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“LIVING A HEALTHY LIFE”

**AN EVALUATION OF
A SELF-MANAGEMENT FOR CHRONIC
CONDITIONS COURSE**

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Abstract

Chronic disease management is a major challenge for health care systems in the developed world. Self-management has the ability to help improve health status, health behaviours and reduce health care utilisation for people with chronic disease. In this exploratory before-after cohort study, questionnaires were distributed to people with chronic disease attending a self-management course offered by Arthritis New Zealand. Ninety-four people at baseline, and at six months, 67 people, completed eight health status, four health behaviour, one self-efficacy, and six health care utilisation measures. The 67 participants at six months also completed seven course evaluation measures in addition to course delivery, social support, course barrier and course attendance measures. The relationship at onset between self-efficacy and health status was analysed using a stepwise regression. Self-efficacy, which accounted for 27% of variance, was significantly related to health distress and to the energy levels of participants. To determine the relationship between self-efficacy and self-management behaviours at baseline, standard multiple regressions were run. Self-efficacy was unrelated to the self-management behaviours of the participants at the course onset. To analyse the mediation effect of self-efficacy on health status a stepwise regression was run, while holding self-efficacy constant. Self-efficacy at six months explained 42% of the variance in baseline self-efficacy, after controlling for baseline self-efficacy in the second model, self-efficacy at six months was significantly related to perceived illness intrusiveness and accounted for an additional 58% of the variance. Two hierarchical stepwise-regressions assessed the mediation effect of self-efficacy on self-management behaviours. Self-efficacy at six months accounted for no additional variance in the participants' self-management skills. Paired t-tests and Wilcoxon matched-pairs signed ranks measured changes in health status, self-efficacy, health behaviours and health care utilisation. No significant improvements occurred in health status. Significant improvements occurred in four health outcomes. Independent t-tests and the Mann-Whitney tests identified significant differences between gender, age and location with health status, health behaviour and health care utilisation outcomes at baseline and at six months. The process evaluation of the course showed general satisfaction. Explanations for the results are offered, limitations of the study are highlighted, and suggestions for future chronic disease self-management research are proposed.

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Chapter 1 Introduction

1.1 Chronic Disease

The term chronic disease collectively refers to conditions that are mostly irreversible, progressive, ongoing and recurring. These conditions result in lasting disability due to the permanent, pathological changes that occur in the body (Gregg, Robertus, & Stone, 1989; Royer, 1998). Chronic disease is increasing globally with serious implications for individuals, governments and society as a whole. Health systems in the developed world are faced with escalating costs due to the increased prevalence of chronic disease.

Traditionally, health systems were developed to deal with acute illnesses, where health professionals with medical knowledge and proficiency diagnosed, made prognoses, and responded with appropriate medical treatment, with, usually, a subsequent cure. The medical model of health care has been less successful in dealing with chronic disease (Lorig, Holman et al., 2000). Moreover, the public health model, which constitutes health promotion campaigns, early detection schemes and health education, has failed to halt the escalation of age-related chronic diseases.

Lorig and Holman (2000) propose a new model for the delivery of health care to people with chronic disease. Two factors are crucial to the model: firstly, the ability of the person afflicted with a chronic illness to proactively self-manage their chronic condition, and secondly, the health professional must take on the role of partner and consultant rather than only diagnosing and prescribing. The patient-doctor partnership empowers people with self-management skills to maximise their chronic care capabilities so as to achieve a better quality of life. Crucial too, is a health care system that is conducive to the development of self-management.

This chapter provides an overview of the effects of chronic disease, the challenges in chronic disease management, and the role of self-management in the context of health care delivery. A framework is proposed for evaluating a self-management course that is

currently being offered in New Zealand (NZ) to people with ongoing recurring conditions, collectively referred to as chronic disease. This *Living a Healthy Life: Self-Management for Chronic Conditions Course (LHL)* is based on the new proposed self-management model (Lorig & Holman, 2000).

1.2 The Impact of Chronic Disease on Individuals

An individual afflicted with one or more chronic diseases must cope daily with the effects of their condition. These diseases may be unpredictable and at times life threatening. Those people afflicted with chronic disease may also have fluctuating symptoms such as pain or decreased functioning. People living with chronic disease may experience emotional anguish due to the continuous threat and fear of developing more severe medical difficulties as their disease progresses. Moreover, having to deal with, and cope with, the unpredictability of their condition can create additional emotional distress (Von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). The processes of chronic disease interfere with a person's everyday functioning. Some may fear or experience social stigma, isolation and misunderstanding by their health professionals, family and friends (Royer, 1998). The chronic disease frequently impinges on the person's life, and on that of their family. It may also create socio-economic problems, with a subsequent reduction of overall quality of life.

Olshansky and Ault (1986, cited in Phillips & Verhasselt, 1994) refer to the approaching era of "delayed degenerative diseases". Chronic disease can leave residual disability, have bouts of remission or relapse, and have major impacts on life: physically, socially, psychologically, economically and vocationally (Funk & Tornquist, 2001; Gregg et al., 1989; Royer, 1998). People with chronic disease may require specific training and education to manage their disease on a daily basis. In addition, some may need rehabilitation, supervision, observation and care for extended periods of time. Chronic disease makes unique demands on the person with the affliction, resulting in extensive physical, spiritual and emotional challenges (Royer, 1998). Not only does it affect individuals and impinge on the wider community, but it also poses a significant economic burden on health systems.

Chronic disease can also affect those people who are caregivers to their chronically ill spouse, friend or family member (Cavanaugh, 1998). Many people are already taking care of an older relative who almost certainly, according to predictions, will have a chronic disease, with or without co-morbidities. Similarly, numerous older adults, who themselves have a chronic condition, take care of their chronically ill spouse or partner. These reasons give further impetus for people with chronic disease to acquire the necessary self-management skills in order to proactively manage their own health care, thereby improving their own quality of life as well as that of their caregiver, family or friends.

“Quality of life” is a multi-dimensional concept that includes “physical health, psychological well-being, social satisfaction, and spiritual contentment” (Chodzko-Zajko, 1999). Nutbeam (1998) explains that the aim of enhancing quality of life, as well as preventing “avoidable ill-health” is particularly important in health promotion, especially to older people, to those individuals with chronic disease, or life-threatening illness and to people with disabilities (p.361).

However, for Māori, wellbeing is not depicted by physical health alone. Māori health can be conceptualised as four walls of a tribal meeting house — *te whare tapa whā* which is representative of an ancestor and “within its structure parts of the body are symbolised” (Durie, 1994, p.196). All four walls of the house are necessary, and need to be in balance to “maintain strength, ensure shelter and give coherence” (Durie, 1994 p.196). Hence, good health for Māori encompasses an intricate combination of the following elements: “*te taha wairua*, spiritual health, including the practice of tikanga Māori in general, *te taha hinengaro*, the emotional and psychological well-being of the *whānau* and of each individual within it, *te taha tinana* the physical aspects of health, *te taha whānau* the social environment in which individuals live — the *whānau* or family, the communities in which *whānau* live and act” (MOH, 1996, p.2). Two other factors also contribute to Māori health and wellbeing: “*te ao turoa*, the environment” and “*te reo rangatira*, which expresses the values and beliefs of people and is a focus of identity” (MOH, 1996, p.2). This conceptualisation of good health for Māori should be

considered during the development and the assessment of health promotion interventions, for example, the *LHL* programme (Glasgow, 1999).

1.3 Causes of Chronic Disease

The increase in chronic disease world-wide is mostly due to improved medical care, technological advances, ageing populations and increased longevity (Walker, McKinney, Cannon-Wagner, & Vance, 2002). Despite some individuals having a genetic disposition to develop chronic disease, Berlant and Pruitt (2003) advocate that nearly 50 percent of such diseases are lifestyle related. For example heart disease, lung disease, cancer and stroke can be attributed to lifestyle behaviours such as lack of exercise, smoking, and poor nutrition (Funk & Tornquist, 2001).

World-wide, populations are ageing. Bodenheimer, Lorig, Holman and Crumbach (2002) state that in 2000 the US had 35 million individuals aged 65 years or older, and these figures are expected to rise to 53 million by 2020. Stephenson and Scobie (2002) state that in NZ people aged 65 and over comprised 12.0 percent of the population in 2000, and this group is predicted to increase to 26.0 percent by the year 2050, because:

1. Firstly fertility rates have declined to sub replacement levels (that is, less than 2.1 births per woman in 1999), which means that the base of NZ's age-distribution pyramid is "thinning".
2. Secondly, fertility rates between 1947 and 1973 rose about 3 births per woman for the entire period, peaking at 4.3 births per woman in the early 1960's. The first cohorts of this 'baby boom' will start to retire by the year 2010, and subsequently the age-distribution pyramid is beginning to "fatten" at the top.
3. Thirdly, the average life expectancy for newborn males has increased from 68.2 years in 1956 to 74.3 years in 1996, and for women there has been an increase from 73 years to 79.6 over the same period. These increases in life expectancy further accentuate the fattening at the top of the age-distribution pyramid (p.2).

Many chronic diseases share some fundamental risk factors, for example societal determinants such as poverty, deprivation, poor diet, insufficient health provisions, inactivity, alcohol abuse and tobacco smoking (Weeramanthri et al., 2003, p.31). Chronic diseases can be prevented by targeting health and lifestyle behaviours through interventions such as health promotion, health education, disease prevention and early screening programmes (Bartholomew, Parcel, Kok, & Gottlieb, 2001; Burke, Milligan, Beilin, Dunbar, & Gracey, 2000; Sorensen, Lando, & Pechacek, 1993; Sorensen, Stoddard, Ockene, Hunt, & Youngstrom, 1996).

1.4 The Burden of Chronic Disease

All over the world in the late 1960s, industrialised economies experienced an escalation in health care expenditure when chronic disease began its ascendancy over acute illnesses (Shoor & Lorig, 2002; Weeramanthri et al., 2003). However, with this predominance of chronic diseases, prognoses and outcomes have become less clear. Glasgow, Orleans and Wagner (2001) state that health systems are severely taxed by the burden of chronic disease and various shortcomings have been identified in the provision and delivery of care for people with chronic conditions.

Chronic diseases have been the major contributors to morbidity and mortality for the last 50 years in the US and now represent 75 percent of all health expenditures in that country (Lorig, Gonzalez, & Laurent, 2000). The burden of disease is exemplified by the more than 99 million people who are annually affected by chronic disease in the US (Wagner, 2001). Cardiovascular conditions affect 58 million Americans and over 16 million have diabetes mellitus (Walker et al., 2002). It is estimated that 31 percent of US children, eighteen years and under, suffer from chronic conditions, such as asthma and recurring ear infections (Newacheck & Taylor, 1992, cited in Funk & Tornquist, 2001). Wagner (2001) asserts that chronic disease costs the United States hundreds of billions of dollars in medical care costs and lost productivity each year. Walker et al. (2002) claim that \$US287 billion was spent on cardiovascular disease alone during 1999.

Similar trends have been observed in other parts of the developed world. In Great Britain estimations are that 17.5 million people are living with chronic disease (Donaldson, 2001). Estimations are that 2.5 million Australians have a chronic condition and this number is predicted to increase to 3.5 million by 2016 (Frendin, 2003). Chronic disease comprises 40 percent (AU\$12.6 billion) of total health care expenditure in Australia, of which 46 percent (AU\$5.9 billion) is spent on chronic diseases in hospitals (Weeks et al., 2003). Wooldridge (2000) stresses that chronic diseases such as arthritis, asthma, heart disease, stroke and diabetes are becoming the biggest health challenges for Australia and the rest of the developed world.

The NZ health system is also increasingly experiencing the impact of age-related and lifestyle diseases. The ageing population, a significant demographic factor of the 21st century, will contribute to the redesign of the NZ health care delivery systems to cope with age-related diseases. Currently, long-term illnesses such as diabetes, arthritis, heart disease, asthma, some forms of cancer, emphysema, multiple sclerosis and hypertension are the main reasons why people in NZ seek health care.

In *Diabetes 2000* it is predicted that by the year 2021 the increase in diabetes for Māori will be 97 percent, for Pacific Peoples, 117 percent, and for New Zealanders of European descent, 47 percent (HFA, 2000). The impact of chronic disease on morbidity and mortality is already considerable in NZ, for example there are approximately 115,000 people with diagnosed diabetes, with a further estimated 40,000 to 60,000 people being undiagnosed. The top eight leading causes of Disability Adjusted Life Years (DALYs) lost in NZ are: ischaemic heart disease, stroke, chronic obstructive respiratory disease, diabetes, depression, asthma, anxiety disorders and lung cancer (MOH, 1999). Since 1980 more than 80 percent of deaths in NZ have been due to chronic diseases (Davis & Ashton, 2001). Ischaemic heart disease accounts for 23 percent of all deaths, and stroke for 9 percent (MOH, 1999). Annually 4700 deaths in NZ can be attributed to tobacco smoking (MOH, 1999).

Complications due to chronic disease result in increased morbidity and mortality, for example, during 1998-1999, 41,243 hospital admissions for people with recorded diabetes occurred, costing approximately \$168 million. Wellingham, Tracey, Rea and Gribben (2003) state that at South Auckland Health (in NZ):

Of the 10 conditions responsible for the most bed day utilisation, the most significant were respiratory infections, cardiovascular disease, chronic obstructive pulmonary disease (COPD), and heart failure. Eighty percent of bed days were utilised by people suffering from these four conditions. Furthermore, diabetes was an often unrecorded, but significant, underlying co-morbidity. This situation is likely to worsen with the predicted doubling of diabetes prevalence by the year 2020 (p.1).

The increasing health expenditures associated with chronic disease management necessitate different models of health care delivery from those required for people needing acute care.

1.5 Chronic Disease Management

In response to the global escalation of morbidity and mortality the World Health Organisation (WHO) recommends that health policymakers should change and redesign health care. The redesign would entail moving from health systems that mainly concentrate on the intermittent treatment of acute illnesses to those systems that meet the continuing needs of people (Epping-Jordan, Bengoa, Kavar, & Sabate, 2001). In the report *Innovative Care for Chronic Conditions: Building Blocks for Action*, WHO provides guidelines for governments, healthcare leaders, and decision-makers on how to cope with the burden of chronic disease (WHO, 2004). Chronic disease management is defined as “an organized, proactive, multicomponent, patient-centered approach to health care delivery that involves all members of a defined population (e.g. provider panel or health plan) who have a specific chronic disease, or a subpopulation with specific characteristics” (Norris, Glasgow, Engelgau, O'Connor, & McCulloch, 2003, p.479).

Health Care Delivery

Delnoij, Klazinga and Glasgow (2002) state that “the emphasis is shifting from acute interventions to monitoring, and from cure to care” (p.1). Schofield, Hasler and Barnes (1990, p.65, cited in Weeks et al., 2003, p.26) propose that clinicians should “aim for the prevention of complications of disease rather than its cure, aim to encourage patients to take responsibility for their own illnesses; aim to minimise the degree of handicap the patients’ disabilities cause them; and aim to help families adjust and adapt to one of their members having a chronic illness”. Lorig et al. (1996) state “tertiary prevention efforts should be guided by the concept of living with and dying with (rather than dying *from*) chronic diseases” (p.2).

Culturally appropriate healthcare, based on best practice models and interventions, coordinated by a multidisciplinary team, and delivered in an integrated, seamless, effective way, will greatly enhance the management of chronic conditions. Evidence-based practice is described as being the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients (Didsbury, 2003, p.317).

The notion of “seamless” healthcare delivery implies an easy, efficient transition for patients as they move through various treatment locales, irrespective of funders. Integrated healthcare delivery is defined as “the methods and types of organisation which will provide the most cost-effective preventative and caring services to those with the greatest health needs, and which will ensure continuity of care and coordination between different services” (Ovretveit, 1998, p.1).

Key Components for Chronic Disease Management Programmes

Many governments have changed the way they deliver, manage and organise health services for chronic disease, with the aim of gaining improved financial efficiencies, alongside improved health outcomes (Harvey, 2003). Cheah (2001) advises that the Disease Management Association of America (DSMA) provides useful guidelines for chronic disease management programmes, which should contain:

1. A population identification process.
2. Evidence based clinical practice guidelines/pathways.
3. A collaborative practice model to include clinician and support-service providers.
4. Risk identification and matching of interventions with patient need.
5. Patient self-management and education (may include primary prevention, behaviour modification programmes, and adherence).
6. A process and outcomes measurement, evaluation, and management.
7. Routine reporting of clinical quality indicators with feedback loop (may include communications with patient, doctor, healthcare purchaser, and ancillary providers).
8. Appropriate use of information technology (may include specialised software, clinical data registries, automated decision support tools, and call back systems) (p.2).

International Applications

In the US a generic *Model for Effective Chronic Illness Care* was developed at the Group Health Cooperative of Puget Sound, Seattle, Washington (Wagner, Austin, & Von Korff, 1996). The model was validated against best-practice programmes and has been implemented in a large number of different health care systems in the US (Glasgow et al., 2001). In addition, the *Chronic Care Model* was incorporated in *The Breakthrough Series Model* of the Institute for Healthcare Improvement (IHI) to enhance chronic care. The collaboration was mutually advantageous, for example, “IHI’s second Christus Shumpert Health System in Shreveport, Louisiana, decreased hospital admissions in the pilot group of patients with congestive heart failure (CHF) by 50 percent and increased to 90 percent the rate of patients self-monitoring their weight, diet, medication, and activities” (IHI, 2003, p.9).

Glasgow et al. (2001, p. 581) assert that the *Chronic Care Model (CCM)* designed by (Wagner et al. 1996) provide an “evidence-based, population-based, and patient-centred” framework for successful outcomes in the delivery of chronic care. The model recognises that health care organisations are embedded in a wider community, and that community policies and resources can affect the care and management of people with chronic conditions. Good relationships between health care organisations and

community organisations are important for co-ordinating efficient care and service to people with chronic conditions. Provision of “culturally and linguistically” appropriate self-management support, involving joint decision-making and problem-solving between the patient and health team enhances health outcomes (Wagner, 2001). Collaborative interactions of proactive, empowered, and knowledgeable patients with well-informed care teams maximise productive chronic care (Wagner, Davis, Schaefer, Von Korff, & Austin, 2001).

Continuity of care involves follow-up assessments, goals setting, collaborative problem solving and action plan development (Wagner, 2001). Based on a comprehensive literature review, Lillis (2003) describes continuity of care as the medical care provided to a patient by a health professional in a primary care setting, over an extended time. Activated patients are motivated, and have the necessary knowledge, confidence and ability to effectively make informed decisions about their own health care management (Wagner, 2001). Wagner asserts that during the collaborative interface with patients, prepared health professionals must have the “patient information, decision support, and resources necessary to deliver high quality care” (p.10). Glasgow et al. (2001) explain that “decision support” refers to health professionals having access to pertinent clinical and preventive information. Decision support is described as evidence-based analysis of each consultation with automated advice on best practice opportunities (J.Wellingham, personal communication, April 4, 2004).

In Singapore “a multipronged disease management approach has been adopted, consisting of patient and family education, promotion of self-management, clinical care process changes, use of various clinical tools and communication plans between caregiver and patient, feedback on patient outcomes, and an information technology infrastructure to support these activities” (Cheah, 2001).

In Australia significant attempts are being made to advance chronic disease management, as exemplified by the “Council of Australian Government (COAG) Coordinated Care Trials, the Enhanced Primary Care (EPC) Programme and the

Chronic Disease Self-Management (CDSMP) Programme” (Harvey, 2003). Commitment by the Australian Commonwealth Government to the development of self-management of chronic diseases is exemplified by AU\$14.4 million in the 1999/2000 Federal Budget, and an additional AU\$21.8 million in the 2003/2004 budget (Frendin, 2003).

In 2001 a new paradigm came to the fore in the United Kingdom (UK), with the publication of a white paper: *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century* (Donaldson, 2001). “Expert patients” have the skills to actively, manage their chronic condition, on a daily basis, through informed decision-making and through having insight into and experience of their own personal disease trajectories (Holman, 2000). Expert patients therefore *produce* health in collaboration with their health professionals, rather than being merely a consumer of health, thus ensuring that they have the best medical treatment possible (Hart, 1995).

