The dietary patterns of individuals with Multiple Sclerosis and associations with food intake behaviours

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Abstract

Background: Multiple Sclerosis (MS) is an autoimmune disease affecting the central nervous system. At present there is no known medical or dietary intervention which can significantly improve MS. However, other health issues (CVD, obesity, malnutrition) can be influenced by diet and have been frequently reported in the MS population. Symptoms such as; walking impairment, bladder and bowel dysfunction, depression, visual impairment, pain, fatigue, tremors and muscle weakness can interfere with the ability to prepare meals. This means that some individuals require assistance with meal preparation. Therefore, the primary aim of this study is to investigate the current dietary patterns of people with MS. It will also investigate if differences exist in the dietary patterns of those who prepare meals independently or with assistance, the prevalence of alternative diets and the impact of dietary patterns. Finally, this study will look at where individuals with MS obtain their nutritional advice.

Design: Participants (n=145) were recruited through the 18 MS societies in New Zealand. Participants completed an anonymous, self-administered, online questionnaire. This included demographics questions, a 57-item Food Frequency Questionnaire (FFQ) and questions surrounding meal preparation (prepared independently or with assistance), alternative diet use and sources of dietary information. Principal component analysis (PCA) was used to determine dietary patterns and independent samples t-test was used to identify associations with meal preparation behaviour and alternative diets tried.

Results: The three main dietary patterns identified were; ‘fast foods and processed meat’, ‘lean meat, fruit and vegetables’ and ‘sweet foods, sweet drinks and alcohol’. The fast foods and processed meats pattern was significantly more likely to be consumed by individuals who had lunch (p=0.024) and snacks (p=0.005) with preparation assistance. Conversely, the sweet

foods, sweet drinks and alcohol pattern was significantly more likely to be consumed by individuals who prepared snacks independently (p=0.030). At least 71% of the study population had tried an alternative diet. The fast foods and processed meats pattern was significantly less likely to be consumed by individuals who had tried a dairy free diet (p=<0.001), gluten free diet (p=0.024), MS recovery diet (p=0.003), vegan diet (p=0.005), vegetarian diet (p=0.007) and/or Swank diet (p=0.042). Those who tried the Swank diet were significantly more likely to consume the sweet foods, sweet drinks and alcohol pattern (p=0.048). Internet was the leading source of dietary advice (43%), followed by MS society (36%), family/friends (30%) and dietitian/nutritionist (21%).

Conclusion: This study indicates that individuals with MS in NZ have different dietary patterns depending on who was involved in meal preparation. It appears that meals prepared with assistance for lunch and snacks are high in fat, sugar and unrefined carbohydrates and care assistants should be involved in nutrition intervention. There is a need for dietary advice for both those who prepare meals independently and with assistance, but with a different emphasis. Individuals following alternative diets are less likely to consume the foods from the fast foods and processed meats pattern. This is possibly because they are more health conscious, educated and interested in nutrition. Individuals consuming the Swank diet could possibly benefit from nutrition advice as it appears that consumption of high fat foods is decreased, and the consumption of sugar dense foods is increased. Internet and family/friends could be potential sources of misleading or confusing information, but MS societies could be an appropriate channel for nutrition advice. The present study contributes to the development of foundations for investigating the dietary intakes and generating targeted health education messages in the NZ MS population.

Preface

This cross-sectional pilot study was conducted through the Department of Human Nutrition, University of Otago, Dunedin, New Zealand. The candidate's primary supervisor, Dr Katherine Black (University of Otago) was responsible for the overall Multiple Sclerosis study design and ethical approval. Co-supervisor Paula Skidmore (University of Otago) was an advisor to the project, assisted with the statistical analysis of the data and provided advice for this section of the methods. Jill Haszard also provided assistance with the statistical analysis and advice for this section of the methods. The Department of Human Nutrition funded this project. The candidate was responsible for the following under supervision:

- Creating the 'Multiple Sclerosis and diets' questionnaire as an electronic format
- Liaising with the 18 Multiple Sclerosis Societies via email and phone calls
- Responsible for the recruitment of 150 participants
- Continuing liaison with the MS societies throughout the 41 day period
- Responding to MS societies and participant questions and comments throughout the data collection period
- Summary report of findings provided to the MS society of Otago
- Cleaning the data ready for data analysis
- Interpreting statistical analyses alongside Paula Skidmore (Senior lecturer, Department of Human Nutrition, University of Otago) and Jill Haszard (Biostatistician, Department of Human Nutrition, University of Otago)
- Collection, entry and coding of the data
- Thesis preparation

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List of Abbreviations

Abbreviation	Meaning
BMI	body mass index
CNS	central nervous system
COPD	Chronic Obstructive Pulmonary Disease
CVD	cardiovascular disease
FFQ	food frequency questionnaire
GP	General Practitioner
MOH	Ministry of Health
MS	Multiple Sclerosis
MUFA	Monounsaturated fatty acid
NZ	New Zealand
PCA	Principal component analysis
SAFA	saturated fatty acid
UK	United Kingdom
US	United States

1 Introduction

Multiple Sclerosis (MS) is an inflammatory and demyelinating disease of the central nervous system (CNS) (1, 2). There is no known medical cure, so management is largely focused on symptom relief (1). Symptoms frequently presented include walking impairment, bladder and bowel dysfunction, depression, visual impairment and pain (3, 4). Symptom burden and increased disability restrict the individuals functioning, ability to perform activities of daily living and quality of life (3). MS has a prevalence of approximately 72.4 per 100,000 population in New Zealand (NZ), with a recent meta-analysis outlining this has been steadily increasing over the past 40 years (5-7). New Zealand is considered to be a high risk country, potentially due to its population's low levels of sun exposure (5). There are higher rates of MS in areas of low sunlight and in genetically susceptible European populations, than in other populations (8-10).

Unfortunately, the MS population experiences heightened vulnerability to obesity, malnutrition and osteoporosis (11-15). These health implications, combined with the effects of disability, hugely impact quality of life (4, 13, 16). The few studies of dietary habits and nutritional status amongst those with MS show that nutritional imbalances are common (13) and diets are mostly sub-optimal (12, 17-19). To the best of our knowledge, the dietary intakes of individuals with MS living in NZ have not been researched. A well-balanced diet in line with the NZ Ministry of Health food and nutrition guidelines is the foundation to decreasing the risk of developing obesity and chronic diseases (20).

Achieving a well-balanced diet is often difficult for this population (21, 22). Symptom burden and disability can impact the ability to prepare meals that are in line with the food and nutrition guidelines (20, 21). Those with severe disability who prepare meals

independently have been shown as having high intakes of ready-to-eat foods, take aways and convenience foods (22). On the other hand, meals prepared by caregivers and care assistance have been reported as lacking essential nutrients and the recommended food groups for adults with disability (23).

Dietary measures have repeatedly been proposed to alleviate symptoms and improve quality of life, yet evidence of their effectiveness is very limited (2). However, alternative diets remain popular in the MS community, with reports of 50-75% of people with MS using these globally (2, 13, 24). Alternative diets are used with the desire to regain a sense of control and/or anecdotal reports outlining success (4, 13, 25). Widely promoted diets include Swank, Kousimine, vegan, dairy free, hebner, raw food, low carbohydrate, gluten free, vegetarian, allergen-free and low fat (2, 13, 26).

Dietary information is commonly sought after diagnosis and these individuals are inundated with reports of diet assisting with symptom relief and reducing relapse rate (20, 22, 27). Common sources of dietary information identified in the literature include; internet, magazines, MS societies, GP, specialist, nurse, dietitian/ nutritionist, other health care professionals, homeopath and family/friends (22, 28, 29).

Diet plays an important role in significant health issues (CVD, obesity, malnutrition), but little is known about the current dietary practices of those with MS. Therefore, this pilot study will investigate the current dietary practices, use of alternative diets, meal preparation behaviours and sources of nutritional information among individuals with MS in New Zealand.

2 Literature review

2.1 Introduction

Multiple Sclerosis (MS) is a chronic neurological disease, with no known cure (1). MS is characterised by pain, depression, urogenital problems, spasticity, fatigue and cognitive impairment (4). Medications are taken to reduce relapse frequency and the deterioration in the amount of neurological damage (2). However, these medications are often unable to provide symptom relief, or improve functioning or quality of life (4, 30). This leaves many individuals with MS feeling as though they have an incurable disease with symptoms that negatively impact their quality of life and an inability for medical treatment to resolve or attenuate these symptoms (4, 13).

In New Zealand, the MS population shows that more women (3:1 gender ratio) and more Caucasians compared to other ethnicities being diagnosed (10, 31, 32). New Zealand is considered a high risk country due to the low levels of sunlight and resultant low vitamin D (2, 9, 10, 26, 33), as well as being a genetically susceptible population (34), leading to the current high and increasing per capita rates of MS (5, 7).

2.2 Dietary recommendations

There are no specific food and nutrition guidelines for individuals with MS endorsed by the New Zealand Ministry of Health. A ‘well balanced, healthy diet’ in line with the healthy eating guidelines for New Zealand adults is recommended (35). Dietary advice can be tailored towards symptoms that can affect nutrient intake such as; reduced mobility, fatigue, tremor, poor sight, dysphagia, cognitive difficulties, depression, pressure sores, and the drug-related side effects of nausea, vomiting, diarrhea, dry mouth and weight gain (36).

