunities to continue participation in society.
- Establish contact with a group of people (for example, the local MS Society) in the same situation, with whom experiences can be exchanged.
- Use periods when feeling fit to do pleasant things.
- Make plans that are not beyond reach.
- Think positively; focus on the positive aspects of life.
- Regard MS as a new start, not as the end of a life that was better.
- Look at alternatives: It is not always possible to get of the symptoms of MS, but a lot can be done towards making symptoms less of an inconvenience.
- Face the future together; MS changes the lives of family and friends. Communicate with loved ones, people are brought together closer because they learn to confront their problems together.

2.6 CONCLUSION

This chapter discussed MS and people's reaction to the impact of MS on their lives. The emotional aspects were described, as well as the self-concept in terms of development and how it is influenced.

Chapter 3 covers the research methodology of the study.

CHAPTER 3

Research methodology and design

3.1 INTRODUCTION

This chapter discusses the methodology used in this study, including the research design, technique and instrument, sampling and data collection and analysis. The ethical considerations are also discussed.

3.2 RESEARCH DESIGN

Polit, Beck and Hungler (2001:167) define the research design as “an overall plan for obtaining answers to the questions being studied, and handling difficulties encountered during the research”. In this study the main focus was on the perceptions of women with MS. Therefore the research approach in this study was qualitative.

3.2.1 Selected design

This study was based on a non-experimental, qualitative research design strategy, which was contextual, exploratory, descriptive, and non-experimental in nature (see sections 3.4.2.1, 3.4.2.2, 3.4.2.3 and 3.4.2.4 for definitions of terms and application).

3.2.2 Rationale for choice of design

The rationale for using a qualitative phenomenological study was to describe and create an understanding of the perceptions of women with MS living in Johannesburg and the East Rand. The phenomenological approach was the most appropriate to capture the perceptions of woman suffering from MS. The context-bound study was descriptive and explorative with the aim of gaining qualitative insight into the respondents' perception of the phenomenon. Limited literature was available to describe the phenomenon under study.

3.2.3 Qualitative research

A qualitative research approach attempts to capture human experience. Meaning in human experience is derived from an understanding of individuals in their social environments (Burns & Grove 1997:28; De Poy & Gitlin 1998:27). Holloway and Wheeler (2001:3) refer to qualitative research as a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live. Researchers use qualitative approaches to explore the behaviour, perspectives, feelings and experiences of people, and emphasize understanding these elements as they are lived through the collection and analysis of narrative data (Holloway & Wheeler 2001:3; Langford 2001:142; Polit et al 2001:26).

Qualitative researchers often conduct a study to examine phenomena about which little is known (Polit & Hungler 1997:18). Qualitative research adopts a person-centred and holistic perspective to understand the human experience and the meaning people attach to everyday life (Brink 1999:119; De Vos 2000:241-246). The basis of qualitative research lies in the interpretive approach to social reality and the description of people's lived experiences (Holloway & Wheeler 2001:3).

Qualitative researchers hold that people's experiences are context bound and cannot be free from time and location. Complete objectivity is impossible and qualitative methodology is not completely precise, because people do not always act logically or predictably (Holloway & Wheeler 2001:8). Phenomenologists believe that human meaning can be understood only through experience (De Poy & Gitlin 1998:27).

Phenomenology uses the lived experiences of people to better understand the social, cultural, political and historical context in which those experiences occur (Polit et al 2001:212; De Vos 2000:80). The purpose of the phenomenological approach is to illuminate the specific phenomenon and to gather information and perceptions through inductive qualitative methods, such as interviews. Phenomenology is concerned with the study of the experience from the individual's perspective. Bracketing and taken-for-granted assumptions are usual ways of perceiving (Holloway & Wheeler 2001:180; Langford 2001:139; Lester 1999:1).

During the enquiry, the researcher used bracketing and intuiting to set aside preconceived beliefs and to develop awareness of the lived experiences (Brink 1999:120; Burns & Grove 1997:532). Bracketing is a process of holding in abeyance preconceived beliefs and opinions about the phenomenon under study. The researcher brackets out any presuppositions in an effort to confront the data in pure form. Intuiting occurs when the researcher remains open to the meanings attributed to the phenomenon by those who experience it (Polit et al 2001:215). Bracketing and intuiting are discussed in more detail in sections 3.3.5 and 3.3.6.

Phenomenological research seeks to describe rather than explain and starts from a perspective free from hypothesis or preconceptions (Lester 1999:1). Qualitative research aims to find out about people and approaches participants to collect a rich, in-depth picture of their perceptions and experiences of the phenomenon (Holloway & Wheeler 2001:11; Polit & Hungler 1997:20).

Qualitative research is concerned with the emic perspective to explore the perceptions of the people involved. The researcher tries to examine the experience from the participants' point of view and to interpret their worlds therefore qualitative research collects data in a real-world setting (Polit et al 2001:210). Immersion to become involved with the participants is necessary to develop a close relationship in order to understand the participants' thoughts and feelings in the natural setting. Immersion helps to provide thick descriptions from the narrative data collected to interpret, explore and come to an understanding of their perceptions.

The research relationship is important to gain access to the participants' true perspectives, therefore the researcher has to adopt a non-judgemental attitude to allow a trusting relationship to develop. The relationship between researcher and participant is a central component of the process and demands a reflective stance on the research (Chenail 2002:3; Holloway & Wheeler 2001:10-14). Immersion makes the project mutually beneficial for both participant and researcher as the interview provides opportunity for reflection (Campbell 1998:3). The researcher needs to think through critically and use reflective thought to explore personal feelings (Burns & Grove 1997:531). Interpersonal and basic interviewing skills are used to build a trusting relationship and to acquire knowledge (Burns & Grove 1997:530; Holloway & Wheeler 2001:14).

3.2.4 Phases of the research process

There were three phases in the research. The phases are not discrete, but overlap to some degree and are interrelated. Each subsequent phase could not be implemented without the previous phase. During each phase the researcher utilised reflexivity, bracketing and intuiting as well as trustworthiness to prevent bias in the study.

The first phase involved formulating the research questions and objectives together with the purpose of the study. The researcher conducted a literature review to become familiar with concepts and literature about the phenomenon. The site was identified as Johannesburg and the East Rand due to geographical and financial constraints.

The second phase consisted of planning the research design and the study. The researcher chose interviewing as the data-collection instrument. The researcher practised tape-recording skills and interviewed persons who met the criteria but would not be part of the population selected for the study in order to practise interpersonal and interviewing skills. A non-probability sampling design and purposive sampling were selected (see section 3.4.2.4).

The third phase involved data collection, analysis and interpretation. Data collection was done by means of semi-structured interviews and field notes taken during and after the interviews. A focus group was held and field notes taken. The interviews and the focus group included tape-recordings and transcribing and typing of verbatim data. Data analysis started immediately after the first interview. After interpreting the data, the researcher reviewed the literature again and studied the findings in relation to existing literature. Figure 3.1 below illustrates the research phases.

Figure 3.1

Phases of the research process

Teken nog

3.3 CONCEPTUAL PHASE

The conceptual phase included the researcher's thoughts and questions about the phenomenon under study as well as the literature review.

3.3.1 Background to the problem

After a close family member of the researcher was diagnosed with MS at the end of 1998, the researcher began to actively seek information about the condition. During this period the researcher continuously had conversations with the diagnosed family member on concerns about changes, feelings, coping mechanisms and perceptions about the impact of the condition. Although the researcher had not commenced the formal study, the situation gave her the advantage of personal insight, feelings and perspectives to understand the experience and perceptions of the individual diagnosed with MS. The researcher's involvement during this period provided insight into the natural setting of a person suffering from MS (Polit et al 2001:15, 466). People differ, therefore settings will differ. The researcher knows the basic setting intimately (Holloway & Wheeler 2001:39). The setting for data collection was in the participants' homes and was based on the convenience of the persons being studied (Langford 2001:150). The experience of being part of a family with MS made the researcher interested in the phenomenon and aware of the need to investigate the perceptions of women suffering from MS, in the context in which it took place. In view of the limitations of studies done in South Africa, the researcher decided to conduct a qualitative study (see annexure E for the personal reflection of the researcher's experience).

3.3.2 Research questions and objectives

The researcher's exposure to the above situation led to the research questions on the phenomenon under investigation:

- What are the lived experiences of women suffering from MS living in Johannesburg and the East Rand?
- What is the impact of MS on the individual?

- What are the emotional, physical, and social challenges and barriers women suffering from MS face?
- How can resilience be enhanced to affect women suffering from MS positively?
- How does MS affect family life?

The aims of the study were to

- explore and describe the perceptions of women suffering from MS in Johannesburg and the East Rand, South Africa
- explore and describe the impact of MS on the participants
- identify and explore the emotional, physical and social challenges and barriers faced by women suffering from MS
- explore women suffering from MS's resilience and provide guidelines to enhance resilience to cope with their changed lives
- determine how women suffering from MS perceive the effect of MS on family life.

3.3.3 Literature review

Burns and Grove (1997:118), De Poy and Gitlin (1998:51), Holloway and Wheeler (2001:31) and Polit et al (2001:43) point out that the aspect of when the literature study should be conducted is related to the purpose of the study. Burns and Grove (1997:118) cite Oiler (1986) that in a phenomenological study, the literature should be reviewed after data collection and analysis so that the information in the literature will not influence the researcher's objectivity.

The researcher's description of a real-world phenomenon should include only what is seen in the situation and not what is read in the literature (Burns & Grove 1997:119). Polit et al (2001:43) state that the researcher should conduct at least a cursory up-front literature review to obtain guidance. In this study, the researcher conducted a literature review before submitting the proposal, which was a prerequisite prior to the commencement of the study.

The object was to obtain background knowledge about the phenomenon under study. Thereafter, a more detailed review was undertaken to orientate the researcher on the condition (MS), the prevalence, etiology, causes and treatment of MS and the impact it has on the individual, family, and social roles. The data obtained from the literature review was used to construct and adopt the conceptual phase, to obtain guidance and to familiarise the researcher with concepts and literature on the topic. The literature study was ongoing throughout the research. After the research findings were analysed and interpreted, the researcher reviewed the literature again to compare and contrast findings.

3.3.4 Reflexivity

Abbott and Sapsford (1997:1) define reflexivity as "a process of constantly reflecting on the content and process of the research". Klopper (1998a:14) describes reflection as "a systematic, ordered process of intellectual and affective activities in which the researcher becomes involved in order to exploit their experiences in the search for new meaning and the evaluation of feelings, thinking and acting in a specific context". Because the researcher is the main research tool, which hears, feels, sees and interprets the participants' words and non-verbal cues, it may create bias and subjectivity. Researchers must therefore purposely engage in a reflective process in which they examine their own perspectives and personal biases to increase objectivity (De Poy & Gitlin 1998:284).

Reflexivity means that researchers critically reflect on their own preconceptions and monitor their relationships with the participants and their own reactions to participants' accounts and actions (Holloway & Wheeler 2001:263). The reflective skills necessary for reflection and the development of a new perspective are description, critical analysis and synthesis. Description implies the ability to recognise and accurately remember prominent events and key characteristics of an experience (Klopper 1998a:37). The components of a situation and existing knowledge must be critically analysed. Synthesis is the integration of new knowledge with previous knowledge (Klopper 1998b:37).

Klopper (1998a:38) states that reflexivity is necessary to

- help the researcher to realise that in a particular situation, the knowledge that is applied is not sufficient to explain what is happening
- analyse data and find the way through the mass of data
- develop a new perspective and show that others should believe in the researcher's interpretations

Reflexivity leads to bracketing, which is used to help the researcher avoid misinterpreting the phenomenon as experienced by the individuals (Burns & Grove 1997:532).

3.3.5 Bracketing

Bracketing is the process of identifying and setting aside any preconceived beliefs and opinions one might have about a phenomenon under investigation. The researcher must identify what is expected to be discovered and then deliberately set aside this idea (Brink 1999:120; De Vos 2000:337; Polit et al 2001:215). Qualitative researchers use bracketing to improve rigour in the research. The researcher brackets out the world and any presuppositions in an effort to confront the data in pure form (Brink 1999:120; Polit & Hungler 1997:204; Polit et al 2001:215). This procedure facilitates seeing all aspects of the phenomenon and the formation of new constructs (De Vos 2000:337). Holloway and Wheeler (2001:11) state that researchers must be open minded though they cannot help having some hunches about what they may find, especially if they are familiar with the setting.

Seamon (2000:12) cites Spielberg (1982:682-687) who describes phenomenological reduction (bracketing) as "an effort through which the phenomenologist works for an openness in regard to the phenomenon under study. The researcher must be careful and guard against any influences of prior to the raw data collection." By bracketing, the researcher questioned her own assumptions and then set them aside in order to act like a stranger to the setting and the phenomenon (Holloway & Wheeler 2001:12). The researcher applied bracketing not to keep what she knew about the phenomenon in abeyance, but to measure all data by deliberately being conscious of it. The reason for bracketing was to reduce bias, and to focus on the participants' description of their

perceptions of MS. Two aspects necessitated the bracketing of any preconceived ideas the researcher had, namely the literature review prior to data collection and the researcher's being part of a family in which a woman is suffering from MS.

Bracketing was achieved through semi-structured interviews with two women suffering from MS, an interview with a professional nurse (to practise interviewing and interpersonal skills), and a narrative description of the researcher's experience. The interviews were seen as practical experience in approaching participants with an open mind and to discover individual experiences and perceptions of the phenomenon.

The pre-exercise helped the researcher with bracketing when approaching the participants in the formal study and to see them as unique individuals with their own perceptions. Burns and Grove (1997:532) state that during bracketing it is necessary to identify beliefs, assumptions and preconceptions about the research topic. The researcher wrote these down at the beginning of the study for self-reflection and external review. These procedures are intended to facilitate openness and new insights. Therefore the researcher wrote a narrative description about her personal experience with the family member suffering from MS. This was done to express her experiences and perceptions and to set them aside to help maintain an open and objective approach when interviewing the participants and analysing the findings (see annexure E).

3.3.6 Intuiting

Seamon (2000:12) describes phenomenological intuiting as "an effort through which the researcher works for openness in regard to the phenomenon under study". Intuiting occurs when the researcher tries to develop an awareness of or openness to the lived experiences of participants and the meanings they attribute to phenomena without forcing prior expectations in the process (Brink 1999:120; Polit et al 2001:215). Intuiting is the process of actually looking at the phenomenon and requires discipline, patience, effort, concentration and complete absorption (De Vos 2000:337; Seamon 2000:13). Intuiting enabled the researcher to keep an open mind, gain new insights into participants' perceptions and not to be biased.

3.4 DESIGN AND PLANNING PHASE

This phase involves how the research is to be conducted, the methodology to be used to answer the research questions and the techniques for data collection (De Vos 2000:123; Polit et al 2001:40). The research and sampling designs were made to ensure rigour, trust and trustworthiness in the study.

3.4.1 Research design

The research design was qualitative (see section 3.2) for the purpose of identifying the essence of lived experiences based on the participants' perceptions (De Poy & Gitlin 1998:273). The research strategy was contextual as the study was context-bound and a contextual explorative-descriptive, qualitative design was chosen for the purpose of providing answers to the problem, research questions and objectives (Brink 1999:11).

3.4.2 Definition of terms

The following terms are used in the research design of this study.

(1) Context

The context is important in qualitative research. Context refers to the space and environment in which a phenomenon takes place. Researchers must be sensitive to the context of the research and immerse themselves in the setting and situation. The context of participants' lives affects their perceptions. Researchers have to take into account the total context of people's lives because their experiences are essentially context bound (Holloway & Wheeler 2001:8-11). Research is therefore context specific and the knowledge derived is embedded in that context and does not extend beyond it (De Poy & Gitlin 1998:100). The researcher should understand the participants' context regarding time, space, locality, culture and history. The events and actions are studied as they occur in everyday, real-life settings. The researcher who understands the context can locate the participants' perceptions and grasp the meanings they communicate (Holloway & Wheeler 2001:11). The data that emerges thus comes not only from the participant's description but also

from the context out of which the description arose (Seamon 2000:29). Data is systematically collected and analysed within a specific context (De Vos 2000:80).

(2) Descriptive

The design wants to obtain accurate information through interviews and a focus group interview, and to describe the phenomenon for the purpose of providing new information about it (Brink 1999:11). The descriptive element in the design offers a complete description of the phenomenon within a given population, without attempting to establish causality or manipulation of the variables or the phenomenon (Polit et al 2001:19). The focus of descriptive phenomenology is what people experience and how they interpret those experiences to form perceptions (Polit et al 2001:215). The purpose of the description is to observe and portray the characteristics of individuals and aspects of a situation or group (Burns & Grove 1997:30; Polit et al 2001:180).

Phenomenological research is an inductive descriptive approach to understand the response of the whole person and aims to describe an experience as it is lived by the person. Descriptive studies are a means of discovering new meanings and describing what exists, and are conducted when little is known about a phenomenon (Burns & Grove 1997:30-31).

In this study, the researcher obtained information through personal experience prior to the official research project. Semi-structured individual interviews and information from a focus group about the perceptions of women suffering from MS were utilised to describe factually their perceptions of the impact of MS. This was done to provide a description of and insight into their experiences and perceptions in context (see section 3.4.2.1). The study focused on women diagnosed with MS and wished to describe what they experience, and their perceptions of the impact of MS on their and their families' lives.

(3) Exploratory

Exploratory research begins with the phenomenon of interest (in this case, MS) with the object of exploring the dimensions of the phenomenon (here, the experiences of women with MS) about which little is known. It provides more insight into the nature of the phenomenon and identifies the

nature of and factors related to the phenomenon (Brink 1999:11; Polit et al 2001:19). Exploratory studies are not intended for generalisation to large populations. They are designed to increase the knowledge of the field of study (Burns & Grove 1997:302). Researchers adopt a qualitative approach to explore people's behaviour, perspectives and experiences. The researcher must be open minded and flexible in exploring sources of information. The experiences of women suffering from MS in South Africa is a relatively new phenomenon that is emerging, therefore the researcher wished to explore how they experience the condition in their daily lives. These experiences have not previously been qualitatively described in context (see section 3.4.2.1). The researcher explored the literature throughout the study to obtain information on the phenomenon. The researcher approached the study with an open mind, without preconceived ideas and with the object of adding to what is known about MS and providing new data on the phenomenon in context.

(4) Non-experimental

Polit and Hungler (1999:155) state that in non-experimental research the researcher observes the phenomenon as it occurs naturally without intervening in any way. Non-experimental research is suitable for the study of human beings for three reasons. First, human characteristics are inherently not subject to experimental manipulation. In this study, the experiences and perceptions of women suffering from MS cannot be manipulated thus the approach is appropriate. Secondly, due to ethical considerations, the manipulation of human variables is not morally acceptable because of potential physical and mental harm to participants. Thirdly, research constraints, such as time, type of participant and finances, make a non-experimental approach more feasible.

In this study the researcher required that the participants verbally state their experiences, therefore the research questions were not suitable for an experimental design and none of the participants was subjected to any testing at any time.

3.4.3 Data-collection techniques

The researcher was the primary instrument or main research tool during the study because the data from the participants were words in the context of the research problem (Holloway & Wheeler

2001:8). This position maintains that the only way to know about the lived experiences of participants is to become intimately involved and familiar with the life situations of those who experience them. In phenomenological research, the researcher develops a rapport with participants and engages in active listening to understand their perceptions and is therefore the primary data-gathering instrument (De Poy & Gitlin 1998:213). The researcher was thus the primary data-gathering instrument because a non-human instrument would not answer the realities of the experiences and perceptions of participants.

Data was collected by means of semi-structured interviews and a focus group (see sections 3.5.1 and 3.5.2). The researcher utilised both techniques to obtain fresh and direct data from the participants, allowing them to speak for themselves and verbally explain their perceptions of the phenomenon. Dialogue enabled the clarification of unclear questions. The interview was initiated by an unstructured, open-ended question followed by probing questions, depending on the participant's verbal response (see section 3.5.2). The two techniques increased the credibility of the findings, prevented researcher bias, and facilitated approaching the phenomenon without preconceptions (Collins et al 2000:181).

The interview aide de memoir comprised two sections, namely for the collection of demographic and of qualitative data on the perceptions of the women suffering from MS (see annexure F). The biographical data included age, marital status, type of MS, type of work, and nationality.

3.4.4 Pre-exercise

Holloway and Wheeler (2001:80) point out that pilot studies are not usually used in qualitative studies, but novice researchers could conduct interviews as a pre-exercise, to get used to the type of data collection. A pre-exercise was done to orientate the researcher and gain an insight into the phenomenon. A pre-exercise ensures that errors can be rectified at little cost.

The researcher conducted the pre-exercise with three individuals: a professional nurse and two women with similar characteristics as the target group. The professional nurse (a colleague of the researcher who had just completed a course in interviewing and interpersonal skills) was interviewed in order to enhance the researcher's interviewing and interpersonal skills. The

interview was conducted at the nurse's workplace and was tape-recorded to ensure correct usage of the tape-recorder. Attention was also given to body language and non-verbal responses as well as the manner of asking questions. This enhanced the researcher's confidence. Two women with similar characteristics to those of the target group were then interviewed as part of the pre-exercise (De Vos 2000:179). The first was a family friend of the researcher's who suffers from MS. The interview took place at the woman's home in a neighbouring town. The interview revealed possible restraints that might emerge when interviewing participants at home. The questions were tested for clarity and comprehensibility. The second was a woman suffering from MS, who visits the researcher's workplace as a regular patient. The interview was conducted at the woman's home and again the relevancy and clarity of questions could be tested as well as the length of time it took to conduct the interview.

The pre-exercise increased the researcher's experience of interviewing and interpersonal skills, familiarised her with qualitative data collection and analysis and gave her the opportunity to

- practise and concentrate on open-ended questions
- probe relevant responses from informants
- approach participants with sensitivity and an open mind
- identify shortcomings in the questions
- build in extra precautions to prevent errors in the interviews
- increase the credibility and trustworthiness of the study
- ensure bracketing of any preconceived ideas
- transcribe and analyse data, which increased her analysis skills
- ensure reflexivity, bracketing and intuiting throughout the study

3.4.5 Sampling design

Sampling is the process of selecting a portion of the population representative of the population being studied (Burns & Grove 1997:41; Polit et al 2001:234). A sample is a subset of the population that is selected to represent the population (Brink 1999:214; Polit et al 2001:234). The researcher chose a non-probability systematic sampling design with a purposive sampling technique based on the information needs of the study as it was convenient and participants were

included in the sample according to the researcher's knowledge of the population (Polit et al 2001:247, 254). The design was also chosen to seek participants with particular characteristics in order to better understand the phenomenon being studied (Burns & Grove 1997:306).