In NZ, the Counties Manukau District Health Board (CMDHB) sanctioned the development of an integrated model for chronic care management for the Counties Manukau Region (Wellingham et al., 2003), in response to the National Health Strategy (MOH, 2000) and Primary Health Care Strategy (MOH, 2001). Figure 1 shows the *Chronic Care Model (Manukau) (CCMM)* which was expanded and adapted for NZ conditions by Dr. Paul Stephenson (J.Wellingham, personal communication, March 20, 2004). It was based on the Robert Wood Johnson Foundation’s National Programme for Improving Chronic Illness Care (ICIC) in the US (Wagner, 2001). *CCMM* makes provision for improved, seamless health care delivery for a selection of target groups: those people with chronic obstructive pulmonary disease, diabetes, congestive heart failure and cardiovascular disease.

The fundamental aims of *CCMM* are to help maximise health outcomes to their full potential for patients, particularly Māori, and Pacific Peoples, and groups experiencing social or economic disadvantage (Wellingham, 2001). In accordance with the *CCMM*,

care is provided in an environment with which patients are familiar, and in partnership with their health care providers, whānau, family and the wider community. It is based on “culturally competent systems and provider skills” and embedded in six *CCMM* pillars.

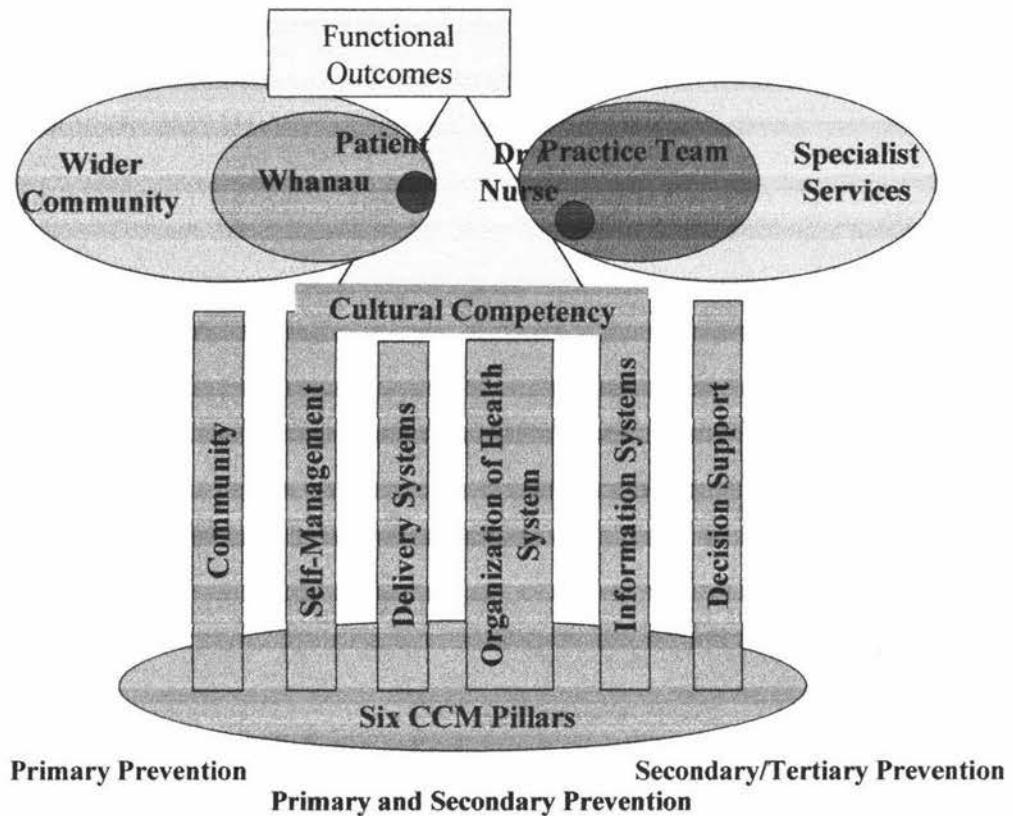


Figure 1. Chronic Care Model (Manukau)

From: *Chronic Care Management – Making the Right Thing the Easiest Thing to Do* by J. Wellingham, 2004 (J. Wellingham, personal communication, March 18, 2004). Reprinted with permission from the author.

Each pillar of the *CCMM* model represents a key aspect of chronic care management, which collectively achieve specific functional outcomes. The six pillars represent: “Community, Self-Management, Delivery Systems, Organisation of Health System, Information Systems and Decision Support.” The prevention and management of

disease is the core focus of a framework that is currently being developed by the Waitemata District Health Board (NZ) to address the increasing burden of disease (Stephenson, 2004).

The primary focus of this present study is self-management, one of the six pillars of the chronic care model.

Collaborative Care and Self-Management

Chronic care involves collaborative, patient-centred treatment plans, despite complex variations in symptoms and manifestations (Wagner, 2001). The goal is to manage chronic disease and co-morbidities effectively in a health care environment where leadership, continuous improvement and encouragement prevail. In the management of chronic disease a new concept has come to the fore – that of people with chronic conditions being their own main caregivers, with specialists and doctors assuming consulting roles. However, Bodenheimer et al. (2002) maintain that in general practice collaborative care is not yet the norm.

The patient-doctor partnership is pivotal in chronic disease self-management. Bodenheimer et al. (2002) assert that the “partnership paradigm” comprises two other parts that are conceptually alike but clinically distinguishable. The parts are collaborative care and self-management education. Weeks et al. (2003, p.27) elucidate “partnership relationships accept that no one discipline or practitioner has an exclusive relationship with a client, and that each person, including the client, brings his or her own unique experience, wisdom and motivation to an illness situation. Thus the quality, intensity and trust found in partnerships can have a profound impact on the therapeutic experience for people with chronic illness, and can make a significant difference to their self-management abilities and outcome”. Specifically, “collaborative care is a description of the patient-physician relationship in which physicians and patient makes health care decisions together. Self-management education takes place in the realm of patient education and includes a plan that provides patients with problem-solving skills to enhance their lives” (Bodenheimer et al., 2002, p.2470).

To enhance the development of the patient-doctor partnership, people with chronic disease can attend (a) self-management education courses, (b) group visits with their main health provider, or in certain cases, (c) medical treatment and disease management is discussed telephonically or by means of the Internet (Holman & Lorig, 2000). In the patient-doctor partnership, the patient is considered an expert in terms of their personal disease trajectories and bodily experiences. The empowered, informed patient accepts responsibility for their own chronic disease management, becoming the principal caregiver, and utilising problem solving skills, to collaboratively interact with the health professional in making decisions to ensure optimum health outcomes (Bodenheimer et al., 2002). Likewise, the health professional, in a medical expert capacity, provides continuous chronic care in a socially, culturally, psychologically, biologically and technically appropriate way.

With the ageing population, and the ensuing increase in chronic disease, the Institute of the Future 2010 claims that baby boomers “will accelerate the movement and awareness of self-care and wellness, and will irreversibly alter the traditional patient-doctor relationship” due to their advanced sophistication (Bodenheimer et al., 2002, p.2469). Wagner et al. (1996) suggest that collaborative problem solving between the health professional and the patient ensures successful outcomes. However, McIver (1999, cited in Weeks et al., 2003) claims that health professionals have been slow to accept patient-directed self-management practices. A key question is whether patients want to assume the role of a partner in the patient-doctor dyad. In a review of the literature, Frosch and Kaplan (1999) found that preferences to take part in the decisions about their medical treatment options declined with age, in spite of adjusting for education levels.

Similarly, inner-city patients with diabetes from low-income families had little interest in making decisions about their treatment. Interestingly Ende, Kazis and Moskowitz (1990, cited in Frosch & Kaplan, 1999) found that the wish to partake in medical decision-making declined as the medical conditions worsened. Frosch and Kaplan (1999) suggest that the impact of patients’ self-efficacy, their cultural and language barriers needs to be empirically ascertained.

Change is required whereby doctors, despite drivers such as “evidence-based medicine, medical litigation and managerialism” place more value on the patient as an expert and partner, with the health professional as a resource, operating in a consulting role, and supporting people with their self-management (Aroni, et al., 2003, p.14). Bodenheimer et al. (2002) and Rollnick, Mason and Butler (2001) support the notion of medical expertise by the health professional, while the person with the chronic disease has expertise in their disease trajectories, its symptoms, fluctuations and overall impact, socially, mentally and physically. Bodenheimer et al. (2002) ask if the doctors who deliver primary care are adequately prepared for this changing paradigm.

Frosch and Kaplan (1999) found that despite patient-centered approaches in medicines, barriers to shared decision-making for doctors included, for example, feeling intimidated by empowered patients, a reluctance to reveal unsure treatment options, and a lack of appropriate communication skills. In contrast, those physicians who supported shared decision making had “previous training in primary care or in interviewing skills, lower patient volume in their medical practices, and more satisfaction with the extent of their personal autonomy” (p.289).

Bodenheimer et al. (2002) predict that the altered patient-doctor relationship will be a “patient-professional partnership, involving collaborative care and self-management education” (p.2469). Self-management is a crucial component of chronic disease management to help achieve required health outcomes, health care utilisation and expenditure (Wagner, 2001). Furthermore, patients must be followed-up to have continuity of care. Hence, the goal of successful chronic disease management is to reduce the impact and sequelae of the disease and its development, to sustain the person’s every-day functioning and to improve their overall quality of life (Lorig et al., 1996). Wagner (2001) specifies that individuals with chronic disease(s) require (a) a continuous healing relationship; (b) regular assessment of how they are doing; (c) effective clinical management; (d) information and ongoing support for self-management; (e) a shared care plan and (f) active, sustained follow-up.

Self-Management Tools

A number of tools have been devised to support the management and facilitation of health care. *The Sharing Health Care Handbook* was developed by the Flinders University of South Australia Co-ordinated Care Training Unit, to actively engage people with chronic disease in the management of their health (Battersby, Reece, Markwick, & Lawrence, 2003). It emphasises that optimum medical care depends on a partnership between the patient and their health care providers in conjunction with their family and caregivers. Self-management skills and the notion of an expert patient are developed by: (a) providing people with information about the co-ordination of their health care services; (b) teaching them how to become active partners in their own treatment and subsequent care plan, (c) teaching them how to prepare for visits to their health care providers, (d) coaching them how to cope physically, emotionally and socially and (e) supplying them with guidelines and recommendations to improve their lifestyle behaviours.

Andrew McLachlan, a cardiac nurse specialist and a chronic care hospital/general practice liaison professional at Counties Manukau (NZ) has developed a tool, *The Wellness Plan*, to advance the patient-doctor partnership in the management of chronic disease (A. McLachlan, personal communication, April 6, 2004). The outcome-based personal care plan considers personal information, health professional information, and the patient's chronic conditions, and lists their medications, and their goals in terms of their health and lifestyle behaviours. Disease-specific action plans are included to help patients cope with any exacerbations in their conditions. The plan also makes provision for frequently monitoring symptoms, and specifies when to have check-ups, thus providing continuous care. *The Wellness Plan* includes education and health promotion materials. The aim of the tool is not only to encourage collaboration between the patient and health professional but also to empower patients to become "expert patients" while receiving evidence-based clinical care. Bodenheimer et al. (2002) stress that all patients self-manage to some extent; the important issue is how effectively they do so.

The efficacy of self-management programmes, as opposed to conventional health education programmes, has been confirmed for various chronic conditions, for example: diabetes (Lorig & Gonzáles, 2000); arthritis (Barlow, Turner, & Wright, 2000); and asthma (Lorig & Holman, 1989). Self-management constitutes people being actively involved in the day-to-day management of their chronic disease, in a partnership with their health professionals (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001), rather than being passive recipients of knowledge transfer and medical supervision. Lorig et al. (1996) assert that “by delaying disability and reducing the toll of suffering and limitations, self-management programmes have the potential for improving quality of life and reducing health care costs” (p.2).

1.6 Health Promotion

The Canadian *Lalonde Report* (1974) can be considered the origin of contemporary health promotion because it altered the focus from caring for illness to caring for health. Today, health promotion can be regarded as a distinct, structured genre of health policy. Canada was the leader in the health promotion area, the Canadian government being the first to identify health promotion for all citizens as a specific governmental target. These guidelines were extended by the promulgation of the 1986 Ottawa Charter of Health Promotion (Green, Poland, & Rootman, 2000; WHO, 1986).

Bennett and Murphy (1999) suggest that health promotion is based on the understanding that individual behaviour and the physical environment in which an individual lives both affect health. Consequently the health promotion premise was extended to include social and environmental variables as mediators of health (WHO, 1991). Likewise, the European Union (EU) has changed its attitude towards the status and challenges of health promotion. The emphasis is now on improving population health, the prevention of human disease, and the eradication of health risk sources (Flynn, 1999).

Despite the variations in the definitions of health promotion, and in their aims, purposes, objectives, procedures and actions, the long-term goal for most health promotion definitions is that of achieving improved health or well-being (Rootman,

Goodstadt, Potvin, & Springett, 2001). Health promotion is defined as “the process of enabling people to increase control over, and to improve their health. To reach a state of complete physical, mental and social well-being an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment” (WHO, 1986). The conceptual framework of the current evaluation of the *Living a Healthy Life Self-Management for Chronic Conditions Course (LHL)* is grounded in health promotion principles. In the current context, it is the process of helping people with chronic disease to increase control over, and to enhance their health and well-being by gaining self-management skills. Nutbeam (1997) emphasises that:

Health promotion is not something that is done *on* or *to* people; it is done with people, either as individuals or as groups. Participation and partnership are valued processes in health promotion. The purpose of this activity is to strengthen the skills and capabilities of individuals to take action, and the capacity of groups or communities to act collectively to exert control over the determinants of health. Thus, *empowerment* of individuals and communities, is a valued outcome (p.28).

1.7 Self-Management

Introduction

Chronic disease self-management is defined as a person with chronic disease “engaging in activities that protect and promote health, monitoring and managing the impact of illness on functioning, emotions and interpersonal relationships, and adhering to treatment regimes” (Gruman & Von Korff, 1996, p.1, cited in Battersby, Reece et al., 2003, p.1). The literature confirms the positive effect of self-management for chronic disease interventions on health status, health behaviours and self-efficacy.

Moreover, a reduction in health care utilisation and health care expenditure is correlated with participation in self-management programmes (Bodenheimer et al., 2002; Ritter et al., 2001). Expanding the previous definition, and based on a comprehensive literature review, Battersby, Reece et al. (2003) propose that self-management involves people

with chronic condition(s) working in collaboration with their caregivers and health professionals, to enable them to:

1. Know their condition and various treatment options.
2. Negotiate a plan of care i.e. Care plan, and review/monitor the plan.
3. Engage in activities that protect and promote health.
4. Monitor and manage the symptoms and signs of the condition.
5. Manage the impact of the condition on physical functioning, emotions and interpersonal relationships (p.2).

Lorig and Holman (2000) state that self-management constitutes five fundamental skills: “problem solving, decision making, resource utilization, forming a patient/health care provider partnership, and taking action” (p.9). Also, self-management enables people to make informed decisions, to adopt new viewpoints and general skills that can be applied to new challenges as they occur, to practice acquired health behaviours, and to sustain or regain emotional strength (Lorig, Mazonson, & Holman, 1993, p.11). Successful chronic disease self-management is therefore contingent on ongoing collaboration between health care providers and individuals with chronic disease, including key stakeholders; on behavioural and lifestyle changes; and on monitoring and problem solving on a daily basis (Lorig et al., 1993; Von Korff et al., 1997; Wright, Barlow, Turner, & Bancroft, 2003).

Moreover, the literature indicates that behavioural interventions are most effective if they are based on learning theories and are incorporated into every-day life (Bandura & Simon, 1977, cited in Berlant & Pruitt, 2003). Bartholomew et al. (2001, p.95) explain that “self-regulatory conceptualization” is the action people take to self-correct or change their health behaviours. Actions that will rectify health behaviours and associated problems may involve self-led teaching, considering options for correcting problems, or developing self-management skills.

Self-management is not a substitute for medical treatment (Lorig et al., 1993; Weeks et al., 2003). Self-management and medical care can holistically complement each other to achieve the best health outcomes possible for people with chronic disease. Thus,

positive outcomes resulting from self-management occur in addition to positive outcomes from medical care. Terminology varies distinctly to describe the notion of self-management: terms such as “self-management”, “self-care”, “self-help” and “self-treatment” are used extensively in the literature. Similarly, self-management constitutes various types, for example, patient education, lay-led self-management courses, information technology directed interventions, self-help groups, individual guidelines, and telephone coaching. Wilson (1999) highlights the crucial role voluntary and charitable organisations play in chronic disease management and enhancing the patient-doctor partnership role. The efficacy of diabetes self-management education in various settings has been shown in terms of effectiveness and economic efficiency, specifically for Type 2 diabetes in community settings, and Type 1 diabetes for adolescents in home settings (Norris et al., 2002).

Patient self-management education is distinctly different to traditional patient health education. Patient health education, involving didactic instruction, provides illness-specific information and practical skills, while self-management education is also concerned with problem-solving skills to help the patient proactively deal with challenges related to their chronic condition. Self-management therefore supplements traditional patient health education (Bodenheimer et al., 2002). Douglas et al. (2002, cited in Aroni et al., 2003) found that patients with asthma assessed the information and treatment recommendations offered by their health professionals, taking into account their own disease trajectory, experience and understanding, and adapted their treatment plan accordingly, giving support to the notion of an “expert” patient.

Based on a comprehensive literature review, randomised trials and 400 meta-analyses Wagner et al. (1996) recommend that successful outcomes in self-management interventions depend on joint problem identification and definition between health providers and patients, setting clear objectives and realistic goals during self-management interventions and planning the achievement of personalised goals. Also the most important issues pertaining to the target group and their health providers need to be identified, and custom-made treatment plans developed. Interventions should

furthermore consider the self-efficacy of target groups and their readiness to change. Other requirements for successful self-management interventions involve teaching, training, and having support infrastructures in place, while also providing ongoing backup services by actively following up on individuals' progress.

Sharing Health Care Chronic Condition Self-Management Course

A self-management training course, *Sharing Health Care Chronic Condition Self-Management Course (Flinders Model)* was developed by the Flinders Human Behaviour and Health Research Unit in Adelaide, Australia as a component of the Sharing Health Care Initiative, and the Enhanced Primary Care Package for Older Australians and People with Chronic Conditions. The course aims to equip general practitioners (GPs), or health professionals (HPs) with the necessary skills, knowledge, techniques and tools to enhance and empower people with chronic disease to better manage their own health care, and to assume an active partnership role with their health providers.

It also provides instruction on how to assess a patient's self-management ability and practices, the development of care plans, and follow-up procedures. A comprehensive manual, *The Chronic Condition Self-Management Education and Training Manual* is provided to course participants as an additional resource. Furthermore, self-efficacy-enhancing strategies such as goal setting and peer support are considered during the assessment (Battersby, Reece et al., 2003). The assessment could be carried out by a general practitioner only, or solely by a health professional, for example a practice nurse, or by both. On completion of the self-management assessment, the discussion with the patient involves determination of proximal goals and appropriate ways of achieving them. This assessment process leads to the development of a "self-management care plan" (Battersby, Reece et al., 2003, p.ii).

The *Flinders Model* describes a number of tools for self-management assessment:

(a) The Partners in Health Scale, (b) The Cue and Response Interview, and (c) Problems and Goals Assessment. An underlying assumption is that the assessment process itself serves as a motivator for chronic disease self-management behaviours and patient

empowerment. In addition it nurtures a patient-doctor partnership. During semi-structured interviews problems are identified and medium-term goals are set. Self-management behaviours are reinforced by an ongoing monitoring and reviewing process (Battersby, Reece et al., 2003). Part of the course also constitutes training the GPs and HPs in motivational interviewing techniques. These are especially effective in enhancing motivation for behaviour change, because during the interview the patient is able to discuss any concerns they might have about their particular health behaviours (Battersby, Reece et al., 2003).

The *Stages of Change Model* is used as a guideline to indicate a person's readiness to change (Prochaska & DiClemente, 1983). According to the model, behaviour change is an iterative process, therefore techniques such as reflective listening, and exploring barriers that may hinder behaviour change initiation or progress are explored during the course. Yet, (Bandura, 1997) contends that "human functioning is simply too multifaceted and multidetermined to be categorized into a few discrete stages" and "a genuine stage theory has three cardinal defining properties: qualitative transformations across stages, invariant sequence of change, and nonreversibility" (p. 412). Oldenburg, Glanz and French (1999) in a review of staged approaches to behaviour change found that these models can be used independently or in conjunction with other models, such as social cognitive theory to facilitate behaviour change. Prochaska and DiClemente (1984, cited in Rankin, 1998) found that during a smoking cessation intervention increased self-efficacy was correlated with progress from the precontemplation stage to the contemplation stage or action stage.