This tailored advice can be seen in the 'Eating guidelines for Multiple Sclerosis' formed by the Multiple Sclerosis society of Canada (37). These highlight 1) guidelines for a well-balanced diet, 2) practical solutions for eating and meal preparation which overcome symptom burden, 3) weight management advice, 4) symptom specific dietary advice and 5) the evidence behind popular alternative diets (37). Although these Canadian guidelines for a well-balanced diet virtually mirror the national guidelines for New Zealand adults, emphasis of the guidelines and tailoring the advice for the MS population is imperative. The effects of a well-balanced diet in the MS population can reduce health implications (obesity, malnutrition and osteoporosis) and may reduce MS symptoms (constipation and fatigue) (12, 13). The incidence, course and level of disability of MS is influenced strongly by comorbid medical conditions that stem from obesity (38). On the other hand, those with MS can also be affected by malnutrition, weight loss, dysphagia and osteoporosis (13). This illustrates the diverse range of health issues experienced by the MS population and the need for tailored advice. However, given the decrease in physical activity that most individuals with MS have, the need for nutrition to attenuate the risk of comorbidities and chronic disease is important.

2.3 Health implications

2.3.1 Obesity

There is a high incidence of weight gain and obesity amongst individuals with MS (11, 12, 39). There is growing evidence that people with disabilities are two to four times more likely to be overweight or obese than the general population (40, 41). Obesity is a serious health problem in the general NZ population and is set to overtake smoking as the leading cause of health loss by 2016 (42). Therefore, it is not surprising that people with MS are

among those affected. In fact, the risk of weight gain is increased amongst those with MS due to; immobility, low energy expenditure, steroid medications, anti-depressants, muscle weakness, fatigue and balance problems (13, 14). In view of the sound evidence that suggests that obesity can lead to cardiovascular disease, hypertension, diabetes and some types of cancer (12), this is a major issue for individuals with MS.

In the general healthy population, weight loss can be achieved through effective physical activity and diet (43). For individuals with MS, physical activity has also been shown to increase quality of life, improve depression, fatigue, pain symptoms, provide social support and self-efficacy (44). However, this is often not feasible for mild-moderately disabled individuals or those who are wheelchair bound. Some symptoms make physical activity and activities of daily life difficult, inducing a sedentary lifestyle (13, 43). This leaves nutrition as the key to weight control.

2.3.2 Malnutrition

Equally malnutrition, weight loss and cachexia are significant problems (13). These are most likely caused by dysphagia, adynamia (lack of strength) or medications which may reduce appetite (13). Malnutrition can impair the immune system, mental function, respiratory strength and increase the risk of pneumonia and nutrient deficiencies (in particular iron and B12 deficiency leading to anemia) (16). These impairments collectively mimic and heighten the effects of the existing MS symptoms of fatigue, muscle weakness and muscle wasting (36).

2.3.3 Osteoporosis

Osteoporosis is another significant health issue for people with MS. The predominance of women, decreased sunlight exposure, lack of weight bearing exercise and sedentary lifestyle place people with MS at a higher risk of osteoporosis (13, 15, 45). Often people with MS avoid sunlight because of heat sensitivity or fatigue (45). Also, as those with MS age, balance and mobility impairments increase the tendency to fall, increasing the risk of fractures. Tremors and balance issues increase the risk of falls in people with MS, which may lead to worsened disability. The risk is further increased in New Zealand, due to the lower vitamin D exposure from the sun due to the latitude of NZ (26).

Some believe that milk can trigger exacerbations and exclude dairy for this reason (26). Also, commonly used low fat diets (Swank and Kousimine) tend to be low in animal and dairy products (26). Diets of this nature that forbid dairy products can lead to calcium and deficiency, which can be extremely harmful to bone health (13). Although Peak bone mass will have already been achieved at MS diagnosis (20 to 50 years of age). Serum calcium levels must be maintained to prevent loss bone mineral density (46), these will be maintained at the expense of bone calcium if inadequate dietary calcium is consumed.

2.3.4 Symptom relief

Effective symptoms management can improve quality of life, reduce the effect of disability on daily activities and assist patients to continue in employment or education (47, 48). Fortunately, nutrition can be useful in managing some severe MS symptoms, such as constipation and fatigue (13, 14, 45).

Constipation is common among the MS population with 41-53% reporting chronic constipation (and 29-51% fecal incontinence) (49). It is a distressing and unpleasant condition, negatively impacting quality of life (47). Often patients become so focused and preoccupied with this symptom it can cause psychological disability (47). Headache, fatigue, feeling bloated, loss of appetite, nausea and vomiting can come secondary to constipation (50), all affecting nutritional intake. If left untreated, it can lead to serious health issues and/or malnutrition. For people with MS, constipation can be alleviated with a high fiber diet, adequate fluid intake, physical exercise, regular bowel routine and medications (12, 49-50), comparable to the constipation guidelines for the general population (51).

Fatigue occurs in up to 92% of individuals with MS and has been described as the most disabling symptom (48, 52). People with MS experience different types of fatigue such as relapse-related fatigue, excessive tiredness after exercise, and excessive daytime sleepiness (48). This can be caused by exhaustion, lack of energy, increased somnolence or worsening MS symptoms (53). From a nutritional perspective, fatigue can be a barrier to meal preparation and grocery shopping (54). Unfortunately, drug treatments generally have not been successful in alleviating fatigue in people with MS (48). Fatigue symptoms are commonly alleviated with a balanced diet, small frequent meals, increasing protein intake and avoiding dehydration and sugary foods (45).

2.4 Dietary intakes

Despite the importance of diet in reducing the health issues in those with MS, some studies report intakes outside of the food and nutrition guidelines. A review of diet among

individuals with MS concluded that they are a result of nutritional imbalances in MS are common due to the wide spectrum of health implications (i.e. malnutrition and obesity) (13).

2.4.1 Weighed food records

Based on 3-day food diaries from 67 women with MS, an American study found intakes were insufficient (10% below the recommended levels for healthy individuals) for carbohydrates, dietary fiber, vitamin E, calcium, and zinc (12). In comparison, intakes exceeded recommendations (10% above the recommended levels) for SAFA, protein, vitamin A, vitamin C, folate and iron. A sample of 80 individuals with MS in a Dutch study also reported dietary intakes using a food diary, but for 14 days (17). These individuals had insufficient intakes of protein, SAFA, MUFA, total fat, cholesterol, folic acid, magnesium and copper compared to the general Dutch population. Interestingly, the two studies produced opposing results. This is possibly due to the differing number of recording days and that one study compared to the general population and the other compared to the 'ideal' intake of the national guidelines.

Weighed food records are a relatively accurate measure of nutritional intake in comparison to dietary recall (55). However, individuals with severe disability and/or poor care assistance may have difficulty completing 3-day or 14-day weighed food records (36). Given the high respondent burden of a 14-day weighed food record, this would be difficult to accurately complete for a healthy adult, let alone an individual with severe disability. Evidence shows that as the severity of MS-related disability increases, so does malnutrition (56). This means, study results can be dependent on the participants who can take part and there have been a reduced representation of malnourished individuals in these two studies.

2.4.2 Food frequency questionnaires

A food frequency questionnaire approach was used for 110 individuals with MS (for >2 years) in an Italian case-control study (18). Individuals with MS had a significantly higher consumption of beef, chicken, lamb, butter and ice-cream than the control group (matched by sex age and BMI). Conversely, the consumption of fruit and most vegetables was higher in the control group than the 110 individuals with MS. An FFQ was also used in 123 women diagnosed with MS in Oregon, America (19). Intakes were low for vegetables and fruits and exceeded the recommendations for dietary fat and saturated fatty acid (SAFA). Given the vulnerability to chronic diseases and the protective effect of fruit and vegetables against this, the low consumption of these food groups in both studies is a concerning finding (19, 22). Both studies acknowledged the limitations of FFQ's as recall bias and random misclassification. On the other hand, the use of a FFQ was demonstrated as a successful tool in identifying the main food groups consumed by MS individuals (18, 22). Due to the low respondent burden of an FFQ (55), this approach may be more likely to capture those with high levels of disability, increasing the likelihood of a more representative sample of the MS population.

A recent survey of 292 individuals with MS found that only 47.5% were engaging in healthy nutritional behaviours (28). Healthy nutritional behaviours included; how often the individual ate 5 servings of fruit and vegetables a day, limited fat intake, read labels and ate regular meals. Over half of the respondents to this survey were overweight or obese and had at least one comorbid condition. The authors of this study identified their sample (n=292) as a representative sample of the MS population. This comprised of mostly female, Caucasian, varying stages of MS and disabled individuals who used mobility aids (i.e

wheelchairs, cane, walker). The limited research on the dietary intakes of individuals with MS suggests that intakes could be improved.

2.4.3 Dietary patterns

At present studies have mainly investigated individual foods or nutrient intakes of those with MS however this can fail to capture the diet in totality. The concept that individuals eat meals consisting of a variety of foods rather than isolated nutrients has led to a push for analysis of dietary patterns (57, 58). Examination of dietary intake data is looked at as an overall dietary pattern by considering how foods and nutrients are consumed in combinations (59). Overall dietary patterns allow for the effective translation into public health messages (57). Principal component analysis (PCA) is a data driven method that produces defined dietary patterns and has been shown to be reliable and valid with using dietary data collected by an FFQ and diet records (59). Food items are collapsed into food groups, entered into PCA and factor loadings are produced which indicate foods consumed together in a pattern. For instance, a pattern with high factor loadings for vegetables, fruits, legumes, whole grains, and fish could be defined as a 'prudent pattern'(59, 60). Equally, a pattern with high factor loadings for processed meat, red meat, butter, high-fat dairy products, eggs, and refined grains could be defined as a 'western pattern'.

An illustration of PCA generated dietary patterns from an FFQ can be seen in an Australian adolescents hypertension study (61). PCA generated three dietary patterns 1) fruit, salad, cereals and fish pattern, 2) a high fat, high sugar pattern and 3) a vegetables pattern. For pattern one this means that fruit, salad vegetables and fish are consumed together in a pattern. For pattern two, high fat foods and high sugar foods are consumed together in a pattern. These patterns can then be used to determine associations with other variables. For

example, this study found that the dietary pattern high in fruit, salad, cereals, and fish was inversely associated with raised diastolic blood pressure among adolescents aged ≥ 16 y (61).

