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Patient- initiated self-care and positive health outcomes in patients living with Multiple Sclerosis: A qualitative study.

Grace Olakunle
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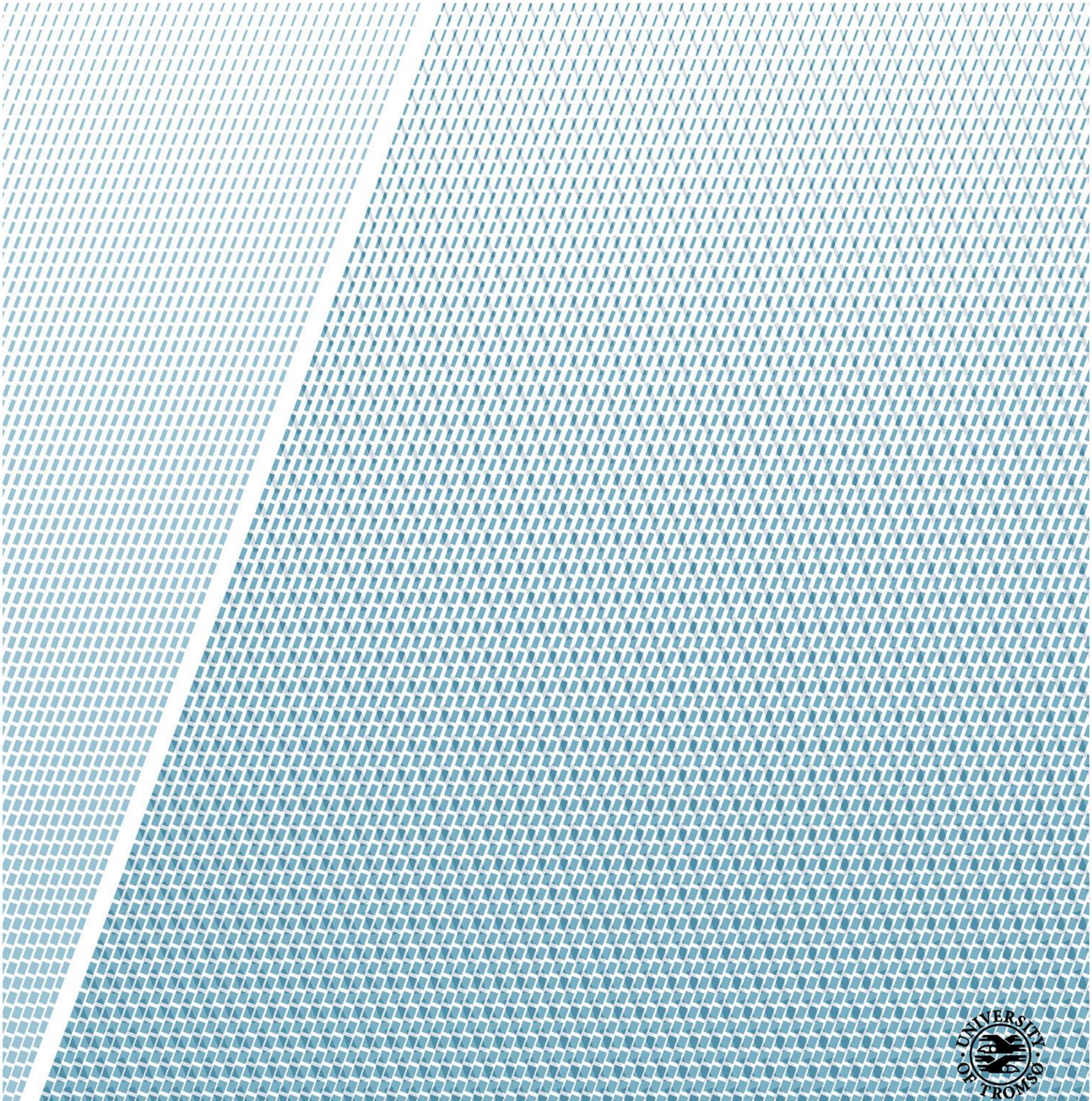
Supervisor: Anita Salamonsen
Senior Researcher NAFKAM



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List of Abbreviations

MS	**Multiple Sclerosis**
CNS	**Central Nervous System**
NAFKAM	**National Research Center in Complementary and Alternative Medicine**
CAM	**Complementary and Alternative Medicine**
WHO	**World Health Organization**

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Abstract

Background:

Multiple sclerosis (MS) is a prolonged chronic disease which often causes severe problems in patients' everyday life and as a result of this it becomes necessary for these patients to make lifestyles changes to effectively handle and cope with their condition. The capability to accept the situation, keep an optimistic mindset and attitude, as well as deal with these lifestyle changes acts as an important factor in establishing an effective management of this disease. The Norwegian Ministry of Health and Care Services defines actions that patients take for themselves, their children, their families and others to maintain their social, physical and mental well-being, as *self-care*.

Aims:

This study purposes to look at the daily routines and self-care practices among patients living with multiple sclerosis who have experienced positive health outcomes related to their self-initiated efforts and the various strategies used by them to live better with their disease. Such knowledge from the patient perspective is important due to the increasing number of persons living with chronic conditions and their long-lasting and complex health care needs that the public health care may not be able to handle effectively without the patient's` involvement.

Methods:

The study was based on content analysis of qualitative questionnaire data. The participants were 78 Norwegian, Swedish and Danish patients diagnosed with multiple sclerosis, who have reported their illness and treatment experiences to a registry and answered a set of open-ended questions on self-care practices.

Results:

The overall findings showed positive effects in the participants' overall well-being and quality of life based on self-initiated changes to their lifestyles. The study results supports the hypothesis that acknowledging and supporting patient initiated self-care in public health programs may represent an important potential in the improved treatment and management of lifelong chronic illnesses like multiple sclerosis.

Conclusions:

Activities related to health care amongst patients living with chronic and long-term diseases seems to go through a steady shift from the traditional *passive* patient methodology to an ***active*** patient position, as more patients seem to take charge of their health care and initiate self-care actions that allow them to live better with their disease. A scientific emphasis on potential positive health outcomes of patients' own efforts as seen from the patient perspective in research, education and public health programs may add to a new and better understanding of patients’ health care needs and the importance of supporting their self-help potential. Due to the fact that chronic disease is one of the world's’ most difficult challenges both with respect to economical and human facets, the positive effects of patient- initiated self-care may be acknowledged as one of the principal resources of any health care system in the future.

Key Words: *Self-care, Chronic illness, Multiple Sclerosis, Salutogenesis, Qualitative study, Self-management, Patients perspective, Mind-set.*

1. Introduction

One of the world’s most challenging and debilitating public health care problems is caused by chronic diseases with a projected 133 million people living with a minimum of at least one chronic condition (1). Due to the complex nature of the different forms of chronic diseases and conditions, it is difficult to accurately define the term. The commission on chronic diseases (1957) however, defines it as “*All impairments or deviations from normal which have one or more of the following characteristics; are permanent, leave residual disability, are caused by nonreversible pathological alteration, require special training of the patient for habilitation and may be expected to require a long period of supervision, observation or care.*” (1, p. 5). Over the last decades, there has been a significant growth in the amount of people living with chronic diseases. Chronic diseases do currently represent the main causes of ill health, disability as well as premature deaths all over the world (1).

Multiple sclerosis (MS) is a long-lasting, incapacitating and chronic infection that affects different parts (e. g. brain, spinal cord) of the central nervous system (CNS) at different intervals. It typically affects young adults, with an estimate of about one in a thousand persons, and with women more at risk twice as often as the men gender-wise and a steady and significant increase in the number of patients (2, 3). At its preliminary stages, MS is often categorized by vital setbacks in its neurological pivotal deficits, which is gradually followed by a substantial degree of recovery referred to as the relapsing-remitting MS stage. The progress in the “relapsing-remitting” MS stage goes on for a period of about 10 years and then it is followed by another MS stage known as a secondary progressive stage (2). Up till date, the effects and what causes the inflammation, lesions and swelling of the CNS is still unidentified and unknown (3). The medical, clinical measures taken to combat this infection are usually associated with areas that are either infected or swollen in the CNS. Although the cause of MS is not fully understood yet, the damage or inflammation to the CNS is said to result from an immune-mediated process, as a consequence of the interrelation between genetic and environmental influences such as habitual and excessive drinking, smoking and insufficiency of vitamin D and other infections (2, 4).