Preliminary reports of the *Flinders Model* indicate that 70 percent of patients felt they had improved their coping abilities due to the Partners in Health programme, 75 percent thought that support from their GPs encouraged them to improve their self-management, while 85 percent believed that the support given by their Service Co-ordinators in a partnership manner enhanced their self-management abilities. In addition, evaluations to obtain feedback from GPs and Service Co-ordinators about the various tools used in the programme were generally positive (Battersby, Reece, Collins,

Markwick, & Holmwood, 2000). Pilot studies to validate the psychometric properties of the Partners in Health Scale indicate that it is a reliable and valid instrument to measure chronic disease self-management (Battersby, Ask, Reece, Markwick, & Collins, 2003). Extensive evaluation of the programme is currently underway (M. Markwick, personal communication, May 11, 2004).

Computer-Based Self-Management Education

Self-management education that is information technology (IT) based, is an area that is currently expanding as an alternative modality of self-management, especially for its utility as a cost saving measure (Simpson, 2000). The Stanford Patient Education Research Centre (PERC) recently developed a computer-based self-management programme, which is offered to individuals with arthritis or diabetes (Lorig, Gonzalez et al., 2000). Lorig and Holman (2000) state that the self-management programme encourages people to proactively manage their chronic disease on a daily basis, in partnership with their health provider. Computer-assisted instruction to enhance asthma-self-management skills has been shown to result in diminished health care utilisation, improved symptoms and functioning, increased knowledge about asthma, and better health behaviours (Bartholomew, Gold et al., 2000).

Telephone Interviewing

Other alternative self-management interventions are currently on trial in Australia, for example, the *Good Life Club Project* concerns self-management programmes for over fifty year old people with diabetes. The programme involves motivational telephone interviewing by trained coaches (Browning & Thomas, 2003; Kelly, Menzies, & Taylor, 2003, p.186). The programme is grounded in the Transtheoretical Model of Behaviour Change (Prochaska & DiClemente, 1984). Preliminary investigations of outcome measures indicate statically significant improvements in 50 percent of the symptom measures, a reduction in health care utilisation, improvements in social functioning and significant improvements in the participants' self-efficacy to manage their chronic conditions.

Personalised Guidelines

This alternative method of self-management involves customised self-management guidelines, which are provided by GPs to patients with chronic disease, to meet the personal disease management needs of their patients. This is exemplified by patients keeping diaries to record for example, their use of peak flow meters for the control and management of asthma (Drummond et al., 1994).

The Heart Guide-Aotearoa

Currently in New Zealand, the development of a self-management programme for chronic disease management and rehabilitation is in progress for New Zealanders with angina, following myocardial infarction or revascularisation and heart failure NYHA class 1-3. The Heart Guide-Aotearoa project is being developed collaboratively by the National Heart Foundation of New Zealand, Te Hotu Manawa Māori, the Ministry of Health and Professor Bob Lewin. Professor Lewin was one of the original developers of *The Heart Manual*, a home-based self-management programme in the UK (Fiona Doolan-Noble, personal communication, April 20, 2004). The programme is grounded in the Cognitive Behavioural Model. The original version, *The Heart Manual* is extensively utilised in the UK and is currently on trial in Holland, Italy and in the US (Lewin, Robertson, Cay, Irving, & Campbell, 1992). The NZ home-based programme will provide step-by step guidelines in a structured self-management programme format for exercise, management of stress, education about risk factors, advice on goal setting and correctly pacing oneself.

“Living a Healthy Life”

The focus of the current study is the *“Living a Healthy Life” Self-Management for Chronic Conditions Course (LHL)* which historically evolved from an Arthritis Self-Management Programme studied over 12 years at the Patient Education Research Centre, Stanford University, US (Lorig & Holman, 1992; Lorig et al., 1993). The original aim of the arthritis study was to determine if an intervention consisting solely of patient education could alter the health behaviour and health status of patients, and their utilisation of health care services. In health promotion literature, health behaviour

is defined as “any activity undertaken by an individual, regardless of actual or perceived health status, for promoting, protecting or maintaining health, whether or not such behaviour is objectively effective towards that end” (Nutbeam, 1998, p.344). Health status is defined as “a description and/or measurement of the health of an individual or population at a particular point in time against identifiable standards, usually by reference to health indicators” (Nutbeam, 1998, p.358).

Lorig and Holman (1992) determined that those participants who exhibited enhanced health status ascribed it to having a sense of increased personal control over the symptoms of their arthritis. This sense of personal control was subsequently operationally defined as perceived self-efficacy (Bandura, 1986). To further investigate the role of self-efficacy in enhancing health status a number of self-efficacy scales were developed. Lorig and Gonzalez (1992) established that increased self-efficacy was more related to health status, rather than with adjustments in health behaviours. Results of the arthritis study showed that four years after participation in the Arthritis Self-Management Course, participants continued reduction in their pain levels occurred, as well as a reduction in health care utilisation and an increased perception of having control over disease symptoms. In this study, self-efficacy to manage chronic disease is operationalised as having confidence in the ability to cope with various health issues (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).

Following these studies, the generic *LHL* chronic disease self-management programme was developed at the Patient Education Research Centre (Lorig & Holman, 1992). The participants in the development of the programme suffered from various chronic diseases, e.g. heart disease, lung disease, arthritis, or had suffered a stroke. A number of participants also had co-morbidities, such as diabetes or hypertension. The analyses of 11 focus groups at the Patient Education Research Centre in which individuals discussed the most important issues that pertained to their chronic disease provided valuable feedback (Lorig & Holman, 1992). Also, extensive literature reviews of disease-specific courses were conducted to extend the already existing knowledge base (Lorig & Holman, 1992).

A randomised, controlled, longitudinal study involving 1000 participants found significant improvements in health status, health care utilisation, self-efficacy and self-management behaviours (Lorig, Sobel, Stewart, Brown, & Ritter, 1999). This final generic *LHL* programme was developed for people with chronic disease(s), such as heart or lung problems, arthritis, diabetes, asthma and other long-term chronic diseases. *LHL* is based on the assumption that even though individuals have problems that are disease-specific, and symptoms that are unique, there are generic challenges and concerns that most people with chronic disease experience daily (Lorig et al., 1996). These challenges are, for example, disability, aches and pains, lack of sleep, breathlessness, stress and anxiety, coping with medication protocols, tiredness, anger and resentment, apprehension, frustration, fear, dietary issues, emotions of depression and helplessness, and problems communicating with loved-ones, friends, family and health professionals (Lorig, Holman et al., 2000).

LHL has been adopted by a number of organisations and countries, for example: The National Health Service (NHS) in Great Britain; the Diabetes Society of British Columbia in Canada, Kaiser Permanente and Group Health Cooperative of Puget Sound in the US (Lorig, Gonzalez et al., 2000, p.1). The programme is widely used in the United States of America, Canada, Great Britain, Australia, NZ, South Africa, China, Scandinavia, Barbados and St. Lucia. It has been translated into Chinese, Vietnamese, Norwegian, Italian and Spanish, while in NZ the *LHL* teaching tools are currently being translated into Tongan and Samoan, under the auspices of Arthritis NZ (P. Antill, personal communication, April 14, 2004).

LHL has been available in NZ since 1998. It is offered by Arthritis NZ, under license from the Stanford Patient Education, Palo Alto, California. The intervention is offered nationally, is community-based and is delivered by health educators who are trained by Master Trainers to become course leaders.

1.10 The *LHL* Course Structure

The following section is concerned with programme process theory, which describes how the programme plans to bring about the proposed interactions with the target group and provide the intended services (Rossi, Freeman, & Lipsey, 1999).

Recruitment and Promotion of the Programme

Arthritis NZ co-ordinates *LHL*, and funds the advertising of the courses in local newspapers. Co-ordination involves advertising and marketing the *LHL* programme, arranging for course leaders in specific areas, and locating appropriate venues for the courses. Finding appropriate venues is often done in conjunction with local course leaders who are knowledgeable about facilities in their particular area. The co-ordinator contacts individuals who may be interested in participating in a course, for example those individuals who have been directly referred to Arthritis NZ. In addition, agencies such as Diabetes NZ are informed of up-coming courses and these agencies refer particular clients to these respective courses.

Advertising and marketing of the *LHL* courses occurs by placing advertisements in newsletters, on some NZ web pages, in local newspapers, posters, community radio and by word-of-mouth (B. Sloan, personal communication, November 5, 2002). (See Appendix A). Arthritis NZ educators generally deal with any pre-programme queries, and arrange for facilities at the chosen venue, for example seating, audio-visual equipment, a podium and refreshments.

The Group

Leaders: In general the course is taught by either two accredited course leaders, employed by Arthritis New Zealand, two peer (lay) leaders, usually volunteers or by one health educator and one peer (lay) leader. At times an assistant, usually a volunteer, who has not undertaken the leaders' course, is required to help the leaders.

Leaders are preferably mature individuals, who have the ability to play active roles in course activities. Expectations of course leaders are that they have the ability to give

constructive feedback to participants and to clearly articulate various aspects of the course, in accordance with the guidelines of the trainers' manual. Also, that they have effective communication skills, which include active listening, asking open-ended questions, and encouraging ongoing dialogue, while simultaneously monitoring group dynamics during the exchange of experiences and ideas. Leaders respect individual differences in participants and place value on their opinions and input. They assist, aid, encourage, and motivate participants to complete tasks and homework during the course, which allows for greater empowerment and processing of course information.

During the interactive leaders' training course, leaders are taught the skills to deal with difficult or problematic situations. Comprehensive trainers' manuals provide guidelines on how each session should be conducted. Each contains an outline of the purpose, objectives, materials and agenda required for each session. Clear guidelines specify how much time should be spent on each activity. *LHL* is strictly run in accordance with the manual provided by Stanford University, and, in keeping with Stanford University prerequisites, no changes or additions to the manual are allowed, other than for cultural or legal requirements. Course leaders are expected to adhere to course standards, prepare for course delivery, utilise appropriate materials, create a positive climate conducive to learning, and develop problem solving skills for participants (S. Sutcliffe, personal communication, March 12, 2002).

Participants: Arthritis NZ has no criteria for admission to a *LHL* course (P. Antill, personal communication, February 12, 2004). Participants in past courses have suffered from a range of chronic conditions, e.g. osteoarthritis, rheumatoid arthritis, asthma, diabetes, multiple sclerosis, heart conditions, migraine headaches and hypertension, some with co-morbidities (Sutcliffe, 2002). Numbers vary between eight to fifteen participants per *LHL* course (S.Sutcliffe, personal communication, March 6, 2003).

The Environment

Two specific environmental factors are considered in the delivery of the course. Firstly the physical environment, i.e. the physical setting where the course will be held, and

secondly, the psychological environment, i.e. the group climate of the participants (Johnson & Johnson, 1997).

The Physical Environment

In accordance with *LHL* philosophy, the course is delivered in a community setting which is centrally located, near public transport facilities and where provision is made for people with disabilities. Seating is arranged in such a way that participants have a full view of each other, i.e. arranging chairs in a circle or horseshoe shape. On arrival participants are welcomed, and nametags are distributed to ease introduction and identification. During the break refreshments are offered.

The Psychological Environment

A basic tenet in the intervention is to create and nurture a cohesive, positive and trusting climate where participants feel comfortable enough to share experiences with each other. Course leaders therefore endeavour to achieve a trusting ambience by being relaxed, friendly, and by displaying a sense of humour (Lorig, Gonzales, & Laurent, 1999). The trusting climate is further promoted by the assurance to participants that confidentiality is maintained at all times.

The Programme Design

The *LHL* course consists of six weekly sessions, each lasting two and a half hours. Course leaders conduct the courses, following a highly prescriptive manual that is supported by ongoing research at Stanford University. Leaders use a variety of techniques during the *LHL* course: lectorettes, demonstrations, participation, interactive discussions, role-playing, practising, didactic sessions, practising with feedback, and problem-solving (Lorig, Gonzales et al., 1999).

As shown in Table 1.1 a broad range of topics is discussed during the course, and self-efficacy enhancing activities involving brainstorming, behaviour modelling, problem solving and action planning are carried out in line with Bandura's Social Cognitive Theory (Bandura, 1986, 1997). Improved self-efficacy occurs as a result of "incremental goal setting and contracting strategy" to make sure that individuals do not

fail in their attempts to change (Lorig et al., 1996). As outlined in the trainers' manuals, an overview of the course is provided during session one (Lorig, Gonzales et al., 1999, p.3) (See Table 1.2). At the onset of the course participants are provided with an additional resource, a loan copy of the book *Living a Healthy Life with Chronic Conditions* (Lorig, Holman et al., 2000).

Table 1.1

Living a Healthy Life Chronic Conditions: Course Overview

	Weeks					
	1	2	3	4	5	6
Overview of Self-Management and Chronic Conditions	<input type="checkbox"/>					
Making an Action Plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relaxation/Cognitive Symptom Management	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feedback/Problem-Solving		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anger/ Fear/ Frustration		<input type="checkbox"/>				
Fitness/ Exercise		<input type="checkbox"/>	<input type="checkbox"/>			
Better Breathing			<input type="checkbox"/>			
Fatigue			<input type="checkbox"/>			
Nutrition				<input type="checkbox"/>		
Enduring Power of Attorney				<input type="checkbox"/>		
Communication				<input type="checkbox"/>		
Medications					<input type="checkbox"/>	
Making Treatment Decisions					<input type="checkbox"/>	
Depression					<input type="checkbox"/>	
Informing The Health Care Team						<input type="checkbox"/>
Working With Your Health Professional						<input type="checkbox"/>
Future Plans						<input type="checkbox"/>

Note. From "Course Leaders Manual 'Living a Healthy Life' Self-Management for Chronic Conditions" by K.R. Lorig, V. González, and D. Laurent, 1999, Appendix 1, p.3. Copyright 1999 by the Board of Trustees, Leland Stanford Junior University. Printed with permission of the author.

Table 1.2

Living a Healthy Life Chronic Conditions Course: Session Overview.

Session One

- Activity 1: Introduction/identifying common problems
- Activity 2: Workshop overview and responsibilities
- Activity 3: Differences between acute and chronic conditions
- Activity 4: Introduction to cognitive symptom management
- Activity 5: Introduction to action plans
- Activity 6: Closing

Session Two

- Activity 1: Feedback/problem-solving
- Activity 2: Dealing with anger, fear and frustration
- Activity 3: Introduction to exercise
- Activity 4: Making an action plan
- Activity 5: Closing

Session Three

- Activity 1: Feedback/problem solving
- Activity 2: Better breathing
- Activity 3: Muscle relaxation
- Activity 4: Fatigue management
- Activity 5: Endurance exercise
- Activity 6: Making an action plan
- Activity 7: Closing

Session Four

- Activity 1: Feedback/problem solving/making an action plan
- Activity 2: Healthy eating
- Activity 3: Distraction
- Activity 4: Enduring power of attorney
- Activity 5: Communication skills
- Activity 6: Problem solving
- Activity 7: Closing

Session Five

- Activity 1: Feedback/problem solving /making and action plan
- Activity 2: Medication usage
- Activity 3: Making informed treatment decisions
- Activity 4: Depression management
- Activity 5: Self-talk

Activity 6: Guided imagery

Activity 7: Closing

Session Six

Activity 1: Feedback/problem solving

Activity 2: Informing the health care team

Activity 3: Working with your health professional

Activity 4: Looking back and planning for the future

Activity 5: Closing

Note. From “Course Leaders Manual ‘*Living a Healthy Life*’ Self-Management for Chronic Conditions” by K. Lorig, V. González, and D. Laurent, 1999, p.3. Copyright 1999 by the Board of Trustees, Leland Stanford Junior University. Printed with permission of the author.

1.11 Theoretical Framework

Theories attempt to explain and predict cognitive processes associated with behaviour change, and form the basis of psychological theorising. Behaviour change may for example, involve individuals becoming more physically active, drinking less alcohol, or, in the context of chronic disease self-management, a person with diabetes becoming more involved in their own disease management by monitoring levels of glucose in their blood. In the context of evaluating interventions systematically Rossi et al. (1999) state that programme impact theory defines the causal sequence through which the intervention is expected to produce change.

Berlant and Pruitt (2003) maintain that health behaviour change occurs through utilising “self-management, self-directed behaviour change or self-regulation” approaches and through employing techniques such as “self-monitoring, goal setting, stimulus control, self-reinforcement, behavioural rehearsal, arranging social support, behavioural contracting, and relapse prevention” (p.210). Similarly, Von Korff et al. (1997) recommend that chronic disease self-management programmes should be grounded in social learning theory and behavioural theories. Application of theories to self-management of chronic conditions relates to learning certain health behaviours and developing the self-confidence to deal with the chronic condition(s), to evaluate and employ social, medical and community support as needed and to monitor and cope with any exacerbations due to chronic conditions (Battersby, Reece et al., 2003).

Self-efficacy, is one of the strongest predictors of health behaviours, and originates in Social Cognitive Theory (SCT) (Bandura, 1997; Schwarzer, 1992). SCT is based on a combination of social learning theories and provides a framework for gaining insight into human cognition, action, motivation and emotion (Bandura, 1997).

According to SCT, behaviour is a “function of both incentives (i.e. reinforcements) and expectancies” (Conner & Norman, 1998, p.17). For example, if the principles of SCT theory are applied to a health behaviour such as exercise, certain processes occur to facilitate behaviour change: (a) participants must consider their health worthwhile (incentive), (b) they should think their current lifestyle risky (a situation-outcome expectancy), (c) they should believe that if they adopted a particular health behaviour, such as exercise, it would reduce the risk to their health, thus having a particular outcome (outcome expectancy) and (d) they should have the belief in their ability to carry out the health behaviour that will lead to a specific outcome (self-efficacy expectancy). Enhanced strength of efficacy beliefs are therefore related to stronger intentions to take action, to make more attempts to achieve goals, and to persevere regardless of barriers or obstacles (Bandura, 1991, cited in Conner & Norman, 1998).

In regard to health promotion, SCT “posits a multifaceted causal structure in which self-efficacy beliefs operate in concert with cognized goals, outcome expectations, and perceived environmental impediments and facilitators in the regulation of human motivation, action, and wellbeing” (Bandura, 1998). Perceived self-efficacy is a key factor in the causal structure because it acts on “motivation and action both directly and through its impact on the other determinants” (p.1). Furthermore, Bandura explains that SCT, as a whole, can identify elements controlling the attainment of abilities that can significantly impinge on and influence physical and emotional health, as well as the self-management of health behaviours. SCT is therefore concerned with the various elements that determine behaviour change, as well as the processes of behaviour change (Bartholomew et al., 2001).

Lorig et al. (1992) suggest that the behaviour changes that occur during self-management programmes are due to the mediating effect of self-efficacy, as conceptualised and defined by Albert Bandura in the late 1970s (Bandura, 1977). Lorig et al. (1996) assert that the *LHL* programme is grounded in self-efficacy theory. Accordingly:

1. The strength of belief in one's capability to do a specific task or achieve a certain result is a good predictor of motivation and behaviour.
2. One's self-efficacy belief can be enhanced through performance mastery, modeling, reinterpretation of symptoms, and social persuasion.
3. Enhanced self-efficacy leads to improved behavior, motivation, thinking patterns, and emotional well-being (p.5).

Maddux (1995) explains that "people respond cognitively, affectively, and behaviorally to environmental events; but, more importantly, through cognition they also exercise control over their own behavior, which then influences not only the environment but also cognitive, affective, and biological states. This principle of triadic reciprocal causation or triadic reciprocity is, perhaps, the most important assumption of social cognitive theory" (p.5). Self-efficacy theory is therefore mainly concerned with the function of "personal cognitive factors in the triadic reciprocity model of social cognitive theory" (p.5).

Bandura (1998) defines perceived self-efficacy as "the beliefs in one's capabilities to organize and execute the courses of action required to produce given levels of attainments" (p.3). Stretcher et al. (1986, cited in McKenzie & Smeltzer, 2001, p.144) propose that self-efficacy is the perception people have in their ability to execute certain desired tasks or behaviours. This perception is situation specific; that is, a person may be self-efficacious when it comes to exercise but not so when faced with having to stop smoking. Thus, self-efficacy is generally considered to be the beliefs people hold about their capability to have control over particular events that impact on their lives. Also, the beliefs they have concerning their ability to set in motion the necessary motivation,

cognitive resources and action needed to control the demands of the task (Bandura, 1986).