No studies have determined the dietary patterns of individuals with MS. However, a cross-sectional study found that a high consumption of fast foods and ready-to-eat dinners was significantly associated with an increased sweets intake (22). Sweets included cakes, cookies, doughnuts, sugar and lollies. Although the dietary patterns were not determined, this gives some indication of the types of foods eaten in combination for those with MS.

2.5 Meal preparation

To avoid the health implications described above (See 2.3 Health implications), it is important the nutrition guidelines are met through an adequate dietary intake. Unfortunately, meal preparation can be tiring and difficult as disability increases especially if fatigue, muscle weakness and tremors are dominant symptoms (21). Moreover, the meal requirements for individuals for MS are often not straightforward. For instance, small, frequent, nutrient-dense, appealing, easily chewed meals and snacks may improve nutritional status for individuals experiencing weight loss, malnutrition and cachexia (22). Equally, the size, frequency and composition of meals and snacks are important for individuals experiencing weight gain, overweight or obesity. Often meal preparation is challenging for individuals with MS and assistance is sought from family, friends and/or care assistance.

A survey of 697 individuals with MS in Canada identified 67% reported needing a primary caregiver (including spouse or partner) (62). Care assistance was required for housekeeping

(49%), shopping (45%), meal preparation (34%), eating (8%) and numerous other activities of daily living. Care assistance was reported to be the highest in people with decreased mobility and increased severity of MS symptoms. Similarly, a descriptive study in Turkey identified 40.6% of people with MS (n=103) required support and of these, 46.5% obtained this support from their husbands/wives (63).

Unfortunately, meal preparation by family, friends or care assistants strongly affects the ability of individuals with MS to engage in nutritional behaviours, thus reducing nutritional autonomy (54). Individuals with MS in a recent qualitative study described family members as the 'gatekeepers' to dietary intake (54). This was based on types of foods that would enter the house and in the preparation of meals. The individuals in this study had mobility aides and were highly reliant on family members for care assistance. Meal preparation on behalf of an individual with MS is an important role due to the leading role nutrition has for avoiding health implications, weight control and symptom relief.

For individuals without care assistance, ready to eat foods, takeaways and other convenience foods are often consumed (36). This is potentially due to difficulties with food preparation faced by those with MS. The Eating guidelines for people with Multiple Sclerosis of Canada, provides specific practical advice for meal preparation. For instance; avoid heavy pans by cooking with the microwave, complete some tasks sitting (i.e. peeling, chopping) and avoid unnecessarily moving around the kitchen by gathering ingredients and tools at one time (37). Initial support may be required from an occupational therapist for practical kitchen equipment and moving around. Also, a dietitian can assist with selecting low fat, salt and sugar ready-to-eat foods and alternatives.

Fatigue symptoms were associated with being too tired to cook in a cross-sectional study of individuals with MS (22). As the level of disability increased, fatigue symptoms were associated with being too tired to cook and too tired to chew. MS symptoms have been recognised as a barrier to preparing healthy meals (28). A cross-sectional observation study in America established that mildly disabled individuals with MS ate at home more than those who were severely disabled (22). The mildly disabled individuals were more likely to eat ready-made meals than the severely disabled individuals. To our knowledge, there is no data on whether individuals with MS in New Zealand carry out meal preparation independently or with assistance and how this relates to diet quality.

2.6 Alternative diets

Despite the nutrition guidelines and tentative evidence that low fat diets meeting the RDIs could positively impact quality of life, alternative diets are widely used by people with MS. Studies from the US, Canada, the Netherlands, Germany and Australia show that 50-75% of people with MS are using alternative diets (2, 13, 24).

Reasons include gaining a sense of control, the desire for the hope of recovery, or for general health and well- being (13). Other reasons to use alternative diets are; due to conventional medicine offering no cure or limited symptom relief, anecdotal reports of alternative medicines being helpful, the holistic nature of alternative medicine or being persuaded by others (25, 64). According to the Cochrane collaboration review, evidence for any benefits from most alternative diets is lacking, despite the large amount of research (2). There was some evidence that a diet high in polyunsaturated fat could produce mildly beneficial effects, though data was classed as being insufficient (2, 24). The review named

the two most commonly used diets used by those with MS as the Swank diet and Kousimine diet. The Kousimine diet is similar to the Swank diet, a diet high in polyunsaturated fat and low in animal fat (2). An Australian self-administered survey investigated alternative diet use among 1230 individuals with MS (25). The most frequently used diets were low-fat (39.8%), low/no sugar (23.8%), gluten free (16.4%) and Swank (11.1%).

2.6.1 The Swank Diet: High polyunsaturated fat, low saturated fat diet

Dr Roy L Swank introduced the idea that the frequency of multiple sclerosis, worsening of disability and death rate was related to fat consumption. Swank believed there was a strong association between MS incidence and animal fat consumption and a negative association with fish consumption (26). His long-term qualitative prospective study followed 144 people on a low saturated fat diet, for 34 years. His research found that a low saturated fat diet (<15g/d) reduced the incidence of mortality, reduced relapse severity and disability (65). A 95% reduced relapse rate was established after following the diet for 3-5 years (58). There was no control group, but many of those enrolled failed to adhere to the strict dietary regime and became the comparison group. There have been numerous publications by Swank et al (65) suggesting 'The Swank diet', a diet very low in saturated fats and polyunsaturated oils, for individuals with MS (2). However, the Cochrane Collaboration systematic review into dietary therapies for multiple sclerosis could not confirm the positive results claimed for the Swank diet due to the unsound research methods (2). This was due to selection bias, lack of control and blinding by the Swank study (13).

Weinstock-Guttman et al suggested a low fat diet with omega-3 fatty acid supplementation could positively affect quality of life and improve fatigue for individuals with MS (66).

This one-year randomised controlled trial followed two dietary interventions. One group followed a low fat diet (15% fat) and an omega-3 supplement, whereas the control group consumed a ≤30% fat diet and an olive oil supplement. The study found supplementation had a slight tendency to improve fatigue symptoms, but this favored the olive oil control group. This was a small sample size (n=31), and results do not support the use of omega-3 supplementation for MS.

While Swank and versions of this diet have claimed to lessen disability, relapse and mortality with no conclusive evidence, low fat eating can be beneficial for other reasons. A 2005 review emphasised that adherence to a lower fat diet (as per the dietary guidelines) could also be advantageous in reducing CVD risk (13). With the lack evidence for low-fat diets in MS, a balanced diet that is low saturated fats and high in monounsaturated fat and polyunsaturated fats remains as the current recommendation (37). Achieving a diet low in fat usually involves reducing the intake of animal products (eg meat and dairy products) therefore intake of calcium, iron and zinc should be monitored if individuals choose to adhere (67). A food habits questionnaire of 2469 individuals with MS in Australia found the majority of participants excluded dietary meat and dairy (68). Study participants were volunteers and more likely to be actively engaged in lifestyle modification, suggesting a low fat diet was being followed.

Other increasingly used complementary therapies include allergen-free, gluten-free, sucrose- and tobacco-free, raw food, vegetarian, pectin- and fructose-restricted, the Cambridge (liquid diets) and the Hebner diet (2, 69). However, the Cochrane Collaboration review was unable to support the use of these diets for MS. Nonetheless, the commonly

followeddiet by people with MS has been reported as low in SAFA, includes fish three times per week and elimination of allergenic foods (26).

2.7 Dietary information sources

Even though the Food and Nutrition guidelines for healthy adults are recommended for individuals with MS, dietary advice is commonly sought by this population (22, 27). Dietary information for MS is available through the internet, books, newspaper articles, pamphlets, written materials through MS societies, food labels, media, care assistants, others with MS, health providers, dietitians/nutritionists and family and friends (22, 29, 54). These individuals are inundated with dietary information that may provide symptom relief or management (54).

Dietary information sources of MS individuals have not been researched extensively. Individuals in an earlier NZ study described generic MS information as being readily available but difficulties finding practical and specific information (27). One study looked the knowledge gap of individuals with MS and highlighted the need for health professionals to be aware of relevant, current and specific information and research (1). Individuals in an Australian study indicated MS societies and MS nurses were the main sources of MS information (29). The identification of dietary information sources will represent appropriate channels for sound, evidenced based dietary advice in this population.

2.8 Conclusion

Nutrition for people with MS is a key issue, particularly due to the vulnerability of these individuals to health implications (obesity, malnutrition and osteoporosis) and the impact symptoms can have on quality of life. Individuals can have unique symptoms and

medication, however a well-balanced diet in line with the Food and Nutrition guidelines for NZ adults may play a vital role in avoiding health implications, weight control and symptom relief. The dietary patterns of individuals with MS have not been thoroughly investigated, but the current evidence largely demonstrates that dietary intakes may not be optimal in terms of attenuating the risk of future chronic disease such as CVD, diabetes and obesity.

Dietary intakes are affected when symptoms and level of disability act as barriers to meal preparation. This can lead to a higher consumption of energy-dense fast foods or convenience foods or the need for assistance with meal preparation. Dietary intakes are also affected when foods or food groups are excluded in response to alternative diets. Despite the lack of evidence for most alternative diets, these may help the individual regain a sense of control over the incurable disease. Also, it has been shown that these individuals are getting nutrition advice from a range of sources, providing mixed advice. Consequently, meal preparation capability, alternative diet use and sources of nutrition advice may be compromising diet quality and causing intakes that fall outside the Food and Nutrition guidelines.

3 Objective statement

This pilot study aims to investigate the current dietary practices of those with MS as several health issues (obesity, malnutrition, CVD, diabetes, osteoporosis) are common in this population and can be affected by diet. To date, there is no research on the dietary patterns, meal preparation behaviours, alternative diet use and/or sources of dietary information used by individuals living with Multiple Sclerosis in New Zealand.