The majority of individuals living with MS usually suffers from clinical symptoms like depletion in energy as a result of fatigue, apprehension and anxiety, pain, uneasiness and discomfort (3). The severity of MS symptoms differs from one MS patient to another and may range from almost unnoticeable to severe or anything in between. The outcome of MS on these patients' lives is consequently wide-ranging and thereby a challenge to foresee. The basic facts about MS that most patients experience is that MS affects them physically, psychologically, emotionally and socially. For instance, effects such as bodily weakness or fatigue, affects the posture and body coordination of MS patients, their sexual needs, bladder and bowel movements, may cause eye sight problems and MS patients often have persistent chronic pain. Some MS patients also experience changes in their mental and emotional mind-set. For example, some MS patients experience difficulties in paying attention, recollecting and processing information and they go through variations in temperament caused by emotional mood swings which can be a factor affecting their social, familial relationships as well as their working environment. These issues have the ability to threaten MS patients' feelings of self-worth, individualism, independence, personality, self-esteem, dignity and overall well-laid plans for the future (2).

MS is not by any way considered a deadly illness and any untimely deaths as a result of MS is probably due to difficulties caused by secondary factors related to this ailment, however the MS patient's life expectancy is considerably diminished in contrast to the general population (2, 3). As a consequence of this, most MS patients have to accept the fact that, at least so far, their clinical and medical symptoms cannot be fully treated through any standard medical measures, cure or treatments (2, 5). It is a challenge for the future to find an effective MS cure, appropriate treatment options, prevention of the disease and so forth. These patients are currently living with a severe chronic disease, and they thus deserve to partake in wide-ranging self- care or management courses to live a better life with MS (5). So far, research involving self-care and multiple sclerosis is inadequate and limited. Up to now, self-care research courses have yet to discourse the pattern of multi-faceted symptoms and secondary illnesses that affects the majority of patients with MS (5).

Several studies have shown that many MS patients choose to use complementary and alternative medicine (CAM) as a way to cope and live a better life with their disease (6). This being the case, one of the primary tasks and focus of recent public health policy is to competently and successfully take care of these long-term illnesses and the liability they place on MS patients, health care providers, health care specialists and the health services provided (7). As a consequence, Patients, health-care authorities, personnel's and researchers need a lot more information and knowledge about potential valuable as well as detrimental health care strategies for living with severe chronic illness (8). This thesis contributes to this knowledge by focusing mainly on patient-initiated self-care and its' possible positive health outcomes in a sample of Scandinavian MS patients.

1.1 Patient- initiated self-care and multiple sclerosis

Self-care can be defined as "*the ability of individuals, families and communities to promote health, prevent disease, maintain health and cope with illness and disability with or without the support of a healthcare provider*" (8, p.10). The principle of self-care deals with the health choices people as patients and individuals in the society make for themselves and their families to become physically and mentally healthy as well as stay fit and uphold this healthy lifestyle. It involves mental and physical training/exercise, vibrant cognitive health, eating well-balanced and healthy meals, practicing good hygiene and avoiding health threats like habitual smoking and excessive drinking in order for them to ward off infection, sickness and disability (8, 9).

The notion of "*patient initiated self-care*" comprises of all the aforementioned but specifically identifies the efforts and choices patients, especially those living with chronic illnesses, make on a regular basis about handling and self-managing their condition (10). Patient initiated self-care is a fundamental and central part of everyday life. It describes the different ways patients take responsibility and charge of their own health and wellbeing, with support from people around them as well as those involved in their care, routine and day to day life (9, 10). This constitutes the actions patients take to change their mindset, meet their psychosomatic, emotional and social needs and take control of their long-term condition by preventing further infection or mishaps. The goals of MS patients in patient-initiated self-care may be to live longer and have an better-quality life-span, drastically reduced degree of chronic pain, apprehension, depression and fatigue, and be more dynamic, energetic and independent (10). Studies have shown that people living with prolonged illnesses may profit extensively if they get support for such self-care (10).

A principal theory in self-management is self-efficiency or efficacy which describes an individual's confidence in performing activities that are fundamental to reaching their desired objective and goal. The degree of self-efficiency is said to be greater when patients excel in resolving issues that are patient-identified (10). Self-care has been shown to reinforce efficacy in patients that are self-efficient as well as strengthen illness and non- illness facets of life among persons with prolonged illnesses and chronic conditions. Nevertheless, it has so far not gotten the merited research attention it deserves among researchers within the field of MS (11).

2. Objectives/Aims of study

This study describes and evaluates patient initiated self-care practices in a sample of Scandinavian patients living with multiple sclerosis at different stages of incapacity and disability. Its aims to study the routine day-to-day self- management or care among MS patients reporting positive health outcomes related to their own efforts. The study objectives are to look at these efforts as well as to discuss the role of self-initiated self-care strategies from the patient's perspective and a public health perspective. It can be important to acknowledge the importance of this subject because with the significant rise in burden of disease as well as growth in the incidence of chronic diseases, there is a need for re-evaluation of strategies and a refocus on health campaign, disease prevention and patient initiated self-care during illnesses and in restoration of public health care systems. This master thesis may provide data and analysis valuable and expedient for this purpose.

2.1 Research Questions

The overall research questions are:

- What do patients with multiple sclerosis do to live better with their illness?
- What changes have been important in achieving this goal?
- How important is the role of such self-initiated health care in the management of multiple sclerosis in effective and successful patient care as seen from a patient perspective?

3. Ethics

The study was reported to the Regional Committee for Medical and Health Research Ethics, Northern Norway (REK) **(appendix 1)** and registered at the Norwegian Social Science Data Services (NSD) **(appendix 2)**. The study is based on data derived from the Registry of

Exceptional Courses of Disease that was recommended by REK and registered at NSD in 2003. The Norwegian Data Inspectorate approved the establishment of the Registry with permission to keep personal data. All participants in the Registry have signed an informed consent form. The patient data delivered to the master student were anonymous.

4. Materials

The empirical data in this study was derived from the Registry of Exceptional Courses of Disease (hereafter "the Registry") and Registry participants who are users of CAM and have experienced improvements of their multiple sclerosis. The Registry was established at the National Research Center in Complementary and Alternative Medicine (NAFKAM), Norway in 2002. Its goal is to create a database available for researching and voicing patients who have experienced unexpected improvement or worsening of their disease and relate these experiences to their self-initiated and self-financed use of CAM. Internationally, NAFKAM is the first research institution to establish such a permanent registry. In many cases, the use of CAM is part of patients' self-care strategies, in other cases not. This study is based on questions from the Registry questionnaire **(appendix 3**) that explore patients' experiences from the use of conventional medicine, CAM and in addition, is specifically addressing the patient's' own efforts (questions 38-42). Answers from the 78 MS patients in the Registry per January, 31, 2015 to the open-ended questions 38-42 on patients' own efforts is the material this study is based on, in addition to background variables such as age, gender, and education. Application for access to anonymous data on MS patients' answers to these questions from the Registry questionnaire was sent to the steering group for the Registry who granted access for materials from the 78 registered MS patients. The data material has been translated from Norwegian, Danish and Swedish to English by the author of this thesis as well as a professional translator.

5. Methods

The study questionnaire (**appendix 3**) consists of closed and open-ended questions. The closed ended questions confounded for age, gender, occupation, patient's date of birth; first health problem registered, and so forth. Descriptive statistical analysis has been used to report on these background variables. Overall, a qualitative methodological approach was used in this study. As the data was already collected, qualitative content analysis was used to analyze the written answers on open-ended questions from the questionnaire. Qualitative analysis crosses over disciplines, fields and subject matters and hints at the importance of the merits of components and on process meanings that are not experimentally studied or measured in terms of amount, quantity, intensity or rate of recurrence (12). Observing a concentrated group of people, comprehensive interviews, content analysis, ethnography, evaluation and appraisal, semiotics are among the many methodologies that are used, but qualitative research in its most simple form encompasses the analysis of any data that lacks structure, including: open-ended assessment surveys like in this study, literature journals, dialogues, audio records, videos, pictures and social media and web pages from the internet (13).

A qualitative method of analysis aims to understand a social or human problem from several viewpoints and angles. This means looking for answers to questions that lay emphasis on how social know-how is formed and makes sense (12, 13). Qualitative data analysis involves a process of building a complex and all-inclusive picture of the sensation of interest. Its manifold realisms occur in any given situation, the researcher's, those of the individuals being investigated, and the reader or observers interpreting the result (14). In comparison to the quantitative method of analysis, the qualitative methodology can add a more insightful comprehension and general understanding of an in-depth knowledge of key issues that are vital to both private and public health issues and well-being in cases like this where there is an inadequacy of prior information (6).

