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DISABILITY AND OPPORTUNITY:
A Case Study Exploring the Support Needs and Long Term Care Options for a Person with Multiple Sclerosis

Thesis submitted by

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In February, 2010

for the degree of Master of Social Policy (Hons)
in the School of Arts and Social Sciences,
James Cook University.

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Eleanor Edgar

Date

Dedicated to Mia and Eloise Rizk

ABSTRACT

This thesis reports on one family's experience when a family member, diagnosed with Multiple Sclerosis, is cared for at home. Particular emphasis is paid to the availability of support services and carer education; the exploration of future care options; and the role of social work in the support of key stakeholders.

A phenomenological approach is used to prioritise the thoughts, opinions and interpretations of the participants. Data was collected through the use of questionnaires and semi-structured interviews with the family member diagnosed with Multiple Sclerosis, his partner and primary carer, other family members and paid carers. Findings discussed in this thesis identify that the woman partner who takes the role of primary carer carries a significant role not only in direct care provision but also in the "project management" required to facilitate home based care. Enhanced carer support is highlighted as a significant need for the family unit, if residential care is to be avoided.

The thesis also highlights the clear opportunity for Social Work as a profession to support and assist families as they work toward achieving adequate services and support whilst concurrently undertaking the processes of transition and adjustment that take place when responding to the chronic care of a family member. However there is evidence to suggest that these opportunities are not taken up and social work is not a source of support for this family.

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Chapter One

Introduction: Focus and Structure of Thesis

1.1 Background

During the 1990's, I worked in Geelong, Victoria, coordinating care teams for individuals affected by HIV/AIDS, then later practised as a medical Social Worker in a ward environment with disabled adults and the elderly in the City of Ballarat, Victoria. The work with the Victorian AIDS Council highlighted the feasibility of younger people with chronic illness continuing to reside at home in their community, providing they had adequate support. Conversely, the experience in the hospital environment exposed me to instances where young people were admitted into long-term residential aged care to ensure that their needs were met in a controlled setting. While nursing care in the latter instance was readily accessible, the young people were effectively alienated from their peers, community and families. It seemed that the chronic illness had come to dominate their lives; in fact, it was their life rather than just being a component of a much bigger picture.

The barriers to achieving optimum service delivery may stem from within the community itself or in the mind of the individual. I believe there is a need to look at the whole picture to achieve an objective understanding of the individual's needs and thus develop strategic, uniquely formulated responses to his/her given situation. Diagnosis of a chronic illness can represent a transitional period for the individual as he/she adjusts to incorporate this component into their state of being; the goal of chronic care should be "…to sustain meaning in life lived with – and in spite of – illness" (Jennings, Callahan & Caplan, 1988, p.10). Given these beliefs I embarked on research to explore these issues further.

This project originally began as PhD research aiming to involve up to 20 participants exploring the services, carer education and future care options available to people with Multiple Sclerosis. I was particularly interested in this chronic disease as I shared this diagnosis. I was well supported by the New South Wales / Victoria Research Committee of the MS Society through liaison with the MS Welfare Worker from the Grampians region. However there was minimal response from potential participants (n = 2) and I subsequently decided that another tack needed to be pursued. Rather than cease the research project altogether, I undertook to complete a case study with one adult with Multiple Sclerosis, his family and carers in relation to services, carer education and future care options. This provided an opportunity for intensive exploration of the issues of community based services, supports, carer education and options for future care from the perspective of an individual diagnosed with Multiple Sclerosis and his/her carers.

Arthur Frank (2004) suggested that "…illness stories weave together three recognizable types of narrative – restitution, chaos, and quest – one of which usually predominates" (211). How people shape their stories is dependent on what they are able to achieve; what the dominant story is and if this image can be enacted. "Let me tell you a story", writes Frank suggesting that people use stories to "…reaffirm, possibly create and possibly to redirect the relationship within which the story is told. … Stories …affirm what people mean to each other and who they are with respect to each other" (Frank, 2000: p 354). Atkinson (1997 cited in Frank, 2000) has suggested that stories have a recuperative role; where illness demoralizes, stories may act as a re-moralization process. Frank states that "…entering the relations of storytelling recuperates persons, relationships, and communities" (p.355). I tell this story acknowledging that it has as much meaning and recuperative effect for me as for the participant

It was envisaged that this process may lead to a 're-storying' or re-framing of each person's understanding as the broader picture becomes increasingly clear and thus situates the individual within a community framework. The research findings suggest that this process occurred as the research participant, his wife and other carers, clearly identify their joint goal of continuing home-based care for as long as is feasibly possible. The husband and wife dyad worked together to achieve an individualized care plan in the home. However, the reliance on the wife and primary care giver as an educator for the family/friend carers together with the problems of accessing age appropriate respite and additional high level services and supports in the home was also highlighted. The carers interviewed stemmed from the immediate family as well as from friendship networks of the couple. One of the carers was employed from a local care agency in her role.

Due to personal health issues I have had to again restrict my original plans and submit this thesis for the degree of Masters of Social Policy (HONS).

1.2 Research Aims

The research aims for this project were three fold:

1. To hear the voices and opinions of the care recipient and his partner/ primary carer, as well as other carers, on the issues of support, services, carer education and long term care options;

2. To determine the availability and suitability of these services, especially given the care recipient's high care needs, and age;

3. To explore the needs of the primary carer and the role social work may play in supporting the family unit affected by chronic illness.

As the research participant in this case study and I share the same chronic illness, both parties came to the research as experts on the topic. The relationship therefore was that of co-researchers (Moustakas, 1994). Harvey suggests that "…knowledge does not reside in a cupboard…it exists in our everyday lives. We live our knowledge and constantly transform it through what we do, as much as it informs what we do" (1990, cited in Shacklock & Smyth, 1998, p.74). This links with the suggestion of Frank (2000) that …"when life is hard, stories can provide those in the storytelling with some distance from whatever threatens them (Frank, 2000: p354).

1.3 Structure of Thesis

This Introductory chapter has provided me with an opportunity to describe how I came to this topic, some of the many hurdles I have encountered and the solutions I chose. I acknowledge the important link between myself and the participants and describe the aims of the research project.

Chapter Two is a summary of the literature relevant to this research. The literature examined includes that which relates to both policies and practice of work with people with disabilities. I have attempted to focus specifically on literature that links the condition of Multiple Sclerosis with more generic discussions to identify similarities and differences for people with this diagnosis.

The Third Chapter outlines the way in which I undertook the research including the important theoretical frameworks which guided my practice. Chapter Four reports the findings from the interviews and draws on the words of the participants to provide for rich, authentic data. In the following chapter (Chapter Five) I discuss the core themes from this data and finally a concluding chapter identifies the key arguments of the thesis.

I move now to Chapter Two which offers a close examination of the literature.

Chapter Two

Literature Review

This chapter explores the literature that has contributed to the development of this study. The issue of disability does not stand alone, rather it rests within the social construct that impacts upon the individual with a disability, his/her family and carers. Consequently, this literature review aims to look at issues from diverse angles to develop a broad picture of the subject matter and allow the reader to fully comprehend the elements which impact upon life for an individual with disability in the Victorian community.

2.1 Disability and Rights

How people with disabilities are perceived within communities influences the manner in which society responds to their needs as well as their rights and opportunities as citizens. The Universal Declaration of Human Rights suggests that all humans are born free and equal in regard to dignity and rights (The United Nations, 1948). This is a powerful statement because it mandates a unity and equality amongst all human beings, regardless of their status. Societal responses to disability have changed dramatically over time and will continue to change in reaction to cultural norms and social conditions. Attitudes towards disability in Australian society have clearly shifted over the decades, adjusting to public health and medical advances as well as changes in community responsiveness to the needs of those with disabilities (Annison, Jenkinson, Sparrow & Bethune, 1996). The introduction of the British model of care into Australian society saw the establishment of institutions to care for people with disabilities and this practice continues to this day, particularly for those who are elderly, mentally impaired and physically disabled.

Today, individuals with disabilities are no longer segregated from the community like lepers of the past, rejected and feared. The culture of viewing those with disabilities as ‘deviants’, failing to fit the social and cultural norms, has slowly experienced a metamorphosis in Australia. Currently, individuals with disabilities are acknowledged by society and responded to in accordance with need. How this ‘need’ is met is variable and dependent upon components which include the prevailing macro social, economic, political culture as well as micro elements such as the directive of support agencies, and financial and carer availability.

The Commonwealth *Disability Services Act 1986* details the principles of service provision for people with disabilities and their next-of-kin / carers (Commonwealth of Australia). Within this Act, there is an acknowledgement of the rights of the individual living with a disability regarding choice, decision making and grievance procedures. Moreover, it is through this Act that the government purse strings to service delivery are held for people with a disability (Annison et al., 1996). The Act holds seven principles and fourteen objectives and defines individuals with a disability as equal to all Australians. The disabled individual's right to a reasonable quality of life is clearly stated in Principle 4 of the *Disability Services Act 1986*:

> People with disabilities have the same rights as other members of Australian society to services which will support their attaining a reasonable quality of life (Commonwealth of Australia).

The disability rights movement reflects a desire to forge the unique identity of disabled people, acknowledging their unique needs and characteristics (Zola, 2003). The use of language in relation to disability has similarly changed over time as societal responses to people with a disability have become increasingly inclusive. The current vernacular sees the term 'patient' shifting to 'consumer'.

2.2 Chronic Illness

The issue of chronic illness is a focus for government and care agencies alike as they stretch the heath care dollar to meet a growing need. Greenberg defines chronic as "…persisting in time, or recurring over a period longer than a few months" (cited in Walker, Peterson, Millen & Martin, 2003, p.36). Chronic illness, as a concept, has experienced a metamorphosis in recent years, shifting from the historic illness category of 'incurable' to the current understanding of chronic disease as being open to treatment modalities (Walker et al., 2003). Moreover, this contemporary response to chronic illness reflects the emergence of the medical and hospital systems. The rise in the instances of chronic illness in the Australian community is being blamed for sapping health care resources. However, this rise in percentage of those affected merely reflects advances in medical care and the increased number of aged within the population (Walker et al., 2003).

Given the growth of chronic illness in society, cost saving is undoubtedly important to make the health dollar spread further (Kraft, 1998). The introduction of Medibank in 1975 and Medicare in 1984 was viewed as ensuring that accessible health care was obtainable by the Australian population (Walker et al., 2003). Since 1999 the Commonwealth funded Enhanced Primary Care (EPC) initiative has been available to individuals with chronic disease. The Commonwealth and State governments funded co-ordinated care trials of integrated models of service delivery for those with complex care needs and chronic conditions (Walker et. al., 2003). Chronic disease management systems, such as the Enhanced Primary Care (EPC) program, represent attempts by government and the medical community to introduce active General Practitioner healthcare planning and co-ordination. Additionally, chronic disease self management programs were similarly put to trial. And yet, J. Daniel Schubert and Margaret Murphy (2005) highlight that patient case notes continue to reflect disease narratives, recording the physical and medical components of the illness rather than reflecting illness narratives which provide a social picture of the experience of illness. It appears that disease classification and control is viewed as central by government thereby ignoring the broader social and individual picture of chronic illness.

Walker et al. claim a bio-psychosocial approach to illness aims to "…explore the relationship between the individual, the illness experience, and the individual's place in the community" (2003, p.20). The authors highlight that disability is not only a physical problem for the individual but a socially constructed status. Thus, the terms disability, disease and chronic illness all represent ongoing incapacity and/or ill health and therefore rest apart from the norm.

Goffman (2003) suggests that stigma is a social process rather than being attributable to an individual and claims that people with a stigma internalise the dominant beliefs of what is normal and acceptable. In this manner they learn they are discredited or fall short of social expectations. Walker and Millen believe that stigma in chronic illness lies in its incurability and "…(the) failure to act appropriately or effectively; to be an active, contributing member of the community" (2003, p.85). Furthermore, Walker and Millen (2003) mention that there may be a social annoyance to the 'overuse' of the sick role, as defined by Talcott Parsons and that chronic illness may be correlated with deviant behaviour, high costs and social welfare by the community at large, due to the long term dependency on the social system that may develop (Walker & Millen, 2003).

Independence and self sufficiency are dominant values in the Australian culture, consequently, maintaining employment despite illness, is viewed positively by society. Further in Australian society, illness continues to be viewed as a 'spoiled identity'(Walker & Millen, 2003). The long term nature of chronic illness and its limitations may lead to the individual affected internalising the stigma. Duval's (2003) research conducted with people with Multiple Sclerosis suggests this group suffer from culturally framed negative attitudes towards their illness. Moreover, "normal' observers may develop psychosocial metaphors which are utilized to devalue sufferers. These metaphors included terms such as 'vulnerability', 'weakness', 'inadequacy' 'dependency' and 'incompetence' (Duval, 2003, p.86).

The National Health and Medical Research Council's (NHMRC) Strategic Development Committee, at its 2001 national workshop on chronic disease explored various issues, including health care access, consumer involvement, the impact of evidence in care and community treatment, newer models of care and access to health care throughout the lifespan (Walker et al., 2003). Walker warns that these activities are often disparate and disconnected yet may be part of an emerging new system for chronic illness care, albeit resulting from economic policies designed to curb health expenditure (2003). The system of care for chronic illness is:

> …(a) by-product of a health system that is subject to the wider national political processes, which in their turn represent such competing interests as the medical profession, health consumer organizations, political parties and health insurers (Walker et al., 2003, p.5).

It is a reasonable assumption that shifts in the chronic health care industry are being driven by the State and Federal governments in a process which is, as Christine Walker and colleagues suggest, haphazard and reactive in nature rather than responsive to preparing the varying stakeholders, including the consumers and health service providers, for imminent change (2003).

The biomedical model has historically played the dominant role in health care for those with chronic illness. However, in recent times there has been an acknowledgement of the need to look at 'living' with the condition; the benefit of the 'living knowledge' that the person with Multiple Sclerosis and his/her carer holds equates to extensive, personal expertise in the illness (Wilson, 2003; Brown, 2003; Ristevski, 2003). Ristevski notes that medical care does not stand alone, rather the need to look at aspects such as social support and welfare services is paramount as is exploring the importance of these components on the individual's life. As detailed by Ristevski, "…how people construct their illness and their lives also needs to be incorporated into a model of care" (2003, p.120). Knight (2003) cites social variables that can potentially impact on the person with Multiple Sclerosis, including socio-economic status, gender, ethnicity, age and education. Ristevski believes it is these variables shape people's "… beliefs, values and perceptions of their lives and their experience of health and illness" (2003, p.122).

While medical management is undoubtedly a core component of health care in chronic illness, follow-up to ensure continuity of care after discharge or an exacerbation is paramount. Ristevski (2003) warns that follow-up appears to be minimal in the current health care system, where output is a key component to achieving "best practice" in medical care. Ideally, partnerships need to be formed between the care recipient and the provider to ensure responsive continuity of care is achieved (Walker, 2003). Black, Grant, Lapslay and Rawson (1994) outline the centrality of the family physician in the management of chronic illness. When counseling individuals who have communication disorders, Holland and Goldberg (2007) suggest developing proactive strategies such as working with the central issues and recognizing that deterioration may occur over time. Holland and Goldberg (2007) also draw on the normalization aspect of allowing ordinary people to live ordinary lives, regardless of their disability label.

Chronic illness will become a facet of life for an increasing number of service users in the years ahead, with the General Practitioner playing an active community role in monitoring medical needs and individual requirements, albeit in tandem with other community supports and services.

2.3 Multiple Sclerosis

Multiple Sclerosis is a disease that is typically diagnosed in the middle years of adulthood and affects the autoimmune system of the individual. Attacking the central nervous system, Multiple Sclerosis can lead to "…demyelation, inflammation and destruction of axons in the brain, spinal cord, and optic nerves" (Luchinetti, Brueck, Rodriguez, & Lassman, 1998, p.1). As McMillan and Wright explain, "…(in MS) the physical symptoms of fatigue, loss (of) vision, strength and balance contribute to the destabilization and loss of employment, family relationships and financial security" (2005, p.2). McGuiness and Peters (1999) expand on this list, specifically adding spasticity, cognitive impairment, tremors, and bowel, bladder and sexual dysfunction. McMillan and Wright suggest that "…the impact of a lifelong chronic disease has many facets and in the case of MS, they are many and varied... It demands a truly whole Government response" (2005, p. 2).