Ever since the conceptualisation of self-efficacy, the construct has received much attention in an array of disciplines and has been used as a predictor, mediator and outcome variable. Maddux (1995) explains that self-efficacy beliefs affect behaviour through “four mediating processes: (a) goal-setting and persistence; (b) affect; (c) cognition; and (d) selection of environment and activities” (p.12). The literature abounds with studies that explore the utility of the self-efficacy construct with regard to enhancing peoples’ functional ability, health behaviours and health status during disease specific interventions, for example: arthritis (Lorig & Holman, 1992; Lorig et al., 1993); diabetes, (Glasgow, 2002); heart disease (Clark & Dodge, 1999); chronic obstructive pulmonary disease (Scherer & Schmieder, 1996); chronic pain (Arnstein, Caudill, Mandle, Norris, & Beasley, 1999; Arnstein, 2000) and asthma (Bartholomew, Shegog et al., 2000). Bandura (1998) proposes that the process of behaviour change occurs in four specific ways of enhancing self-efficacy and behavioural capability:

Skills mastery relates to people achieving performance attainment through the actual accomplishment of a given task or behaviour as a result of their own actions (Bandura, 1986). People who are successful in carrying out a task or behaviour, develop a strong sense of self-efficacy. Bandura (1998) suggests that failure to perform a task or behaviour correctly, weakens the development of self-efficacy, but that the development of a strong belief of efficacy is dependent on conquering difficulties by persevering. Skills mastery is accomplished during the *LHL* course through weekly action planning to carry out specific behaviours and through providing feedback.

Modeling refers to people observing social role models as they perform certain desired behaviours or tasks. By vicariously experiencing the thought processes, knowledge, teachings and behaviours of social models, observers can increase their self-efficacy through acquiring useful abilities and strategies to cope with and manage their chronic conditions. Vicarious experiences may involve examples of prolonged effort to obtain

proficiency in a task or behaviour, such as stress management. By observing the sustained attempts of the models, onlookers will experience increased confidence that they too have the abilities to master similar tasks or actions (Bandura, 1998). During *LHL*, peer or lay leaders who themselves have a chronic condition assume the role of social models.

Social persuasion involves leaders verbally persuading people that they have the abilities to master and attain goals, behaviours or tasks. Verbal persuasion and encouragement prompts individuals to try harder and longer to achieve capabilities, especially if they doubt their own abilities and perceive that they have shortcomings. As a result, people develop the ability to realistically recognise the need for putting effort into their own endeavours, as well as persisting with their own attempts to attain goals (Bandura, 1997). The influence of peers and leaders facilitates social persuasion during the *LHL* course.

Somatic and emotional reinterpretation refers to how people think about and judge their own abilities. Individuals tend to interpret their own emotional and physiological reactions, such as anxiety, stress, or worry, as indications of inefficacy. If they experience hurt, pain, or exhaustion during activities that require endurance, strength or stamina, people with low self-efficacy may think it indicates physical weakness. They need to be persuaded to realistically reinterpret how they think and how they judge their own capabilities (Bandura, 1997). The *LHL* course provides participants with the opportunity to reinterpret symptoms and emotions using cognitive symptom management skills.

Bandura (1986, 1997) proposes that three distinct dimensions or factors influence self-efficacy judgement: (a) *magnitude*, which refers to the difficulty or complexity of a performance that an individual believes they can accomplish, (b) *strength*, which relates to how strongly a person believes in their ability to perform a task or behaviour despite barriers and obstacles, and (c) *generality*, which is concerned with the amount or extent to which the efficacy expectation can be generalised to other circumstances. Self-

efficacy judgements relate *not* to the skills a person has, but to their judgement of what they can achieve with the skills they have (Bandura, 1986). Thus, individuals assess, process, weigh up and incorporate various pools of information about their ability, and they control their alternative behaviour and the effort they expend on that behaviour accordingly (Bandura, 1977). The impact and sequelae of chronic disease necessitates developing lifelong self-management skills that will help improve the patient's overall quality of life and hopefully slow down the progression of the chronic disease (Bandura, 1997).

The literature shows that participation in *LHL* is associated with enhanced health behaviours and health status, improved communication between health professionals and patients, and improvements in health care utilisation due to the mediating role of self-efficacy (Lorig, Sobel et al., 1999; Lorig et al., 2001). Given that self-efficacy is amenable to change, a core aim of *LHL* is to enhance the self-efficacy of course participants thereby providing them with the necessary self-management skills and confidence to pro-actively manage and deal with the complications, symptoms, disability and beliefs of helplessness that often stem from having a chronic condition.

Thus, in the context of this *LHL* study, self-efficacy questions are posed in such a way that each item determines the extent to which the participant perceives their ability or confidence to “do” or “carry out” a specific action at the *present* time, rather than having an intention to do so in the future (Bandura, 1997; Maddux, 1995; Schwarzer, 1992). The self-efficacy of participants may increase during *LHL*, owing to practising daily self-efficacy enhancing strategies of performance mastery, modeling, reinterpretation of their physical symptoms, social persuasion and action planning. It is hypothesised that enhanced self-efficacy has a mediating effect on health behaviours, health outcomes and health care utilisation (Bandura, 1986).

Based on these assumptions of self-efficacy theory, and the exploratory nature of the study, the following research questions were posed:

1.12 Research Questions

To test the basic theoretical assumptions of self-efficacy theory:

1. Is self-efficacy related to health status, health behaviours, and health care utilisation in this research sample?
2. Does self-efficacy mediate the effects of *LHL* participation on health status, health behaviours, and health care utilisation?

To evaluate the impact of the *LHL* course:

3. Does participation in *LHL* enhance health status, health behaviours, self-efficacy and health care utilisation?
4. Are there any significant differences between men and women, between those participants who are fifty years and younger and those participants over fifty years old, and between those participants living in the North or South Islands of New Zealand, in terms of their health status, health behaviours and health care utilisation outcomes at the onset of the course and again six months later.

To evaluate the process of the *LHL* self-management course:

5. Were participants satisfied with the course in general, and with the service delivery of *LHL*?

Chapter 2 Method

Contact was made with the major stakeholder, Arthritis NZ on March 12, 2002 in Wellington, at a meeting between Dr. Christine Stephens (Massey University), Ms. Susan Sutcliffe (Support Services and Quality Manager, Arthritis NZ) and the researcher. As no formal evaluation of the *LHL* has been carried out in NZ in the past, the feasibility of an exploratory pilot study to measure the impact of the programme was discussed (S. Sutcliffe, personal communication, March 12, 2002). The main liaison person for the researcher was Ms. Pam Antill (National Training Manager of Arthritis NZ).

2.1 Research Design

This study consisted of a before/after cohort study using survey methodology. Dyer (1995) recommends using survey methodology to reach participants who are dispersed over a large geographical area. In this study participants lived in fifteen centres in both the North and South Islands of NZ (See Appendix B). The survey method was regarded as the best method for this study because some course participants may have felt disinclined to complete the questionnaire at the course venue. They were therefore able to complete the questionnaires at home, at a time and place that was convenient for them and when they felt physically strong enough to do so, thereby limiting sources of artefact related to the physical setting and acquiescence (Conrad & Maul, 1981).

Furthermore, due to the anonymity of their responses, and the external nature of the researcher, survey format was a suitable method for the collection of confidential information (Coolican, 1999; Cooper & Schindler, 1998; Punch, 1998). Surveys decrease interviewer bias, which may occur during face-to-face interviews (Goddard & Villanova, 1996). Expenses can be kept to a minimum, and the surveys can be distributed over large geographic regions, as exemplified in this study where the second questionnaires were posted to a large number of individuals across NZ (Cooper & Schindler, 1998).

2.2 Participants

The target group was recruited from individuals who attended *LHL* courses between July 2002 and April 2003. Participants were representative of a range of chronic conditions, for example, rheumatoid arthritis or rheumatic disease, hypertension, musculoskeletal conditions such as fibromyalgia and osteoporosis, osteoarthritis and degenerative arthritis, heart disease, asthma and diabetes.

To obtain baseline data (T1), questionnaires were distributed to 174 participants who attended *LHL* courses across NZ. Of these 174 questionnaires, 94 were completed, yielding a response rate of 54%.

Of the 94 participants who completed the T1 questionnaires, 92 (98%) provided their personal details, so that they could receive the second questionnaire at six months (T2) after completion of the course, and 2 (2%) did not. Of the 92 participants who received the T2 questionnaires 67 returned their questionnaires yielding a response rate of 73%.

Demographic Characteristics

The key demographic characteristics of the sample are outlined in Table 2.1. Analysis of the data revealed that the participants comprised 75 (82%) women and 17 (18%) men. Their ages ranged from 21 years to 88 years ($M = 59.11$, $SD = 15.039$). Thirty-two (36%) of the participants were in the oldest age group, those 70 years and older, 17 (19%) were in the 60 to 69 years age group. Fifteen (17%) of the participants were in the 50 to 59 years age group, 14 (16%) in the 40 to 49 years bracket, 8 (8%) in the 30 to 39 years age group, and the minority, 4 (4%) were in the youngest age group, those participants 29 years and younger.

More than half of the participants were married or had a domestic partner 51 (56%), a quarter 23 (25%) were widowed, the rest of the participants 17 (19%) were either separated, single or divorced. When asked about their ethnicity most of the participants identified themselves as Pakeha, NZ European or New Zealander 76 (83%), as Sri Lankan Tamil 11 (12%) or as NZ Māori 5 (5%).

Education levels varied, the majority 39 (46%) of the participants had senior or high school qualifications obtained in New Zealand or overseas, followed by 31 (37%) participants with postgraduate, graduate or overseas graduate qualifications, while 15 (17%) of the participants either had no school qualifications, were not sure what level of education they had, or had primary school qualifications. Twenty-eight (31%) of the participants had one chronic condition, while 63 participants had co-morbidities, comprising just over two thirds (69%) of the target group (n=91).

The top seven chronic conditions are outlined in Table 2.2. These included: rheumatoid arthritis or rheumatic disease (36%), osteoarthritis or degenerative arthritis (33%), hypertension or high blood pressure (29%), musculoskeletal conditions such as aches and pains, fibromyalgia, osteoporosis and other musculoskeletal conditions (26%), heart disease (17%), diabetes (17%) and asthma (17%) respectively.

Other chronic conditions that participants had were: neuropsychiatric conditions (8%); chronic fatigue or other diseases (6%), neurological diseases (6%), chronic pain syndrome (5%); gastrointestinal diseases (5%); vascular disease (4%); cancer (4%), skin diseases (3%); eye diseases (2%); other lung diseases (2%); Endocrine diseases, blood diseases, emphysema or chronic obstructive pulmonary disease; urogenital problems, infections, and gynaecological disorders 1% each.

Table 2.1

Demographic Characteristics

Variable	Frequency	% of Total
<u>Gender (n=92)</u>		
Female	75	82
Male	17	18
<u>Age (n=90)</u>		
70 years and over	32	36
60 to 69 years	17	19
50 to 59 years	15	17
40 to 49 years	14	16
30 to 39 years	8	8
29 years or younger	4	4
<u>Marital Status (n=91)</u>		
Married or domestic partner	51	56
Widowed	23	25
Single, separated or divorced	17	19
<u>Culture or Ethnicity (n=92)</u>		
Pakeha/NZ European	76	83
Sri Lankan Tamil	11	12
NZ Māori	5	5
<u>Education Level (n=94)</u>		
Senior/high school	39	46
Post-graduate/graduate	31	37
Primary/ not stated or unknown	15	17

Table 2.2

Top Seven Chronic Conditions

Chronic Conditions	%
Rheumatoid arthritis, Rheumatic Disease	36
Osteoarthritis, degenerative arthritis	33
High blood pressure	29
Musculoskeletal Conditions, Aches and Pains	26
Diabetes	17
Heart disease	17
Asthma	16

Note. Chronic Conditions — due to multiple responses total may not equal 100 percent.

2.3 Outcome Measures

The Stanford sample questionnaire was revised by rewording parts of it for NZ conditions and extended to include a course evaluation component. The wording and language in some items were altered from the Stanford questionnaire to ensure that New Zealanders with varying education levels understood the questionnaire.

The final adapted instruments at T1 and at T2 consisted of ten sections respectively (See Appendix C and Appendix D). Biographic items were omitted in the second (T2) questionnaire, however, for the purpose of the process evaluation, a section was included to ascertain the participants' general impressions of the course. The various sections were labelled as follows: Background; General Health; Symptoms; Physical Activities; Coping with Symptoms; Physical Abilities; How your Illness Affects Your Life; Confidence about Doing Things; Daily Activities; Medical Care and Course Evaluation.

Background

Ethnicity: The question regarding ethnic affiliation was changed from the Stanford model to represent eight ethnic groups or cultural affiliations in NZ: NZ European or Pakeha, NZ Māori, Samoan, Cook Island Māori, Tongan, Indian, Chinese and Asian. Participants were given an optional item "other" to complete, in the event of their ethnicity not been listed.

Age: A single item asked the age of the participants in years. This question was reduced to six groups, those 29 years and younger, 30 to 39 years, 40 to 49 years, 50 to 59 years, 60 to 69 years and 70 years and over. It was also dichotomised into those participants fifty years and younger, and those over fifty years old.

Gender: A dichotomous male or female scale was used to determine the gender of the participants.

Education Levels: Items were adapted to conform with the NZ education system: Primary School, NZ School Certificate, NZ Higher School Certificate, NZ Sixth Form Certificate, NZ University Bursary/Entrance/Scholarship, other NZ Secondary School Qualifications, Overseas Secondary School Qualifications. In addition other completed qualifications included NZ Polytech Certificate or Diploma, Graduate, University Degree, Postgraduate Degree, Certificate or Diploma or other Overseas Qualifications. Also, one item provided an option for participants to state “I don’t know” if they were unsure of their education level. This item was reduced to three categories: Post-graduate, graduate or overseas qualifications; senior school or high school qualifications and primary school, not stated or unknown school qualifications.

Marital Status: Five single-choice items were provided to determine whether participants were married or had a domestic partner, were single, separated, divorced or widowed. This was reduced to three categories: married or domestic partner; widowed, and single, separated or divorced.

Medical diagnoses: A single item asked participants about their chronic condition(s). Participants were asked to choose from nine potential chronic conditions: (1) diabetes; (2) high blood pressure (hypertension); (3) asthma; (4) emphysema or chronic obstructive lung disease (COPD); (5) other lung disease; (6) heart disease; (7) osteoarthritis or degenerative arthritis; (8) rheumatoid arthritis or rheumatic disease or (9) cancer. Participants were also given the option to write down any other conditions that they suffered from. The following diseases were individually coded: vascular disease, neurological diseases, allergies, blood diseases, other musculoskeletal conditions, chronic pain, ear, nose and throat conditions, endocrine diseases, eye diseases, gastrointestinal diseases, chronic gynaecological conditions, neuropsychiatric problems, skin diseases (excluding cancer), urogenital and other conditions such as chronic fatigue syndrome and an item for other disorders that are not listed above.

General Health

Self-Rated Overall Health: A single-item measure of the respondents’ health status. Respondents rated their own health as excellent (1) to poor (5). A lower score denoted

better health. The item is highly predictive of future mortality. The scale has a test-retest reliability time 0.92, representing consistency or stability over time (Lorig et al., 1996).

Symptoms

Two sub-scales, the energy/fatigue scale and the health distress scale were incorporated in the questions under the heading “Symptoms”, pertaining to how participants had felt over the previous two weeks.

Energy/Fatigue Scale: Five items measured energy/fatigue across a six-point Likert scale, ranging from “none of the time” (0) to “all of the time” (5). These items pertained to how often participants had felt worn out or tired over the previous two weeks, as well as their levels of energy during that time. Estimations of reliability for this scale are high. A higher score denoted more energy. Internal consistency reliability was .89 and test-retest reliability .85 (Lorig et al., 1996).

Health Distress Scale: Four items measured health distress levels across a six-point Likert scale, ranging from “none of the time” (0) to “all of the time” (5). Questions related to how often, during the previous two weeks, participants had felt discouraged by their health problems and fearful about their future health. Also whether their health was a worry in their lives and if they were frustrated about their own health problems. A lower score denoted less health distress. Reliability estimations were high for these scales with the coefficient alpha estimate .87 and test-retest reliability .87 (Lorig, Sobel et al., 1999).

Three *Visual Numeric Scales* were utilised to measure to what extent participants had been affected by fatigue, shortness of breath and pain over the previous two weeks. The scales ranged from “no” fatigue, shortness of breath or pain (0) to “severe” fatigue, shortness of breath or pain (10). Lower scores indicated less fatigue, shortness of breath or pain.

Physical Activities

Time Spent on Physical Exercise: Participants were given a matrix on which to indicate the types of aerobic exercise they did and how much time they spent on each type of exercise. The exercise scale ranged from less than 30 minutes per week to more than 3 hours per week. Two sub-scales were included to determine aerobic, and strengthening or stretching exercise. The types of exercise included five aerobic exercises, and one strengthening or stretching exercise, as well as an open-ended question for the respondent to state other exercise not listed in the matrix. A higher score denoted more time spent exercising. Test-retest reliability for the aerobic exercise scale is .72. The estimate of test-retest reliability for the strengthening or stretching exercise is low at .56 (Lorig et al., 1996).

Coping with Symptoms

Cognitive Symptom Management Scale: Cognitive symptom management is a self-management skill that helps participants deal with any discomfort, pain, or other unpleasant symptoms owing to their chronic disease. Cognitive symptom management involves participants utilising cognitive resources to distance themselves from their discomfort, or conceptualising their discomfort as another sensation. It involves the ability to play mental games, sing, practise progressive muscle relaxation, visualisation or positive self-talk. A higher score denoted more use of these self-management skills. The Cognitive Symptom Management Likert-type scale consisted of six points, which ranged from “never” (0) to “always” (5). Reliability estimates are high, with coefficient alpha .75 and test-retest reliability .83 (Lorig et al., 1996).

Physical Abilities

Health Assessment Questionnaire Disability Scale: Participants were asked to select the answer that best described their ability to do the following tasks: tie their shoelaces, do up their buttons, get in and out of bed, lift a full glass to their mouth, walk outdoors on flat ground, wash and dry their entire body, bend down to pick clothing off the floor, turn a tap on or off, and get in and out of a car. A lower score denoted less disability from the impact of their disease. The scale consisted of eight items on a four-point

Likert-type scale. The scale ranged from “without any difficulty” (0) to “unable to do it” (3) and has an internal consistency reliability of .85 (Lorig et al., 2001).

How Your Illness Affects Your Life

Illness Intrusiveness Scale: To determine how much the participants’ chronic condition(s) and treatment interfered with their life, an illness intrusiveness scale, consisting of five sub-scales, was utilised. It consisted of thirteen items, which were measured across a seven-point Likert scale ranging from “not very much” (1) to “very much” (7). The items signified: their perception of being healthy; what they drank or ate; their work; playing sport or physical recreation; participating in quiet recreation or hobbies; their financial circumstances; their interaction and relationship with their spouse or domestic partner; their sex life; their relationships and social activities with their family, friends, neighbours or groups; their religious or spiritual activities, their involvement with community or civic activities and self-improvement or self-expression activities. The five sub-scales measured physical well-being and diet; work and finances; marital, sexual and family relations; recreation and social relations; and other aspects of life. A lower score denoted less illness intrusion. Internal consistency of the Illness Intrusiveness Scale is high at .89 (Lorig et al., 2001).

Confidence about Doing Things

Self-Efficacy Scales: The self-efficacy for managing chronic disease scale determines the confidence participants have in their ability to cope with their chronic disease, specifically their: fatigue, physical discomfort, emotional distress, symptoms, in addition to having the ability to do: different tasks and activities to manage their health problems, and do other things rather than taking their medication to reduce the impact of their disease on their everyday life. A higher score denoted higher self-efficacy. The scale consisted of six items measured across a ten-point Likert-type scale ranging from “not confident at all” (1) to “totally confident” (10). Estimate of reliability is high with an internal consistency reliability of .91 (Lorig et al., 2001).

Daily Activities

Activities Limitation Scale: To determine the extent to which the health of participants interfered with their everyday life, during the previous four weeks, four items asked about interference with social activities, hobbies, and household chores and errands, across a five-point Likert-type scale. The activities limitation scale ranged from “not at all” (0) to “almost totally” (4). A lower score denoted less social role limitations. Internal consistency reliability is .91 and test-retest reliability .68 (Lorig et al., 1996).

Medical Care

Communication with Physicians Scale: To determine the communication level of the participants with their doctors, a three-item scale was included which was measured on a six-point Likert-type scale ranging from “never” (0) to “always” (5). Items pertained to preparing a list of questions for the doctor, asking the doctor questions and discussing problems that may be related to their illness. A higher score denoted improved communication skills. The scale has an internal consistency reliability of .73 and a test-retest reliability of .89 (Lorig et al., 1996).