5.1 Qualitative Content Analysis

Qualitative content analysis design was used to analyze the open-ended questions from the questionnaire. Qualitative content analysis is a commonly used procedure for making replicable and valid interpretations from texts or other significant material to the contexts of their use (15). It is defined as "*any technique for making inferences by systematically and objectively identifying special characteristics of messages*" (15, p.240). To form an analysis based on this point of view, it infers that digital photographs, films or any item that can be made into text are receptive to content analysis. Content analysis defines a clique of analytic methods ranging from impressionistic, intuitive, interpretive studies to systematic, strict word-based analyses (15, 16). Research using qualitative content analysis focuses on the structures of language as a source of communication with emphasis on the content or contextual meaning of the text. The records gotten from the data might be oral, hard copy or photocopy and print, electronic form and acquired from narrative answers to open-ended survey questions as discussed in this thesis, formal interviews, focus groups, opinions, or print media such as articles, manual, books or guides (16). The key differences among these tactics are methods used in coding, where these coding's originated from and if it is credible (14). In the process of the evaluation of a content analysis, the context institutes all the data, information and knowledge that the analyst applies to certain text, whether the text data is in the system of systematic or scientific theories, evidence related to empiric data, basic intuitions or the knowledge of reading habits (15, 17).

For the purpose of this study, the available data was first intensively read as a whole, and ideas and themes were written down. In the next step, the text data was re-read and categorized based on the revealed main empirical themes and more refined themes and sub-themes. Theories of factors that may influence health outcomes (*Pages 20-33*) were found to contribute substantially to a deeper understanding of the identified empirical patterns and were thus included in the further categorization and explanations of the empirical results. In the discussion, other empirical studies and theoretical approaches, including critical perspectives, were added to gain more in-depth and transferrable knowledge.

6. Results

6.1 Background Data

As of January 31, 2015, 406 patients were included in the Registry (71% women, 29% men). Of these, 78 patients were diagnosed with MS, 49 from Norway (33 women, 15 men), 26 from Denmark (20 women, 6 men) and 3 from Sweden (2 women, 1 man). These 78 Scandinavian MS patients ranged in age from 35 to 67 years, with a mean of 50.6. More than half of them had higher education. Nineteen had been using alternative treatment exclusively over longer periods of time.

6.2 The Importance of self-initiated positive change

The main focus of this analysis is how the participants managed their life with MS. One major result, 3 themes and 7 sub-themes were brought out from this analysis. The overall finding of this study is that *positive change* was the most important factor for all the participants in their strategies to live a better life with MS. Due to an experienced lack of conventional treatment options, most of the 78 participants found that they had to “*self-manage*” their illness and its conditions. Day by day, they decided what they were going to eat, whether or not they would exercise, to what level or boundary they would prefer to exercise, what limits their bodies could handle, what diets to modify or change to and which natural herbs or supplements to consume.

The overall priorities with regards to the participants' social and personal lives were positively altered for the better and influenced the majority of these patients to change the way they viewed their condition, with most having to cultivate a different and changed way of life, mind-set as well as a new attitude and approach to their way of thinking and living with MS. The participants experienced major advancements in their health and general welfare due to various factors that had a positive effect on the way they handled their disease. These factors are integrated into the three main themes revealed from the analysis; ***Psychological, Physical and Precipitating*** factors.

- ➢ Psychological factors define the emotional state of mind, feelings and thoughts, mental state, actions and other cognitive features that affect the view of how the human mind reacts and functions. In this study, the main psychological factors refer to stress mainly in the participants' working situations and personal relationships (18).
- ➢ Physical factors on the other hand deal with the provision of what is essential and necessary for good physical health, well-being, preservation and protection of the human body which in this study is the physical activities performed by the participants like training and exercise, nutrition and diet (19).
- ➢ Precipitating factors are for the purpose of this study defined as elements that cause, activate or add to the incident of an illness or condition which in turn elicits a behavioral response. They are both internal and external (20, 21). Precipitating factors trigger patients to change their perspectives as well as create awareness in relation to how they can cope with the symptoms attributed to an illness and condition like MS.

MS has a huge impact on an individual's sense of self and worth. An absence of a positive change in the aforementioned factors as well as other practical limitations may lead to a huge sense of loss of self, loss of enthusiasm for living and depression, especially when the individual can no longer perform activities that were formerly valued (22). It thereby becomes necessary to re-assess and re-define one's self-image in order to deal with the limitations imposed by MS. Each time the patient experiences a new loss of utility or self, this sense of loss has the chance to be improved (22). Psychological, physical and precipitating factors builds up this chance by influencing patients mentally, socially, physically and psychologically which in turn impacts decisions, routines and relations in their day- to day living with MS.

In the following analysis

- **Table 1** and later **Table 2** summarize the self-care strategies and solutions applied by the study participants. The tables are further explained in the text.
- **Direct quotations** from several of the participants are used to further illustrate the themes and subthemes that were derived in the analysis.

Table 1: Self-care strategies to live better with MS

Factors resulting in positive change	Self-care strategies applied by the participants to live better with MS
Psychological Factors	➢ Limiting the impact of stress on their daily lives, resistance and self-initiative ➢ Prioritizing ones needs and values ➢ Set limits and goals and focus on them. ➢ Priorities in Job situations. ➢ Appreciating and upholding the positive aspects of life ➢ Making constructive use of precious time and energy
Physical Factors	➢ Important changes in physical and mental activities ➢ Positive changes in diet/nutrition ➢ Focusing on physical needs, aspirations and abilities ➢ Engaging in trivial vocations and interests ➢ Curbing destructive and detrimental habits
Precipitating Factors	➢ Triggered awareness ➢ Internal and external strategies ➢ Building up social and emotional as well as financial support ➢ Maintaining mutual/ beneficial relationships ➢ Maintaining a positive self-image ➢ Surrounding oneself with positive energy ➢ Valuing family members, work colleagues ➢ Re-evaluating personal values and friends

6.3 Psychological Factors

6.3 1. Reduced Stress

Managing stress was one of the main self-care strategies for most participants. Almost all of them emphasized that managing stress well was a vital part of gaining an acceptable degree of well-being. Many were not only coping with the symptoms of the disease, but also with other "normal" life events like work situation and personal issues like divorce, family matters, loss and other additional problems. As many as a third of the MS patients in this study directly expressed that less stress generally had a major effect on their lifestyle. One patient put it as simply as:

> *"MS and stress do not belong together …" Patient 44*

Another equated:

> *"… Less stress = weaker symptoms …" Patient 13*

Many believed that stress escalated their MS symptoms. Managing stress was described as a form of physiological and mental health promotion. Two patients described their experience as:

> *"I have noticed that I feel good when things are going well at work, without much stress, stressful period gives "heavy/tired, legs…" Patient 28*

> *"I have learnt that resting is very important. I have attended yoga courses for more than 10 years and practice relaxation and meditation. If I do not get enough rest, I become tired and weak, especially in my legs. I am better now at not allowing stress and worrying to take control. Sometimes it is not so easy to avoid and I have negative symptoms. I eat normal and healthy meals and have cut off wheat – especially in cooking. I feel that I have to also cut off sugar, but it is not so easy … the most important thing for me is mental…" Patient 62*

Looking at the issue of stress from a scientific point of view, the association between MS and stress is a vital one. MS is generally known as an auto-immune syndrome, whereby the body assaults itself as if it is an alien aggressor. This aggression leaves the scars and lesions that appear most often in scanned (MRI) test results (23). Therefore, if these patients react negatively to stress, their symptoms of MS intensifies and becomes much worse. For most of the participants in this study, reducing the amount of stress helps to avert setbacks and prevent relapse and episodes of this condition. Some patients expressed that they had to make radical changes in almost all aspects of their lives as well as to their physical environment to avoid stress:

"I have divorced my husband, changed my diet, I rest more than before, meditate, avoid as much as possible any situation that stresses me ..." Patient 14

"I have moved to the mountains in calmer surroundings with nature … make sure I avoid stress, focus on things that work but at the same time accept that which is difficult and painful…" Patient 1

"I sold our old house, bought a new one and have a new and safer environment/existence …" Patient 55

"I have taken two trips to the South since I was diagnosed; I am in so much better shape down there!!! ..." Patient 25

Other patients had to make personal conscious efforts to change their lifestyles in order to reduce stress:

"It is clear that my attitude to a lot of things has changed. I am not so "particular" with simple things like car washing, house cleaning, painting the house and such things …"

Patient 11

"I have reduced a lot of tasks - I relax more …" Patient 10

"The most important for me is that I "take it easy more often" even though today I do a lot of strange things, I did much stranger things earlier…" Patient 12

According to the theory of change as a central factor which would be looked at in *Table 2*, the changes narrated may be interpreted as positive changes. These refer to the overall strategies and decisions made by the participants that had experienced a positive effect on the course of the disease.