Therefore, this study will:

1) Describe the current dietary patterns of individuals living with Multiple Sclerosis in New Zealand.

2) Investigate associations between dietary patterns, meal preparation behaviours and alternative diet use.

3) Describe the sources of dietary information used by individuals with Multiple Sclerosis in New Zealand.

4 Methods

4.1 Study design

This cross-sectional, pilot study collected self-reported information concerning the dietary intakes, meal preparation behaviours, alternative diet use and sources of dietary information among individuals with MS living in New Zealand, as part of an ongoing study. This study was reviewed and approved by the Department of Human Nutrition, University of Otago, as well as ethics committee approval and Maori consultation. (Appendix A).

4.2 Participants and recruitment

Participants eligible for this study were over 18 and under 75 years of age, those who were computer literate and who were diagnosed with Multiple Sclerosis, residing in New Zealand. Participants were recruited through liaison with the eighteen MS societies around New Zealand, listed in **Table 4-1**. Contact details for the MS societies were obtained from the Multiple Sclerosis New Zealand website (70). MS societies were emailed with study details and asked if they would be willing to assist with data collection. Societies assisted by posting a description of the study plus the link to the online questionnaire on respective Facebook pages, in newsletters or by forwarding on to member's emails. As the questionnaire invitations were anonymous, it is unknown which MS Societies took part in forwarding on study details. The anonymous online questionnaire was hosted by Sogo Survey (Online survey development software, Virginia, America) and could be completed at the participant's convenience with pilot testing suggesting it took 20 to 25 minutes to complete. The questionnaire was kept open for 41 days and in this time.

Table 4-1 The eighteen Multiple Sclerosis Societies in New Zealand who were contacted to assist with recruitment

Multiple Sclerosis Societies invited to assist in recruitment		
Northland MS Society Inc	MS Society of Auckland and North Shore	MS Waikato Trust
Bay of Plenty MS Society Inc	Rotorua & District MS Society Inc	Hawkes Bay MS Society Inc
Taranaki MS Society Inc	Wanganui MS Society Inc	Central Districts MS Society Inc
Wellington MS Society Inc	Malborough MS Society Inc	Nelson MS Society Inc
West Coast MS Society Inc	MS & Parkinsons Society of Canterbury Inc	South Cantebury MS Society Inc
Otago MS Society Inc	Southland MS Society Inc	

4.3 Questionnaire content

The online questionnaire was divided into two main sections, 1) Demographic and dietary behaviours and, 2) a food frequency questionnaire.

4.4 Demographic and Dietary behaviours

The first section of the questionnaire was prepared compiled based on information gained through discussions with the MS society, it was subsequently tested via group discussions with individuals and carers of individuals with MS. This section involved participants providing; demographic data, meal preparation behaviours, alternative diets used and sources of dietary advice. Participant's gender, date of birth, height and weight were recorded as well as identifying how many others shared their home. Participants were asked who predominantly prepared their meals by selecting, 'you', 'a family member', 'friends' or 'a care assistant' for each of the meals; breakfast lunch, dinner and snacks. These were condensed into 'you' and 'other' (family, friends and/or care assistant) for the analysis. Participants were presented with a list of ten commonly followed diets among the MS community (identified in the literature) and asked to indicate which diet(s) they had tried. Diets incorporated into the questionnaire included Swank, vegetarian, vegan, low carbohydrate, MS recovery diet, gluten free, dairy free, raw food, low fat and/or Paleo. Lastly, participants selected the information sources used to seek nutrition advice by ticking all that applied from the eleven options; 'doctor GP', 'doctor specialist', 'dietitian/nutritionist', 'nurse', 'homeopath', 'magazines', 'other health care professional', 'internet', 'MS society', 'family/friends' and 'other sources'.

4.4.1 Food Frequency Questionnaire

The 57-item, semi-quantitative FFQ was used to assess habitual food intake over the past 12 months. This FFQ was designed in 2013 for use in New Zealand adults. This is a modified form of a longer validated published FFQ (71), which has also been shown to be reliable and valid (72). The FFQ included the food groups; dairy, fruit, vegetables, meat, breads and cereals, fast foods, beverages and sweets/baked goods and serving sizes (as per MOH recommended serving sizes) for each food. Frequency of intake was estimated by asking, 'please tick the circle that best tells how often you eat the following foods' and participants could select one of the following response categories: 'never or less than once per month', '1-3 per month', '1 per week', '2-4 per week', '5-6 per week', '1 per day', 2-3 per day', '4-6 per day'. The FFQ also included questions that identified supplement use, added sugar and types of cold breakfast cereal, spreads, oils and milk. Participants quantified the amount of fruit, vegetables, breads/cereals, meat/poultry, fish/seafood serves they consumed per day/week.

4.5 Statistical Analysis

The questionnaire answers from Sogo survey were exported into a Microsoft Excel (*Microsoft® Excel®. Version 14.3.2 ©Microsoft* Corporation 2010). Data was exported from SoGo survey with assigned codes, and some questionnaire answers were coded by the thesis author. After exclusions (n=5), all sections had a >84% response rate, so data was imputed for those with missing values, using the question median. For analysis, data were transferred into SPSS (SPSS Inc. Released 2008. SPSS Statistics for Windows, Version 18.0. Chicago: SPSS Inc).

Principal component analysis (PCA) was used to derive dietary patterns based on 13 food groups. Data on 57-food items were collected in the FFQ, and 55-food items (water and tea & coffee excluded) were collapsed into 13 food groups (**Table 4-2)**. In order to produce robust PCA results it is recommended that at least 10 participants per food group are needed (73), which meant that 130 participants would need to provide complete FFQ data for analysis. Therefore the grouping scheme was based on the similarity of nutrient profiles (i.e. vegetables), foods with similar culinary usage (i.e. meat and meat products), and that no more than 13 food groups were entered into PCA. Dietary patterns were identified through principal component analysis (PCA) using Stata Statistical Software (release 12, Starta, College Station), using Z scores of FFQ frequency of intake data (portion sizes included) for the 13 food groups. The data set was run through PCA twice, once including seven participants with high reported intakes of certain fruits and vegetables (identified during data entry), and once without. Results essentially remained unchanged when these data were included, so data from these participants were included in the final analysis.

An independent samples, two-tailed t-test was conducted to find associations between the three dietary patterns and whether the meals (breakfast, lunch, dinner and snacks) were prepared independently or not. The same analysis was used to assess dietary pattern associations with alternative diet used (Swank, vegetarian, vegan, low carbohydrate, MS recovery diet, gluten free, dairy free, raw food, low fat and paleo). If variances were not determined to be equal between groups by the Levenes test, then the t-test was run without the assumption of equal variances.

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Table 4-2. Thirteen food groups analysed in principal component analysis, based on foods investigated in the Food Frequency Questionnaire

Food Group	FFQ Food Item
High fiber bread, pasta, rice, cereal	Wholemeal bread (including sliced bread, tortillas, pita etc) Brown rice and Wholemeal pasta High fiber cereals (including porridge, muesli, bran flakes, All bran etc)
Low fiber bread, pasta, rice, cereal	White bread (including sliced, tortillas, pita etc) White rice and Couscous Other pasta (e.g. Spaghetti, spirals, instant noodles) Other cold breakfast cereals (e.g. Light n tasty, Special K etc) Crackers, crispbread (e.g. vitawheat, cruskits etc)
Lean meat & other protein sources	Eggs Beef pork or lamb (e.g. mince, roast, steak, stew, casserole, lasagna, frozen dinners) Chicken, turkey, duck, tuna, salmon, sardines, mackerel Other fish and seafood (e.g. cod, hoki, sole, gurnard, shrimp, mussels, oysters, crayfish) Nuts
Processed meat	Sausages, hotdogs Salami, ham, luncheon, bacon and other processed meats Meat pies, sausage rolls Fried fish, battered fish, breaded fish, fish fingers.
Vegetables	Tomato's (fresh and canned) and tomato based sauce Beans and legumes (e.g. green beans, runner beans, baked beans, lentils, chickpeas) Salad greens (e.g. lettuce, cucumber, celery, rocket) Other greens (e.g. broccoli, cauliflower, spinach, silverbeet, cabbage, brussel sprouts, bok choy, chinese cabbage, watercresss, puha), Onions, leeks Potatoes, kumara, pumpkin, other root vegetables (e.g. carrot, beetroot, parsnip, turnips, yams) Other vegetables (e.g. corn, mushrooms, asparagus, courgette, eggplant, capsicum).
Fruit	Bananas Apples and pears Citrus fruit (includes oranges, mandarins, grapefruit, lemons) Stone fruit (includes apricots, plums, nectarines, peaches) Berries (includes strawberries, blueberries) Dried fruit (e.g. raisins, sultanas, prunes) Other fruit (e.g. kiwifruit, grapes, feijoa, pineapple, mango, rhubarb, tamarillos, guava, pawpaw, melon)

Table 4-2. Thirteen food groups analysed in principal component analysis, based on foods investigated in the Food Frequency Questionnaire

Food Group	FFQ Food Item
Milk and milk products	Milk (includes hot drinks, cereals, creamed soups etc) Ice cream Yoghurt Low fat cheese(includes cottage, ricotta, low fat cheddar) Cream based dairy (includes cream, sour cream, cream cheese)
Sweet foods, baked goods	Chocolate/chocolate bars Sweets and lollies Biscuits, cake, brownies, slice Croissant, pie, danish, brioche, muesli bars Pancakes, waffles, sweet buns, scones Jam, preserves, syrup, honey.
Fast foods	Hot chips/French fries Potato chips/crisps/corn chips Pizza, hamburgers International takeaway (includes Chinese, Thai, Turkish, Indian, Japanese)
Oils, fat and salt	Oils (e.g. vegetable oil, olive oil, salad dressing, frying oil) Fats (e.g. butter, margarine, spreads and in baking) Iodised salt (in cooking or at table).
Alcohol	Alcoholic beverages; beer, wine, spirits.
Artificially sweetened drinks	Low calorie drinks; diet coke, coke zero, sprite zero.
Sweetened drinks	Sweet drinks; sprite, coke, fruit juice, raro, cordial.