Health Care Utilisation: To measure health care utilisation six single-item measures were included. These items related to how many times the participants visited a medical doctor (test-retest reliability .76); the number of visits made to the hospital emergency department (test-retest reliability .94), how many times the participants were hospitalised for one night or longer (test-retest reliability .89), and how many total nights they spent in hospital (test-retest reliability .97) (Lorig et al., 1996). The following new measures, not in the US model, were added: how many total nights the respondent spent in a hospital in the past 6 months, how many total nights they spent in a nursing home or minimum care facility, and how many times the participants went to an urgent care or after hour care other than their hospital emergency department (Ritter et al., 2001). A lower score denoted lower health care utilisation.

Course Evaluation

Seven items were included for the process evaluation of *LHL*, these measures determined the course worthiness, the respondent's ability to cope with their own health, the course length, session length, course venue, overall satisfaction with course leaders, and whether the participants would recommend the course to others. The items were measured across a Likert-type scale, ranging from "strongly disagree" (1) to "strongly agree" (7). A higher score denoted more satisfaction with the course in general and the course delivery.

To determine the preference that course participants had for the type of people who could be course presenters, a single-choice question containing three items was given with the following options: (a) health educators, (b) peer leader, or (c) one health educator and one peer leader.

To determine whether some participants experienced obstacles or barriers that made it difficult for them to attend the course a yes or no dichotomous scale was included. If participants answered yes, an open-ended question format was used for an item that asked the respondent to name the most important barrier or obstacle that they had encountered.

An item to determine if participants had the support of their family, loved ones or significant others to participate in the programme was included, using a yes or no dichotomous scale.

An item to ascertain if participants attended all six sessions of the course was included utilising a yes or no dichotomous scale. Participants who indicated that they did not attend all the sessions were asked to indicate which session(s) they had missed.

2.4 Procedures

This study was developed in accordance with the Code of Ethical Conduct provided by Massey University Human Ethics Committee. The project was reviewed and approved

by the Massey University Human Ethics Committee, Palmerston North Protocol 02/54 (See Appendix E).

The baseline questionnaires (T1) were distributed at the first session of several *LHL* courses from July 24, 2002 to April 30, 2003, while the follow-up questionnaires (T2) were sent to the participants' homes, six months, later between January 24, 2003 and October 30, 2003. Susan Sutcliffe and Pam Antill notified the *LHL* health educators of the survey by means of the internal communication systems of Arthritis NZ.

The researcher provided Susan Sutcliffe (Arthritis NZ, Wellington) and Pam Antill (Arthritis NZ, Auckland) with survey packs, which they distributed to those Arthritis NZ centres where self-management courses were imminent. All course participants received a survey pack at the first session, and were asked to return it to the researcher, via Massey University, in the enclosed freepost envelope.

Each survey pack contained (a) a copy of the "*Living a Healthy Life*" questionnaire, (b) a freepost self-addressed envelope, and (c) an information sheet (See Appendix C and Appendix F respectively, for the baseline questionnaire and the information sheet).

Participants each received an information sheet that introduced the researcher, and outlined the nature and purpose of the study. Participants were informed that if English was their second language they may ask a support person to help them read or complete the questionnaire. Care was taken to assure participants of confidentiality and anonymity, and that no attempt would be made to identify them. In addition, assurance was given that the questionnaires were locked away during the research and would be destroyed after completion of the study. However, data would be stored for five years in a locked cabinet in the office of the study supervisor, Dr Christine Stephens, as specified by Massey University.

Participants were informed that should they have any concerns about the research they could contact the Massey University Human Ethics Committee or the researcher's

supervisor, Dr Christine Stephens at the School of Psychology, Massey University, Palmerston North. The information sheet explained that because the questionnaire was anonymous, completion of the questionnaire was indicative of consent being given for participation in the study. Participants had certain rights, for example the right to decline to participate in the study, to refuse to answer certain questions, and to clarify questions that were unclear. Participants were assured that the results would only be used for the investigation and that a summary report would be posted to them after completion of the study.

Six months after receipt of the completed first questionnaire a second survey pack was forwarded directly to each respondent by the researcher. In spite of the researcher knowing the names and addresses of participants no direct contact was made between participants and the researcher, and confidentiality was therefore maintained. Similarly, anonymity was further assured by the researcher, rather than Arthritis NZ, posting the second questionnaires directly to the course participants. The second survey pack contained an extended version of the "*Living a Healthy Life*" questionnaire.

The second information sheet reminded participants of the study, and also thanked them for returning the baseline data in the first questionnaire (See Appendix D and Appendix G respectively, for the follow-up questionnaire at six month (T2) and the information sheet at T2). The second pack contained a free post envelope to return the follow-up questionnaire to the researcher, via Massey University.

Chapter 3 Results

3.1 Data Screening

Data was entered into a Statistical Package for Social Sciences (SPSS) data file, version 11. It was checked for accuracy, and incomplete data was discarded. Data analyses were carried out in distinct stages. The following section provides an overview of the data analyses, including descriptive and inferential data analyses.

3.2 Data Analyses

Bivariate correlations were conducted to determine the relationship between self-efficacy at T1 and T2 respectively, with health status and health behaviour variables.

Regression analyses were carried out to measure independent and joint effects of the variables on outcome measures. Three kinds of multiple regressions were run: (a) standard multiple regression, (b) stepwise regression and (c) hierarchical stepwise regressions.

These regressions were carried out to determine the (a) *relationship* of self-efficacy to manage chronic disease (self-efficacy) with (i) health status variables and (ii) health behaviour variables and to test the (b) *mediating effect* of self-efficacy between *LHL* and (i) health status variables and (ii) health behaviour variables.

Regression analyses were not conducted on health care utilisation variables due to abnormal frequency distributions.

Paired t-tests were performed to detect differences between the means of the following outcome measures at baseline (T1) and 6 months later (T2): health status, health behaviours, and health care utilisation. The Wilcoxon matched-pairs signed-ranks test was carried out on data that had abnormal distributions because this test does not

assume normal distribution and the results are based on ranking (Brace, Kemp, & Snelgar, 2003).

Independent t-tests were performed to determine significant differences between men and women, between those participants who are fifty years and younger and those participants over fifty years old, and between those participants living in the North or South Islands of New Zealand, in terms of their health status, health behaviour and health care utilisation outcomes at the T1 and T2. The Mann-Whitney U-test was used to compare the data where assumptions of normality were not satisfied (Brace et al., 2003).

Due to the exploratory nature of the pilot study the alpha level was set at .05 for inferential statistics. Probability levels less than 0.05 were described as two-tailed *p* values.

3.3 Descriptive Data Analyses

The means, standard deviations (*SD*), and Cronbach's Alpha coefficients are listed in Table 3.4. The majority of the Cronbach's Alpha Coefficients indicate moderate to high levels of internal reliability (.68 to .90) at T1. The Cronbach's Alpha Coefficients at T2 also have moderate to high levels of reliability (.77 to .92). Two Illness Intrusiveness Measures, (Physical Wellbeing and Diet) and (Work and Finances) have low reliability levels at .52 and .58 respectively.

The following section describes the health status, self-efficacy for managing chronic disease, health behaviours and health care utilisation of course participants at the commencement of the course.

Forty-two (45%) of the participants rated their health as good, 36 (38%) rated their health as poor to fair, and 16 (17%) rated their health as very good to excellent ($n=94$) ($M = 3.23$, $SD = .80$) ($n=94$).

Nearly three-quarter of the participants, 66 (74%) reported low energy levels the previous month ($M = 1.97$, $SD = .79$) ($n=89$). Forty-two (46%) of the participants indicated that they never or hardly ever felt distressed about their health in the previous month, while 40 (47%) indicated that they “sometimes, or usually” were distressed and 8 (8%) indicated that they were “always or mostly” experiencing ‘health distress’ ($M = 2.10$, $SD = 1.14$) ($n = 90$).

In regards to fatigue, at T1, 57 (62%) of the participants scored their “fatigue” between 0 and 5, and 38% scored it from 6 to 10. A higher score denoted more “fatigue” ($M = 4.98$, $SD = 2.11$) ($n = 92$).

On a scale of 0 to 10, the majority of participants 82 (88%) scored their “shortness of breath” between 0 and 5, while 11 (12%) of the participants scored it from 6 to 10. A higher score indicated more severe “shortness of breath” symptoms. The results suggested that this symptom was not a major health problem for participants ($M = 2.10$, $SD = 1.14$) ($n = 93$). Pain scores were evenly spread amongst the participants. Forty-seven (50%) participants scored their “pain” level between 0 and 5 and similarly, 47 (50%) of the participants scored their “pain” between 6 to 10 on the scale. Pain symptoms were moderately high at T1 ($M = 5.03$, $SD = 2.85$) ($n = 94$.)

The majority, 75 (81%) of the participants scored their “physical abilities” as either 0 or 1 which indicates that they could perform certain tasks “without” or “with some” difficulty ($M = .49$, $SD = 0.44$) ($n = 92$). Whereas moderate levels of “social role activities limitations” were noted ($M = 1.77$, $SD = .98$). In general, participants indicated some “illness intrusion” due to their disease symptoms and treatment ($M = 3.04$, $SD = 1.3$) ($n = 89$).

The level of confidence participants had in their ability to manage their chronic disease was indicative of their baseline “self-efficacy to manage their chronic disease” level. Results showed average confidence levels to manage chronic disease and to deal with the symptoms thereof ($M = 5.42$, $SD = 2.11$) ($n = 87$).

Self-management skills associated with “cognitive symptom management” were low at the commencement of the course ($M = 1.42, SD = .94$) ($n = 83$) and participants had some abilities to “communicate with the doctor” ($M = 2.59, SD = 1.29$) ($n = 91$).

Of the 94 participants at baseline, 84 (89%) did “stretching and strengthening” exercises every week ($M = 25.71, SD = 39.00$). Also, 65 (69%) participants did weekly “aerobic exercise” ($M = 99.00, SD = 99.31$) ($n = 94$).

Actual “doctors’ visits” over the previous six months ranged from 0 to 30 visits ($M = 4.62, SD = 4.87$) ($n = 92$). Visits to the “emergency department” over the previous six months ranged between 0 and 2 ($M = .10, SD = .34$) ($n = 90$). The number of times participants had been “hospitalised” over the previous six months ranged between 0 to 3 times ($M = .14, SD = .44$) ($n = 90$). Participants indicated that their total number of “nights spent in hospital” in the previous six months had been between 0 and 15 times ($M = .52, SD = 2.04$) ($n = 90$). The number of nights that participants had spent in a “nursing home or minimum care facility” ranged from 0 to 21 nights ($M = .39, SD = 2.40$) ($n = 88$). The number of times that participants had attended “other urgent care” facilities ranged between 0 and 5 times ($M = .24, SD = .95$) ($n = 91$).

3.4 Inferential Data Analyses

RESEARCH QUESTION 1

The relationships between the variables were examined using Pearson Product Moment Correlation Coefficients. Multiple Regression procedures were used to test if self-efficacy was related to health status, health behaviour and health care utilisation.

Bivariate Correlations

To answer Question 1, Pearson Product Moment Correlation Coefficients (correlation) were conducted between self-efficacy and the health status variables, health behaviour variables and health care utilisation variables (See Table 3.1)

The correlation between self-efficacy for managing chronic disease and energy/fatigue was moderate, significant and positive suggesting that as self-efficacy increases so

energy levels increased ($r = .46, p <.001$) ($n = 83$). A moderate, significant negative correlation was found between self-efficacy and health distress, indicating that as self-efficacy was enhanced so the participants' distress about their health decreased ($r = -.41, p <.001$) ($n = 85$). A moderate, significant negative correlation between self-efficacy and fatigue over the previous two weeks was found, indicative that enhanced self-efficacy for managing chronic disease was related to a reduction in fatigue ($r = -.41, p <.001$) ($n = 86$). A weak to moderate, significant negative correlation was found between self-efficacy for managing chronic disease and daily activities ($r = -.33, p <.01$), suggesting that enhanced self-efficacy was related to a decrease in the amount that the participants' illness affected their daily activities ($n = 85$).

Weak, significant, negative correlations were found between self-efficacy and each of the following health status variables: self-rated health ($r = -.27, p <.01$) ($n = 87$), shortness of breath ($r = -.22, p <.05$) ($n = 87$), self-efficacy and pain the previous two weeks ($r = -.27, p <.01$) ($n = 87$), physical abilities ($r = -.25, p <.05$) ($n = 86$), and perceived illness intrusiveness ($r = -.26, p <.05$) ($n = 83$). In each case this indicated that as self-efficacy for managing chronic disease increased so these symptoms decreased.

But, self-efficacy had no relationship with any of the following: cognitive symptom management, communication with the doctor, stretching/strengthening exercise or aerobic exercise. It did however have a weak to moderate, significant negative correlation with visits to the doctor ($r = -.26, p <.05$) ($n = 85$), suggesting that increased self-efficacy was related to a decrease in doctors' visits.

Regression Analyses

To determine if self-efficacy at baseline (Self-EfficacyT1) was related to health status (Health StatusT1), cognitive symptom management (CSMT1) and communication with the doctor (CDrT1), a series of multiple regressions were conducted. Before each analysis multivariate assumptions were checked. All these assumptions were met.

Table 3.1
 Pearson Product-Moment Correlation Coefficients Among Self-Efficacy and Health Status Variables at Baseline

		1	2	3	4	5	6	7	8	9	10
1	Self-Efficacy	--	-.27*	.46**	-.41**	-.41**	-.22*	-.27*	-.25*	-.33**	-.26*
2	Self-Rated Health		--	-.26*	.44**	.42**	.28**	.04	.20	.22*	.27*
3	Energy/Fatigue			--	-.45**	-.66**	-.07	-.50**	-.26**	-.47**	-.47**
4	Health Distress				--	.44**	.23*	.51**	.43**	.45**	.43**
5	Fatigue					--	.18	.49**	.37**	.42**	.54**
6	Shortness of Breath						--	.16	.13	.17	.16
7	Pain							--	.65**	.52**	.46**
8	Physical Abilities								--	.47**	.39
9	Activities Limitation									--	.65**
10	Illness Intrusiveness										--

* Correlation is significant at the .05 level (two-tailed)

** Correlation is significant at the .01 level (two-tailed)

Due to the exploratory nature of this pilot study and the primacy of any of the health status variables not yet established, a stepwise regression was chosen for the regressions. To determine if Self-EfficacyT1 was related to CSMT1 and CDrT1, standard multiple regressions were run.

Regressions were not run on exercise or health care utilisation outcomes due to their abnormal distributions, indicating that they did not meet multiple regression assumptions for normal distributions. Tabachnick and Fidell (2000) recommend transformation of variables with abnormal distributions. However, based on the exploratory nature of this study, and the small sample at T2, these transformations were not carried out.

Independent variables that were highly intercorrelated were not included in the regression equation. These correlations were: “pain in the past two weeks” (PainT1) with “health distress” (Health DistressT1) which was a moderate to strong, significant positive correlation ($r = .51, p <.001$) ($n = 90$); PainT1 with “physical abilities” (PhAbT1) which was a strong, significant positive correlation ($r = .65, p <.001$) ($n = 92$); PainT1 with “daily activities” (DailyActT1) which was a moderate to strong significant positive correlation ($r = .52, p <.001$) ($n = 91$); “Fatigue in the past two weeks” (FatigueT1) had a strong, significant negative correlation with “energy/fatigue” (Energy/FatigueT1) ($r = .66, p <.001$) ($n = 88$), while FatigueT1 correlated with “perceived illness intrusiveness” (PIIT1) showed a moderate to strong, significant positive correlation ($r = .54, p <.001$) ($n = 88$).

Regression of Self-EfficacyT1 on Health Status Variables

To see if Self-EfficacyT1 was related to Health Status T1 a stepwise regression was run. Self-EfficacyT1 was regressed on the following health status variables at T1: energy/fatigue (Energy/FatigueT1), health distress (Health DistressT1), self-rated health (SRHT1), physical abilities (PhAbT1), and perceived illness intrusiveness (PIIT1). Health DistressT1 and Energy/Fatigue T1 were the only significant predictors of Self-Efficacy at baseline. As displayed in Table 3.2, in the final model, Self-EfficacyT1 was significantly related to Health DistressT1 and Energy/FatigueT1, and accounted for

27% of the variance, Adjusted $R^2 = .267$, $F(2,75) = 15.04$, $p < .001$. Lower levels of “health distress” were related to higher self-efficacy scores, while higher “energy” levels were related to higher self-efficacy scores.

Regression of Self-EfficacyT1 on Cognitive Symptom Management

To assess if Self-EfficacyT1 was related to CSMT1 a standard multiple regression was conducted. Self-EfficacyT1 was regressed on CSMT1. As shown in Table 3.2, no significant results were obtained, which indicated that self-efficacy, was not related to cognitive symptom management at T1.

Regression of Self-EfficacyT1 on Communication with the Doctor

To determine if Self-EfficacyT1 was related to CDrT1 a standard linear regression was conducted. Self-EfficacyT1 was regressed on CDrT1. As shown in Table 3.2, results were non-significant indicating that self-efficacy at baseline was not related to communication with the doctor.

Table 3.2

Results for Self-Efficacy at T1 Regressed onto Health Status and Health Behaviour Variables at T1

Variable	Beta	R	R ²	Adj.R ² .
Health Distress	-.328*	.535	.286	.267
Energy/Fatigue	.286*	.108	.012	-.001
Cognitive Symptom Management	.108	.173	.030	.018
Communication with the Doctor	.173			

$p < .05^*$

RESEARCH QUESTION 2

To assess the mediation effect of self-efficacy at T2 (Self-EfficacyT2) between *LHL* and the health status variables, a stepwise regression was run on health status variables at T2, while holding Self-Efficacy at T1 constant.

To test the mediation effect of self-efficacy at T2 (Self-EfficacyT2) between *LHL* and health behaviours two hierarchical stepwise regressions were run respectively, on

“cognitive symptom management” (CSMT2) and on “communication with the doctor” (CDrT2), while controlling for Self-EfficacyT1.

Regression of Self-EfficacyT2 on Health Status Variables

Self-efficacy for managing chronic disease at T2 (Self-EfficacyT2) was regressed onto the following health status variables at T2: “energy/fatigue” (Energy/FatigueT2), “health distress” (Health DistressT2), “self-rated health” (SRHT2), “physical abilities” (PhAbT2) and “perceived illness intrusiveness” (PIIT2), while controlling for Self-EfficacyT1.

As shown in Table 3.3, in Model One, Self-EfficacyT2 explained 42% of the variance in Self-EfficacyT1 and was statistically significant, Adjusted $R^2 = .417$, $F(1,54) = 40.363$, $p < .001$.

In Model Two, which controlled for Self-EfficacyT1, Self-EfficacyT2 was significantly related to PIIT2 and accounted for an additional 58% of the variance, Adjusted $R^2 = .584$, $F(2,53) = 39.630$, $p < .001$ (See Table 3.2). Perceived Illness Intrusiveness improvements were related to improvements in self-efficacy at T2.

Regression of Self-EfficacyT2 on Cognitive Symptom Management

To assess the mediation effect of self-efficacy at T2 (Self-EfficacyT2) between *LHL* and the cognitive symptom management (CSMT2), a hierarchical stepwise multiple regression was carried out. Self-EfficacyT2 was regressed onto (CSMT2) while holding Self-EfficacyT1 constant.

As shown in Table 3.3 in Model One, Self-EfficacyT2 accounted for 39% of the variance in Self-EfficacyT1, Adjusted $R^2 = .390$, $F(1,57) = 38.058$, $p < .001$.

From Table 3.3 it can be seen that in Model Two, which controlled for Self-EfficacyT1, that CSMT2 accounted for no additional variance.

Regression of Self-EfficacyT2 on Communication with the Doctor

To assess the mediation effect of self-efficacy at T2 (Self-EfficacyT2) between *LHL* and communication skills with the doctor CDrT2, a hierarchical stepwise multiple regression was carried out. Self-EfficacyT2 was regressed onto CDrT2, while holding Self-EfficacyT1 constant.

As shown in Table 3.3, in Model One, Self-EfficacyT2 explained 40% of the variance in Self-EfficacyT1, Adjusted $R^2 = .402$, $F(1,59) = 41.386$, $p < .001$.

From Table 3.3 it can be seen that in Model Two, which controlled for Self-EfficacyT1, that CDrT2 accounted for no additional variance, as results were non-significant.