The researcher approached individuals who met the criteria because of the need for a sample of experts. Holloway and Wheeler (2001:122) cite Patton (1990) who states that purposeful sampling provides information for an in-depth study with information-rich cases. The researcher selected participants who could contribute to the study and answer the research questions. A potential problem with this method is sampling bias (Polit et al 2001:253). The rationale for this method was not to generalise the findings to all women in South Africa, because it was contextually bound.

3.4.5.1 Criteria for the selection of informants

Morse (1991) (cited in Holloway & Wheeler 2001:122) describes reliable participants as people who are willing and able to critically examine the experience and their response to the situation, share their experiences or perceptions with the researcher, and are also knowledgeable and reflective. The women in this study explained their social reality and perceptions (Holloway & Wheeler 2001:219). In order to participate in the study, the women had to meet three criteria, namely they had to be diagnosed with MS, had to live in Johannesburg or the East Rand, and had to be fluent in English or Afrikaans (ie, able to read, write and communicate in either language).

The sample was homogeneous in gender and condition (MS). The sample was also heterogeneous regarding home language, different cultures and stage and type of MS (Holloway & Wheeler 2001:1230).

3.4.5.2 Population

A population is the entire group of persons of interest to the researcher who meet the criteria the researcher is interested in studying (Brink 1999:132; De Poy & Gitlin 1998:163; Polit et al 2001:467). According to Polit et al (2001:234), the accessible population comprises those cases that meet the criteria and are easily accessible for the researcher. In this study, the population was women living with MS in Johannesburg and the East Rand, South Africa.

3.4.5.3 Sample

The entities that make up the samples and populations are elements. In nursing research, these elements are usually people (Polit et al 2001:234). In qualitative research, there is no need to determine the number of participants to be interviewed because the goal is not to generalise findings but the sample must be representative of the population. If the sample size is small, there is reason to suspect bias (Polit et al 2001:249). Qualitative research requires that the data to be collected must be rich in description and therefore the sample will be redefined as insight is gained (De Vos 2000:254). The required sample size will depend on the collection of data and will be made on a systematic basis and on rational grounds although Patton (1990) (cited in Holloway & Wheeler 2001:128) points out that there are no guidelines for sample size in qualitative research.

In the focus group, the sample was closely linked to the research topic. Holloway and Wheeler (2001:112) refer to Morgan (1998) who maintains that a small sample is better for complex topics. The principle of saturation applied when repetition and confirmation of previous data occurred and there was no need to increase the number of participants (Polit et al 2001:44). Data saturation occurs when redundancy is achieved, which can be done with a small sample if each participant's information is of sufficient depth. Phenomenological studies are based on samples of ten or fewer participants (Polit et al 2001:248).

3.4.5.4 Sample size

The researcher approached ten women from a list supplied by the Multiple Sclerosis Society to take part in the study. The women all suffered from MS and were different ages and in different stages of the disease. The women were contacted telephonically to obtain consent for the interviews and an appointment was made to suit each participant. Of the possible participants, one declined to participate and one was on an extended overseas holiday. The participants who gave consent met the selection criteria.

The participants agreed and gave consent to participate in the study (see section 3.8). An interview was conducted with each of the participants, which was analysed and transcribed. Follow-up interviews were conducted with some of the participants to clarify certain issues. The data was

analysed and categorised. Subsequent interviews followed until saturation and redundancy occurred. Table 3.1 below represents the biographical data and distribution of participants interviewed.

Table 3.1 Participants' biographical data

Total of participating participants until saturation	8
Participant mortality (refused to take part)	2
English-speaking participants	4
Afrikaans-speaking participants	4
Age of participants	27-57 (average = 42)

Of the eight participants who consented to be interviewed, four chose to be interviewed in English and four in Afrikaans. The ages of the participants varied between 27 and 57 years.

In this phase the trustworthiness and ethical considerations were taken into account (see sections 3.7 and 3.8).

3.6 EMPIRICAL PHASE

The empirical phase is the actual collection of the research data and the preparation of the collected data for analysis (Brink 1999:60; Polit et al 2001:41). The research problem was derived from the empirical world and the findings generated through research are used within the empirical world (Burns & Grove 1997:6).

Qualitative researchers use communication as a means of gathering data, therefore qualitative data is in the form of words and is analysed in terms of individual responses and descriptive summaries (Burns & Grove 1997:29). Words are part of language that can be studied as communication. Communication encompasses the entire sphere of human interaction and behaviour. All behaviour, whether verbal or nonverbal, is communication (Pera & Van Tonder 1997:195; Searle 2000:254). In order to communicate effectively, people should be aware of racial, cultural and social factors, which may influence people's behaviour (Pera & Van Tonder 1997:195). In this study, communication provided information and helped the researcher to understand the participants' perspective and draw conclusions through interpretation.

The data collection was reflective to allow the participants to express their perceptions. The collection of raw data was done by means of interviews and a focus group.

3.6.1 Interviews and field notes

The researcher relied on interviews as the main data-collection technique in order to obtain an inside view of the phenomenon. Burgess (1984) (cited in Holloway & Wheeler 2001:79) describes a qualitative interview as "conversation with a purpose". The purpose of interviews is to discover participants' feelings, thoughts and perceptions. Marshall and Rossman (1999) (cited in Holloway & Wheeler 2001:80) state that the interview should focus on past, present and, in particular, the essential experience of participants. In this study, each interview was different, although distinct patterns were common.

Semi-structured open-ended interviews were the most appropriate data-collection strategy for this study. The questions focused on the areas to be covered. The sequencing of questions was not the same for every participant as it depended on the process of the interview and each one's responses. The aid de memoir ensured that similar types of data were collected (Holloway & Wheeler 2001:82). The semi-structured open-ended questions allowed the participants to reflectively explain their perceptions. The interviews were conducted face to face in the comfortable environment of the participants' own homes. This restricted the researcher's ability to control the environment but it was the natural setting for the participants (Polit et al 2001:189). It was also conducted in their homes because of some participants' mobility problems. As the perceptions of women with MS were being investigated, the researcher had to keep in mind that participants' fatigue could be a problem. The interviews were therefore conducted at a time that was convenient and comfortable for the participants.

The researcher considered a duration of one to one and a half hours as suitable because the reflective character of the interviews could tire participants (Holloway & Wheeler 2001:86). Each participant was interviewed individually, after an appointment was made that suited them. Before conducting the interview, the researcher

- Thanked the participant for her time and willingness to be part of the study.

- Reminded the participant of consent and agreement (see annexure B).
- Explained that the interview was semi-structured and that probing questions would derive from the information the participant described.
- Requested permission to record the interview (Holloway & Wheeler 2001:86).
- Explained that two tape-recorders would be used for safety reasons; if one did not record, the other one would.
- Assured the participant that all information would be kept confidential.
- Informed the participant that a follow-up interview might be necessary to clarify information.

Two tape-recorders were used during the in-depth interviews. They were tested before the interviews and placed so that they did not distract the participants' attention (De Poy & Gitlin 1998:227; Holloway & Wheeler 2001:87). The tapes were marked properly for each individual interview with dates and pseudonyms, for example, 2/2/04 A1. This represented the date of the interview, the number of the tape, and the number of the participant being interviewed. During the interviews, the researcher showed sensitivity to the participant's uniqueness and entered her world with compassion (Holloway & Wheeler 2001:11). Travelbee (1966) cited in Searle (2000:259) maintains that the researcher is able to establish rapport, because she possesses the necessary knowledge and skills required to assist the participants and because she is able to perceive, respond to and appreciate the uniqueness of the human being who is a participant. In this study, the researcher established a relationship with the participants by being non-judgemental, a good listener, friendly, open, honest and sincere, flexible, empathetic and understanding (De Vos 2000:308; Holloway & Wheeler 2001:14).

Before and between each interview the researcher bracketed any preconceived ideas of her own experiences and perceptions.

The interviews started with a broad open-ended question, "How does MS influence your life?" This involved a reflective description and thinking over the experiences and perceptions. Then the participant was allowed to talk freely. During the interview, the researcher observed, listened and questioned aspects that were needed for more information. Responsive listening and non-verbal responses also formed part of the communication during the interviews. Responsive listening

refers to the process of listening and responding to both the obvious and underlying themes and feeling of the other person's communication.

Real listening consists of understanding the meaning of the message, remembering to store information for retrieval later, learning from the communication and situations, and using non-verbal communication to improve the interview process.

To be able to truly listen requires empathy, respect, unconditional acceptance, genuineness, concreteness and congruency (Greeff 1998:155). Non-verbal responses are those responses used by researchers to make participants feel that they really care and are attitude. One should face the person, have an open body posture, lean slightly forward, make eye contact and seem relatively relaxed (Greeff 1998:156). Pienaar and Spoelstra (1999:74) cite Nieuweijer's (1988) ways to enhance communication with frequent gazes, eye contact and shorter spatial distance in seating arrangements. In this study, the researcher observed participants' on-verbal cues, including facial expressions, personal appearance and tone of voice (Greeff 1998:154).

The researcher used probing questions and prompts in an attempt to obtain more information and reduce anxiety. The purpose of probes was to obtain elaboration and meaning (Holloway & Wheeler 2001:84). The researcher made use of Patton's (1990) types of questions (cited in Holloway & Wheeler 2001:83) during the interviews:

- Experience question: What adjustments did you experience in your family life after being diagnosed?
- Feeling question: How did you feel when you were diagnosed?
- Knowledge question: What would you say about the support you received from the MS Society?
- Grand tour question: Tell me, what did you experience as the greatest change since being diagnosed?
- Mini tour questions: Can you describe what happens when you realise you cannot do your own cooking anymore?

After the interview the researcher asked the participants whether a second interview could be conducted for more information, if necessary. The researcher also explained that after data analysis she would consult them to verify whether it was a true reflection of their experiences (Holloway & Wheeler 2001:257). During the interviews, the researcher took notes on any probing questions and non-verbal reactions of the participants. Non-verbal reactions were written down to give dense descriptions of each interview before transcriptions and analysis.

3.6.2 Focus group

A focus group is an interview with a group of people with common experiences, to elicit ideas, thoughts and perceptions (Holloway & Wheeler 2001:110; Polit et.al 2001:265). The focus group interview was semi-structured and guided by the researcher (Collins et al 2000:177). The focus group was held to obtain a variety of opinions on the impact of MS on the women suffering from MS. The interaction between the participants and the researcher helped her to discover how the women thought and felt about particular issues in MS. According to Robinson (1999) (cited in Holloway & Wheeler 2001:111), focus group interviews are set up to obtain accurate data on a limited range of specific issues within a social context where people consider their own views in relation to others. Before the interview, the researcher thanked the participants for their time and willingness and reminded them that the interview would be tape-recorded. Merton and King (1990) (cited in Holloway & Wheeler 2001:114) suggest a spatial arrangement of a circle. The spatial seating arrangement tends to establish a more relaxed and informal climate that is normally conducive to sharing information (Spoelstra & Pienaar 1999:56). In this focus group, the group members decided it would be better to sit around the table which was also round as refreshments were served during the discussion, and most of the participants had difficulty in moving. The windows were open to ensure adequate ventilation.

The interview started with a broad statement and then the group was free to discuss it. The group interview had a clear agenda to prevent the discussion becoming vague (Holloway & Wheeler 2001:115). Five questions were carefully developed, as time was a restriction since the duration of the interview was one to one and a half hours (McNamara 1999). The researcher took notes during the discussion and used the same interpersonal skills as in the face-to-face interviews. Participants who seemed shy were also asked direct questions as to allow all members to take part. Nine

participants (excluding the researcher) attended the focus group. Table 3.2 below represents the focus group participants' biographical data.

Table 3.2 Biographical data of the focus group

Total number of persons attending focus group	9
Total number of persons with MS	4
Women with MS	4
Social worker	1
Support persons of those with MS	4
Age of MS sufferers in focus group	50-66 (average = 58)

Four women suffering from MS took part in the focus group and all of them had different types of MS and were in different stages of progression. One was in a wheelchair, the others could still walk with mobility aids and one had speech difficulty. The support persons in the focus group were all family or friends of the participants. The social worker was the support group's social worker and had been invited as she was a person working with persons suffering from MS.

3.7 DATA ANALYSIS PHASE

Data analysis is to organize, provide structure and elicit meaning. The analysis of qualitative data is an active and interactive process (Polit et al 2001:383). Data analysis started after the first interview.

3.7.1 The researcher's role in the data analysis

The researcher used reflexivity, bracketing and intuiting (see sections 3.3.4, 3.3.5 and 3.3.6) to exclude all preconceptions of the phenomenon. Analysis occurs immediately the researcher enters the field and continues throughout the researcher's engagement in the field (De Poy & Gitlin 1998:274). Morse and Field (1995) (cited in Polit et al 2001:383) identify the intellectual processes of comprehending, synthesising and theorising in qualitative analysis.

- *Comprehending.* The researcher wants to learn about what is going on. When comprehension is achieved the researcher is able to prepare a description of the

phenomenon under study, and no new data add much to the description, thus saturation occurs.

- *Synthesising*. This involves sifting data. At the end of synthesis some general statements can be made.
- *Theorising*. This is the systematic sorting of data. Alternative explanations are developed and fitted against data, until the most parsimonious explanation is obtained.

3.7.2 Data analysis

The data analysis phase comprised labelling the tapes, transcribing the interviews and sorting the notes, organising the data collected, coding and categorising, and describing a phenomenon (Holloway & Wheeler 2001:235).

3.7.2.1 *Transcribing the interviews*

After the interviews the researcher played the tapes and listened to the participants' tone of voice and responses. Then the researcher read the notes and transcribed the interview verbatim in order to analyse the raw data and become aware of the important issues in the data (Holloway & Wheeler 2001:236). The Afrikaans interviews were first transcribed and then translated into English for the purpose of data analysis by the QSR NU*DIST Power Point 4 computer program. After the transcription, the tapes were replayed to ensure transcription accuracy. The notes were written up in full to give a clear description of the observations.

3.7.2.2 *Organising data*

Through organisation and management, the researcher brings structure and order to the mass of data. All tapes, notes and transcriptions were cross-checked, labelled and stored for later retrieval. All the data were read through over and over again to look at themes and emotions. Reflective and close reading can lead to possible alternative meanings and bring out discrepancies (Holloway & Wheeler 2001:238).

3.7.2.3 Coding and categorising

Codes are labels given to sections of data. Coding proceeds towards the development of preliminary categories, which become the tools used to sort and classify subsequent information (De Poy & Gitlin 1998:276; Holloway & Wheeler 2001:239). During categorising the data is scrutinised for similarities and differences (De Poy & Gitlin 1998:276). The QSR NU*DIST Power Point 4 computer program was used for categorising the data (Mouton 2001:108). In the study, units were extracted from the interviews and focus group. Similar units were clustered together into categories. All the categories were then organised and the themes emerged from these categories.

3.8 TRUSTWORTHINESS

Trustworthiness in qualitative research means methodological soundness and adequacy. If the research is to have validity, its readers will have learned something as well as grasped the essence of the phenomenon under study (Holloway & Wheeler 2001:245). In phenomenology, the primary focus is to obtain an in-depth, rich description of the phenomenon therefore generalisability is not the main concern but the truthful representation of the participants' perceptions and experiences (De Poy & Gitlin 1998:283). Qualitative researchers use Lincoln and Guba's (1985) model to ensure validity and reliability and to evaluate the quality of the data in their findings (Polit et al 2001:331). The four components of trustworthiness are credibility, transferability, dependability and conformability (Lincoln & Guba 1985:290). Truth-value, applicability, consistency and neutrality were also described in the four components, where applicable (De Vos 2000:331). Table 3.3 illustrates the components of trustworthiness.

Table 3.3 Trustworthiness

Component	Criteria	Application by researcher
Credibility (Truth-value)	Reflexivity	Bracketing and intuiting in each phase of the research process.
	Prolonged engagement	Involved with the phenomenon since 1997. Trusting relationship with participants. Involved with literature review and interviews for one year.
	Peer debriefing	Pre-exercise interview and data analysis evaluation of supervisors.

Component	Criteria	Application by researcher
Transferability (Applicability)	Participant debriefing	Research data analysis and findings examined by supervisors. Researcher checked with participants and discussed themes that emerged.
	Authority of researcher	Involved with the phenomenon since 1997.
	Interview technique	Pre-exercise increased interview and analysis skills as well as interpretation of findings. Conducting pre-exercise to improve interviewing skills. Conducting the interviews competently.
	Structural coherence	Recorded and transcribed the interviews. The supervisors examined it for dependability and confirmability. A professional editor edited the final product.
	Purposive sample	Sampling was purposeful and experts with knowledge and experience provided input.
	Dense description	Data provided about participants, research context and setting was adequately provided.
Dependability (Consistency)	Stepwise replication	Data was coded and recoded. Researcher checked codes, themes, and categories. Supervisors compared and examined them.
	Inquiry audit	Supervisors audited the research process.
	Dependability occurs with credibility	Researcher achieves credibility as described in 3.8.1.
Confirmability (Neutrality)	Audit trail	Researcher audited all the phases of the research process under supervisors' supervision.
	Confirmability occurs with: credibility transferability dependability	Research project established rigour with the decision trial and proved confirmability through credibility, transferability and dependability. Conclusions and interpretations derived directly from the data.

The four components will be discussed in detail in the following sections.

3.8.1 Credibility

Credibility is ensuring that research findings are in accordance with the reality of participants; in other words, how true the findings of a study are within the context in which it was done. Truth-value determines whether the researcher has established confidence in the credibility of the

findings of the study. This is usually obtained from the discovery of human experiences as they are perceived by participants (Klopper 1998a:315). Holloway and Wheeler (2001:255) state that the researcher's findings are at least compatible with the perceptions of the participants under study, and that the participants recognise the meaning that they themselves gave to the phenomenon and the truth of the findings in their own social context.

3.8.1.1 Prolonged engagement and experience

Prolonged engagement is the investment of sufficient time in data collection activities to have an in-depth understanding of the phenomenon under study (in this case, the perceptions and lived experiences of the women with MS). Prolonged engagement is important for building trust and rapport with participants (Polit et al 2001:313). In this study, the researcher is a registered nurse who encountered a few persons with MS and has a close family member who was diagnosed six years ago. This gave the researcher experience of the disease and living with someone with MS, which reflects the researcher's prolonged engagement with the phenomenon. Enough time was spent with the participants to build and develop a trusting relationship.

3.8.1.2 Member checking

The researcher continually tested her data with the participants' perceptions during the interviews by asking for clarification (Matwa, Chabeli, Muller & Levitt 2003:14). The purpose of member checking was to find out whether the participants' reality was presented, provide opportunities for the participants to change mistakes they felt had been made, and assess the researcher's understanding and interpretation of the data (Holloway & Wheeler 2001:257).

Participants were given a summary and an interpretation of the interview to check on the researcher's accuracy and understanding of the account and to add and verify clarity (Holloway & Wheeler 2001:258).

3.8.1.3 Reflexivity

The researcher wrote field notes on the interview setting, her impressions of the participants, observation of non-verbal cues, as well as her own feelings and interpretation of the whole interview process (Matwa et al 2003:14). Reflexivity, bracketing and intuiting were a major concern in the whole study and were accomplished by being as open as possible, establishing rigour and preventing bias.

The researcher wrote a narrative description to ensure bracketing and intuiting (see annexure D). The analysis of the written essay made the researcher aware of possible preconceived ideas and biases. Bracketing and intuiting were used throughout the study.

3.8.1.4 Interview technique

Pre-exercise interviews were conducted to refine the researcher's interviewing technique as she was a novice (see section 3.4.3) (Holloway & Wheeler 2001:80). The pre-exercise improved the researcher's interviewing skills. During the interviews with participants, precautions were taken to improve techniques with questioning and probing. Face-to-face interviews were conducted with participants as well as a focus group.

Field notes were taken to enhance the credibility of the data. The same aspects were covered in the interviews and focus group, which add to the consistency of data.

3.8.2 Transferability

Transferability is ensuring that the findings are applicable in other settings (Polit et al 2001:316). According to Lincoln and Guba (1985) (cited in Polit et al 2001:316), transferability can be done by thick descriptions provided to those interested in making a transfer to reach a conclusion. When transferability is considered, the participants should be representative. In this study, the researcher selected participants making sure they were suitable and representative of the group under study (Holloway & Wheeler 2001:14).

Purposive sampling was used. The researcher does not have to transfer findings to other settings, but must present sufficiently descriptive data so that it is possible for others to make a comparison (Lincoln & Guba 1985:290). The information was based on the perceptions of women with MS living in Johannesburg and the East Rand. Transferability might be possible in some of the findings, but generalising will not be totally possible.

3.8.3 Dependability

Consistency determines whether findings would be consistent if the inquiry were to be replicated with the same participants in a similar context (Klopper 1998b:316). Dependability refers to data stability over time and conditions. Dependability can be proven by undertaking stepwise replication or by submitting the study for audit (De Vos 2000:331; Polit et al 2001:315). In qualitative research, the researcher and participants are the instruments assessed for consistency. To be dependable, the findings of the research should be checked and audited by external checks.

3.8.4 Confirmability

Confirmability refers to the objectivity and neutrality of data, which was achieved when truth-value and applicability were established (Lincoln & Guba 1985:300; Polit et al 2001:315). Having raw data available on tape and transcriptions will ensure that information can be confirmed. Confirmability means that findings are derived from data free of bias, by means of reflexivity and audit trials (De Vos 2000:331; Polit et al 2001:316). Dahlberg et al (2001) (cited in Holloway and Wheeler 2001:255) also demand intellectual honesty and openness from the researcher, as well as sensitivity to the phenomenon.

3.9 ETHICAL CONSIDERATIONS

Ethical considerations were an important aspect in the study. After approval to conduct the study was obtained from the University of South Africa, permission was obtained from the Ethics Committee of the University of South Africa as well as the Gauteng Health Department, Research and Epidemiology department (see annexure A). The Multiple Sclerosis Society was contacted for a list of possible participants. The researcher followed the Belmont Report's (1978) three principles of beneficence, respect for human dignity and justice (Polit et al 2001:75).

3.9.1 Beneficence

This principle can be divided into two: beneficence is the duty to do good while non-malevolence is the duty not to inflict harm (Pera & Van Tonder 1997:23). This principle is probably the most fundamental in research and contains multiple dimensions. The researcher kept this principle in mind throughout the study.

3.9.1.1 Freedom from harm

Although in this study physical harm was not to be considered, the psychological consequences needed sensitivity. The researcher must not only avoid inflicting physical harm, but also emotional, psychological, spiritual, moral or any other harm, including harm to the dignity of participants (Pera & Van Tonder 1997:23). MS is a condition that has major psychological effects on an individual. The researcher was sensitive with probing questions that could psychologically harm participants. The researcher ensured participants of her honesty, strove to maintain integrity and was sensitive to participants' emotions. The study was an emotional experience for researcher and participants. The researcher told participants that if they felt that parts of the interview would be too much for them emotionally or hurt them, they were welcome to withdraw (Polit et al 2001:90).