The MS Newsletter, Key News Keeping You Up To Date, details that in Australia, 5 people are diagnosed with MS each working day. The average age of those diagnosed is 30, with three times as many women as men (MS Australia, 2007: p 1). In the Federal Budget submission 2006/2007 of MS Australia, the Access Economics (2005) report estimated that MS costs the Australian community nearly $2 billion per year. As the common age of onset is between 20-40 years, it is a disease which impacts upon the financial security of the individual affected and his/her family, as well as the offspring that depend on them. Solari, Ferrari and Radice (2006) concluded in their research that studies assessing the psychosocial consequences of Multiple Sclerosis in the community are scarce. Solari et al. conducted research to determine the self-perceived health status of people with Multiple Sclerosis, living in the Italian community, over a 5 year time span. The results suggested that of the 205 participants in the postal survey, "…the proportion of those severely impaired doubled over the study period; nevertheless in 23% of participants the disease remained mild over a median duration of 11 years" (Solari et al., 2006, p.13). The researchers concluded that the "…psychosocial burden affects not only people with MS but also their significant others" (Solari et al., 2005, p.243).

While a cure for Multiple Sclerosis remains elusive at this stage, treatments such as Interferon and Tysabri have proved to be beneficial in controlling symptoms and enabling some patients to continue their desired lifestyles. As detailed by Swain, there are three main goals of treatment in the field of Multiple Sclerosis, namely "…to delay progression of the disease, manage chronic symptoms, and treat acute exacerbations" (cited in Koch & Kelly, 1999: p15). Khan, McPhail, Brand, Turner-Stokes and Kilpatrick (2006) conducted a study into the experience of disability and the symptoms of Multiple Sclerosis in the Australian community. The researchers utilized a prospective cross sectional community survey with the participants, comparing the perceptions of the Multiple Sclerosis patients, carers and treating doctors in regards to the quality of life, carer stress and utilization of health services. The mean age of participants was 49 years and each had a confirmed diagnosis of Multiple Sclerosis, with quantified neurological, mobility and cognitive deficits. The findings suggested that Multiple Sclerosis patients with severe symptoms had a:

> …significantly reduced quality of life and increased carer burden than those with milder disability, but discordance between patients, carers and doctors was noted in their perception of problems and symptom experience. Rates of depression (67%) and work-related problems were high, but vocational support was rarely provided. Forty persons used Interferon, of whom 20 had secondary progressive Multiple Sclerosis; 39% reported difficulty in

> accessing rehabilitation services and only 10% were referred to medical rehabilitation units (Khan et al., 2006, Abstract, p.1).

Khan et al. (2006) concluded that Multiple Sclerosis patients' use of rehabilitation and support services appeared to be lacking when compared to other similarly disabled patients. Multiple Sclerosis is a disease known for its changing temperament and sometimes progressive nature.

The use of alternative therapies has become popular in the area of Multiple Sclerosis. These strategies may include meditation, acupuncture, herbal or vitamin supplements, chiropractic intervention and massage. Simmons (2006) suggests that women with Multiple Sclerosis are more likely to use philosophical and spiritual help than their male counterparts. The inter-disciplinary, Australia-wide, MS Longitudinal Study (current) will explore the environmental, social and behavioural factors that may have an effect on the development of Multiple Sclerosis. Professor George Jelinik (2000) focuses on preventative treatment for Multiple Sclerosis, thus slowing down or halting the deterioration early after diagnosis. Jelinik supports the theory that five elements need to be addressed to achieve this, namely diet, meditation, exercise, sunlight and visualisation. The benefits of a low fat diet for those with Multiple Sclerosis was first recommended by Professor Laver Swank in 1950 who suggested that the dietary change from unsaturated fats to saturated fats, which occurred at the time of industrialization, was involved in the cause of Multiple Sclerosis (Jelinik, 2000). Jelinik (2000) expands on Swank's theory to incorporate the need to eliminate animal fats and dairy products whilst introducing mind-body connection elements such as meditation and sunlight.

The role emotions play on illness has been well documented and Jelinik draws on the work of a medical colleague, Bernie Siegel, who explored the manner in which patients become 'active' participants in their own healing. The process of becoming active participants is achieved when patients view the illness:

> …as a challenge and an opportunity for personal growth. They tackle the illness actively, rather than being passive recipients of doctor's treatments.

> They go to every source of information, are open-minded about unconventional therapies, try everything. They feel empowered by the discoveries they make to take control of their illnesses, and indeed, their lives (Jelinik, 2000, p.75).

Matson and Brooks developed a model of adjustment to Multiple Sclerosis, identifying four stages of adjustment: denial, resistance, affirmation, and integration (McGuiness & Peters, 1999). McGuiness and Peters explain the stages in detail, suggesting:

> During the denial phase, patients might be unwilling to accept the diagnosis and might seek a second (or third) opinion. Individuals attempt to continue life as they had lived before the diagnosis. In time, they accept the diagnosis and move toward pursuing activities aimed at controlling the disease. They actively seek information about MS and possible treatments or cures; this is the resistance phase and is often characterized by the attitude that 'It won't get me down'. During the affirmation stage, new meanings are constructed, life values and priorities are rearranged, and individuals grieve the loss of their former identities. The final stage of adjustment is integration, in which individuals acknowledge the illness but no longer centre their lives around it. Integration must be re-established with each downward trend in function; therefore, individuals may move forward and backward throughout each stage as their MS progresses (1999, p. 2).

The beneficial role of Multiple Sclerosis clinical nurse specialists has been documented and is supported in other countries, including the United Kingdom and the Netherlands (McGuiness & Peters, 1999). Indeed, the role of the clinical nurse specialist is key for coordination and intervention. McGuiness and Peters (1999) discuss the nursing role in relation to Peplau's Interpersonal Relations Model from 1952, noting the flow between the patient and nurse, with the collaborative interplay that emerges. McGuiness and Peters suggest that the overall goal of this care is "…the continued development and strengthening of the nurse-patient relationship, which is used to facilitate patients' continued adaptation to MS” (1999, pp.4-5). Oeseburg, Jansen and De Keyser (2004) mention the gatekeeping role of the General Practitioner, noting that their research indicated contacts with other health professionals were rare amongst the Multiple Sclerosis participants. Their findings suggested that effective rehabilitation, can also “…lead to a better performance of certain actions by the patients themselves” (Oeseburg et al., 2004, p.218). Oeseburg et al.’s finding aligns with Kersten el al.’s (2000a) research that indicated Multiple Sclerosis patients valued rehabilitation and visits by a clinical nurse specialist and perceived both actions to be beneficial. Unmet needs were identified prior to the implementation of the Transmural Care Model for Multiple Sclerosis that is utilized in the northern area of the Netherlands; however the involvement of a clinical nurse specialist helped to alleviate these needs. Oeseburg et al (2004) concluded that the clinical nurse specialist role effectively conducts “…needs assessment(s) and serves as a coordinator and monitor of the care process and initiatives to improve care” (Oeseburg et al., 2004, p.219).

In Australia such a role description is more likely to be assumed by a case manager. Here the role is important in establishing a partnership with the person who has Multiple Sclerosis that may help build their sense of personal control and autonomy (Somerset, Sharp & Campbell, 2002). A case manager will provide, Northrop (2005) suggests, the link to supports that may effectively assist in the preservation of independence, dignity and self esteem while concurrently relieving some of the day-to-day burden. Victorian Government options such as Community Care Packages (CACP), Home and Community Care Packages (HACCP), Home and Community Care (HACC), Extended Aged Care at Home Packages, creative options for respite, as well as in-home respite and residential respite, represent services that the people with Multiple Sclerosis can access in the community. The Commonwealth Department of Social Security (Centrelink) provides components including the disability pension, health care card and mobility allowance which undoubtedly play a valuable role for some people living with chronic illness.

It is important that Multiple Sclerosis does not cloud the overall medical condition of those affected and that active preventative healthcare delivery is paramount to ensure detection, prevention and treatment of conditions such as osteoporosis and cancer. The Australian response to Multiple Sclerosis care appears to differ from state to state, however there has been Commonwealth government agreement for the need to include specific drugs on the Pharmaceutical Benefits Scheme, including Interferon drug therapy and Tysabri. This represents an expensive undertaking by Government as these treatments are costly and represent only one of the medications that may be needed for Multiple Sclerosis care specifically.

2.4 Future Care Options

The supported living options currently available to the elderly are not necessarily suitable to younger adults with chronic illness; groups such as the Young People Living in Nursing Homes (YPINH) consortium are beginning to address this issue (Donohoe, Wineman & O'Brien, 1996). Donohoe. K. M.(1996) wrote anecdotally of the premature and precipitous admissions to residential care and researched the issue of whether individuals with chronic progressive disability would use innovative long-term care services as an alternative to institutional placement. Donohoe's research findings suggested that the subjects consistently reflected comments indicating strongly that "…alternative long-term care services are needed and would be utilized" (Donohoe., 1996, p.379). Nevertheless, it appears this issue has been relatively unresearched.

The International Year of Disabled Persons in 1981, highlighted to the State and Federal Governments the need for concern in the areas of welfare, rights and inclusion in society of disabled members. The Victorian Department of Human Services (DHS), completed a report in 2005 entitled *Responding to the needs of younger people in Victoria's Residential Aged Care services*. The aim of the project incorporated identifying options that included

> …create(ing) opportunities for younger people seeking to move out of residential care to more appropriate community options; prevent(ing) inappropriate admissions of younger people to residential care….(DHS, 2005, p.3)

The DHS report suggests the need for change in regard to the use of residential aged care for younger people with disabilities, noting that there is:

> a clear need to expand and improve the range of accommodation, care and support options available to young people with nursing home or hostel equivalent care needs…(DHS, 2005, p.3).

The Council of Australian Governments (COAG) meeting held on 17th February 2006, detailed their commitment to reducing the numbers of young people in nursing homes. With Commonwealth, State and Territory funding, a new five year program ('My Future, My Choice') commenced in July 2006. The program entailed working closely with the younger people, their families and carers and targeted people less than 50 years of age who accessed residential aged care. COAG aimed to develop a program that would:

> …provide cost-effective alternative residential care services for some younger people with disabilities, improve support services for those who continue to stay in residential aged care and may assist younger people who are at risk of entering nursing homes (COAG, 2006, p.11).

Katharine Donohoe (1996) conducted research to determine whether adults with progressive disabilities would choose long-term community care services over institutionalization as their conditions worsen. Donohoe concluded that if given a choice, most participants would use services within the community in preference to institutionalisation. These services included home health aides, adult day-care and community residences and family respite. Donohoe notes that planning for long-term care is typically undertaken by the elderly or for those with developmental delays or who are mentally challenged. There has been no mention of care for younger people with Multiple Sclerosis.

2.5 Lived Reality

Hardiker and Tod discuss the impact of chronic illness for the individual affected, noting:

> …the persistence and relative permanence (of chronic illness)…make it difficult for people to manage their lives. Premature invalidism and death or social isolation may occur if those affected cannot handle the uncertainties of chronic illness or their social arrangements break down…(1982, p.640).

David Levinson (1986) developed a theory of adult change which suggested that adults experience changes in their individual life structure as they journey through the adult years. This 'life structure' is, according to Levinson, the "…underlying pattern or design of the person's life at a given time" (1986, p.6). During periods of change, a transitional period occurs during which the adult re-examines, adjusts or alters his/her previous life structure (Levinson, 1986). Moreover, how he/she responds to the continual challenge of chronic illness is influenced by diverse variables including the individual's psychosocial and ego development together with adaptation to adult life and the personal transformation that has taken place (Erikson, 1950). Erikson (1950) discusses a period of 'ego integrity versus despair' in later life where there is the opportunity for a culmination of all the previous stages and life experiences and "…acceptance of oneself as one is" (Bee, 1992, p.67).

How each individual responds to the challenge of chronic illness is unique, depending on diverse variables, including the initial prognosis, disease progression, the available support network and the sense of hope, or lack of it, that prevails. It appears a sense of hope needs to remain alive and active in the individual, with hope leaving the door ajar to future experiences. As Julie Binder outlines:

> [C]hronic illness with impairment intrudes upon an individual's daily life, activities, relationships, and future hopes and aspirations. It disturbs the previously harmonious relationship between the body and self and forces the

> individual to find ways to accommodate or adapt to progressive functional losses and limitations (Binder, 2004, p.186).

Chronic illness impacts upon the individual, personally and socially; as such it is "…uniquely personal and universally human" (Jennings, Callahan & Caplan, 1988, p.7). As Corbin outlines:

> ..when a body becomes severely disabled, there is often a body/mind split…People start saying, 'I am more than my body'. A reminder that, even if the body can't function the person within it is still there, wounded perhaps, but present (Corbin, 2003, p. 259).

Living with Multiple Sclerosis has been described as living on a roller coaster (Donohoe, 1996; McGuiness & Peters, 1999). The unpredictability of the illness makes planning difficult for those with Multiple Sclerosis and their carers; the challenge being trying to control the illness rather than being controlled by it (Donohoe, 1996). Research into quality of life in relation to physical and social environments conducted with adults who have disabilities suggested that the participants who reported an excellent or good quality of life attributed that to:

> …feelings of control over their bodies, minds and lives, including being able to drive; being able to perform expected roles; having a 'can do' attitude; finding purpose, meaning, and harmony in life; having a spiritual foundation and outlook; constructing and living in a reciprocal social world, including emotional give and take; and feeling satisfied when comparing oneself with others. Adults with disabilities did not deny or diminish their disability but felt satisfaction came from doing a good job with their lives (Albrecht & Devlieger, 1999, p.31).

Chronic illness may threaten the integrity of components of the person's life and may lead to unwanted dependency on others thus transforming roles within intimate and family relationships (Jennings et al., 1988). The individual’s self identity, self image and understanding of the purpose of life can be shaped and transformed through chronic illness (Jennings et. al, 1988).

> …The ordeal of chronic illness can be experienced as an enabling experience, one that sharpens the person’s appreciation of remaining powers and abilities, quickens sensibilities and talents that had been dormant, and brings out a depth and strength of character previously untapped and unrealized. Alternatively, along with social stigma and isolation, chronic illness can leave the individual bereft of purpose and deeply alienated from the condition of his or her own body and the truncated future possibilities of life (Jennings et al., 1988, p.7).

Multiple Sclerosis invariably enters an individual’s life during the middle years of adulthood, during the period known for training, employment, career development, forming relationships and families. A media release from MS Research Australia details the findings from a survey on the effect of Multiple Sclerosis on employment, suggesting “…people with MS often have lower income levels and are far less likely to be in full-time employment than the general population” (MS Research Australia, 2005, p.2).
Social and medical responses to the individual with a disability may reflect dominant beliefs and practices. Service delivery and supports can be lost amidst an economic rationalist driven program of care which does not easily fit with the needs of long term medical care and monitoring. According to Christine Walker (2003) self-management programs are a process for addressing the costs entailed in chronic care. Community based self management being considerably less onerous on the public purse than hospitalization and intense medical intervention. The Australian Chronic Disease Self-Management Program argues training courses in self management may instigate savings in areas such as the Medical Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) (Walker, 2003). The notion of General Practitioner driven program management and ‘continuity of care’ addresses this in part, but because of the General Practitioner’s central role in allocating access to resources and services, the service user

consistently remains the less powerful component of the partnership. Peter Greenberg identifies four types of patient/clinician relationship, namely ‘paternalistic’, ‘informative’, ‘interpretative’ and finally, a ‘deliberative’ model where the relationship “…involves the clinician assisting the patient to define their own values…acting as a ‘teacher and friend’” (Greenberg et al., 2003, p.47).

Frank (2004) discusses an experience of advanced Multiple Sclerosis as detailed by essayist Nancy Mairs. Calling herself a ‘cripple’, Mairs believes that the social responses to people with disability reflect issues of power and control. Mairs asserts “…I am disabled only from your point of view (you from mine). Whoever gets to define ability puts everyone else in place” (Frank, 2004, p.38).