Table 3.3

Results for Self-Efficacy at T2 Regressed onto Health Status and Health Behaviour Variables at T2

Variable	Beta	R	R ²	Adj.R ²
Self-EfficacyT1	.654***	.654	.428	.417
Perceived Illness Intrusiveness	-.471***	.774	.599	.584
Self-EfficacyT1	.633***	.633	.400	.390
Cognitive Symptom Management	.059	.635	.404	.382
Self-Efficacy T1	.662***	.642	.412	.402
Communication with the Doctor	-.196	.671	.450	.431

$p < .001$ ***

RESEARCH QUESTION 3

Table 3.4 shows the paired t-test results to determine if participation in *LHL* improved health status, enhanced self-efficacy, and improved health behaviours such as self-management. Statistically significant mean differences between T1 and T2 are indicated in the table. Wilcoxon matched-pairs signed-ranks tests were conducted on two skewed variables: exercise behaviour and the health care utilisation.

Table 3.4

Means, *SD*, Cronbach's Alpha Coefficients for *LHL* Outcome Measures with Significant Changes Indicated at Six Months

Outcome Measures	Time One (Baseline)				Time Two (6 months)			
	n	M	SD	α	n	M	SD	α
<u>Health Status</u>								
Self-Rated Health (Scale 1-5) ↓= better	94	3.23	0.80		67	3.36	0.75	
Energy/Fatigue (Scale 0-5) ↑= better	89	1.97	0.79	0.72	66	2.00	0.84	0.76
Health Distress (Scale 0-5) ↓= better	90	2.10	1.14	0.86	66	1.94	1.16	0.88
Fatigue Visual Numeric (Scale 0-10) ↓= better	92	4.98	2.11		63	5.35	2.30	
Shortness of Breath Visual Numeric (Scale 0-10) ↓= better	93	2.05	2.31		64	2.72	2.73	
Pain Visual Numeric (Scale 0-10) ↓= better	94	5.03	2.85		64	5.09	2.70	
Physical Abilities (Disability) (Scale 0-3) ↓= better	92	0.49	0.44	0.88	66	0.48	0.47	0.88
Activities Limitations (Scale 0-4) ↓= better	91	1.77	0.98	0.84	66	1.91	1.08	0.92
Intrusiveness: Physical Wellbeing & Diet (Scale 1-7) ↓= better	94	3.31	1.70	0.68	67	3.26	1.54	0.52
Intrusiveness: Work & Finances (Scale 1-7) ↓= better	93	3.76	1.85	0.72	67	4.11	1.74	0.58
Intrusiveness: Marital, Sexual, Family Relations (Scale 1-7) ↓= better	90	2.56	1.60	0.75	63	3.02	1.98	0.87
Intrusiveness: Recreational & Social Relations (Scale 1-7) ↓= better	93	3.47	1.48	0.71	67	3.78	1.62	0.81
Intrusiveness: Other Aspects Of Life(Scale 1-7) ↓= better	92	2.60	1.44	0.67	66	2.94	1.64	0.79
Perceived Illness Intrusiveness ↓= better	89	39.54	16.79	0.90	63	40.46	17.48	0.92
<u>Self-Efficacy</u>								
Self-Efficacy For Managing Chronic Disease (Scale 1-10) ↑= better	87	5.42	2.11	0.90	65	5.69	2.08	0.92
<u>Self-Management Behaviour</u>								
Cognitive Symptom Management (Scale 0-5) ↑= better	83	1.43	0.94	0.80	63	1.89*	1.00	0.81*
Communication With Physician (Scale 0-5) ↑= better	91	2.59	1.29	0.79	65	2.94*	1.30	0.77*

* $P < .05$ paired t-tests, two-tailed.

Health Status

As noted in Table 3.4 no significant improvements occurred in the following health status outcomes: “self-rated health”, “energy/fatigue”, “health distress”, “fatigue”, “shortness of breath”, “pain”, “physical abilities”, “activities limitations” and “perceived illness intrusiveness”.

Self-Efficacy

The increase that occurred in “self-efficacy” was not statistically significant. (See Table 3.4).

Health Behaviour: Self-Management

There were statistically significant differences in the means of two health behaviours at T2: “cognitive symptom management” and “communication with the doctor” (See Table 3.4).

Cognitive Symptom Management

Participants had significantly increased their practice of cognitive symptom management six months after participation in *LHL*, $t(58) = .1395, p < .05$.

Communication with the Doctor

Significant improvements were shown in the means of participants’ communication with their doctor six months after participation in *LHL*, $t(63) = 2.701, p < .05$.

Health Behaviour: Exercise

Some minor improvements were found in the mean number of minutes that participants spent doing stretching and strengthening exercises. At T1, 49 (58%) ($n=84$) of the participants spent time doing stretching and strengthening exercises ($M = 25.71, SD = 39.00$). At T2 the percentage of participants participating in stretching and strengthening exercise increased substantially, 44 (72%) ($n=61$). The time that participants actually spent doing the stretching and strengthening exercises, increased by 3.8 minutes per week from T1 to T2 ($M = 29.51, SD = 41.08$).

Aerobic Exercise

Statistically significant differences were found in the times participating in aerobic exercise between T1 and T2, as indicated by Wilcoxon matched-pairs signed-ranks ($z = 2.423$, $N - \text{Ties} = 25$, $p < .05$, two-tailed).

Improvements were detected in both the time spent doing aerobic exercise, and the number of participants who were exercising. Participants spent 11 minutes more time per week on aerobic exercise such as walking, swimming, bicycling or using exercise equipment at T2 compared with T1. Also, at T1, 65 (69%) ($n = 94$) of the participants took part in aerobic exercise ($M = 99.00$, $SD = 99.31$), while at T2 the number of participants had increased to nearly three-quarters of the T2 participants 48 (72%) ($n = 67$) ($M = 110.00$, $SD = 100.09$).

Health Care Utilisation

Visits to the Doctor

Wilcoxon matched-pairs signed-ranks show that the number of visits to the medical doctor decreased significantly at T2 ($z = 2.048$, $N - \text{Ties} = 50$, $p < .05$).

Visits to the Emergency Room Department

Wilcoxon matched-pairs signed-ranks show that the number of times participants attended a hospital emergency department decreased significantly at T2 ($z = 2.496$, $N - \text{Ties} = 10$, $p < .05$).

No significant changes occurred in the “number of nights participants were hospitalised”, the “total nights participants spent in hospital”, the “total nights participants spent in a nursing home or minimum care facility”, and the “number of times participants attended other urgent care” over the previous six months.

Research Question 4

Independent t-tests were conducted to test if there were any significant differences between men and women, between those participants fifty years and younger, and those over fifty years old, and between those participants living in the North Island or South Island of NZ, in terms of “health status”, “health behaviour” and “health care utilisation outcomes” at T1 and T2 (See Appendix H).

Assumptions of t-tests were met. The independent t-tests results showed significant differences in the means, on average between men and women, between those fifty years and under, and those over fifty years; and between participants from the North Island and the South Island of NZ. The Mann-Whitney U-test was used to compare the data where assumptions of normality were not satisfied. Brace et al. (2003) state that the Mann-Whitney test is “the non-parametric equivalent of the independent t-test” and useful for data that is skewed (p.71).

Health Status

At T1, women reported they had significantly less “energy” ($M = 1.89, SD = .76$) than men ($M = 2.46, SD = .70$), $t(85) = 2.731, p < .01$.

Significant differences were found between participants who were fifty and under ($M = 3.59, SD = .93$) who rated their health more poorly at T1 than did those participants over fifty ($M = 3.06, SD = .93$) $t(38) = 2.67, p < .01$. They had less “energy” ($M = 1.71, SD = .87$) than the older group ($M = 2.11, SD = .70$), $t(83) = 2.23, p < .05$. At T1 they also described having had more “fatigue” over the previous two weeks ($M = 5.69, SD = 2.13$) than those over fifty ($M = 4.55, SD = 1.98$), $t(86) = 2.41, p < .05$. The younger group reported that their “illness intruded” significantly more on various aspects of their lives, compared with those fifty years and older ($M = 47.81, SD = 15.38$) ($M = 34.94, SD = 15.72$), $t(84) = 3.54, p < .01$.

At T1, South Island participants described having had significantly more “fatigue” during the previous two weeks ($M = 5.36$, $SD = 1.98$) compared to North Island participants ($M = 4.39$, $SD = 2.21$), $t(90) = 2.19$, $p < .05$.

Self-Efficacy

The means between gender, age, location and “self-efficacy” at T1 or T2 were not significant.

Health Behaviour

No differences were found between men and women in regards to their health behaviours.

At T1, participants over fifty years old were able to utilise “cognitive symptom management” skills better ($M = 1.59$, $SD = 1.00$) than those participants fifty and under ($M = 1.19$, $SD = .68$), $t(70) = 2.06$, $p < .05$. This was also the case at T2 ($M = 2.07$, $SD = 1.14$) compared to people fifty years and younger ($M = 1.59$, $SD = .56$), $t(58) = 2.19$, $p < .05$.

At T1, participants from the North Island were able to utilise “cognitive symptom management” skills better ($M = 1.68$, $SD = 1.06$) than the participants in the South Island ($M = 1.26$, $SD = .81$), $t(81) = 2.04$, $p < .05$. At T2, South Island participants were able to communicate better with their doctors ($M = 3.23$, $SD = 1.10$) than participants in the North Island ($M = 2.51$, $SD = 1.47$), $t(63) = 2.24$, $p < .05$.

Health Care Utilisation

There were no significant differences between men and women or between participants living in the North or South Islands of NZ in terms of “visits to the medical doctor”, number of visits to the hospital “emergency” department, number of times “hospitalised”, total “nights spent in hospital”, total nights spent in a “nursing home” or “minimum care facility” or other “urgent care”.

There was a significant difference between the number of times those participants fifty years and under went to other “urgent care”, compared to those over fifty years old, both at T1 ($U = 695.000, p < .05$) and at T2 ($U = 298.000, p < .05$).

Research Question 5

To answer question five and for process evaluation, feedback was obtained from participants about aspects of the course delivery and the course in general.

Course Evaluation

The mean scores for all items related to the various delivery aspects of the *LHL* course were generally high, indicating overall satisfaction with the course. Using a ratings scale from “strongly disagree” (1) to “strongly agree” (7) the majority of participants indicated that the course was overall worthwhile ($M = 5.64, SD = 1.332$); the course length was satisfactory ($M = 5.80, SD = 1.406$); the length of each session was acceptable ($M = 6.08, SD = 1.266$); and the course venue was satisfactory ($M = 6.19, SD = 1.220$). The highest score obtained was for satisfaction with the course leaders ($M = 6.40, SD = 1.170$). The majority indicated that they would recommend the course to others because of its high quality ($M = 6.11, SD = 1.301$). Participants indicated that after taking the course they had gained some confidence in their ability to cope with their health ($M = 4.98, SD = 1.641$).

Course Presentation

When asked by whom the course should be taught 36 (60%) of the participants indicated that they would like the course to be taught by one health educator and one peer (lay leader), 19 (32%) supported having health educators alone teach the course and 5 (8%) supported the course being taught by peer (lay) leaders only.

Family Support and Barriers

Forty-nine (80%) of the participants had support from their family, loved ones or significant others to participate in the course, while 12 (20%) participants had no support. Forty-nine (80%) had no barriers or obstacles to overcome to attend the course. Twelve (20%) of the people who did have barriers provided feedback about these barriers as being: “money and babysitters”, “bad headaches”, “fatigue after a day’s

work”, “pain”, “parking problems”, “unwell”, “every week for so many weeks”, “transport”, “being able to attend each week (no other choices of times of day)”, and “I had to take my Swiss ball, it was more comfortable to sit on than a chair”. Transport was identified as a common problem for participants.

Course Attendance

Fifty (79%) of the participants attended all six sessions of *LHL*, 10 (16%) missed one session and 3 (5%) missed two or more sessions (n = 63).

Chapter 4 Discussion

4.1 Overview

This study investigated the process and impact of *LHL*, a chronic disease self-management course, which is designed to help people with chronic disease to cope better with various aspects of their health.

The most striking findings of this study were the significant improvements that occurred in the participants' ability to use cognitive symptom management skills, to communicate appropriately with the doctor, to increase aerobic exercise time, and to decrease doctors' visits. These significant improvements corroborate similar studies elsewhere (Dongbo et al., 2003; Lorig & Holman, 1992, 2000; Lorig et al., 2001; Lorig, Sobel et al., 1999; McGowan, 2001; Wright et al., 2003).

Moreover, in accordance with self-efficacy theory, the results showed significant support for a relationship between self-efficacy and health status, and also provided support for the mediational role of self-efficacy. Lorig and Holman (2000) state that for health behaviours, pain levels, disability, fatigue, health distress and health care utilisation to significantly improve, self-management courses should be presented in reliable and consistent ways. However, in this study, significant behavioural changes occurred regardless of the confidence participants had in their ability to deal with their chronic conditions. This chapter explores these interesting and unanticipated findings.

The first research goal was to investigate if the confidence participants had in their ability to manage their chronic disease at the onset of the course was related to their health status at that time. Self-efficacy and energy levels were significantly and moderately related suggesting that as the participants' confidence in their ability to manage their disease increased so too did their energy levels. Moderate, significant inverse correlations between the participants' confidence in their ability to manage their disease and the extent of their health distress were found, which suggested that as the

participants' self-efficacy to manage their chronic disease increased, so their feelings of distress associated with their health decreased. Similarly the moderate, significant inverse correlation between self-efficacy and fatigue suggested that as the self-efficacy increased, so fatigue levels decreased.

A weak to moderate, significant inverse correlation was found between self-efficacy for managing chronic disease and the social role activities limitations. This implied that when the confidence participants had in their ability to manage their disease increased, a decrease occurred in the amount that the participants' illness affected their daily activities. Similar inverse relationships were found between self-efficacy and each of the following health status variables: "self-rated health", "shortness of breath", "pain during the previous two weeks", "physical abilities" and "perceived illness intrusiveness". In each case the inverse relationship indicated that as the participants' self-efficacy for managing chronic disease was enhanced, so these respective symptoms decreased.

The confidence participants had in their ability to manage their disease had no significant relationships with cognitive symptom management, communication with the doctor, stretching/strengthening exercise or aerobic exercise. These results suggest that the significant improvements noted in three health behaviours of the participants occurred regardless of the confidence they had in their ability to manage their chronic disease. Self-efficacy had a weak to moderate, significant inverse correlation with visits to the doctor suggesting that as self-efficacy increased so doctor's visits decreased.

To further investigate the relationship between self-efficacy and the health outcomes, the regression analyses showed that self-efficacy to manage chronic disease was related to health status, particularly the distress participants experienced about their health and their levels of energy. Self-efficacy contributed to over a quarter of the variance (27%) in 'health distress' and "energy/fatigue" levels and the relationship was unlikely to be due to chance. Moreover, the relationship between self-efficacy and these two health status variables was in the expected direction, showing that a decline in self-efficacy

was related to worsening feelings of distress about health, and to improved energy levels. These results are in accordance with studies carried out by Lorig and colleagues (Lorig & Holman, 2000). These results were consistent with the findings at the bivariate level.

The relationship between self-efficacy and energy levels were the strongest, and contributed to 21% of variance, while the relationship between self-efficacy and health distress was weaker, and explained 16% of the variance. Particularly important in the context of self-management and health status, is the belief people have in their efficacy to control matters that impact on their everyday lives (Bandura, 1986). As shown from these results, the perceived self-efficacy of the participants at baseline was related to health distress and energy levels. While it is not possible to infer a definitive causal directionality of the observed effects, these findings are consistent with an expanding body of literature, which asserts that self-efficacy exerts an effect on the functional status and health behaviours of people with chronic disease (Holman & Lorig, 1992). The significant relationships found between baseline self-efficacy and baseline health status variables, provide some support for self-efficacy theory; that self-efficacy and health status are related, albeit that the significant relationship was only evident in a few health status variables.

The stepwise regressions showed no support for a relationship between the baseline self-efficacy of course participants and two self-management skills: “cognitive symptom management” and “communication with the doctor” respectively. The reason for the absence of empirical support in the regressions for this relationship is unclear and requires further investigation. The lack of this relationship suggests that the participants’ self-efficacy to manage their chronic disease was not directly related to their ability to use self-management skills. Correlational findings supported the non-significant relationships. Yet, the literature abounds with examples of self-efficacy and health behaviour relationships, especially the ability of self-efficacy to predict enhanced health behaviour changes (Bandura, 1997; Maddux, 1995; Schwarzer, 1992). These

non-significant results may be a function of the research design, the participants, the measures used in this study or the inferential statistics chosen for the data analyses.

The second research goal was to test the mediational hypotheses of self-efficacy that participation in *LHL* would affect the self-efficacy of the participants to manage their chronic disease and in turn would affect their health status six months after completion of the course. Similarly, that participation in *LHL* would affect the self-efficacy of the participants to manage their chronic disease and in turn would affect their health behaviours, specifically self-management skills, six months after completion of the course.

A stepwise regression was run to determine the mediational effect of self-efficacy on health status six months after the intervention. The participants' self-efficacy was regressed onto their health status variables, both at six months, while baseline self-efficacy was held constant. The stepwise regression analyses showed a significant relationship, accounting for an additional 58% of variance, between self-efficacy and the way that participants perceived their illness and how its treatment intruded on various aspects of their everyday lives. These highly significant regressions provided support for a mediational effect of self-efficacy on the health status of participants. The mediation effects occurred in the desired direction. It seems that, as hypothesised, the relationship between *LHL* and health status was mediated by self-efficacy.

As alluded to in the literature review, the mediational role of self-efficacy and health behaviour change has been demonstrated in numerous studies, for example, arthritis rehabilitation (Marks, 2001); post-cardiac infarction (Ewart, 1992); chronic disease management (Lorig, Sobel et al., 1999); compliance with medication (Brus, Van der Laar, Taal, Rasker, & Wiegman, 1999) and health status (Holman & Lorig, 1992). The data for this study was collected from a longitudinal study, at baseline and again six months later. The repeated measures design provided stronger support for a causal relationship, particularly as self-efficacy at baseline effect was held constant during the mediation analyses. Thus, the results of these regression analyses support to some extent, self-efficacy theory that, as a result of participation in the *LHL* intervention,

participants were able to cope better with the extent that their illness intruded on their lives (Lorig & Gonzalez, 1992; Bandura, 1986).

Hierarchical stepwise regressions were run to test for the mediation effect of self-efficacy six months after the *LHL* course finished on the two health behaviour variables. The first hierarchical regression involved regressing the self-efficacy of participants at six months on a self-management behaviour involving “cognitive symptom management” at six months, while controlling for baseline self-efficacy. The regression showed a non-significant relationship between self-efficacy and “cognitive symptom management” which accounted for no additional variance. This result indicated that the significant changes that were observed in the “cognitive symptom management” skills of the participants’ six months after participation in *LHL*, cannot be attributed to the mediating role of self-efficacy.

The second hierarchical stepwise regression tested for the mediation effect of self-efficacy at six months on the self-management skill “communication with the doctor”. The self-efficacy of the participants six months after participation in the course was regressed on “communication with the doctor” at six months, while holding the baseline self-efficacy constant. The mediational theory was not supported: “communication with the doctor” accounted for no additional variance as the results were non-significant.

It is surprising that the regression analyses did not support the mediational hypothesis between *LHL* and the health behaviours of participants, despite their significant behaviour changes that occurred at six months in: “cognitive symptom management,” “communication with the doctor” and “aerobic exercise”. These unexpected results suggest that these significant behavioural changes occurred irrespective of the mediational role of self-efficacy as found in other studies (Arnstein, 2000; Arnstein et al., 1999; Lorig, Sobel et al., 1999).

The third research goal was to determine if participation in *LHL* improved the participants’ health status, their self-efficacy, self-management and health behaviours,

and whether any changes occurred in the health care utilisation of participants. It is surprising that no significant improvements occurred in health status outcome measures of the participants and even more surprising is that the self-efficacy of participants to manage their chronic disease did not improve significantly. However, significant improvements were evident in the ability of the participants to employ cognitive skills to manage the symptoms of their disease and to use appropriate communication skills with the doctor. During *LHL* the patient-doctor relationship was enhanced by teaching participants appropriate communication skills with their health professional to augment the notion of collaborative care (Holman, 2000). Significant improvements occurred in the communication skills of the participants, which can possibly be attributed to participation in the course.