3.9.1.2 Freedom from exploitation

In qualitative research, the psychological distance between the researcher and participant decreases because of immersion and the trusting relationship, but this also increases the risk of

exploitation. Participants were assured that their participation and the information given by them would not be used against them (Polit et al 2001:76). Special precaution was taken not to expose the participants, with any personal information that could be linked with them in data presentation. This was done by labelling tapes in a code known only to the researcher. The list of participants was kept secure but separate from the tapes and field notes (Holloway & Wheeler 2001:61). Participants were assured that the tapes and notes would be destroyed after the study was completed (Patton [1990] cited in Holloway & Wheeler 2001:62).

3.9.1.3 Benefit from research

The researcher considered the risk-benefit ratio and kept the risk minimal by approaching participants individually and explaining the aim and purpose of the study. As the study was on the perceptions of women with MS, the relationship could benefit the participants emotionally in the sense that they could express their emotions. The possible benefit was thus greater than the possible risk (Burns & Grove 1997:208). Other benefits included the description and understanding of experiences and perceptions of women living with MS. The results could contribute to guidelines on assessment and management by referral sources; have a positive influence on the perceptions of women coping with MS; help people working and living with persons with MS to anticipate their perceptions, and enhance cooperation in the treatment regimen.

3.9.2 Respect for human dignity

This principle includes the right to self-determination and to full disclosure (Polit et al 2001:77).

3.9.2.1 The right to self-determination

The right to self-determination is based on the ethical principle of respect for persons, which states that humans are capable of self-determination and have the freedom of choice (Burns & Grove 1997:200). The participants had the right to decide whether they wished to participate, were approached purposefully and no remuneration was offered. They decided voluntarily to participate and knew they were free to withdraw at any stage (Brink 1999:39; Holloway & Wheeler 2001:66). Verbal and written consent was obtained prior to interviews, accompanied by a covering letter (see

annexure A). Individuals who refused to participate were not forced, threatened or intimidated and their choice was respected.

3.9.2.2 The right to full disclosure

Full disclosure means that the nature and purpose of the study is explained fully and people have the right to refuse to participate. Self-determination is dependent on full disclosure (Polit et al 2001:78). The researcher explained the aim and purpose of the study to the participants, the types of interviews and observations, as well as other data-collection procedures (De Poy & Gitlin 1998:153).

3.9.3 The principle of justice

This principle includes the participant's right to fair treatment and to privacy.

3.9.3.1 The right to fair treatment

Fair treatment includes that participants be selected and included on the basis of the research requirements; non-prejudicial treatment of participants who refuse to take part or who withdraw; participants' access to the researcher at any point in the study to clarify information; sensitivity to and respect for participants' beliefs, habits, lifestyle, culture and emotions as well as courteous and tactful treatment at all times (Polit et al 2001:81-82).

3.9.3.2 The right to privacy

Privacy is the right of individuals to determine the time, extent and general circumstances under which private information will be shared or withheld (Burns & Grove 1997:203). As the research was done by interviewing participants in their own homes, there was an element of intrusion of privacy therefore to avoid unnecessary intrusion, it was done when it suited the participants (Polit et al 2001:82).

Anonymity assures that information cannot be linked to participants. The researcher promised the participants that information provided would be treated with the strictest confidentiality and would not reveal their identity. Confidentiality and privacy were assured verbally and in writing. The following precautions were used to ensure confidentiality:

- The list of names, recordings, transcriptions and notes was kept in a locked locker.
- The list of names was kept separate from the recordings, transcriptions and notes.
- No names were attached to the tapes, transcriptions or notes (Polit et al 2001:82)

3.10 CONCLUSION

This chapter described the research design, population, sample, sampling, and data collection. A short description of data analysis was presented with the measures to ensure trustworthiness. The ethical considerations and principles of beneficence, respect for human dignity and justice were also included. Chapter 4 covers the data analysis and findings.

CHAPTER 4

Data analysis and findings

4.1 INTRODUCTION

This chapter discusses the data analysis and the findings of the study, particularly the emotional responses, physical and social challenges, coping responses, and the effects on the participants' roles as well as resilience.

4.2 BIOGRAPHICAL DATA

The biographical data reflected the personal details of the participants of this study (see table 4.1).

- *Age*

Of the participants, one was younger than 30, two were between 40 and 50, and five were between 50 and 58.

- *Type of multiple sclerosis*

Five participants suffered from relapsing-remitting MS while three suffered individually from primary progressive, secondary progressive and progressive relapsing MS (see chapter 2, figure 2.6). All the participants had been diagnosed for longer than six years and their vocational abilities were affected.

Table 4.1 represents the ages, types of MS, period of diagnosis and the effect on the participants' vocational abilities. All the participants had been in full-time employment before diagnosis and those who can no longer work receive a disability grant.

Table 4.1 Participants' biographical data

AGE	TYPE OF MS	PERIOD SINCE DIAGNOSIS	VOCATIONAL ABILITIES AFFECTED
27	Relapsing-remitting	7 years	Cannot work anymore
40	Relapsing-remitting	7 years	Works flexitime
46	Relapsing-remitting	11 years	Works part-time from home
50	Relapsing-remitting	14 years	Cannot work anymore
54	Relapsing-remitting	7 years	Works from home on a contract basis
57	Progressive-relapsing	8 years	Has a morning post
54	Primary-progressive	6 years	Cannot work anymore
58	Secondary-progressive	12 years	Cannot work anymore

4.3 THEMES, CATEGORIES AND CODING SYSTEM

The QRS NUD*IST Power Point 4 qualitative analysis program was used for the descriptive/interpretive approach, organisation, and accurate, comprehensive analysis (Holloway & Wheeler 2001:246). With the QRS NUD*IST program, the researcher created categories and codes from the data obtained from the semi-structured interviews and the focus group. After examining all the categories and codes, the researcher identified the following themes that impacted on the participants' lives while suffering from MS:

- emotional responses to the chronic and disabling disease
- physical challenges to be overcome
- social challenges endured
- role changes
- coping and resilience
- perceptions of how they can improve their lifestyles

The themes and categories, ranging from the most general to the most specific, and coding system are outlined below:

- Level 1: Themes
- Level 2: Categories
- Level 3: Codes
- Level 4: Text (Data) units (quoted participants' responses).

The researcher identified and examined the themes with reference to supportive literature in an attempt to describe the lived experiences of women suffering from MS. The themes assisted the researcher to achieve the following research objectives:

- to explore and describe the perceptions of women suffering from MS in Johannesburg and the East Rand, South Africa
- to explore and describe the impact of MS on the participants
- to identify and explore the emotional, physical and social challenges and barriers experienced by women suffering from MS
- to examine the resilience of women suffering from MS and to provide guidelines to enhance resilience to cope with their changed lives
- to determine how women suffering from MS perceive the influence of MS on family life

4.4 EMOTIONAL RESPONSES

Most emotional responses to MS are normal reactions to a long-term unpredictable illness (Fraser et al 2002:83). The negative emotional responses are evident in expressions of shock, denial, fear, anger, guilt, frustration and depression but positive expressions include acceptance, adaptation and resilience.

4.4.1 Shock and denial

Fraser et al (2002:84) describe shock as being temporarily overwhelmed and unable to connect feelings and information and point out that this reaction is more common with the initial diagnosis. Denial in the early stages after diagnosis and some sense of disbelief are a normal reaction. Denial or minimizing a problem can protract the development of adaptive behaviour (Biogen Information Series 1999a:13; Fraser et al 2002:85). Table 4.2 illustrates participants' responses of shock and denial.

Table 4.2 Shock and denial

SUBCATEGORY	MEANING UNIT
4.4.1.1 Shock (F 2 2 1)	<p>I was horrified when I was diagnosed. (G1)</p> <p>I cannot describe to you how I felt that day. I didn't know what had hit me. It was so unrealistic and it only sank in later. (J1)</p> <p>It's not very clear to me. You know, it happened at a time in my life when so many things happened to me, so MS was the last thing on my mind. (D1)</p>
4.4.1.2 Denial (F 2 2 1)	<p>I was in denial and refused to think that I could look like that (in a wheelchair) ten years down the line. (C1)</p> <p>In the beginning I didn't want to go near them (MS society), because I didn't want to see people in wheelchairs. I was petrified. (D1)</p> <p>I did not really feel anything, I was sort of in denial. I really did not think it was that (MS) ... so I went into denial and decided that they'd made a mistake, I do not have MS. (A1)</p>

4.4.2 Fear and anxiety

Fear and anxiety are defined as a feeling nervous or worried that something bad is going to happen in Wehmeier (2001:42, 427). Fear is defined in Wehmeier (2001:427) as a noun: (1) the bad feeling that you have when you are in danger, (2) when something bad might happen, or (3) when a particular thing frightens you. As a verb it is defined as: (1) to be frightened of somebody or something, or (2) the state of feeling nervous or worried that something bad is going to happen.

Fraser et al (2002:86) state that in a culture obsessed with the concept of personal independence, loss of the ability to be independent and in control may make a person feel fearful. Stuart and Laraia (1998:274) define anxiety as "a diffuse apprehension that is vague in nature and associated with feelings of uncertainty and helplessness". Colman (1999:104) points out that a common generalised anxiety disorder is not focused on any specific circumstances but related to everyday events or activities. Every new symptom, every new attack and each new treatment regimen may represent a loss of certainty and control (Coyle & Halper 2001:86). Table 4.3 depicts how participants described fear and anxiety.

Table 4.3 Fear and anxiety

SUBCATEGORY	MEANING UNIT
4.4.2.1 Fear of uncertainty (F 2 2 2)	<p>For me, the biggest problem is fear, because you don't know what is going to happen, and I don't know what my body is going to do or how bad it's going to be. (D1)</p> <p>... and the fear of going blind, I'm very concerned ... (C1)</p> <p>... but the unsure feeling of when it (relapse) might happen again is terrible ... (J1)</p>
4.4.2.2 Fear of progression (F 2 2 2)	<p>I got such a big knot in my stomach, thinking that I might one day look like that ... (F1)</p> <p>Progressed conditions really upset me, because it scares me to death that I might become what they are now. (A1)</p> <p>It is absolute fear that controls you; you don't want to get involved with these people (MS support group). You refuse to look at people in wheelchairs. (C1)</p>
4.4.2.3 Fear of vocational problems (F 2 2 2)	<p>People get very frightened, especially when they are still working. They are scared of being retrenched. (D1)</p>

4.4.3 Anger and frustration

Fraser et al (2002:87) state that anger can be directed at the disease or can be displaced, say, towards family, co-workers, medical personnel, God, or the person suffering from MS. Anger can be heightened by the fear a person experiences. The unpredictability and loss of control can make people suffering from MS angry and resentful. Anger and frustration can be a great problem because people suffering from MS have difficulty understanding what to do with it and how to express this. Coyle and Harper (2001:86) point out that it is important to channel anger and to express the emotion in a constructive way at the disease itself and not towards loved ones. Table 4.4 represents the participants' experience of anger and frustration.

Table 4.4 Anger and frustration

SUBCATEGORY	MEANING UNIT
4.4.3.1 Anger and frustration when not being able to do a task (F 2 2 3)	<p>I get angry and frustrated and then I want to scream. (F1)</p> <p>I become frustrated and angry when I struggle to do something, but I don't have the strength to throw a tantrum, so sometimes I just yell. (G1)</p> <p>I feel angry when I can't do things that I must do. I don't really do anything to get rid of the anger; it just goes away after a while. (A1)</p> <p>It sometimes makes me feel angry. I have never been dependent on other people, and when I need somebody to do things for me that I used to do myself, it makes me angry and frustrated. (A1)</p>
4.4.3.2 Anger and frustration because of dependency (F 2 2 3)	<p>I hate to ask people to help me. I've always been very independent. (G1)</p> <p>I feel frustrated because now I have to ask my husband to drive me places. (K1)</p> <p>I can only lie on my back and every evening it's the same frustration because he (husband) doesn't know how to get the pillows right. (C1)</p>
4.4.3.3 Anger and frustration directed to others (F 2 2 3)	<p>And I used to get miserable with the children when they went to play tennis, because I am jealous that I can't play anymore. (C1)</p>

4.4.4 Hopelessness and powerlessness

Thelan et al (1998:73) hope is a force that helps survival. Hopelessness is a subjective state in which the individual sees limited or no alternatives available. Powerlessness is the perception that a person's own action will not significantly affect an outcome. The range of powerlessness varies and is dependent on the person's perceived control of the situation, amount of losses experienced and the availability of social support. A person's degree of hopelessness is related to the perception and duration of powerlessness. People who interpret bad events as permanent and pervasive are more likely to feel relatively helpless and depressed than those who are relatively optimistic (Beers 2004:2). In addition, this author also states that feeling of helplessness and hopelessness has been associated with illness. Pessimistic people are more often in more health and prone to depression (Beers 2004:2). Feelings of hopelessness and powerlessness pose a

significant threat to a woman's independence and perception of competence (Morgante 2000:3).

Table 4.5 illustrates participants' expressions of feeling hopeless and powerless.

Table 4.5 Hopelessness and powerlessness

SUBCATEGORY	MEANING UNIT
4.4.4.1 Powerlessness, because they are not believed as being sick (F 2 2 4)	<p>I felt rather strange at the time and didn't know what to do because he (doctor) did not take too much notice of it. (K1)</p> <p>A lot of tests were done and everything came back normal and I was sent home to carry on and I didn't know what was wrong with me. I was sick and knew something was wrong but nobody believed me, and at one stage I wanted to commit suicide. (J1)</p> <p>How do you explain that one day you are OK and the next day you can't do your work? People can't see MS, therefore you are not sick. (D1)</p>
4.4.4.2 Hopelessness regarding loss of control and independence (F 2 2 4)	<p>I was stripped of everything that was important to me... (C1)</p> <p>MS has stolen my life. I was always very independent, now I'm useless. (G1)</p> <p>I don't like being dependent at all, but there is nothing I can do about it. (B1)</p>

4.4.5 Guilt

A woman suffering from MS may experience a great deal of guilt, which may have to do with a real or perceived inability to fulfil roles and responsibilities in different areas of life. Guilt is thus a common feeling amongst persons suffering from MS (Biogen Information Series 1999b:29; Coyle & Halper 2001:86; Fraser et al 2002:87). Table 4.6 depicts participants' experience of guilt.

Table 4.6 Guilt

SUBCATEGORY	MEANING UNIT
4.4.5.1 Guilt because of the effect on loved ones (F 2 2 5)	<p>If I go into hospital, they (children) become scared, I don't like to do that to them. (K1)</p> <p>Every time I have to go into hospital, my eldest son is like, "Mom, not again", and then I must explain, and it's not nice to do it to them. They (children) experience fear. (D1)</p>
4.4.5.2 Guilt regarding behaviour towards loved ones (F 2 2 5)	<p>One day I realised how selfish I was, I was always leaning on her and then I felt guilty and realised it's unfair. (J1)</p> <p>The children suffered because of my miserable jealousy, because I can't play tennis anymore. (C1)</p> <p>I feel so inadequate because I don't do anything anymore. I feel sorry for him (husband), he works so hard and then he must come home and do everything here as well. (G1)</p> <p>And he (husband) does not know how to put the pillows and then I get upset and chase him out and then I feel guilty afterwards. It's bad. (C1)</p>

4.4.6 Depressive mood

Grief is a normal reaction to the types of changes that occur in MS. Grief is often focused on a specific event and generally time limited, while depression is more severe, pervasive, and persistent (Halper & Holland 1997:89). According to Fraser et al (2002:92), depression tends to magnify concerns and the subjective perception of symptoms in MS. Halper and Holland (1997:90) state that 50% of people with MS experience a major depressive episode some time during the course of their illness and is responsible for the high suicide rate amongst MS sufferers. Few diseases are as affected by emotional status as MS, therefore depression is very common amongst persons suffering from MS (Halper 2001:217). Table 4.7 represents participants' experience of depression and suicidal feelings.

Table 4.7 Depressive mood and suicidal feelings

SUBCATEGORY	MEANING UNIT
4.4.6.1 Depressive mood with emotional outbursts (F 2 2 7)	<p>There are days that I feel sorry for myself and then I cry all day long when there is nobody to see me. (C1)</p> <p>It is bad. Emotions seem to gain control then you start crying forever. (F1)</p> <p>I keep my pose well, but at times it gets too much. It comes in phases, where you can control your emotions but at other stages it just gets too much to control and then you just burst out crying. (F1)</p>
4.4.6.2 Depressive mood with suicidal feelings (F 2 2 7)	<p>I got extremely depressed and became a little suicidal, but I didn't do anything. But I did think about it a lot, and then I just carried on. (D1)</p> <p>At one stage I tried to commit suicide, due to the fact that I was so disheartened. I still suffer from depression and I take anti-depressants. (J1)</p>
4.4.6.3 Depression affecting social life (F 2 2 7)	<p>It was very bad at one stage. I didn't want to go out of the house. It was so bad I didn't even go out of the front door, really. But it's better now. It used to be very bad, now my depressive mood does not last long. (G1)</p>

In this study, the researcher found the following emotional challenges experienced by the participants consistent with those on the National Multiple Sclerosis Society website:

- clinical depression as well as less severe depressive symptoms
- grieving for losses related to the disease
- stress and reactions to stressful situations
- generalised distress and anxiety
- emotional instability or mood swings (National Multiple Sclerosis Society 2004:1-6)

MS is a generally disabling, progressive and unpredictable disease that can cause significant anxiety, distress, fear, denial, guilt, anger, and frustration from the moment of its very first symptoms (National Multiple Sclerosis Society 2004:1).

4.5 HEALTH-ILLNESS PERCEPTION

Wehmeier (2001:864) describes perception as an idea, a belief or an image you have as a result of how you see or understand. In addition, Rooney (2001:1078) defines perception as (1) the process of using the senses to acquire information about the surrounding environment or situation and (2) an attitude or understanding based on what is observed or thought.

In this study, the health-illness perception refers to how the women suffering from MS interpret society's and the family's feelings and attitude about their condition and includes their perception of the cause of the disease and expectations of the future. In their study of illness perceptions, depression and coping in people with MS, Sprinks and Horn (2003:8) found significant differences between people with subtypes of MS. Coyle and Halper (2001:89) state that a woman suffering from MS may perceive her world to be shrinking. In this study, the researcher found that each participant had unique health-illness perceptions as discussed below.

4.5.1 Causation and precipitating factors

The cause of MS is unknown although the following potential theories are put forward:

- MS is an autoimmune disorder or response to an environmental trigger.
- There is probably an infectious trigger or virus for the disease. A number of viruses are thought to trigger MS, such as Herpes virus 6, Rubella and Epstein-Barr virus (Singer 2000:9).
- There is a genetic susceptibility that may predispose certain individuals to the disease (see chapter 2, section 2.2.3).
- There is a circulating toxin in the cerebral spinal fluid (Biogen Information Series 1999b:11-14; Graham 2000:6-7; Halper & Holland 1997:12; Underwood 1996:854).

Table 4.8 illustrates different participants' views on the cause.

Table 4.8 Causation

SUBCATEGORY	MEANING UNIT
4.5.1.1 Shock and emotional trauma (F 3 1)	<p>We don't know if it's shock, because when my mom died, it was really something. It was a real shock and we were very, very close. Maybe that triggered it. (G1)</p> <p>It could have been the emotional trauma that I experienced earlier in my life. My mom died when I was sixteen, and also my divorce from my first husband, which was the biggest trauma I had. (A1)</p>
4.5.1.2 Ancestry (F1 6)	<p>Genetics probably down the line might have had it, that I can not trace as they (Scottish origin) have a high prevalence. (K1)</p> <p>I believe that it's hereditary from my mother's side (German origin). There might have been earlier family members with it, but it was not diagnosed as MS. (A1)</p>
4.5.1.3 Disease/infection related (F 3 1)	<p>It could well have been my hysterectomy. I got septic afterwards. (C1)</p> <p>I had a sore throat and started experiencing terrible diarrhea. That was apparently my first attack. After that I was paralysed on the right side and was wrongly diagnosed with a stroke. (E1)</p> <p>It probably has something to do with my diabetes. (B1)</p>
4.5.1.4 Stress related (F 2 2 6)	<p>After my ordeal with my sepsis and hysterectomy, I went and studied. The study stress the following year was terrible. (C1)</p> <p>I was in a very high, stressful job, so that could have had an effect. (K1)</p>
4.5.1.5 Environment (F 3 1)	<p>The climate we live in, temperate condition, a combination of it, who knows? K1)</p> <p>I grew up in a cold area, and they say that could be a reason. (J1)</p>

The above findings of the perception of stress causing MS are consistent with findings from a study by Zang, Yu, Gran, Li, Caldida, Ventura, Chan and Rostromi (2004:1-10) in Denmark. This would seem to link a significant stressful life event to the development of MS.

4.5.2 Progression of the disease

The period when a woman suffering from MS realises that she is getting worse is an extremely difficult time. Table 4.9 depicts how participants verbalised their expectations of the disease progression.

Table 4.9 Progression of the disease

SUBCATEGORY	MEANING UNIT
4.5.2.1 Feelings when encountering persons with progressed conditions (F 3 4)	<p>I didn't feel like seeing all these sick, lame and crippled people and I refused to think that I could look like that ten years down the line. (C1)</p> <p>You are scared. I didn't want to attend anything in the beginning, especially newly diagnosed. This absolute fear that controls you, you don't want to get involved with these people. You refuse to look at people in wheelchairs and how they struggle to get along. (F1)</p> <p>I don't go to support group meetings anymore because the progressed conditions really upset me. It scares me to death that I might become what they are now. (A1)</p> <p>In the beginning I didn't want to go near them. I was petrified so I didn't want to get involved because I didn't want to see people in wheelchairs. (D1)</p>
4.5.2.2 Progression expectations (F 3 4)	<p>I don't know what is going to happen. I don't think I will be any worse; after twelve years I'm still pretty OK. (D1)</p> <p>Look, the Beta-Interferon is pushing back the attacks. I have not had an attack for more than two years now, so I think the Beta-Interferon is working. I don't expect to get any worse. (K1)</p> <p>You know, I have secondary-progressive MS and am weakening slowly but surely every day. Others seem to get a relapse, but I don't know what that is. In the beginning what I had was maybe relapses, because I don't get them anymore. (C1)</p> <p>I hope I will still be the same, or better. I don't think I can get much worse. Hopefully this is it. (G1)</p> <p>If I look back at the pattern, I think I will be more or less the same for the rest of my life. (E1)</p> <p>I prefer not to predict what might happen, but I hope, I really hope that I will not deteriorate any further. And that is only hope as I can't say. (J1)</p>

4.5.3 Experience of treatment regimen

Two groups of medications are used to treat MS: medications to alter the course of the disease and ones to treat symptoms (Fraser et al 2002:13). Some women suffering from MS are proactive about disease management and others are uninvolved or more passive about treatment (Halper 2001:64). Table 4.10 illustrates participants' perceptions of their treatment regimen.