6.3.1.1 Job situation

With regards to reduction of stress in job/working situation, priorities differed among the participants. Not surprisingly, having a job seemed to be important, most often to avoid financial stress. For a few however, their main argument was that not having a job was related to stress because working helped boost their self-esteem and self-worth:

> *"I have very little desire to stop working, even though I understand that working drains me of the little energy I have …" Patient 59*

For some, working outside the home had more of a positive effect on the way they handled and managed stress and other stressful situations because it gave benefits such as salary, health benefits, and retirement options. It provided a more predictable and stable future for them as they did not have to worry about their financial stability and status. This pertains not only to the participants but their family and loved ones like wives, husbands, children and other extended family members as well. However, for most of the participants, having a full-time job was experienced as very demanding and therefore also stressful. Based on such experiences, most had to make changes in their work lives. The changes ranged from reducing their working hours to retirement or resignations. Participants with different reasons but the same views on work as being too demanding and stressful narrated:

> *"I had to leave a very demanding middle-leadership job to work in a counselling job that is not so demanding all the time…" Patient 22*

> *Stopped working – rest a lot…" Patient 59*

> *"I have reduced my daily activities considerably… on 50% disability discharge, adjusted my work…" Patient 61*

> *"Radical changes in my working situation (because of the need for) … stress reduction …" Patient 63*

Two patients had different perspectives on the effect of not having to worry about their financial situation, but were both in agreement that this helped them to focus more on their illness:

> *"Unusual stress at the end of 2004 could have led to an attack in the New Year, sick leave, rehabilitation and disability that started immediately after the diagnosis can have given calm and stability of the sickness lapse …" Patient 20*

> *"I got my pre-pension funds. Without this I would not have the TIME to work with my disease to get better as much as I do. I got paid 100.000 kroner from a fund for "chronic illness". Without this money I would not have had the economy to do all the efforts to get healed that I did…"Patient 48*

Of the 78 patients in the material, about 30 attributed one of the reasons for living a better quality of life with MS to their change in work situation. In summary, most of them agreed that stressing less, reducing their work hours and having more time to rest led to fewer attacks and episodes of fatigue and thus to better health and quality of life in their everyday lives with MS, although most considered financial stress due to less income as a burden.

6.3.2 Personal relationships

This category as shown in *Table 1 (Pg. 19)* relates to consciously appreciating and upholding the positive aspects of life. In this study, this ranged from participants changing their mind set to making drastic private changes in their personal lives especially in order to achieve a better, less stressful lifestyle and atmosphere in which they were able to focus on living better with their chronic illness. Many participants felt that this was crucial in dealing with the challenges of living with MS. Like some participants described:

> *"I have taken responsibility for my own life and health. … I spend a lot of time on my own psyche and getting to know myself for better or worse …" Patient 37*

> *"I am determined for my life to be as good as possible, considering my situation before, I have accepted that I cannot be the way I was before I was diagnosed with MS…" Patient 12*

"I see myself as responsible for my own life and health. I have made my choices and my body has responded to them …" Patient 36

"I was divorced in 1998 so I could focus on myself, and what was good for me …"Patient 8.

"Came out of a bad relationship in 1992 and into a good relationship in 1993– my current one …" Patient 9

"Got divorced so I can steer my life in an appropriate way in relation to my illness ..."Patient 35

These statements not only showed that the participants had to make personal sacrifices to try to battle their illness, but also to accept that they had to take radical steps in their personal relationships to make the best of living with their MS. This further demonstrates how these various strategies are interwoven. Some patients had to make priorities and they identified issues that merited their attention from issues that did not:

"I have become better at saying stop and not let myself get stressed … whatever I was not able to finish today, I leave until another day …" Patient 8

Some participants in this study meant that MS gave them a new perspective and made them view their situation in a different way. They expressed that it was of crucial importance that they prioritized their goals. This assures that personal effort was allocated to more important activities and that less important activities were perceived as insignificant:

"I set limits for activities (limited my workload) Think positive! Alternative treatment has taught me to put the positive sides of my existence in focus …" patient 17

Another participant concluded by accepting the fact that she has to live with her MS and thus needed to change her focus to learn to live a better life with this lifelong condition:

"I have learnt to live with MS. I cannot be bothered to stress myself either physically or mentally. I have learnt that resting is important. I do not walk if I can drive a car. I am willing to spare the little energy I have. That stress, worries creates a negative impact on me. I ignore the little things that do not matter. That all conflicts can be resolved somehow, if not, they are not such big conflicts after all …" Patient 64.

For some patients, having social relationships were regarded as central to the experience of high degree of quality of life, both in terms of receiving love, support, and validation of themselves and in terms of the satisfaction of caring for others. For some, the social relationships in their everyday life with MS were perceived as really positive:

"I was a partner to a strong care-needing wheelchair user who also had MS. This led to me being better in disposing my apportioned energy." Patient 2

In some cases, personal relationships were threatened by the disease and some had to leave partners or sacrifice bad relationships in order to get better.

"I got a divorce in the same period from a man I did not have strong feelings for. He did not allow for any form of emotional outburst at all" Patient 12

In other cases, children were turned to caregivers as they had to sacrifice either their social lives or education to take care of their ill parent:

"My daughter had to quit school at the age of 17 to stay home with me as I could not take care of myself. She was with me for 5 years until I went to the old people's home in 1997…" Patient 11

However, most participants focused on the positive aspect of having a social relationship as being crucial in living a better life knowing they have MS. One participant stated:

"Feel that my family and friends have become more positive in relationship to me. I feel that they both admire and respect me because I have a hold on things and do everything to keep myself healthy. They are all happy because I am healthier, happier and a more positive person …" Patient 26

As many as 56 of the 78 participants directly expressed that they had to go through some kind of self-initiated changes with regard to prioritizing personal and private relationships, as well as establishing meaningful ones in order to establish and live a better life with MS.

6.4. Physical factors

6.4.1 Training/Exercise

Physical exercise had a favorable and beneficial effect for most of these participants living with MS. This included improvements in their temperament, discomfort, pain, fatigue, quality of life, sexual performance, recreation, and psychosocial functioning. The level of training or exercise varied from patient to patient, with a few not training at all:

"I sleep and rest as much as I need and want … I cannot be bothered to exercise". Patient 56

Going for "normal trips" outdoors and steady work out in the gyms were important to several of the participants:

"… take care of myself, stay in good physical shape, make trips out in nature a lot, go for nature walks in the mountains during the summer and winter, pay attention to my body signals …" Patient 27

"Training and physical activity for 1-2 hours, 3 times a week …."Patient 55

"Conditioning, physical and muscle strength helps me have a better everyday life …" Patient 54

For some participants, training not only included physical aspects, but also mental. One of them believed that physical training on its own was not sufficient to help live a better life.

"I meditate daily using Silva methods training. These mental tools have helped me a lot …" Patient 15

"Exercising at nnn center-> gives energy. Psychosomatic treatment, less pain for some hours. Water therapy/training at nnn center -> less pain for some hours, Positive social company. Adult education at nnn -> Important to Train the brain and fingers (English, PC, song/music) -> gives a good feeling of mastering something, care school!!!!!!" Patient 19

"Exercise, make trips out in nature, yoga, flexible job (part-time), play music (…, guitar and violin) diet …" Patient 39

Other aspects could include physical therapy, swimming and riding, enrolling in music or dance classes or taking part in activities that could stimulate the mind and other senses as well as other structured training. Some participants felt that hiking and other kinds of walks were enough exercise, as they had experienced that it was important to set limits based on bodily signals and how much the body was able to handle in order to best manage the symptoms of MS. About 20 patients out of the 78 included in the study attributed physical activities directly to the positive effects on their quality of life with MS.