Significant improvements occurred in the time spent doing aerobic exercise and the number of times participants visited the doctor in the last six months. These improvements in self-management skills, health behaviours and the reduction in health care utilisation is in accordance with the findings of other researchers (Lorig & Gonzalez, 1992; Lorig & Holman, 1989, 1992; Lorig et al., 1993; Lorig et al., 2001; Lorig, Sobel et al., 1999).

However, both the non-significant findings in the health status of the participants and the self-efficacy of the participants are unexpected. Lorig and Holman (2000) assert that “both baseline self-efficacy and changes in self-efficacy are associated with future health status. Thus it appears that enhanced self-efficacy is at least one of the mechanisms responsible for the improvements in health status demonstrated by those attending self-management programs” (p.15). Based on Lorig’s assertion, the non-significant improvements in health status can be attributed to (a) the baseline confidence that participants had in their ability to manage their chronic disease (which in this case was average) and (b) that attendance at the *LHL* course made no impact on the participants’ self-efficacy. These non-significant findings therefore need further investigation.

What is unclear in these results, is that it seems that participation in *LHL* improved the participants' health behaviours regardless of: (a) a significant relationship between the confidence that participants had in their ability to manage their health problems and their self-management behaviours, or (b) the mediational affect of self-efficacy between *LHL* and the participants self-management behaviours, or (c) significant changes in self-efficacy at baseline and 6 months later. These unanticipated findings are contrary to self-efficacy theory which states that "the strength of belief in one's capability is a good predictor of future motivation and behaviours" (Lorig & Holman, 2000, p.15).

As described in this literature review self-efficacy can be viewed in terms of magnitude, strength and generality, and the majority of studies assess the strength dimension, which was also the case in this project. The strength dimension refers to the confidence that people have in their ability to execute certain behaviours in specific circumstances (Maddux, 1995). Bandura (1977) emphasises that the potency or strength of perceived self-efficacy is not a linear relationship to a given behaviour. This notion suggests that the perceived confidence that people have in their ability to carry out a task or behaviour can vary according to the degree of difficulty of the task or behaviour and the degree of the strength of their belief.

According to Bandura (1997) the non-linear relationship exists because people need to reach their unique self-efficacy threshold before trying the task or behaviour. Bandura also asserts that higher levels of self-efficacy may not necessarily increase the likelihood of carrying out the task or behaviour. In this study multiple regression assumptions for multivariate normality were met but it is possible that some of the participants had not reached their particular self-efficacy threshold, and hence a non-linear relationship exists. As their performance mastery improves the relationship will become more linear and manifest as being significant. Should this be the reason for the non-significant relationships, enhancement of skills mastery during the *LHL* course needs to be addressed.

Also, Bandura (1997) states that empirical support suggests that if individuals wrongly assess their self-efficacy beliefs, then in general, their self-efficacy beliefs surpass their behaviour. But in evaluative situations or in situations where group or social observations are carried out, actual behaviour may exceed self-efficacy judgements. These observations may partially provide an explanation for the unexpected “self-efficacy” findings in this study. Did the participants in this study provide conservative appraisals of their self-efficacy, because they perceived the research situation as “evaluative”, despite their health behaviour changes. From Bandura’s tenet, it appears that as individuals improve their self-knowledge over time, evaluative factors become irrelevant, and their health behaviors become more aligned to self-efficacy judgements. It would be of interest, in the future, to ascertain, whether the self-efficacy beliefs of the participants had become aligned with the significantly improved behavioural changes that occurred in this study.

Schwarzer (1992) emphasises that during the behaviour change process individuals move through two distinct stages: a motivational and a volition stage. Perceived self-efficacy is crucial for each stage. Schwarzer proposes that self-efficacy and outcome expectancies are the most important predictors of intentions, and that there may be a temporal and causal order between the two constructs. Schwarzer suggests that if people have no prior experience in the health behaviour they are considering (as may have been the case in this study) then outcome expectancies may supersede self-efficacy in terms of influence. Once the behaviour has been sufficiently mastered, the effect of self-efficacy becomes more significant for developing an intention. Schwarzer emphasises the importance of determining at what stage individuals are within the behaviour change process when developing intervention programmes.

Conversely, in regards to stage theories, Bandura (2000) states “the behaviouristic, psychodynamic and existential theories, from which this ‘transtheoretical’ collection is forged, offer contradictory prescriptions on how to change human behaviour. The menagerie of interventions is not transtheoretical, which implies an over-reaching integration of seeming diversity. It is atheoretical.” (p.311). Bandura emphasises that

“effective interventions must target the constellation of determinants governing health habits in given individuals, not contrived stages” (p.311). Yet, the presumed utility of the stage models lies in their ability to direct the designs of interventions. This is done so that people receive health promotion programmes that are matched to their readiness to change, thus maximising the impact of the specific intervention on a particular behaviour (Abraham, Norman, & Conner, 2000).

As mentioned in the literature review, Battersby, Reece et al. (2003) incorporate a stage approach in their self-management programme. Also, Oldenburg et al. (1999) state that social cognitive theory can be useful for gaining insight into the various stages involved in behaviour change. DiClemente et al. (1991) have shown that self-efficacy varies across the various stages of change, and is characteristically lowest in the precontemplation stage. At that stage, people have had little or no feedback about their performance, or have no intention to change their health behaviour (Redding & Rossi, 1999). Despite these contradictory views about stage theories, *LHL* may have been ineffective for changing the self-efficacy of individuals who were in the early stages of “precontemplation” or “contemplation stage” for health behaviour change, hence the absence of significant improvements in self-efficacy at six months (Ockene, Ockene and Kristeller, 1988, cited in Oldenburg et al., 1999) and (Ershof, Mullen and Quinn, 1989, cited in Oldenburg et al., 1999).

The aforementioned discussion still provides no clear answer to why the health outcomes in this study occurred regardless of significant self-efficacy relationships or changes. Lorig and Holman (2000) state that if *LHL* is delivered in a consistent manner, significant improvements in self-efficacy relates to significant improvements in health status and health behaviour. In this study the relationship between self-efficacy and illness intrusiveness was definitely established, however, despite the improved health behaviours, no relationship with self-efficacy was established. Due to the lack of a significant relationship between the participants’ self-efficacy to manage their chronic disease and the participants’ health behaviours it is recommended that Arthritis NZ highlight to course leaders the important fact that self-efficacy improvement during

LHL is a *crucial* component of the programme. Furthermore, that enhanced self-efficacy is based on performance mastery, modeling, reinterpretation of symptoms, and social persuasion, as discussed earlier in this document. Bandura (1997) advises that support and encouragement are the strongest ways to improve confidence appraisals, especially if the action can be ascribed to the persons' own endeavours.

The fourth research goal investigated if there were any significant differences in relation to gender, age and geographic location in terms of their health status, health behaviour and health care utilisation outcomes at the commencement of the course and again six months later.

In this study the majority of participants were women, over fifty years old, married or living with a domestic partner, NZ European (Pakeha), had high school education and had two or more chronic conditions. The women reported having significantly less energy than the men did, at the commencement of the course. No significant gender differences were found with regards to self-efficacy, health behaviour or health care utilisation at baseline or six months after completion of the course.

Sixty-three (70%) of the participants were over fifty years old (n=90) and 27 (30%) were fifty years and under (n=90). Of interest was that there were significant differences between these two groups in terms of their health status at the commencement of the course. The younger group had less energy, and described more fatigue and more illness intrusion on their everyday lives than their over fifty years old counterparts. The younger group was less able to utilise cognitive symptom management skills to cope with their disease at the beginning of the course, as well as six months later. No significant differences were found between these two age groups at baseline, or six months after completion of the course in terms of their self-efficacy to manage their chronic disease.

Cassileth et al. (1984, cited in Deeg, Kardaun, & Fozard, 1996) explain that distress symptoms are less in older people than in younger people because (a) chronic disease

may have “social advantages” in that older people receive more “attention and concern” from others, (b) older people maybe more adept at dealing with stressful situations, (c) “the perspective and expectations of older people may be more commensurate with adaptation to illness” and (d) older people may have a physiological advantage, which enables them to “adapt to illnesses that are epidemiologically associated with older age” (p.131).

Fifty-six participants (60%) lived in the South Island of NZ, and 38 (40%) in the North Island (n=94). At the onset of the course South Island participants reported significantly more fatigue than the participants in the North Island did. At baseline, participants from the South Island made less use of “cognitive symptoms management” skills to cope with their chronic disease when compared to their North Island counterparts, but six months after completion of the course they were able to utilise another self-management skill, “communication with the doctor” more than those participants in the North Island. No significant differences were noted between participants who lived in the North Island and South Island of NZ in terms of their self-efficacy to manage their chronic disease.

The literature provides extensive support for the impact of societal expectations in studies of physical activity, for example, exercise and fitness, which showed that women participate less in exercise, than men, due to their job, family and home responsibilities (Green, Hebron, and Woodward, 1986, cited in Bennett & Murphy, 1999). This study showed similar trends, that women under fifty described more fatigue, less energy, and more illness intrusion on their everyday lives, than those over fifty years old. It can be assumed that this group may have younger families, are still in the workforce, have less time to exercise, and feel more negative about their health.

Furthermore, extensive empirical support for the impact of social and environmental influences on health has been shown (Bennett & Murphy, 1999). Reedy, Fleming and Adesso (1992, cited in Bennett & Murphy, 1999) state that in spite of men having a shorter life expectancy than women, they are more positive than women about their

health status, describe fewer visits to the doctor, less symptoms associated with their disease and have fewer “acute non-life threatening” diseases than women (p.12).

Lorig et al. (1996) state that years of education can be considered an alternative to measuring socio-economic status as years of education are related to income. In this study 39 (46%) of the participants had some high school education, while 31 (37%) had tertiary qualifications, which indicate a moderate to high level of education. Variations in health status and health behaviours can be ascribed to socio-economic status. These relationships can be due to differences in standards of living, lifestyles, environmental impact and geographic locations. Bennett and Murphy (1999) state that lower socio-economic groups account for more stressors in everyday life, have less control over their surroundings, and less social support. Bennett and Murphy (1999) emphasise that social support is a strong mediator of health status. In this study, the minority 12 (20%) of participants reported that they had no support from their family or loved ones, and had experienced some obstacles to attend the course (n = 61). It is possible that physiological, social, behavioural and socio-economic factors may have mediated the significant differences found in terms of health status, health behaviours and geographic location.

The fifth research goal was to obtain feedback from the participants about the course in general and about the service delivery of the course. Aspects of the process evaluation of the *LHL* self-management course were described in the literature review, for example the recruitment of course participants, the promotion of the course, the group structure, the physical environment, the programme design, the course overview and a session overview. In general, the feedback of the participants was positive. The majority indicated that they found the course worthwhile, the course length and session time exactly right, and the course venue satisfactory. The participants reported high satisfaction with the course leaders. However, they reported moderate feelings of confidence in their ability to deal with their health after participation in the course, which corroborates to some extent, the self-efficacy findings of the t-test results.

The course participants indicated that they would prefer it if one health educator and one peer led the *LHL* courses. Lorig et al. (2001) found no significant differences in the health status, health behaviour, and health care utilisation outcome of participants who were taught by either two peer leaders, two health educators or one peer and one health educator. In China, Dongbo et al. (2003) compared outcomes in terms of lay-taught and professional-taught leaders. Significant changes showed in self-rated health and fatigue. Participants who were taught by peer leaders showed significant improvements in their levels of fatigue compared with those participants taught by professional-taught leaders. In contrast, self-rated scores improved with professional-taught leaders compared to lay-taught leaders. These analyses were not conducted in this study due to the small sample size and incomplete data.

Scheirer (1994, cited in Rossi et al., 1999) states that process evaluation “verifies what the program is and whether or not it is delivered as intended to the targeted recipients. It does not, however, attempt to assess the effects of the program on those recipients — that is the province of impact evaluation” (p.197). The positive feedback from the *LHL* participants indicates a general sense of satisfaction with the process, activities, operation, and service delivery of *LHL* by Arthritis NZ. Due to the external nature of the researcher to Arthritis and time restraints associated with this project the evaluation excluded (a) a formal programme monitoring, which is concerned with the implementation procedures associated with the programme in NZ and (b) a cost-benefit analysis and (c) a cost-effectiveness analysis (Rossi et al., 1999, p.365). The financial analyses would provide insight into the programme costs compared to the savings in health care expenditure, due to the reduction of healthcare utilisation associated with the programme (Ritter et al., 2001).

Of particular importance to this study and to future self-management studies, is the question of whether the programme reached the appropriate target population. A limited number of *LHL* courses were held during the research time span. It was interesting to note that some of the towns with the smallest populations were able to conduct more than one course, while in the major cities with the highest populations no or one course

was held. The limited number of courses suggested a deficiency in reaching the target populations. Rossi et al. (1999) define target population as “the unit (individual, family, community) to which a program intervention is directed. All such units within the area served by a program comprise its target population” (p.36). Given that there is no criteria to participate in the course, and as indicated in the literature review, NZ has an escalating burden of disease, it is therefore recommended that in-depth needs assessments be conducted to identify these target populations clearly, and appropriate marketing strategies be developed to reach these people with chronic disease.

The reason for the small number of self-management courses offered by Arthritis NZ over the research period may be that the *LHL* programme is still in its infancy in NZ and relatively unknown to health professionals, district health boards, and organisations involved with chronic diseases. In addition, other constraints may be involved: lack of funding, insufficient numbers of trained leaders, and time constraints. Glasgow and Toobert (2000, cited in Lorig et al., 2001) found that when people with diabetes in GP practices were asked whether they would participate in a diabetes self-management programme 40% responded positively. Kaiser Permanente, is the biggest medical institution, serving “6.5 million members in 16 states” of the US (Shortell & Kaluzny, 1997, p.5). Within this health services organisation recruitment of participants for self-management programmes, is conducted through correspondence with disease specific groups, with 5% to 10% of patients agreeing to participate in the course in response to one letter (Lorig et al., 2001).

Given the current development of a framework for chronic disease management in NZ (Stephenson, 2004; Wellingham et al., 2003), the potential exists to integrate self-management programmes, such as *LHL* as an integral part of the patients’ spectrum of chronic care, thereby maximising health outcomes for all patients.

Limitations of this Study

A number of general caveats need to be considered during the interpretation of these results. As this is a pilot study, the findings needs to be interpreted with a certain degree

of caution, due to the small sample size, the demographics of the particular target groups and the exploratory nature of the study.

Participants in *LHL* were dispersed over a large geographical region in the North and South Islands of NZ and the researcher was dependent on the internal communication systems of Arthritis NZ for alerting staff to distribute the questionnaires. The researcher would have preferred to communicate follow-up reminders and requests for participation by telephone as done at Stanford (K. Lorig, personal communication, June 18, 2003). However, this would have breached the ethical prerequisites of the study in regards to privacy and anonymity.

Participants completed the questionnaires at home at their own convenience, a procedure that was used to prevent possible artefact. To ensure a larger sample an extra 30 minutes could be added to the first session for participants to complete the baseline questionnaires, however, this would negate the precautions taken against demand characteristics associated with the study. Marketing the course appropriately, and training more course leaders may ensure that more courses are held, particularly in large metropolitan areas.

It is possible that some participants may have enlisted a helper to complete the questionnaire. This may have introduced bias in the data due to social desirability response set. Also, some of these results might have been affected due to self-selection bias, because participants themselves chose to attend the respective *LHL* courses. Hence, the findings of this study can be generalised only to people with chronic diseases who have attended an equivalent *LHL* course (Lorig, Gonzales et al., 1999).

Considering the small sample, the participants were representative of the chronic disease distributions in NZ (as alluded to in the literature review), as well as the current ethnic make-up of NZ, which consists mostly of NZ Europeans (Pakeha) (80%), Māori (13%), Pacific Peoples (7%), Asian (7%) and Other (0.7) (New Zealand Statistics, 2001). It should be noted that no Pacific Peoples participated in the study. Of the Sri

Lankan Tamil group, only 3 of the 11 (27%) participants completed the second questionnaire. Due to the small sample size of this study, comparisons of the various subgroups in terms of the health outcomes could not be carried out.

Data about health care utilisation was dependent on recall, and may have been unreliable with over-or-under-estimations of visits to, and nights spent at health care facilities. Within the restraints of the current research project, the researcher was unable to corroborate health care utilisation by means of comparative health provider records. To overcome this problem Sudman and Bradburn (1974, cited in Kidder & Judd, 1986) recommend that participants keep a diary of health care utilisation.

It is possible that some participants may have been susceptible to retrospective bias thereby inflating their perceptions of their distress or symptoms associated with their disease. However, if this bias existed, it might not have affected all health status variables, for example the pain levels of participants were very similar at baseline and six months later.

A limitation of the instrument used in this study was that the section "Background" did not contain measures about the participants' "duration of their disease", or their "employment status". The relationship between perceived self-efficacy at the onset of the course and health status, may be a reflection of the affective states of the participants. Participants who were "newly diagnosed" with their chronic disease may have been vulnerable to negative affective states, which may have been a source of artefact (Bandura, 1995). Bandura asserts that perceived self-efficacy plays a central role in regulating affective states, through "beliefs concerning personal control of action, thought and affect" (p.362). An individual who has high negative affect experiences emotions such as distress, fear or anger, while an individual with low negative affect feels for example peaceful, composed, and free of frustrations or concerns (Ewart, 1995). Based on Bandura's assertions, the perceived self-efficacy of the participants regulates their affective states, which may be either positive or negative, depending on the beliefs they have in their personal control, of their behaviours, their

thought processes and emotional distress Bandura (1995). Hence the need for the inclusion of “duration of disease” in the measure.

Furthermore, Lewis and Daltroy (1990, cited in Holman & Lorig, 1992, p.308) assert that on diagnosis of a chronic disease, some individuals feel overwhelmed by uncertainties and conceptualise the disease through a variety of “cultural and metaphorical understandings. Within these understandings, symptoms may have different individual and symbolic meanings”. For example, discomfort and pain may be considered as regular symptoms of illness, or as signs of deterioration and grounds for negativity and depression. Similar claims have been made by Ewart (1992), who studied heart attack survivors in regards to their health distress and fear of exercise. Ewart argues that “the fact that the heart attack is sudden, unexpected, and beyond personal control, leaves deep feelings of uncertainty and dread. Bodily sensations that would have gone unnoticed before the illness now cause alarm; states of fatigue that might have been ignored are anxiously scrutinised” (p.287).

Petrie, Weinman, Sharpe and Buckley (1996) found that heart attack patients “who believed that their illness could be cured or controlled thought that it would be shorter and less serious than did patients who thought that their illness could not be controlled. The expectation of a long illness was related to perceptions of serious consequences and physical symptoms in association with the disorder” (p.1192). From these studies it seems that when people suddenly become ill their interpretation of the situation would be distinctly different to those people who have had their diagnosis for awhile. Thus the time factor may be a confound in this study, as well as the affective state of the participants due to the unpredictability of chronic disease, fluctuations in symptoms and the absence of reinforcement during the six month period between baseline and at six months.

The psychometric properties of the self-efficacy instrument in this study contained items from two previously developed self-efficacy scales: (a) self-efficacy to manage disease in general and (b) self-efficacy to manage symptoms (Lorig et al., 1996).

Bandura (1997) states that “to achieve explanatory and predictive power, measures of personal efficacy must be tailored to domains of functioning and must represent gradations of task demands within those domains. This requires clear definition of the activity domain of interest and a good conceptual analysis of its different facets, the types of capabilities it calls upon, and the range of situations in which these capabilities might be applied” (p.42). Thus, in this study, all the items for measuring “self-efficacy to manage chronic disease” incorporated specific terms designed to measure the strength and confidence of the participants’ beliefs in their ability to carry out the specific self-management tasks. A limitation of this study was that the evaluation of self-efficacy was based on only one self-efficacy measure, rather than a composite self-efficacy measure (Jensen, Turner, Romano, & Karoly, 1991).

The data used for the baseline evaluations was cross-sectional, and changes that occurred in the study cannot be ascribed to any particular cause. As the study occurred in a “real-world” setting and was a before-after, cohort design, the results may have been caused by other factors rather than by participation in *LHL*. Moreover, the sample size was 94 at the commencement of the course, and 67 at time two. The sample sizes were adequate to maintain the ratio of “ $N \geq 50 + 8m$ ” (where m refers to the number of independent variables) for the correlations (Tabachnick & Fidell, 2000, p.117). Tabachnick and Fidell (2000) recommend that for regression analyses the ratio between cases and the independent variable should be 40 to 1, thus, although these requirements were met, the small sample size limited the number of variables which could be included in the regression models. As this was an exploratory study, a smaller number of cases may be acceptable at the cost of losing some predictive power. As for random error, power of the analyses may also have been lost due to the small sample, and to employing two-tailed tests to measure probability distributions in the data (Tabachnick & Fidell, 2000).