5 Results

5.1 Participant characteristics

A total of 150 individuals volunteered to complete the anonymous online questionnaire. However, a total of five participants were excluded following data cleaning, (n=3) due to more than 10 missing FFQ answers and (n=2) due to no information on age. A total of 145 usable questionnaires were used in the final analysis. A total of 145 individuals with MS were included in the final analysis. Participant characteristics are presented in **Table 5-1**. There was a women:men ratio of 3:1, which is comparable with the national prevalence of MS (74). The mean age was 52.3 years (21-75 years) and the mean BMI was 24.96 kg/m^2 (16-55 kg/m^2).

Table 5-1. Demographic characteristics of participants (n=145) including gender, age, BMI category and people who live in their home

Demographics	Category	Number of participants (%)
Gender	Male	34 (23.4)
	Female	111 (76.5)
Age (years)	21-30	8 (5.5)
	31-40	15 (10.3)
	41-50	40 (27.6)
	51-60	42 (28.9)
	61-70	29 (20)
	71-75	11 (7.6)
BMI category (kg/m^2) n=142	<18.50	6 (4.2)
	18.50 – 24.99	81 (57.0)
	25.00 – 29.99	36 (25.4)
	≥30.00	19 (13.4)
Number of people who live in their home n=143	1	23 (16.1)
	2	65 (45.5)
	3	21 (14.7)
	4	22 (15.4)
	5	7 (4.9)
	6+	5 (3.5)

Footnotes: [1]Percentages may not add up to 100% due to rounding
[2]BMI classification was taken from WHO 2004.

5.2 Dietary patterns of individuals with Multiple Sclerosis

Principal component analysis identified three major dietary patterns, which explained 42.8% of the variance. **Table 5-2** displays the factor loadings for the three dietary patterns produced from the FFQ. Loadings of ≥ ±0.30 on a food group were considered to be strongly associated with the dietary pattern. The first dietary pattern produced in this analysis was; "Fast foods and processed meat" which loaded positively for, 'low fiber bread, pasta, rice and cereals,' 'processed meat,' 'milk and milk products,' 'sweet foods and baked goods' and 'fast foods.' The second dietary pattern was; "Lean meat, fruit and vegetables" which loaded positively for, 'lean meat and other protein sources,' 'vegetables' and 'fruit.' The last dietary pattern was; "Sweet foods, sweet drinks and alcohol" which loaded positively for, 'sweet foods and baked goods,' 'sweetened drinks' and 'alcohol' and negatively on 'high fiber bread, pasta, rice, cereal,' and 'low fiber bread, pasta, rice, cereal.' The three patterns were named based on the food items they loaded highly for. These patterns explained 18.4, 13.6 and 10.8% of the variation in food intakes, respectively.

Table 5-2. Factor loadings for the three dietary patterns determined by principal component analysis (n=145)[1]

	Fast foods and processed meat	**Lean meat, fruit and vegetables**	**Sweet foods, sweet drinks and alcohol**
High fiber bread, pasta, rice, cereal	0.21	0.28	**-0.32**
Low fiber bread, pasta, rice, cereal	**0.30**	0.17	**-0.34**
Lean meat & other protein sources	0.05	**0.52**	0.12
Processed meat	**0.45**	-0.06	-0.17
Vegetables	-0.22	**0.54**	0.06
Fruit	-0.09	**0.51**	-0.03
Milk and milk products	**0.39**	0.05	-0.11
Sweet foods, baked goods	**0.34**	0.09	**0.52**
Fast foods	**0.43**	0.03	-0.14
Oils, fat and salt	0.27	0.10	0.09
Alcohol	0.04	0.16	**0.39**
Artificially sweetened drinks	0.18	-0.14	0.05
Sweetened drinks	0.24	-0.08	**0.52**
Eigenvalue	*2.40*	*1.76*	*1.40*
Explained variance (%)	*18.4*	*13.6*	*10.8*

[1]Absolute values ≥ 0.30 are in bold

5.3 Meal preparation

The majority of individuals with MS in this study prepared their own meals (**Figure 5-1**). Dinner preparation had the highest level of assistance, with 33% obtaining assistance from friends, family or care assistance. Conversely, snacks preparation had the lowest level of assistance, with only 11% obtaining assistance from friends, family or care assistance for their preparation.

As shown in **Table 5-3,** individuals who prepared lunch meals independently were significantly less likely to consume the fast foods and processed meat pattern compared to individuals who did not prepare lunch meals (p=0.024).

Individuals who prepared snacks independently were significantly less likely to follow the fast foods and processed meat pattern (p=0.005) and significantly more likely to follow the sweet foods, sweet drinks and alcohol pattern (p=0.030) compared to individuals who did not prepare snacks independently.

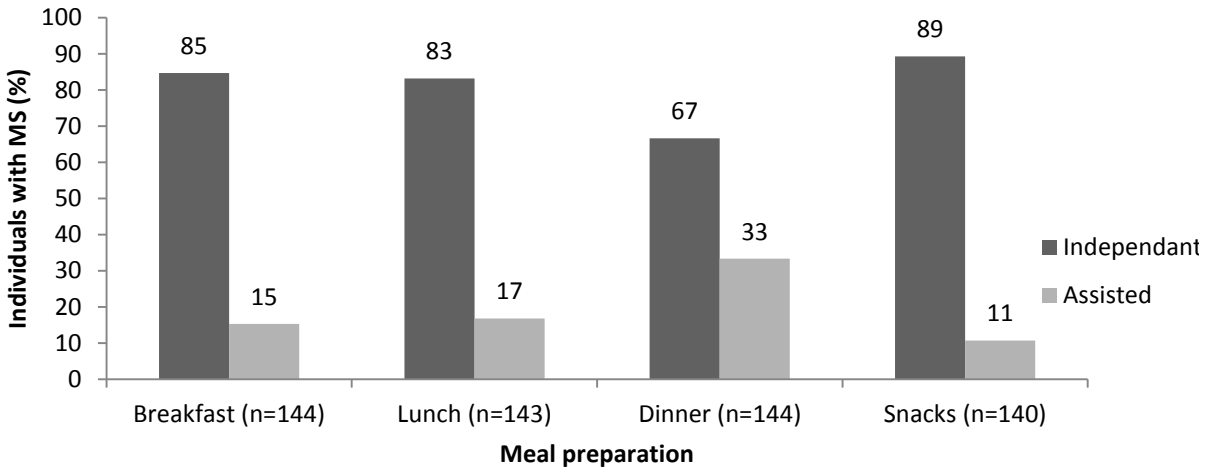

Figure 5-1. Meal preparation completed independently (yes) or by family, friends and/or care assistance (no) among individuals with Multiple Sclerosis, displayed as percentages.

Table 5-3. Number of individuals with Multiple Sclerosis who prepare breakfast, lunch, dinner and snacks independently or assisted (i.e. by friend, family or care assistant), and the associations of these with each of the three dietary patterns.

Meal	Dietary pattern[1]	Prepare meal independently	n	Mean ± SD	p-value
Breakfast	Fast foods and processed meat	No	22	0.2 ± 1.19	0.454
		Yes	122	-0.0 ± 0.97	
	Lean meat, fruit and vegetables	No	22	0.1 ±0.03	0.520
		Yes	122	-0.0 ± 1.02	
	Sweet foods, sweet drinks and alcohol	No	22	-0.2 ± 0.16	0.315
		Yes	122	0.0 ± 0.09	
Lunch	Fast foods and processed meat	No	24	0.4 ± 1.05	0.024*
		Yes	119	-0.1 ± 0.98	
	Lean meat, fruit and vegetables	No	24	-0.1 ± 0.91	0.560
		Yes	119	0.0 ± 1.03	
	Sweet foods, sweet drinks and alcohol	No	24	-0.2 ± 0.81	0.246
		Yes	119	0.1 ± 1.03	
Dinner	Fast foods and processed meat	No	48	0.2 ± 0.99	0.089
		Yes	96	-0.1 ± 1.01	
	Lean meat, fruit and vegetables	No	48	-0.1 ± 0.89	0.424
		Yes	96	0.0 ± 1.06	
	Sweet foods, sweet drinks and alcohol	No	48	-0.1 ± 0.96	0.460
		Yes	96	0.1 ± 1.01	
Snacks	Fast foods and processed meat	No	15	0.7 ± 1.04	0.005*
		Yes	125	-0.1 ± 0.96	
	Lean meat, fruit and vegetables	No	15	-0.1 ± 0.81	0.839
		Yes	125	0.0 ± 1.01	
	Sweet foods, sweet drinks and alcohol	No	15	-0.5 ± 0.98	0.030*
		Yes	125	0.1 ± 0.99	

*$p < 0.05$

[1]Dietary pattern identified in Principal Component Analysis (PCA)

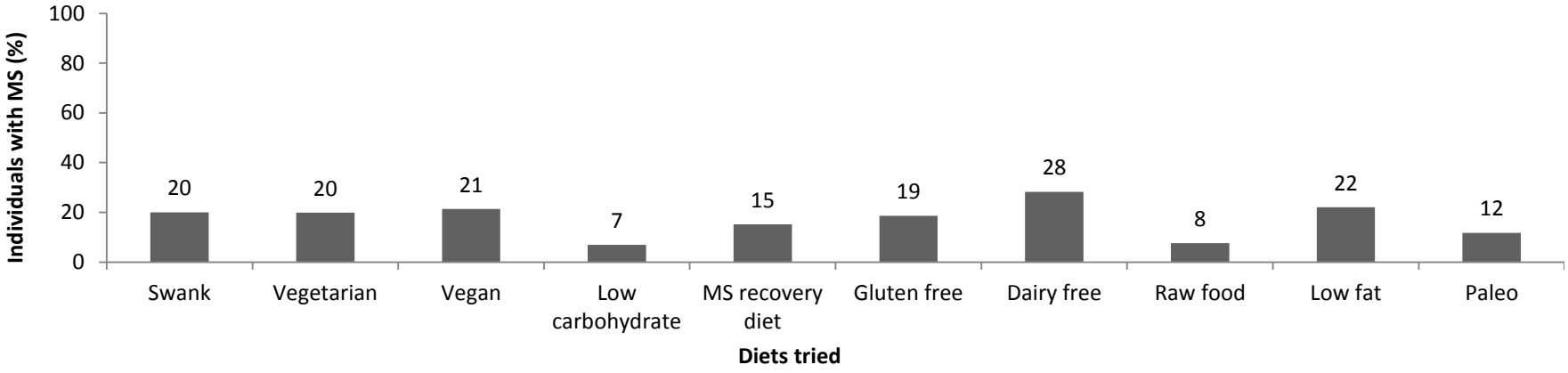

Figure 5-2. Alternative diets tried by individuals with Multiple Sclerosis (n=145), displayed as percentages.