Writing became Nancy Mairs’ door through which she ensured she remained an active participant of society regardless of her bodily incapacity. Through writing, Mairs avoided becoming just the ‘body that requires care’ and reciprocity in relationships with others remained active. She stated “my infinitely harder task…is to conceptualize not merely a habitable body but a habitable world; a world that wants me in it” (cited in Frank, 2004: p 65).

Drawing on the work of Kleinman, Walker details

> Chronicity is not simply a direct result of pathology acting in an isolated person. It is the outcome of lives lived under constraining circumstances with particular relationships to other people. Chronicity is created in part out of negative expectations that come to be shared in face-to-face interactions – expectations that fetter our dreams and sting and choke our sense of self. Patients learn to act as chronic cases; family members and care-givers learn to treat patients in keeping with this view. We collude in building walls and tearing down bridges. We place complex individuals in simple, unidimensional roles (the disabled, the life-threatened) as if this were all they are and can be. We turn our backs on poisonous relationships. We become part of demoralizing situations, and add unhelpfully to feelings of threat and fear…(2003, p.60)

Perceptions of disability are therefore personally and socially driven, with some chronically disabled persons choosing to fit the socially devised model of ‘disabled’, whereas others strive to challenge this status quo.

2.6 Carers

The Australian Health Department noted in 2005, that all carers of people with long-term neurological conditions are to be assessed to receive appropriate support and services which recognize their needs as carers and as individuals in their own right (Commonwealth of Australia, 2005). Achieving successful home based care appears to be dependent primarily on the person with Multiple Sclerosis and his/her principle carer. The carer is primarily responsible for assisting the person with Multiple Sclerosis and cooperating with the many diverse services offering care and support in the home. Primarily women are unpaid carers to people with disabilities or the aged and numbered approximately 2.6 million in 2003 (Australian Government, 2008, p.6). In their research with people with Multiple Sclerosis, Gobdetz (1969) identified the carer as the “responsor” and suggested this role is vital in home based care and yet is ‘under investigated’ and not fully acknowledged within the medical model. With chronic illness becoming increasingly commonplace and affecting all sectors of society, the role of “responsor” is now vital to government as a means of cost containment and achieving continued home based care (Hardiker and Tod, 1982). In the discussion paper *Developing a National Disability Strategy for Australia* (2008), the Australian Government details outcomes which reflect a more inclusive approach to the people with a disability and their carers, addressing issues such as economic deprivation, enhanced social inclusion, choice, wellbeing and opportunities in life. The need for families and carers to be well supported was similarly acknowledged as a core outcome (Australian Government, 2008, p.10).

McMillan and Wright state the average informal care burden of a person with Multiple Sclerosis in Australia is 12.3 hours per week; consequently carer support is a paramount consideration to funding plans (McMillan & Wright, 2005, p.11).

> MS is a disease that is largely treated in the community…This points to the benefit of increasing the investment in self management and other education programs, so the management of the disease by individuals and families and generic care workers is more effective (McMillan & Wright, 2005, p.13).

Lack of personal time, opportunities for respite, degree of stress, difficulty in performing caregiving activities and perceived social support have been identified as key elements for consideration in the caregiver relationship (University of Akron, 1995). Discussing the notion of care, Frank suggests care is "…when each person's dignity depends crucially on how each treats and is treated by the other" (2004, p.211). Thus, care is a multi dimensional concept, with both the carer and the care recipient being active players. Chronic illness may challenge moral family scripts of obligation and care as well as traditional responses to meeting the needs of members (Jennings et al., 1988). Sandra Kenney, Priscilla O'Connor and Teresa Enterlante (2000) conducted a correlational research study designed to explore the relation between patient perception of family health and functional improvement achieved through inpatient rehabilitation. This study was designed to determine if health within the family unit, or the lack of it, impacted upon rehabilitation outcomes. However, no positive correlation was observed.

Wright and Leahey (2005) note that patients do not live in a void; rather variables such as treatment options, technology, the health and social system will influence patient opportunities and choices. The authors suggest health practitioners think interactionally and reciprocally about families, acknowledging the interplay between "…health and illness and the family" (Wright & Leahey, 2005, p.10). Carers play a central role in community care, yet this role is not family specific and may incorporate diverse bodies which include employed carers, friends, neighbours and colleagues.

Khan et al. (2006) conducted a study into the experience of disability and the symptoms of Multiple Sclerosis in the Australian community. The researchers used a prospective cross sectional community survey with the participants, comparing the perceptions of the

Multiple Sclerosis patients, carers and treating doctors. The study examined quality of life, carer stress and use of health services. The mean age of participants was 49 years; participants had a confirmed diagnosis of Multiple Sclerosis, with quantified neurological, mobility and cognitive deficits. This data was ascertained from a tertiary hospital database. Khan et al. (2006) concluded that whilst Multiple Sclerosis patients had rates of disability and symptom experience which were close to other diseases, their use of rehabilitation and support services appeared to be lacking. Aronson, Cleghorn and Goldenberg (1996) mention that their large, population-based survey of people with Multiple Sclerosis and their caregivers, conducted in Ontario, suggested that available respite care is rarely used by caregivers. The authors suggest "assistance arrangements and use of services, each from the point of view of persons with MS and their caregivers, must be taken into account in efforts to prolong home care and to postpone early institutionalization of persons with MS" (Aronson et al., 1996, p.354).

In examining the application of a stress and coping model of care-giving in Multiple Sclerosis, Pakenham (2001) reported that approximately one third of the eighty-nine caregiver participants cited significant levels of psychological distress. Pakenham subsequently examined another group of carers exploring the positive impact of Multiple Sclerosis on their lives, finding positive elements within the carer-care recipient dyads (2001). However, despite these more positive outcomes the notion of "chronic sorrow" was used as a descriptor of the carer experience in Multiple Sclerosis (Pakenham, 2001). As Binder (2004) notes in situations of chronic illness the patient and the family alike undergo significant change in family dynamics. This finding was similarly mentioned by Hakim, Bakheit, Bryant, Roberts, Mcintosh – Michaclis and Spackman who observed that Multiple Sclerosis has "…a profound negative effect on patients and their relatives" (2000 cited in Binder, 2004, p.186). An on-line survey conducted by MS In Focus (2007) sought responses from care recipients and carers alike. Both parties were asked if their relationships with one another had changed since either support was needed or care sought. The results suggested that the care recipients at 38% and carers at 41%, felt that their relationships had suffered. Moreover, in regard to caregiving tasks as identified by the carers and people with Multiple Sclerosis, the care recipients' perception of the required care provision was considerably less than the care providers (MS In Focus, 2007, p.25). This had a substantial impact on relationships.

Achieving long term community based care, as is the goal of many people with disability and /or chronic illness, requires substantial medical, financial and care agency support, as well as family/carer education and dedication to the task. While there are other elements which influence positive experiences in community based care, it appears these are the core elements when assessing the viability of continued community care. Wright and Leahey (2005) highlight the need for nurses to consider a collaborative approach when assessing patients and cite the family-centered care model as both respectful and responsible when assessing clients. This model has been incorporated into care directives across the public and private sectors. Wright and Leahey (2005) developed the *Calgary Family Assessment and Intervention Models* to be used in working with families; highlighting the need to hear patients and their families, acknowledging their unique coping processes and their strengths and weaknesses that have developed over time in response to requirements that have emerged.

Aronson et al. (1996) detail in their research findings that the mean age of caregivers was about 50 years; both sexes were represented equally and the majority were related to the care recipient, usually a spouse. Most carers were unpaid in the caregiving role and provided diverse assistance, particularly in homemaking activities. In an outcome similar to the "MS in Focus survey, Aronson was identified that "…caregivers perceive(d) a greater caregiving burden than is reported by care recipients" (1996, p.360). Research conducted by Sato, Ricks and Watkins (1996) included 21 caregivers of people living with Multiple Sclerosis. The caregivers reported needs relating to their role, including practical needs, assistance with child care, household duties, finances and meal preparation. Furthermore, it was highlighted by the caregivers that they had needs in relation to learning about the disease process, receiving practical training in caregiving as well as receiving written information on Multiple Sclerosis (Sato et al., 1996).

Kersten, George, McLellan, Smith and Mullee (2000) explored the perception of unmet needs of people with Multiple Sclerosis, their families, and professionals in five European countries. In three of these countries, the findings suggested needs were felt in intellectual and social fulfillment, employment, social activities, and hobbies. Moreover, amongst the 125 participating carers, it appears the most pressing unmet needs were those for increased finances, support services and information.

In Victoria, the Commonwealth Carer Resource Centre, Carer Respite Centre/Carer's Choice and Commonwealth Carelink Centre provide active support for carers, aiming to offer personal support and information, respite planning and referrals to other agencies. They actively acknowledge the role of carers and assist them to maintain their own quality of life, as well as that of the person with Multiple Sclerosis. Assistance may be required with issues including finances, eligibility criteria, safety in the home, emergency support, loss and grief and self care. It appears that providing care to a person with Multiple Sclerosis involves commitment and acting as a go-between for the person with Multiple Sclerosis and the services and supports required. Carer support agencies provide a foundation for carers in the community, offering them support and information in their caring role.

2.7 Self management

For some people with Multiple Sclerosis, self management can represent a form of self empowerment, with the individual monitoring their own care requirements and service support. As the number of people with chronic disease has increased, the responsibility for care has become increasingly community based and, when possible, service user and family based. Following the commitments promised with deinstitutionalization, community care is perceived by government as a preferable, economic alternative to the hospital or institutional options. Holloway and Lymbery (2007) note the current global trend for the service user to play a central role in determining their needs and shaping their own package of care.

The idea of consumer “self management” of their own chronic disease process and the promotion of the same appears not to be purely about empowerment and medical care, as economics plays a significant role in its promotion. The Australian Government introduced the Chronic Disease Self Management initiative in 1999. The concept of ‘self-management’ at this time assumed the introduciton of formalised education programs which included education on the illness, its treatments and advice on coping strategies (Walker, 2003; Gonon, Soler, Langewitz & Perrochoud 1999; Barner, Mason & Murray, 2003; Lahdensuo 2003). According to Walker, ‘self management’ includes “…information, developing action plans, self-monitoring, undertaking exercise where appropriate, interacting with health professionals and accessing services and supports” (2003, p.55). This differs somewhat from purely ‘self-monitoring’ which incorporates learning the symptoms and body cues that signify change and developing strategies for avoiding flare ups (Walker, 2003). Noreen Clark (2003) teases out the notion of self-regulation and disease management, suggesting the former represents self regulation by the patient who is making observations and judgments to achieve a personal goal or end point. Identified strategies may be modified or changed over time with others possibly influencing the chosen strategies. Walker (2003) mentions that community organisations, such as the Epilepsy Foundation and the NSW/VIC MS Society, play a role in Australia to fill the gaps in the specialist social supports required by those with complex chronic illness. The NSW/VIC MS Society represents a body which provides diverse services, including information, counseling, assessment, education programs and family support to its members.

Martin and Peterson suggest the current financing models for health need continual review to ensure their relevance, vision and strategy. These models include Health Care Agreements, Medicare, PSB and a multitude of divisional and blended payments (Martin & Peterson, 2003). Walker suggests it is unlikely that individuals with chronic illness will explore self management purely as a means of substituting high cost medical care for low cost self management (2003). However, other literature conversely asserts that self management may represent a means to reduce costs whilst concurrently ensuring independence and a sense of ownership over his/her health status and ongoing care.

Walker continues, stating that collaborative efforts between health professional educators and patients may effectively develop his/her sense of ownership of the education program ensuring that "…people whose very identities have been challenged by their illnesses are given the opportunity to build or rebuild a sense of self" (Walker, 2003, p.62). A healthy sense of self can be encouraged through knowledge provision in the areas of self help, self management, self monitoring and day to day self care.

Sullivan, Wilken, Rabin, Demorest and Bever (2004) discuss two different modes of coping strategies, namely problem-focused coping and emotion-focused coping. The authors mention a 1999 study of those coping with and adjusting to a diagnosis of Multiple Sclerosis which suggested that problem-focused coping corresponded to better adjustment (Sullivan et al., 2004). Problem-solving is most often used, according to these authors when taking action is viewed as something that will solve the problem. In general, social support is related to a better psychosocial adaptation to Multiple Sclerosis and thus, a feeling of hope and an ability to cope with the uncertainly of the disease (Sullivan et al., 2004).

Noreen Clark (2003) wrote of the interplay between the social and physical environments in the individual's response to chronic illness, suggesting that patients can achieve positive outcomes which may include "…better monitoring of a condition, fewer symptoms, enhanced physical and psychosocial functioning, and reduced health care use" (Clark, 2003, p.1). However, as Clark notes, changing behavioral patterns is a challenging process to put into practice for primary prevention, let alone in secondary prevention to manage the effects of disease. People living with chronic conditions can become expert managers of their conditions, with a range of influences affecting the individual's ability to manage disease and the presenting symptoms (Clark, 2003). According to Clark, these influences include the family and their support or lack thereof. Moreover, the patient-physician relationship or partnership is central to achieving effective management. Clark (2003) goes on to describe how effective disease management by patients can achieve a positive effect in controlling symptoms.

Clark examined whether diabetic patients were more likely to manage disease effectively, and noted the negative correlation between younger ages and daily diabetes monitoring. It seems clinicians are not able to confidently predict which patients will follow medical regimens and those who will not. To be labelled either ‘fully compliant’ or ‘non-compliant’ are categories which Clark (2003) suggests are hard to predict, thereby highlighting the need for clinicians to develop management strategies beyond the use of medicines. Differing formats for learning may be preferred; including patient only, the inclusion of family members, one-on-one settings or group settings (Elsay, Ellis, Brown & Pichert, 2001; Wilson, Scamagas, German, Hughes & Lulla, 1993). Elsay et al. warn that significant gaps exist between patient understanding and improvement of disease management due to the

> …emphasis on clinical settings for program delivery, neglect of the factors beyond patient behaviour that enable or deter effective management…reliance on short-term rather than long-term assessments, and failure to evaluate the independent contribution of various program components (2001, p.1).

In the field of chronic illness, promoting not only self management but voluntary sector support and involvement, combine to meet government policy objectives of cost cutting and promoting individual independence within the broader community. Ristevski suggests voluntary organisations, families and carers have provided services to the chronically ill that “…are innovative, flexible, specialist in nature and focused on individual, social, economic and clinical needs” (2003, p.120). These services incorporate, according to Ristevski (2003), strategies that encourage personal empowerment, self help, self management and continuity of care. When an illness is not ‘repairable’ and therefore does not fit the biomedical model with its focus on symptom management, diagnostic classification and acute care, a ‘misfit’ occurs (Knight 2003). The focus needs to shift away from cure and a swift exit from the medical system, to one of long-term control and medical management, together with continuity of care and health promotion (Brown, 2003: Ristevski, 2003). Many researchers suggest hospital wards do not play a dominant role in the care of the chronically ill, rather the central role is held in the community setting with illness self management and assistance by family and carers as paramount (Ristevski, 2003, Braithwaite, 2003; Edgar, 1992; Papadopoulos, 2003; Wilson, Moore, Rubin & Bartels 2003). For the chronically ill individual, assuming a 'sick role' (that is passive and devoid of responsibility) in response to health professionals, is not conducive to achieving self management and control (Lupton, 2003: Turner, 2003). Self management empowers the afflicted individual and carer dyad. Moreover, this model of care meets broader social and economic objectives of diffusing chronic care costs and ensures self and family/community responsibility for care and health continuance is held as paramount. Citing Fries, Koop, Sokolov, Beadle and Wright (2003), Walker notes that "self-management, including health promotion strategies, has the potential to lower patient service use by 7 to 17 per cent"… (2003, p. 57).

Millen and Walker (2002) suggest that people with chronic illness may adopt strategies to hide their disabilities in order to avoid stigmas. Moreover, research suggests socioeconomic status and its relationship to chronic health may influence individual responses (Lawrence, 1999; NHS, 1992; Daly, Duncan, Kaplan & Lynch, 1998; Adler, Boyce, Chesney, Cohen, Folkman, Kahn. & Syme, 1994). Syme developed a hypothesis in relation to socioeconomic status and health, which suggests

> …that the social class gradient in disease may best be explained by the concept 'control of destiny'…(meaning) it is healthy for people to be able to influence the events that impinge on their lives (Walker, 2003, p.60).