6.4.2. Nutrition/Diet

When it comes to nutrition and diet, the majority of the participants turned to different dietary programs/advisers and/or CAM practitioners for help. Their main motive was the desire to try anything that might contribute to better health by representing a better and healthier alternative to their existing habits. Many of the participants changed their diets and gave up types of food that they believed were more or less detrimental to their health and well-being. One patient gave a detailed narrative of the self-initiated changes she had made to her diet as well as other personal aspects in order to improve her well-being:

> *"… I do not drink milk, alcohol or caffeinated drinks. I eat vegetarian meals and take vitamins and supplements. I practice Q-link. I am interested in body/ psyche and am doing further research; I read up on topics and integrate them in my life. It gives meaning in my life. I have, for example, changed my diet myself based on all the information I have found myself. The same applies to my discovery of my B12 deficiency and the treatment that followed. I am convinced about the connection between the body and soul and in relation to that I would like to mention that I have found things that make me enthusiastic. (Riding, writing) and, through this enthusiasm and engagement more energy comes to my mind and therefore also to my body. Both because there is something to live for and because my body it is doing better when I am happy. In any case I have generally found a way to balance physically so I don't lose energy by dwelling too much on negative feelings. It is like describing a physical mechanism but as I have experienced, it works as usual for me to "keep myself on fire" by setting goals and focusing on them. What I can and will. With relation to the possible effect that my condition is getting better, I notice that I have to open up to unresolved feelings that I have hidden away so that I can use all my energy on my physical well- being and to create a new life …"Patient 35*

Some other participants changed their diets to certain diets recommended by specialists to help battle some of the symptoms of MS and increase their quality of life. For instance, one patient was convinced that her change of diet was a very important aspect of the positive change she had experienced in her well-being:

> *"In consultation with Dr. Birgitta Brunes I have changed my diet with advice from the MS-center at the (nnn) hospital. ...I have stopped with red meat, fat and milk products. From the autumn of 2008 I cut out all sugar and yeast, according to the diet of Ann Borrak, Also artificial sweeteners and natural sweeteners, for example dried fruit and normal fruits. This autumn I have been in really good shape and believe that this diet is an important reason for it …" Patient 60*

Another participant attributed her increased well-being to her change in diet only:

> "*I started with a diet change after the introduction of the MS diet in Hospital in nnn. I was admitted after a long-standing attack. After a change of diet plan to the MS diet, I have not had any significant attack since. I therefore believe that the MS diet plus the right amount of vitamins, oils and minerals reduce the sickness activities. MS diet is infection reducing …" Patient 40*

Some of the participants, however, did not consult any dietitian or specialist or used such professional advice, but changed their diets based on what they themselves assumed were healthier options than what they were used to:

> *"I have stopped taking milk, pork, food with seasoning. I am convinced in the food direction ..."Patient 44*

> *"I eat using the plan of MS diet (not fanatically), I take fish oil as a supplement, I train, exercise to the extent I am able to, mental training ..." Patient 40*

> *"I have changed my diet. I do not eat pork. Eat a lot of fish and lean meat (moose). Less sugar and fat. Lots of fruits and vegetables. Lots of omega 3 and vitamins. My thinking is very healthy. Keep myself in good physical shape …" Patient 25*

> *"I take a lot of very different vitamins and minerals at a daily basis and I eat diets that are poor in saturated fat and very often fish. I also swim once a week and work out a little at home every day to the best of my ability …" Patient 29*

Other participants believed that their former bad nutritional habits might have contributed to worsen the symptoms of MS. Ending these habits thus would help to improve their everyday life with the disease and increase their wellbeing. For example, the following four patients who earlier had different bad habits experienced positive health outcomes from self-initiated change of their habits:

> *"When I go to a party and for example have been drinking, it takes longer for me for the alcohol to go out of my system. That is why I have to eat healthier, drink less – exercise more the more energy I would have …" Patient 27*

> *"I have taken control of my life and health. I let all the food/ nourishment – all that I put in my mouth - be my medicine. I also use a lot of time on my own psyche to know myself for better or worse. I am willing to spend money on natural diets that give my body nutrients and energy … Patient 36*

> *Daily omega 3 has given me a better concentration and less joint pains. Abstaining from sugar has removed the pain in my neck and back …" Patient 67*

> *"I eat more vegetables; I do not drink so much beer or spirits ... I eat more vitamins. After my last attack (three and a half years ago) I started working part time, it has given me more time for treatment (including diet) and extra rest …" Patient 28*

As many as forty-six of the 78 participants credited their healthier lifestyle and general well-being to changes in their diet. Generally, good nutrition has the potential to enhance and improve quality of life and well-being and thereby reducing the possibility of lifestyle diseases and secondary illnesses. An exploratory investigation online using the search words "*multiple sclerosis*", and "*diet*" came up with an estimate of about six million references relating to these terms! This clearly shows that many nutritional diets and plans are extensively used and strongly endorsed in the general MS user circles. However, no productive effects from any definite or specific diet have so far been confirmed in the scientific literature. Therefore, the advice given in most of such studies is that the general guidelines related to diet and nutrition should be followed, adhered to and sustained (24).

6.5. Precipitating Factors

Precipitating factors refer to the internal influences like fatigue, stress and external influences from the outside environment that affect patients in a cognitive way. These factors may affect patients mentally and lead to changes in their personality, as well as impact their social relationships and the environment which includes their close family members and the social circles they are part of. These factors either contribute positively or negatively to their symptoms of MS. In this study, participating factors created an awareness in the participants which triggered strategies both for the internal and external aspect on how to cope with MS as well as having a better and healthier lifestyle living with the illness.

6.5.1 Internal strategy

Twenty-two of the 78 participants attributed a positive effect on their quality of life with MS to the internal and external self-help strategies that they adopted. Many of the participants described a situation where they had to step up and make decisions regarding what was important and then take the necessary steps to prioritize it. For some, it involved making choices about their personal lives, acceptance, improving their self-esteem and self-worth as well as changing their mind-set. Most participants also had to adopt a personal strategy for how they looked at and were going to cope with MS. Different participants emphasized various points in their strategies:

“*I am convinced about being aware of the mental state and to make sure I fill every day with positive things, and LOTS of joy contributes to make the days and life better. I am pretty sure depression and heavy thoughts have a negative effect on the infections in the body.” Patient 68*

“I have admitted that I cannot do the same things as before, but I have also become older …” Patient 6

“I try to live with the sickness and not fight it … avoid meeting ’walls’…” Patient 2

One of these participants described her strategy and the effect of planning on how to cope with MS like this:

> *"I have constant strong pains in my left foot and underneath which makes me very tired. Therefore I am good at planning what I will do. It is almost like a puzzle where until you put a piece, you cannot take another piece out. Before I lived impulsively and in higher gear …" Patient 5*

For most participants, however, it was as simple as one patient put it:

> *"I have learnt to listen to my body …" Patient 14*

6.5.2 External strategy

For some participants, the most important self-initiated self-care factors were external. External strategies refer to the stress placed on the participants in certain circumstances by people around them as well as their environment which in turn negatively affects their perceived level of stress. External strategies led these MS patients to create a better atmosphere that was less stressful, and for one patient (*Patient 73)* it also involved moving to a better climate. For other participants, however, the natural environment was not a major issue. For them, maintaining a social relationship was central to their well-being and coping with MS. Some of these participants dealt with huge losses in varying aspects of their social lives which were not at all positive. One male patient narrated his ordeal:

> "…*Divorced…which had a negative effect on me and my children, relocation which had a negative effect on me and my children, thrown out of the house by my wife, negative effect on me and my children …" Patient 62*

For most participants, the positive effects far outweighed the negative as most of the strategies they adopted both internally and externally contributed to a better well-being in their living with MS.

6.6 Minor themes related to positive change

Other sub themes that emerged in this analysis included patients that articulated the importance of consciously boosting the positive areas of their lives by sharing their spiritual beliefs. A few participants adopted pain controlling strategies by using psychosomatic treatments for reduction of pain as well as gave up bad habits like smoking and excessive drinking. Although these patients were in minority, these changes represent important empirical examples of factors that may become important self-help strategies to attain better quality of life in MS patients and other patients living with chronic illness. Like one patient summarized:

> *"I have allowed myself to rest more, become happier in everyday life, appreciate everything in my life, ask for spiritual help and listen to messages from the spiritual side …" Patient 4.*

In summary, these various themes illustrate a central challenge of MS, which is how to adapt to the illness while at the same time preserving an acceptable, satisfying lifestyle.

