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UNIVERSITY OF ALBERTA

LIFE SATISFACTION AND OCCUPATIONAL BEHAVIOUR OF INSTITUTIONALIZED PERSONS WITH MULTIPLE SCLEROSIS

BY

SUSAN C BURWASH

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
AND RESEARCH IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF MASTER OF
SCIENCE

DEPARTMENT OF OCCUPATIONAL THERAPY

EDMONTON, ALBERTA
SPRING, 1991

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ISBN 0-315-66586-6

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DEGREE: Master of Science

YEAR THIS DEGREE GRANTED: 1991

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ENTITLED Life Satisfaction and Occupational Behaviour of Institutionalized Persons with Multiple Sclerosis

SUBMITTED BY Susan C. Burwash

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE

DEGREE OF Master of Science

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Date: April 4, 1991

ABSTRACT

The purpose of this study was to describe characteristics of institutionalized persons with multiple sclerosis (MS) with regards to demographic characteristics, to describe the level of life satisfaction of these individuals, and to identify factors which may be associated with life satisfaction. The study is based on a model of human occupation used in occupational therapy. This model suggests that life satisfaction is likely to be influenced by the extent to which individuals have hope, have control over valued aspects of daily life, participate in roles which are important to them, have skills, and engage in activity within a facilitative environment.

Forty respondents living in seven extended care facilities were interviewed using a questionnaire which included both quantitative and qualitative questions assessing life satisfaction, and six factors representing elements of the model which might be associated with life satisfaction.

The results suggest that institutionalized persons with MS report low levels of life satisfaction, express considerable hopelessness and lack of control, and otherwise appear to have considerable disruption in aspects of habituation, skill performance and output of occupational behaviours. Two factors, hopelessness and expected control, were significantly associated with life satisfaction. Age at diagnosis was also associated with levels of life satisfaction. Multiple regression analysis showed that 5 variables together (age at diagnosis, expected control, hopelessness, role incumbency and number of valued daily activities) predicted 45% of the variance in life satisfaction. Hopelessness scores were by far the strongest predictor of life satisfaction scores, followed by age at diagnosis.

The study provides support for the model, and also suggests potential intervention strategies for occupational therapists working with institutionalized persons with MS. The study also suggests that there is an ongoing need for community-based services for persons with MS.

ACKNOWLEDGEMENTS

The author wishes to express sincere appreciation to the following individuals:

My supervisor, Dr. Sharon Warren and thesis committee members, Professor Gail Gilewich, Dr. Jim Vargo and Dr. Jennifer Rodgers - for their ideas, encouragement and assistance during the extended life of this project;

Dr. Laura Krefting and Mr. Doug Krefting - for their inspiration, understanding and friendship;

The administrators, occupational therapy supervisors and staff of the extended care facilities;

The study respondents, who gave so generously of their energy and time;

My family and friends, who called me when I didn't call them;

And, above all, John Vellacott - who helped make the whole process seem possible and probable, and whose love, patience, perspective and sense of humour supported my occupational behaviours and positively influenced my life satisfaction.

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CHAPTER I

Introduction

Occupational therapists believe that individuals are inherently motivated to explore and master their environments and themselves, and that this exploration and mastery is enacted through engagement in occupational behaviours. While occupational behaviours include a wide range of activities, those of most interest to occupational therapists are occupations which pertain to self-care, productivity and leisure.

Occupational behaviour is thought to be initiated, maintained and produced through a cycle of intake, throughput, output and feedback by individuals within their environments. This open system model of human occupation (Kielhofner, 1985) suggests that information and feedback from the environment (intake) is processed by three "subsystems" in individuals (throughput), who then produce occupational behaviours (output), which in turn result in responses from the environment as to the efficacy of the behaviour (feedback). Individuals are perceived to be functional when they are able to meet both their own needs and desires and the demands of the environment. Dysfunction occurs when, through disease, injury or changes in the environment, individuals are not able to maintain a cycle which allows them to satisfy these needs, desires and demands.

The role of occupational therapy (OT) is to " prevent disability; and to promote, maintain or restore occupational performance, health and spiritual well-being" (Dept. of National Health and Welfare and Canadian Association of Occupational Therapists, 1987, p.45). OT interventions may focus on the individual, the environment or on both individual and environment. Although occupational therapists also work with individuals with acute conditions, a major focus has been on assisting individuals in adapting to chronic conditions or to the long-term sequelae of disease or injury. One of these long-term and chronic conditions is multiple sclerosis (MS).

MS is the most common disease of the central nervous system among young adult Canadians. It is most frequently diagnosed in persons 20 to 40 years of age, is characterized by a wide range of symptoms and an unpredictable course, and may lead to considerable disability.

OT interventions with persons with MS have generally emphasized assisting individuals to stay in the community through a focus on: energy conservation and work simplification, upper extremity coordination and strength, activities of daily living (ADL) such as dressing, eating and other self-care tasks, adaptations and aids, home maintenance and vocational assessment/training, and wheelchair evaluation and training (Macdonald, 1976; Matthews, 1985; Schapiro, 1987; Simons, 1984; Spenser, 1988; Trombly & Scott, 1989; Wolf, 1985). These interventions address both person and environment. Their common goal is to assist the individual in maintaining occupational behaviours related to self-care and productivity in the home and work environment for as long as possible. Despite these interventions, and the interventions of other health care professionals, some individuals with MS are still institutionalized. It is these individuals who are the focus of this study.

The MS Society estimates that there are about 5000 persons with MS in Alberta (personal communication, Multiple Sclerosis Society of Canada, July, 1989). A Canadian survey of persons with MS suggests that, at any point in time, approximately ten percent of individuals with this disease are institutionalized (Bennett, Hamilton, Neutel, Pearon & Talbot, 1977). Persons with MS are, on average, twenty years younger than other residents of long-term care settings (Cockerill, Aird, & Walter, 1987).

In Edmonton, a survey conducted by the administrators of one nursing home district with 1200 beds found that eight percent of its residents had MS, and that these residents accounted for the majority of residents under the age of 65 (Edmonton Nursing Home and Auxiliary Hospital District 24, 1984). A Calgary nursing home district reports that six percent of residents have MS. The average age of residents with MS in this district is 53; whereas the average age of residents without MS is 79 (personal communication, Carewest, June 8, 1989).

Given this information, it seems likely that individuals with MS may comprise a large proportion of the population of institutionalized physically disabled adults under 65 years of age. Although there have been some recent attempts to address the specific needs of this population in a clinical context through provision of rehabilitative services, the research literature does not yet report studies which address the issue of life satisfaction and the factors which may contribute to life satisfaction of institutionalized persons with MS. The medical and psychological literature has tended to focus on diagnosis, development of quantitative assessment techniques used to measure the impact of the disease on functional and emotional status, and symptom management. The rehabilitation literature has been primarily concerned with symptom management (especially as it pertains to functioning at home and at work) and with physical and emotional adaptation to disability.

There are a number of reasons to explore the life satisfaction of institutionalized individuals with MS and, particularly, the potentially alterable factors which may contribute to life satisfaction. Persons with MS are often institutionalized at an earlier age, and are, therefore, likely to be institutionalized for longer periods of time than most residents of extended care facilities. Most persons with MS retain a degree of cognitive awareness, and are likely to be able to identify pertinent factors which influence their level of life satisfaction while living in the institution. Identification of factors contributing to, or constraining, life satisfaction may suggest possible changes in institutional policies, procedures or programmes; community rehabilitation services; and in individual responses to the experience of institutional living.

The purpose of the study was to characterize this population with regards to demographic characteristics, to describe the life satisfaction of institutionalized persons with MS, and to identify factors which may be associated with life satisfaction. The study is based on a model of human occupation used in occupational therapy. This model will be described in detail in Chapter II. In Chapter III, literature describing MS symptoms, course, possible etiology and classification will be reviewed, within the conceptual context of the model of human occupation, along with research regarding factors pertinent to life satisfaction of chronically ill and institutionalized persons.

CHAPTER II

Theoretical Framework

The importance of using explicitly stated theoretical frameworks in research and clinical practice has received increasing attention in the occupational therapy literature (Conte & Conte,1977; Krefting,1985; Mosey, 1989; Reed, 1984). There are many models for occupational therapists to choose from, however, most of these models have a narrow focus inappropriate to the questions associated with this study. Reed (1984), in her review of more than thirty occupational therapy models, describes these more specialized models as practice models and distinguishes them from theoretical models, one of which is the model of human occupation. The study reported here is based on this emerging theoretical model.

The model is an attempt to combine early precepts of occupational therapy with general systems theory. Its purpose is to describe the occupational nature of human beings, explain occupational dysfunction and provide a rationale for the use of occupations in therapy (Kaplan & Kielhofner, 1989). A comprehensive description of the model was first presented in a series of articles (Kielhofner, 1980a, 1980b; Kielhofner , Burke & Igi, 1980; Kielhofner & Igi, 1980) in the American Journal of Occupational Therapy. These were followed by a variety of books and articles describing the application of the model in clinical practice and research (Barris, 1982; Duellman, Barris & Kielhofner, 1986; Elliot & Barris, 1987; Gregory, 1983; Kaplan & Kielhofner, 1989; Kielhofner, 1985; Kielhofner, 1986; Kielhofner, Barris & Watts, 1988; Smith, Kielhofner & Watts, 1986). The purpose of this section is to provide a brief review of the model.

The central concept of the model is that of occupation. This is defined as an "output of information and action to achieve purposeful ends" (Kielhofner, Burke and Igi, 1980, p. 580). Although occupation may include a wide variety of purposeful activities, occupational therapists are most interested in those everyday actions related to self-care, work and play. Occupation is seen as a basic human need, a drive towards activity governed by an intrinsic motivation to explore, to be competent, and to achieve and master (Kielhofner, Barris & Watts, 1988).

The model describes a cyclical process by which human beings initiate, produce and maintain occupation through interaction with specific environments. This open system process includes four inter-related phases - intake, output, feedback and throughput.

Intake refers to the input of energy and information to the human open system from the environment. Although this includes both physiological and symbolic intake, the model focuses primarily on intake of information necessary for occupational performance. The term intake is used in preference to the term input as a way of differentiating between an active search for, versus a passive receiving of, information from the environment (Kielhofner, Barris & Watts, 1988).

Intake and feedback are closely allied concepts. The distinguishing characteristic of feedback in this model is that feedback provides specific information to the human open system about the impact of behaviours produced by the system. Two types of feedback are described - that which comes from persons and objects in the environment (external), and that which is a result of individuals' own internal judgement as to the efficacy of their interactions with the environment (internal). Internal feedback includes feelings of pleasure and satisfaction.

Output is conceptualized as including both information and action. The output of information, described in the model as feedforward, allows individuals to anticipate the results of action, and to attribute meaning to objects, events and people that are being or will be encountered. Action refers to the use of skills in acting on the environment. The crucial role of output in maintaining and modifying the cycle is related to two characteristics of the human open system: (1) the primacy of function over structure, and (2) circularity. The precedence of function over structure in open systems means that structures change as they are used, and that function is not determined solely by structure. The concept of circularity describes the idea that what a person does determines in part what he or she becomes - doing is becoming (Fidler & Fidler, 1978). Thus the importance of output, of occupation, in occupational therapy treatment.

The contribution of throughput in the model is as the organizing link which joins intake, output and feedback. Throughput is described as the transformation of energy or information by the human system and the modification of that system to adapt to the incoming energy or information. Throughput is thought to be effected through the functioning of three hierarchically arranged subsystems operating within each individual. The highest subsystem is that of volition. This subsystem is considered to be responsible for motivating behaviour. The second subsystem is habituation; this subsystem is thought to be responsible for organizing behaviours into routines and thus maintaining behaviour. The third and lowest subsystem is that of performance. This level is described as consisting of the skills which are available to produce occupational behaviours. Systems theory suggests that higher levels direct or organize lower levels, and are dependent on, or constrained by, lower levels (Kielhofner, 1978).

Each throughput subsystem is further differentiated into a number of components. The volition subsystem is described as being composed of: (1) the universal human motivation towards exploration and mastery, and (2) a set of individualized internal images about oneself. These internal images (personal causation, values and interests) are acquired through past interaction with the environment and determine, to a large extent, individual preferences for specific occupations. Personal causation refers to individuals' perceptions about their effectiveness in interacting with the environment - their judgement, based on past experience, about whether they have the relevant skills and the opportunity to use those skills to achieve desired outcomes. Values are defined as being a basic commitment to action , "serious attachments to ideas, customs and institutions that result in an individual's feeling of being identified with a group" (Kielhofner & Burke, 1980, p. 577). Values determine priorities, influence choices about behaviours, and provide a sense of obligation to perform to certain standards. Interests are individual preferences for specific occupations which come from the experience of having found enjoyment, satisfaction and social approval through involvement in those occupations.

The model describes two components of the habituation subsystem - roles and habits. Roles act as a source of identity, and are perceptions about sets of required behaviours which accompany certain social positions. The manner in which roles guide habituation is dependent upon the extent to which individuals believe that they occupy specific roles and the extent to which they are recognized by others as filling those roles. Roles change over time, and these shifts are determined partly by social/cultural norms, and partly by individual choices. Individuals have their own idiosyncratic perceptions about the behaviour required of them in the roles they hold. Habits are described as those automatic routines which allow individuals to organize their time and meet role demands. They organize skills into routines and are acquired through repetition. Habits are discussed in the model in terms of their degree of organization, social appropriateness and flexibility.

The components of the performance subsystem are skills and skill constituents. The model details three types of skills: perceptual-motor, process, and communication/interaction. Perceptual motor skills are those which allow individuals to process sensory information and produce skilled movement. Process skills are described as being the ability to plan and to problem solve, to organize action in time and space (Kielhofner, Barris & Watts, 1988). Communication/interaction skills are related to the ability to give and receive information and to deal with other people. The constituents which support skills are both the neurological and musculoskeletal systems, as well as what the model labels as a symbolic constituent. This symbolic constituent is described as individualized rules or images, acquired through exploration, imitation and repetition, that guide skilled performance.

The model of human occupation also attempts to describe aspects of the environment which influence, and are influenced by, human occupation. The environment is conceptualized as consisting of four layers: objects, tasks, social groups and culture. Each of these layers contributes to the level of arousal of the open system and exerts environmental press - the demand to perform in certain ways. Arousal and press are affected by the availability, complexity, flexibility and symbolic meanings of objects; and by the complexity, time boundaries, rules, seriousness and social nature of tasks. The size, function, complexity and boundaries of social groups determine their arousal and press, whereas culture has an impact on arousal and press by defining the nature of work and play, and setting rules about what happens where and when.

This complex model has been used to describe occupational function and dysfunction with a variety of persons with physical and psychosocial disabilities, including persons with MS. The model describes dysfunction as "a disruption of the open system cycle that manifests itself in a decrease, cessation or imbalance of output and in a consequent disorganization of the internal subsystems and their components" (Kielhofner, 1985, pp. 73-74). Three levels are identified in the continuum of occupational dysfunction:

inefficacy, incompetence and helplessness. Inefficacy in the human open system is associated with a reduction of or interference in output, accompanied by dissatisfaction, and a reduction in personal causation. Interests, values, roles and habits may also be affected. Incompetence is said to exist when the routine and adequate performance of tasks associated with occupational roles is disrupted, and there is a major reduction in personal causation, along with possible disruption of interests, values, roles, habits and skills. Helplessness is defined as a complete or nearly complete disruption of output combined with loss of personal causation, interests and values. Roles and habits may be lacking or very disrupted, and there may be major skill deficits.

The following chapter will review literature describing the physical, psychological and social phenomena associated with MS, and attempt to describe the impact of the disease on the functioning of the human open system.