Table 4.10 Experience of treatment regimen

SUBCATEGORY	MEANING UNIT
<p>4.5.3.1 Perception of the usefulness of treatment regimen (F 6)</p>	<p>I use Beta-Interferon, subcutaneous injections three times a week and I am on Serepax for my balance. It really works for me. (K1)</p> <p>Presently my main medication would be Liaresol for the spasms and Ditropan for my bladder, which is also affected, and then something for pain. I use evening primrose to oil all my joints, and that would be it. But nothing really helps for MS; it's just for the symptoms. (C1)</p> <p>Every time I go into hospital, I get a Cortisone drip, 1 000 mg of Cortisone a day. Although the Cortisone helps, it's also vicious and some of the side-effects are not nice. (D1)</p> <p>I was on treatment that consisted of a Vitamin B12 injection weekly, an anti-depressant, Anaphrinil or Tofronil 75mg, daily and an anti-inflammation tablet like Brufen daily and an amino-acid and I must say that it really helped me. But I cannot afford it any longer because I don't have a medical fund, and the state doesn't give that kind of treatment. (J1)</p>
<p>4.5.3.2 Experiences with alternative treatment (F 6)</p>	<p>Nothing helps, nothing really helps, but we have tried everything, We've been through it all from medical to spiritual to alternative, various diets to machines, herbs, cannabis. Man, we've been through it all. At the moment I do take some vitamins, and some anti-inflammatories for the pain, that's all. The machines are a treatment where they strap you in and connect electrical wires to you and then they send currents through your body, but it had no effect on me. (G1)</p> <p>I had a very positive experience shortly after my diagnosis with Reiki. It comes from the Japanese for healing, and has to do with life energy or chi, which flows through the person doing Reiki. It is a kind of self-healing. (K1)</p> <p>Soon I am going to a doctor who specialises in Botox injections, which I hope will help for the spasms I suffer from. (C1)</p>
<p>4.5.3.3 Concerned about expense of treatment (F 6)</p>	<p>I cannot afford it any longer because I don't have a medical fund, and the state doesn't give that kind of treatment. (J1)</p> <p>I just hope that the medical fund pays for the treatment. I will see once I get there. (C1)</p>
<p>4.5.3.4 Experiencing side-effects (F 6)</p>	<p>With an acute attack I used to go into hospital for a cortisone drip and I came out quite bloated, but with the Beta-interferon I only make ugly marks. (K1)</p> <p>After the Cortisone, you come down and you get very low for about three weeks. You are just too sick to do anything. It's terrible. (D1)</p>

4.5.4 Experience of information received

Coyle and Halper (2001:1) state that when diagnosed with a progressive incurable disease, it is normal for people to want to understand more about the nature of the disease and its impact on their lives. Upon diagnosis people would assume that the person who made the diagnosis would provide the patient with some information and counsel them. Table 4.11 represents the perceptions of the participants about information received on diagnosis.

Table 4.11 Experience of information received

SUBCATEGORY	MEANING UNIT
4.5.4.1 Perception of information given at diagnosis (F 1 5)	<p>No, the neurologist never told me anything. What I know I had to find out myself. I read the report that the neurologist wrote for the doctor and was very upset about it, and then the doctor told me about MS. (C1)</p> <p>No, nothing they didn't really tell us what was going on. We went onto the Internet and books to find out what we wanted to know. (G1)</p> <p>The neurologist did not really explain it to me. Then I went back to my doctor and he only told me either I would land in a wheelchair or if I'm lucky not! I informed myself by reading up and looking for stuff on the Internet. (D1)</p> <p>I think I had a good head start in the sense that I knew what to expect and what really happened inside my body, and after that I could determine what I wanted to know about the illness. (E1)</p>
4.5.4.2 Perception of MS Society (F 3 4)	<p>The day I went I was pleasantly surprised by their cheerfulness and I realised how much I was missing. (C1)</p> <p>I was very inquisitive about it and wanted to know everything about MS and joined a support group straightaway. (F1)</p> <p>I became a member of the MS society and received a lot of information from them. Thereafter I moved to Springs, and joined the support group there, where I have also met other MS patients and so with their sharing, I became aware of MS. (J1)</p> <p>I used to belong to a support group but I don't anymore. I feel that my condition is in such a stage that the progressed conditions upset me, so I don't go to support groups anymore. (A1)</p>

The National Multiple Sclerosis Society (2004:1) emphasises that lack of knowledge about the disease adds to the anxieties commonly experienced by people who are newly diagnosed.

4.6 PHYSICAL CHALLENGES EXPERIENCED

Physical challenges include the mobility problems that people suffering from MS experience because of their own body dysfunctions. Mobility impairment is the main factor contributing to physical disability. It restricts the individual's ability to participate in normal family, social, vocational and recreational activities (Blake & Bodine 2002:299-312).

4.6.1 Mobility challenges experienced

Wehmeier (2001:754) defines mobility as "the ability to move around easily from one place to another". Halper (2001:204) describes mobility as "the ability to change and control body position". Symptoms that contribute to altered mobility in MS include spasticity, tremor, weakness, loss of balance, pain and fatigue. According to Halper (2001:204), more than 50% of patients with MS need some form of mobility assistance during the course of their disease. Mobility restriction is a common physical disability among individuals with MS. Psychological, socio-cultural, environmental, political, and economic influences are among the factors that affect the mobility of a person with MS (Chan & Heck 2000:7). Table 4.12 illustrates the mobility problems encountered by participants in the present study.

Table 4.12 Mobility challenges experienced

SUBCATEGORY	MEANING UNIT
4.6.1.1 Hygiene (F 3 2 1)	<p>Well, I shower now more than bath, because I tend to have a little difficulty getting in and out of the bath. (K1)</p> <p>We are busy changing our bedroom's bathroom, so that she can drive into the bathroom and shower because the way it is now she can only get to the door, she can't get in with her scooter and it becomes a problem, especially if I'm not here. (G1)</p> <p>I like to bath though, but it is difficult and I normally sit on a big plastic bowl or on the side of the bath and wash. (C1)</p> <p>My husband has to help me into the bath, and then I sit on a big bowl, to make me stop slipping and to make it easier to get out again. (F1)</p>
4.6.1.2 Getting dressed (F 3 2 2)	<p>It is just difficult to get my pants up when my legs pull up. (C1)</p>

<p>4.6.1.3 Movement difficulties due to symptoms (F 3 2)</p>	<p>I can't fasten buttons anymore, so I just wear T-shirts. My feet are ornaments, there is a pair of shoes in the bathroom but it is not for walking. I just put them on if we go out, because I do not like to go barefoot. I wear socks though. (G1)</p> <p>All my blouses don't have buttons, so I don't have to struggle. And then I prefer to wear pants and flat shoes that fasten with Velcro, not very fashionable but it works for me. (E1)</p> <p>I think I have a definite deficit, like if I go to the Rand Show, which involves a lot of walking, I have to sit down quite often. Sometimes I get tired and I need to sit down for 15 minutes to rest, and I sometimes have tremors if I don't take my medication. So yes, but it does not affect my ability to take blood or put up a drip or things like that. I don't feel the ground or floor under my feet very well; it feels like cotton wool, I don't have that sense of stability. (K1)</p> <p>I'm scared of stairs but I can still go up and down. Going up stairs is easier than going down stairs because I'm scared of falling down. (D1)</p> <p>My work is sewing and it's really a challenge because I can't always hold the material. My hands won't cooperate with me. That's my biggest physical challenge. (A1)</p>
<p>4.6.1.4 Mobility problems with aids (F 3 2 3)</p>	<p>I can't make use of the crutches anymore because I just fall over, because my balance is affected (C1)</p> <p>I recently went with my mother to a mall and couldn't get into the toilet because of the door that wouldn't close if I go in with the shop rider, and then I had to stop outside and shuffle in. (J1)</p>

Mobility impairment is the main factor contributing to physical disability. It restricts the individual's ability to participate in normal family, social, vocational, and recreational activities. Thus, the person with mobility difficulty is not only physically challenged but also has to overcome social attitudes in order to participate fully in the community. Therefore, mobility is not only an individual's physical problem, but also a population health issue and a societal issue (Chan & Heck 2000:7).

4.7 SOCIAL CHALLENGES EXPERIENCED

Wehmeier (2001:1129) defines social as (1) to be connected with society and the way it is organised, (2) connected with your position in society, (3) connected with activities in which people meet each other for pleasure. In addition, Wehmeier (2001:1129) also defines sociable as enjoying spending time with other people.

Environmental factors make up the physical, social, and attitudinal environments in which people live and conduct their lives (Blake & Bodine 2002:299-300). According to Fraser et al (2002:98),

people suffering from MS and experiencing symptoms such as poor balance, gait problems and bowel or bladder problems may feel embarrassed about going out in public. These people then become isolated and their self-esteem is affected. Halper (2001:214) points out that as MS sufferers' condition deteriorates, their social roles are also affected and can significantly impair their quality of life.

4.7.1 Role changes

There can be significant role changes in a woman suffering from MS. Women who previously managed most of the domestic work may require more assistance from family members. These role changes within the family cause the woman to experience feelings of incompetence, inadequacy (Biogen Information Series 1999a:24; Frankel 1997:14; Fraser et al 2002:92; Halper & Holland 1997:101). As immobility affects a woman, she might feel less feminine which can also affect her role as a woman. Table 4.13 illustrates how participants described the effects on their roles.

Table 4.13 Role changes

SUBCATEGORY	MEANING UNIT
4.7.1.1 Female role changes (F 8)	<p>Yes, you loose your dignity but you must keep up your spirit because that is what is being reflected. (F1)</p> <p>It is very true that you lose your dignity, especially when your bladder starts with its problems. It is embarrassing and you lose your femininity. (F1)</p> <p>I don't think my femininity has been affected that much, because I still put make-up on and wear some jewellery, use perfume and dress up smartly. (J1)</p>
4.7.1.2 Role changes within the family (F 8)	<p>Yes, I'm (the husband) a housewife now, I can cook and I can use a washing machine. Hell, I'm good man! (G1)</p> <p>He is really a good housewife! (G1)</p> <p>No, I would not say so. If anything, I push my husband to be a bit more involved, so he helps me more in the house. (K1)</p> <p>No, not role changes, but I did employ a live-in help that could also drive me around. (A1)</p> <p>I have a full-time helper who has been taught how to help me. She also cleans the house and does the cooking. (C1)</p>

4.7.2 Isolation

According to Phillips (2002:97), MS is a lonely disease because sufferers find it increasingly difficult to relate to able-bodied people and anything that reduces their sense of isolation is a good thing. Isolation is also partly due to a troubled self-esteem (Graza 2001:2). Table 4.14 depicts participants' experience of isolation.

Table 4.14 Isolation

SUBCATEGORY	MEANING UNIT
4.7.2.1 Feelings of isolation (F 3 3)	<p>I was so used to doing my own thing, it frustrates me to sit here the whole day and I have a need to go out for a while, but my husband is always tired when he comes home from school and doesn't want to go to the mall. It all depends on the facilities available at functions because that will determine if I will or will not attend anything (C1)</p> <p>But then you go to Carnival City and you cannot get a disabled seat in the cinema because they have all the kids sitting there. We had such an unpleasant argument with the management. We went to see a show in the big top arena where they have a row of wheelchair seats but you struggle because everybody has to go past you. They kick your feet purple and blue. That's why we decided not to go in future. (F1)</p> <p>For a long time I didn't want to go out of the house, and we also didn't invite people here. It was so bad, I did not even go out the front door at all, really. It was very difficult for both of us. (G1)</p> <p>I am alone at home and it frustrates me that I am always alone. (B1)</p> <p>I still went out a lot till about ten years ago, because I was more mobile then. Now I prefer people to come and visit me in the comfort of my own home because I seem to struggle in strange places. (E1)</p>

4.7.3 Perception of people's attitude

Colman (1999:100) describes attitudes as "the favourable or unfavourable feelings, thoughts, and behavioural dispositions that people have toward other people, objects and abstract ideas". Fraser et al (2002:94) state that discrimination toward anyone different in society is easily targeted toward persons with disabilities. Respectful and caring inclusion in the everyday life of the community for people with disabilities is fairly new and *incomplete* (in Fraser's terminology). Table 4.15 illustrates participants' perception of family, co-workers, medical personnel and the general public's attitude.

Table 4.15 Perception of people's attitude

SUBCATEGORY	MEANING UNIT
4.7.3.1 Family's attitude (F 8 1)	<p data-bbox="539 383 1434 450">My husband gets impatient with me because he does not know how to help me. (C1)</p> <p data-bbox="539 483 1434 584">My husband and son ignore my condition. As far as they are concerned, it does not exist. My daughter handles it very well and is understanding and supportive. (A1)</p> <p data-bbox="539 618 1434 651">My sister and my kids get scared and it also disrupts our lives. (D1)</p>
4.7.3.2 General public's attitude (F 8 1)	<p data-bbox="539 689 1434 723">People in general don't think about disabled people. (G1)</p> <p data-bbox="539 757 1434 824">Once at a takeaway place I felt very dizzy, so I think I walked funny, so this person said to his friend, "She is probably drugged!" (K1)</p> <p data-bbox="539 857 1434 925">The problem with being in a wheelchair is that you become invisible. Everybody talks over your head and nobody sees you. (C1)</p> <p data-bbox="539 958 1434 992">The world out there is not very accepting. (F1)</p>
4.7.3.3 Medical personnel's attitude (F 1 5)	<p data-bbox="539 1025 1434 1126">They are not sensitive enough, especially us, the nurses, have to learn more about it, we have to tell the patient more about it. The neurologists, well they kind of, they give you your diagnosis and please don't expect anything more! (K1)</p> <p data-bbox="539 1160 1434 1227">They don't tell you what is wrong with you and they are not very helpful. It seems that a whole lot, most of them don't know anything, not even the doctors! (G1)</p> <p data-bbox="539 1261 1434 1350">I have never experienced any understanding on their part ever. They don't know what it is. Now that I am in the shop rider it is better, but they were very insensitive when I was still walking, and it is because they don't understand. (J1)</p>

4.7.4 Self-concept

Today's society is obsessed with the human body and women struggle to keep themselves looking "perfect", and women with disabilities have not escaped that stress. Isolation affects people's self-esteem and self-concept (Graza 2001:2) (see section 4.7.2). People's self-concept refers to their view of themselves, an image that has developed over years. The self-concept comprises people's attitudes about themselves, perceptions of personal abilities, body image and identity and a general sense of worth. A person's sense of self-worth, self-confidence and self-roles in the family and society are all dimensions of the self-concept (Smeltzer & Bare 2000:56). Table 4.16 represents participants' perceptions of their self-concept:

Table 4.16 Perception of self-concept

SUBCATEGORY	MEANING UNIT
4.7.4.1 Perception of effect on self-concept (F 8 2)	<p>If something has been affected, it is rather my independence that took a blow. (K1)</p> <p>My self-esteem took a huge knock because you cannot walk among people and especially strangers, I'm always afraid I will fall. (J1)</p> <p>Because I have such severe bladder and bowel problems it's very embarrassing, and it really affects me. I feel so ashamed to go somewhere and maybe I can't control it. I'm so useless. (G1)</p> <p>If people invite us over for supper or something, I feel reluctant to go because I am scared I might have a problem with my bladder and, you know, it's very embarrassing because what will they think of me? People don't always understand what this is all about. (A1)</p> <p>You lose your dignity but you must keep up your spirit, because that is what is being reflected. (F1)</p> <p>It is very true that you lose your dignity, especially when your bladder starts with its problems. It is embarrassing. (F1)</p>

Daily (1999:2) stresses that the diagnosis of MS or the impact of any subsequent exacerbation is a psychologically traumatic event that can change a person's sense of security and safety in the world. Aspects of life that previously seemed reliable and trustworthy suddenly become frightening and undependable. The traumatic impact of MS is intensified because the course of the illness cannot be predicted. Table 4.16 makes this clear.

4.7.5 Types of symptoms

MS is more than a challenge; it is a disease of chronic uncertainty and change, of unpredictable loss and adjustment. The symptoms, however mild or severe, impact on the person living with it (Singer 2000:14). Figure 4.1 graphically illustrates the symptoms mostly experienced by the participants.

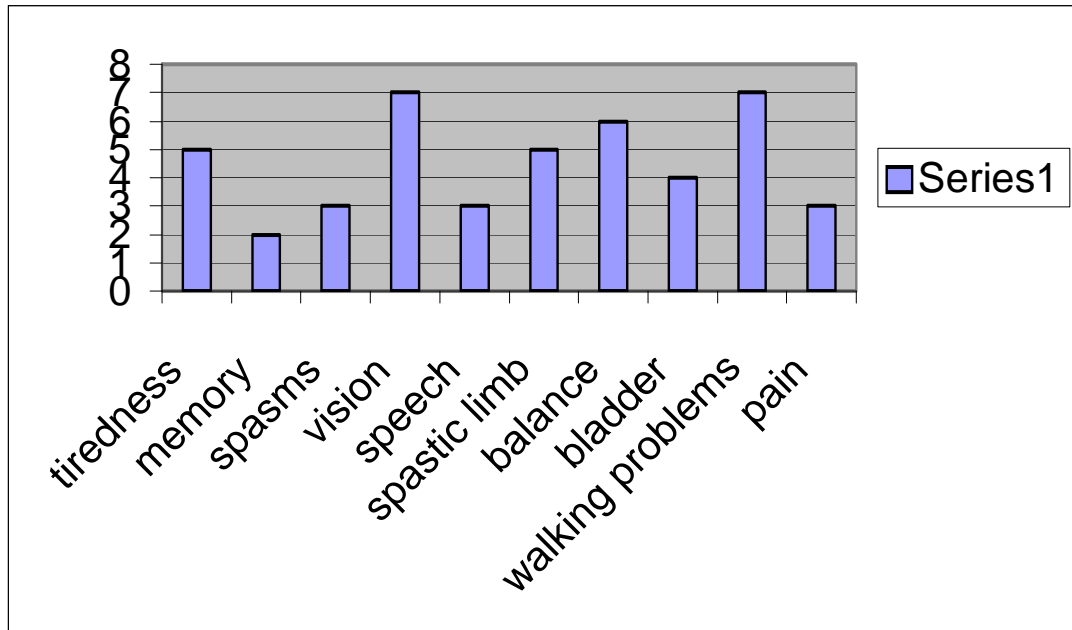


Figure 4.1

Symptoms commonly experienced

From figure 4.1 it is clear that among the participants, walking problems followed by vision problems were the most common while memory problems were the least experienced. The symptoms experienced can affect the self- concept.

4.8 COPING RESPONSES AND RESILIENCE

Coping responses are means of coming to terms with a chronic, disabling, unpredictable disease. Every person responds differently to MS therefore coping responses also differ. When coming to terms with the diagnosis of MS, patients must accept that MS has become part of life. Searle (2000:401) describes resilience as the ability to overcome handicaps and barriers and emphasises that resilience is a crucial factor in growth and development and the achievement of a constructive power base. Women suffering from MS have many handicaps and barriers to overcome. Table 4.17 illustrates participants' positive emotions, and personal, physical and social adjustments which show their coping abilities and resilience.

Table 4.17 Coping responses and resilience

SUBCATEGORY	MEANING UNIT
4.8.1.1 Positive emotions (F 2 1)	<p>There is some positive in having MS, because I am more tolerant with other people now and also because of my nursing, I can now counsel people with problems more effectively. It is not a wonderful thing, but it makes you think of what really is important and brings your life into perspective. (K1)</p> <p>I think the whole set-up at the hospital I'm attending was very positive When I realise other able persons can't do things much better than what I can...well, it is a nice feeling! (E1)</p> <p>I have to stay positive because I believe that will keep me from becoming immobile. (A1)</p>
4.8.1.2 Personal (F 2 1)	<p>My spirituality and my work that I do with alternative healing seem to stabilize my condition. I see myself as resilient because, well, if something is difficult I find a way to do it differently and I don't sulk over things I can't do. I think that is just the way I am, my personality. Focus on today, do what you can today. Don't focus on the future and what can happen. Live for today. (K1)</p> <p>I just learn to live with it, and it's very important to just be happy. There is so much you can be grateful for. I think my ability to laugh also helps me to overcome most of my problems. (D1)</p> <p>You know, for us it's a journey. You learn as things happen, and it's not so bad anymore, but you don't know where you're going to end up. You just take every day as it comes. I'm very grateful to have my husband. Without him ... I don't know, he is just wonderful. We've adapted, you know, adapt or die. We still love each other, there's no doubt about that. (G1).</p> <p>You have to accept that you have MS. But there is not a thing you can't do; it is just finding another way that works for you. (E1)</p> <p>The main thing that keeps my condition is the willpower to stay mobile, positive thinking, being busy and not thinking about the disease too much and doing things myself as much as possible. I see myself as resilient because if I am down, it is not forever, it's just for a few minutes and then I pull myself together and then it's over and I carry on. (A1)</p> <p>There are so many things that I have to be thankful and grateful for, but I have made peace and accepted it and live day by day. (C1)</p>
4.8.1.3 Physical adjustments to assist in the bathroom (F 7)	<p>I have a railing in the shower. I like to bath though, but it is difficult and I normally sit on a big plastic bowl or on the side of the bath and wash. I also have a special toilet seat and rail next to toilet. (C1)</p> <p>We are busy changing our bedroom's bathroom, so that I can drive into the bathroom. When I bath we put a rubber rug into the bath to stop me from slipping, but it is very difficult. He (husband) helps me. I can't shower because I can't stand; mainly I sit on the loo and wash myself. (G1)</p> <p>I have a rail in the bathroom that I can hold onto because I fall easily. (B1)</p>

4.8.1.4 Physical changes to clothing (F 7)	<p>I prefer to wear pants and forget about dresses. I wear tackies now because they are the only shoes I can walk with, but barefoot is still the best. (F1)</p> <p>I wear dark pants or loose, long dresses. I am being very honest about it, with the dark pants it's not so obvious if you have an accident! (D1)</p> <p>I adjusted my clothing so all my blouses don't have buttons and I prefer to wear pants. My shoes all fasten with Velcro and are flat. It's not fashionable but it's comfortable. (E1)</p>
4.8.1.5. Physical changes to their homes (F 7)	<p>A railing in the lounge to assist me because of the two steps that hinder me and the domestic worker knows exactly how to help me over the steps. (C1)</p> <p>The only change we have made is here in the lounge. We made it an open plan as it is now, so that I can move around with ease. We've put in the glass doors here with the ramp, so I can drive into the house. We have taken out the rugs and replaced them with tiles because I used to trip over the rugs, but nothing major! (G1)</p> <p>I had a ramp made for me, so that I can ride right to my door where I had railings put on to assist me. (J1)</p> <p>We lifted the floor in the living room because it had three steps, so that was a problem for me. (E1)</p>
4.8.1.6 Adjustments to life style (F 7)	<p>I have a portable phone, it is always with me. This way I can get help, for example if I fall in the room and there is no one at home. I belong to the East Rand MS support group, and I am part of a research group that they use and that is the way for me to go. (C1)</p> <p>I have my own wheels (shop rider) so now I can drive around everywhere! (G1)</p> <p>I have been using the shop rider for the past two years and it is wonderful. I can go wherever I want to, and the crutches I use to walk outside, although it would only be for short distances. (J1)</p> <p>I reduced my caffeine and sugar intake and I try to eat healthily because our bodies use up more protein and amino acids. I also bought pots with glass see-through lids because of the damage to my right hand so now I don't have to lift the lids while cooking. (E1)</p>
4.8.1.7 Social adjustments (F 3 3)	<p>Because I seem to struggle in strange places, I prefer people to come to my house. It's comfortable and suits me fine. (E1)</p> <p>I have put my name down at the care centre for in case something does happen and I can't help myself anymore. I just live day by day and have to make provision for myself. (J1)</p> <p>I make use of a wheelchair in shopping malls. That way I don't get tired, people don't look at you funny and I don't have to struggle to keep my balance and look at the things. (E1)</p> <p>Before we go somewhere, we find out about the facilities and terrain. It all depends on the facilities that are available because that will determine if I will or will not attend anything. (C1)</p>

	I normally try to find out before the time about the area and then decide what I have to do. (B1)
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Individuals use different mechanisms and strategies to cope with changes in their health. Their responses range from facing each change and adapting positively to denying change or choosing inappropriate or ineffective strategies to cope with change (Chan & Heck 2000:7).