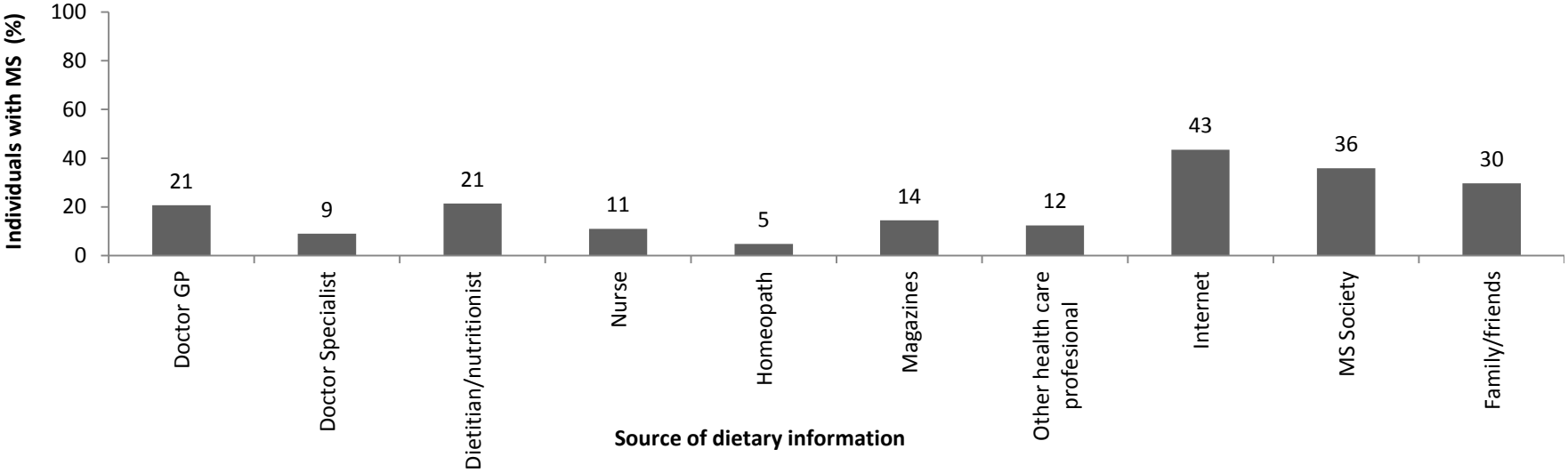

Figure 5-3. Sources of dietary information by individuals with Multiple Sclerosis (n=145), displayed as percentages.

5.4 Alternative diets

Of the 103 people who had tried alternative diets (71% of the study population), dairy free (n=41) was the most commonly tried diet, followed by low fat (n=32), vegan (n=31), swank (n=29), vegetarian (n=26) and gluten free (n=27) (**Figure 5-2)**. Individuals who tried the Swank diet were significantly more likely to follow the sweet foods, sweet drinks and alcohol pattern (p=0.048) and significantly less likely to follow the fast foods and processed meat pattern (p=0.042) than those who had not tried the diet. Individuals were also significantly less likely to follow the fast foods and processed meat pattern if they had tried a dairy free diet (p=<0.001), vegetarian diet (p=0.007), vegan diet (p=0.005), MS recovery diet (p=0.003) and/or gluten free diet (p=0.024) compared to those who had not tried these diets (**Table 5-4)**.

5.5 Sources of dietary information

The internet (n=63) was the most common source of dietary information followed by MS societies (n=52), family/friends (n=30), dietitian/nutritionists (n=31), doctor GP (n=30), magazines (n=21), other health care professionals (n=18), nurse (n=16), doctor specialist (n=13) and homeopath (n=5) **(Figure 5-3)**.

Table 5-4. Associations between the three dietary patterns identified in principle component analysis and alternative diets tried by individuals with Multiple Sclerosis.

Diet	Dietary Pattern	Tried diet (y/n)	n	Mean ± SD	p-value
Swank	Fast foods and processed meat	No	116	0.1 ± 1.05	0.042*
		Yes	29	-0.3 ± 0.72	
	Lean meat, fruit and vegetables	No	116	-0.0 ± 1.02	0.254
		Yes	29	0.2 ± 0.91	
	Sweet foods, sweet drinks and alcohol	No	116	-0.1 ± 1.00	0.048*
		Yes	29	0.3 ± 0.93	
Vegetarian	Fast foods and processed meat	No	119	0.1 ± 1.01	0.007**
		Yes	26	-0.5 ± 0.81	
	Lean meat, fruit and vegetables	No	119	0.0 ± 1.01	0.278
		Yes	26	-0.2 ± 0.99	
	Sweet foods, sweet drinks and alcohol	No	199	-0.0 ± 1.00	0.401
		Yes	26	0.2 ± 0.96	
Vegan	Fast foods and processed meat	No	114	0.1 ± 1.02	0.005**
		Yes	31	-0.4 ± 0.82	
	Lean meat, fruit and vegetables	No	114	0.0 ± 1.01	0.541
		Yes	13	-0.1 ± 0.98	
	Sweet foods, sweet drinks and alcohol	No	114	-0.0 ± 1.00	0.402
		Yes	13	0.1 ± 0.95	
Low carbohydrate	Fast foods and processed meat	No	135	-0.0 ± 1.00	0.610
		Yes	10	0.2 ± 1.12	
	Lean meat, fruit and vegetables	No	135	-0.0 ± 1.01	0.751
		Yes	10	0.1 ± 0.87	
	Sweet foods, sweet drinks and alcohol	No	135	-0.0 ± 0.95	0.169
		Yes	10	0.4 ± 1.50	
MS recovery diet	Fast foods and processed meat	No	123	0.1 ± 1.00	0.003**
		Yes	22	-0.6 ± 0.88	
	Lean meat, fruit and vegetables	No	123	-0.0 ± 1.00	0.284
		Yes	22	0.2 ± 1.01	
	Sweet foods, sweet drinks and alcohol	No	123	-0.0 ± 0.97	0.196

Diet	Dietary Pattern	Tried diet (y/n)	n	Mean ± SD	p-value
		Yes	22	0.3 ± 1.12	
Gluten free	Fast foods and processed meat	No	118	0.1 ± 1.01	0.024*
		Yes	27	-0.4 ± 0.86	
	Lean meat, fruit and vegetables	No	118	-0.0 ± 1.02	0.353
		Yes	27	0.2 ± 0.91	
	Sweet foods, sweet drinks and alcohol	No	118	0.0 ± 1.08	0.855
		Yes	27	0.0 ± 0.50	
Dairy free	Fast foods and processed meat	No	104	0.8 ± 0.10	<0.001*
		Yes	41	-0.5 ± 0.10	
	Lean meat, fruit and vegetables	No	104	-0.0 ± 1.1	0.960
		Yes	41	0.0 ± 0.73	
	Sweet foods, sweet drinks and alcohol	No	104	-0.0 ± 1.13	0.746
		Yes	41	0.1 ± 0.49	
Raw food	Fast foods and processed meat	No	134	0.0 ± 1.00	0.185
		Yes	11	-0.4 ± 1.03	
	Lean meat, fruit and vegetables	No	134	-0.0 ± 1.00	0.211
		Yes	11	0.4 ± 0.97	
	Sweet foods, sweet drinks and alcohol	No	134	-0.0 ± 0.95	0.124
		Yes	11	0.5 ± 1.40	
Low fat	Fast foods and processed meat	No	113	-0.0 ± 1.03	0.745
		Yes	32	0.0 ± 0.91	
	Lean meat, fruit and vegetables	No	113	-0.0 ± 1.04	0.988
		Yes	32	0.0 ± 0.88	
	Sweet foods, sweet drinks and alcohol	No	113	0.1 ± 0.96	0.268
		Yes	32	-0.2 ± 1.10	
Paleo	Fast foods and processed meat	No	128	0.0 ± 1.00	0.230
		Yes	17	-0.3 ± 0.97	
	Lean meat, fruit and vegetables	No	128	0.0 ± 0.95	0.600
		Yes	17	-0.2 ± 1.34	
	Sweet foods, sweet drinks and alcohol	No	128	-0.0 ± 0.97	0.093
		Yes	17	0.4 ± 1.12	