Issues such as "…mastery, self-efficacy, a sense of control and powerlessness" may also influence individual responses" (Walker, 2003, p.60). Self management effectively places control back on the individual with Multiple Sclerosis, acknowledging his/her right to choose and the management of services and support; it has a wonderfully empowering ring but is it really just shifting responsibility from social care to the individual and his/her family and support network. Peter Scourfield (2005) writes on the move in the United Kingdom toward 'program modernization', suggesting this reflects a shift in philosophy to promote independence and self responsible behaviour (p 1). The term ‘govern at a distance’ seems to have entered the vernacular. Kemshall explains this notion, noting that:

> in advanced liberal societies governmentality is displaced to the micro-domain of individual and locale, with the residual role of welfare agencies constituted as facilitating prudential choices through the provision of expert knowledge and in the provision of ‘rational choices’ for the individual (cited in Scourfield, 2005, p.112).

2.8 The Role of Education

Research suggests that education programmes encourage people to self manage their chronic illnesses, improve their perceptions of control, promote lifestyle changes as well as reduce anxiety and depression (Barlow et al, 2000; Stuifbergen & Rogers, 1997; Hanger & Wilkinson, 2001). Education for those affected by Multiple Sclerosis and their carers appears to have focused primarily, though not exclusively, on the disease and its symptoms. This is important, but as mentioned by Mark Hepworth, Janet Harrison and Nicole James (2002), the initial focus for information may shift in response to symptom changes, disease progression and needs. Baker conducted research in the United States with individuals who had recently had an acute exacerbation of Multiple Sclerosis and suggests that:

> people tended to fall into the category of either ‘monitors’ or ‘blunters’, that is, people ‘either want information to handle an uncontrollable event or turn away from it because information is perceived to increase their level of anxiety (cited in Hepworth et al., 2002, p. 7).

Tina Koch and Shayne Kelly conducted research to identify strategies for managing incontinence with women who have Multiple Sclerosis and concluded that the participants were “…hungry for knowledge about their condition and attempted to make sense of the medical discourse that they intertwined with their personal experiences” (Koch & Kelly, 1999, p.23). Holland (2006) recommends that educating patients about treatment involves both psychological and technical issues for nurses. This issue is equally pertinent when educating families and carers (Halper, 2006). Education for young people with chronic illness ideally maximizes their chances for future independence (Walker & Millen, 2003).

Embrey (2005) conducted research in the United Kingdom to determine the advantages of education in promoting client empowerment to patients. As mentioned by Somerset, Sharp and Campbell (2002), self management provides an active role for the individual affected by Multiple Sclerosis, empowering them whilst ensuring that their needs are met. Embrey noted that a 1998 audit in the United Kingdom revealed that information provision subsequent to diagnosis was poor. The National Institute for Clinical Excellence (NICE), 2003 study developed best practice techniques pertaining to Multiple Sclerosis in the United Kingdom and set out guidelines including those relating to education. They recommend:

> People with MS should be enabled to play an active part in making informed decisions in all aspects of their MS health care by being given relevant and accurate information about each choice and decision (NICE study, 2003 cited in MacLean & Russell, 2005, p. 755).

Embrey (2005) mentions that specialist Multiple Sclerosis nurses in the United Kingdom have "…been promoting best practice by encouraging self-management and positive attitudes and helping patients to feel more in control of the management of their condition" (p. 34). Cubbin (1992) details the integral role nurses play in health promotion and education. No mention is made of education to empower carers, yet a co-ordinated approach to care is promoted by Embrey. Similarly, June Halper (2006) mentions the key role skilled nurses can play in a variety of areas, including health care, education and the spiritual and psychosocial needs of service users. It is interesting to note carers are not considered a part of the multi-disciplinary team; the historic professional divide appears to be apparent regarding this response.

Leino-Kilpi and Luoto (2001) noted the benefit of patient education in regard to active self management of disease, self empowerment, compliance to suggested regimes and self-care skills to reduce complications. The authors suggest there are two types of education, namely ideological and practical and suggest that high quality education requires the presence of both. The former represents education that details components of the illness, treatments and the possible consequences, whereas the latter includes educating patients on nursing interventions and the need for compliance to meet care needs. Leino-Kilpi and Luoto (2001) mention the importance of familial education regarding patient care. Murphy, Cheeson, Burman, Arnold and Galloway (2001) cited the need to be mindful of patient and carer literacy level and ensure education material is graphic, uses simple words and is culturally sensitive. The dyad of the patient and carer forms an ideal self-management tool, as the objective and subjective views meet in the development of ongoing care plans and action strategies.

Attending education sessions may provide an opportunity to access social and peer support, as well as a venue for information gathering and the development of an enhanced sense of control and the promotion of personal control (Walker, 2003). Black et al (1994) identified in their research the importance of education and counseling about Multiple Sclerosis for families. The MS Trust conducted qualitative and quantitative research with questionnaires to determine the information needs of people with Multiple Sclerosis. The MS Trust details that "…someone with MS should be seen as a person, and not only as a person with MS, but one who is likely to want to take an active role in life. Information should be provided that helps achieve this goal…People with MS generally welcomed information" (MSTrust, 2002, p.1).

Ward, Turpin, Dewey, Fleming, Hurwitz, Ratib, von Fragstein and Lymbery (2004) researched the effect of home-based educational intervention in reducing the incidence and the risk of falls and pressure sores in adults with progressive neurological conditions in the City of Nottingham in the United Kingdom. The randomized controlled trial entailed 114 participants; 45 of whom had Multiple Sclerosis. The conclusions suggested that "…education for people with progressive neurological conditions can have negative effects" (Ward et al., 2004, p.717). According to Ward et al, the rationale for this statement being the declining functional ability experienced and the lack of positive effects on well-being, falls or skin sores.

A study combining questionnaires and focus groups by Mark Hepworth, Janet Harrison and Nicole James (2002) researched people with Multiple Sclerosis to determine their information needs, the type of information being sought and its transfer. The research demonstrated that there is considerable scope for improving the provision of information and it was noted that this action would enhance the quality of life of participants. They further suggested that information provision needs to be sensitive to the cognitive and physiological condition of the person with Multiple Sclerosis. Over half (n = 65) of the responses received found it "…difficult to find out about drug treatments, research trials, balance problems, emotional changes, stress, new and unusual symptoms, and also about state benefits and entitlements" (Hepworth et al., 2002, p.9). It seems that not all the participants actively sought information, yet a number indicated that information they would have liked was accessed via others with the condition or their General Practitioner.

The role of General Practice appears as central in chronic care; with General Practitioners acting as gatekeepers, educators, monitoring agents and playing a coordinating role to the multi-disciplinary care teams (Burns, Carter, Bonney, Truskett, Powell Davis & Harris 2000; Cranney, Warren, Barton, Gardner & Walley 2001; Freeman & Sweeney, 2001; Watkins, Harvey, Langley, Gray & Faulker 1999; Cabana, Rand, Powe, Wu, Wilson, Abboud & Rubin 1999; Langley, Faulkner, Watkins, Gray & Harvey 1998; Dowie 1998; Gupta, Ward & Hayward, 1997). Burns et al. (2000) suggest that relationships with particular patients may influence the individual General Practitioner's application of evidence based practice. Moreover, the authors note that more research is needed to explore organizational capacity for General Practitioners to provide quality care to their patients.

Education is the central component to achieving home based care as it ensures that the person with Multiple Sclerosis and their carers have the knowledge and skills to respond to expected and unexpected fluctuations and change.

2.9 Supports and Services

Living with the chronic illness Multiple Sclerosis is a challenge, not only for those diagnosed, but those directly and indirectly affected, including family, friends, colleagues and more recently, the community at large though service delivery. Choice and the ability to access community services are, according to Northrop (2005), key elements to assist in achieving the goal of remaining in the community and avoiding premature institutionalization.

Jennings, Callahan & Caplan (1988) note the growth in the service and support sector in the United States, warning that most of us will experience some form of chronic illness in later life due in part to medical advances that allow us to live longer. While this research is 20 years old, it highlights the current reality that we need to consider innovative ideas in service delivery to those with chronic illness as well as the goals/ethics in this area of care. In 1988, the *Hastings Centre Report* was completed in the U.S., exploring the needs and problems of the chronically ill. This report highlighted the expected growth in chronic illness, suggesting, that how America responds to this growth is a 'litmus test' for the character of society, its services and support systems (Jennings et al., 1988). Ensuring that the chronically ill achieve the tasks of daily living, maintain their independence and sense of self worth are detailed as aspects that need to be encompassed in a guiding vision, providing an image of "…how a just and good society should accommodate the special needs of its chronically ill members, care for them, and support them in their quest to live meaningful lives with – and in spite of – their chronic illness" (Jennings et al., 1988, p.3). Oeseberg noted in his research that many of the Multiple Sclerosis patients and families involved had failed to receive assistance from community or rehabilitation services (Oeseberg, 2004).

McMurray (2004) states that health services need to be coordinated to avoid compartmentalization by health departments. Aoun, Kristjanson and Oldham (2006) conducted a national survey in 2003 in Australia to explore the challenges in care and service provision experienced by people diagnosed with a neurodegenerative condition and also by their carers. Of a total of 503 patients and 373 carers who participated, the core issue identified was their need for better supportive care. Aoun, Kristjanson and Oldham (2006) researched patient and carer thoughts about what this meant and concluded that having access to financial support via pensions as well as components such as suitable equipment, home modifications, home support and respite, is paramount to achieving a sense of empowerment and being able to make informed decisions (Aoun et al., 2006).

The MS Trust report (2006) completed by Longborough University recommends that information should be provided for people with Multiple Sclerosis that is positive in manner, developed in such a way that helps and motivates people to take action, sensitive to the desire for information and its possible impact on the individual. It should use the most appropriate form of communication, formats and access different types and sources of information as well as enabling access to others with this illness. A qualitative study conducted by Williams, Nicholas and Huntington (2003) explored the use of a highly innovative digital TV pilot service, suggesting that text was a better medium for conveying some types of information.

Co-ordination of service delivery was another area that Aoun et al. (2006) highlighted as needing improvement. The patients surveyed indicated that their wish was to continue living at home for as long as possible and mention was made of the importance of accessible respite care (Aoun et al., 2006). Care requirements that could herald the need to move away from the home environment, include lack of mobility, disease progression, personal care issues, carer needs, loss of income, functional abilities, spousal support or expenses required for home modifications and equipment (Aoun et al, 2006). Ad hoc service delivery was explored by Bent, Tennant, Swift, Posnett, Scuffham and Chamberlain, (2002) and compared a team approach in care provision to young people with physical disabilities in the United Kingdom. Bent et al. concluded that the team approach represented no significant differential in cost, yet was likely achieve an enhanced participation in society for the young physically disabled client (Bent et al, 2002**).** For example, service delivery within country areas is notoriously problematic due to issues such as distance, travel costs, decreased access to professional assistance and the limited numbers of available carers.

Wollin, Yates and Kristjanson concluded in their research with people affected by Multiple Sclerosis that those in rural and isolated communities reported "…the most difficulties with services and they had to move to obtain the support and services they needed (Wollin et al., 2006, p.24). In rural America, teleconferencing between patients and/or patients and physicians or nursing care providers has proven to be beneficial in addressing distance challenges and reducing feelings of isolation. Clarann Weinert (2000) reported on a Women to Women Project conducted to promote health promotion strategies to isolated women who have a chronic health condition. This computer based system entailed support group interactions and displayed few technical difficulties and was easy to use. The overall goal, explains Weinert, was to implement health promotion strategies delivered in a social context and to evaluate group members psychosocial health. Weirnet concludes that the women were overwhelming positive about the project, engaging in support group exchanges and in the health teaching component. Hill, Schillo and Weirnert (2004) similarly explored the effect of a computer-based intervention with women living with chronic illness in rural areas. The researchers concluded that the benefit of social supports and the development of self-help groups, based on the intervention, were notable. Canadian research conducted by Aronson et al suggested "no rural-urban disparity in service provision, utilization or satisfaction" (Aronson et al., 1996, p.354). However, this was not my experience when providing social work services and assessments in the Ballarat region of Victoria during the 1990's, which closely linked with those described by Wollin et al and Weirnet. Geographic location posed barriers to home visits, accessing post discharge care and allied health assistance as well as on-going active, home care service delivery.

McMillan and Wright suggest a:

> segment of funded carer services should be recognizably different from formal disability services in that they are able to assist with tasks that these other services would not do, and require specialist skills (child care, financial counseling, work backfill). These services need to be lifestyle friendly, flexible and age appropriate; are available over the long term course of the disease and offer improved case

> management input to ensure good planning and packaging of all services (2005, p.13).

The costing analysis completed by Access Economics exploring unpaid and informal care, quantified that unpaid care represents the biggest financial cost to the Australian community in regard to Multiple Sclerosis care, representing 43%; with a replacement value of $4.9b per annum (cited in McMillan and Wright 2005:12). As McMillan and Wright explained,

> ...due to the early onset of MS, many family carers are of working age, and the unpaid care duties often disrupt their working potential. This is a double blow for the family of a person with MS because when the need for care emerges, often the individual will have reduced or given up work – compromising the financial security of the family. Family carers of people with MS assist with personal care, meal preparation, home and garden activities, house maintenance, financial management, transport and child care (2005, p.13).

Donohoe et al. (1996) concluded in their research with middle-aged adults with chronic illness that the use of services was less than expected, yet an increase would be considered by participants in the event of happenings such as the deterioration of their condition, caregiver's illness and socialization needs (Donohoe et al, 1996). It appears that the relationship structure of the person with Multiple Sclerosis and his/her carer are influencing variables towards the need for institutional care (Donohoe, 1996). The anecdotal observations by researchers suggesting that single, divorced or participants being cared for by a parent or child, were more likely to experience admission to care facility (Donohoe, 1996). Donohoe et al. (1996) and Revenson (1994) note the need for accessible nursing care, social and structural supports and family respite. Black, Grant, Lapslay and Rawson (1994) identified the main areas of personal needs not being met for people with Multiple Sclerosis in New South Wales were, respite care, family support and support from other people with Multiple Sclerosis.

Tracking down the available supports and services has been identified as problematic for some, resulting in feelings of frustration (Wollin, Yates & Kristjanson, 2006; Northrop, 2005). Allen and others concluded in their research that a key component to achieving home based services appears to be having a "…clearly identified lead professional at each stage of the caring trajectory" (cited in Wollin et al., 2006, p.24). Khan et al. (2006) concluded in their research that there were high rates of depression, poor quality of life and an apparent lack of access to and use of, appropriate rehabilitation and support services.

Research suggests that in the area of Multiple Sclerosis care the demand on health care services and facilities appears to be generally only in some areas, including physiotherapists, community nurses, home help (Moorer, Suurmeijer & Zwanikken 2000). Services by physiotherapists and from home help increase notably in the event of an exacerbation (Moorer et al, 2000). Somerset, Campbell, Sharp and Peters (2001) conducted a cross-sectional survey to determine the health-care preferences of people with Multiple Sclerosis. Their findings indicated a wide variation in preferred services and unmet needs and identified the need to involve people with Multiple Sclerosis in the identification of their preferences (Somerset et al, 2001).

Accessible services and supports are paramount in community based chronic care, as without these structures being in place, the whole process of home based care becomes unfeasible and too stressing for people with Multiple Sclerosis, family and friends. Invariably, it is a member of the multi-disciplinary team from a hospital, rehabilitation facility or council who provides the initial support, completes the assessment and deems which services and supports are most applicable and necessary. Historically, the service user was 'informed' what was required and what he/she was eligible to access. Younger people with disabilities want to self-direct their care…" (Northrop, 2005, p.68).

Margaret Holloway and Mark Lymbery (2007) suggest that the historic process is now changing, with the service user (person with Multiple Sclerosis) starting to have increased control.