CHAPTER III

Literature Review

Clinical Description of MS Diagnosis, Course, Etiology and Symptoms

MS is a generally nonfatal demyelinating disease of the central nervous system (Zeldow & Pavlou, 1984). It is most frequently diagnosed in young adults who are 20 to 40 years old. Women are more likely than men to have the disease, by a ratio of 2: 1 (Devins & Seland, 1987). The estimated rate of prevalence in Canada varies - from a rate of one per 1,500 (Noseworthy, 1986) to one per 500 (personal communication, Multiple Sclerosis Society of Canada, July, 1989). Based on these estimated rates of prevalence, the number of people with MS in Canada may range from 16,500 to 49,500 cases.

Diagnosis

Initial diagnosis has typically been difficult; the diagnosis is usually a clinical one, based on identification of symptoms of central nervous system (CNS) lesions over a period of time, and on exclusion of other possible causes (Devins & Seland, 1987). The average time between onset of initial symptoms and diagnosis was reported to be approximately two years by Nelson, Hamman & Burks (1983). Recent improvements in neuroradiological techniques, such as the use of nuclear magnetic resonance (NMR) imaging have assisted physicians in making earlier diagnosis possible (Kesselring, Ormerod, Miller, du Boulay & McDonald, 1989;

Willoughby & Paty, 1990).

Course

The disease course is often unpredictable. Four types of disease course are described by Scheinberg & Smith (1987). They suggest that approximately 20% of persons with MS have a "benign" course with primarily visual or sensory symptoms, few exacerbations of disease activity and nearly complete recovery of function. Another 25% have a "relapsing/remitting" course. This course is similar to the benign course, except that there may also be symptoms of weakness, imbalance or lack of bladder control. The 40% of persons with MS who have a "relapsing/progressive" course have periods of exacerbation followed by periods of remission, but experience a progressive loss of function. A remaining 15% have a "progressive" course from the onset. Persons with this illness course do not have periods of exacerbation and remission, but rather a steady deterioration of function. Paty and Poser (1984), on the other hand, suggest that 20% of persons with MS have a normal life span with relatively mild functional impairment, 50% have a relapsing/remitting course and 30% have a progressive course which results in considerable disability. Although there are some initial signs and symptoms which may generally predict the prognosis (Sanders, Bollen & Vander Velde, 1986), prediction of the disease course for any one individual is difficult. Individuals initially diagnosed as having a benign or relapsing/remitting course may ultimately be classified as having a progressive course, while some individuals may have an acutely progressive course from onset

(Franklin & Burks, 1985). Many individuals classified as having a progressive disease course adjust and adapt to increasing losses over a period of 10 to 20 years. Only in their later years are they admitted to extended care facilities because of increased MS related disabilities which are not being effectively managed at home.

Etiology

The etiology of MS is presently unknown. A variety of causal agents or events have been suggested including infection, exposure to toxins, nutritional deficits, lead poisoning and thrombophlebitis (Chusid, 1976). Current thought suggests that genetic predisposition and exposure to an infectious agent, possibly a virus, may trigger the development of the autoimmune responses which result in demyelination (Matthews, 1985; Whitaker, 1987).

Symptoms

Symptoms of MS can be classified as being primarily sensory, primarily motor or a combination of sensory and motor. Alternately, they may be characterized as primary (directly a result of demyelination of an area of the CNS), secondary (a result of complications arising from primary symptoms), or tertiary (the impact of primary and secondary symptoms on emotional, social and vocational functioning) (Scheinberg & Smith, 1987). It is the tertiary symptoms of the disease which are the focus of this study.

Initial symptoms of MS often include sensory disturbances of the limbs, disturbances of gait and balance, temporary visual loss in one or both eye(s), and blurred or double vision (Franklin & Burks, 1985; Scheinberg

& Smith, 1987). As the disease progresses, symptoms may include numbness and parasthesias, visual disturbances, pain, weakness and impairments of gait, coordination, bladder and bowel control, and sexual functioning. Fatigue is another extremely common symptom. Persons with with MS may also exhibit changes in cognitive functioning as the disease progresses.

More than 70% of persons with MS experience disorders of sensation, such as numbness and parasthesias (Scheinberg & Smith, 1987). These disturbances may be unrelenting or transient. The most common sensory disturbances are Lhermitte's sign (a brief shooting pain radiating down the spine following neck flexion) and mild loss of vibratory sense in the legs (Franklin & Burks, 1985).

Visual disturbances typically involve either loss of vision or inability to focus. Loss of vision may be a consequence of optic neuritis, which is a common presenting symptom in MS. A more gradual loss of vision may result from demyelination of the visual system. Blurring of vision or nystagmus may also result from MS, and are more common than is complete loss of vision. These visual disturbances typically impair ability to read (Franklin & Burks, 1985; Scheinberg & Smith, 1987).

Pain is another symptom sometimes associated with MS. Pain may be associated with disease-related changes in the spinal cord or nerve roots. Pain may also be a result of spasticity. Pain can also be a consequence of damage to joints resulting from from abnormal positioning (Franklin & Burks, 1985).

Weakness is usually accompanied by spasticity and is a result of myelin damage in the pyramidal tracts. Although weakness may occur throughout the body, weakness of one or both legs is most common (Alexander & Costello, 1987). Lack of coordination, disorders of balance and tremour may also be present as a result of cerebellar involvement (Franklin & Burks, 1985).

Weakness, spasticity, lack of vibration sense, incoordination and poor balance are all factors which may combine to make ambulation exceptionally difficult. Individuals may first exhibit gait abnormalities, followed by inability to walk without bracing, a crutch or cane, and may ultimately be completely unable to walk. These same factors may result, over time, in lack of ability to independently use a wheelchair (Turner, 1987). This progression, and the frequency of impaired ambulation as a cardinal symptom of MS are reflected in the commonly used Disability Status Scale (often referred to as the Kurtzke scale) which uses a 10 point rating focusing on mobility to assess level of disability (Kurtzke, 1965).

Bladder and bowel disturbances are also common symptoms of MS. Approximately 60% of all persons with MS experience urinary complaints during the course of the disease (Scheinberg & Smith, 1987). The most frequent symptoms are urgency, frequency and incontinence. Catheterization may be recommended as one response to these symptoms. Constipation is another commonly reported MS symptom (Franklin & Burks, 1985).

Sexual functioning is also frequently disrupted. Inability to achieve or maintain an erection, inability to achieve orgasm, loss of libido and spasticity interfering with sexual activity are reported as the most frequent complaints (Kalb, LaRocca & Kaplan, 1987). In one study, 91% of male respondents and 77% of female respondents reported a change in their sexual lives (Lilius, cited in Kalb, LaRocca & Kaplan, 1987).

Fatigue is another common MS symptom. 65% of persons with MS report fatigue (Scheinberg & Smith, 1987). Many individuals report that they feel more energetic in the morning than in the afternoon. This fatigue is frequently exacerbated during warm weather. Fatigue is an invisible symptom, yet can have a significant impact on function.

Cognitive impairment often accompanies these physical symptoms. Estimates of the frequency of cognitive impairment vary widely from 0% to 90% (Rao, Hammeke, McQuillen, Khatri & Lloyd, 1984; Staples & Lincoln, 1979), although a recent critical review of the research suggests that the best evidence shows that more than 50% of persons with MS develop cognitive dysfunctions (Rao, 1988). Some of this variation is likely a result of differing criteria used to classify impairment and of different methods of examination (Kaplan, 1984; Peyser, 1984; Rao et. al., 1984). The focus of recent studies has been on persons with a chronic progressive course (Beatty, Goodkin, Monson, Beatty & Hertsgaard, 1988; Rao et al., 1985). The cognitive functions which are most likely to be impaired are memory, abstraction and problem-solving (Peyser & Becker, 1984; Rao, 1985; Sullivan, Edgley & Dehoux, 1990). There has been some debate about whether depression and euphoria are primary symptoms of MS and/or whether they are associated with cognitive impairment. There has been little research to unequivocably support such hypotheses (Berrios & Quemada, 1990; Devins & Seland, 1987; Fennel & Smith, 1990), although there is a suggestion that emotional symptoms may be related to the degree of cerebral versus spinal involvement, with persons with cerebral involvement being being more likely to exhibit emotional disturbances (Fennell & Smith, 1990).

As can be seen from the preceding description of MS symptoms, the disease may have a major impact on physical and cognitive functioning and on the daily lives of persons with MS and their significant others. Some individuals will experience only some of the symptoms; some will experience most or all of the manifestations of the disease. While there is no single constellation of symptoms which predict institutionalization, the presence of any combination of these symptoms, in combination with factors pertaining to availability of caregivers, may lead to entry to a care facility.

Treatment and Management of MS

Because there are no known therapies which consistently arrest or alter the course of MS, specific medical and rehabilitative treatment of the disease is directed primarily at control of symptoms rather than at curing the disease (Robinson, 1987; Scheinberg & Holland, 1987). Medical approaches to symptom control and management have included the use of medications and surgical interventions.

Anti-inflammatory medications are generally used on a short term basis during exacerbations to treat muscle weakness and other motor disabilities. Medications which may decrease spasticity, pain and fatigue may be employed. Management of bladder and bowel symptoms may also involve use of medication (Scheinberg & Holland, 1987). Antidepressive medications may be prescribed in some cases. The outcomes of drug trials which seek to arrest the course of the disease using antiinflammatory, immunosuppressant or antiinfective medications have generally been disappointing (Slater & Scheinberg, 1987).

Surgical interventions which may contribute to the management of primary and secondary symptoms include severing of nerves and tendons to decrease spasticity and pain, and skin grafting to repair decubitus ulcers (Alexander & Costello, 1987). These interventions are typically tried only after more conservative interventions have failed.

Drug therapy and surgical interventions have frequently been used in conjunction with a variety of rehabilitative therapies which seek to minimize fatigue and increase strength, decrease spasticity and tremor, allow for management of bowel and bladder dysfunctions, decrease pain, improve speech, prevent decubitus ulcers, compensate for sensory loss, train in adapted ADL activities and address social-emotional issues (Block & Kester, 1970; DeSouza & Worthington, 1987; Matthews, 1985; Robbins & Rosenthal, 1987; Russell, 1976; Schapiro, 1987; Turner, 1987).

Wolf (1985) describes occupational therapy intervention with persons with MS as focusing on five areas: energy conservation and work simplification, upper extremity coordination and strength, ADL adaptations and aids, home maintenance and vocational assessment/training, and wheelchair evaluation and training. These occupational therapy interventions are also described by other writers (Macdonald, 1976; Matthews, 1985; Schapiro, 1987; Simons, 1984; Spenser, 1988; Trombly & Scott, 1989). Beyond an acknowledgement that depression and/or euphoria may be present in persons with MS and one reference to the importance of meaningful activity (Shannon, 1988), the OT literature seldom explicitly discusses the importance of social and emotional factors in the treatment of persons with MS. Yet it may be the social and emotional aspects of OT treatment which are most important to clients with chronic diseases like MS where adaptation, maintenance of function and prevention of further disability are a primary focus. Opportunities to interact with others and to engage in productive activities are two important options that OT can offer. An Australian study suggests that persons with MS receiving OT treatment perceive its benefits as being related to "having something to do" and the social nature of the treatment sessions (Simons, 1984).

The treatment and rehabilitation approaches described previously may be appropriate and effective during certain phases of the disease course and inappropriate or ineffective at others. In addition, the generally lengthy and unpredictable course of MS means that the work of symptom control and rehabilitation takes place primarily outside the hospital unit or the MS clinic (Robinson, 1987). This means that persons with MS

> begin a lifetime of individualized patterns of management. These responses to the illness are likely to be carried out by patients and their significant others more often than by professional practitioners because there are few widely applied clinical approaches to the disease.(Brooks & Matson, 1982, p. 2129)

Social and Emotional Aspects of MS

There is a considerable body of sociological and anthropological literature describing adaptation to physical disability in general, and to specific conditions. Within this literature, there are both qualitative and quantitative studies which attempt to explain the process of adaptation and the factors which may influence adaptation to MS (Brooks & Matson, 1982; Duval, 1984; Maybury & Brewin, 1984; Pavlou & Stefoski, 1983; Rodgers, 1988; Zeldow and Pavlou, 1984). There are attempts to describe how adaptation contributes to life satisfaction, emotional distress, or psychological functioning. Locker (1983) points out that the traditional concept of adaptation presumes adjustment to a stable physical condition, whereas chronic deteriorating disorders such as rheumatoid arthritis and MS have an unstable and unpredictable course and may, therefore, require a variety of adaptive strategies.

Brooks and Matson (1982), in one of the few longitudinal studies addressing social-psychological adjustment to MS analyzed four sets of variables which they thought might influence adjustment: (1) socio-demographic - gender, family income, living arrangements and education; (2) disease-related - number of reported "episodes", severity of episodes, changes in physical mobility, daily impairment and symptoms; (3) medical - frequency of medical attention , and type of medical specialist used, and (4) social-psychological - self-concept, locus of control, effect of MS on relationships and coping strategies. They measured adjustment using self-concept across a seven year period as the criterion. They described their respondents as having a slowly progressive course, with many being in the middle and later years of a chronic disease They reported that females are more likely than males to exhibit positive adjustment, and that hours of employment and living arrangements are also pertinent to adaptation. Most of the 103 respondents reported slight changes in mobility, but number of disease episodes appeared to be the strongest disease-related factor impinging upon adjustment. Persons living in nursing homes reported themselves as more disabled and less fortunate than others. Respondents with internal locus of control, and who had coping strategies which emphasize acceptance of the disease rather than use of religion or family as resources, reported more positive self-concepts. In general, most respondents maintained positive self-concepts across time. Brooks and Matson suggest that maintenance of positive self-concept equals adjustment, but they do not discuss the process by which positive self-concepts are maintained.

A study of adjustment which focused on knowledge of MS and social relationships found that knowledge, level of disability, and demographic variables such as sex, age, time since diagnosis, education or marital status were not associated with adjustment as measured by the General Health

Questionnaire (GHQ) and a self-esteem scale. The only factor which was found to relate to adjustment was time spent in contact with non-disabled persons (Maybury & Brewin, 1984). Most of the respondents in this study did not have a progressive course; type of disease course was not used as an independent variable.

Davis (1970), in a qualitative study of 29 individuals with MS, focused on the process of adjustment to MS, a process which she conceptualizes as a "status transition" from health and well-being to non-health and disability. The symbolic-interactionist approach is used as a theoretical frame of reference for her explorations. She makes the point, as would those using the model of human occupation, that "an individual's state of health cannot be isolated from his daily living situation" (Davis, 1970, p. i). She explores the transition process by examining four lifestyle components: social identity, physical mobility, relationships with family and friends and work roles, and impact of three coping strategies ("passing", normalization and withdrawal) on these components.

The impact of MS on age-related career and developmental tasks is also discussed by Davis and by Lapham & Ehrhart (1986). Although one in four persons with MS is working, maintaining employment can require considerable effort on the part of the worker with MS, his/her employer and his/her co-workers (Glazier & Young, 1988; Holland, Kaplan & Hall, 1987). Difficulties in maintaining or acquiring employment are most frequently related to gait and mobility disturbances, visual deficits, fatigue and bowel or bladder dysfunction (Kornblith, LaRocca, & Baum, 1986;

Poser, Bauer, Ritter, Friedrich, Beland & Deneke, 1981; Scheinberg, Holland, LaRocca, Laitin, Bennett & Hall, 1980, 1981). While there may be strategies which can be used to deal with such difficulties, it has been suggested that these strategies are more likely to be successfully implemented in employment situations where the worker is a hard-to-replace, highly educated, highly skilled white collar worker (Howard, Till, Toole, Matthews & Truscott, 1985).