6.7 Complementary and alternative medicine

As described in the materials section, the sample of MS patients in this study included satisfied users of complementary and alternative medicine (CAM). For many of them, CAM was an important strategy of self-care. Most of the participants turned to CAM because they had in one way or another experienced severe side effects from the conventional treatments that they had received. For most participants, the use of CAM was a way to take control of their lives, solidify and reassess their efforts and in this process, better understand and cope with their MS. For the participants in this study, the use of CAM included a number of practical applied therapies, exercise, vitamins, herbal and mineral supplements, relaxation practices, meditation, acupuncture and massage. Their reasons for CAM use were that they felt that they needed these treatments to try to cure or live better with their MS symptoms which involved pain, weakness as a result of fatigue and last but not least, and a high degree of stress related to different aspects of their living with a serious chronic disease. Two patients perceived the support and self-help from their use of CAM as the main reason for their increased well- being:

"Locked to reflexology, therefore had to change my diet. I eat just cod, lamb, chicken and fish. I eat hyben powder after which I slowly gained more energy. I take Omnimin, Dal-C- min and EPA.GLA daily for the past 8 years. Practiced yoga for 10 years, and in the last 2 years, twice weekly…Patient 9

" A change of diet with a combination of reflexology + acupuncture, once a week , exercise in a training center with help from a physiotherapist twice a week, I go to yoga once a week, …" Patient 49

One male patient had lost his ability to walk properly, and found in this stressful situation that his use of CAM helped him to cope better with different aspects of his changed life with MS:

"Better Balance, physical energy, reduced urinating at nights, waiting for the medicine LDN to give me back my walking function…I take daily walks indoors with my wife…"Patient 45

6.8. Summary

6.8.1 Self-initiated change may positively affect quality of life in MS patients

All the participants in this study seem to have developed positive self-care strategies for living a better life with MS. Almost all participants described their quality of life as better than, or at least as good as, average in comparison with the general population. The results suggest that self-initiative is strongly linked with professed control, with *change* being a central and defining factor. Self-initiated change thus seems to positively arbitrate the relationship between the effects of having MS and quality of life. These findings of the study are summarized in *Table 2*:

Table 2: Self-initiated Change and Positive Impact on Quality of Life

Issues arising	Prioritize Plan Perception Result/Solution	Changing priorities Adapting to changes identified Identify resources available Planning ahead
Positive change as a central factor	Sentience/Awareness Strategies Practical solutions Re-evaluation	Self- initiative to take/ make decisions Elimination of stress triggers both internally and externally Valuation of benefits Moral/financial support

7. Discussion

This paragraph discusses the study results against relevant theoretical perspectives on coping with chronic illness and earlier empirical studies relevant to patient initiated self-care in patients living with MS. The discussion also debates the limitations and precincts as well as strengths of the study and its possible consequences to education and public health care programs. How can an ailing patient with a chronic illness like MS also live a healthy life with the disease? As corroborated and proven by the participants in this study, one of the main answers is by choosing a behavior and action that will promote health. The World Health Organization (WHO) views health as "the *optimal level of function and well- being within the possible* *limitations imposed by a physical or mental impairment."* (25, p. 3). As MS changes or even progresses, the overall physical and emotional capacity can be fostered and improvement achieved within realistic goals. Taking control of one's life through self-care and personal initiative in order to enjoy the full advantage of good health is important irrespective of having MS or not (4, 25). One of the goal and objective of this thesis was to see if the routine day-to day self-care of a chronic and prolonged condition like MS, lies in the hands of the patients, their mindset and personal initiatives to live a better life and thus is not initiated by medical benefactors and their counterparts. The study also investigates whether self-initiated health is effective in handling multiple sclerosis from the patients' point of view. If so, should self-initiated change then become a teaching focus in the education of patients and health care specialists in order to lessen disability and ill-health, thus improving health effects and their outcomes? The results of this study suggest that the self- initiated changes made by the participants helped create positive effects on their day to day well-being and coping in their individual lives with MS. How important then is the role of such self-initiated health care in the management of MS as seen from a patient and public health perspective?

7.1 MS patients' self-care response to illness and changes important in achieving their goals

I began this inquiry with the aim of gaining a better understanding of important and under-explored issues related to self-care and multiple sclerosis. I hoped to learn from the study participants the importance of self-initiative in living and coping with MS, the challenges they eventually encountered in their daily lives and community/context, as well as the strategies/ changes they applied into addressing and dealing with such challenges. In line with the results of this study, other studies show that for patients with MS, the management of their long-term condition significantly alters their everyday behavior on a constant basis. Although some MS patients have reported positive results from medical treatment, most are left with problems of adapting, coping and living with their illness. Personages and their families must also adapt to their lifestyle and regular public relations to lesser than average health grade (26, 27). Some participants may have asked their physicians, other self-help groups, and/or CAM practitioners for advice. The general agreement for the majority of the participants in this study, however, was to resort to self-care routines or strategies that they themselves had developed, assessed and found to help, or believed may help lessen the manifestations of the disease. The *varying insight* of these participants confirmed the complexity as well as showed how interwoven the personal strategies they used were. The changes they made in the management and coping with MS by using different self-help strategies included the use of CAM and had a positive effect on their well-being and quality of life. Most of the narratives by these participants showed that changes made in their diet, exercise, job situations, personal lives and environment were interwoven with each other and were all important in the attained effect to live better with MS.

In most of the research on MS, the focus has been on the physical facets and provider-initiated treatment rather than self-initiated strategies to live a better life with the disease such as those explored in this study (6). Over the last decades, there has been a growing interest in coping with chronic disease, with the so far existing literature mainly referring to *teaching* of self-care and coping strategies to patients. This study, however, addresses what characterizes *patient initiated* self-care practices of MS patients, and focuses on the importance of such patient initiative in self-care to strengthen the patient-evaluated quality of life and sense of well-being.

So far, patient initiative in self-care among MS patients has been closely connected to MS patients’ widespread use of CAM. A qualitative study on MS and coping among users of CAM showed that MS patients using CAM were more active in handling and coping with their disease and reported better self-evaluated quality of life than MS patients who were not using CAM (6). Most of the prior studies on MS and coping are centered on QoL-questionnaires, and focus on enhancing the information and mediation programs in the conventional health care system. It has been argued that qualitative research on MS and coping, like this thesis, is necessary to complete the picture of the complexity, flexibility and evolution of the patients' coping strategies (6, 28). A recent mixed methods study on the use of CAM among Nordic MS patients confirmed the importance of patients' self-initiated use of CAM as an important factor in self-care and its' self-reported positive outcomes (28).

7.1.1 Results of other scientific studies on self-care in the management of chronic illness

A thought-provoking qualitative study compared and differentiated self- initiated self-care practices of 51 Danish and 35 American patients with MS at their varying stages of disability and periods of incapacity (27). The outcomes showed that the most common self-care behaviors were due to lethargy and fatigue, weakness and depression which are comparable to the behavior and actions of the participants in this current study (5, 27). The most recurrent self-care practices for both the American and Danish participants were also similar to this study in terms of the patients learning to recognize their limits, planning activities when one has the most energy, and organizing and planning to conserve energy and get enough rest. There were also similarities found in the concerns about the advancement of the disease as well as loss of independence. This suggests that what motivate patient's self-care initiatives is their need to take charge and gain control over the everyday life with the disease and their feeling of uncertainty about the future. The authors conclude that the empowering role of self-initiated self-care strategies in chronic disease may rise above and beyond the dissimilarities in health care organizations and their services (27).

A current analysis piloted by the Department of Health in the UK surveyed people's approach to self- initiated care. This study estimate that about 77% of all participants answered that they lived a healthy way of life, of which 82% of those with long term illnesses acquiesced to take a dynamic and active part in self-care (29). The survey also revealed that patients in disadvantaged societies and cultural-ethnic interest groups showed little or no interest in taking an active role in self-care, although there was no link between deprivation or ethnicity and self-care in patients with long term illnesses (29). However, there was some indication of a breach between insight on the part of the Department of Health as to what really constitutes self-care as patients reported low levels of specific targeted self-care conducts like for example taking part in sporting activities, simple procedures like drinking water or consuming five servings/portion of fruit or vegetables. Nevertheless, all the patients reported a heightened interest in self-initiated care, which they agreed involved leading a healthy lifestyle, as part of a bigger picture in managing and treating major effects of their condition as well as taking care of protracted infections and their causes (29).

Other individuals that participated in the same survey revealed another interesting subject matter known as "*barriers to self-care*". The survey characterized the main obstacles to self-care as *time* and *money*. Other obstacles to self-care were absence of knowledge about health, shortage of equipment, an inadequacy of health or treatment information and knowledge, disinterest, little or no self-esteem or confidence, shortage of training and skills, complex or differing information, and a lack of support from primary care authorities and professionals. Those with debilitating health or prolonged illnesses were more likely to report that absence of backing and support from professionals was the main barrier. According to their opinions, factors that would assist self-care included an improved knowledge of health conditions and their treatment, more advice and boost from health specialist and professionals, more information or equipment, and expert training and courses (29).