*p < 0.05, **p <0.01

6 Discussion

6.1 The dietary patterns consumed by individuals with MS in NZ

This is the first study to describe the dietary intakes in a population of individuals with MS in New Zealand. The main finding was the identification of the three main dietary patterns; 'fast foods and processed meat', 'lean meat, fruit and vegetables' and 'sweet foods, sweet drinks and alcohol'. The strongest pattern, the fast foods and processed meats pattern, resembles a combination of foods similar to the western dietary pattern (see **Table 5-2**) (75, 76). Foods characteristic of the western pattern are mainly energy-dense, high in fat (mostly SAFA), cholesterol, protein, sugar, salt, processed and fast foods and low in unrefined carbohydrates (22, 58, 77). Globally, the western dietary pattern has become increasingly common, raising concerns of obesity and secondary lifestyle diseases (78, 79). In view of the disability-induced decline in energy expenditure seen in those with MS, the prominent consumption of this pattern could contribute to gains in fat mass due to its energy density. However, the second strongest dietary pattern (lean meat, fruit and vegetables pattern) suggests healthy foods are being consumed in combination in this study population. This pattern somewhat resembles a prudent dietary pattern, described in previous studies as; high in vegetables, fruit, fish, legumes, whole grains or wholemeal bread and low-fat dairy (60, 61, 80). There is an increasing body of evidence outlining the protective role of fruit and vegetables in heart disease, stroke, chronic obstructive pulmonary disease (COPD), diverticulosis, hypertension and other non-communicable diseases (46, 81, 82). Given that the diets of those with MS have been previously described as low in fruit and vegetables (18, 19), and past reports describe a low engagement in healthful nutritional behaviours (54), this finding is encouraging. The third pattern was mostly a combination of sugar-dense foods.

Excessive intake of these non-nutrient, energy-dense foods, is a major driving force escalating the rates of obesity and type II diabetes (20, 83). The high loading of sweetened drinks on this pattern could contribute to an increased risk of type II diabetes as an intake of 1-2 serves/day has been shown to increase diabetes risk by 26% in healthy adults (84). A high intake of alcohol, along with consuming sugar-sweetened drinks, dependence on fatty convenience foods (e.g. pies, crisps, cakes & biscuits) have been shown to contribute to obesity among individuals with MS (36). In a study of 155 social drinkers with MS, there was a higher intake of energy, fat, protein and carbohydrate on days of alcohol intake, than on days with no alcohol (85). One study showed fast-foods and ready-to-eat dinners were high in those with MS (22). Further, this study found a high fast-food intake was associated with high intakes of sweet foods and baked goods, suggesting poor dietary intakes. This is in line with the present study which also suggests poor dietary intakes overall and highlights the need for more dietary advice and ongoing support among individuals with MS.

6.2 Meal preparation behaviours

This study suggests that family, friends and/or care assistants are providing lunch meals and snacks that are high in fat, sugar and unrefined carbohydrates to those with MS. Equally, previous research has shown that foods prepared by staff members in care settings often lack essential nutrients and recommended food groups (23). There is no published literature for MS, but caregivers responsible for the food preparation of intellectually disabled adults identified a lack of time and resources as the barriers preventing them from preparing meals in line with the nutritional guidelines (86). Despite the importance of achieving optimal nutrition, those responsible for food preparation usually lack basic nutrition knowledge and skills (23, 87). Nutritional inadequacy, manifested in obesity will further escalate risk of

hypertension, diabetes, heart disease and osteoporosis and reduce quality of life (88). Yet the regular intake of appropriately portioned and well-balanced meals has been shown to reduce health implications in adults with disabilities in an intervention study (89). On the other hand, those preparing snacks independently seem to have an increased consumption of sweet foods, sweet drinks and alcohol. This is similar to previous studies that show individuals without care assistance are more likely to consume ready to eat foods, takeaways and other convenience foods (36). This is potentially due to difficulties with food preparation faced by those with MS and these foods are mostly easily accessible, can be kept at home and don't require extensive preparation and/or effort to acquire. The barriers that interfere with independent meal preparation ability in MS have been identified as impairment, lack of money, being too tired, lack of convenient facilities, and interference with their other responsibilities (90). Therefore, these factors may be contributing to the higher intake of these sweet foods amongst those who independently prepare their snacks. This is an interesting finding and suggests different dietary intakes between those who prepare foods themselves and those requiring assistance, however, neither type of intake would be classed as optimal. Therefore future education on diet may be required with the emphasis slightly different depending on the level of independence.

6.3 Alternative diet use behaviours

With at least 71% of this study population reporting to have tried at least one alternative diet, this research shows that these are widely used, regardless of the limited evidence surrounding their efficacy (2). Over half of the alternative diets used by individuals in this study examined were negatively associated with the consumption of the 'fast foods and processed meats' pattern. This means, those active in trialing alternative diets are less likely

to select westernised foods. This could suggest that these people are possibly more health conscious and motivated to obtain good health and nutrition. People who are health conscious and more likely to maintain a healthy lifestyle tend to be female, middle aged, more educated and people who plan ahead (91-93). This correlates with our study population being mostly female (76.5%) with a mean age of 52.3 years and a BMI within the healthy range (24.96kg/m^2). A study in the UK demonstrated that a high consumption of fruit, salad and vegetables and a low consumption of high-fat foods was associated with self-assessed 'good' or 'excellent health' (94). Well balanced vegetarian and vegan diets have been associated with excellent health long term (95). Regardless of the motivations behind alternative diet use, this study shows that those who have actively tried alternative diets are less likely to consume the fast foods and processed meats dietary pattern, which may be beneficial in reducing the risk of secondary health issues influenced by diet. An interesting, but unsurprising finding was the dietary pattern associations with those who have followed the Swank diet. Following the Swank diet involves a strict low fat diet (<15 g total fat) (65). It appears that these individuals have reduced dietary fat intake, but replaced this nutrient with sugar-dense foods, therefore overall energy intake is possibly remaining much the same. This may have implications for other health issues that are affected by diet (obesity, CVD) and appropriate nutrition advice should be provided to those choosing to use the Swank diet.

6.4 Sources of dietary information

The internet was the leading source of nutritional information in this study, which is in line with several other MS studies (29, 96-98). The quality of websites providing information on MS has been previously reviewed and described as extremely variable (99). Therefore, as

this study did not obtain details on the sites visited for information, it is difficult to determine the quality of nutritional information. However, due to the unknown nature of MS, individuals must keep up to date with new knowledge but information from the internet is not always up to date, or accurate (99). A recent study of 8586 individuals with MS in America reported females with higher education level and those with less disability were more likely to use the internet for MS information (100). On the other hand, MS Societies have been described as the leading source of nutritional information, as well as the highest rated desired information provider by those with MS (29). It is therefore encouraging that MS societies were used by 36% of our study population, however, it must be noted that the participants were recruited via the MS society and this could have biased the results. Although MS societies (in Australia) were believed to be good for providing general MS information, but they had little information regarding MS symptoms, prognosis and treatment (29). Therefore, it would appear that the NZ MS societies provide more nutritional information, although it was beyond the scope of this thesis to investigate the MS societies of Australia. It is disappointing that only 21% of people in this study sought dietary information from a dietitian/nutritionist (uses an evidence based approach), especially given the high use of alternative diets, and mixed credibility of these diets (2, 13, 24).

6.5 Strengths and limitations

Dietary data were collected using a reliable and valid FFQ for NZ adults (71, 72). FFQs have been shown as a successful tool in collecting dietary data in the MS population (18, 22), even with the known limitations of overestimation and misunderstanding of portion sizes or food groupings (55). Not only are there inaccuracies in recall of past diet by any method but

there are large ~~intra-~~variations in diet which makes the process of characterising typical diets of the entire study population difficult.

Using PCA to identify dietary patterns, rather than isolated nutrients, provides data that are easier to interpret and translate into diets, especially for translation into a public health interventions (59). However, PCA is a subjective measure and it is based on the way the foods are grouped (see **Table 4-2**). As mentioned previously, PCA requires ≥10 participants per food group. Foods were grouped as best as possible inside these constraints, but there were certain foods that would have been ideally separated further. For instance, the fats, oils and salt group would ideally be separated due to the differing types of fats and health properties of these. Also, jam was grouped along with the sweet foods and baked goods group, even though it is usually eaten in a much smaller serving size than the other items in this group. Also, this study does not document the proportion of participants meeting the dietary guidelines for fruits, vegetables and grains, which could be derived from the FFQ.

It must be acknowledged that health-conscious individuals interested in nutrition are more likely to participate in diet-related surveys (92). This study relied on volunteers and the willingness of MS society representatives to promote the study. If an MS society did not forward the study invitation onto members, this would exclude a whole province from participating and this is unknown due to the anonymity of recruitment invitations. Participants were restricted to those who had computer literacy and access, and disability levels that allowed for full participation. This questionnaire did not examine disability level or mobility (e.g. wheelchair use), type and severity of symptoms and ability to work. These would have allowed for a clearer interpretation of the dietary pattern associations found, such as the impact of disability on meal preparation. Likewise, education, income, transport,

access to care assistance and health services information may have impacted the ability to engage in healthy behaviours, altering the strength of associations identified. Also, it must be acknowledged that although the average BMI was adequate when data were collected for this study, chronic poor diet and lack of physical activity could mean increases in weight, which we did not measure. Although the mean BMI of participants was in the normal weight range, this masks the fact that just below 40% of individuals in this study were overweight or obese. A further limitation to this study is the participants interpretation of survey questions. For instance, 'meal preparation' is subjective. This could be considered as preparing a ready-to eat meal or cooking a piece of toast. Likewise, the question, "have you tried any of the following diets', may be considered as a weak measure. The individual may have only followed the loose philosophy/idea of the diet. Also, the questionnaire only asked whether they had ever tried the diet, so the individual may not be using the alternative diet at the time of the FFQ administration, when associations were made with dietary intakes. Due to the lack of sufficient studies with which meaningful comparisons of dietary intake, emphasis must be given to the exploratory nature of this study.