The Model of Human Occupation Applied to MS

Multiple sclerosis has been described in a case study which used the model of human occupation as a framework (Kielhofner et al., 1985). The model of human occupation theorizes that disturbances in lower subsystems constrain the function of subsystems above them. The impact of chronic progressive diseases such as MS and rheumatoid arthritis on occupational behaviour is conceptualized as being related to changes in the habituation and volition subsystems. These are thought to occur as a result of the constraints arising from unpredictable changes in skill performance influenced by disease signs and symptoms.

Skill performance may be affected in a number of ways. Perceptual-motor skills may be impaired due to changes in mobility, fine motor control, vision and muscle strength and endurance. Process skills, which rely on cognitive functioning, may also be impaired, with the result that individuals have difficulty with the problem-solving activities which might have compensated for deficits in other skill areas (Nelson, Thompson, Heaton, Burks & Walker, 1982; Rao & Hammeke, 1984; Staples and Lincoln, 1979). Communication/ interaction skills may be impaired because of motor, sensory and/or cognitive deficits which impact on the ability to receive and send information and to interact with others.

Changes in skill performance are likely to lead to changes in habituation. Davis (1970), examining what she calls "transitions to a devalued status", reports changes in daily activity patterns described by her respondents with MS due to changes in mobility, social interaction and ability to perform work-related tasks. Because of the unpredictable course of MS, individuals with the disease may need to be flexible in their habit patterns. New habits may have to be developed which take symptoms such as fatigue and sensory-motor deficits into account. Yet development of new habits may be hindered by deficits in cognitive functioning.

Roles may change; as the disease progresses, the skills and habits necessary for adequate role performance may become so impaired that roles such as worker and caregiver may have to be relinquished either temporarily or permanently. The internal and external pressures related to role relinquishement may vary from individual to individual, but any role change has the potential to be distressing, and may result in loss of identity and decreased self-esteem (Jackoway, Rogers & Snow, 1987). Heard (1977) suggests that an important focus of occupational therapy must be on assisting for individuals with chronic disabilities in taking on new occupational roles. This may be complicated, again, by the unpredictability of the disease course, by cognitive deficits which lead to difficulties in negotiating and learning new roles, and by societal conventions which do not acknowledge the possibility that persons with disabilities can be involved in a full range of roles.

In addition to giving up former roles, individuals with MS are likely, at some point in their illness, to take on a variety of "sick roles". The term "sick role" was first introduced by Parsons (1951) and defines the rights and obligations of persons who are ill. Parsons suggested four features of the sick role: (1) that the sick person is not held accountable for his or her inability to perform socially-sanctioned roles because the illness is seen as being beyond that individual's control, (2) that sickness is a legitimate cause for being excused from normal role responsibilities, (3) that the sick person shares with society basic assumptions about the undesirable nature of illness, and (4) that the sick person seeks medical assistance and follows medical advice in order to return to health.

Parson's work has been criticized by a number of writers (Brody, 1987; Gordon, 1966). Gordon (1966) describes several important differences between the sick role and the "impaired" role. A summary of the criticism describes concerns about the lack of critical examination of the role of medical authorities, the assumption of the existence of one rather than a multiplicity of sick roles, and the lack of a longitudinal perspective on the process of transitions between illness and health (Brody, 1988).

The process of taking on a sick or impaired role and enacting it is described as the "illness career" of the disabled individual (Twaddle & Hessler, 1987). This career involves changes in social identity and status. Banks (1973) describes the process of transition as having three steps: (1)

noticing symptoms which interfere with function, (2) adopting a sick role either by changing activities and/or by seeking treatment, and (3) becoming a patient of a health care professional.

The particular difficulties of making status transitions in the illness careers of persons with MS are well described by Stewart and Sullivan (1982), who point out that difficulties in recognizing symptoms and diagnosing the disease change the manner and speed with which persons with MS take on the sick role. They point out the importance of role negotiation in pre-diagnosis behaviours of persons with MS. It is likely that this need continues post-diagnosis and involves not only the medical and rehabilitation establishment, but also relationships with family, friends and social groups in that individual's environment (Robinson, 1988; Williams & Wood, 1988). Biographical works by writers with MS (Brack, 1981; Didion, 1979; Ginther, 1978; Mairs, 1986; Ottenberg, 1978; Webster, 1989) and their families (Strong, 1988) also describe the difficulties inherent in role negotiation.

The influence of MS on individuals' skills and role-related daily routines may have a major impact on volition. The often unpredictable course of the illness, and the lack of clearly effective treatment strategies may influence sense of internal control. People with MS may respond to these aspects of the illness and to the generally pessimistic prognosis by feeling that their situation is hopeless. This may be associated with a variety of emotional disturbances. Estimates of the frequency of depression range from 10 to 60% of all persons with MS: studies using controls and standardized instruments suggest rates of 26.8% to 36% (Minden, Orav & Reich, 1987). Rates of depression and other emotional disturbances appear to be higher in persons with either an acute exacerbation or with a progressive disease course (Dalos, Rabins, Brooks & O'Donnell, 1983; Zeldow & Pavlou, 1987).

Individuals may be forced to re-examine their values, interests and goals within the context of their changing abilities. Strauss (1975) describes the social and psychological tasks of living with a chronic illness as being: prevention and management of medical crises, control of symptoms, carrying out of prescribed care regimens, prevention or acceptance of social isolation, adjustment to the "trajectory" of the disease, attempts to "normalize" social interactions and lifestyle and assuring adequate funding for required medical care. He points out some of the influence of uncertain trajectories (a term roughly analogous to disease course) on performance, self-identity and psychological well-being. Corbin and Strauss (1988) discuss the "unending work and care" that goes into managing chronic illness, particularly the work in which chronically ill individuals and their families engage. Kaufert and Kaufert (1984), in a study of the long term effects of polio, suggest that studies of the trajectory of an illness be combined with an awareness of how that trajectory interacts with the aging process.

Finally, aspects of the physical, social and cultural environment may have an impact on individuals with MS. Architectural barriers, lack of appropriate adaptive equipment and aids, and inadequate or inappropriate physical assistance may all have an influence on what persons with MS are able to do, and, as a result, how they feel about themselves and their lives (Kraft, Freal & Coryell, 1986; S. Phillips, personal communication, 1989; Robinson, 1988; Warren, Cockerill, Paterson & Patterson, 1986). The extended care environment is often limited in objects, tasks and social groups available to residents. The potential impact of the cultural environment is important. Duval (1984); Webster (1989); Wright (1983); Jennings, Callahan & Kaplan (1988); and Kaplan (1988) argue that attitudes towards disabled persons, norms that dictate the role behaviour expected of individuals in specific age groups, political and economic policies, and a culture that gives priority to acute disease amenable to cure may all have an impact on facilitation or constraint of occupational behaviours of persons with MS. The impact of MS on performance, habituation and performance within a specific environmental context may contribute to changes in emotional state, morale and/or life satisfaction.

> When the future seems bleak with goals uncertain or obliterated, pleasure in activity diminished, and meaning and purpose eroded, it is difficult for the individual to make adaptive choices to engage in occupation. Maintaining a satisfying and productive life through positive choices is a major task for the chronically disabled person. The strength of past success, a belief in the ability to cope with problems and strong personal values are strengths upon which many persons draw in order to adapt to disability, but they become extremely vulnerable under the stress and pressure of chronic

> progressive disease. These factors may all converge to produce various levels of occupational dysfunction. (Brooks & Matson, 1982, p. 2129)

Effects of Institutional Living

In the Alberta context, auxiliary hospital care is defined as care designed for "persons usually chronically ill or disabled, who require a less intensive level of care than is provided in acute care hospitals. Treatment [may include] rehabilitation to a point where return to the community or transfer to a nursing home or other facility is possible, [or provision] of nursing and medical care...even though there is little prospect of rehabilitation" (Government of Alberta, 1988, p. 105). Nursing home care is defined as provision of "supervised personal care for people who are not ill enough to require hospitalization in an acute care or auxiliary hospital, but require assistance with activities of daily living ..." (Government of Alberta, 1988, p. 107). Residents in Alberta facilities are assessed using a patient classification system which determines whether individuals require nursing home or auxiliary hospital levels of care. Extended care facilities provide both auxiliary hospital and nursing home levels of care, and may also offer other services such as day programmes.

There is a considerable body of recent literature which explores the effects of institutional living on older persons (Baltes, Honn, Barton, Orzech & Lago, 1983; Baltes & Reisenzein, 1986; Gubrium ,1975; Kahana, Liang & Felton, 1980; White & Janson, 1986). Much of this literature addresses issues of control and autonomy, and their impact on mortality, activity, life satisfaction and a variety of other variables (Hofland, 1988; White & Janson, 1986). High constraint environments have been shown to be associated with lower life satisfaction (Wolk & Telleen, 1976).

There is also a body of literature (generally of less recent vintage) that describes the experiences of persons with intellectual or psychiatric disabilities in living in large institutions. There is, however, a remarkable lack of literature describing the experience of younger physically disabled persons living in long-term care facilities. Elliott (1982), in Living in hospital:The social needs of people in long-term care, does discuss the need to consider social integration of residents of all ages in long-term care facilities. There have been no articles describing the long-term care experiences of persons with MS, although one article profiling the "younger nursing home patient" did describe a considerable proportion of residents as having a diagnosis of MS or other neurological impairment (Greenwald & Linn, 1972). A recent report on long-term care in Alberta devotes only two paragraphs to discussing the needs of younger extended care centre residents, although statistics included in the report show that 14.05% of the extended care population is under the age of 65 (Government of Alberta, 1988).

Life Satisfaction Research

There is a very considerable body of literature addressing the issue of life satisfaction. Life satisfaction is variously referred to as morale or happiness. A wide array of populations have been measured with a variety of tools. After a brief discussion of the concept of life satisfaction and a description of the measurement tools used to quantify this most subjective of states, this review will focus on the literature describing life satisfaction of institutionalized persons.

Writers describing the development of life satisfaction measures trace interest in subjective well-being to the mid 1940s (George, 1981; Horley, 1984; Larson, 1978). Early attempts to develop life satisfaction measures were made by Neugarten, Havighurst and Tobin (1961). Life satisfaction is seen as an indicator of good mental health, quality of life, and as an outcome of successful aging (George & Bearon, 1980). Life satisfaction is conceptualized as differing from happiness in at least two ways: (1) life satisfaction is seen a referring to a long-range perspective, whereas happiness is seen as a more transitory state, and (2) life satisfaction is thought to be more a result a cognitive appraisal than is happiness. Life satisfaction is thought to be different from morale in that morale is more related to predispositions to handling challenges. However, all three terms have been used interchangeably in the research literature; in addition, they have all been used as an indicator of adaptation to illness.

This lack of conceptual clarity has led to the development of a wide variety of "life satisfaction" instruments. Some of the most widely used are variations of the Life Satisfaction Index-A (LSI-A) first proposed by Neugarten et al. (1961). Adams' (1969) version of the LSI-A is only one modification. There are three other versions - the LSI-B, the LSI-Z (Wood, Wylie & Sheafer, 1969) and the ten-item version proposed by Edwards and Klemmack (1973). Life satisfaction has also been measured using the

Cantril Ladder (Cantril, 1965), the Philadelphia Geriatric Center Morale Scale (Lawton, 1972), and the Affect Balance Scale (Bradburn, 1969). Lohmann (1977), using a sample of 259 subjects over 60 years of age, found a high level of correlation between seven scales which claim to measure life satisfaction, morale and adjustment. She suggests that these measures reflect a common underlying construct which encompasses life satisfaction, morale and happiness.

In spite of the ongoing discussion about the usefulness of life satisfaction measures (Gubrium & Lynott, 1983; Larson, 1978), each of these scales continues to be widely used in research. One major focus has been the study of life satisfaction of elderly institutionalized persons. In these studies, life satisfaction is often the dependent variable used to assess the impact of variations in demographic factors in combination with other independent variables. Aspects of institutional living that have been found to be associated with life satisfaction for elderly residents have included: high degree of perceived control (Langer & Rodin, 1976; Ryden, 1984; Wolk & Telleen, 1976); predictability of the environment (Krantz and Schulz, 1980); internal locus of control (Fawcett, 1976); external locus of control (Felton & Kahana, 1974); self-assessed health status (Carstensen & Whitbourne, 1978) and availability of, and participation in, valued roles and activities (Elliott & Barris, 1987; Riopel, 1983).

There are also a number of studies reported in the literature which address the issue of life satisfaction of persons with disabilities (Boschen, 1990; Cameron, Titus, Kostin & Kostin, 1973; Xerxa & Baum, 1986).

Typically, these studies compare life satisfaction of groups of persons with and without disabilities. The results of these studies suggest that, on the whole, the life satisfaction of persons with disabilities is similar to that of non-disabled persons. Although there have been some studies which measure life satisfaction of non-institutionalized persons with MS (Counte, Bieliauskas & Pavlou, 1983; Granger, Cotter, Hamilton, Fiedler & Hens, 1990), there is no report in the literature specifically describing life satisfaction of institutionalized members of this population.

This review of the literature described some of the physical, psychological and social phenomena associated with MS, and attempted to describe the impact of the disease on the functioning of the human open system. The literature describing the effects of institutional residence and research on life satisfaction was also presented.

CHAPTER IV

Specific Aims

The purpose of this study was to describe life satisfaction of institutionalized persons with MS, and to identify factors related to intake (the perceived environment of extended care facilities), throughput (volition, habituation, and skill performance), and output (activity) which may be associated with the life satisfaction of this population. Specifically, this study sought to provide answers to the following research questions:

(1) How can this population be characterized with regards to demographic characteristics such as age, gender, age at diagnosis, marital status, number of children, number of family members in or near Edmonton, average number of visits per week, ethnic origin, religious affiliation,educational level and pre-admission occupation ?

(2) What level of life satisfaction is reported by these respondents ?

(3) How can these individuals be described in terms of various components of occupational behaviour, including: *intake* - as measured by perception of the environment of the institution; *throughput* variables including: volition - as measured by locus of control, and expectancy of future success/failure; habituation - as measured by role occupancy; and skill - as measured by ability in ADL; *output* as measured by participation in a variety of valued self-care, productivity and leisure activities ?

(4) Are any of the measured aspects of occupational behaviour associated with level of life satisfaction of institutionalized persons with MS ?

(5) Are any of the measured demographic variables associated with life satisfaction ?

(6) Do factors such as length of time in the institution, disease activity and use of mood altering drugs act as intervening variables to influence life satisfaction ?

(7) What are some of the perceived "turning points" in the process of institutionalization: what happens prior to entry into the institution, what helps people stay at home, what makes it difficult to stay at home, what was the precipitating event leading to institutionalization, views regarding extended care before entry and currently, things or people that help/hinder, recommended changes, and barriers to community re-entry ?

Table 1 illustrates the hypothesized relationship between life satisfaction (the dependent variable in this study) and the selected components of the model of human occupation represented by the independent variables, and lists the tools used as measures of each variable.