4.8.1 Perceptions on improving quality of life

MS creates many problems. Most can be solved with a positive attitude and a divide-and-conquer technique. The implication of the losses caused by MS is that sufferers have the right to be treated fairly. The goal should be to function outside of the disease, given the constraints it imposes (Yanofsky 2000:14). Table 4.18 represents participants' views on what can be done to improve the quality of life of persons suffering from MS.

Table 4.18 Improving quality of life

SUBCATEGORY	MEANING UNIT
4.8.2.1 Perception on what can be done to improve quality of life of persons suffering from MS (F 7)	<p>Counselling, not only for people with MS. There are a lot of people with different problems and by speaking about them, counselling helps to teach them about alternatives. (K1)</p> <p>I really believe that these workshops and meetings where everybody, and especially the family, is involved help and contribute a lot because they concentrate a lot on the patient but they also realise that the other family members are also affected by your condition. (C1)</p> <p>I think the doctors should be more, can I use the word, blunt. They should call the partner in and spend time with the couple telling them, "Look, your wife/husband has got what they've got, and this is what you can expect." (G1)</p> <p>It's so important for them to be able to talk to someone. Yes, of course, to relieve the stress and to let them see perspective and that not all of us land up in wheelchairs. And another important thing is to open up to them, because they are scared and they must learn to ask for help. (D1)</p> <p>Maybe to make other people aware of the sickness so that they can assist them better and maybe the state can issue them the medication they need. (J1)</p>

	I think the government should start making provision for people, like MS patients that don't have money. Maybe a plan to give them cortisone drips, or other medication that helps at provincial hospitals or whatever. And walking aids, crutches or wheelchairs for free. I think there must be legislation that all buildings must be accessible to people who are immobile or disabled. (A1)
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4.9 CONCLUSION

This chapter presented the data analysis and findings of the study, including the categories and themes. Reference was also made to the literature reviewed. Chapter 5 discusses the conclusions and recommendations of the study.

CHAPTER 5

Conclusions, limitations and recommendations

5.1 INTRODUCTION

In chapter 4 the results of the research were discussed and substantiated by reference to the relevant literature in order to place the research findings into context. In this chapter the conclusions, limitations and recommendations of this research are presented and discussed. Recommendations made by the participants to improve quality of life will be presented. The limitations of the research are explained.

5.2 SUMMARY OF THE STUDY

The findings and recommendations as described are centred on the lived experiences of the eight participants whom were interviewed, the collected experiences from the focus-group participants, the research question, objectives and the themes emerging from the data analysis. The research questions to be answered were:

- What are the lived experiences of women suffering from MS in Johannesburg and the East Rand?

The research objectives were aimed at:

- to explore and describe the lived experiences of women suffering from MS
- to explore and describe the impact of MS on the participants
- to identify and explore the emotional, physical and social challenges and barriers experienced by the women suffering from MS
- to explore women suffering from MS resilience and to provide guidelines to enhance resilience to cope with their changed lives
- to determine how women perceive the influence of MS on family life

To arrive at the research questions and objectives the researcher conducted a literature review to gain information regarding the phenomenon. The participants were drawn from the population using a non-probability purposive sampling technique and consisted of an expert sample of eight women suffering from MS. The concept of the lived experiences of women suffering from MS was under investigation during the interviews and the focus group.

During data analysis, reflexivity, bracketing and intuiting were implemented as the basis for analysis. The three main themes elicited during the interviews and focus group were emotional responses, physical and social challenges experienced. Lincoln and Guba's (1984) model of trustworthiness for qualitative research was used to ensure that all data obtained was trustworthy. Several practical strategies appropriate to the four criteria of trustworthiness were applied namely: credibility, transferability, dependability and confirmability. From the data analysis themes with categories and subcategories emerged and recommendations were formulated to improve quality of life and resilience for women suffering from MS.

5.3 FINDINGS OF THE STUDY

The purpose of this research was to explore and describe the lived experiences of women suffering from MS in Johannesburg and the East Rand. For the purpose of drawing conclusions, the objections set out in chapters 1 and 4 will be enumerated and discussed. The conclusions will be discussed in conjunction and according to the themes.

5.3.1 Emotional responses

It was found that being diagnosed with a progressive unpredictable and incurable disease such as MS has a variety of emotional responses. In paragraph 4.4.1 the participants mentioned that being diagnosed was a shocking experience. The event was experienced as traumatic and had an impact on the women's person and her personal roles while her family and work life was also impacted on. The diagnosis of MS was threatening and elicited psychological reactions and emotions from these women. Emotions such as shock, denial, frustration, anger, fear, anxiety and guilt were experienced and led to psychological reactions such as hopelessness, powerlessness and depression which is in keeping with literature such as Biogen Information Series (1999a:13,

29); Coyle and Halper (2001:86); Fraser et al (2002:85-92); Halper and Holland (1997:89); Morgante (2000:3) and Thelan et al (1998:73). These emotions ultimately had an impact on the women being diagnosed emotional and social well-being as well as their coping responses and resilience.

The findings show intensive emotional experiences that were mostly categorised as negative emotions (see table 4.2 Shock and denial; table 4.3 Fear and anxiety; table 4.4 Anger and frustration). This led to the conclusion that women diagnosed with MS experience shock, denial, fear, anxiety, anger and frustration and that these emotions were experienced over and over again with each new symptom or exacerbation.

The initial response of shock and denial was experienced with diagnosis as the situation seemed unreal to the women. It was found that after the initial emotional response of shock the emotions such as frustration and guilt together with the psychological responses of depression and feelings of hopelessness and powerlessness was more of a permanent nature (see table 4.5 Hopelessness and powerlessness; table 4.6 Guilt; table 4.7 Depressive mood).

Guilt was experienced in different categories that ranged from the effect on loved ones to guilt regarding behaviour towards loved ones. The women suffering from MS also face compromised quality of life, with suicidal thoughts and depressed moods according to Blake and Bodine (2002:299) as can be seen in table 4.7 Depressive mood. Depressive mood were experienced because of the feelings of powerlessness and hopelessness as the physical and social challenges became more difficult to overcome. This, in turn, led to feelings of uselessness and inadequacy according to Morgante (2000:3) MS pose a significant threat to an individuals' independence and feelings of competence. Anger and frustration was experienced towards the disease and family members because the participants could not be as mobile and active as before, and the family did not know how to help the sufferer. Therefore the conclusion is that family members are in need to better understand the woman suffering from MS.

Most of the participants seemed to be optimistic about the future although it was also found that they were realistic about their condition and the progression thereof (see table 4.9 Progression of

the disease and table 4.17 Coping responses and resilience) which reflect a hopeful response and can be a sign of resilience. It seemed that the experience of acceptance was only reached by some of the participants.

5.3.1.1 Conclusions

The implication of this dense emotional experiences lead to the conclusion that being diagnosed and live with the unpredictability and uncertainty of MS were threatening the psychological, physical and social well being of the women suffering from this incurable disease. From this conclusion arise the perspective that there is a need to recognise the emotional implications experienced with every relapse or new symptom. Another conclusion that were made was that the traumatic event of diagnosis were not in all participants well handled, which directs for improvement in counselling and giving such a devastated diagnosis by medical personnel.

5.3.1.2 Recommendations

Recommendations regarding the emotional experiences are mainly centred around supporting the women suffering from MS, understanding and anticipating these emotional responses and the emotions experienced by their families. This can be done through counselling on a one-to-one base with the women suffering from MS as well as with the family and also follow-up counselling sessions. It is recommended that counselling and support will ease the emotions experienced. Thus medical personnel must be skilled in counselling and know where to refer the person suffering from MS for support.

5.3.2 Health illness perception

Every participant had unique health illness perceptions, the health illness perception refers to how the women suffering from MS interpret society's and the family's feelings and attitude about her condition. The health illness perception also includes her perception of the cause of the disease and expectations of the future. A woman suffering from MS may perceive her world to be shrinking according to Coyle and Halper (2001:89) this statement was found to be true in the participants of this study (see table 4.5 Hopelessness and powerlessness). It was found that most participants felt

that a traumatic or stressful event was the cause of their condition (see table 4.8 Causation and precipitating factors). In the health illness perception to the progression of their condition the participants seemed realistic (see table 4.9 Progression of the disease). Although the experiences of the treatment regimen differed in relation to the different types of MS suffered by the participants, it was also found that some only used treatment with an acute attack and does not use a continuous treatment regimen (see table 4.10 Experience of treatment regimen). A strong need for clear and correct information emerged. It was found that the experiences of receiving information about the condition were mostly experienced as inadequate as can be seen in table 4.11 Experience of information received. An interesting finding was that most of the participants also tried some alternative treatments although none could give prove or testament that it improved their condition. The attitudes of society and family will be discussed under social challenges in paragraph 5.3.4.

5.3.2.1 Conclusions

In describing and investigating the health illness perception of women suffering from MS it was found that the constant state of change becomes a challenge for the individual with MS to adapt and to accept. The participants were realistic in their view of disease progression but it was also found that these women were hopeful that their condition will not deteriorate further or that a cure would be found, which can also be concluded by the fact that some tried alternative treatment. An alarming finding was that most participants felt that a continuous treatment regimen would not help their condition. It can also be concluded that receiving information about the condition was mostly inadequate and therefore causes distrust towards health care workers.

5.3.2.2 Recommendations

It is recommended that information should be given without delay and that medical personnel and health care workers learns more about MS and the implications thereof in order to give adequate health information to persons diagnosed with MS to enhance realistic health outcomes and improve acceptance of their changed life. Follow-up sessions and a referring system to a support group is recommended. Through adequate information compliance to a treatment regimen will be enhanced, which, in turn, will create a feeling of improved control and enhance health illness

perception and resilience. According to Crickmer (2000:1), it is believed that people cope most effectively with a chronic illness when understanding the range and severity of symptoms.

5.3.3 Physical challenges

Participants categorised physical challenges into personal difficulties (bodily dysfunctions due to symptoms) and structural difficulties (physical barriers such as steps). The physical challenges both structural and personal were experienced in different degrees by all the participants and every participant had a unique way of coping with these difficulties. Mobility impairment is the main factor contributing to physical disability. It restricts the individual's ability to participate in normal family, social, vocational, and recreational activities (Blake & Bodine 2002:306; Fraser et al 2002:46). In table 4.12 the mobility challenges experienced by the participants are described in detail and include daily life activities such as hygiene, getting dressed, movement difficulties due to symptoms and mobility problems with aids.

5.3.3.1 Conclusions

The conclusion about physical challenges was that the person with mobility difficulty is not only physically challenged but also has to overcome social attitudes in order to participate fully in the community. In the study the conclusion was reached that the physical challenges, whether as a result of bodily dysfunctions or structural difficulties, faced by women suffering from MS affected every aspect of their lives. A conclusion was made that most public places in Johannesburg and the East Rand was not very disability accessible or user friendly.

5.3.3.2 Recommendations

A need for disabled accessibility to every day public places emerged from the findings and therefore it is recommended that the government look into the problem of inaccessibility and to improve disabled peoples lives and that mobility aids be more readily accessible to improve quality of life. It is also recommendable that the media (television, papers and magazines) is used to educate the general public about not only MS, but about disability.

Therefore, health care professionals addressing mobility issues in individuals with MS should direct their services not only at the individual level but also at the population and societal levels (Chan & Heck 2000:7)

5.3.4 Social challenges

To be social means to enjoy spending time with other people (Wehmeier 2001:1129). Environmental factors make up the physical, social, and attitudinal environments in which people live and conduct their lives (Blake & Bodine 2002:300). Discrimination toward anyone different in our society is easily targeted toward persons with disabilities. Respectful and caring inclusion in the everyday life of the community is incomplete according to Fraser et al (2002:94). Women suffering from MS experience family, co-workers, medical personnel and the general public's attitude on a daily basis and more intense than women who don't suffer from the disease. Women suffering from MS then become isolated and their self-esteem becomes affected. As the women suffering from MS, condition deteriorates their social roles are also affected and can significantly impair their quality of life (Halper 2001:214).

Role changes are discussed in detail in paragraph 4.7.1 and in table 4.13 Role changes, the perceptions of the participants can be reviewed and was found to be consistent with role changes mentioned in the following literature: Biogen Information Series (1999a:24); Halper and Holland (1997:101); Frankel (1997:14) and Fraser et al (2002:92). It was found that most participants felt that their female role or femininity was affected due to some of the symptoms and that therefore their dignity has been lost. Role changes experienced within the family was in the nature that family members had to take over certain household tasks that made the women felt incompetent. These role changes within the family cause the woman to experience feelings of incompetence, inadequacy.

Women suffering from MS experience family, co-workers, medical personnel and the general public's attitude in different manners in their daily lives as was described in paragraph 4.7.3 and in these perceptions are as mentioned by the participants in table 4.15 Perception of people's attitude. It was found that different attitudes exist within the family. Attitudes perceived differ from

family members being irritated or impatient or ignoring the condition to family members handling it well and give support and understanding.

The perception of the attitude of the general public emerged mostly as unaccepting and that normal people don't think about disabled persons and are not sensitive to them. A concerning finding was made that health care workers and medical personnel's attitude are also perceived as not sensitive enough and that understanding by them for symptoms or needs was hardly ever experienced.

Self-concept refers to one's view of oneself, an image that has developed over many years. The self-concept comprises attitudes about oneself, perceptions of personal abilities, body image and identity and a general sense of worth (Smeltzer & Bare 2000:56). In the perception of self-concept (paragraph 4.7.4 and table 4.16 Perception of self-concept) shows that experiencing the symptoms can have an effect on the self-concept. It was found that women suffering from MS experienced that their independence and self-esteem is affected which led to depression and hopelessness as discussed in paragraph 5.3.1.

According to Phillips (2002:97), MS is a lonely disease because sufferers find it increasingly difficult to relate to able-bodied which is also reflected in paragraph 4.7.2 and table 4.14 Isolation. Feelings of isolation was expressed as frustration to be alone and not being able to go out on their own due to immobility, and family members inability to understand their isolation. Due to symptoms women suffering from MS also at times lack the confidence to break their isolation.

5.3.4.1 Conclusions

As the women suffering from MS, condition deteriorates their social roles are also affected and can significantly impair their quality of life (Halper 2001:214). It can be concluded that the family as well as the female role of women suffering from MS are affected. The perception of other people's attitudes influences the distortion of the self-concept, leading to isolation and that these women are not able to cope with the situation, which affect their quality of life and resilience. Another conclusion was that health care workers have an important role to play but are not showing understanding or sensitivity and that the general public needs to be educated to be more aware of disabled people in general.

5.3.4.2 Recommendations

It is recommended that women diagnosed with MS and their families receive continuous and adequate counselling regarding emotions, expectations and what measures can be taken to improve their resilience and coping responses. Health care worker should educate and train in counselling and should be made more aware of their duty to disabled persons.

5.3.5 Coping responses and resilience

This theme portrays the way women suffering from MS copes with the treat of a chronic, disabling, unpredictable disease. Every person responds differently to MS and therefore coping responses also differ. Searle (2000:401) describes resilience as the ability to overcome handicaps and barriers.

According to the findings of the emotional challenges (paragraph 5.3.1) coping and adjustments of women suffering from MS appeared to be a rather emotional focused response than a problem focused response. It was found that women suffering from MS experienced a wide array of emotions as described in paragraph 5.3.1. To be able to adapt and accept that MS have become part of your life these emotions have to be endured. It was found that adjustments were made to their physical environment and social circumstances, to adapt to the MS (see table 4.17 Coping responses and resilience). It was found that the attitudes of other persons towards women suffering from MS has a definite impact on their social well-being, their coping responses and resilience as discussed in 5.3.4.

It was found in this study that there are definite perceptions on how life can be improved for MS sufferers (see paragraph 4.8.2 and Table 4.18 Improving life) MS creates a wide array of problems. Most are solvable with a positive attitude and a divide and conquer technique. The goal should be to function outside of the disease, given the constraints it imposes (Yanofsky 2000:14).

5.3.5.1 Conclusions

The constant state of change becomes a challenge for the individual with MS to adapt and to accept (Chan & Heck 2000:7). It was concluded that accepting and adapting to living with MS had it difficulties for both the woman suffering from MS and the family members. The conclusion was reached that women who's family members are supportive copes with their changed life-style better and are more resilient than those that experience little or no support from family members. Another conclusion that emerged was that MS sufferers felt that the government should be more aware of disabled people, and that counselling done by health care workers lack knowledge and understanding.

5.3.5.2 Recommendations

On diagnosis and with counselling sessions the family must be involved in order to enhance coping resources and skills as well as resilience of the women suffering from MS and her family.

5.4 RECOMMENDATION FOR FURTHER RESEARCH

The study was context bound to women suffering from MS living in Johannesburg and the East Rand. The findings of this qualitative study cannot be generalised beyond this study. When considering the transferability of these findings the context in which the study was done should be taken into consideration. The need for a more comprehensive research study in other regions of the country that includes a larger and more representative sample of MS sufferers with a more structured methodology might be a possibility. Such findings can contribute to establishing policies or developing a model to utilise in the future for the improvement of quality of life in MS sufferers. It can also contribute to increase the awareness and knowledge of the phenomenon amongst people who work with MS sufferers. The information obtained might serve as a framework for assessment and management by referral sources. Results will provide authorities, such as the government and institutions insight into the needs of those suffering from MS, to provide more comprehensive support and services.

MS is more than just a physical problem and more than a problem for the individual. This qualitative study did not need to determine or measure the exact impact MS has, it must be viewed as an issue that affects other dimensions, at the individual, population, and societal levels.

5.5 STRENGTHS

This study conceptualise the lived experiences of women suffering from MS in Johannesburg and the East Rand. Strengths of the study include the following:

- The qualitative study, semi-structures interviews and the focus group have let the participants speak for themselves, and the findings clearly showed how the effects of living with MS have been experienced. This was not a laboratory-orientated study but it was implemented in the field, which was the life-world of the women suffering from MS. The researcher was open to any experiences to produce fresh and direct data.
- The findings portray a comprehensive, holistic bio-psycho-social description, with emotional responses, physical and social experiences as well as coping and resilience mechanisms, which did not concentrate on preconceived ideas.
- The researcher was conversant with the situations and was more accessible to the women suffering from MS, due to her familiarity with the living context in which the study was conducted. Because the researcher was a member of a family in which a woman suffered from MS. This provides more insight into the lived experiences of women suffering from MS.
- These findings made a contribution to the knowledge and understanding of the lived experiences of women suffering from MS, and the emotional physical and social context of these women's lives. The findings increased the knowledge of the phenomenon and establish an understanding of the lived experiences of women living with MS. This knowledge is important and significant to persons working with these women, who need to anticipate women suffering from MS reactions in the emotional physical and social facets of life as the same events are experiences over and over again with every new symptom or exacerbation. The recommendations can be utilised to implement effective strategies to ensure positive outcomes and to improve coping and resilience as well as the quality of life of persons suffering from MS.

5.6 LIMITATIONS

Certain limitations were identified in the study, namely: researcher's bias, participant effect, and data collection and analysis.

The researcher was a member of a family in which a woman was diagnosed and suffered from MS. This could have increased bias. To prevent bias the researcher implemented reflexivity, intuiting and bracketing through all the stages of the study, did member checks and two experienced researchers reviewed the interviews, transcriptions, analysis and coding.

Another limitation could be possible participant effect. Because the data collection was in the form of semi-structured interviews and a focus group, the participants could withhold some of their in-depth experience. Personal and private experiences could be withheld during the data collection due to lack of total anonymity to the researcher and because of the effect MS have on their self-esteem. This could bias the data and the findings.

The nature of a qualitative study relied on the researcher's judgement of data collection and analysis. The researcher was the main data collection instrument with semi-structured interviews and focus group and analysis of the data thereafter. However, this possibility of bias was prevented during all the stages of the study through strategies of trustworthiness, reflexivity, bracketing and intuiting.

5.7 CONCLUSION

This chapter focussed on the conclusions of the research findings. Findings and recommendations were discussed according to the themes derived from the study. Possible future studies were recommended. The strengths and limitations of the research were also described.

Hopefully, this research contributes to understanding the lived experiences of women suffering from MS, and that the findings and recommendations can serve as a basis for future research projects and for consideration during future changes in health policies.

It is also hoped that the experiences of the participants could be used to formulate policies and procedures, which can contribute to making living with MS a less traumatic and a more positive experience.

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Annexure A

**Letters requesting permission from
Gauteng Health Department
to conduct research**

**Letter requesting permission from the
Ethics Committee
to conduct research**

L de Villiers
PO Box 1486
Heidelberg
1438

14 January 2004

Dr L Rispel
Head: Department of Health
Private Bag X085
Marshalltown
2107

Dear Dr Rispel

PERMISSION TO CONDUCT RESEARCH

I hereby apply for permission to conduct research. The research is for an M Cur degree in advanced nursing sciences in the Department of Health Studies at the University of South Africa. The topic is: The perceptions of women with multiple sclerosis (MS).

The aim of the study is to investigate and describe the perceptions of women with MS in Johannesburg and the East Rand. The purpose will be to describe how these perceptions influence their day-to-day experiences, in order to make a contribution to influence persons with MS more positively.

As the study is qualitative, in-depth interviews will be conducted with women living with MS and a focus group will be conducted with some of the women visiting the MS clinic. Ethical considerations will be utilised to prevent harm and to protect the confidentiality of the participants.