2.10 Government Frameworks

In Australia, *The Rights of Disabled Persons* (1975) legislation sets out society's obligations to people with disabilities, stating that they have the right to

- protection from discrimination on the basis of their disability;
- be treated with dignity and respect
- have access to education, training and employment relationships, a social life and a family life assistance to enable them to become as independent as possible in all aspects of life (Annison et al., 1996, p.37).

The Commonwealth *Disability Services Act 1986*, Principle 5, Objective 13 details that

> Services should be designed and administered so as to provide people with disabilities and encourage them to make use of, avenues for participating in the planning and operation of services which they receive and the Commonwealth and organizations should provide opportunities for consultation in relation to the development of major policy and program changes (Disability Services Act, Commonwealth of Australia (1986)).

Morris promotes an empowering view of responding to clients who have a disability, looking at their view of life rather than our own. She argues that "…disabled individuals and communities should direct and manage services designed to support them towards independence" (cited in Payne, 1997, p.252). Human rights have been acknowledged and declared in different formats worldwide. The Australian Human Rights and Equal Opportunity Commission reviews Disability Rights on a regular basis, most recently in September 2006. The Australian Commonwealth *Disability Services Act 1986* details a clear acknowledgement of the individual's rights to "…respect for their human worth and dignity" (Annison et al., 1996, p.38). Moreover, Principle 3 of this Act suggests that

> …people with disabilities have the same rights as other members of Australian society to realize their individual capacities for physical, social, emotional and intellectual development (Annison et al., 1996, p.38).

A discussion paper relating to the development of a National Disability Strategy of the Australian Government (2008) details the aim of improving "…support and remove(ing) barriers for people with disability, their families and carers" (Australian Government, 2008, p.). The paper suggests Government's desire for an inclusive discussion with the disabled and their carers on these issues. For the nearly four million Australians with long term impairment there is a need for Government to develop a new "…whole-of-government, whole-of-life approach to disability issues which tackles the social and economic divide between people with disability and those without" (Australian Government, 2008, p.4). Moreover the role of unpaid carers in the field of disability is acknowledged. Research conducted by the Australian Institute of Family Studies in 2008 suggesting families and carers experience high rates of "…mental health problems, poorer physical health, employment restrictions, financial hardship and relationship breakdown (Australian Government, 2008, p.6).

The *Victorian State Disability Plan 2002-12* was released in 2002 and details the Victorian Government's belief that "…people with a disability should be able to live and participate in the life of the Victorian community, with the same rights, responsibilities and opportunities as all other citizens of Victoria" (DHS, 2002). This plan has a ten year outlook and aims to change the approach taken in regard to supports and services for the disabled. It details goals including the development of individualized planning and support, with enhanced support in relation to housing, partnerships and government direction (Department of Human Services, 2008). Consequently, a review of the support system as a whole is envisaged, with the goal of developing a flexible, responsive and empowering system for the disabled in Victoria.

The Victorian community initiatives for supporting individuals with a disability have included the Home and Community Care, Community Aged Care (CACP) packages, Extended Aged Care at Home (EACH) packages and in-home/residential respite.

Victoria's primary health care system is developing strategies to best respond to the increasing burden of chronic disease in the community. These strategies include providing funding to Primary Care Partnerships and Community Health Services which aim to provide "planned, managed and proactive care" to people living with chronic disease through community based health services and the provision of services within an integrated health care system (Australian Government, 2008).

The Victorian government envisions chronic disease management as being systems which are person-centred and reflective of the needs of the people with chronic illness (Australian Government: 2008). The Fairer Victorian policy, *Care in your Community* (launched in 2006) details a ten year vision for modern health care and notes that the role of Primary Care Partnerships (PCP) is central to achieving this vision. PCP represents integrated service delivery and professional involvement with the care recipient in the assessment and management of care systems. General Practitioners may choose to play an active part in the PCP process. The Victorian Government report on chronic disease management program guidelines for Primary Care Partnerships and Community Health Services suggests that instances of chronic disease are increasing in the Australian community, representing 70% of the overall disease burden (Australian Government, 2008). This figure is expected to rise by 10 % by the year 2020. Hence, the development of initiatives such as the The Early Intervention in Chronic Disease (EIiCD) and the Integrated Chronic Disease Management (ICDM) program, represent avenues of funding for facilitating integrated service system provision in chronic care now and in the future (Australian Government, 2008).

2.11 The Role of Social Work

The growth in the occurrence of chronic disease within society and the concurrent patient need in this respect has already been discussed and documented. Social Work has an active history of working with people with disabilities, yet the role of social work in this field is currently being challenged by diverse health professional groups.

Within the current eligibility review of the Australian Association of Social Work (AASW), the need to understand the context of social work practice with the disabled is cited, together with the need for practitioners to focus on empowering and achieving non-oppressive practices (Australian Association of Social Workers, 2008). As a discipline, social workers are encouraged to take a broad psychosocial approach to assessment, encompassing the individual, family, social and societal aspects which may impact upon service users. The person with Multiple Sclerosis may experience exacerbations as well as periods of relapse and remission. The kaleidoscope of symptoms and their disruptive effect on every day functioning effect not only the person with Multiple Sclerosis, but his/her family and carers. The professional resource centre of the National MS Society in New York suggest there is a considerable adjustment process for all concerned, from diagnosis through the acute episodes and then adjusting to the residual effects and the threat of incomplete recovery. It appears there is a clear role for social work intervention to facilitate this adjustment process and ensure that the required services, supports and educative functions are commenced. Advocacy is a key role of social work and in the care of Multiple Sclerosis patients this role may be particularly relevant as the individual addresses the issues of disability insurance, employer negotiations, early retirement and government support (Jiwa, 2003). Moreover, spiritual care may be incorporated by social work as part of their holistic care, thereby assisting the person with Multiple Sclerosis to find meaning amidst the challenges the Multiple Sclerosis may pose (Holloway, 2007).

> Since the inception of social work involvement in almoner care, the profession has gradually established itself as a unique body, with an identifiable approach to practice and a Code of Ethics reflecting humanistic values. Moreover, this philosophy acknowledges human beings right to self determination and self realization during the lifespan. Social work represents a profession that is disciplined by specific standards of practice, which are designed to ensure the purity of purpose and practice of social work practitioners in the field (Holloway, 2007, p.272).

While government has been instrumental in refocusing societal attitudes and responses towards the care of the disabled members of the Australian community, it has also been manipulative of the manner in which this response has been formulated. Why is the social work voice so difficult to hear? asks Dr Lonne, National President of the AASW. Discussing the marginalization of social work, Dr Lonne suggests that factors such as "…rampant neo-liberal ideologies, globalization, economic transformations and rationalizations, and managerialism.." have been instrumental in shifting the power away from professionals (AASW, 2007, p.9). Dr Lonne mentions his concern that the declining influence of social work may have significant long-term effects on those whose lives are already difficult, including people with disabilities (AASW, 2007). It seems that social workers are in danger of being viewed by society as mere technicians of government social welfare (AASW, 2007). The AASW has a membership of 6,500, this compares poorly to the Australian Psychological Society (APS) membership of 15,000 (AASW, 2007, p.3). The prospects for growth regarding social work are slow, according to Dr Lonne, and new positions are "…often filled by people from other disciplinary/educational backgrounds, which do not necessarily embrace social work values and approaches" (AASW, 2007, p.10). Holding onto turf appears to be the current challenge for the social work profession.

While the profession of social work is focused on spreading itself thinly over an ever increasing diversity of areas, it is failing to hold onto its ground in the area of community based care for the disabled members of the community. The Australian Association of Social Work National Bulletin 2007 details that the National President reports an "…agenda of change and progression' for the profession (AASW, 2007, p.3). Dr Bob Lonne suggests:

> We need to critically examine the issues at hand and our future visions for the profession, and to respectfully engage in the debates and alternative viewpoints, and out of this to find directions that most agree will further our aims and association (AASW, 2007, p.4).

For those members of the community living with a disability and requiring services, the decrease in the number of social workers providing care and case management may result in an increasingly top-down system of social welfare. It appears that government policy drives the agenda and management controls service delivery with minimal questioning or challenge. Social workers are adept members of multidisciplinary teams and accustomed to working in partnerships to ensure the differing components of the given situation are covered in the response and allowing for person-centred planning (Jones, Cooper & Ferguson 2008; Coulshed & Orme, 2006).

Opportunities exist for social work to become a prominent player in the care of the people with disabilities within the community. As a profession, social work requires practitioners to question and challenge the prevailing system and advocate welfare reform to better meet client and community needs. Pauline Hardiker and Vicky Tod (1982) note the slow, insidious, ongoing and relentless nature of chronic disease, not only for the person afflicted but his/her family and carers. This ‘wearing persistence’ may impact upon the degree of invalidism as well as the social arrangements and social isolation experienced. Social work is ideally suited to work with this dynamic, thereby assisting and challenging the individual whilst at the same time challenging the social and cultural responses to ensure that the individual has his/her needs met in an equitable manner.

Chapter Three

Methodology

3.1 Introduction

I sought to conduct research with a person who has the chronic illness Multiple Sclerosis and with those who care for him. The research was designed to explore the services, supports and carer education currently accessed by this person and his carers. The consideration of continued care within the community was discussed with these participants, viewing this option as an alternative to accessing long term, residential care that may be geographically isolated from family, friends and home communities.

As the participant and I share the same chronic illness, both parties came to the research as experts on the topic. The relationship therefore was that of co-researchers (Moustakas, 1994). Harvey (1990) refers to the fact that knowledge exists within our everyday lives and is in a continual process of transformation to which we respond (cited in Shacklock & Smyth, 1998, p.74).

3.2 Theoretical frameworks

The theoretical frameworks which inform this research include a phenomenological approach and a feminist methodology. A phenomenological approach was utilized, ensuring the thoughts and opinions of the participants were heard and their interpretation of the world was presented (Kellehear, 1993). This aligns with Bray and Mirfin-Veitch's (2003) belief that research provides families with an avenue to enable their voice to be heard. Phenomenological research can be variously interpreted and applied, according to Barnacle (2001). Representing the 'study of phenomena', this research "…begins with wonder... opening up the unknown" (Barnacle, 2001, p.3). Ritchie (2001) suggests qualitative research enables exploration of meaning and understanding, the social construction of reality and its value-laden nature and the close relationship between the researcher and those participating in the research.

There are many understandings and definitions of feminism making it impossible to consider feminism as one coherent and homogeneous theory. Many authors consider feminism to consist of a number of diverse strands each signaling "to the broader public that feminism is not a monolithic ideology" but is instead marked by a "range of different approaches, perspectives, and frameworks [which] a variety of feminists have used to shape both their explanations for women's oppression and their proposed solutions for its elimination" (Putnam Tong, 1998, p. 1-2). An example of the diversity of feminist thought can be found in Tong's first introductory text about feminism when she identified liberal, socialist, radical, psychoanalytic, postmodern and existentialist feminist traditions in her overview of feminist theory (Tong, 1989). In a second edition, ten years later she added eco-feminism and global feminism (Putnam Tong, 1998) and since then Lotz (2003) has described a number of versions of what she labels 'Third Wave feminism'. This project is not based on one particular strand of feminism but instead understands feminist research as "social research on gendered lives" (Ramazanoglu, 2002, p.5).

Stemming from a feminist theoretical base, standpoint theory was utilized to explore the lives of men and women and their experiences of oppression, to develop a more complete understanding of their lived reality (Maynard & Purvis 1994). This theory enabled the exploration of the disempowered position of participants, 'the disabled' and carers alike, by the 'disablism' prevalent within society. Studies suggest that more women than men are diagnosed with Multiple Sclerosis on a ratio of 3:2 (Jelinek, 2000). Maynard and Purvis (1994) suggests that individual experience needs to be positioned into a social framework to address "…some of the silences" (Maynard & Purvis, 1994, p.24). Gender issues regarding female control and/or subjugation within society may develop a more complete picture of participant's lived realities. Maynard and Purvis (1994) draw on Sandra Harding's suggestion that objectivity includes the systematic examination of existing beliefs and practices. Each participant will have his or her own standpoint and differing understandings of reality will therefore emerge.

A feminist analysis effectively builds a 'picture' of participant responses and their experience of services, supports, carer education and thoughts on future care. Moreover, the researcher will bring her own 'self' to the project, thereby bringing her values, experiences and standpoint variables to the research (Maynard & Purvis, 1994). Maynard and Purvis (1994) suggest that the researcher variables require consideration in the process of analysis, alongside those of the participants. Feminists accept that there is no process of analysis that effectively neutralizes "…the nature of social interpretation" (Maynard, 1994, p.133). Aiming to explain the grounds behind certain beliefs or statements at least acknowledges the complexity of forces behind these elements (Maynard, 1994, p.133). Feminism represents a politically driven philosophy which acknowledges and challenges the prevailing power relations between men and women, drawing attention to the structural factors which impact upon the lives of individuals within society. It can be used to analyse the private and public lives of men and the social framework they live in, with its prevailing cultural controls, inequalities, power relations and injustices that influence their existence. Maynard and Purvis (1994) discuss the process of mixing methods to maximize input into the research. Certainly, in this research a "multi-sourced" approach has been utilized which encompasses interviews with the female and male carers, stemming from within the family and friendship network as well as from a community care agency. Feminist analysis is not a homogenous ideology, rather there are multiple feminist lens that reflect specific and diverse elements of the ideology and research stemming from a feminist analysis reflects this diversity.

The data is grounded in experience which is a reflection of the participant's understanding of reality and his own lived experiences (Maynard & Purvis, 1994). Ritchie (2001) mentions the qualitative process of writing research results in narrative, with inductive reasoning taking place with a focus on language and discourse. Ricoeur (2003) suggested that the meaning of the lived experience of individuals becomes known to others through processes of interpretation. Strandberg, Norberg and Jansson (2003) suggest the interview data is read, re-read and then the interpretations critiqued and verified. Comprehending what the text says and the meaning behind the language is thus a gradual process, which is influenced by diverse variables, including the researcher beliefs and knowledge as well as current literature (Ricoeur, 2003).

Huberman and Miles suggested the process of qualitative data analysis is threefold: data reduction, data display and conclusion drawing (Berglund, 2001). The structural, narrative analysis utilized in this research identifies core themes and sub themes, allowing the researcher to develop an understanding of the individual's lived experience (Reissman, 2006; Moustakas, 1994). Meaningful units or core themes drawn from the transcriptions, are condensed and compared with each other; each of these units stemming from a thorough, critical and systematic examination of the transcript material to find how these core elements explain what the text holds (Strandberg et al, 2003). The core themes are clustered, labeled and quantified (Kellehear, 1993; Moustakas, 1994). Having determined the 'essences' within the data, I investigated how these general phenomena or essences are constructed (Alvesson & Skoldberg, 2000). Husserl in 1913 detailed that the individual's experience was part of a process, implying that

> …every individual experience must be seen as embedded in and bearing the imprint of a conceptual world…a world which is continually changing, shifting its 'horizons' in past and future time…(cited in Alvesson & Skoldberg, 2000, p.38)

3.3 Research Methods

A qualitative approach using questionnaires and semi-structured interviews were implemented with the dyad of the person receiving care and his primary carer. Further carers were then interviewed separately about their role as a carer and the education they had received specifically to assist with this service delivery. The participant receiving care originally became known to me via an international MS website (International Federation of Multiple Sclerosis) where people with MS are able to contact each other and learn how other people are coping with the illness. I initially invited members of this group in general to participate in this research. This one participant contacted me.

The case study method utilized in this research represents 'focal sampling' whereby an individual and his carers were interviewed in a specific time period (Kellehear, 1993). Sarantakos (1993) states case research can involve studying individual cases in their home environment, utilizing a variety of data collection methods. Moreover, Sarantakos (1993) suggests case studies have characteristics which include studying whole units in situ, noting that the study of a single unit as one study allows the respondent to act "…as an expert and not just a source of data" (Sarantakos, 1993 p259). Certainly, this research affords an image of the care recipient's situation from his, and also his carers, viewpoints as experts.

Neuman (2006) identifies that case study research helps researchers "connect the micro level, or the actions of individual people, to the macro level or large scale social structures" (p41). Such a method was well justified in this situation where the experience of one person shares valuable insights into the relationship between people with disabilities and the state and the broader society.