In conclusion, this pilot study provides background into the dietary patterns of those with MS in New Zealand. The overall dietary intake seems less than optimal. Dietary advice for both those who prepare meals with assistance and independently require intervention, but tailored with a different emphasis. The use of alternative diets for MS may be improving overall dietary intakes, but further information is required surrounding the use of the Swank diet. This information found in this study can be used to substantiate an appropriate public health intervention aimed at improving diet quality to attenuate the risk of future chronic diseases (CVD, diabetes). These findings may assist in the tailoring of MOH food and

nutrition guidelines for healthy adults to those with MS. MS societies may be an appropriate channel for delivering this tailored nutrition advice.

7 Application to dietetic practice

The New Zealand Dietitians Board (2010) defines a dietitians scope of practice as: *"The [application of] scientific knowledge about food and nutrition to individuals and groups in states of health and disease to promote optimal health outcomes within the social, economic, and cultural context of the New Zealand population".* Therefore, dietitians are required to work within the evidence based guidelines, while tailoring advice to the individual. As MS cases continue to rise in New Zealand and alternative diets remain popular (even with the mixed evidence of their benefits), it is likely that dietitians will consult with these individuals more frequently. The dietitian must consider the health implications (obesity and secondary diseases, malnutrition and osteoporosis), alternative diet use, symptom severity and meal preparation roles and food behaviours.

The New Zealand MOH food and nutrition guidelines remain the current dietary recommendations for individuals with MS. However, there is a lack of public health resources, such as pamphlets and booklets that tailor this advice appropriately. Because of this, individuals are seeking advice from the internet, MS societies, family/friends (as the top three sources of dietary information identified in this study). Information sought from the internet and family/friends may provide misleading or confusing dietary advice.

The present study contributes to the development of the foundations for investigating the health implications of dietary patterns for individuals with MS living in New Zealand. It is hoped that the findings of this study can contribute to generating targeted health education messages in order to promote a healthier diet in this population. This applies particularly to the differences this study found in dietary patterns between those who prepare their own meals and those who have assistance. Our findings suggest that people responsible for food

preparation (family, friends, care staff) need to be incorporated in to any nutrition intervention. Based on the conclusions of this study, education resources targeted at MS sufferers and caregivers should include practical tips for meal preparation and information on alternative diets, for example, *"If following a low fat diet, care must be taken in the amount of sugar-dense foods consumed."*

8 Reference List

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9 Appendices

Appendix A: Ethics Approval

Form Updated: November 2013

UNIVERSITY OF OTAGO HUMAN ETHICS COMMITTEE APPLICATION FORM: CATEGORY B

(Departmental Approval)

Please ensure you are using the latest application form available from: http://www.otago.ac.nz/administration/committees/otago000864.html

1. University of Otago staff member responsible for project:
Surname First Name Title (Mr/Ms/Mrs/Dr/Assoc. Prof./Prof.)

Black Katherine Dr

2. Department/School:

Human Nutrition

3. Contact details of staff member responsible *(always include your email address)*:

katherine.black@otago.ac.nz

4. Title of project:

5. Indicate type of project and names of other investigators and students:

Staff Research	X	**Names**	Dr Paula Skidmore
Student Research	X	**Names**	Natasha Bourke
Level of Study (e.g. PhD, Masters, Hons)			MDiet
External Research/ Collaboration		**Names**	
Institute/Company			

6. When will recruitment and data collection commence?

March 2014

When will data collection be completed?

February 2015

7. Brief description in lay terms of the aim of the project, and outline of the research questions that will be answered (approx. 200 words):

Multiple Sclerosis (MS) is an autoimmune disease affecting the central nervous system. Several "diets" have been promoted as attenuating the symptoms associated with MS. However, little is known about the actual dietary patterns of individuals with MS or where they obtain their nutritional information from. Therefore the primary aim of this project is to describe the dietary patterns individuals with MS. It will also investigate the prevalence of the "special diets" and the nutritional beliefs of MS sufferers.

The aims of this project are:-

1. Describe the sources of nutritional information MS patients consult.
2. Describe the dietary attitudes and beliefs of MS patients.
3. Investigate the prevalence of "special diets" amongst MS patients.

Thus answering the research question what are the nutrition related attitudes and beliefs of MS patients in New Zealand?

8. Brief description of the method. Include a description of who the participants are, how the participants will be recruited, and what they will be asked to do:-

Participants will be recruited through the MS societies in New Zelaand, they will be recruited via the internet and email from the MS society database. Those who show an interest in the study will be provided with more detailed instructions on how to complete the online questionnaires. This will also provide the potential participants with an opportunity to ask any questions they have which are related to the study. At this point individuals will be invited to participate in the anonymous online study.

Individuals who indicate an interest in the project will be asked to complete the following measures:

1) Three questionnaire on their attitudes and beliefs towards nutrition and diet*

*See appendices for all questionnaires.

9. **Disclose and discuss any potential problems**: (For example: medical/legal problems, issues with disclosure, conflict of interest, safety of the researcher, etc)

***Applicant's Signature:** Katherine Black

Name (please print): KATHERINE BLACK

Date: 29/02/2014

**The signatory should be the staff member detailed at Question 1.*

ACTION TAKEN

☐ Approved by HOD ☐ Approved by Departmental Ethics Committee

☐ Referred to UO Human Ethics Committee

Signature of **Head of Department: Linda J. Holloway

Name of HOD (please print): Linda Holloway

Date: 5/3/14

**Where the Head of Department is also the Applicant, then an appropriate senior staff member must sign on behalf of the Department or School.

Departmental approval: *I have read this application and believe it to be valid research and ethically sound. I approve the research design. The research proposed in this application is compatible with the University of Otago policies and I give my approval and consent for the application to be forwarded to the University of Otago Human Ethics Committee (to be reported to the next meeting).*

IMPORTANT NOTE: As soon as this proposal has been considered and approved at departmental level, the completed form, together with copies of any Information Sheet, Consent Form, recruitment advertisement for participants, and survey or questionnaire should be forwarded to the Manager, Academic Committees or the Academic Committees Administrator, Academic Committees, Rooms G22, G23 or G24, Ground Floor, Clocktower Building, or scanned and emailed to either gary.witte@otago.ac.nz. or jane.hinkley@otago.ac.nz

[Reference Number: *as allocated upon approval by the Human Ethics Committee*]
[*Date*]

Dietary intakes and beliefs of individuals with Multiple Sclerosis

INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the Aim of the Project?

This project is being undertaken by the Human Nutrition department at the University of Otago. We would like to obtain a clearer understanding of your attitudes and beliefs towards nutrition and where you obtain your dietary information. The overall aim of this study is to describe the dietary intakes and nutritional beliefs of New Zealander's with Multiple Sclerosis, with the hope that this information can be used to form future dietary interventions.
This project is being undertaken as part of the requirements for Natasha Bourke's MDiet.

What Types of Participants are being sought?

- *Recruitment method*
  Participants will be recruited through the MSsocieties, they will be via email and/or the internet from the MS society database.

- *Selection criteria (where relevant)*
  Individuals who have been diagnosed with MS.

  Individuals aged 18-75 years

- *Exclusion criteria "People who meet one or more of the exclusion criteria set out above may not participate in this project, because in the opinion of the researchers and the University of Otago Human Ethics Committee, it involves unacceptable risk to them."*
  Individuals without MS

  Individuals aged under 18 years or over 75 years

  Individuals who are fed via a enteral feeding tube

- *Number of participants to be involved*
  500

- *Description of any benefit or access to information which the participant will have access to as a result of participating in the research*
  If you would like, we will provide you with access to your individual results and a copy of the final write up which will include the average values for the group.

What will Participants be Asked to Do?

Should you agree to take part in this project, you will be asked to .....

1) Complete three questionnaire on your attitudes and beliefs towards nutrition and diet. This is a paper based questionnaire designed to ask you about your current dietary beliefs in the form of agreement or disagreement with various statements. These questionnaires should take no more than 20-25 minutes to complete.

Please be aware that you may decide not to take part in the project without any disadvantage to yourself of any kind.

What Data or Information will be Collected and What Use will be Made of it?

There is a distinction between the raw data or information collected by the researcher and the data/information that is set out in the completed research. The potential participant has a reasonable expectation to know:

- We will collect information about your general health, dietary intakes, your attitudes and beliefs relating to nutrition and health, as well as information about where you obtain your nutritional/dietary information and your access to food
- We will also ask you your age, gender and education level.
- All data will be used to obtain a group average.

- *Who will have access to the data or information?*
  The data will be accessed by Dr Katherine Black, Dr Paula Skidmore and Natasha Bourke.

- *How will data or information be securely managed, stored and destroyed?*
  The data collected will be securely stored in such a way that only those mentioned above will be able to gain access to it. Data obtained as a result of the research will be retained for **at least 5 years** in secure storage. Any personal information held on the participants *such as contact details* may be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

- *What data or information will be reflected in the completed research?*

  The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity.

- *Will the participants have the opportunity to correct or withdraw the data/information?*

You will be given the opportunity to view the data and information that relates to you when you complete the project, at this point you will be given the opportunity to correct any data you believe is incorrect.
Upon completion of the entire project we will send you a copy of your information and data with the group averages.

"This proposal has been reviewed and approved by the Department of Human Nutrition, University of Otago".

Can Participants Change their Mind and Withdraw from the Project?

Participants should normally be given the opportunity to withdraw themselves and their data or information from the project. The information sheet should include a statement such as:

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact:-

Dr Katherine Black

Department of Human Nutrition

University Telephone Number:[03] 479 8358

Email Address: katherine.black@otago.ac.nz

This study has been approved by the Department stated above. However, if you have any concerns about the ethical conduct of the research you may contact the University of Otago Human Ethics Committee through the Human Ethics Committee Administrator (ph 03 479-8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.