The Department of Health Studies at the University of South Africa has already approved my research project. My supervisors are Mrs M van der Merwe and Dr SP Hattingh. They can be contacted at (012) 429-6338 or (012) 429-6303.

Thank you for your cooperation and support.

Yours sincerely

.....
Lynn de Villiers (Mrs)

Fax: 016 3495259

E-mail: tiptip@absamail.co.za

PO Box 1486
Heidelberg
1438

18 February 2004

Dr SP Hattingh
Department of Health Studies
University of South Africa
PO Box 392
UNISA
0003

Dear Dr Hattingh

PERMISSION TO CONDUCT RESEARCH FROM THE ETHICS COMMITTEE

I hereby apply for a letter of consent from the Ethics Committee to conduct research. Gauteng Department of Health has requested such a letter before they can give me permission to conduct my research on: "The perceptions of women with multiple sclerosis." I contacted Mrs M van der Merwe and she suggested requesting such a letter from you.

Thank you

Lynn de Villiers (Mrs)

Annexure B

**Letter from Gauteng Health Department
granting permission to conduct research**

**Letter from the Ethics Committee
granting permission to conduct research**

Annexure C

Letter to participants

PO Box 1486
Heidelberg
1438

1 January 2004

Dear Participant

Multiple sclerosis (MS) is a condition that is not always understood by others, therefore the decision was made to do research on the perceptions of women with MS.

The aim of the study is to describe the perceptions of women living with MS in Johannesburg and the East Rand, and how these perceptions influence their day-to-day experiences, in order to make a contribution to influence persons with MS more positively.

I would appreciate if you would take part in my research project and be an informant. The data will be gathered through a semi-structured interview, and possible follow-up interviews (if needed) to clarify data. The interviews will be recorded on tape, but all information will be kept strictly confidential.

Thank you in anticipation for your willingness to be a participant.

Sincerely yours

.....
L de Villiers
RESEARCHER

Annexure D

**Agreement between
participant and researcher**

Agreement

I, on this day of 2004

hereby consent to

- being interviewed by L de Villiers on the topic "The perceptions of women with multiple sclerosis"
- follow-up interviews, if necessary
- the interviews being audio-taped
- the use of data derived from these interviews by the interviewer in the research report as she deems appropriate

I also understand that

- I am free to terminate my involvement or to recall my consent to participate in this research at any time I feel like it
- information given up to the point of my termination of participation could, however, still be used by the researcher
- confidentiality will be maintained by the researcher and my identity will not be linked to information
- more than one interview may be necessary
- no reimbursement will be made by the researcher for information given or participation in this project
- I may refrain from answering questions should I feel these are an invasion of my privacy
- by signing this agreement I undertake to give honest answers to reasonable questions and not to mislead the researcher
- I will be given the original copy of this agreement on signing it

I hereby acknowledge that the researcher has

- discussed with me in detail the purpose of this research project
- informed me about the contents of this agreement
- pointed out the implication of signing this agreement

- In co-signing this agreement, the researcher has undertaken to
- maintain confidentiality and privacy regarding the participant's identity and information given by the participant
- arrange in advance a suitable time for an interview to take place
- safeguard the duplicate of this agreement

Participant.....

Researcher.....

Date.....

Annexure E

**A personal reflection of the
researcher's experience**

Experience of the researcher

In the early nineties I saw a movie about an actress who had Multiple Sclerosis, and became interested in the condition and read up on it. Over the years my mother had a few "funny" spells that we all considered hysteria. In 1997 she went for tests with a neurologist, which included an MRI scan. She phoned me afterwards very relieved with a diagnosis of MS. I was stunned, being a professional nurse who had some experience with patients and a bit of knowledge. On asking her what she knew or was told about MS, she replied that it was something that comes and goes and that it was nothing serious! I was too shocked to tell her the truth and perhaps was not able to face the reality of the situation myself.

As time went by there were relapses and remissions. During relapses she became violent, depressed, and verbally abusive. Then one day, after a blind spell, I confronted her with the truth about the condition and how her actions were affecting the rest of the family. I told her I was no expert, but was still her daughter and did not like to be shut out of her life with MS. Our relationship became one of friends and support when it came to MS. Every time a symptom showed up, she would tell me, I would comfort her and read up on it. Very recently she mentioned that she fears the day she has to use a wheelchair, and I started to tell her about the new battery types! After a long pause she started laughing, saying that was not exactly what she wanted to hear. I then realised that I did not take her feelings and fears into consideration but sometimes a bit of truth and humour could also do good.

She is a very independent person and does not like to feel dependent or incompetent. Two years ago she could not cope with the pace at work as a clerk anymore. The management of the company were very understanding and offered that she could make the materials they need at home. Now she still has a job, earns an income, stays independent, but does it on her own time at home.

MS affects the whole person, physically, psychologically and socially. I realised that MS affects not only the person with MS, but also those around them, such as family, friends and colleagues. I perceived that on diagnosis people are not given the correct information neither

are their loved ones informed what to expect. This leads to perceptions of incompetence, insecurity and being a burden to others which, in turn, leads to loneliness and depression for women with MS. Women with MS feel less feminine. They are afraid to raise their concerns about symptoms and other issues as they also perceive that they will worry their loved ones.

MS is unpredictable and a condition that does more psychological damage than physical damage.

Annexure F

Aide de memoire

AIDE DE MEMOIRE

BIOGRAPHICAL DATA

Age:

Address:

Marital status:

Family status:

If not married, do you live alone or with other people?

How are they related?

Were you born in SA?

If not, in which country?

Did your parents immigrate?

Language at home:

WORK STATUS

Do you work, and if so what kind of work?

Length of service:

Were any changes made to accommodate you at work?

DIAGNOSIS

How long since diagnosis?

Type of MS:

Method of diagnosis:

Do any other members of your family have the condition?

How are they related?

DISEASE PROGRESSION

How do you think your condition will be next year?

What are your expectations of the disease progression?

What has your experience helped for your condition?

Which symptoms do you experience mostly?

Do you have any notion/theory of why you contracted the disease?

MOBILITY STATUS

(Mobile, Mobile with difficulty, Mobility aide, Wheelchair, Bed bound)

How long in this status?

IMPACT OF THE DISEASE

How did you feel when you were diagnosed?

Do you feel you were given adequate information when you were diagnosed?

What changes did you experience at work and home?

What emotional challenges have you experienced/barriers have you encountered?

What physical challenge/barrier affects you the most?

How do you overcome this problem?

Do you experience social barriers/challenges? Tell me about them.

Do you see yourself as resilient, if so why?

What do you find helps most to cope with your changed life?

What do you think can be done to help persons with MS to cope better?

Which of your family members were affected most by your condition, and why?

How does your family cope with the changes in your life?

Are there any role changes in the family?

Do you find that MS has impacted on your life in a positive way, why/negative way, why?

How was your role as a woman (femininity) affected?

How does being more dependent on others make you feel?

If you realise that you cannot do some task, what feelings do you experience?

How do you cope with feelings of independence and incompetence?

Anything else you can tell me about your perceptions on MS?

Annexure G

Example of a transcription

A1 - Mrs M

Biographical data

Area: East Rand, Springs
Age: 54
Marital status: Married
Family status: Two grown children, not living with her
Born: SA
Language: English and Afrikaans
Type: Relapsing-remitting

Interview

I: Good morning.
P: Good morning.
I: Thank you for your participation.
P: You're welcome.
I: Did your parents emigrate from another country?
P: No, not at all.
I: Previous ancestry?
P: Yes, from Portugal and Germany.
I: How many years ago or how long ago?
P: From the 1600s.
I: OK, do you work?
P: I work from home. I used to work, but I work from home now.
I: So I presume that this change was made to accommodate you in your work situation?
P: Yes, it was.
I: How did that happen?
P: Well, the stress of the traffic, travelling to and from work, I couldn't really handle that very much, and the heat. I would become tired by two, three o'clock in the afternoon and it was difficult for them to give me flexi-hours, because they didn't really have the flexi-hour option for their workers. And then they offered me a contract to work from home.
I: OK, so what kind of work do you do?
P: I do sewing.
I: And doesn't it make you tired?
P: It does, but I have the option to go and lie down and rest whenever I want or feel the need to.
I: OK, how long since you were diagnosed?
P: Six years.
I: Six years, and what type of MS do you have?
P: I have relapsing-remitting.
I: And how were you diagnosed?
P: With an MRI scan.
I: Do any other members of your family have it?
P: Not that I know of.
I: And previously in your ancestry?
P: There might have been, but it was not diagnosed as MS, because they did not have the facility then.

- I: So what happened to that person?
- P: I know of one lady who became paralysed and landed up in a wheelchair eventually, and one male person who had difficulty in walking, especially in the right leg.
- I: And how were they related?
- P: The lady was my mother's aunt and the man was my mother's cousin.
- I: So both were on your mother's side?
- P: Both on my mother's side.
- I: And your mother is from which ancestry?
- P: She is German.
- I: German. How do you think your condition will be next year?
- P: I think it will be the same as what it is now.
- I: What is your expectation of your disease progression?
- P: I think my condition will stay more or less for the same the rest of my life. I don't believe it will become worse.
- I: What have you found helps mostly for your condition?
- P: Helps mostly?
- I: Yes, what do you do to make it stay, what helps you medication wise, anything?
- P: Oh, the main thing that keeps my condition is the willpower to stay mobile and not become paralysed; positive thinking, being busy, not thinking about the disease too much and doing things myself as much as possible.
- I: Do you use any medication?
- P: I go on a Solu-medrol drip at times when I have an acute attack, but apart from that I only use vitamins, multivitamins, and that type of stuff. I don't really use medication.
- I: When you have an acute attack, what are the symptoms?
- P: Well, mostly it will be double-vision, or tunnel vision; sluggish in walking; sometimes my bladder blows up. It is different types of symptoms at different stages. It's not ever the same.
- I: So every time it's different?
- P: Different.
- I: So you don't know what to expect?
- P: Exactly.
- I: What symptoms do you experience mostly on average?
- P: Mostly on average, is a burning sensation in some parts of my arms and legs, tunnel vision, numb or dead places in some parts of my body, especially on the left, my big toe and so on. Then I really have trouble with my bladder, and my eyesight is really bad.
- I: Do you have any notion or theory why you contracted the disease?
- P: I think, I really believe that it's hereditary from my mother's side. But then, on the other side it could have been trauma that I experienced early in my life, in my early twenties.
- I: Trauma, do you mean emotionally or physically?
- P: Emotionally.
- I: Emotionally. Do you want to speak about it?
- P: My divorce.
- I: Oh.
- P: From my first husband, and I would say that was the biggest trauma I had. It was quite a trauma.

- I: Oh, so after, the divorce from your husband, what happened that you think it might have caused it?
- P: I started having attacks that in the beginning they thought it was epilepsy. I could not see properly, I had no headaches though, but I could not see properly and it almost felt like a really bad migraine. My face pulled to the one side, my tongue slurred, and I could not remember what happened to me at that stage.
- I: Ok, so since you were diagnosed, I mean, how did it come to it? What happened?
- P: I also had an attack, like I just described to you about the tongue slurring, the eyesight, the face pulling, I could not see, I could not see at all. In fact, just before they diagnosed me, this attack that I had was so bad that I even started talking nonsense. I knew I was talking nonsense, but I could not stop myself. My face pulled so badly that my left eye was enlarged, and was open the whole time.
- I: Ok, and then you went to the doctor, or what?
- P: I went to the doctor, and he said at that stage I might have had a light stroke, but then he decided to send me to a neurologist, and I went about three days after I had the attack. He then did the MRI scan and I was then diagnosed as a possible case of MS.
- I: When you were sitting in the doctor's rooms at the neurologist after the MRI scan, did he tell you? Or who told you about it?
- P: He told me about it.
- I: And how did he tell you?
- P: He asked me to sit down, and then he said he was sorry, but he had some bad news for me, but he could not be too sure, because he had to make me realise that it might not be the problem. And then he told about what MS is. He gave me two videotapes to go and view at home, which I had to take back the next day. And then he told me that I might possibly have this disease.
- I: And how did you feel when he told you?
- P: I did not really feel anything, it was just another illness, although he said it was incurable, I did not think it was that. I was sort of in denial. I really did not think it was that.
- I: Would you say that when you were diagnosed you were given enough information about the disease?
- P: Not totally. I had plenty, but at the time I was sort of diagnosed with MS I don't think the doctor felt the need to really tell me everything, because he did not want to scare me in the first place and in the second place he was not too sure that I did have MS. So he did not really tell me everything. I think when a patient is diagnosed even when the doctor tells you things about MS, you don't really know until you experience what MS is really about.
- I: So, you would say, if you are diagnosed he must tell you some things but give you the option to come back for more information.
- P: Yes, give an option of where people can go to get information, because even a neurologist cannot tell you everything. Tell them to contact a support group, for instance, where people can share their experiences, or where a newly diagnosed person can go and say, "Listen, what is this all about? What is going to happen to me?" So somebody can tell you. The neurologist has got different people that he sees every two to three months maybe. He doesn't see them every day, he does not really know what they really experience. The best place to get information about MS is your support group.
- I: Did you go to a support group?
- P: Yes, I belong to a support group.

I: Do you go regularly?

P: I don't anymore. I feel that my condition is in such a stage that the progressed condition really upsets me because it scares me to death that I might become what they are now. And at this stage I want to stay positive, so I don't go to support groups now anymore. I know what can happen now. I know, I have seen the people. I have talked to them, so I know what to expect. I know what I can look out for, and I know what I can expect. But I am scared if I go there it depresses me.

I: With regard to your mobility status, are you still mobile? Is there any difficulty in mobility?

P: From time to time, I do have not very serious difficulty. In the beginning, after I was diagnosed, for a year or so I really had difficulty moving. I was in a lot of pain. I experienced a lot of stiffness, sometimes my left leg just would not go with me. But I have not had it for the last three or four years. So my mobility is quite good. Apart from sluggishness sometimes, it is quite good.

I: Do you use any mobility aids?

P: No.

I: Not at all. What changes after diagnosis until now did you experience in your home? Did you make a lot of changes in your home?

P: No, not at the moment. I did not really make any changes. The only change that I made is the fact that I can't do things like paint and drill holes in the walls anymore that I used to do. But I have accepted that. But changes in the house, no, I did not do anything else.

I: Did you have somebody to help you in the house before with the housework?

P: Yes, I did.

I: And do you still have someone?

P: I still have someone. The only other change that I did make is that I employed somebody who can drive a vehicle, so that when I do have an attack of tunnel vision or something and I have to be at a place, then I can go there.

I: So you still have somebody doing the housework and then you have this person who can drive you around when needed?

P: It is the same person.

I: The same person. You said that when you go to the support group that it has an effect on you and you sometimes feel depressed afterwards. What emotional challenges did you experience?

P: I am not a depressed person, but at the support groups, some of the people were very negative, especially some of them who had progressed and might be not as mobile as they used to be. I sometimes felt guilty and I went into denial, and decided that they had made a mistake, I do not have MS because how can these people look like this and I can still be mobile and do things for myself and they cannot? So I decided to stay away from there. I do not get depressed when I am on my own. I get angry and frustrated.

I: How do you let go of the anger?

P: I feel angry when I cannot do things that I have to do, especially with the sewing, or if I am in the kitchen and I drop food on the floor or something like that. I don't really do anything to get rid of the anger; it just goes away after a while. After a while I realise I cannot do this, so that's it, I cannot do it. Tomorrow I may be able to do it again.

I: And what physical challenges do you experience?

- P: The only challenge now is the fact that I cannot always hold the material when I do sewing. My hands won't co-operate with me. That, to me, is the biggest physical challenge that I have and to really make my hands work for me, and they do not always want to.
- I: You also said that your mobility is sometimes sluggish. Does that have any affect on you?
- P: Yes it does. It is very frustrating if I want to do things and I am slow and sluggish and maybe even a little bit of pain when I move sometimes, not always. But I have become slower than I used to be and it could be my age, because I am getting older, but I don't put it down to age. I have sisters that are older than me, and they can do things much faster than me, so it's got nothing to do with age. The only thing it has to do with is MS.
- I: You also say that you have a lot of bladder problems. You said you have somebody who drives you around sometimes, so I presume you do a lot of travelling?
- P: Yes, I do.
- I: Does it affect you?
- P: Yes, it does. It's actually very embarrassing, and it affects me in a way that I am scared to go places. At that stage the bladder plays up for a while and then gets better, and then starts again. I never know when it's going to start playing up and then I won't be able to control myself. So that is very, very embarrassing and it does keep me away from places. If I have to go to a place, I get back immediately. I don't stay because I am scared something might happen.
- I: Do you experience any social problems challenges or barriers?
- P: Just the fact that, you see, if people invite us over for an evening for supper or something, I feel reluctant to go, because I am scared I might have a problem with my bladder and, you know, that is embarrassing. That is a social barrier. I do not communicate with people socially anymore because it is difficult for me. People don't always understand what this is all about. I sometimes don't have the energy to do things, I just sit still and they don't understand that. I don't really communicate socially anymore.
- I: Do you see yourself as resilient?
- P: Yes, yes I think I am. But if I am down, it is not for ever on end; it is just for a minute or a moment, or angry for a moment and then it is over, and then I carry on. I have to stay positive because I believe that will keep me from becoming immobile or whatever.
- I: So you believe in positive thinking. Is there anything specific you do?
- P: Just I am a very positive person. I am not really a negative person. I just decided for myself I am not going to land up in a wheelchair, I am going to walk until the day I die, and that is all.
- I: I see, what do you think can be done to help people with MS to cope better?
- P: I think, in the beginning especially, to just realise what the illness is about, belong to a support group, to take what's good from them, because it affects every person differently. They can stay in a support group, because it is sometimes good for some people to see that other people understand what they are going through. And there are some people who do not have the finances, and the MS society is really trying to help there. I am talking about having walking aids and so on as they cannot afford it. They cannot afford the medication. I think that government, as such, should stop looking into one disease only, and start making provision for people like MS patients that do not have money and maybe have a plan to give them the solu-medrol drips at provincial hospitals or whatever, because they don't do that anymore, and I think that they need it and cannot afford it.

I don't really know what else they can do. Oh, and they can make buildings accessible to people who are immobile and that type of thing.

I: Like stairs?

P: Yes, yes!

I: Do you have problems with stairs?

P: Even though I am mobile, I experience a lot of problems with climbing stairs. You come to the middle or the second stair even, and it feels like your legs just will not take you any further and it is difficult for people. There must be ramps, there must be lifts. Most of the newer buildings do help people. But I found that the place where I used to work, I had to go in the back door sometimes, not to climb the front stairs to get into the building, and it is miles to the back. I had to travel with my car, and then I had to walk for quite a while and distance. People don't always think about disabled people.

I: So you would say there are ten stairs but now you have to walk five hundred metres to get to the same place?

P: Exactly, but I don't have to climb. It does not work so much on my knees, but there should be legislation that owners or tenants should see that a building is accessible for disabled people.

I: Do you see yourself as disabled?

P: No, but I see other people that are disabled, that have MS and other diseases, are paralysed, or had a car accident or whatever. And they battle and there should be legislation in South Africa that every building should be accessible for people with disabilities.

I: Who of your family members were affected most by your condition?

P: I would say my husband.

I: Your husband, how?

P: He does not want to accept the fact that I have MS, he does not understand it. I tried to give him literature on the subject, but he does not want to read it. I think he has an attitude that if he ignores it, it will go away. He does not accept the fact that I have MS.

I: How does your family cope with the changes in your life, I mean like changes in your home?

P: I think sometimes my husband is jealous or that he feels I am more privileged to be able to work from home. Sometimes he thinks that I am not doing anything, but I am.

I: Are there any role changes in your family?

P: Not really, not really.

I: Not really, and do you feel that MS has impacted your life in a positive or negative way?

P: A little bit negatively, because I have always been a busy person, and now being slow and sluggish and not always able to do things. And on the social side a bit too, because I am a people person, and it is difficult sometimes not being able to or being scared to go to friends, or to be active or whatever.

I: You said that you have sisters. Do any of them have a problem?

P: My sisters have not been tested, but it does not seem that any of them have problems.

I: How do your sisters cope with it?

P: Very supportive.

I: And your children, how do they cope with it?

P: My daughter copes with it very well and is also very supportive. My son is like my husband: I don't have the disease as far as he is concerned, so I don't have it.

- I: When you want to do something and you realise you cannot do it anymore, how does it make you feel?
- P: It sometimes makes me feel angry. I have never been dependent on other people, and when I do need somebody to do things for me that I used to do myself, it makes me angry, it makes me frustrated. But then, on the other hand, I am glad that I do have people who can help me.
- I: Any other feelings that you experience?
- P: Only anger and frustration, that is all.
- I: Sometimes you feel angry and dependent. How do you cope with these feelings or the incompetence?
- P: I can't really cope with it. That is why I get angry. If I could cope with it, with the feeling of incompetence, I would not get angry. I don't want to be dependent on people; I want to do things for myself. And I am a very impatient person, if I want something done, I want it done now, and people cannot always run and do things now, so it affects me badly. I don't want to be dependent on other people.
- I: So what do you think would help you to cope?
- P: I don't know, I really don't know what would help me. Maybe going to a psychiatrist, but I don't think it will work. Not that I don't want to go to a psychiatrist or a psychologist or somebody, but it is just in my nature to be a little hasty and maybe I think I can do things better than other people. I don't know, maybe it's just that and I don't think I can get used to the fact that I can't do it anymore.
- I: Do people sometimes get nasty?
- P: No, not at all. They all have an "oh shame" attitude and I don't think they know what it is really about. The public out there don't know what MS is all about. They may know more about Aids and those things, but if you tell them you have MS, they always think you have osteoporosis or something. They don't know what it's about, they don't know at all. But no, they're not nasty.
- I: Do you sometimes experience that perhaps your legs don't want to go or you can't speak properly and they think you're making it up?
- P: That I have experienced and what I have also experienced is at the times when I walk a little bit strangely as far as my movement is concerned, South African people do not have patience with anybody who is disabled. They take their parking spaces, and walk right in front of you. The Black people are more polite about it; if they see you battling to walk, they will try to get you across the street. The white people, unfortunately, and I am one myself, could not care. They would walk right over you, they do not mind. You can get there on your own time.
- I: Anything else you can tell me about your perceptions of MS?
- P: Maybe I am in denial about whether I really have MS. I don't think there is anything else that I can say. If only people had told me in the beginning that pain is the most uncomfortable thing about MS.
- I: How does MS affect your day-to-day experiences? Tell me about a bad day.
- P: A bad day, on a bad day you will get up, and you don't want to get up, you are too tired. And if you do get tired, everything is late. You feel frustrated; you feel the day must just end. On a good day, you get up, you can walk nicely, and go on with your day-to-day chores and you feel quite happy about it. But a bad day is a bad day, the MS is bad.
- I: Do you struggle to get dressed?