Table 1 - Expected relationship between variables

MODEL VARIABLE	HOW MEASURED	EXPECTED RELATIONSHIP TO LIFE SATISFACTION
INTAKE		
•ENVIRONMENT	SCES	PERCEIVED ENVIRONMENT HIGH IN SYSTEM MAINTENANCE AND CHANGE DIMENSION WILL BE POSITIVELY ASSOCIATED WITH LIFE SATISFACTION
THROUGHPUT		
•VOLITION	BHS	INVERSE RELATIONSHIP-HIGH LEVELS OF HOPELESSNESS ASSOCIATED WITH LOW LIFE SATISFACTION
	LDC	PERSONS WITH HIGH EXPECTANCY OF CONTROL WILL HAVE HIGH LIFE SATISFACTION
•HABITUATION	RCL	PERSONS PRESENTLY INVOLVED IN VALUED ROLES WILL HAVE HIGH LIFE SATISFACTION
•SKILL	ISS	NO ASSOCIATION
OUTPUT		
•ACTIVITY	OQ	LARGER NUMBERS OF ACTIVITIES RATED AS IMPORTANT WILL CORRELATE WITH HIGH LIFE SATISFACTION SCORES
FEEDBACK		
•SATISFACTION	LSI-A	DEPENDENT VARIABLE

SCES = SHELTERED CARE ENVIRONMENT SCALE • BHS = BECK HOPLESSNESS SCALE • LDC = LOCUS OF DESIRED CONTROL • RCL = ROLE CHECKLIST • ISS = INCAPACITY STATUS SCALE • OQ = OCCUPATIONAL QUESTIONNAIRE • LSI-A = LIFE SATISFACTION QUESTIONNAIRE-A

CHAPTER V

Research Methods

Study Participants

The participants in this study were persons with MS residing in seven extended care facilities in Edmonton. Four of the seven centres are administered by a common administration, while the remaining three are operated by church-based organizations. Most of the centres offer both nursing home and auxiliary hospital levels of care. Only those individuals with a definite diagnosis of MS as noted on the institutions' medical records were included in the sample. Individuals who were unable to communicate in English, physically unable to communicate or who had been assigned a legal guardian due to cognitive impairment were excluded from the study. Persons who were not full-time residents of the extended care centres were also excluded from the sample.

The researcher, at the request of facilities' research committees, did not contact possible respondents directly but provided a contact letter to be distributed to possible respondents by occupational therapy staff. Occupational therapy staff were asked to approach all respondents who met the study criteria. Respondents were asked to contact occupational therapists in each centre to indicate their willingness to participate in the study. The names of these individuals were then forwarded to the researcher. Respondents indicating an interest in participating were contacted in person by the researcher to arrange times for the interviews.

Respondents who agreed to participate were screened for cognitive impairment using the Mini-Mental Status Examination (MMSE) (Folstein, Folstein & McHugh, 1975), and the Vocabulary subscale of the Weschler Adult Intelligence Scale - Revised (WAIS-R) (Wechsler, 1981). These two screening tools were used because they were brief and did not rely heavily on skilled physical performance. Both have been used in previous MS research (Beatty, Goodkin, Monson, Beatty & Hertsgaard, 1988; De Smedt, Swerts, Geutjens & Medaer, 1984; Devins, n.d.; Rao et al., 1985; Staples & Lincoln, 1979). The MMSE is a widely used screening tool for assessing cognitive status and has demonstrated reliability, validity and acceptability to subjects (Folstein, 1983). It has been used to assess the cognitive functioning of persons with MS living in the community, using a score of less than 20 as an indicator of severe impairment (Devins, 1989). The vocabulary subtest of the WAIS-R was used because vocabulary subscale scores have high correlations with WAIS-R full scale scores (average intercorrelation of $\underline{r} = .81$) (Wechsler, 1981) and because this subtest does not rely on physical performance skill. It has also been suggested that the attributes measured by the verbal subtest may be more resistant to the impact of brain disease than are those measured by the performance subtests (Lezak, cited in Fennell & Smith, 1990). Scoring for the WAIS-R was reviewed by a psychologist.

The results of such testing identified respondents who were considered unlikely to be able to provide meaningful information because they were not alert or had severe cognitive impairment. Respondents scoring below 20 on the Mini-Mental Status Examination or below a scaled score of 5 on the WAIS-R vocabulary subscale were excluded. These relatively low cutting scores were established with the understanding that, by doing so, some moderately cognitively impaired respondents would be included in the study. However, it was felt that even those respondents with considerable cognitive impairment would be able to provide meaningful information about their life situation and life satisfaction.

Since the study was restricted to Edmonton, a large sample size was not expected. However, a minimum goal of 44 participants was set in light of the number of independent variables being measured (see sample size calculation in Appendix A). A sample size of 40 was actually achieved.

Data Collection

All participants received a letter signed by the researcher describing the purpose of the study (Appendix B). Patients were informed that the purpose of the study was to determine how they felt about their lives in general, and whether various aspects of their functioning and living arrangements influenced how they felt. The consent form (included as Appendix C) reiterated this information. Respondents were informed that their participation was entirely voluntary, and that the specific information given would be kept confidential. They were also offered a copy of the study results (attached as Appendix E).

Facility administrators were informed about the research project and offered a copy of the overall findings. Contact with administration emphasized that the purpose of the project was to explore factors which may influence life satisfaction of institutionalized MS patients from a holistic perspective, and that the researcher was more interested in intrapersonal, interpersonal and environmental factors which may influence life satisfaction, rather than in conducting a specific evaluation of any one facility. This may have served to minimize any tendency on the part of institution staff to influence respondents' participation or response.

Interview Schedule

Each study participant was asked to indicate the most convenient time for an interview at the facility. Most interviews took place in an interview room off the nursing unit, although those respondents with private rooms were sometimes interviewed in their rooms. During the first meeting, the consent form was reviewed and basic demographic information collected. All respondents were then screened, using the MMSE and the Vocabulary subtest of the WAIS-R. These two screening instruments were administered in approximately twenty five minutes. All information in this and subsequent interviews was elicited through verbal questioning, as many of the respondents had physical disabilities which led to difficulties in reading and writing.

Following this screening interview, at least two interviews were required to complete the instruments and interview questions. The total interview time per respondent varied from two to almost eight hours, as some respondents were seen more than three times in order to complete the questionnaire. Portions of the final interview were audiotaped and transcribed. The interviews were scheduled within one week of each other.

A single interview, of longer duration, was considered to be too lengthy when taking the physical condition of the respondents into account.

The initial interviews were conducted using a standard questionnaire (see Appendix D). The scales used have been assessed for reliability. Each has also been tested for content validity, most for concurrent validity and some for construct validity. Psychometric properties of the scales will be reported in the following scale descriptions.

Life satisfaction, the dependent variable, was measured using the eighteen-item version of the LSI-A (Adams,1969). This scale, modified from the original LSI-A developed by Neugarten, Havighurst and Tobin (1961), is a multi-dimensional measure of life satisfaction. Although the scale was originally designed as a method of describing general feelings of well-being among older persons in order to identify components of "successful aging" (McDowell and Newell, 1987), it has been widely used in a variety of quality of life and life satisfaction research projects with different age groups. The choice of a scale was complicated by the conceptual confusion surrounding the terms "life satisfaction", "well-being", "morale" and "quality of life". The original LSI-A is described by its authors as being primarily a measure of morale and is conceptualized as measuring five components of morale: "zest", resolution and fortitude, congruence between desired and achieved goals, positive self-concept and mood tone. Factor analyses suggest that the LSI-A may measure three specific components: congruence, mood tone and optimism or zest (Hoyt and Creech, 1983) as well as tapping one additional unnamed factor (Adams, 1969).

The LSI-A was chosen for a number of reasons. It has been used in other recent research with individuals with MS (Counte et al., 1983). Although the LSI-A was originally developed for use with elderly populations, Adam's version of the scale has been used in a extensive survey of life satisfaction of American adults over the age of 18 (Louis Harris & Associates, 1975). It captures some, although not all, aspects of adaptive functioning described in the model of human occupation. McDowell and Newell (1987) and George and Bearon (1980), in their reviews of life satisfaction measures, judge the LSI-A to be a convenient, easily administered instrument with more than adequate psychometric properties.

Adams (1969), in a survey of 508 elderly adults using the eighteen item LSI-A and a two point scoring method, found a mean life satisfaction score of 12.5 with a standard deviation of 3.6. Harris, using the same scale, but with a three point scoring method, found mean scores of 26.7 for persons 18 to 64 (N = 1,457) and 24.4 for those over 65 (N = 2,797). The study reported here uses an 18-item format with three point scoring; LSI-A scores computed in this manner may range from 0 to 36.

Adams reports that biserial correlations between the means of the positive response group for each item and the mean LSI-A score for the whole sample range from .16 to .55, but does not report correlations for specific items. Internal consistency of this version of the LSI-A is variously reported as alpha = .90 ((Edwards & Klemmack, 1973) and alpha = .84 (Wolk & Kurtz, 1975). The LSI-A correlates well with other measures of life satisfaction, morale and adjustment (Lohmann, 1977), although some of these correlations can be expected to be high because the scales contain similar items.

The independent variables include some of those which have been associated with life satisfaction in the institutionalized elderly, as well as those which have been used in studies of other adult populations. Each variable is also associated with a component of the model of human occupation. Independent variables which are potentially alterable were the focus of interest:

1. Measure of intake

Aspects of the environment of the extended care centres were measured using the Sheltered Care Environment Scale (SCES) developed by Moos & Lemke (1984) as part of the Multiphasic Environmental Assessment Procedure. The SCES is one of a range of social climate scales developed by Moos and his associates (Moos, 1974, 1987). This 63-item questionnaire has seven subscales which assess resident and/or staff perceptions of three social climate dimensions: relationships, personal growth and goal orientation, and system maintenance and change (Moos & Lemke, 1987). The system maintenance and change dimension includes questions which tap residents' perceptions of organization, resident influence and physical comfort with questions such as: is this place very well organized, are suggestions made by residents acted on, is it ever hot and stuffy in here ? The system maintenance and change dimension of the SCES was used to measure aspects of the institutional environment; the remaining two dimensions were considered to have considerable overlap with instruments measuring other components of the model. The instrument has been tested on a normative group of 244 facilities (including nursing homes, residential care facilities and seniors' apartments but not auxiliary hospitals). A revised version tested in 151 facilities with 1,041 residents and 792 staff members, showed that six of seven subscales have acceptable to high internal consistency (alpha ranging between .59 and .76). Split-half reliabilities were moderate to high (ranging from .69 - .80 for residents and from .59 - .83 for staff). The authors also assessed subscale stability, and found that stability was moderate to high on five of seven subscales, and that the scale was also sensitive to changing conditions over time. Normative data are reported for a sample of 1,973 residents and 2,042 staff in nursing homes. Although respondents in this study completed the entire scale, only those questions contributing to the system maintenance and change dimension were used in data analysis, as these items appear to have the least potential to overlap with other variables measured during the study, and as previous research (Shadish, Orwin, Silver & Bootzin 1985) suggests resident well-being is related to all three subscales of the system maintenance and change dimension. Scores on the SCES system maintenance and change are computed by determining the number of responses answered in the scored direction divided by the total number of answers and multipled by 100 to produce a percentage.

2. Measures of throughput -

Volition

Locus of control was measured using the Locus of Desired Control Interview Questionnaire (LDC) (Reid, Haas and Hawking, 1977). This instrument is based on a well known locus of control scale (Rotter,1966), but is specifically designed to address issues pertaining to control in an institutional setting. Reid et al. (1977), in two studies, report reliability index scores (Cronbach's alpha) of .64 and .66 for the scale, and "significant" item-total correlations. The scale measures two aspects of control - the Desire subscale measures desire for control, and the Expectancy subscale expectancy of achieving control. A total score, which is the sum of the cross-products of the two subscales, can also be computed. Reid and Ziegler (1980,1981) suggest that Expectancy scores may be more effective predictors of adjustment than are Desire scores. Thus, while study participants were asked to answer both the Desire and Expectancy questions, Expectancy scores only will be reported. Scores on the Expectancy subscale may range from 7 - 28, and are a sum of scores for each of the seven questions.

Belief in skills, belief in efficacy of skills, and belief in success/failure in the past and in the future was measured using the Beck Hopelessness Scale (BHS) (Beck, Weissman Lester, & Prexler, 1974). Factor analysis suggests three factors. Beck et al. conceptualize these factors as: affective, motivational and cognitive. The reported internal consistency of this scale is alpha = .93 (KR 20) and the item-total correlations range from .39 to .76, with a majority being above .60 (Beck et al., 1974). The scale has also been tested for concurrent validity. Correlations between the scale and clinical ratings of hopelessness and ratings on other measures of hopelessness were all above .6 ($p < .001$). The predictive validity of the scale in anticipating suicide attempts has also been noted (Beck, Steer, Kovacs & Garrison, 1985; Wetzel, Margulies, Davis & Karam, 1980). The scale has been used in at least one other MS research project (Sanford & Petajan, 1990), with psychiatric patients, and with two samples of hospitalized physically disabled persons -those with chronic conditions and those with acute conditions (Green, O'Mahoney & Rungasamy, 1982). A Canadian study of outpatients with chronic heart failure has also used the scale (Rideout & Montemuro, 1986). This 20-item scale yields scores ranging from 0 to 20.

Habituation -

Role occupancy was assessed using the Role Checklist (RCL) (Oakley, 1982). This instrument, originally designed to measure role dysfunction in persons with psychiatric conditions, has also been used in research with older persons and with persons with physical disabilities. The instrument asks respondents to indicate past, present and future participation in ten listed roles as well as to indicate other roles not listed; in addition, respondents are asked to rate the value of each role. A study of test retest reliability, using percent agreement and estimates of kappa, shows moderate to substantial agreement (Oakley, Kielhofner, Barris & Reichler, 1986). Scores for this measure were the number of highly valued roles in which individuals currently participate.

Performance -

Physical and functional disability was measured using the Incapacity Status Scale (ISS). The ISS is a functional ability scale specifically for MS research, and is based on work by Granger (Kurtzke, 1981a, 1981b). An early study of the scale yielded an internal consistency of alpha = .93 (Fog, Heltberg, Kyhn, Mellerup, Raun & Zeeberg, 1984). Inter-rater reliability in one study was .94 (Granger, Cotter, Hamilton, Fiedler, 1990). It correlates well with two other related measures of functional status - Granger's Long Range Evaluation System (LRES) and the Barthel/PULSES index (correlation coefficients of .87 and .94 respectively) (Granger, 1981). The ISS was chosen in preference to the more commonly used Kurtzke Disability Status Scale (DSS) or Extended Disability Scale (EDSS) because it evaluates a wide range of impairment/disability, rather than focusing primarily on ambulation. This 16 item scale may have scores ranging from 0 to 64.

3. Measures of output

Output was measured with the Occupational Questionnaire (OQ) (Riopel, 1983). This self-report measure asks the respondent to identify what he or she does in a normal day; whether the respondent considers the activities work, play, rest or daily living task (type); the degree of competence and pleasure experienced while engaging in activity (personal causation), the worth of the activity to the individual (value), and the degree of enjoyment associated with each activity (interests). This instrument is currently under development, however, a preliminary study (Riopel, 1983; Smith, Kielhofner & Watts,1986) suggests that the instrument is both reliable and valid. Smith, Kielhofner and Watts report test-retest agreement ranging from 68 percent (for activities and time performed) to 87 percent (type of activity). Concurrent validity was measured by calculating agreement between the instrument and an activity diary. Agreement ranged from 82 percent (activity and time of activity) to 97 percent for ratings of type of activity. For the purposes of this study, the score on this measure was the number of activities rated as both highly valued and competently done reported in a typical day.

Other factors which have been associated with life satisfaction of institutionalized individuals, and which might act as intervening variables, were also measured:

(1) *Length of time in the institution* was recorded from the medical record. Tobin and Leiberman (1976) suggest that morale drops immediately after institutionalization, is at its lowest after two months, then rises to a plateau after approximately one year.

(2) *Disease activity* was defined as the incidence of disease-related complications serious enough to require vital signs recording on a greater than daily basis or transfer to acute care facilities during the six month period prior to being interviewed for the study. This information was taken from the medical record. Devins and Seland (1987) suggest that disease activity (exacerbations and disease progression), along with functional losses, are identified with increased emotional distress in persons with MS.

(3) *Use of mood-altering drugs* was noted from the respondents' medical records.

Finally, respondents were asked to identify the "turning points" in their adaptation to MS-related institutionalization and in their life satisfaction. They were encouraged to comment on factors, not specifically addressed in the questionnaire, which they felt had or will influence their life satisfaction while in the institution.