Another interesting quasi-experimental study done in Iran to assess the effect of self-care on quality of life of patients with MS showed that teaching programs in self-care strengthens physical ability and would positively affect quality of life in terms of the patients' private and social lifestyle, their economic position and environmental relations and its factors (30). In conclusion, these studies suggested that information and knowledge are likely to be key factors in any effort to increase self-care actions among the public, supported by the work of health authorities and experts (30). These findings are also recognizable in this current study, but a major difference is that the MS patients in this study laid emphasis on the importance of *self-initiated* approaches to cope and live better with their MS symptoms. This is in line with Scandinavian studies underlining that change cannot be implemented from the outside – it demands involved, active and motivated patients (6, 28). This brings us to another important issue, namely the patient perspective on management and handling of MS.

7.2 The importance of the role of self-initiated health care in the management of MS as seen from a patient- perspective

Patients living with prolonged diseases and conditions like the participants in this study face an extensive amount of trials which includes medical predicaments, how to manage and control their symptoms, and varying degrees of societal isolation and segregation (7). From the patient perspective, however, MS is perceived as a long term illness that interferes with important aspects of ordinary and routine life that have been up till that time, taken for granted. To be able to adjust and adapt to this disruption, the patients have to face the challenges related to their illness and how to deal with them in their individual situations and contexts. These patients can either choose to relegate/segregate themselves from the rest of the society or decide to accept their condition as a principal part of who they are and their personality (7). The ways that these patients cope with and manage their conditions may differ from where they come from (background), their socio-economic statuses, their private and intimate understanding and experience of living with a long term chronic condition, their local milieu and their domestic and family engagements (7).

For the MS patients in this study, their self-initiated role in managing the symptoms attributed to MS and the disruption caused by MS in their everyday lives cannot be overestimated. For many, the changes in their lifestyles, exercise, diet plans, private lives and increased self-esteem have been very successful factors in significantly improving their quality of life and sense of well-being, which are important factors in patients' self-evaluated health despite disease symptoms. According to this study, the role of self-care as seen from the patient perspective can be fundamental in living a better life with a serious, chronic disease. The majority of the MS patients in this study may significantly have reduced the chances of developing long-term complications by improving their self-care activities. It is reasonable to think that patients who understand more about their condition, like the patients in this study, may also show closer amenability with "provider-initiated" cure. However, in order to help patients become active participants in their own care and to enable them to achieve the positive changes necessary in managing the disease, it is important to ensure that persons living with chronic disease have the necessary self-care skills and accept and support for self-care activities in the public health care system to prevent complications. These skills can be successfully supported by programs in public health care as long as the patients are given the opportunity to be active and take part in both decision making and the implementation process (6, 31).

7.2.1 Limitations of self-initiated care in the management of MS

Although the importance of self-care are increasingly understood and supported by health care professionals and public health programs/white papers like e.g., the recent Norwegian white paper *Future Care* (32). Self-care still often causes a strain between the patients 'autonomous rights and the health care providers' professional responsibility in the provision of evidence based care. These tensions are reflected in professional concerns about the need for monitoring of patients with long term conditions and for professional contribution into courses such as "*the expert patients programme*" (7). Self-care teachings like those given in this program can offer a wide range of services, but there are also concerns that such programs may take an unsatisfactory account of patient unpredictability. For example, some patients with long term conditions develop stories that highlight their positive adjustment to their illness. This may for example be the case with the participants in the Registry reporting positive health outcomes (6, 33). Health care professionals may place boundaries on patient participation and not engage with aspects of self-care outside their professional perspective (6, 7, 29). Further crucial obstacles and barriers to engagement with self-care as seen from the patient perspective include personal inconvenience of time and money, inadequate information and support from health authorities, sensitive reactions to long term conditions; target to modify behavior which is motivated by apparent benefits and shortcomings, social effects, self-efficacy, individuality and self-perception as well as the information and skills to support behavioral change (6, 7, 29).

Most of the participants in this study expressed that they had experienced unexpectedly positive improvements of MS symptoms that they related to their own efforts, including their choice and use of CAM. Based on studies on MS patients from the Registry, it has been argued in favor of a theory of successful coping for non-compliant patients with MS who themselves are aware of health-related change processes (6, 31, 33). It is important, however, that active patients who initiate self-care activities are understood neither as a normative patient standard nor as displaying patient behavior that can be controlled or developed from the outside (6, 31). Although changes in the public health care system may help most people living with chronic illness to cope with their illness and promote their faith in their own health resources, peoples' own efforts should never be a compulsion, both for ethical and moral reasons (31).

Patient-centered patient education should therefore be approached as the best way of communicating information and its meanings to the individual patient. This information can be approached from two different perspectives: An ideological and practical point of view (34). The ideological perspective stresses the role that information plays from the point of view of patient autonomy, self-esteem, and pride. For example, as far as health matters are concerned, the patient has the right to know. The ideological perspective can also be described as emancipatory. The purpose of information is to make patients aware of their health, the alternative treatments available, and the consequences. Evidence, knowledge and information also help to disperse the sense of uncertainty and insecurity that often comes with the onset of chronic and/or serious illness (34). As demonstrated and discussed in this study, the importance of control, self-initiative and meaning seem to be crucial for MS patients in their attempts to accept and live a better life with MS. These patient perspectives and how they best may be addressed in health care to improve health and quality of life can be theoretically analyzed in terms of Antonovsky's theory of sense of coherence.

7.2.2 Theoretical understanding: Antonovsky's notion of salutogenesis

The main findings of the study discussed here, may be further understood with reference to Aaron Antonovsky's (1987) well-established theory of sense of coherence, with the three components comprehensibility, manageability, and meaningfulness. This theory infers that a person with a high sense of coherence will find things understandable, have the means to manage challenges and find it substantial to use these resources to cope and move to a healthy state of both body and mind (35). Although numerous empirical studies on sense of coherence have been conducted, I have not been able to track any systematic review of this perspective applied in studies of MS and self-care. However, I argue that Antonovsky’s theories are relevant to the current study on the importance of self-initiated care to live better with MS because Antonovsky’s idea of salutogenesis may be analyzed and interpreted as a notion away from the standard pathogenic viewpoint. The pathogenic viewpoint mainly focuses on diseases, whereas the salutogenic viewpoint refers to an alternative understanding of the dynamics that keep people in good health or headed in the direction of healthy living (36). Antonovsky’s major question dealt with comprehending what factors that made some individuals who were dealing with stressful and difficult situations in both their health and lifestyles to stay healthy and why other individuals did not. His theories relate to a diversified and encompassing point of world view and can help us understand why and how people move towards health and cope more effectively with chaotic and stressful factors in life, e.g. when living with a long-term chronic condition like MS.

Antonovsky refers to an individual’s sense of coherence as a stress resource oriented idea**,** which consists of clarity, manageability, and meaningfulness and focuses on health, solution and problem-solving. To have the capability to care for oneself as well as the ability to change a personal lifestyle or life situation into a healthier one is to have *self-care ability* (35, 36). In accordance to this study, Antonovsky's theories confirm that there may be relevant alternatives to biomedical approaches to better understand factors that keep people healthy or keep them moving towards health, including various self-care strategies (6, 31, 36). MS patients' self-care initiatives may help them move towards health and cope more successfully with stressful factors in life. Such initiatives should as a consequence of this be acknowledged and initiated as possible important health care resources both in education of patients and health care professionals, in public health programs and in clinical practice.

7.3 Potential for support of self-care in improving the management of MS

Many people living with chronic conditions seem to identify themselves as being active self-care managers, who have to rely on a variety of support in '*undertaking*' the lengthy, extensive and often *'difficult'* work needed to cope and live a good life with a chronic disease like MS. The support for self-care is though still at its infant stage, but is increasingly viewed as a fundamental component in the management of long term conditions and as such serves as a salutogenic approach to health care (31, 37). This study suggests that supporting self-care can improve the quality of life in patients with chronic illness like MS, as for majority, self- initiated care has had a positive effect on their overall well-being and thus their quality of life. A number of studies have found a link between patient-centered self-care education, behaviors and psychological outcomes, stress, coping and quality of life. An evaluation of more than 550 scientific studies suggests that it is advisable both for to health care professionals and the public health system to show support for self-care, in particularly through focusing on behavioral change, self-worth and efficiency (38). While the outcomes of these individual studies are diverse and mixed, the totality of evidence suggests that supporting self-care can have benefits for people's attitudes and behaviors, quality of life, clinical symptoms and how they use healthcare resources (38, 39). Some studies suggest that the evidence for supporting self-care is only modest. This may be explained by the fact that a wide range of activity is described as '*self-care support*' and some of the interventions may be more effective than others. Previous analysis relating to the support for self-management and care have tended to combine initiatives that focus exclusively on how the information is revealed and accessed rather than on interventions that actively target the alterations in both behavioral facets and self-value. However, these varying interventions may have different results so combining them could resolve the outcomes (38, 39).