For the purpose of this research pseudonyms were given to the dyad of care recipient (James) and primary carer (Jane) and additional carers to protect their privacy and maintain confidentiality. In December, 2006 James made telephone contact with me which enabled me to discuss the proposed research project, determine if James accessed support and services in the home and seek permission to forward an invitation to his home address. James and Jane agreed to participate and thus documents pertaining to participation in the research were sent to their household for themselves and any additional carers. Copies of a tick-box questionnaire (Appendix 4) seeking demographic details, consent forms (Appendix 5) and a stamped, addressed envelope for these documents to be returned to me were also forwarded.

Once the forms were completed and returned, I initiated telephone contact with each carer, outlining the study in more detail and answering any queries. For this study participating carers needed to provide support/services to James for at least 1 hour per week on a regular basis (e.g. weekly or monthly). An interview time and date was arranged with the participants to take place in a setting of their choosing; several of the carers requested telephone interviews (n=4) due to personal commitments and location, the other interviews took place in the care recipients' home. The interviews with James and Jane were sequential and took place in their home. My interviews commenced with disclosure of the confidentiality and privacy statements of JCU and a brief outline of my experience of Multiple Sclerosis. The overview of the research project was also provided. The interview with James extended for a 90 minute time span as did the interview with Jane. Interviews with the carers were over a 45 minute time span (See Interview schedule – Appendix 6).

3.4 Limits to the Study

Limitations to the study include the geographic dispersal of carers across the State of Victoria. Moreover, the fluctuations in cognition and levels of fatigue James experienced influenced how the research was conducted and led to the emergence of a dyad. James had previously been assessed by an Aged Care Assessment Team of the Commonwealth of Australia as requiring high level or nursing home level care. This assessment outcome reflects the high level of care James requires in his 24 hour needs; for example hoists are required for all lifts, he is totally wheelchair dependent and has a supra-pubic catheter in place, requiring monitoring and emptying. Assistance is also required by James with feeding, showering, dressing, toileting and achieving further tasks of daily living. This high level care is designed for people who are very dependent. The individual accessing this type of care represents a member of a vulnerable population who may have others choosing what is best for them, thereby losing their autonomy, right to choice, self-will and privacy in the process (Lubkin & Larsen, 2006). Limitations of this research design include the reliability of family carer reports, given their familial relationship to the care recipient and diversity amongst the carers, who include people from within the family and friendship network as well as one paid community carer.

The decision to interview both James and Jane was reached due to the increased fatigue James had been experiencing when the interview was taking place. James was experiencing significant problems with his short term memory and was also unable to recall specific details and dates pertaining to his illness. Jane was interviewed on two occasions, firstly, as the other half of the dyad and secondly, as one of the group of carers being interviewed. All of the interviews occurred during March/April, 2008. The participants, male and female alike, are seen as the 'experts' of their own situation and lives in this research. The interviews with the carers (n=8) were briefer than with James and Jane as they focused more succinctly on issues of care provision and their perception of carer education.

There are inherent power differences within the researcher/participant relationship. Rather than 'giving' the subjects a voice, the researcher organizes a setting, of the participant's choice, for the interviews to take place. This collaborative relationship is reciprocal in nature and will generate insights for both the researcher and participant, becoming a force for change to both parties (Sparkes, 1998).

Ethical considerations include those of ensuring participant confidentiality, lack of deception and ensuring participant's rights are upheld (e.g. involvement can be withdrawn at any time during the research process, by request). All participants were volunteers, having control over how much information they chose to divulge and contact with Lifeline or the local MS welfare worker was available if the participant became distressed as a result of their involvement. Interview tapes and the copies of transcripts will be held in safe-keeping at James Cook University for a period of 5 years.

Chapter Four

Findings

4.1 Introduction

In this chapter I present the outcome of the interviews conducted with each of the participants. The familial relationship between the person being cared for and the five family carers that were interviewed, namely his wife and their four children, is clearly reflected in their responses to the interviews which focused on ascertaining their views on services, support needs and carer education. Two friends, who were also carers were interviewed along with one paid carer. The following chapter discusses these outcomes in the context of the literature.

4.2 James

When asked about his experience of living with Multiple Sclerosis, James initially started detailing the various side effects he has experienced since diagnosis, suggesting that the stem cell transplant proved to be a turning point *"…it probably got worse from that day forward".* Taking a regime of tablets daily to help manage his illness, James was unable to recall the exact medications.

James felt that while people did not initially understand the diagnosis, he noted that nor did he. James stated that the family was supportive, although he explained that it has

> *"…taken them a while, um. My youngest daughter, she was told when she was seven. She's only ever known me after I was diagnosed so ah, she's settled down now".*

In relation to self perception the issue of visual challenge was immediately cited, followed by ambulatory challenges; to lighten the gravity of the discussion, I was assured by James that his "head works most of the time"! His experience in the workplace leading up to premature retirement was sad due to the loved nature and challenge of his job in finance; however his employer was supportive and allowed him time to slowly adjust to the change in status. He mentioned that

> *"it was very good that I worked for a large organization because, ah, they have deeper pockets than a smaller organization"*

James appears to have made the shift from full time to part time employment, then retirement on a Centrelink pension gradually with family offering support as necessary. For example, James' brother erected a purpose built house that is wheelchair friendly and another brother assists financially.

The internet has typically been utilized as the key source of information on Multiple Sclerosis, although this is now problematic due to the vision difficulties James is experiencing. One of the carers has utilized her time to learn about the issues James wishes to search, conducts the search on his behalf and reports back the information found. Support services for James have typically been accessed through the local shire council; James stated that he has been lucky in accessing these services and is able to play an active part in organizing them, although he noted that organizing these services was a process of trial and error for his spouse.

Self management of the illness was difficult for James to quantify, yet he felt that between him and his wife they were achieving this goal. James was stoic about the negative impact the stem cell transplant had had on his cognition. The subject of General Practitioner management program for chronic illness was raised, however James prefers to have limited contact with his General Practitioner, stating

> *"I see him infrequently, which I like"*

When asked about the involvement of a social worker over the years, James' response became confused with the support he has, and is currently receiving, from a psychologist.

The researcher asked how he feels his needs will best be met in the future and James responded

> *"Um, I'm very fortunate that this grey matter does work, not always but sometimes it does and surprisingly well I think. Um, I've forgotten it but then I remember it and think; that's what it was. So, what I would like to do in the future is to just become more comfortable with, um, my vision impairment and while there is no cure for this thing, which gives me the shits sometimes"*

I posed the question to James that if he was to wake up tomorrow and imagine a future that was perfect, how would he imagine the situation and what would alter that image? James pondered a little then suggested that if he could wake up tomorrow and this whole thing was lifted from his shoulders, he'd think "you beauty"!

4.3 Jane

Jane explained that whilst she and her husband James were initially focused on beating the disease; battling on and continuing to keep going has been their approach. Early retirement eventually took place for James due to his rapid deterioration and decline. This shift saw Jane take up the reins to the tune of 50 hours per week at work as well as rearing four children and acting in her carer role.

Others came along, Jane explained, to help in a crisis and assist with childcare so she could visit James in hospital. However, she described that

> *"…it was a disease, you know, that didn't exist according to them and they weren't in the lounge room every Saturday when toddlers were running round the house and making noise and he'd go to sleep in the lounge and scream because they'd wake him up…So, we kept going and keeping up a front for that …"*

But it was not just a part time thing and Jane finds that even now, eleven or so years later, people naively focus on the positives, mentioning how James has stabilized, yet remaining oblivious to Jane's reality and the impact of her 24 hour care. She spoke of wanting to achieve James' wishes in relation to their children and their education even though she felt he had lost sight of this image now. The move from an urban environment in Melbourne to one near the seaside has resulted in a purpose built house suitable for James, yet coming with the price of geographic isolation from family, friends and the older children. Not only has the challenge of this move taken place, but Jane also spoke of the:

> *"revolving door that now perpetuates in their home, as carers move in and out and the telephone rings, it's like running a mini hospital* (Explaining that) *the invasion is necessary yet it's really only two hours of the day out of twenty-four..."*

Jane is now involved writing children's books about Multiple Sclerosis and utilizes the computer to conduct literature searches to keep up to date with the current research on the illness. Jane views the weeks spent by James in respite as her time of self care, secure in the knowledge that he is safe. However, he often regresses and will ask her if it is because of his behavior that she has put him into respite; he can become very emotionally reliant upon contact with her. The physical and emotional drain of caring for a high level patient is described by Jane as being on an *"…emotional roller coaster all the time"*. James does not have a community care program with his General Practitioner and Jane questions the validity of taking up a General Practitioner's hours with this process. Again, self management was viewed as something she could undertake on James' behalf. A social worker had been accessed in the past specifically in the aftermath of the stem cell transplant and to provide Jane with an opportunity to view their situation realistically, noting just how much deterioration had actually occurred.

Jane spoke of her husband as a very courageous, lovely person noting

> *"On a personal level, I don't know if it's worth it because I don't know what's down the track. I don't know whether I'm going to be dead by the time I'm fifty…It's the best that I want to do for James now and while I think that he's got a*

> *better quality of life in this environment, I'll want to keep providing it. Whether I do or can, I don't know".*

When asked how she felt James' needs will best be met in the future, Jane responded

> *"I can only really think for now and just anything and everything comes to mind. Okay, I suppose I'd like, I suppose it would be beneficial if he was out of the house more often, you know at the beginning of the day and come home at the end of the day; that would be majorally fantastic"*

I posed the question to Jane that if she were to wake up tomorrow and imagine the future that was perfect for her, what would it look like and what would alter that image? Jane stated

> *"um. Just to get some peace. Peace. Very gently. Peaceful".*

4.4 Carer interviews

A total of eight carers were interviewed, their ages ranging from 19 - 67 years. One was a care agency worker, five were family members and two were friends. Of the eight, the wife, a friend and the youngest daughter resided with James on a full time basis. Regular time spent with James varied in length; ranging from full time spent by the wife and family friend, every day contact by the youngest daughter, weekend visits by the three other children and another friend who all live in the city and a one hour per week visit by the paid carer.

Personal education levels reached by the carers are postgraduate degrees held by the wife and family friend and university degrees held by the three children and friend who live away. The youngest daughter is currently enrolled at TAFE and the paid carer completed Year 10 and private agency training as a carer, she is the only person to be remunerated for their role, all the others received no payment. Each carer was interviewed separately with the same set of questions.

The carer responses indicated that individually they perceived their role in differing ways. James' offspring typically commenced their response with their role within the family unit, then moved onto describe aspects of the care they provide for him.

> *"Well, for one I'm the daughter. And, I suppose if you call me a bit of a carer because I do, like, you know the occasional day, putting him to bed, feeding him, um, doing, taking him to the coffee shop, lots and lots of things… And the way I feel about that is it's a bit hard, coming I've grown up like that, so I'm sort of used to it by now. I don't know any better because I was only three" (Youngest daughter, aged 18)*

> *"I'm Dad's son, um, and I suppose I, I try to, um, I suppose mitigate the effect of MS has on his life…I see that as a way of mitigating the losses that have occurred because of what MS has taken from him" (Youngest son, aged 21)*

> *"Okay. Well I don't actually live with him, he's my Dad and when I go down to MC to visit my parents, I help out wherever I can" (Eldest son, aged 23)*

> *"I see my biggest role as a son who is trying to help out" (Youngest son, aged 21)*

Friends and the paid carer suggested that their role was mainly to provide primary care, companionship and support for James and also assistance to Jane,

> *"I'm a helping hand for James, more as an extra hand for Jane. Maybe a bit more muscle when needed rather than fine tuning anything so much. Um, at times I do take over some of the role from Jane when she's not around' (Family friend, aged 55)*

Jane described her role as being *"…everything from detailed care when required to project management. How long is a ball a string!"*. It appears that for her, a proactive and reactive approach is required within the role, with co-ordination being a key facet with so many different people moving through the house each day to provide care. Interestingly, she did not state her spousal relationship to James.

Forms of support offered by the carers included project management, personal care, community access, physical support, social and emotional support, companionship, friendship, computer usage and assistance with internet searches.

> *"I'd say more physical (support) mental sort of but sometimes when he's upset I obviously can't relate to what he's going through so it's a little harder in that sort of department but I try my best to make him stay positive and he's pretty good at staying positive anyway" (Youngest daughter, aged 18)*

> *"…. You just treat them as your brother or sister. You know, no different. I don't take any notice what's wrong with them. I like to make people laugh, I love to tell jokes, things like, I like to make people happy" (Agency carer, aged 67)*

> *"Mainly the company; the company is probably the best thing for him at this time" (Eldest daughter, aged 19)*

In relation to education received in their role as carer, a minimal number stated that they were specifically trained as either Registered Nurses (n=1) and Attendant Carers (n=2), with most having received training on specific elements of care whilst in the role from family of the care recipient. Two of the offspring mentioned that they had attended camps held by the MS Society for the children of those living with Multiple Sclerosis and it was noted by one of the offspring that "*…they told us a few things at the camp*" but no mention was made of education per se. There seems a heavy reliance on parents to educate their own children in aspects of personal care, which is a heavy burden when they are also busy learning about, living with and adjusting to the condition and the individual's care requirements.

> *"…I've already mentioned to you as far as education is concerned, um, Mum has shown me a few things, um, whether that is because she's closer to the coal face than me or her nursing, I don't know. It's probably a combination of those two. I found out about the MS at the same time that he did, straightaway. I've just sort of grown up with it from Grade 2 so that's 15 years. So, as far as education, I think I remember a few times when I was a young kid going out with my siblings and the whole family, going out to camps when they specialized in MS and they told us a few things but I don't remember anything specific. I think I just picked it up" (Youngest son, aged 21)*

> *"Oh, no formal education about the matter. But we used to go to this; I don't know what it was. It was like this kids MS camp, for kids whose parents have Multiple Sclerosis. Went to this thing, where they drew pictures. Some after school care. That sort of thing. You learn't a bit about it there. Um, um. I've mainly learn't from having my father with MS" (Eldest daughter, aged 19)*

> *"Because I'm not doing the catheter procedure very often, Mum did it one day to demonstrate it and I did it the next" (Youngest son, aged 21)*

> *"At times I'm not really comfortable with it; the whole showering thing, toileting thing but I can manage the catheter" (Youngest daughter, aged 18)*

> *"Probably nothing really; nothing more than informal. I've picked up, well anything that's medically related I've only picked up second hand from Jane who at least had some training in nursing and so on years and years ago. Um. But everything else is just picked up by watching what other people do it and then occasionally thinking, maybe I can adapt something differently one way or another" (Family friend, aged 55)*

While society has a heavy reliance on these carers performing their role, doing so relying on informal education or support appears to have been the experience for many. When sought to give their understanding of social work services, the carer responses overall appeared to be more guess work than informed. A number had had experience in medical settings and drew their understanding of social work from this exposure (n=2), however for most, the profession of social work seemed difficult to quantify. When asked what she knew about social work services, one carer responded that she knew *"nothing at all"*. Another aligned social work closely with socializing and interacting with others. Further salient responses in relation to social work included

> *"that they help people in need I guess. There's all sorts of different fields like child care, like my Dad's care I guess" (Youngest daughter, aged 18)*

> *"I guess I don't know much about social work but I guess they could help him physically or mentally like help him organize, I don't know services or programs or anything that he can go to or participate in. It's a bit elusive isn't" (Family friend, aged 23)*

> *"Oh, people can do social work for general people, disadvantage wise, social impairments, things like that just to brighten up their day. Otherwise, I think they offer counseling or things like that, for people living with disadvantage or disability or for the person who is experiencing it. So, yeah" (Agency carer, aged 67)*

The carers were asked what options they feel are available to people with Multiple Sclerosis when their care needs increase. The responses were diverse, some highlighting the use of respite care to relieve the primary carer and offer a change of environment for the care recipient, whereas others mentioned active family intervention and increasing the home care provided; one carer gingerly voiced the option of residential care and noted the aged care aspect of this mode of care provision. Adjusting and increasing areas of support, as required, was mentioned by several carers, the aim being to keep James at home for as long as possible with “institutionalization” being perceived as an option of need rather than choice.