- P: I used to, but I adjusted my clothing accordingly. But the only thing that I really find difficult is that I cannot fasten my bras at the back. I cannot fasten them at the back and funnily enough, no bra company makes bras for people to fasten in the front, so I had to change them. Fortunately I can do it, but other people can't. It is very difficult if you have a sluggish or sore dumb arm to turn it to the back, and fasten your bra there, especially if you wear long bras like I do. You cannot fasten them at the back, you can't.
- I: Thank you very much. Is there anything else?
- P: No, fine.
- I: Thank you very much for your time. I appreciate it.
- P: It is a pleasure.

FIELD NOTES

House very neat.

Very strong personality.

No obvious changes seen in house; crutch in kitchen, sometimes uses it when walking with difficulty.

Has a slight limp when walking; regularly rubs right arm, and says it is always burning.

Has medical aid.

Annexure H

Newspaper excerpts

Take one dose of dagga – that's doctor's orders

Amsterdam – The Netherlands is to make dagga available as a prescription drug to treat chronically ill patients.

It would be world's first country to do so, a top Dutch health official said yesterday.

The Dutch government has given the country's 1 650 pharmacies the green light to sell cannabis to sufferers of cancer, HIV, multiple sclerosis (MS) and Tourette's syndrome from this week in a ground-breaking acceptance of the drug's medicinal use.

"It's a historic step. What is unique is that we are making it available on a prescription-only basis through pharmacies," said Willem Scholten, head of the Office of Medicinal Cannabis at the Dutch Health Ministry.

The Netherlands, where prostitution and the sale of dagga in coffee shops are regulated by the government, has a history of pioneering social reforms. It was also the first country to legalise euthanasia.

The government, which recognised that many chronically ill people were already buying dagga from coffee shops, said it should be prescribed by doctors only when conventional treatments had been exhausted or if other drugs had side-effects.

The Health Ministry recommends patients dilute the dagga in tea or turn it into a spray in a nebuliser. – Reuters

MS-lyers ontsteld oor beperkte medisyne

Interferon beta nie meer op talle fondse se lys vir chroniese siektes

Antoinette Pienaar

Honderde Suid-Afrikaners met meervoudige sklerose (MS) is hoogs ontsteld nadat verskeie siekefondse besluit het om van 1 Januarie nie meer chroniese dekking te bied vir 'n middel wat hul lewensgehalte drasties verbeter nie.

Sommige van die middels waarvoor hulle wel betaal, is glo nie eens vir MS geregistreer nie.

Mense met MS was aanvanklik bly oor die nuus dat dié siekte een van die 25 chroniese siektes is wat alle siekefondse van volgende jaar verplig is om te dek ingevolge nuwe medisynewetgewing.

Nou blyk dit talle siekefondse hou by 'n medisyne-lys van die Raad op Mediese Skemas (RMS) waarop een van die belangrikste middels, genaamd interferon beta, nie verskyn nie.

Die RMS het gister bevestig hy gaan dié lys in Maart hersien nadat Meervoudige Sklerose Suid-Afrika (MSSA) 'n klag by hom ingedien het.

Me. Madelein du Toit (47), 'n MS-lyer van Bedfordview, gebruik al twee jaar interferon, maar het pas by haar siekefonds gehoor haar chroniese voordele dek dit nie meer nie.

“Daarsonder kan my toestand só versleg dat ek binnekort met 'n kierie

sal moet loop of 'n rolstoel sal moet gebruik.”

Mnr. Con Mackie (60) van Johannesburg het pas 'n dispuut verklaar met sy siekefonds nadat hy gehoor het sy chroniese voordele vir MS is voortaan beperk tot R8 000 per jaar. “Dit dek skaars 'n maand se voorraad interferon. Dis die enigste middel wat die verloop van die siekte kan keer.”

Mackie gebruik reeds krukke en 'n rolstoel. Sonder die medisyne loop hy die gevaar om sy beweeglikheid heeltemal kwyt te wees.

Volgens mnr. Fanie du Toit, nasionale voorsitter van MSSA, is ander middels op siekefondse se lys soos metotreksaat (ametopterien), siklofosfamied en asiatioprien nie vir MS geregistreer in Suid-Afrika nie, maar wel vir kanker. Dit word glo vir MS gebruik, maar net eenmalig as laaste uitweg as iemand reeds baie siek is.

Daar is na raming meer as 4 000 MS-lyers in Suid-Afrika van wie 500 tot nou toe interferon deur hul siekefondse kon kry. Met die nuwe medisynevoordele kan tot 300 hul dekking verloor.

Siekefondse is ingevolge die nuwe medisynewetgewing se regulasies verplig om te betaal vir alternatiewe medisyne indien een van die middels op sy verpligte medisyne-lys nie werk nie of erge newe-effekte veroorsaak.

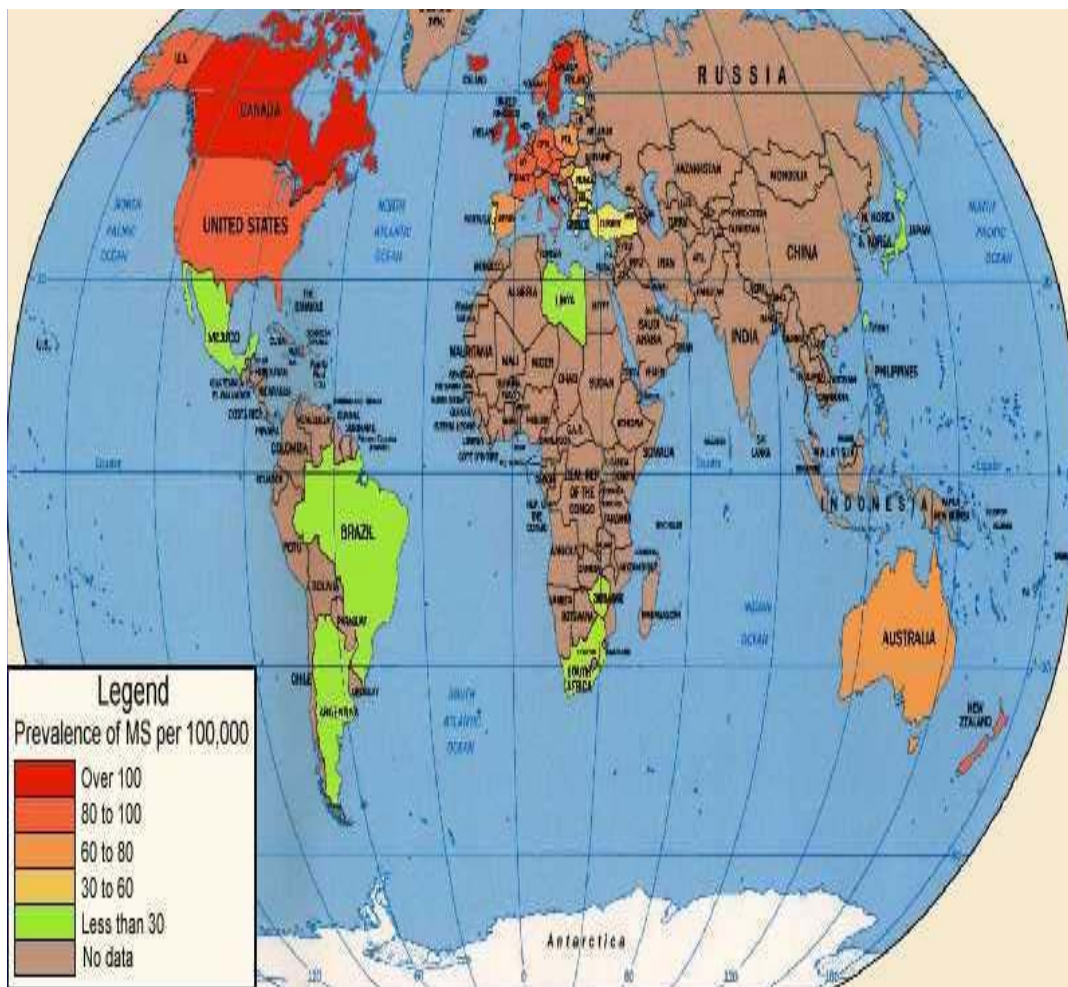
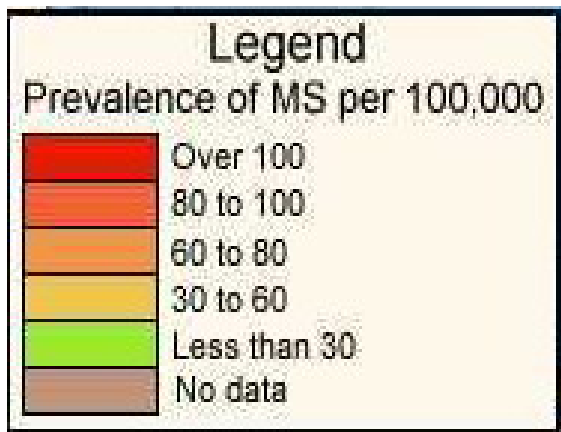


Figure 1.1

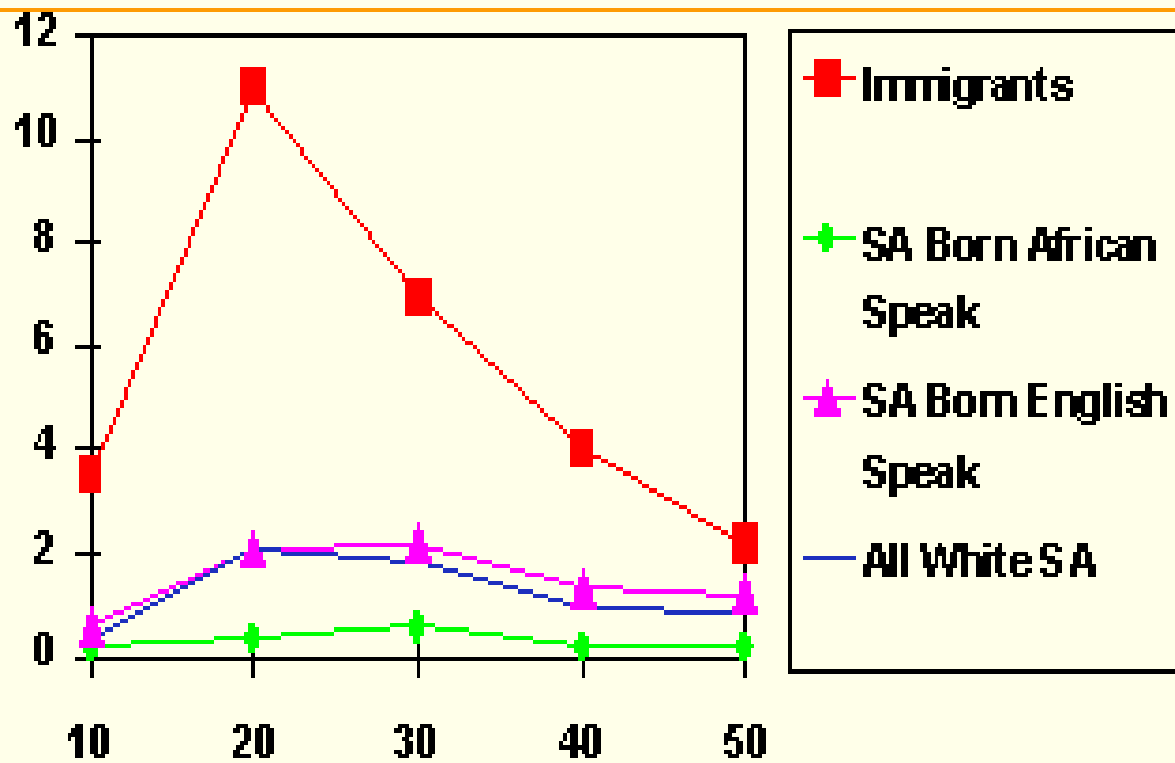
World map of prevalence of multiple sclerosis

(Jones 2002:14)



Figure 1.2
 Map of Johannesburg and the East Rand
 (Southern Africa Places 2003:1)

Incidence of MS in South Africa



Y axis: annual incidence (1/ 100 000), X axis: age

Figure 2.1
Incidence of multiple sclerosis in South Africa
(La Porte 2001:9)

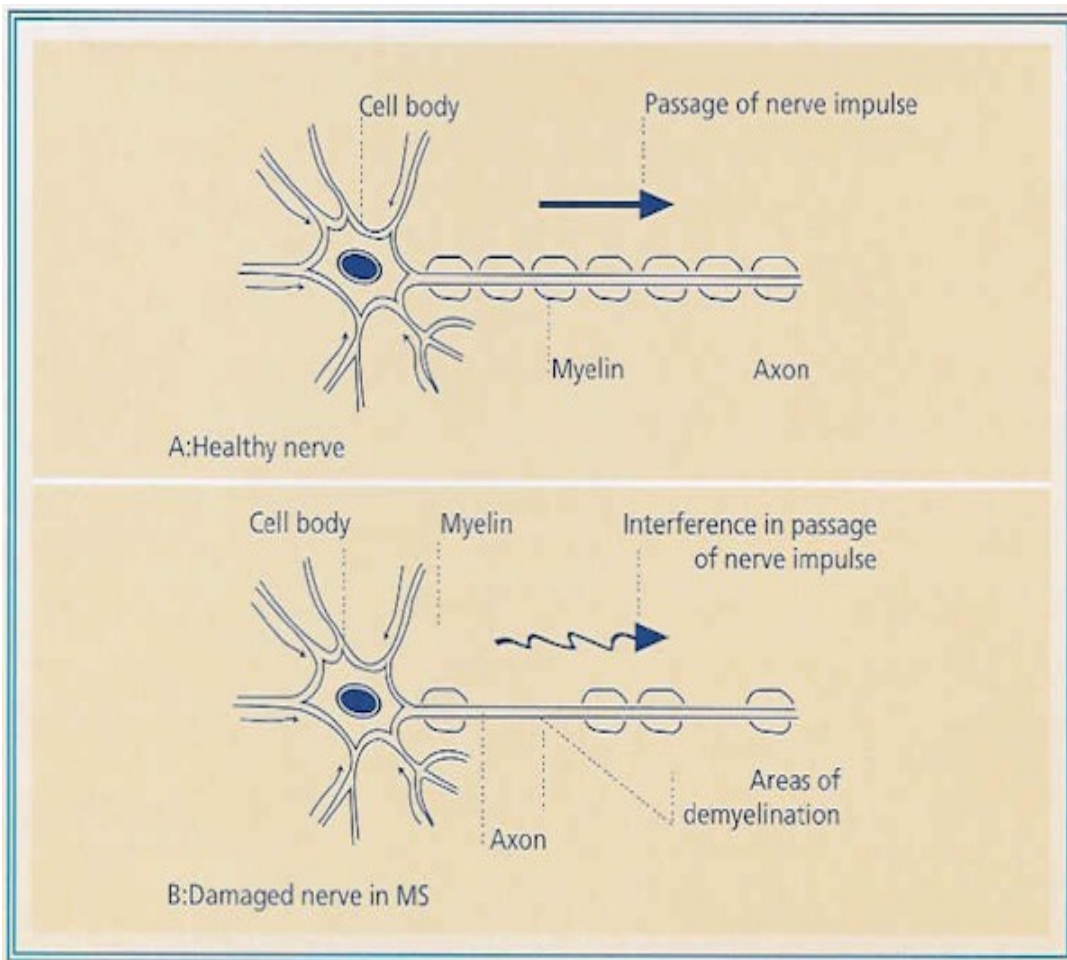


Figure 2.2

The axon

(Biogen Information Series 1999a:9)



Figure 2.3

Brain scan of a person with multiple sclerosis

(Discovery Health 2003:1)



Figure 2.4

A computer-digitised colour-enhanced magnetic resonance imaging scan
(Abrahams 2001:93)

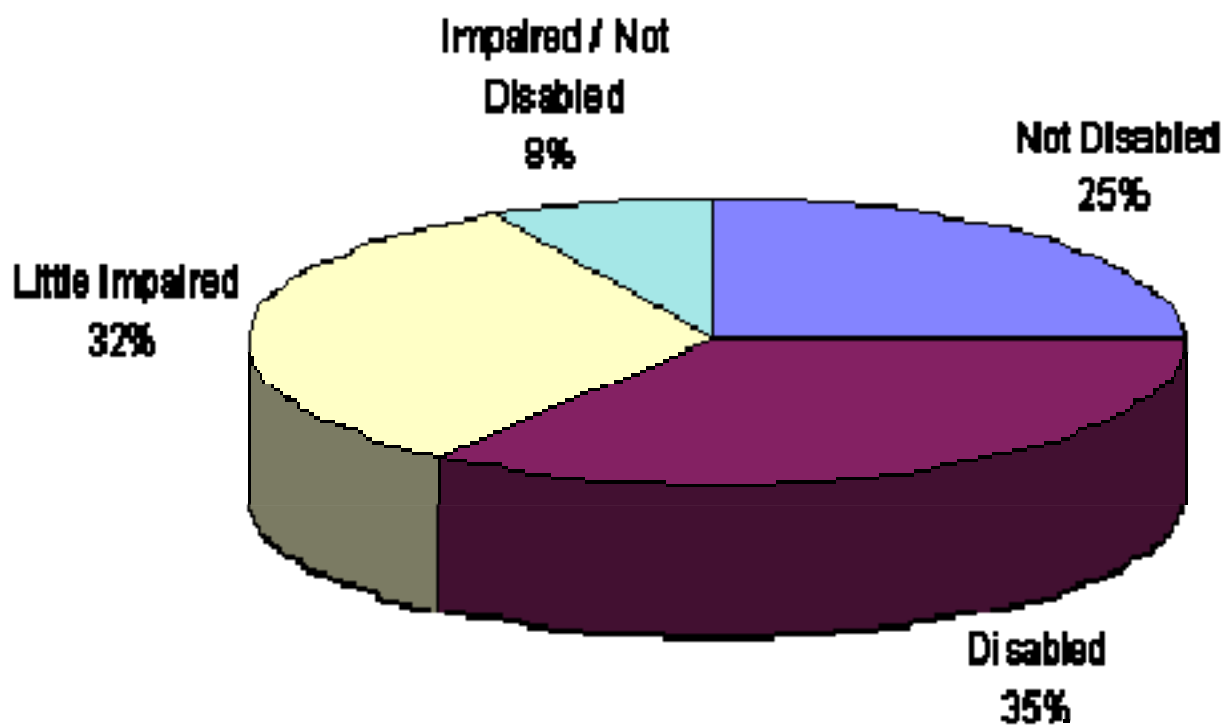


Figure 2.5
Prognosis of multiple sclerosis patients 10-20 years on
(Yanosky 2000:8)

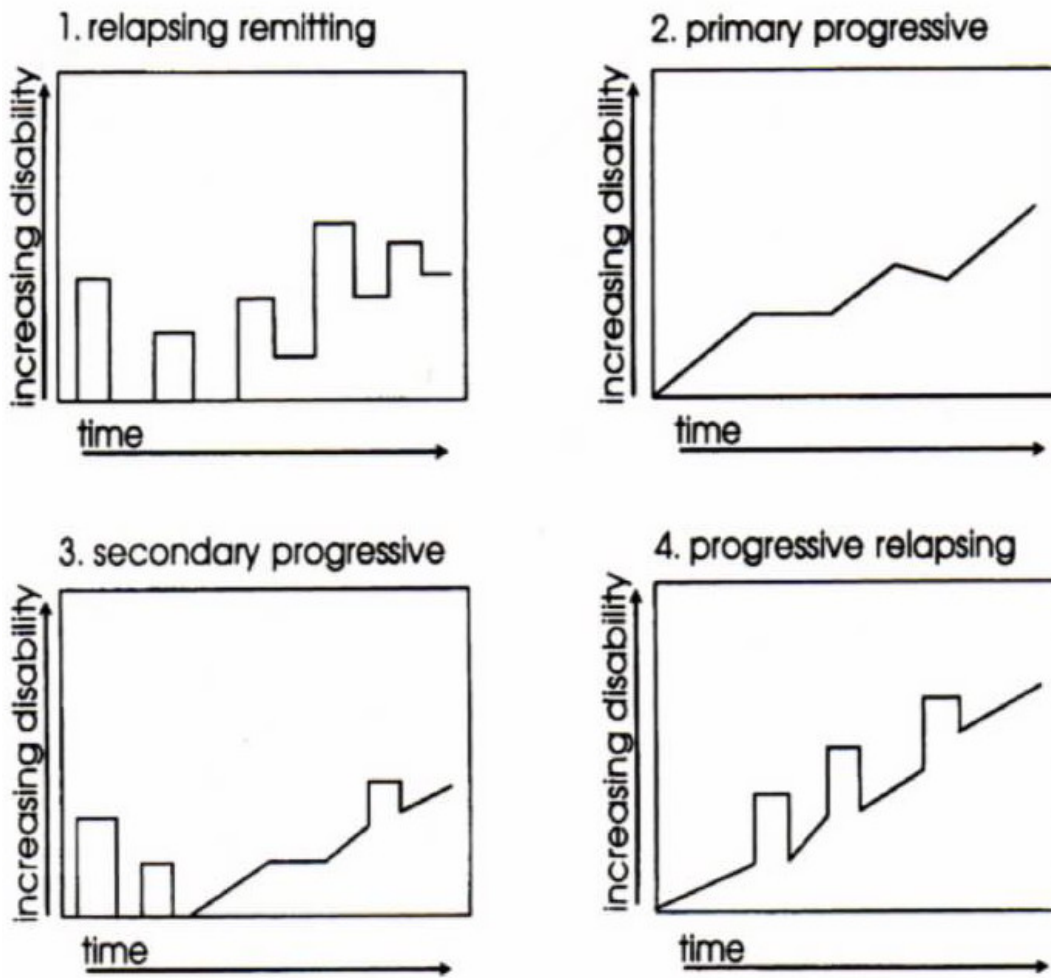


Figure 2.6

Types and courses of multiple sclerosis

(Coyle & Harper 2001:10)

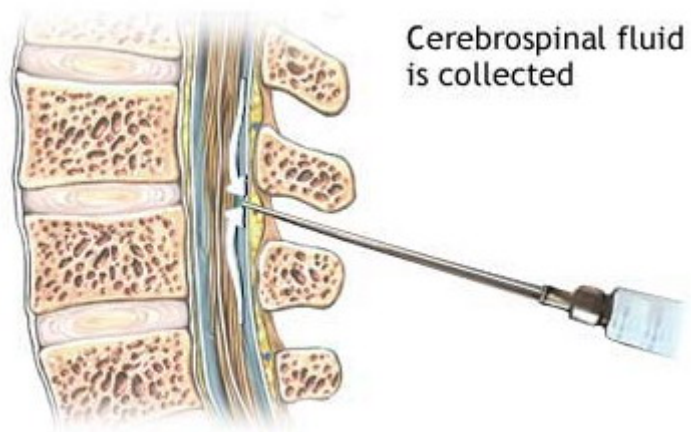


Figure 2.7
Area of lumbar puncture
(Abrahams 2001:91)