An active support of self-management has been said to have the potential of alleviating the pressure on health and social services caused by labor force deficiencies, rising demand for services, population increases and budgetary constraints. However, implementing these interventions is unlikely to make a significant impact on the overall health of the population or on the sustainability of health and social care systems (38). Self-care is likely to work best when implemented as part of wider initiatives to improve care through educating medical practitioners, applying best evidence, and using technology, decision aids and communal and municipal partnerships efficiently and effectively (38, 39).

7.3.1 Interventions/research showing support and limitations for self-care

Interventions relating to the support of self-care advocate for patient's individual and emotional construction of their own self-initiated health care program (37). This is in line with self-constructed knowledge bases on health, illness and treatment constructed by MS and cancer patients in the Registry (33). A possible intervention should be shaped in part by the culture and values of these patients. This would in turn have the potential to help determine the ambitions each person has in pursuing self-care strategies and the roles available for the health authorities and eventually public health care system in supporting them (31,37). The support that patients may receive from such interventions within public health care may have the capacity to explore the patients' overall capabilities (social, emotional and cultural). This is because the search for improved health outcomes may involve a delicate balance between supporting and helping to modify the ideas surrounding a patient's life with MS (37). The profits and benefits to be gained from self-care are ample and substantial and should not be overlooked. Nevertheless, for most of the patients in this study, self-care remains a positive factor in their day-to-day living with MS. However, self-care can and should be placed in a broader, encompassed setting of competent behavioral alteration and public assignation (7, 27, 37). A high quality study based on the support for self-care should involve the following assistance to its patients at all levels of health care management:

- Make available new and up-to-date data materials, information handbooks, manuals as well as health campaigns that are related to the patients' capability to deal and manage their chronic illness and the conditions related to it (7).
- Health care professionals should be educated in the different skills needed and they should take part in resourceful patient centered conferences, where updated information to manage the effect of the condition on their patients could be taught as well as to create a common tactic in handling decisions effectively (7).
- Sanctioning changes in the health service facilities to allow open admittance to out-patient clinic schedules and other sources of assistance (7)

Countries like the US and UK have developed high-prioritized patient defined programs referred to as *lay* or *peer led* programs as part of interventions to support self-care. However, such initiatives have yet to get the accolades they deserve as their effects have been scrutinized and queried (37). Issues related to minor progress in health condition and the low turn up of people in attendance to such programs suggested that such extensive, organized self-care programs might not be inspiring to individuals with chronic illnesses. Reasons given might have to do with patients believing that such programs are too sterile and complicated and cannot relate to the emotional complexities and needs involved in living a meaningful life with a chronic illness like MS (29, 37). One of the recommendations given suggested that support for self-care is best done through "*a trusted health professional in the context of routine service delivery rather than through classes*" (37, p. 3). This intimates that primary care should be an integral part of the support for self-care. This might not be the ultimate solution in addressing the issue of the unmet needs for both emotional and social support, but it is, however, an important start and has the potential of evolving if given the chance. Currently, with health care experts' increased accountability and devotion to evidence based guidelines for disease outcomes, its impact on encouraging patients' rights and control of their health state is a central part of their concern (29). Involved patients are also a main focus in recent Norwegian white papers (32).

Another challenge facing interventions relating to the support for self-care may be the concern that most health care providers might not be adequately equipped with the knowledge required to effectively and efficiently support self-care. It is assumed that health care professionals focus more on giving consultation than paying attention to core psychological and social issues of crucial importance to their patients. There is also the issue of health care providers diminishing the positive outcomes of self-care on patients which might impact negatively on how they cope and manage their situation (37). The key point here is that although the support of self-care by health care professionals may seem complex and time-consuming, it has to be valued as an important and effective part of health care. More effort should thus be put into finding a middle ground and creating a balance that would benefit both parties- the perspective of self-care patients and the perspective of health care professionals (37, 40)

Self-care support does need to be rooted within an ongoing affiliation with a trusted health care provider but a one size fits all approach will not do. Suggested recommendations to support patients' self-care efforts are open-mindedness and emotional concern not only for the effect of the clinical symptoms of this disease but also the psychological and emotional aspects that most patients have to deal with to be able to live better with their disease (29, 37, 41). Another significant way of supporting patients' efforts is to contribute to the effective doctor-patient communication with patients in general, and perhaps "deviant and non-compliant" CAM users in particular (6, 31). Health care professionals also need to interact with patients in a manner that is consistent with how they integrate self-care into their everyday lives, edifying and coordinating their own "self-care program." (41, 42)

7.4 Patient-initiated self-care and possible benefits to public healthcare systems

The support for patient-initiated self-care has been known to make significant contribution to health outcomes and quality of life. These health outcomes would not only be beneficial to patients and health care professionals, but will also contribute to the public health care system in general. The well-recognized "*Wanless report*" suggests that the prospective costs of health care are very much reliant on '*how well people become fully engaged with their own health.*'(29, p.3). This means that there should be a general recognition of self-care as one of the prime resources of a good health system (42). This study showed that most of the participating MS patients treated their symptoms through their own initiatives and efforts and paid for them out-of-pocket, sometimes in well-functioning communication with involved health care professionals.

8. Methodological Considerations

The results revealed in this study were based on open-ended questions from questionnaires filled out by MS patients participating in a registry collecting patient experiences from public health care and self-care including the use of CAM. Qualitative content analysis was used to analyze the written answers to open-ended questions selected from the questionnaire. The overall benefit of this selection strategy is the exclusive information gained about unusual cases that have been assessed by the patients as exceptionally positive courses of MS due to their self-care that included use of CAM. A weakness of this study can be the lack of generalizability. This effect can for instance be detected in our analysis of MS patients in the Registry as non-compliant patients coping with their MS through their choice and use of CAM, compared to compliant patients coping with their MS through the use of conventional health care (6, 31). Useful lessons may be learned, however, about unusual cases or extreme outcomes that are relevant in improving more typical public health programs (31). One of the backgrounds of this study was the need for more research on the underexplored knowledge on MS patients' self-care strategies as seen from the patient perspective. I tentatively suggest that this study with its explorative and relative perspective can provide new knowledge relevant to further research of the importance of the patient's self-initiated self-care efforts in regard to chronic and complex illnesses. Conveying facts as well as knowledge gained in qualitative, explorative studies as working theories in further research initiatives may epitomize valuable contributions on topics of which one has little earlier knowledge and where patients' perspectives and experiences may be the crucially relevant source to innovative knowledge (31, 43). The internal validity in this study was ensured through approval of the case presentations by the patients, by the researcher reading through and analyzing the data material of all 78 Scandinavian MS patients in the Registry and applying theoretical approaches to this material as well as comparing the results with previous studies done on MS and/or self-care.

9. Conclusion

There is a steady rise in health care costs and services all around the world due to the increasing prevalence of chronic diseases. This study have revealed that being an active patient who initiates and practice self-care strategies such as living a healthy lifestyle, avoiding stress and taking control over the disease seem to be a very important part of effective self-care leading to positive health outcomes for MS patients. To improve positive health outcomes, individuals, patients, public health authorities, and public health care systems will need to acknowledge the importance of supporting and developing patient-initiated self-care. Although the results of this study are tentative, the patterns and hypotheses are important knowledge from the patient perspective and correspond well with relevant empirical studies and theories about health and illness. The results of this study should thus be further explored through different research designs in the future. In this modern era of technology where there is unlimited access to information, and a public health focus on the involved and active patient, the self-management of one's health will clearly be part of future health care. It is my opinion that a "*patient own efforts*" model is here to stay in terms of a changed and strengthened patient position toward health care authorities, health care professionals and public health care systems. It is therefore important to follow the straightforward principle of patient initiated self-care which suggests that both the individuals living with illness and health care providers should focus and encourage the *theory* of what the patient *can* do and *want* to do in the situation and context he/she is part of, rather than what the patient *cannot do*.

> *"Everyone should be concerned about the future. That is where we will be spending the rest of our lives…"*
>
> Future Care: Ministry of Health and Care Services. Meld. St. 29. (2012-2013)

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APPENDICES