> *“Um. Well, I suppose over the last few years the whole exercise here really has been designed to keep James at home because it seems increasingly that the only further stage is he will need some sort of institutionalizing and my personal feel on that is to not only postpone that as long as possible but to only um, get into it when something happens that we can’t seem to find some way to adapt to within the house. It may not come to exactly that but then it will be an even more difficult choice. If it’s something that’s grey as to whether it can be accommodated within the house, then it will be an extremely difficult decision when that time arises. I guess when it does; I’m hoping in a sense that it’s no decision and will basically decide the issue for itself” (Family friend, aged 55)*

> *“um. I thought they were very limited. Um. From the information that I get from family discussions around the table and with my boyfriend who is the eldest son of this person, my understanding is that it’s an aged care facility, which is not something J is keen to move into…Once it gets time that he’s unable to live in the family home, here are limited options available.” (Family friend, 23)*

> *“I’ve got no idea what’s out there. And, but if they, what I often think about is when they go into respite care as their partner or carer is going away for a couple of weeks, that must be very hard because James likes to go out for coffee. At this other place where he goes, I don’t think he can go for coffee. And also, they change things around. I don’t think those places listen to what the person is capable of doing…” (Agency carer, aged 67)*

> *“James used to be able to stand up in the shower and we could pull his trousers up and everything like that but every time he went into respite, he wasn’t allowed to stand on his feet, they’d just put him in the hoist. But in the end, it just stopped because he couldn’t stand any more. It used to take us a week or something to get*

> *him back to standing up, you know and getting him off his bottom…" (Agency carer, aged 67)*
>
> *"There must be a place where they have respite care. I don't think it's motivated to people with MS. I think it's motivated to the aged…" (Family friend, aged 23)*

The experience of respite care seems to have been mixed; certainly when I first met with James during a respite period in Melbourne it was confronting to find this relatively young man located in a room at the end of a corridor in the dementia specific, closed ward of the facility. It appeared that he was in a position of being seen, but not heard, isolated from company and his family and peers, cared for and safe, yet alone with his illness.

Chapter 5

Discussion

5.1 Introduction

As detailed by Alvesson and Skoldberg (2000), an individual's experience of disability resides within their own response to the illness, the responses of their significant others and the evolving social responses towards disability in the Australian community. Consequently, the data rests within the current social constraints of the Victorian Government and community as well as that of the Australian Government (Wright & Leahey, 2005; Khan et al., 2006; Aronson et al., 1996).

Action is presently being taken, for example, by the Australian Government in the establishment of discussion sessions relating to disability in the community. The focus is to improve the support and remove the barriers disabled people, their families and carers have experienced. While currently in the embryonic stages, it is envisaged these discussions will assist in the development of a "…whole-of-government, whole-of-life approach to disability issues" (Australian Government, 2008, p.4). It is interesting to note the Australian Government's reference to the United Nations' *Convention on the Rights of Persons with Disabilities*, stating that these rights need to be both acknowledged and incorporated into policies and programs for disabled service users and their families (Australian Government, 2008). However, recognition is also made; that for those living with profound disability and complex needs, Government should ensure that their access to support and living arrangements are met (Australian Government, 2008).

This discussion is divided into the core themes raised during the interviews (Riessman cited in White & White, 2006). The research was designed to allow the voices and opinions of the participants to be heard and interpreted in relation to contemporary society and the environment within which the care is taking place (Maynard & Purvis, 1994; Ricoeur, 1976). Thereby highlighting changes in social responses and thinking towards the disabled over time (Annison, Jenkinson, Sparrow & Bethune, 1996)

5.2 Sense of Control and Access to Support

It appears that James was consulted in relation to the support services he accesses via the Home & Community Care Program (HACC) and stated that he has a sense of control over this service delivery and thus it represents an empowering process (Morris cited in Payne, 1997; Annison et al, 1996). This sense of control by James reflects society's acknowledgement of the rights of the disabled to have control over their life (Annison et al., 1996; Cocks & Stelik, 1996; Frank, 2000; Victorian State Disability Plan, 2002; Commonwealth Disability Services Act, 1986).

Government intervention influences the degree of access James and Jane have to supports and services (Australian Government, 2008; Victorian State Disability Plan 2002). Jane describes organizing this structure as entering a maze of service agencies and potential supports which need to be walked through to find the most appropriate path for them (Oeseberg, 2004; Aoun et al., 2005; Wollin, Yates & Kristjanson, 2006). The dyad of James and Jane appears to have a problem focused approach to management and each hurdle that has presented itself has been systematically addressed through responsive action (Sullivan et al., 2004; Hardiker & Tod, 1982). Jane represents a 'monitor' with her self described approach of case management in the home situation and to the changing needs of James (Hepworth et al., 2002; Northrop, 2005; Hardiker & Tod, 1982). Jane seems to perform this role in isolation from active support and guidance as they journey through the illness trajectory. General Practitioner, Social Worker and agency assistance has been minimal; rather it is through a process of trial and error that adequate supports and services have been established. James' comment that he only contacts the General Practitioner "infrequently" may suggest that contact is made for primarily medical issues rather than to explore social and community supports that may be applicable at any stage (Schubert & Murphy, 2005). The approach James and Jane have taken to identify which supports and services may be of most benefit to them acknowledges the rights of the disabled, and their carers, to self choice in decision making as consumers (Zola, 2003).

5.3 Education

There is also a heavy reliance on Jane to provide education to the carers on the high level care requirements and techniques that are now required (Walker et al, 2003). This was a concerning practice, given the increased responsibility it places on Jane to act as an educator, particularly when issues of occupational health and safety need to be considered when providing high level care. All of these responsibilities have been at a significant cost to Jane's physical and emotional capacity and health. The fact that most of the carers are either family or friends with only one being a paid carer reflects a significant cost saving for the Government where stretching the health dollar is paramount (Kraft, 1998; McMillan & Wright, 1982; Jenning, Callahan & Caplan, 1988; MS Trust, 2002; Hepworth et al., 2002). Aronson et al. (1996) state that research suggests no rural-urban disparity in service provision, use or satisfaction, however it appears that education and the use of the Primary Care Partnerships program was lacking as neither James nor Jane were aware of this program's existence; Jane feeling this would be a misuse of the General Practitioner's time (Walker et al, 2003: Ristevski, 2003). In this case, the primary carer is female and thus represents the social norm (Sato, Ricks, & Watkins, 1996).

Computer technology provides an element of oneness in the Multiple Sclerosis community where those affected and their carers are able to access information, support, interaction with others and education with relative ease. Impaired vision has proven difficult for James, yet he acknowledged that utilizing a 'voice over protocol' on the internet may assist in this regard. Carer education, specifically the lack of it, was notable amongst the carer responses particularly in regard to personal care techniques, symptom changes and disease progression (Hepworth, Harrison & James, 2002; Halper, 2006; Ward et al., 2004; Koch & Kelly, 1999; Leino-Kilpi & Luoto, 2001). Given the 2005 Access Economics report noting the replacement value for the unpaid carers in the Australian community, surely caring for this resource and ensuring appropriate access to education and training is paramount (Ward et al., 2004;O'Hara et al., 2002)..

5.4 The Impact of the Disease on Family

The description James and Jane provide of the illness' progression aligns with Greenberg's definition of chronic, yet James clearly views the event of the stem cell transplant and its failure as a turning point within this continuum (Walker et al., 2003). It was concerning that Jane spoke of her fatigue and her perception that the carer role may eventually lead to her premature demise (Jennings et al., 1988). Given the recent Commonwealth and State drive to provide more active support to carers, undoubtedly this reflects a broader need within society as well as her own feelings. The "chronic sorrow" as mentioned by Pakenham (2001) was evident in Jane's language and her description of the steady illness progression that has taken place, impacting upon their family life when the children were young and in particular the childhood of the youngest child who is described as having only known James post diagnosis (Binder, 2004:Duval, 2003). How individuals adjust to the challenges and changes that may occur with chronic illness appears to be influenced by diverse variables such as Jane's response of dividing James' life into a before and after disability continuum (Levinson, 1986; erikson, 1950; Bee, 1992; Bindor, 2004; Corbin, 2003; Albrecht & Devlieger, 1999). I wonder how this impacts upon his perception of self and imagine a focus on normalization, rather than on division, may have been of assistance to James in this regard (Holland & Goldberg, 2007). The issue of the impact of disability on children and young adults was certainly highlighted in this research and points to a need for further investigation into this area.

The 'disabled' label and chronicity role (Walker, 2003) have been reframed by the family as one of 'courageous', nevertheless disability has led to the emergence in the life of the family of elements such as premature retirement for James, current reliance on Centrelink for an income, economic deprivation, geographic and social isolation as well as carer overload and fatigue, particularly for the female primary carer as she has had to balance work, child care and her caring role (Maynard & Purvis, 1994:Knight, 2003). Akin to Mairs (Frank, 2004), James appears to have reached a stage of grace/integration in relation to the debilities of Multiple Sclerosis on his body, focusing instead on working at enjoying each given day, his family and friends (Matson & Peters, 1999: McGuiness & Peters, 1999). Jane spoke warmly of her relationship with James and noted that

> *"…For me personally, and for the person that I'm doing it for, yes. But for other people and if you didn't have, if you didn't have a very, very courageous lovely person that you were caring for and different marriages are very different, as you know. An average marriage and you could take it or leave each other and there's lots of people out there like that I guess you could say I, mm don't know if this is going to be worthwhile; I guess I wouldn't advise everyone to do it… It's the best that I want to do for James now and while I think that he's got a better quality of life in this environment, I'll want to keep providing it. Whether I do or can, I don't know"*

5.5 Respite

The issue of respite care in a residential facility opened the discussion to the fact that at present in Victoria there are few options for individuals like James, who require high level care, but are younger than those requiring aged care (Donohoe, 1996; COAG, 2005). It is concerning to note the paid carer's comment on the physical deterioration that took place when James was accessing residential respite for a prolonged period. I visited James during this period in a residential facility in Melbourne. The 'respite room' was located at the end of a long hallway within a locked unit for wandering high level care patients, most of whom were affected by dementia. Invariably residential respite care is a care recipient and carer's first introduction to residential care. It therefore represents an invaluable opportunity to present a mode of care that is caring, mindful of the individual and his/her desires, supportive of the family unit and offers an age-appropriate and stimulating environment (Wright & Leahey, 2005). Jane described her introduction to organizing respite care for James, stating

> *"…unfortunately he has to go to those kinds of places because he is high level, rated as high level, and many nicer places, with younger people, they won't look at him"*

Indeed, James spoke of his pending discharge from respite as release from Alcatraz! Annison et al. (1996) wrote of individual rights and respect for human worth and dignity.

The episode in respite care does not portray a picture of rights being either acknowledged or met.

5.6 Self Management and Social Work

Self management reflects a form of self empowerment and acknowledges the expertise of the care recipient and carer in their own lived experience of the illness and may also reflect improved outcomes for the patient (Holloway & Lymberry, 2007; Ristevski, 2003: Solari et al, 2005: Siegel in Jelinik 2000). Ideally, self management has been developed to enable patients to better manage and take responsibility for their own chronic illness. Similarly, access of community rehabilitation and support services appears to be central to the cared recipient and carers alike in providing support, encouragement and expertise in chronic care (Khan et al, 2006; Oeseburg et al, 2004; Kersten et al, 2000; Somerset, Sharp & Campbell, 2002)). Social work could play a valuable role as a facilitator, enabling the patients self management goals to be realized.

There is a clear role for Social Workers to lobby government and act as advocates, who are willing to explore options for alternative long term care services or enhanced support in the home when it is required. Support for younger adults with chronic illness has been identified by the state and federal governments, however action in this regard will take time to achieve (Donohoe, Wineman & O'Brien, 1996; DHS, 2005; COAG, 2006; Donohoe, 1996). The Queensland body, "Youngcare", appears to be a leader in this regard, establishing residential facilities specially designed to cater for the needs of younger people who require a high level of care.

The fact that social work continues to remains a rather elusive concept which the carers who had not had hospital experience in their careers, had difficulty describing and fitting into the picture of care, is sadly not surprising to many members of this profession (AASW, 2007). An MS Australia social worker had been accessed at one stage and Jane felt the intervention was helpful in assisting her to realistically view the present situation. Jane described this intervention with the social worker as being told to

> *"… get up, just kicking me in the backside or to sort of wake up and see just how much deterioration had occurred right under my nose"*

There is clearly a role for social work in holistic care as well as advocacy and assistance for people with Multiple Sclerosis and their carers as they work their way through the 'welfare maze' (Jiwa, 2003; Holloway, 2007). Social workers may work with individuals and families through processes of adjustment and change, which acknowledge the reality that further deterioration may occur over time (Holland & Goldberg, 2007). Social workers may also assist in alleviating the isolation that individuals with a disability may experience within the community; allowing them to be just ordinary people, living ordinary lives (Holland & Goldberg, 2007).

Chapter Six

Conclusion

The research provided an opportunity for me to explore with the participants the issue of community based services, supports, carer education and options for future care for an individual diagnosed with Multiple Sclerosis. The role Social Work could play in chronic care was also explored.

The narratives of the participants reflected a common theme of jointly working to keep James in his home environment and ensuring that each hurdle in their way is addressed to enable this path to be continued for as long as possible (Donohoe, 1996). Amongst the carers, there was a general recognition that residential respite care is required to ensure that Jane has occasional breaks from her role, with the notion of long term residential care being only talked of within family discussions when considering the options available to James (Wright & Leahey, 2005). The issue of aged residential care was raised and seen as unsuitable given James' age and disposition: moreover, James clearly stated his desire to remain at home (The United Nations, 1948; Disability Services Act 1986;.Walker et al., 2003;Ristevski, 2003; Donohoe, Wineman & O'Brien, 1996; COAG, 2006; Northrop, 1005). The financial cost of the disease on this couple saw James moving from employment in the finance sector, to being a stay-at-home dad while Jane was employed full time. However, at the time of the interview, James and Jane were dependent upon Centrelink, and family, for their financial support (McMillan & Wright, 2005).

With self management being actively sought by James and Jane, they have jointly ensured that as the illness progresses or changes, adjustments are made to the care program and appropriate services accessed (Solari et al, 2005; Khan et al., 2006; Donohoe, 1996). It seems that this process is activated without constant referral to the General Practitioner, who seems to be viewed as the person that assists them with other issues, not specifically Multiple Sclerosis related (Schubert & Murphy, 2005). **This**

finding does not fit with the previous suggestion that the role of General Practitioners appears to be central in chronic care and supports Burns et al. (2000) in their suggestion that more research is needed regarding the G.P./patient relationship and organizational capacities for the provision of quality care. While the notion of self management aligns with the economic rationalist agenda of care programs being promoted by Government (State and Federal), without adequate supports to assist in identifying which supports and services are required and would be beneficial, it can be a very isolating and confusing process for those providing care in the home (Jennings et al., 1988; Walker, 2003; Gobdetz, 1969; Hardiker & Tod, 1982; Australian Government, 2008; McMillan & Wright, 2005; Pakenham, 2001; Aronson et al., 1996; Donohoe, 1996; Revenson, 1994).

The participants had difficulty situating a role for Social Work in James' care which is perhaps indicative of the problems of the marginalization of the profession, as mentioned by Lonne (2007). No social work services were accessed to assist in organizing service delivery in the home (Aoune et al., 2006). There appeared to be a reticence by Jane to access social work and there was undoubtedly a confused perception amongst the participants as to what social work could offer. This finding alerts the need for the profession of social work to be more assertive and educate the community on the elements it can provide in practice (AASW, 2007).

The lack of access to education programs is lamentable and problematic considering the carers are working with an individual who is requiring high level care (Sato et al., 1996; Barlow et al, 2000; Stuifbergen & Rogers, 1997; Hanger & Wilkinson, 2001; Halper, 2006; MS Trust Report, 2006). **The seaside location of James and Jane's current residence may have proven to be problematic in relation to attending education programs however current technology opens the doors to the use of options such as teleconferencing and computer based education, which do not appear to have been utilized with James and his team of carers (Weinert, 2000; Wollin et al., 2006).** Lifting machines and full assistance with all transfers is now required by James and education is a key component towards safely utilizing this equipment. While the older children were residing elsewhere, the youngest daughter was at home and assisted with her father's personal care, as required. It appeared that the personal nature of this care was a struggle for this young person, who noted "at times I'm not really comfortable with it; the whole showering thing, toileting thing but I can manage the catheter". Social Work could play an active role in this respect, thereby ensuring that this situation is properly assessed, recommendations made and referrals lodged for additional support, as required.