Analysis

(1) Descriptive statistics were used to:

(a) characterize respondents on selected demographic variables: age, gender, age at diagnosis, marital status, number of children, number of family members in or near Edmonton, average number of visits per week, ethnic origin, religious affiliation, educational level and pre-admission occupation ;

(b) describe other possible intervening variables such as length of time in extended care, number of disease-related incidents and use of mood altering medications;

(c) describe the reported level of life satisfaction of institutionalized respondents; and

(d) characterize respondents on independent variables related to the model which might be associated with life satisfaction.

(2) The association between life satisfaction and independent variables (using measures of association appropriate to the level of the data) were computed, as were the associations between life satisfaction and demographic variables, and life satisfaction and possible intervening variables, using an alpha level of .05.

(3) Multiple regression and stepwise regression analysis with variables that contributed to more than one percent of the variance on correlation techniques was also undertaken.

(4) Interview transcripts were summarized to identify common experiences in the process of institutionalization and adjustment to institutional living.

CHAPTER VI

Results

The information collected in the study is both quantitative and qualitative. The quantitative data will be presented and discussed first, and includes descriptive statistics summarizing the scores for cognitive screening, the demographic characteristics of the sample, description of respondents' status regarding possible intervening variables, levels of life satisfaction, and scores on measures associated with model variables. Associations between life satisfaction and the independent variables will be reported, as will associations between life satisfaction and demographic variables and between life satisfaction and potentially intervening variables. A summary of the information collected during interviews with respondents will then be presented and discussed.

Response Rate

The respondents in this study were residents in seven Edmonton extended care facilities. 30 respondents were residents in four extended care centres administered by a central board, while the remaining 10 subjects resided in 3 non-affiliated facilities. Overall response rate was 86%, with response rates ranging from 70% to 100% of eligible respondents. There were no respondents excluded from the study due to lack of ability to speak English. There were three reasons why potential respondents were excluded by the occupational therapists at each centre: impaired cognitive functioning, severe dysarthria preventing verbal communication, or (in three cases) emotional distress which clinicians felt would be further exacerbated by participation in the study. All respondents except one, who was hospitalized with a dual diagnosis of MS and chronic obstructionary pulmonary disease, could be classified as having a chronic progressive disease course. The number of persons with MS in each facility, the number of possible respondents who were excluded by study criteria, the response rate for eligible respondents and the number of respondents from each facility is detailed in Table 2.

Table 2 -Response rate by facility

FACILITY	TOTAL # OF RESIDENTS WITH MS	EXCLUDED BY STUDY CRITERIA	RESPONSE RATE-ELIGIBLE SUBJECTS	EXCLUDED THROUGH SCREEN	INCLUDED IN STUDY
AFFILIATED FACILITIES					
A	34	17	88%	2	n=13
B	20	5	73%	2	n=9
C	11	1	70%	1	n=6
D	2	0	100%	0	n=2
NON-AFFILIATED FACILITIES					
E	2	0	100%	1	n=1
F	5	1	100%	0	n=4
G	11	3	75%	1	n=5

Respondent Scores on Cognitive Screening

There was considerable variability in both the MMSE and WAIS-R vocabulary subtest scores of study participants. Mean score and standard deviation on the MMSE was 25.37 and 3.23 respectively. Scores ranged from 20 to 30. Most respondents lost three to five possible points because they were physically unable to complete two or three of the tasks presented in the MMSE. Several MMSE tasks require visual acuity and/or steady hands.

The mean scaled score on the WAIS-R vocabulary subtest was 8.88, with a standard deviation of 2.20. Respondents' scaled scores ranged from 5 (the cut-off score established for this study) to 13. It is highly likely that some respondent's WAIS-R vocabulary scores were influenced by their physical condition, as some respondents had speech difficulties which made it difficult for them to elaborate upon their answers and/or for the interviewer to understand what they were saying.

Demographic Characteristics of the Sample

The demographic characteristics of the sample are summarized in Table 3. The mean age of respondents was 54.5. This is similar to the mean age of MS residents previously reported by a large auxiliary hospital district in Calgary (personal communication, Carewest, June 8, 1989). The mean age of nursing home and auxiliary hospital residents in Alberta in 1986 was 80.6 and 77.7 respectively (Government of Alberta, 1988). Thus, the age gap in this study between respondents and other residents is likely to be similar to that found earlier by Cockerill, Aird, & Walter (1987), who report that persons with MS are, on average, twenty years younger than other residents of long-term care settings.

The sample included 26 females and 14 males, a not unexpected finding, based on the previously described female/male ratio of 2 : 1 found in MS epidemiological studies. Most respondents had been diagnosed with MS while in their early thirties. Forty percent were married, 67.5% had one or more children, and 87.5% had at least one family member living in or near Edmonton. Eighty percent had visitors during a typical week.

Ethnic origin of respondents was predominantly European; the largest group came from Great Britain, followed by those from Ukraine and other eastern European countries. There were no respondents with southern European, African, Asian or Australian backgrounds. The sample group included more Protestants than Catholics. Forty five percent had attended university or a technical institute after completing high school, and a majority had worked in skilled, semi-skilled or professional occupations prior to entering extended care. There were four former nurses in the sample, as well as clerical workers, accountants, sales persons, teachers, radio and computer operators, boilermaker/welders, a florist, a farmer and an auctioneer. Six female respondents reported that they had previously worked in the home.

Respondents and non-respondents were compared on the basis of age, gender, length and institution of residence, in order to determine if they varied in any systematic way which might bias study results. No statistically significant differences were found between respondents and non-respondents on any of the factors analyzed, although non-respondents tended to be younger than respondents. The differences in response rates between facilities appear to be related to facility therapists' decisions to exclude some potential respondents for clinical reasons, such as emotional distress, even though those respondents met the study criteria. Two respondents offered to participate and then withdrew from the study following screening; both were female and both expressed considerable discomfort during cognitive testing. Both of these respondents had low scores on the screening tests and one refused to complete the WAIS-R screening.

Table 3 - Characteristics of sample group (N=40)

AGE		
	MEAN	54.52
	STANDARD DEVIATION	10.11
	RANGE	32-79
GENDER		
	FEMALE	65% N=26
	MALE	35% N=14
AGE AT DIAGNOSIS		
	MEAN	33.75
	STANDARD DEVIATION	9.80
	RANGE	19-55
MARITAL STATUS		
	MARRIED	40% (N=16)
	DIVORCED	22.5% (N=9)
	WIDOWED	10% (N=4)
	SINGLE	20% (N=8)
	SEPARATED	7.5% (N=3)1.55
NUMBER OF CHILDREN		
	MEAN	1.55
	STANDARD DEVIATION	1.37
	RANGE	0-5
NUMBER OF FAMILY MEMBERS		
	MEAN	3.12
	STANDARD DEVIATION	3.28
	RANGE	0-19
NUMBER OF VISITS PER WEEK		
	MEAN	3.1
	STANDARD DEVIATION	2.95
	RANGE	0-15
ETHNIC ORIGIN		
	GREAT BRITAIN	32 % (N=13)
	EASTERN EUROPE	22% (N=9)
	WESTERN/NORTHERN EUROPE	30% (N=12)
	OTHER	16% (N=6)

Table 3 (cont.) - Characteristics of sample group (N=40)

RELIGION		
	PROTESTANT	52.5% (N=21)
	CATHOLIC	27.5% (N=11)
	NONE	20% (N=8)
EDUCATION		
	GRADE SCHOOL ONLY	10% (N=4)
	HIGH SCHOOL	45% (N=18)
	UNDERGRADUATE	25% (N=10)
	TECHNICAL/VOCATIONAL	20% (N=8)
OCCUPATION		
	STUDENT	2.6% (N=1)
	HOMEMAKER	15.4% (N=6)
	PROFESSIONAL	20.5% (N=8)
	SKILLED	41% (N=16)
	SEMI-SKILLED	20.5% (N=8)

Respondent Length of Residence, Disease Activity and Use of Mood Altering Medications

Mean length of residence in extended care was 64.95 months. Fifty four percent of the respondents had experienced at least one MS-related illness episode during the previous six months. These complications included urinary tract infections, visual disturbances, and decubitus ulcers. Almost 75% of respondents were taking medications which have potentially mood altering effects. The most commonly used mood-altering medications were Lorazepam and Halcion. Lorazepam is an anxiolytic medication with sedating properties, while Halcion is a so-called "hypnotic" used for those individuals with sleep disturbances (Canadian Pharmaceutical Association, 1986). A variety of antidepressant medications were also used by respondents. Thirty percent of respondents (eleven female respondents and one male respondent) had been formally diagnosed by their attending physician as suffering from mood disorders; these were classified on the medical record as manic-depressive disorder, reactive depression, endogenous depression or, most commonly, depression. Respondent status as related to potentially intervening variables is presented in Table 4.

Table 4 - Potential intervening variables

TIME IN EXTENDED CARE (MONTHS)		
	MEAN	64.96
	STANDARD DEVIATION	40.04
	RANGE	2-180
MEDICATIONS		
	YES	71.4%
	NO	28.6%
MS RELATED ILLNESS EPISODES PAST 6 MO.		
	MEAN	.857
	S.D.	1.004
	RANGE	0-4

Respondent Scores on Life Satisfaction Measure

Scores on the LSI-A for this group of respondents are presented in Table 5.

Table 5 - Scores on life satisfaction measure

Measure	Mean	Std. Dev.	Minimum	Maximum
LSI-A	17.05	7.31	1	31

The mean life satisfaction score of 17.05 (SD 7.31) found in this study appears to be lower than that found in the Counte et al. (1983) study of a non-institutionalized sample of persons with MS, although direct comparison of mean scores from the two studies is difficult because of differences in scoring methods. Counte et al. (1983) noted that life satisfaction scores were related to trait anxiety, total number of hospitalizations for all reasons, age and life stressors during the past year. In their study, higher life satisfaction was found among respondents who were younger, less anxious, and had experienced fewer life stressors and fewer hospitalizations. The mean age of their sample was lower than that in the present study and all were still living in the community.

The life satisfaction scores found in the current study were considerably lower than those found in a sample of Americans adults (Louis Harris & Associates, 1975). Mean life satisfaction scores in the Harris study (which used the same scoring procedure as this study) were 26.4 for the total sample, 26.7 for those aged 18 - 64 and 24.4 for those aged 65 and over. None of their younger respondents scored below 6, whereas 7.5% of the respondents in this study had scores from 1 - 6. More than 88% of their respondents had scores higher than the mean score found in this study.

Respondent Scores on Independent Variables

The independent variables represent six facets of the model of human occupation. Scores for the independent variables are presented in Table 6.

Table 6 - Respondent scores on independent variables

Measure	Mean	Std. Dev.	Minimum	Maximum
SCES	57.82	14.73	27	84
LDC	18.57	4.45	9	28
BHS	7.95	5.42	1	20
RCL	2.66	1.58	0	8
ISS	36.85	8.37	17	53
OQ	1.92	1.05	0	5

SCES Scores

A direct comparison of SCES scores with the normative sample reported in the Multiphasic Environmental Assessment Procedure manual is difficult, since Moos and Lemke (1984) present subscale scores but not dimension scores. The pattern they report for the system maintenance and change dimension is that organization and physical comfort subscales typically have higher scores than does the resident influence subscale. This pattern is consistent with that found in the present study. By summing the subscale scores reported for Moos' and Lemke's sample of nursing home residents , and then computing a mean dimension score, a comparison can be made between the normative group, composed of respondents from 127 American nursing homes, and the respondents in this study. The mean dimension score for the normative group equals 60.6, with a standard deviation of 10. A local study with 138 auxiliary hospital and nursing home residents, yielded a mean dimension score of 57.3, with a standard deviation of 10 (Lipinski & Johnson, 1988). These two studies report scores comparable to that found in the present study (M = 57.82, SD = 14.73).

LDC Scores

Comparison between the LDC scores found in this study and in other research is also somewhat difficult. The version of the scale used in this study is an abbreviated one using seven situations as compared to a later version which contains 35 situations. Articles describing research with the expanded scale (Baltes, Wahl & Schmid-Furstoss, 1990; Reid & Zeigler, 1980; Ziegler & Reid, 1979) do not give mean scores. They do, however, report positive relationships between expectancy of control and life satisfaction in institutionalized and community-dwelling elderly persons. This positive relationship was also evident in the current study.

BHS Scores

The hopelessness scores (M = 7.95, SD = 5.42) found in this study are high; they appear to be in agreement with those found in a large (N= 236) MS study using the BHS as one of the measures (Sanford & Petajan, 1990). Sanford and Petajan report that both clinical rating and patient self-report of distress were lower than that indicated by BHS scores (personal communication, Eva Sanford, November, 1990). The mean hopelessness score from the present study is higher than those reported in previous research focused on persons with acute and chronic illnesses (Green, O'Mahoney & Rungasamy, 1982; Rideout & Montemuro, 1986). The mean hopelessness score reported in the Green et al. (1982) study of 60 physically ill individuals was 3.75, with a standard deviation of 2.7. The mean hopelessness score for chronically ill respondents was 4.2, with a standard deviation of 3.2. Rideout and Montemuro's (1986) study of individuals with chronic heart failure reported a mean hopelessness score of 7.04, with a standard deviation of 3.74. All of these reported means are lower than those found in this study, suggesting that the individuals participating in this study have high levels of expressed hopelessness when compared to other physically ill individuals, although BHS scores in this study compare with those found in one study of persons with chronic conditions.

RCL Scores

All respondents reported that they currently performed fewer valued roles (M = 2.66, SD = 1.58) than they had in the past. The RCL scores representing number of currently performed and highly valued roles reported by respondents was small ; 52.5% of the sample group said that they had 2 or less valued current roles, and only one person listed more than 4 roles. Current, highly valued roles as family member and friend were listed most frequently, and these were roles which respondents hoped to continue to fill in the future. The least frequently reported roles were, perhaps predictably, roles relating to home maintenance, work, study, and caregiving. This is not to say that these roles were not identified by some respondents, although most often such roles were reported as "I do some things that are sort of like work (study, home maintenance, caregiving) here at the centre." The number of future roles predicted by respondents varied widely. Some respondents stated that they felt that they would be able to fill more roles than they did currently, others predicted that the number of roles they would be able to fill in the future would remain the same or diminish. As the RCL has not yet been used with a variety of large sample groups, it is difficult to say how the number of roles reported by respondents in this study compares to other individuals with or without disabilities. Role loss is described as a potential hazard of institutionalization. A study using the instrument with elderly nursing home residents (Duellman, Barris & Kielhofner, 1986) reported a mean of 2.91 (SD = 1.85) for present roles. This value is much closer to that found in the present study, as contrasted with the Elliott and Barris (1987) study which used the RCL in a study of non-institutionalized elderly persons. The mean number of present roles reported in their study was 5.46 (SD = 1.6).

ISS Scores

ISS scores were highly variable (M = 36.85, SD = 8.37). There were seven respondents who were disabled to the extent that they required assistance with all or most ADL tasks. At the other extreme, three respondents were still able to walk with assistance, and performed most ADL tasks independently. The remaining 30 respondents were mobile in either a manual or electric wheelchair, and performed some ADL activities independently. Several respondents reported that they were not currently performing all of the ADL tasks of which they were capable, as doing so would interfere with established care routines at the facility.

OQ Scores

OQ scores (M = 1.92, SD = 1.05) suggest that the number of highly valued and competently done activities reported by respondents was small for most respondents, with 40% of all respondents reporting no more than one highly valued and competently performed daily activity. Many respondents had difficulty identifying activities that they were competent in performing, and saw the need for staff assistance as a reflection of their own incompetence. There were a small number of respondents who perceived that their ability to teach and direct staff in performing activities was an indication of their own competence. Two other respondents were planning to take a course which focused on the skills required to manage a personal care attendant. Activities described by many respondents were primarily recreational in nature, and included watching television, listening to music, reading, visiting and attending organized activities in the extended care centre. Respondents in four facilities mentioned a competitive "quiz show" activity as an important activity; however this activity occurs only once weekly, and conflicts with care routines for some respondents. Several respondents also noted that being able to independently perform some daily ADL functions was a highly valued activity which they competently performed within the limitations of their physical condition. Two respondents mentioned computer training and use as important activities.