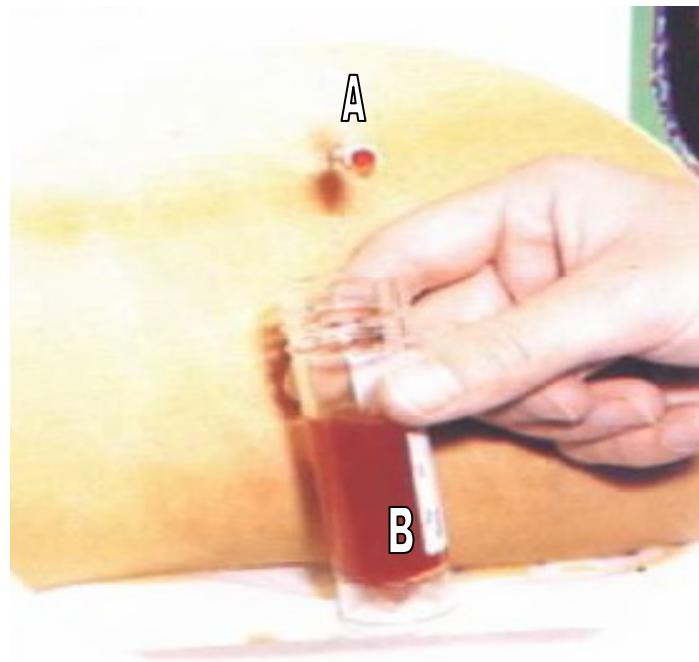


Figure 2.8
Lumbar puncture procedure
(Abrahams 2001:93)

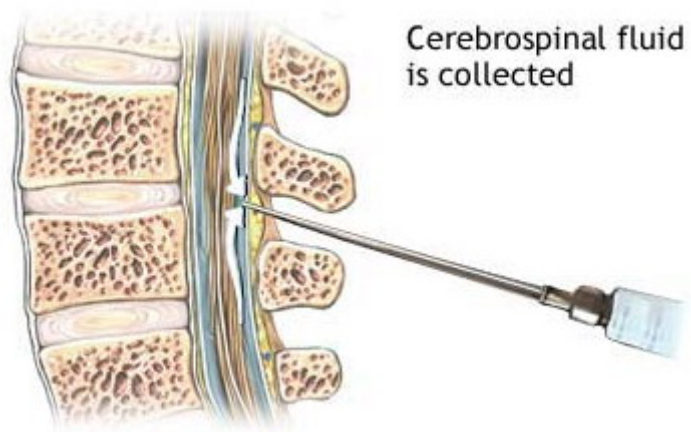


Figure 2.7
Area of Lumbar puncture

(Abrahams 2001:91)

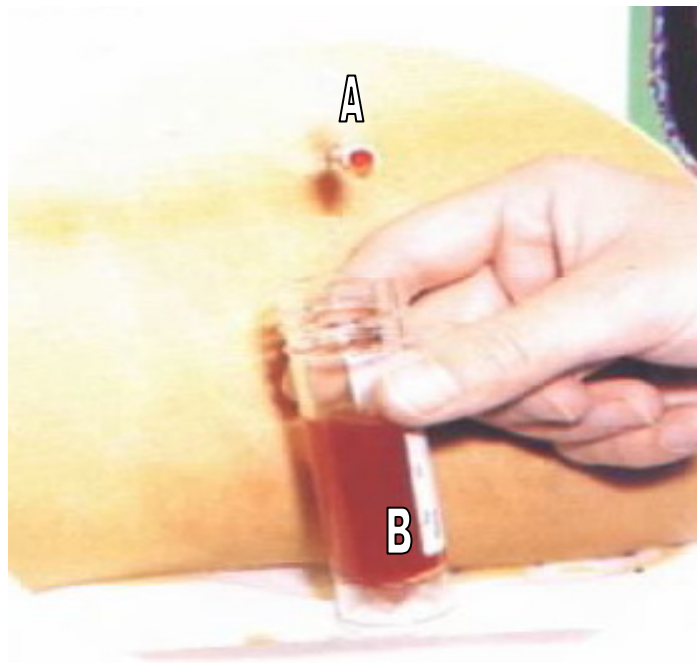


Figure 2.8
Lumbar puncture procedure

(Abrahams 2001:93)

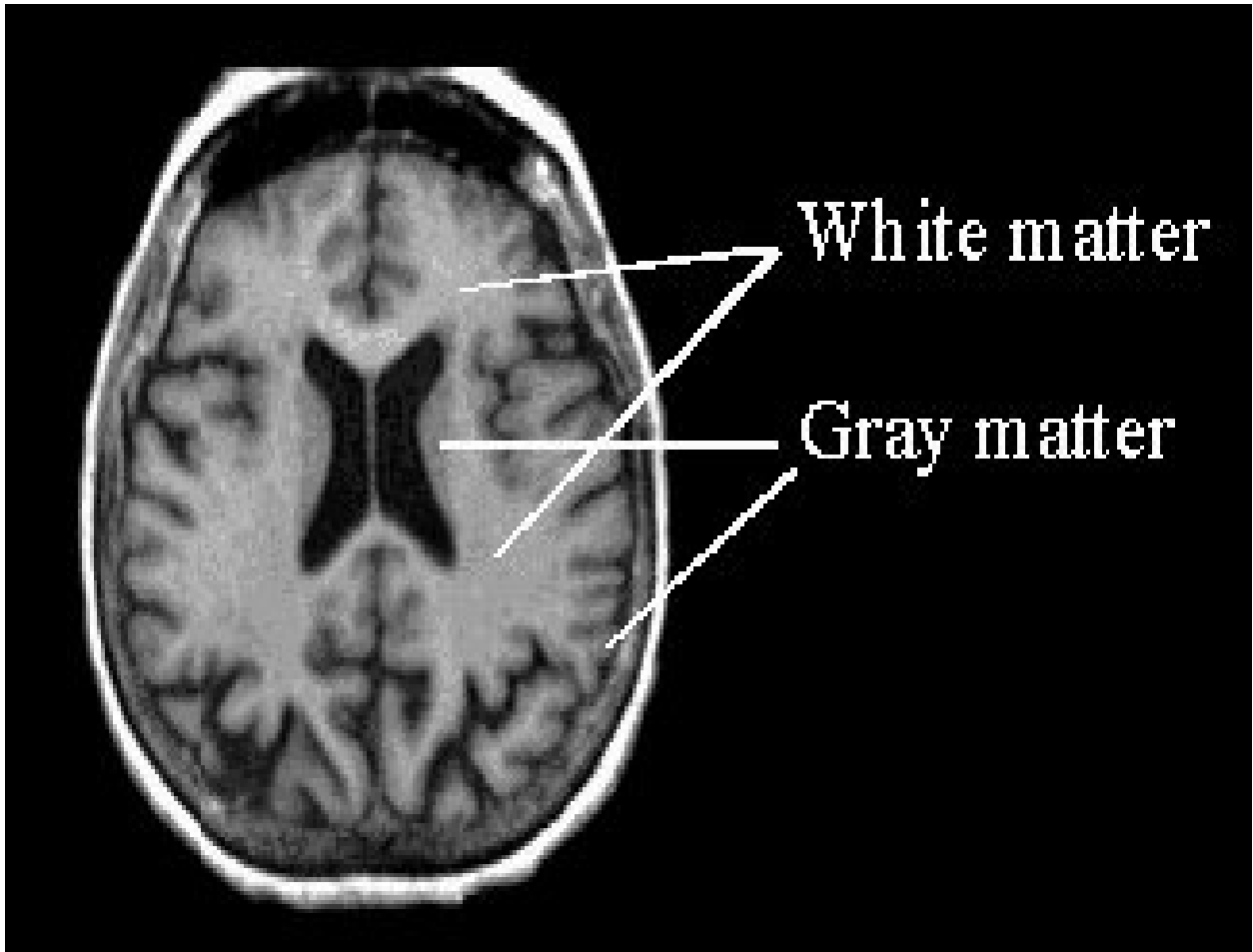


Figure 2.9
Magnetic resonance imaging of a normal brain
(Yanosky 2000:19)

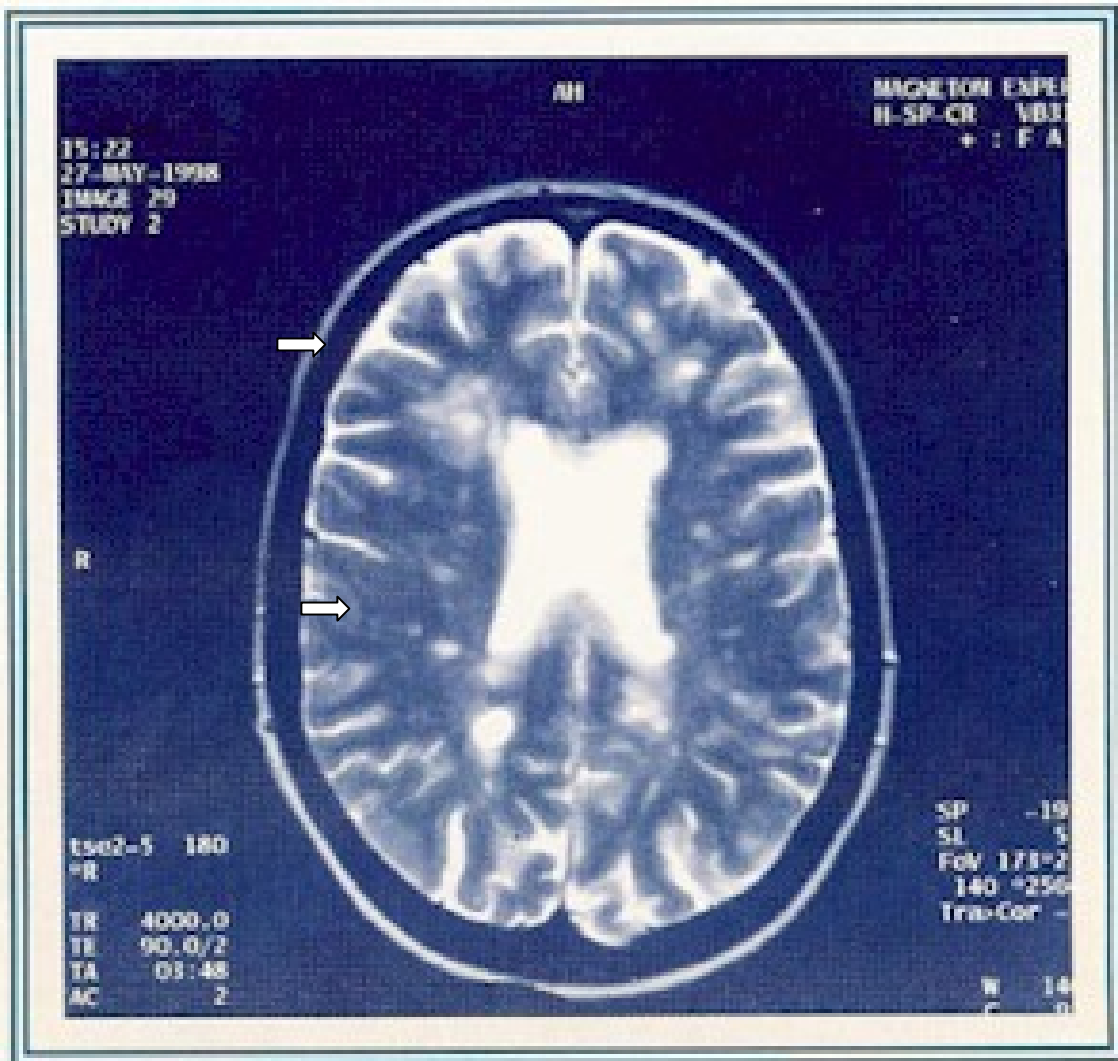


Figure 2.10

Magnetic Resonance imaging of a brain with multiple sclerosis lesions

(Biogen Information Series 1999b:23)

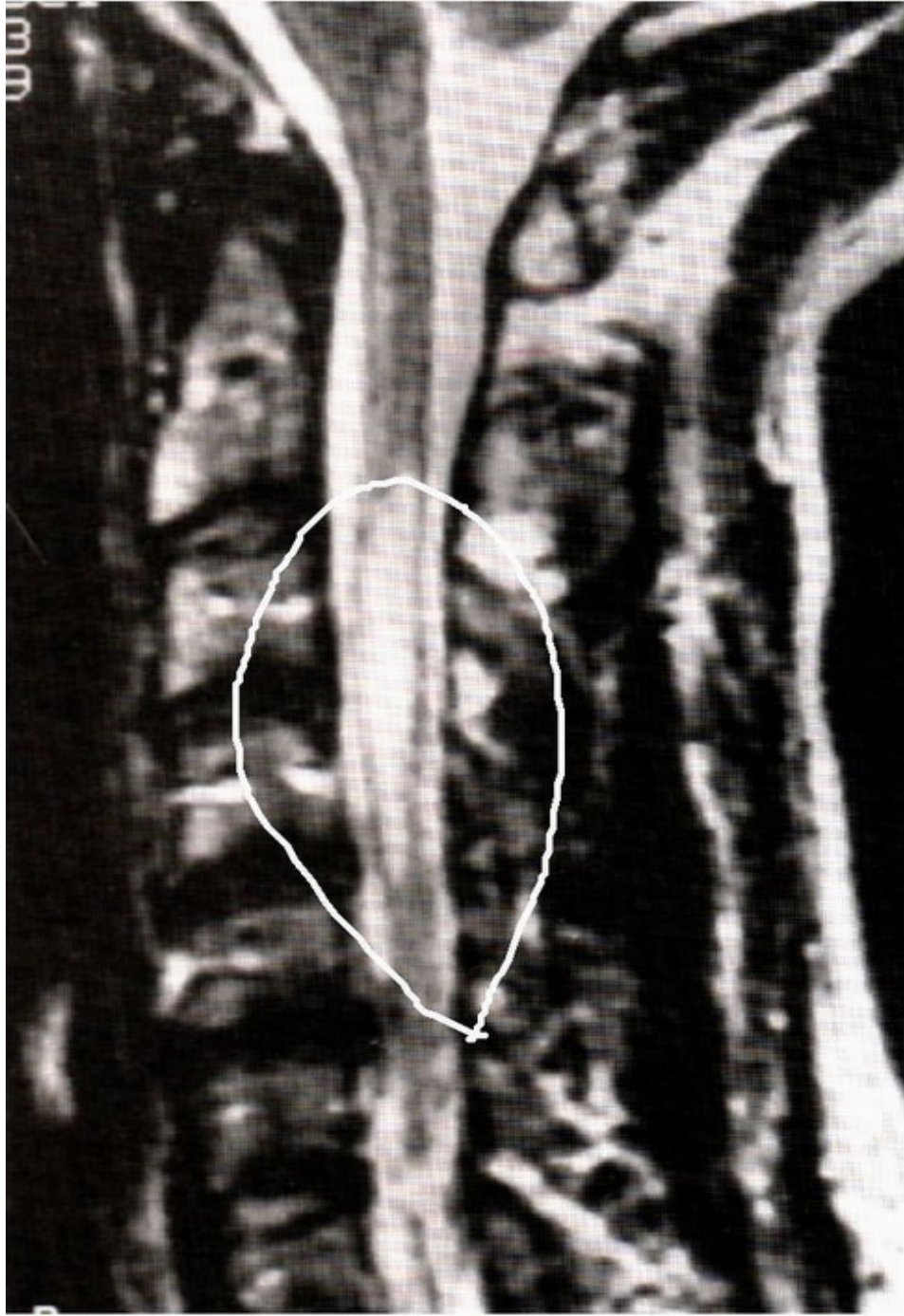


Figure 2.11
Magnetic resonance imaging of the spinal cord
(Smeltzer & Bare 2000:1719)

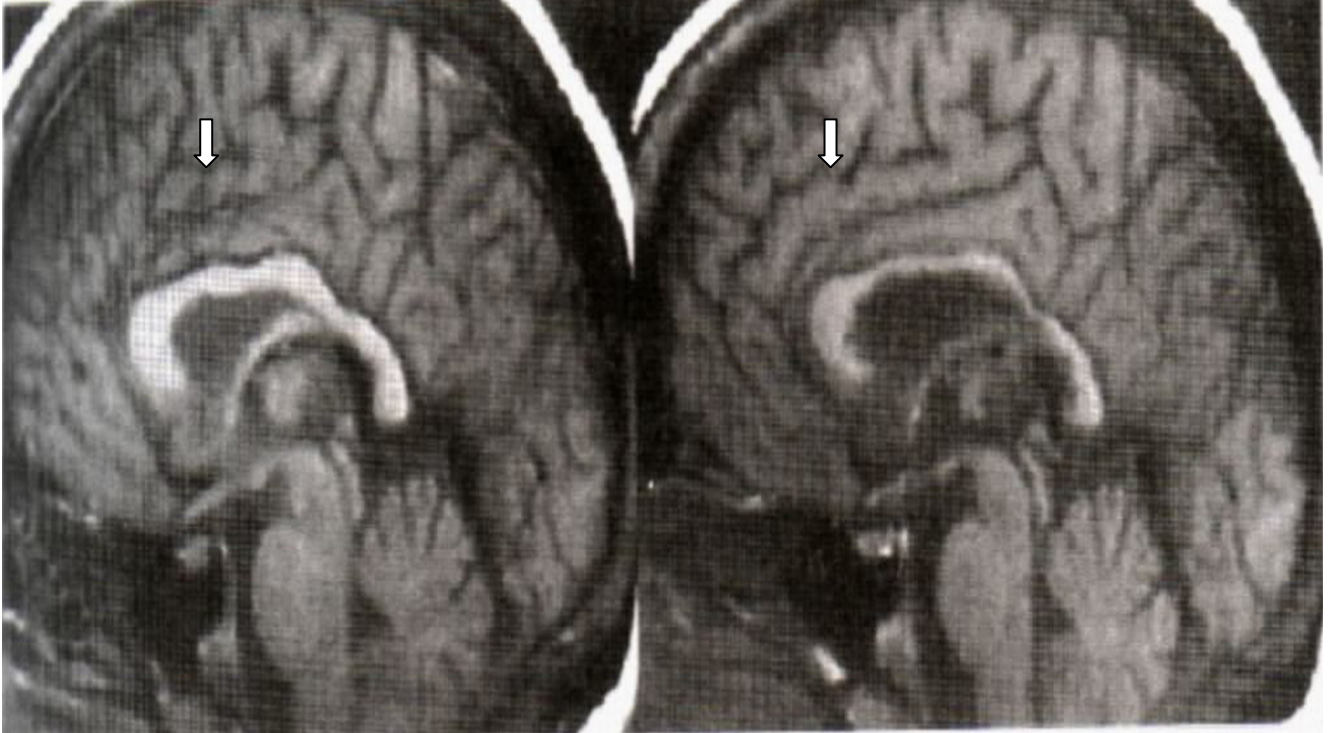


Figure 2.12
Brain atrophy in multiple sclerosis
(Coyle & Harper 2001:21)

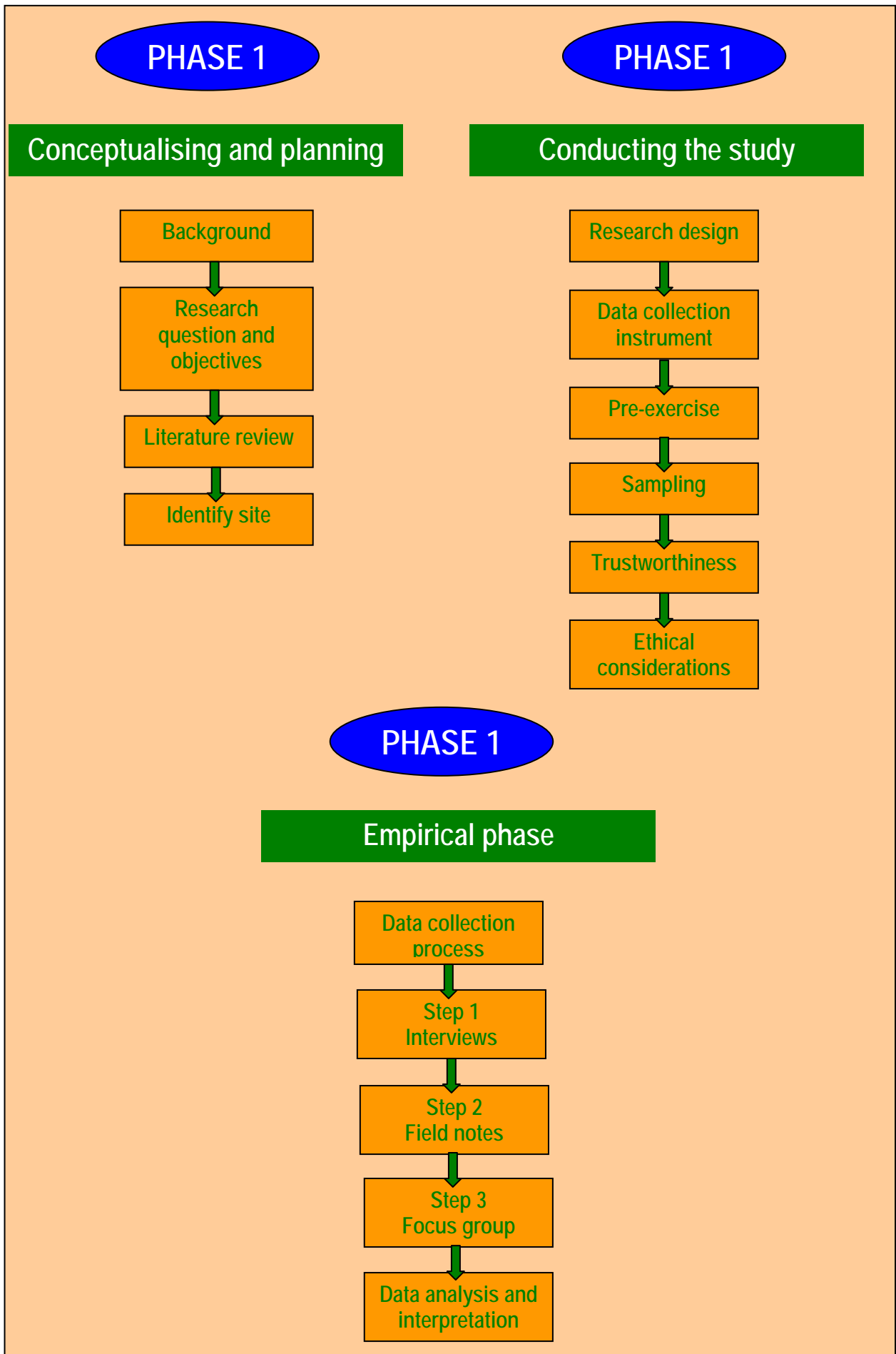


Figure 3.1
Phases of the research process