The care management required of Jane was a matter of personal choice to ensure James' quality of life was upheld (Somerset, Sharp & Campbell, 2002; Northrop, 2005). However, she was experiencing fatigue and isolation from the older children, family and friends and felt isolated from other aspects of her life because they had moved to the seaside to access a purpose built house suitable for James' needs. The internet also provides a valuable tool that can be actively utilized to facilitate group meetings for education, peer and carer support and discussion. **The impact of chronic illness on the family unit was notable, with family members working together to achieve desired outcomes by providing personal care, companionship, time-out for the primary carer and discussing as a family about the situation at hand.**

Other areas worthy of consideration in future research include the financial challenge that a diagnosis of Multiple Sclerosis may impose on families, due to the diagnosis typically occurring during the middle of the lifespan and the cost of chronic care (Walker, 2003). Moreover, research into the support and education on Multiple Sclerosis for the children of people who live with the condition may be worthy of consideration. Exploring the issue of respite care and the de-conditioning that may occur if the person with Multiple Sclerosis is not encouraged to maintain his/her flexibility/ strength and the possible use of physiotherapists during respite to counteract this occurrence could also be researched. It is important to explore more fully the role social work can play in chronic care, specifically in relation to the person with Multiple Sclerosis, his/her family and carers to assist in organizing supports and services, identify inequities and promote self management that is well informed and conversant with what services are available (Brown, 2003; Rivestski, 2003; Braithwaite, 2003; Edgar, 1992; Papadopoulos, 2003, Wilson et al, 2003; NICE study, 2003 cited in MacLean & Rusell, 2005; Lenino-Kilpi and Luoto, 2001). .

In conclusion, the final words of this thesis are those of the primary carer, Jane. Responding to an article in *The Age* Newspaper, Jane wrote to the editor and drew to light the reality of people with disabilities and their carers**. It appears the weight of providing 24 hour care, struggling to access services as well as having to educate and monitor the carers is truly a burden to bear. As** Jane stated

> In my experience, unless you are familiar with the health system and computer literate, you will struggle to navigate the convoluted levels of government as you attempt to access services. I care for my husband (49), who was diagnosed with Multiple Sclerosis 16 years ago. When it comes to his quality of life, I am very assertive. Previously I thought I was busy managing his needs, working full time and supporting four teenagers. Now I know what busy is as I deal with a fragmented bureaucratic system (the age.com.au/news/letters/many;22/4/2008).

Terminology

Aged Care Assessment (ACAT)

This body assesses and approves older people, and those with disabilities, for Australian Government subsidized aged care, such as residential aged care and flexible care (Extended Aged Care at Home) packages.

Creative Respite Options

A recent initiative of Government which offers carers '…time out to put their feet up or participate in a creative activity…'

Chronic Illness

Resting in the same gamut as disability, chronic illness reflects the ongoing incapacity of the disease. Hardiker and Tod (1982) suggested that the persistence and relative permanence of chronic illness may result in premature invalidism occurring.

Centrelink Department of Social Security

Disability Defined in WHO (1980) as "any loss or abnormality of psychological, physiological or anatomical structure or function" .

Enhanced Primary Care

Commonwealth of Australia initiative for people with a chronic disease, designed to introduce the General Practitioner into healthcare planning and co-ordination.

HACC Home and Community Care program which is funded by the Victorian State Government. the HACC target population is "…people of any age living in the community with a moderate, severe or profound disability who, in the absence of basic support services, would be at risk of premature or inappropriate admission to long-term residential care or hospital admission…(HACC /consultation paper, 2006, p.8)

Respite	**“**is a temporary relief from caregiving responsibilities that provides intervals of rest and relief for the caregiver” (Lubkin & Larsen, 2006, p.272).

High Level Care

A category of care provision and needs, as devised by the Commonwealth of Australia, which represents the requirement for 24 hour/nursing home level care. This level of care provides functionally very dependent people with either complete or almost complete assistance with the majority of tasks required in daily living.

CACP	Community Aged Care Program, typically provided by local councils and funded by Government Home and Community Care Packages, representing low level (Hostel) care requirements.
EACH	Extended Aged at Home packages, designed for those with High Level care requirements who wish to reside at home rather than in residential care. For the CACP & EACH packages the care recipient contributes towards the cost of the daily service delivery (for example, approximately 17.5% of the basic rate of pension is charged.

Self Management

According to Walker, self management includes “…information, developing action plan, self-monitoring, undertaking exercise where appropriate, interaction with health professionals and accessing services and supports” (Walker, 2003, p.55).

Interdisciplinary teams

Representing diverse professionals, these teams work together to "…identify and analyze problems, plan actions and interventions and monitor results of the care plan (Lubkin & Larsen, 2006, p.267)

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Appendices

Appendix 1

Questionnaire for use by participants diagnosed with Multiple Sclerosis

Name …………………………………………… **Date** ………………

Date of Birth …..………….

Year of diagnosis of MS ………………

Sex

Female ☐

Male ☐

Type of MS (current)

Relapsing-remitting MS ☐

Primary Progressive MS ☐

Secondary Progressive MS ☐

Residential details

Lives alone ☐

Lives with partner/family ☐

Lives with carer ☐

Lives with friend/others ☐

Other ☐

Level of education achieved

Year 10	☐	
Year 11	☐	
Year 12	☐	
TAFE course	☐	
Apprenticeship	☐	
University degree	☐	
Postgraduate course	☐	
Other	☐	Please detail

Employment

Employed – full time	☐
Employed – part time	☐
Home duties	☐
Unemployed	☐
Volunteer	☐
Retired	☐
Other	☐

Current (accessed within the past 6 months) medication, treatments & therapies

List of medications taken for MS

Betaferon ☐

Avonex ☐

Rebif ☐

Copaxone ☐

Baclofen ☐

Anti-depressants ☐

Other ☐

Please detail

Allied Health services Yes ☐ No ☐

Physiotherapy ☐

Occupational Therapy ☐

Podiatry ☐

Psychology ☐

Speech Therapy ☐

Social Work ☐
Dietician ☐

Audiology ☐

Dental ☐

Treatments Yes ☐ No ☐

Acupuncture ☐

Meditation ☐

Visualisation ☐

Counselling ☐

Sunlight/Vitamin D ☐

Chiropractor ☐

Yoga ☐

Pilates ☐

Vitamins/Minerals ☐

Hydrotherapy ☐

Monitoring diet ☐

Swank Diet ☐

Walking/Exercise ☐

Swimming ☐

Co-ordinated care with GP ☐
Services & supports (accessed within the past 6 months)

Yes ☐ No ☐

Home Help ☐

In-home respite ☐

Residential respite ☐

District Nursing ☐

Personal Care ☐

Private Nursing ☐

Child care ☐
Gardening ☐
Transport ☐
Day Centre ☐

Council Services ☐
Case Management ☐
Community Care Package ☐
Home & Community Care Package ☐
Neighborhood House ☐
Community Health Centre ☐

(please return the completed form to the researcher in the enclosed envelope)

Questionnaire for use by participating carers

Name ………………………………………………Date

Name of care recipient ……………………………………………………..

Age of carer ….………….

Relationship of carer to the person accessing care

(Please tick if applicable)

Partner	☐	
Wife	☐	
Husband	☐	
Daughter	☐	
Son	☐	
Relative	☐	
Friend	☐	
Agency carer	☐	Name of Agency

Care provided

Personal care	☐	
Toileting	☐	
Community access	☐	
Companionship	☐	
Shopping assistance	☐	
Household maintenance	☐	
Meal assistance	☐	
Other	☐	Please detail

Level of education achieved by carer

Year 10	☐
Year 11	☐
Year 12	☐
TAFE course	☐
Apprenticeship	☐
University degree	☐
Postgraduate course	☐

Other ☐ Please detail

Education or training received to date by the carer relating to the care of an individual with MS

None ☐

Minimal ☐

Carers course ☐ Please detail

Disability care training ☐ Please detail

MS Australia carer education ☐ Please detail

Nursing ☐ Please detail

Other ☐ Please detail

(please return the completed form to the researcher in the enclosed envelope)

Appendix 2

INFORMED CONSENT FORM

PRINCIPAL INVESTIGATOR	*Eleanor Edgar*
PROJECT TITLE:	*Disability & Opportunity*
SCHOOL	*JCU School of Social Work*
CONTACT DETAILS	

Opportunities exist for people living with Multiple Sclerosis to continue residing in their home communities, accessing friends and family and still actively engaging in a life that is not dominated by the condition. *The key research aim is to explore the lived experience of a person with MS and his carers to hear their voices and feelings about the subject of community based care, carer education and future care options. The role for social work in the chronic care of individuals with MS in the community will also be explored.*

Each participant will be asked to complete a brief tick-box questionnaire and sign this consent form. These documents need to be returned to the researcher in the envelope provided. The researcher will then make phone contact with each participant to arrange a time and date for the interviews. If the carer is employed by a community agency, they will need to seek written permission from the agency, agreeing to their involvement as participants in this study.

The person with MS will participate in a two hour, semi-structured interview and the carers will be interviewed separately for one hour. The interviews can take place at an agreed location. The interviews will be taped by the researcher and the tapes will be held in safe keeping for 5 years after the research has been completed, at James Cook University in Townsville.

Participation in the research is voluntary and you can cease participation at any time. This research is being conducted as part of a PhD thesis and a summary of the findings will be provided to all participants at the end of the study. No participant names will be used in any written documentation of the research and all information will be de-identified.

The aims of this study have been clearly explained to me and I understand what is wanted of me. I know that taking part in this study is voluntary and I am aware that I can stop taking part in it at any time and may refuse to answer any questions.

I agree to participate in a taped interview with the researcher

Yes ☐ **No** ☐

I agree to complete the provided questionnaire

Yes ☐ **No** ☐

I understand that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval.

Yes ☐ **No** ☐

I give permission for my carers to speak with the researcher
Yes ☐ **No** ☐

Name: *(printed)*	
Signature:	**Date:**

INFORMED CONSENT FORM

PRINCIPAL INVESTIGATOR	*Eleanor Edgar*
PROJECT TITLE:	*Disability & Opportunity*
SCHOOL	*JCU School of Social Work*
CONTACT DETAILS	

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Consent form for the carer

The aims of this study have been clearly explained to me and I understand what is wanted of me. I know that taking part in this study is voluntary and I am aware that I can stop taking part in it at any time and may refuse to answer any questions.

I agree to participate in a taped interview with the researcher

Yes ☐ **No** ☐

I agree to complete the provided questionnaire

Yes ☐ **No** ☐

I understand that any information I give will be kept strictly confidential and that no names will be used to identify me with this study without my approval.

Yes ☐ **No** ☐

Name: (printed)	
Signature:	**Date:**

Parent/guardian consent required if the participant carer is under 18 years of age

Name of parent/guardian : (printed)	
Signature:	**Date:**

Appendix 3

QUESTIONS FOR INTERVIEWS

For use with participants who have MS

1. Chronic Illness / MS

Living with a chronic illness is a challenge we both live with. Can you tell me about your experience of living with MS, initially and today.

Prompts What do you currently do on a daily basis to help manage your illness?

Have you recently sought out alternative methods and have they been useful to you?

Tell me about any changes or modifications that have been necessary?

How do you feel the MS has impacted on your relationships?

3 Reaction of Others/Self image

People around me responded in different ways to my diagnosis. How do you feel others responded to your diagnosis?

Prompts How did family members respond to your diagnosis?

How do feel they have adjusted over time?

How do you see yourself today?

4. How do you feel others have responded to your changing needs; in the workplace and in the community

Prompts How do others treat you?

How do you prefer to have been treated?

To what extent have you experienced discrimination as a result of your condition?

What reasons do you think people might give to justify discrimminatory behaviour?

5.Financial issues

Being diagnosed with MS and living with the condition may alter financial conditions; do you feel this has been the case for you?

Prompts When did you stop working full time?

Has there been legal involvement to address financial issues?

How have you found living through this process?

What Government involvement was and is sought and what would have been helpful?

6. Supports/Services

How do you see the use of supportive services in your life and do you feel the supports and services you access are useful and help you achieve your goals?

Prompts How did it feel for you to agree to access support so you could achieve some tasks?

What has been of most assistance to you on a regular basis?

What aspect has been important to helping you maintain independence?

How have you been able to access the support you need?

The welfare system is sometimes described as a 'web' that clients navigate to find the services they want. What was your experience when accessing services/support?

Prompts How did you locate the services you needed?

Did you find the process straightforward or bewildering?

Who assisted you with this process?
How would it have been easier?

7. Education

There seems to be a mountain of information on MS which is changing all the time. If you want to, how can you keep up-to-date with the latest research and thinking about MS?

Prompts Can you think of any other avenues that might be useful to learn more?

What sorts of things would you like to know about?

Computers can be useful for information; do you feel this would be relevant to you?

What are the different options open to you in relation to education?

Have you accessed education sessions about MS?

8. Carers

My husband is my primary carer and friends give us a hand when we need it. Can you describe your care?

Prompts How did you meet your primary carer?

How long have you been accessing care from this person?

Describe your care?

Have parts of accessing care have been difficult to accept?

What is the most special part of your relationship?

Do you feel in control of your community care program and is it offering what you had hoped?

Prompts Were you given a choice of who provided care, and when it occurs?
Were you invited to interview prospective carers so you could choose who was most suitable for you?

Has this care met your needs?

Have any issues arisen with this care over time?

Do you have community activities that you attend on a weekly basis?

Which activities have you chosen to add into your program?

Are you encouraged to access to wider community through these activities?

What do these activities give you?

How are these activities useful to you?

Do you have regular contact with your General Practitioner?

Prompts How would you describe this relationship?

What sorts of issues has he/she addressed on your behalf?

Do you have a program of care that he/she oversees?

How could this relationship develop to better meet your needs?

10 Self Management

Self management is a term that equates to control for me. What do you know about the idea of self management of MS?

Prompts What does self management mean for you?

How would you achieve self management?

How might you do differently in relation to monitoring your illness and needs?

Is it proper for others to tell you how to manage your disease?

11. Social work

Have the services of a social worker been accessed during your illness?

Prompts What services or supports have been accessed?

How did it feel to work with a social worker and what did it involve for you?

Do you have a social worker working with you and your primary carer at the moment on your changing needs?

Do you think a social worker would be of assistance to you today?

12 Modification of home environment

Has it been necessary for you to change elements of your home environment to meet your needs?

Prompts Tell me about any changes or modifications that have been necessary?

Who helped you with any alterations?

Was any financial assistance sought or offered with the alterations?

What difference do the house alterations have on your day-to-day life

13 Ongoing care

How do you feel your needs will be best met in the future?

Prompts How do you imagine you can best achieve continued community based care?

Have your accessed residential respite?

What was residential respite like for you?

Is residential care something you would ever consider for yourself on a permanent basis and what do you feel would lead you down this path?

Questions for carers:

Explain how you see your role for the person with MS and how does it feel for you to be providing care.

Prompts What does your caring role entail?

How do you approach providing care?

Describe your relationship with the care recipient?

Which forms of support do you offer that you feel are particularly helpful to the person with MS and his/her carer?

Prompts What support network is available to you?

Do you have a supervisor to discuss your work or any concerns?

What do you think is the most important aspect of your role?

Who should decide the focus of the care you provide?

Do you feel controlled in your role?

What education have you received to assist you in the role of carer?

Have you received any training relating to your role?

Has carer education been important for you?

Are there areas that you feel education would be helpful to you as a carer?

Is there an area that you feel education would assist you to provide care?

What options do you feel are available to people with MS when their care needs increase?

When would providing care in the home become too problematic for you?

At what point does your agency start to explore other options of care with the person who has MS

Have you been involved in the process of relocating a person with MS from the community into residential care and what led to this decision?

What would you like to be able to discuss with the person with MS in relation to available alternatives?

Word Count: 30, 479