Associations between Life Satisfaction and Independent Variables

The LSI-A scores, while not strictly interval level data, have frequently been reported as such in the literature, and will be treated as such in this study. The independent variables were measured using a variety of scales; some are true interval level measures, while others (while technically only ordinal level) have been presented in the literature as interval level data. They have been analysed as interval level data for this study. Correlations between the dependent variable and each independent variable were computed using a microcomputer-based statistical analysis programme (Abacus Concepts Inc, 1986).

Measures of correlation are used to demonstrate the degree and direction of relationship between two variables. A Pearson product-moment correlation technique can be utilized in situations where both measurements correlated are comprised of continuous data, and where a linear relationship appears to exist between the variables being correlated (Munro, Visintainer & Page, 1986; Riegelman & Hirsch, 1989). Scatterplots were used to determine whether linear relationships appeared to exist between LSI scores and scores on measures representing the independent variables. Visual analysis suggested that there was a linear relationship between LSI and SCES, BHS, LDC and ISS scores only. Scores on both the RCL and OQ showed extremely limited variability, and there was no linear relationship evident between scores on these two measures and LSI scores. Significant Pearson product-moment correlations were found between LSI scores and scores for two of the measures - the Beck Hopelessness Scale ($r = -.684$, $p < .0005$,) and LDC - Expectancy ($r = .358$, $p < .025$). Both associations were in the predicted direction. Although the associations between life satisfaction and all other variables were nonsignificant, all associations were in the predicted direction. The results of correlation analysis are found in Table 7.

Table 7 - Correlations between LSI and Independent Variables

Variable	Covariance	Correlation	r^2
SCES	8.142	.076	.006
LDC	11.674	.356	.128
BHS	-27.099	-.684	.468
RCL	1.258	.109	.012
ISS	.601	.01	.00001
OQ	1.288	.168	.028

Associations Between Demographic Characteristics and Life Satisfaction Scores

There was a significant association between age at diagnosis and LSI-A score ($r = -.329$, $p < .05$). Diagnosis at an early age was associated with higher life satisfaction scores. No other demographic characteristic was found to have an impact on LSI-A scores.

Associations Between Possible Intervening Variables and Life Satisfaction

Association between LSI score and time spent in extended care approached, but did not reach, significance. There was no association between number of disease related illness episodes in the previous six months and life satisfaction scores. Similarly, there was no association between use of mood altering medications and life satisfaction.

Multiple Regression Analysis

Multiple regression analysis was also performed, using only those independent variables, demographic characteristics or possible intervening variables which were found to contribute to more than one percent of the variance. Multiple regression analysis allows researchers to predict the dependent variable using two or more optimally combined independent variables (Glass & Hopkins,1984). The resulting $\underline{R}^2$ value indicates the amount of variance in LSI-A scores accounted for by the predictor values. Beta coefficients were also calculated. These values, also called standardized regression coefficients, convert scores so that each has a mean of 0 and standard deviation of 1. The beta coefficient reflects the amount of change that could be expected in LSI-A scores for one standardized unit change in independent variable scores, when scores for the remaining independent variables are held constant. This allows researchers to directly compare the predictive value of the variables (Norman & Streiner, 1986).

Results of the multiple regression analysis can be found in Table 8. Five variables together accounted for 45% of the variance in life satisfaction. The beta coefficients are also presented. The beta coefficient for BHS is more than three times larger than that of any other predictor. Thus, BHS scores are at least three times as strong a predictor of LSI-A scores as the next strongest predictor, age at diagnosis.

Table 8 - Multiple regression LSI: 5 variables				
DF	R	R^2	ADJ. R^2	ST. ERROR
39	.72	.52	.45	5.413
SOURCE	DF	ANALYSIS OF VARIANCE SUM SQ.	MEAN SQ.	F-TEST
REGRESSION	5	1090.65	218.13	
RESIDUAL	34	996.124	29.298	7 [illegible]
TOTAL	39	2086.77		p= [illegible]01

BETA COEFFICIENTS

PARAMETER	VALUE	ST. ERROR	ST. VALUE	t-VALUE	PROBABILITY
INTERCEPT	19.523				
AGE AT DX	-.14	.092	-.188	1.515	.139
LDC	.194	.215	.118	.904	.3721
BHS	-.841	.175	-.623	4.803	.0001
RCL	-.063	.653	-.013	.096	.9242
OQ	-.241	.999	-.035	.241	.8108

Stepwise Regression

A stepwise regression of BHS, Age at Diagnosis, LDC, RCL and OQ on LSI-A was also completed. The results of this analysis also suggest that BHS scores explain most of the variance in LSI-A scores. It is also the only variable which was found to be statistically significant in the stepwise regression. Age at diagnosis was entered into the equation in step two, and explained an additional 3% of the variance in LSI-A scores. None of the other variables were found to contribute to explaining the variance of LSI-A scores.

Interview Information

While most respondents spent considerable time in explaining their answers to individual questionnaire items, they were also asked to respond to nine open-ended questions which asked them to consider: the impact of MS symptoms just prior to admission, why and how they had managed at home prior to admission, what specific incidents (if any) led to the decision to enter extended care, their feelings about extended care facilities prior to admission, their feelings about extended care now, the things and people who had helped/hindered in their adjustment, changes that the facility could make and perceived barriers to community re-entry. These questions attempted to address possible factors which might have influenced life satisfaction and/or been turning points in each individual's adjustment to nursing home life. Most, although not all, respondents answered these questions at length and in considerable detail. The following section summarizes responses to these questions.

Symptoms Prior to Admission

The most common symptoms reported by respondents just prior to admission included problems with ambulation leading to inability to safely move about at home. Most respondents had spent some time in acute care facilities prior to entering extended care, and several had used the emergency beds available at one centre prior to transferring to the centre in which they currently live. Some respondents could not identify specific physical symptoms, but stated that inability to care for themselves, ill health of caregivers and/or conflict with family members had been a problem prior to admission.

Factors Which Helped Respondents to Stay at Home

Most respondents reported assistance from family or friends was instrumental in keeping them at home for as long as they did. Approximately 25% also utilized the services of paid home-makers, with varying degrees of satisfaction and success. One respondent had a very satisfactory long-term paid caregiver, and entered the extended care facility only after this caregiver died. Another reported that he had "gone through three aides in four months". Two respondents said that conflicts between their families and paid caregivers precluded ongoing use of these services.

The importance of continuing to work or being active in parental and community activities was cited as important by some respondents. Being "stubborn", strong and determined was mentioned by respondents as another important factor in staying at home. Three respondents, all male, reported that the result of this stubbornness, in some cases, was that they stayed at home long after they became unable to care for themselves. Only one respondent mentioned the importance of home adaptations. although many respondents reported that the lack of changes to the home environment made staying at home difficult. Some respondents stated that they stayed at home as long as they did only because the waiting list for extended care beds was very long.

What Made it Difficult to Stay at Home

Many respondents reported that they found it difficult to stay at home alone because they did not feel safe; several had fallen and been unable to get help, and two male respondents had been unable to feed themselves and become malnourished. More than 25% reported that their spouses were unwilling to provide care. Three respondents were institutionalized after their spouses became ill themselves. Two respondents were institutionalized following the death of their spouses, while three others entered the extended care facility after their marriages ended in divorce. Another respondent noted that his early retirement from work had led to conflicts with his [illegible] which in turn led to his admission to the extended care facility.

Turning Points Leading to Institutionalization

Almost all of the respondents experienced institutionalization as being a decision that they had made, albeit reluctantly. Those who did not make the decision reported that either their physician or family members had made the decision. A few respondents could not remember how the decision had come about. Most did not report a specific "turning point" which led to institutionalization, but, rather, a gradual realization that this might be necessary. Both male and female respondents mentioned that their decision to enter an institution were based, in whole or in part, on an awareness of the strain of caregiving on their spouses and/or families. Often respondents did not have the opportunity to choose which facility they entered, although many had since transferred to their preferred facility, or had transferred to a private room or a newer wing in the facility.

Respondents who could identify a turning point precipitating admission described a variety of precipitating events. Loss of a caregiver through divorce, illness or death was the precipitant most frequently identified by respondents. Having an indwelling catheter which respondents were unable to manage themselves was also described as a turning point. This also determined the level of care that respondents would receive, as persons needing nursing care are not typically able to reside in lodges, nor can individuals under 65 years of age cannot easily access low cost home care services.

Feelings About Extended Care Facilities Prior to Admission

10% of the respondents were nurses or nursing assistants and had worked in extended care facilities prior to becoming disabled with MS. These respondents were virtually the only persons in the sample who had prior knowledge of the extended care environment. A common response from this group was that they had hoped to never be so disabled as to need the services provided by a nursing home. Most of the other individuals in the sample knew little about nursing homes. The prevailing impression was almost universally negative. Respondents said that they felt that nursing homes were "a dead end, the end of the world" , "places where people come into to die". Several respondents said that they had hoped they would die before they were disabled enough that living in an extended care centre seemed the only option. Only two respondents reported positive feelings about the nursing home prior to entering a facility; both felt that they would be able to receive the care that they needed there.

Present Feelings About Extended Care Facilities

Most respondents saw the facility as the best possible option, but were guarded in expressing any enthusiasm beyond that - "A necessary evil", "the best I can do at the moment", "essential for my survival", "a last resort" are some representative statements from this larger group of respondents. Respondents expressing either strongly positive or strongly negative feelings about extended care centres were less numerous than the "best possible option" group.

Those who expressed positive feelings about the facilities described a sense that the facility was now their home. Several said that they are now anxious to return to the facility after trips outside. Of those reporting positive feelings, many mentioned that there were opportunities which they had not anticipated prior to admission to be involved in activities and to get the care they need. A smaller group of respondents expressed very strong negative feelings about the facilities. The factors identified by this group include dissatisfaction with the location, the social and physical environment, the presence of a large number of residents with dementias, and/or the level of care provided (either too little or too much).

Things or People That Help

Personal contact with nursing staff, assistance from occupational and physical therapy staff, activities and visits with volunteers, being able to have a private room, and opportunities for visits home were identified as positive factors. There was an almost unanimous complaint about staff inability to spend time with residents, and many respondents noted that this seemed to be getting worse over time, as staffing levels appeared to decrease. Shortages in both well trained nursing and rehabilitation staff were noted by many residents.

Although most respondents reported that their facility offered many activities, only a few respondents reported regular participation in activities as a factor which helped them. Most activities were seen as being targetted at older residents - one resident summarized her feelings by saying "if I hear another polka, I'm going to scream". Activities which offered opportunities for intellectual challenge or small-group social activities such as a gourmet dining club and a personal growth group were identified as important. Many of the respondents had been or were still involved in resident's councils, however only 10% of individuals identified this participation as important to them.

The importance of "outside" contacts, either family, friends or significant others was mentioned by several respondents. These respondents kept in touch through visits, by telephone calls and through correspondence. Two respondents reported that their romantic relationship had a positive impact, and were planning to leave the facility to live together.

The other important factor identified by some respondents was activity. Keeping busy, through studying, being involved in MS Society activities or helping other facility residents were identified as positive strategies.

Things or People That Hinder

The three most common complaints were related to staffing patterns, lack of privacy, and lack of same-age companionship. Staff were seen as over-worked and therefore unable to spend much time with residents. Some respondents felt that nursing staff required more training, while others expressed a concern about whether staff really cared or were simply "there for the paycheque". Two respondents reported disappointment that staff were not able to meet the high standards for personal care and housekeeping that these residents still held for themselves. High levels of staff turnover were also mentioned as a concern because some respondents felt that they were constantly training new staff to help them in their routines. Dissatisfaction over cuts or unexplained changes in rehabilitation programmes were described by several respondents. One respondent reported resentment about having to continually prove, to rehabilitation staff who were re-assessing him, that he continued to be unable to perform most ADL tasks.

Lack of privacy was a concern. Several individuals reported that they had or were having difficulties with a room-mate, or that there was a total lack of communication between themselves and their room-mate. None of the respondents had a same-age room-mate, even in the one facility which had a unit for young physically disabled adults. Lack of cognitively intact fellow residents to talk to was another concern - "they're all slightly screwy".

The other hindrances reported by respondents included staff inflexibility regarding morning and evening routines; lack of control over menus, food quality and mealtimes; intrusive and unwanted visitors; and aspects of the physical environment of the facility (room size, wheelchair accessibility).

Changes That Might Make Things Better

Most of the suggestions made by respondents in response to this question were related to factors they had already mentioned as satisfiers/dissatisfiers in previous questions. Many emphasized the importance of staff assisting them to remain as independent as possible. Three respondents were especially concerned about this - they felt that staff were unwilling to let them try things independently because staff did not have the time to supervise while the residents completed the task. Several respondents also emphasized the importance of ensuring that the staff were professionally trained, competent and caring.

The importance of not categorizing people with MS was noted by several respondents. They expressed a perception that staff responded to them as "MS'ers" rather than as individuals. The importance of some acknowledgement by staff of the age difference between respondents and most of the other extended care residents when planning activities, and concerns about lack of cognitive stimulation were mentioned by several respondents as issues needing attention.

Barriers to Returning to the Community

Few respondents reported that they were planning to return to the community. Many had, at one time, considered this option, and two respondents had explored group home options. Only 10% of respondents were actively planning to move to non-institutional settings. Barriers cited included the sense that the extended care facility was now home, concern about family caregivers, financial constraints preventing hiring of personal care attendants or home modifications, lack of the necessary home health care options in the area, uncertainty about disease course, and concern that the energy needed to find and move into a new residence was more than some respondents felt they could muster. The fear of failure, of not being able to cope with independent living and then having to wait for an extended care bed, was mentioned by some respondents as a consideration - " I couldn't handle another disappointment". One respondent who had explored group home options felt that the group home environment was no better than her current situation in the extended care facility. Some respondents had been discouraged from looking for other options by their families or their doctors; some felt that there were valid concerns which their significant others were expressing, others simply felt that medical staff or family members were not willing to assist them in gaining more independence.

CHAPTER VII

Discussion

This study describes the characteristics of a group persons with MS who are extended care centre residents with regards to demographic and systems variables, reports high degrees of hopelessness and suggests an association between life satisfaction and volition and between life satisfaction and age at diagnosis. Although no other variables were found to be significantly associated with life satisfaction, the results suggest that many institutionalized individuals with MS also exhibit signs of occupational dysfunction in habituation and performance subsystems and in activity output. This chapter will explore the results further, discuss the limitations of the study, suggest the implications of the results for clinical practice and recommend possibilities for further research.

Demographic Data

The demographic characteristics of the sample are of some interest. The mean age for the sample group is very close to that reported by a large nursing home district in Calgary. Although no data was collected on the mean age of residents without MS for the seven facilities involved in the study, it is likely that the 20 year age gap (identified in a previous Canadian survey) between residents with and without MS also exists here, and has an impact on the responses of persons with MS to activities and routines in extended care. The other probable cohort-related gap between this group and other residents is level of education; 45% of respondents had taken some post-secondary or technical training. If activities are planned to take into account the interests of the majority, it seems likely that the activity and lifestyle desires and needs of younger, better educated residents with MS might be under-addressed in the extended care centre.

The gender distribution in the sample is in accordance with the 2 : 1 female to male ratio reported in the MS literature. There was no statistically significant difference between men and women as pertains to marital status, although there were four widows in the group and no widowers. More women than men identified marital breakdown or illness and death of a spouse as a precipitating or concomitant event to institutionalization.

Reasons for the association between life satisfaction and age at diagnosis found in this study are somewhat difficult to explain. Current age was not associated with level of life satisfaction, however diagnosis at an earlier age was associated with higher life satisfaction. This result seems contrary to that which might be intuitively predicted. It may be that individuals diagnosed in early adulthood have adjusted their expectations about what life experiences and satisfactions were going to be available to them as adults, whereas those diagnosed later in life face more discrepancy about what was, and what now will be, possible. It it also possible that the LSI-A, by the very nature of the questions it asks, focuses on the discontinuities between early adulthood and present status: persons reporting negative changes between their early adult experiences and their present status are identified as having lower life satisfaction. This may result in an accentuation of the differences between individuals diagnosed earlier and those diagnosed later in adulthood

Most respondents do have family members living nearby, and most have visitors during a typical week. Some respondents reported that they had moved to the city, and chosen an extended care facility in a specific location, so as to be close to family members. Eight respondents reported having no visitors during a typical week. The remaining 32 had, on average, more than three visits per week with family and/or friends, with the range being one to fifteen. One study suggested that psychological adjustment of persons with MS is related to the degree of contact that these individuals have with non-disabled individuals (Maybury & Brewin, 1984). The current study measured life satisfaction and not adjustment; no association was found between life satisfaction and numbers of visits per week. Nevertheless, many respondents did describe visits (either family or friends coming in, or visits home on weekend passes) as something which helped them to feel more satisfied.

Possible Intervening Variables

The mean length of residence in extended care was almost five years, with the range being from two months to fifteen years. Although there was no significant association found between time in extended care and life satisfaction, each of the three respondents who had been in a facility for less than six months expressed considerable dissatisfaction about their situations. All three reported that they had not become involved with activities or with other residents, preferring to spend much of their time alone. The lack of association found in this study could be related to the fact that most respondents had resided in extended care well beyond the one year period following institutionalization in which Tobin and Leiberman (1976) suggest that morale is typically at its lowest.

Disease activity was not associated with life satisfaction. This result may be somewhat surprising, in view of the study reported by Dalos et al. (1983) which suggested a strong association between disease activity and emotional state. The Dalos et al. (1983) study used the General Health Questionnaire (GHQ) as a measure of emotional status. This scale is commonly used as a screening tool to identify emotional disturbances, and is not a measure of life satisfaction. It is also likely that the Dalos et al. (1983) study reports the emotional responses of persons with disease courses different than that found with a majority of respondents in the present study. Persons with relapsing/remitting or relapsing/progressive disease courses are likely to experience emotional distress during periods of exacerbation; the impact of this distress on life satisfaction is not clear.

It also appears important to differentiate between individuals' own assessment of their health status and clinical assessment of health status. The Dalos et al. (1983) study, like the present study, used occurrence/non-occurrence of MS symptoms during the previous twelve months as a measure of health status. Edwards and Klemmack's (1973) study of adults age 45 and older assessed impact of both self assessed health status and number of ailments in the past month and year; perceived health was associated with life satisfaction, while number of ailments (a more objective measure) was not. Research with an elderly population has also suggested an association between life satisfaction and self-assessed health status

(Markides & Martin, 1979; Reed, 1978). Both the study reported here and that of Dalos et al. (1983) used objective measures. Because there was no question in the current study that directly asked respondents to rate their health, it is difficult to say how many respondents perceived themselves as healthy or unhealthy. The researcher observed that some respondents in the present study described themselves as ill, while others reported that they were "healthy except for the MS".

The lack of association between use of mood-altering medications and life satisfaction is also of interest. This result may be related to a number of factors. All respondents who were on any type of medication with potentially mood altering effects or side effects were classified as taking mood altering medications. Respondents taking potentially mood altering medications were not all diagnosed as having mood disorders. Individuals respond in different ways to medications. Mood altering medications typically have an impact on immediate affective state; the impact, if any, of medication use on reported level of life satisfaction is unclear.

Level of Life Satisfaction

The level of life satisfaction found in this study appears to be lower than that found both in the Counte et al. (1983) study of a non-institutionalized sample of persons with MS and in Louis Harris & Associates' (1975) study of American adults. The reason why this sample reports lower life satisfaction than that found in other studies is somewhat unclear. Perhaps it is the result of the sample chosen for study. Many MS studies have excluded respondents living in extended care facilities. One previous study which did include both persons with MS living in the community and those living in hospital (Brooks & Matson, 1982) suggested that the fact of institutional residence was, in itself, related to seeing oneself as more severely disabled and less fortunate than others. Brooks and Matson (1982) used a self-concept measure rather than life satisfaction as their dependent variable, so direct comparison is not possible. They conclude that most persons with MS adjust well and maintain a positive self-concept across time. While this may be so, it is quite likely that self-concept and adjustment are not synonymous with life satisfaction. It may be possible, for instance, to have a good self-concept and be "well adjusted", yet still report decreased life satisfaction. This might be particularly true for persons with MS who may be forced, because of health, marital strife, financial or other reasons to abandon independent living for an institutional residence. This might explain why the life satisfaction scores for this specific sample of persons with MS are lower than for those found with persons with MS who still live in the community.

The reason for the low levels of life satisfaction reported in this sample as compared to those found with other disability groups and with the institutionalized elderly may lie in the nature of the disease which afflicts this group of respondents. MS typically is diagnosed in persons who are at an age where they will have just completed their education and may have started establishing a family and a career. The process of getting a diagnosis and the uncertainties regarding prognosis, as well as the variable and unpredictable symptoms of MS, are undoubtedly associated with major changes in what individuals see as their possible futures. An instrument such as the LSI-A, which asks persons to reflect on how their lives have been, compared to how they might have been, is likely to reflect the degree to which the system trajectory of each respondent was altered because of MS. Several of the LSI-A questions (such a: "I would not change my past life even if I could", "I've gotten pretty much what I expected out of life", "as I grow older things seem better than I thought they would be", "as I look back on my life I am fairly well satisfied") were answered negatively by many respondents. It is unlikely that anyone expects and would be completely satisfied with having a disease like MS which has the potential to have such devastating physical, cognitive and psychosocial impacts.

Associations between Life Satisfaction and Independent Variables

Life Satisfaction and Institutional Climate

The expected association between life satisfaction and social climate was not found. This result is somewhat perplexing. Previous research with the SCES has suggested that an association may exist. It is possible that the aspects of the environment measured by the system maintenance and change dimension of the scale are not those which are strongly associated with life satisfaction, and that it is the relationship and/or the personal growth and goal orientation dimension of the SCES which best predicts life satisfaction. Previous research has found that it is not the quantity of social interactions but the quality, and associated activities accompanying interaction, that predict satisfaction (Conner, Powers & Bultema, 1979).

Edwards and Klemmack (1973) noted, for instance, that informal participation with nonkinsmen (sic), particularily in activities involving neighbouring, is associated with higher life satisfaction. The current study did, to some degree, attempt to measure type of social interaction through the use of the RCL and number of activities through the OQ.

Life Satisfaction and Hopelessness

The strongest association, by far, between life satisfaction and the independent variables in this study was between life satisfaction and hopelessness. The high degree of association between these two variables might be the result of both variables measuring a common underlying construct. Both the life satisfaction and hopelessness measures ask respondents to summarize past experience, report their current assessment of their life situation and make predictions about future events based on this appraisal. The LSI-A asks mostly about the past and present, with some focus on the future, whereas the BHS focuses more on the present and the future.

It is also possible that the association between life satisfaction and hopelessness scores might be related to the degree to which LSI-A and BHS items reflect the realities of living with MS. For example, almost all respondents answered the questions " I can't imagine what my life would be like ten years from now" and "The future seems vague and uncertain to me" in the affirmative. Almost all felt that the statement "I have made plans for things I'll be doing a month or a year from now" was unrealistic; many said that they live one day at a time as they cannot predict whether they will be able to participate in planned activities and prefer to be pleasantly surprised when they can participate rather than disappointed when they cannot.

This disinclination to set goals and make plans for the future is one hallmark of hopelessness as defined in the BHS; it is also, quite possibly, a coping strategy developed by persons with MS as a way of dealing with the uncertainties of MS. Brooks and Matson (1982) asked persons with MS to describe their coping strategies. Persons who reported strategies which emphasize acceptance and active integration of MS symptoms into their lifestyle had higher self-concept scores across time than other respondents. Wright (1983) talks about the need to ground hope in reality. She also noted that one strategy used by adults was that of maintaining a hopeful attitude by purposefully keeping the future vaguely defined and living one day at a time. Webster (1989) talks about MS and hope and emphasizes the importance of acknowledging reality:

> Hope is a necessary component of living with the disease, as it is a necessary part of life. But hope is only possible after full acceptance of present reality and potential consequences. To use hope, either of change or improvement, as a barrier to complete realization of the potential consequences of MS seemed not only self-defeating but impossible. For me, hope could only come into play after acceptance....Hope was used as a weapon. For me, hope is important but comes into play only within the parameters of experienced reality. And then, it is hope of living fully and with

> some integrity within the given context of my life (Webster, 1989, pp. 28-29).

Life Satisfaction and Perceived Control

The association between life satisfaction and perceived control was not as strong as between life satisfaction and hopelessness. Nevertheless, it was significant. A high degree of perceived control has previously been found to be associated with life satisfaction of elderly nursing home residents (Langer & Rodin, 1876; Ryden, 1984; Wolk & Telleen, 1976). It seems probable that the respondents in this sample, because they are part of a cohort of "educated consumers", do expect to have considerable control over daily routines, possessions, visits, interactions with physicians and privacy. Certainly those respondents who felt that their desires to have control were not being respected expressed considerable resentment and anger towards staff and other residents, or anyone identified as preventing control over these aspects of daily living. Interestingly, degree of perceived control was not related to physical status. Several very physically disabled respondents reported that they had considerable control, while other respondents with low ISS scores reported that they had very little control. Control does not, then, relate only to the ability to perform certain tasks oneself, but also to the degree to which one can influence others to complete tasks for you in a manner which meets personal standards and expectations. The results of this study suggest that individuals who are able to maintain control over the aspects of institutional life described in the LDC, either through their own physical efforts or through training staff and others, appear to perceive themselves as being less helpless and are more satisfied with life.

Life Satisfaction and Roles

Previous studies suggest that there may also be an association between life satisfaction and availability of, and participation in, valued roles and activities (Elliot & Barris, 1987; Riopel, 1983). This association was not convincingly shown in this study. There was, however, no explicit measure of the availability of valued roles and activities. Respondents were asked only to identify what roles they had,were, or planned to fill. The roles that respondents most frequently reported as current and planned future roles were those of family member and friend. All other roles were mentioned much less frequently, and no respondents identified roles additional to those listed in the RCL. All respondents were currently occupying fewer roles than they had in the past. Some individuals did discuss the limited roles available to them in the setting, so it may be possible that these perceived constraints had an impact on the number of roles reported.

Life Satisfaction and Performance Skill

The association between life satisfaction and level of disability has also been explored in the literature. There are a number of studies which address the issue of life satisfaction of persons with disabilities (Boschen, 1990; Cameron, Titus, Kostin & Kostin, 1973; Rideout & Montemuro, 1986; Xerxa & Baum, 1986). Typically, these studies compare life satisfaction of groups of persons with and without disabilities. Other studies compare life satisfaction of persons with different types of disabilities. The results of these studies suggest that, on the whole, the life satisfaction of persons with disabilities is similar to that of non-disabled persons. Much of these research has focused on persons with disabling conditions which are somewhat predictable and constant in their effects. There has been some suggestion that persons living with less predictable and fluctuating conditions may experience greater difficulties in adjusting to disability. It is not possible, from this study, to ascertain whether respondents have adjusted well to their disabilities, however current level of disability of individual respondents was not associated with level of life satisfaction.

MS researchers have also explored the extent to which physical disability is associated with satisfaction or adjustment (Dalos et al., 1983; Granger et al.,1990; Maybury & Brewin, 1984; Zeldow & Pavlou, 1984). Each of these studies suggests that level of disability is not associated with adjustment or life satisfaction. Most of these studies used Kurtzke scores as a measure of disability, although one used a subscale of the Sickness Impact Profile. The Kurtzke scale relates primarily to ambulation, and not to performance of ADL tasks. One recent study in the occupational therapy literature (Xerxa & Baum, 1986) suggested that life satisfaction is related to satisfaction with performance of home management and social/community problem-solving skills. This association might be expected, as Markides & Martin (1979) suggest, because studies which use specific satisfaction measures as predictors of overall satisfaction are likely to find associations as a result of the fact that each predictor measures satisfaction.

Life Satisfaction and Activity Output

There has also been some suggestion that life satisfaction is related to level and quality of participation in activities (Gregory, 1983; Markides & Martin, 1979; Riopel, 1983). This association was not found in the present study. The lack of association may be a result of the limited variability in the number of valued daily activities reported by most respondents. It did not appear that respondents, especially those with extremely limited mobility, could easily access activities which were enjoyable and important to them. The researcher had some difficulty in getting responses to the OQ. Many respondents seemed unable to rate activities for competency. This may be related to respondents' perceptions that many activities are done for, rather than by, them and that the ratings would therefore reflect staff competence and not their own skill.

The small number of valued daily activities reported by respondents may also reflect the tendency of some respondents to spend all or most of their days in their rooms; while some respondents were very active and participated in many activities, there were several respondents in each of the larger extended care centres who did not participate in any therapy or recreational activities with other residents. This would necessarily limit the number of activities available to respondents, and may reflect a coping style marked by withdrawal. Davis (1970) describes withdrawal as one of three strategies used by her respondents in dealing with MS. Some respondents reported that they intentionally isolated themselves, feeling that they had nothing in common with other residents, and that the activities planned for residents were not of interest to them. Several respondents pointed out that they were not like the other residents.

Study Results in Context of the Model of Human Occupation

The primary intent of this study was not to test the premises of the model of human occupation. Nevertheless, the study design does allow us to examine the degree to which one variable in the model is associated with other model variables. It also provides an opportunity to explore whether the direction of association found between variables reflects the links suggested in the theoretical model.

The study results provide equivocal support for the model. The model postulates that life satisfaction (a measure of feedback) is associated with the functional status of the volition (represented in this study through measures of expectancy of success/failure and locus of control), habituation (measured in this study by number of valued roles) and performance (measured with an ADL scale) subsystems. The model further describes satisfaction as being associated with level of output (measured in this study by an activity questionnaire) and environmental conditions which impact intake (represented in this study by scores on a social climate measure). The strongest, and the only significant, associations found in this study were between life satisfaction and volition (both expectancy of success/failure and locus of control). Associations between life satisfaction and other variables (habituation, performance, output and environment), while not significant, were in the direction suggested by the model.

Kielhofner (1984) points out that feedback is influenced by overall system functioning, including harmony between volition and output. He suggests that the interworking of volition, habituation and performance and the affiliation of the system to the environment determines function and dysfunction. He cautions that dysfunction is a result of disruption in a series of dynamic system conditions and is not simply associated with the status of discrete system components (Kielhofner, 1986a, 1986b). Thus identifying the status of each component without an overall measure of system functioning may not provide an accurate measure of function, as each part of the system facilitates or constrains other parts of the system. This study did not use a measure of overall system functioning. Such measures are only now becoming available and would certainly be of benefit in future studies.

The researcher further questions whether life satisfaction is an appropriate measure of system feedback. Kielhofner (1985) initially described the LSI as a useful measure of feedback. The association found between life satisfaction and volition in this study might suggest that life satisfaction, like expectancy of success/failure and locus of control are components of the volition subsystem, and that a measure of happiness or current affective state might be a better indicator of feedback. Kielhofner's recent refining of the model (personal communication, November, 1990) discusses states and traits. It may be that life satisfaction is a more enduring trait, while happiness is a state. Perhaps measures of affect, which have a shorter temporal focus, are more useful measures of feedback - individuals experience a state of happiness, that state may then be incorporated into a longer-term trait which is related to individuals' tendency to view life as good and their own lives as satisfactory.

Limitations of the Study

There are a number of limitations associated with this study which must be acknowledged. The sample was not a random one, but rather a sample of convenience. There was a likely bias in selection of respondents, with a small number of individuals judged by therapists as emotionally less stable being excluded. This may have led to higher mean life satisfaction scores and lower mean hopelessness scores than would have been found if these individuals had been included in the study. Potential respondents who may have been cognitively intact but were unable to communicate verbally were also excluded. The impact of excluding this group of respondents is less clear. Although the study included respondents from Edmonton only, there is no reason to believe that the experience of these persons with MS would differ substantially from others in cities throughout Alberta and Canada. Respondents came from seven extended care facilities, each with unique physical and staff resources, programming and administrative features. Thus the generalizability of the study results is not limited to residents of one type or size of extended care facility.

The number of respondents in the sample was small, thus limiting the power of the study to detect significant associations if they did, in fact, exist. The hypothesized relationships between life satisfaction and the variables measured in this study were in the expected direction, although only three associations were statistically significant. The use of a larger sample size might have increased the power of the study to detect significant associations where they did in fact exist.

Another potential limitation of the study is related to the measures chosen. Each was chosen for its relationship to aspects of the theoretical model, yet the variables which they represent may not be those which have the greatest association with life satisfaction of institutionalized persons with MS. An ongoing difficulty in occupational therapy research is availability of appropriate research instruments. Although all of the instruments used in this study have demonstrated reliability and validity, the issue remains as to whether the complex issues which this study attempted to measure are, in fact, measurable with quantitative measures alone. The use of qualitative techniques, or qualitative and quantitative techniques in combination, appears more promising. Certainly, respondents in this study were more than willing to explain and expand upon their answers to the standardized instruments, and to discuss turning points in their response to MS and to living in extended care facilities.

Finally, it must be emphasized that association does not imply causation or direction; for instance, low life satisfaction and hopelessness might be related but neither one cause the other, likewise low life satisfaction may lead to hopelessness not vice versa.. Much of the variance in life satisfaction scores remains unexplained by the independent variables, therefore other factors, not measured in this study, must have contributed to each respondents' current satisfaction.

Conclusions

The purpose of the study was to describe characteristics of institutionalized persons with MS with regards to demographic characteristics, to describe the life satisfaction of these individuals, and to identify factors which may be associated with life satisfaction. The results suggest that institutionalized persons with MS report low levels of life satisfaction, express considerable hopelessness and lack of control, and otherwise appear to have considerable disruption in aspects of habituation, performance and output of occupational behaviours. The impact of environmental factors on life satisfaction was not reflected through measures of association, but was clearly described by respondents as being related to lack of same-age companionship, lack of age appropriate activities, lack of privacy, dissatisfaction with staffing and a variety of other concerns. Many respondents had entered an extended care facility only because they were no longer able to rely on family members for caregiving, and could not access adequate homecare services.

The results of this study suggest that much could be done to increase the satisfaction and/or happiness of institutionalized persons with MS. One way of doing this would be to push for increased funding for homecare services so that these individuals could live in the community and remain involved and in control of the roles and activities which are important to them, and yet receive assistance with ADL and other tasks as needed. It is probable, given the answers of some respondents in this study, that some current extended care residents may not wish to, or feel they realistically can, return to the community. Thus it will be important to also address the concerns of these individuals. In order to do so, attention will need to be paid to both aspects of individual functioning and to the extended care centre environment. Occupational therapists, with their focus on both the individual and his/her environment and with their knowledge of ways to minimize the impact of MS symptoms, might be ideally suited to work with persons with MS both in the community and in the extended care environment.

Implications for Practice

The focus of occupational therapy with persons with MS, as reflected in the literature, has been primarily on aspects of physical functioning. While physical function may have an impact on all other parts of the human open system, it does not appear to be a major determinant of overall system status, and appears to have little or no direct association with life satisfaction. OT's appear to have spent less time exploring and documenting the importance of social, emotional and environmental factors or the significance of meaningful activity in working with persons with MS. They have not been alone in this. Brooks and Matson (1982) point out that rehabilitation programmes tend to neglect social-psychological processes in favour of a focus on physical function and ADL. The results of this study suggest that it may be the social and emotional aspects of OT treatment which are most important to clients with chronic diseases like MS.

Opportunities to interact with others, to exert control over one's participation in productive roles and activities and to modify the environment to meet one's needs and desires can be provided through OT interventions (Dunning, 1972; Kannegeiter, 1980).

These interventions have a role in assisting individuals to maintain or regain hope. The preservation of hope can be crucial in adapting to a chronic illness. Hope appears to be a necessary condition for action; in order to carry out the unending work and care that Corbin and Strauss (1988) describe as necessary to coping with chronic illness, individuals must act. Hope may focus on restoration of function, but more typically the focus will be on ways in which to adapt to altered function. Kielhofner (personal communication, 1990) suggests that one outcome of occupational therapy is that of helping individuals to establish "possible futures". He describes volition as linear, and narratively structured. He postulates that therapeutic activities enable individuals to become aware of possibilities in their own life narratives. Magill and Vargo (1977), in describing the role of OT in combatting helplessness and hopelessness, suggest cognitive-behavioural strategies which emphasize (among other things) the importance of perceived control, interaction with helpful others, and involvement in activity.

Occupational therapists must be active in offering individuals with MS choices in daily activities and tasks; training them to be competent managers of staff and/or family caregivers; supporting them in advocating for an environment where there is a place for personal objects, tasks and preferences; providing activities which are challenging and age appropriate; as well as teaching basic ADL and compensatory physical and cognitive performance skills. Respondents in this study noted again and again that extended care centre staff need to provide services of this type. They also reported that some of these services are already being provided, but emphasized that more could and should be done because of the value of such activities to their satisfaction with life in an extended care facility. Activities and opportunities that were noted specifically by respondents included those which had either a cooperative or competitive focus, required cognitive effort, involved contact with peers and family or friends, and took place outside the extended care centre. Visits home, a competitive quiz-show game, a gourmet dining club, microcomputer training, attendance at community college courses, visits to shops and cultural centres, a personal growth group and attendance at MS Society activities were noted as examples of activities that were appreciated by respondents.

Recommendations for Future Research

It is the researcher's hope that this study will be only one of a series of rehabilitation research endeavours which address the needs of young and middle aged persons with MS. This study was an initial attempt to describe a population which had previously not been a focus for research. Further research might focus on comparing persons with MS living in the community with those living in extended care centres, in order to further explore why some individuals remain in the community even when significantly disabled while others are institutionalized. Longitudinal studies might be useful in explaining, in more detail, the turning points leading to institutionalization.

The study showed associations between life satisfaction and some aspects of volition. Future studies utilizing correlation techniques might be augmented through using path analysis methods, in order to better show the interrelationships between variables.

Study designs which showed the impact of specific therapeutic interventions or environmental modifications on the overall functioning or on volition, habituation, performance and output of individuals with MS would give occupational therapists needed feedback on the services they offer. Further exploration of the role of cognitive impairment and of various cognitive strategies used by persons with MS on overall system functioning might also be of great benefit.

This study also provided support for a model of occupational therapy practice. Only some of the measurement tools used in the study were designed specifically to reflect components of the model; future research might be better served by using tools expressly designed to measure overall system function as well as the status of system components.

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APPENDIX A

SAMPLE SIZE CALCULATION

Power test (after Cohen & Cohen, 1983)
Ho: $R^2 < .25$
H_A: $R^2 \geq .25$

At an alpha level of .05 and a study power of .75, given 6 independent variables, L = 12.29.

$$F^2 = \frac{R^2}{1 - R^2}$$

$$= \frac{.25}{.75}$$

$$= .33$$

Where k equals the number of independent variables and n* is the number of subjects required:

$$n^* = \frac{L}{F^2} + k + 1$$

$$= \frac{12.29}{.33} + 6 + 1$$

$$= 44.24$$

Therefore, in order to find .25 variance at an alpha level of .05 with a power of .75, approximately 44 subjects are needed.

APPENDIX B
LETTER OF INTRODUCTION

Dear :

The Faculty of Rehabilitation Medicine and seven Edmonton-area extended care facilities are cooperating to study the life satisfaction of persons living in extended care centres. Your facility administrator and the Occupational Therapists in your facility have agreed to notify residents with MS about this study. If you agree to participate in the study, an interviewer from the University will visit you at the centre. She will ask you questions about how satisfied you are with your life now, and about factors which might influence your satisfaction, including your living arrangements. Two interviews will probably be needed to collect the information necessary. Each interview will take approximately 45 minutes, and both interviews will take place within a ten day period. Some participants may be asked for a third interview.

Part of these interviews will be audiotaped, but the tapes will be erased as soon as the materials are transcribed. Some data will also be taken from your medical record. After all participants have been interviewed, you will receive a summary of the findings.

All the information you give will be kept confidential. Although each facility will be informed of the overall results of the study, no resident's individual responses will be available to facility staff.

If you are able to help, please contact the occupational therapist who works on your unit. She or he will pass on your name to me, and I will contact you to set up a time for your first interview. If you have any concerns or questions about the study, please contact either Susan Burwash at 437-4215 or Dr. Sharon Warren, Faculty of Rehabilitation Medicine, University of Alberta at 492-7856.

Thank you for considering my request. Your time will be greatly appreciated, and we hope that the findings may suggest ways to improve the life satisfaction of persons with MS living in extended care centres.

Susan Burwash
Graduate Student
Department of Occupational Therapy, University of Alberta

APPENDIX C
CONSENT FORM
LIFE SATISFACTION OF INSTITUTIONALIZED PERSONS WITH MS

Susan Burwash
Graduate Student
Department of Occupational Therapy, University of Alberta
492-2499

This is to certify that I,________________________________, have agreed to participate in a study to be conducted by Susan Burwash from the University of Alberta. The purpose of this study is to describe the life satisfaction of persons with MS who are living in extended care centres, and to identify factors which may be associated with life satisfaction.
It is my understanding that:

1. I will be asked to answer questions about how satisfied I am with my life now, and some of the factors which may influence how satisfied I am. Part of the interview will be taped-recorded by the interviewer, but all tapes will be stored in a locked cabinet and erased six months following completion of the study.

2. I have been informed that some information from my medical record will be required, and give my permission for this material to be used in the study.

3. My participation in the study is voluntary. I may withhold answers to any questions and am free to end the interviews at any time.

4. Any information collected in the study will be treated confidentially. Research reports and articles will not identify me by name or initial and quotes made by individual participants will be reported in a way that protects my identity.

5. I will receive a copy of the findings, but I may not necessarily benefit directly from participating in the study. I have read and discussed the above and agree to participate in the study.

____
PARTICIPANT'S SIGNATURE DATE

____
WITNESS' SIGNATURE DATE

____
PRINCIPAL INVESTIGATOR DATE

APPENDIX D
QUESTIONNAIRE

LIFE SATISFACTION IN INSTITUTIONALIZED PERSONS WITH MS

BACKGROUND INFORMATION
DEMOGRAPIC INFORMATION

Respondent's ID:____________________
Place of residence:____________________
Date of interviews: 1.____________________
2.____________________
(3).____________________

Respondent's :
Age:____________________

Gender: ____________________

Age when diagnosed:____________________

Marital status:____________________

Number and ages of children: ____________________

Number of family members in Edmonton or vicinity: __________

Average number of visits/week from family,friends:__________

Ethnic origin: ____________________

Religious affiliation:____________________

Highest educational level attained: ____________________

Pre-admission occupation:____________________

From respondent's medical record:

Length of time institutionalized ____________________

Disease activity, ie incidence during past six months of any disease-related complications serious enough to require vital signs recording on a greater than once-daily basis, or admission to acute care facility: __________

Use of mood-altering medications: ____________________

PAGES 130 - 147 CONTAIN COPYRIGHTED MATERIAL AND HAVE BEEN OMITTED. MATERIAL OMITTED INCLUDES:

LIFE SATISFACTION INDEX
SHELTERED CARE ENVIRONMENT SCALE
LOCUS OF DESIRED CONTROL SCALE
BECK HOPELESSNESS SCALE
ROLE CHECKLIST
IC=NCAPACITY STATUS SCALE
OCCUPATIONAL QUESTIONNAIRE

"TURNING POINTS"

CAN YOU TELL ME ABOUT THE TIME BEFORE YOU CAME INTO THE EXTENDED CARE CENTRE ? WHAT WAS HAPPENING WITH YOU PHYSICALLY, EMOTIONALLY, IN YOUR ABILITY TO MANAGE YOUR MS SYMPTOMS AND PHYSICAL CHANGES ?

WHAT WERE THE THINGS THAT HELPED YOU STAY AT HOME AS LONG AS POSSIBLE ?

WHAT WERE THE THINGS THAT MADE IT DIFFICULT TO STAY AT HOME ?

WHAT WAS THE "TURNING POINT" THAT LED TO YOUR ADMISSION TO THIS FACILITY ?

HOW DID YOU FEEL ABOUT BEING HERE BEFORE YOU CAME?

HOW DO YOU FEEL ABOUT BEING HERE NOW ? HAVE THERE BEEN ANY PEOPLE OR EVENTS THAT HAVE HAD AN IMPACT ON HOW YOU FEEL ABOUT BEING HERE?

WHAT THINGS OR PEOPLE HELP OR HINDER YOU IN HOW YOU LIVE YOUR LIFE HERE ?

WHAT CHANGES MIGHT MAKE THINGS BETTER FOR YOU ?

DO YOU THINK THAT THERE IS ANY CHANCE YOU COULD RETURN TO THE COMMUNITY ? WHAT THINGS WOULD HELP/PREVENT YOU FROM RETURNING ?

APPENDIX E

RESULTS: LETTER TO RESPONDENTS

Dear ______________________:

Several months ago, I came to your extended care centre to ask you to participate in a study of persons with MS who live in extended care facilities. You were kind enough to agree to participate in the study, and very generous in spending time answering the many questions I asked you. I would again like to thank you for your participation, and share some of the information collected in the study with you.

The purpose of this study was to describe some of the characteristics of institutionalized persons with (MS), to describe the level of life satisfaction of these individuals, and to identify factors which may be associated with life satisfaction.

Forty people living in seven extended care facilities were interviewed using a questionnaire which tried to assess life satisfaction, and six factors (hopelessness, sense of control, roles, ability to manage activities of daily living [ADL] tasks, number of valued activities and perception of the extended care environment) which might be related to life satisfaction.

The results suggest that many institutionalized persons with MS report low levels of life satisfaction, express considerable hopelessness and lack of control, and appear to have a considerable decrease in numbers of roles, ADL tasks and activities in which they are involved. Two factors, hopelessness and expected control, were associated with life satisfaction.

Age at diagnosis was also associated with levels of life satisfaction, with persons who were diagnosed at younger ages reporting greater levels of satisfaction than those diagnosed when older.

Many of you identified ways in which the extended care centre could make improvements through such things as: staffing levels, staff training, changes in the physical environment and/or the rules and routines, and recreation activities which are intellectually challenging and suited for younger rather than older adults. You also identified some of the things which are provided now and are important such as: availability of private rooms, opportunities for activities outside the centre, visits home, and relationships with other residents, with volunteers and/or staff. Some of you were hoping to leave the centre, but were not sure you could manage without homecare services.

The study suggests that extended care centre staff and residents need to address some of the concerns that were identified in order to increase the level of satisfaction and allow individuals to feel more hopeful. The study also suggests that there is an ongoing need for community-based services for persons with MS. I will also be sharing the results of the study with the occupational therapists who work at each centre. I hope that your participation in this study will lead to discussion and to changes that are important to you. Thank you again for agreeing to talk with me; I enjoyed our discussions very much.

Sincerely.