This study is the first evaluation of the impact of *LHL* in NZ therefore no local data was available with which to compare this present study.

The Stanford Model has been adopted in numerous countries. Due to the lack of local data, similar programmes in Canada, China, the UK and US are alluded to, and used to put the current NZ study into context (See Appendix I). Change scores are based on changes that occurred between Time One and Time Two (T2-T1)(Wright et al., 2003).

As shown in Appendix I sample sizes varied across the five countries from 94 in New Zealand to 489 in the US. In all five studies the majority of respondents were married or living with a partner. The majority of participants were women, European, and English speaking, apart from the study done in Shanghai, China where the majority of the participants were women, from Han ancestry, and married. The mean age range of participants was between 59 years in NZ and 67 years in Canada.

In NZ, 69% of the study's participants suffered from two or more chronic diseases, and similarly the UK study indicated that 75% of its participants reported co-morbidities. The chronic diseases reported in NZ, China, Canada and the US studies were very similar, mainly chronic lung disease, heart disease, diabetes, rheumatoid arthritis, hypertension, and osteoarthritis. The UK study had quite different chronic diseases, for example mainly myalgic encephalomyelitis, osteoporosis, polio and endometriosis.

The UK study was exploratory in nature and had the second smallest sample (n = 185). Small to moderate improvements were found for "self-efficacy to manage symptoms and disease", "cognitive symptom management" and "communication with the doctor", with a reduction in the "health distress" experienced by participants. No statistically significant changes occurred in "health care utilisation" or "exercise behaviour".

Allowing for the exploratory nature of this study, the small sample, and the positive outcomes in some of the measures, further exploration of the utility of *LHL* in NZ is recommended.

Future Research

The most important recommendation is that the current research be replicated to measure the effectiveness of *LHL* using a randomised, controlled, longitudinal study, a larger sample size and an extended questionnaire. It is recommended that the

longitudinal study be carried out over three years, and that it includes a qualitative component. A larger sample would allow for the analyses of relationships within specific chronic disease subgroups and for the measurement of the impact of the intervention across various subgroups.

It is suggested that the extended questionnaire include (a) additional demographic particulars, and (b) measures of efficacy beliefs in terms of “gradations of attainments” (Bandura, 1997, p.63).

The measures at three years are particularly relevant with regards to the maintenance of and adherence to health behaviours, both requiring “a resilient sense of efficacy” based on “self-regulatory capabilities and the functional value of the behavior” (Bandura, 1997, p.287).

Assessment of the efficiency of *LHL* in relation to the reduction in health care utilisation will assist in determining programme costs versus programme outcomes (Lorig et al., 2001; Ritter et al., 2001). These efficiency measures would involve “cost-benefit analyses and cost-effectiveness analyses” (Rossi et al., 1999, p.365).

Chapter 5 Conclusion

A pilot study was carried out to explore the impact of a generic self-management programme, offered by Arthritis NZ, on health outcomes of people with chronic disease, living in New Zealand. In addition, self-efficacy theory, in which the programme is grounded, was examined in terms of its relationship to the various outcome variables and in terms of its mediation affect.

Several drivers for the development of self-management programmes were identified in the literature review, for example the impact of chronic disease on individuals, and the causes and burden of chronic disease, not only in NZ, but also in the rest of the industrialised world. At the macro level, consideration was given to the health care delivery systems, the key components for chronic disease management programmes were identified, particularly in regards to international and national applications. Based on international developments, the monetary value of collaborative care and self-management programmes was emphasised especially in regards to the potential reduction in health care utilisation by people with chronic disease. The notion “self-management” was defined and explored in various settings, and in interpretation. Various models for self-management were investigated, as well as recent developments in the area.

This pilot study was exploratory, designed to test self-efficacy theory, as well as testing the impact of *LHL* on health status, health behaviour and health care utilisation. Hence, extensive data analyses were conducted to determine the impact of the programme on these health outcomes. The data obtained six months after completion of the programme was from a longitudinal design, to investigate causal relationships. The measures used in the study were existing measures which have been extensively validated and checked for reliability (Holman, 2000; Lorig & Gonzalez, 1992; Lorig & Holman, 1989, 1992, 2000; Lorig et al., 1993; Lorig et al., 2001; Lorig et al., 1996; Ritter et al., 2001). The relationship between self-efficacy with health status was verified, as well as support for a mediating affect between the intervention and health status, which is in accordance

with self-efficacy theory. In addition, significant changes occurred in the health behaviour and health care utilisation practices of participants, which corroborate international studies.

An unexpected finding, contrary to self-efficacy theory, was that these self-management and health behaviour changes occurred regardless of self-efficacy to manage chronic disease. The absence of the role of self-efficacy in these behaviours was verified in three assessments (a) non-significant findings in the t-tests, (b) the stepwise regressions and (c) the hierarchical stepwise regressions. These respectively measured the means at baseline and six months later, the relationship between self-efficacy and two health behaviours, and the mediating affect of self-efficacy between *LHL* and the health behaviours. These findings need further exploration, particularly in regards to self-efficacy enhancement during the self-management course sessions.

Crucial prerequisites for effective self-management of chronic disease are the following: having knowledge about the disease, attaining specific behavioural skills and having confidence in the ability to deal with the vicissitudes of chronic disease and its trajectories. Based on the positive outcomes of this exploratory study, *LHL*, offered by Arthritis NZ, provides the means for gaining these prerequisites.

Finally, Lorig et al. (1996) states “self-efficacy in dealing with chronic disease is not simply a matter of knowing what to do. Rather, it reflects a capability to organize and integrate cognitive, social and behavioural skills to meet a variety of purposes. Coping with challenges posed by chronic disease requires not only knowledge and skills but also a belief in one’s ability to use those skills in realistic contexts and a belief that the use of the skills will produce desired outcomes” (p.6).

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Appendix A Advertising Leaflets

LIVING A HEALTHY LIFE

with CHRONIC CONDITIONS

Do you have a long term illness such as asthma, diabetes, lupus, heart condition, arthritis or any other?

This Self-Management Course consists of a 2½ hour session each week for six weeks and is led by leaders who are trained and supported by Arthritis New Zealand. Some of the leaders themselves have chronic conditions and have learned Self-Management Skills from the course.

The next course in your area will be held at:

St Chad's Anglican Church

Cnr. Centreway Rd & Florence Ave, Orewa

- Manage symptoms
- Communicate with health professionals
- Fight Fatigue

commencing

Tuesday 20th April 2004

10.00 to 12.30

- Make daily life easier
- Learn new skills
- Lessen frustration

Phone: Sue Elley (09) 424 2269

To secure your place in this course please complete the attached registration form and return A.S.A.P with \$30.00 registration fee, and/or phone to confirm attendance.
Cheque to be made payable to – Arthritis New Zealand

✂.....

Postal address - Arthritis New Zealand
P O Box 74581 Living a Healthy Lifestyle Course
Market Road commencing: 20th April, 2004
Auckland Orewa

Name

Address

Phone No.Cheque enclosed.....



Nothing beats a chronic condition like Self-Management

Have you got ongoing medical problems?

Whatever health issue you're facing it's time to take charge and enjoy a better quality of life.

Living a Healthy Life

- A fun interactive course to help you
- (manage pain & fatigue
 - (lessen depression & frustration
 - (increase fitness & self confidence

Discover You Can

Inquire today about this innovative self-management course. Contact your local Service Centre of Arthritis New Zealand.



ENABLING A BETTER QUALITY OF LIFE

Te whakapiki i te kounga ora

Appendix B Location of Participants

LOCATION OF COURSE PARTICIPANTS

NORTH ISLAND

- 1 Auckland
- 2 Greytown
- 3 Masterton
- 4 Mt Maunganui
- 5 Napier
- 6 Tauranga
- 7 Te Awamutu

SOUTH ISLAND

- 1 Blenheim
- 2 Christchurch
- 3 Dunedin
- 4 Invercargill
- 5 Nelson
- 6 Oamaru
- 7 Otago
- 8 Timaru

Appendix C Questionnaire (Baseline)

“Living a Healthy Life”

Questionnaire



2002-2003

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/54. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Regional Human Ethics Committee: Palmerston North. Telephone 06-3505249 or email S.V.Rumball@massey.ac.nz

Please read the instructions carefully and answer all questions.

Do not spend a lot of time on each question; usually your first answer is best.

Completing this questionnaire implies your consent to participate in this study.

IDENTIFICATION INFORMATION

Please note that identification information will be removed from the survey information on receipt by the researcher. It will be kept separately from the research data. Identification information will be issued with a code which will be recorded on the survey information. No attempt will be made to match identification information to survey information.

SUMMARY INFORMATION

I would like to receive summary information of the research results.

Yes No

PARTICULARS

Name-----

Address (Street):-----

Suburb-----

City/Town/Region-----Postal Code-----

Course Date (First Day) -----

Participation Code

Participation Code

Background

1. Which ethnic group do you belong to? Tick the space or spaces that apply to you.

- | | |
|--|---|
| <input type="checkbox"/> New Zealand European/Pakeha | <input type="checkbox"/> Tongan |
| <input type="checkbox"/> New Zealand Māori | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Samoan | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Cook Island Māori | <input type="checkbox"/> Asian |
| <input type="checkbox"/> Other----- | (e.g. Dutch, Japanese, Tokelauan, Indian) |

2. Please complete: Age at last birthday:----- Please tick Gender: Female Male

3. Please tick the **highest** school qualification:

- | | |
|--|---|
| <input type="checkbox"/> Don't Know | <input type="checkbox"/> Primary School |
| <input type="checkbox"/> NZ School Certificate | <input type="checkbox"/> NZ Sixth Form Certificate |
| <input type="checkbox"/> NZ Higher School Certificate | <input type="checkbox"/> NZ University Bursary/Entrance/Scholarship |
| <input type="checkbox"/> Other NZ Secondary School Qualification | <input type="checkbox"/> Overseas Secondary School Qualification |

4. Do you have any **other completed** qualifications (Please tick the qualification(s) that apply to you)?

- | | |
|--|--|
| <input type="checkbox"/> NZ Polytech Certificate or Diploma | <input type="checkbox"/> University Degree |
| <input type="checkbox"/> Postgraduate Degree, Certificate or Diploma | <input type="checkbox"/> Overseas Qualifications |

5. Are you currently (Please tick **only one**)?

- | | |
|--|-----------------------------------|
| <input type="checkbox"/> married or domestic partner | <input type="checkbox"/> divorced |
| <input type="checkbox"/> single | <input type="checkbox"/> widowed |
| <input type="checkbox"/> separated | |

6. Please indicate below which chronic condition(s) you have:

- Diabetes High blood pressure Asthma Emphysema or COPD

Other lung disease *Type of lung disease:* _____

Heart disease *Type of heart disease:* _____

Arthritis or other rheumatic disease *Type of arthritis/rheumatic:* _____

Cancer *Type of cancer:* _____

Other chronic condition (s) *Specify:* _____

General Health

1. In general, would you say your health is?

(Please circle one)

- Excellent.....1
- Very good.....2
- Good.....3
- Fair4
- Poor5

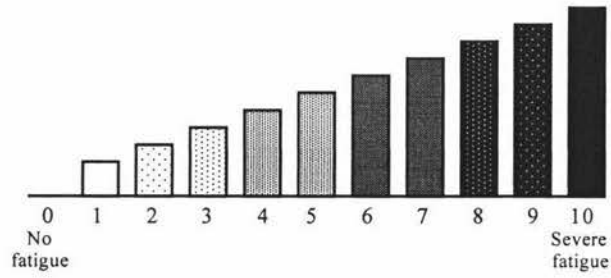
Symptoms

How much time during the past 2 weeks..

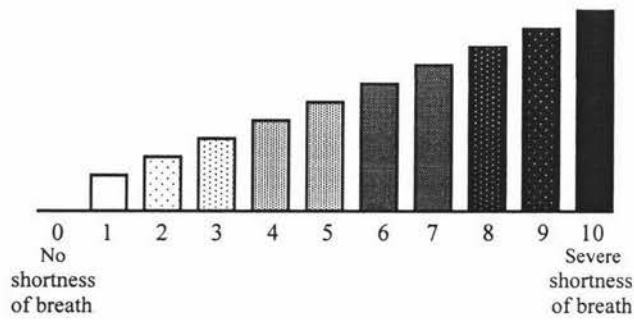
(Please circle one)

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. Did you feel worn out?.....	0	1	2	3	4	5
2. Were you discouraged by your health problems?.....	0	1	2	3	4	5
3. Did you have a lot of energy?.....	0	1	2	3	4	5
4. Were you fearful about your future health?.....	0	1	2	3	4	5
5. Did you feel tired?.....	0	1	2	3	4	5
6. Was your health a worry in your life?.....	0	1	2	3	4	5
7. Did you feel full of energy?.....	0	1	2	3	4	5
8. Were you frustrated by your health problems?.....	0	1	2	3	4	5
9. Did you have enough energy to do the things you wanted to do?.....	0	1	2	3	4	5

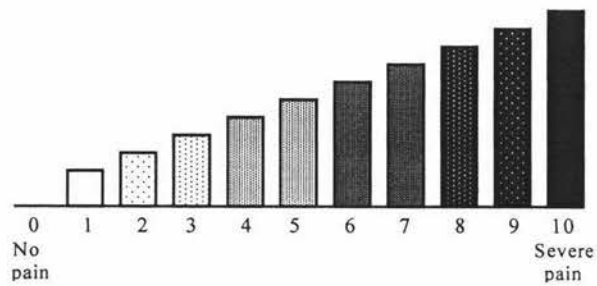
10. We are interested in learning whether or not you are affected by fatigue. Please *circle* the *number* below that describes your **fatigue** in the **past 2 weeks**:



11. We are interested in learning whether or not you are affected by shortness of breath. Please *circle* the *number* below that describes your **shortness of breath** in the **past 2 weeks**:



12. We are interested in learning whether or not you are affected by pain. Please *circle* the *number* below that describes your **pain** in the **past 2 weeks**.



Physical Activities

During the past week, even if it was not a typical week, how much total time (for the entire week) did you spend on each of the following? (Please circle one number for each question.)

	none	less than 30 min/wk	30-60 min/wk	1-3 hrs per week	more than 3 hrs/wk
1. Stretching or strengthening exercises (range of motion, using weights, etc.).....	0	1	2	3	4
2. Walk for exercise	0	1	2	3	4
3. Swimming or aquatic exercise	0	1	2	3	4
4. Bicycling (including stationary exercise bikes).....	0	1	2	3	4
5. Other aerobic exercise equipment (e.g. rower, stairclimber, cross-trainer etc.).....	0	1	2	3	4
6. Other aerobic exercise Specify _____	0	1	2	3	4

Coping With Symptoms

When you are feeling down in the dumps, feeling pain or having other unpleasant symptoms, how often do you (Please circle one number for each question):

	Never	Almost never	Some- times	Fairly often	Very often	Always
1. Try to feel distant from the discomfort and pretend that it is not part of your body	0	1	2	3	4	5
2. Don't think of it as discomfort but as some other sensation, like a warm, numb feeling.....	0	1	2	3	4	5
3. Play mental games or sing songs to keep your mind off the discomfort	0	1	2	3	4	5
4. Practice progressive muscle relaxation	0	1	2	3	4	5
5. Practice visualisation or guided imagery, such as picturing yourself somewhere else	0	1	2	3	4	5
6. Talk to yourself in positive ways	0	1	2	3	4	5

Physical Abilities

Please tick the **one** best answer for your abilities.

At this moment, are you able to:	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do
1. Dress yourself, including tying shoelaces and doing buttons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Get in and out of bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Lift a full cup or glass to your mouth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Walk outdoors on flat ground?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Wash and dry your entire body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Bend down to pick up clothing from the floor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Turn tap on and off?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Get in and out of a car?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How Your Illness Affects Your Life

The following items ask about how much your *illness(es)* and/or its *treatment* interfere with your life. **Please circle the one number that best describes your current life situation.** If an item is not applicable, please tick the box to indicate that this aspect of your life is not affected. Please do not leave any item unanswered.

How much does your illness(es) and/or its treatment interfere with:

1. Your feeling of being healthy Not applicable
 Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
2. The things you eat and drink Not applicable
 Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
3. Your work, including job, house work, chores, or errands Not applicable
 Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much

How much does your illness(es) and/or its treatment interfere with :

4. Playing sports, gardening, or other physical recreation or hobbies Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
5. Quiet recreation or hobbies, such as reading, TV, music, knitting, etc. Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
6. Your financial situation Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
7. Your relationship with your spouse or domestic partner Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
8. Your sex life Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
9. Your relationship and social activities with your family Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
10. Social activities with your friends, neighbours, or groups Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
11. Your religious or spiritual activities Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
12. Your involvement in community or civic activities Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
13. Your self-improvement or self-expression activities Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much

Confidence about Doing Things

For each of the following questions, please *circle* the number that corresponds with your **confidence** that you can do the tasks regularly at the present time.

How confident are you that you can...

- | | | | | | | | | | | | | | | | | | | | | | | | | |
|--|-------------------------|---|---|---|---|---|---|---|----|--|--|--|--|---|---|---|---|---|---|---|---|---|----|----------------------|
| 1. Keep the fatigue caused by your disease from interfering with the things you want to do? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 2. Keep the physical discomfort or pain of your disease from interfering with the things you want to do? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 3. Keep the emotional distress caused by your disease from interfering with the things you want to do? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 4. Keep any other symptoms or health problems you have from interfering with the things you want to do? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 5. Do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
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| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 6. Do things other than just taking medication to reduce how much your illness affects your everyday life? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px; text-align: center;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |

Daily Activities

During the **past 4 weeks**, how much...

- | | | (Circle one) | | | |
|--|---------------|--------------|------------|----------------|-------------------|
| | Not
at all | Slightly | Moderately | Quite
a bit | Almost
totally |
| 1. Has your health interfered with your normal social activities with family, friends, neighbours or groups..... | 0 | 1 | 2 | 3 | 4 |
| 2. Has your health interfered with your hobbies or recreational activities | 0 | 1 | 2 | 3 | 4 |

During the **past 4 weeks**, how much...

		<i>(Circle one)</i>			
	Not at all	Slightly	Moderately	Quite a bit	Almost totally
3. Has your health interfered with your household chores	0	1	2	3	4
4. Has your health interfered with your errands and shopping	0	1	2	3	4

Medical Care

1. When you **visit your medical doctor (your GP or Specialist)**, how often do you do the following (*please circle one number for each question*):

	Never	Almost never	Some- times	Fairly often	Very often	Always
a. Prepare a list of questions for your medical doctor	0	1	2	3	4	5
b. Ask questions about the things you want to know and things you don't understand about your treatment	0	1	2	3	4	5
c. Discuss any personal problems that may be related to your illness	0	1	2	3	4	5

2. **In the past 6 months**, how many times did you visit a medical doctor?
Do NOT include visits while in the hospital or to a hospital emergency department. ... _____ visits
(If you visited two different medical doctors on the same day, for example your GP and medical specialist, count it as two visits.)

a. Did you include any visits to a chiropractor, acupuncturist, podiatrist, physiotherapist, or other alternative health provider in the number above? Yes No

If yes, how many visits did you include in the number above? _____ visits

b. Did you include any visits to a psychiatrist, psychologist, family counsellor, social worker, or other mental health provider in the number above? Yes No

If yes, how many visits did you include in the number above? _____ visits

3. **In the past 6 months**, how many times did you go to a **hospital** emergency department? _____ times

4. **In the past 6 months**, how many times were you hospitalised?
 for one night or longer? _____ times

5. How many total NIGHTS did you spend in the hospital **in the past 6 months?**
(do NOT include nights in a nursing home or other minimum care facility)..... _____ nights
6. How many total NIGHTS did you spend in a nursing home or other minimum care facility **in the past 6 months?** _____ nights
7. **In the past 6 months**, how many times did you go to **OTHER urgent care or after hour care, NOT the hospital emergency department?** _____ times

*Many thanks for taking the time to complete the
questionnaire!*



Charlene Pretorius

Appendix D Questionnaire (Six Months)

“Living a Healthy Life”

Questionnaire



2002-2003

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/54. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Regional Human Ethics Committee: Palmerston North. Telephone 06-3505249 or email [S.V. Rumball@massey.ac.nz](mailto:S.V.Rumball@massey.ac.nz)

General Health

1. In general, would you say your health is:

(Circle one)

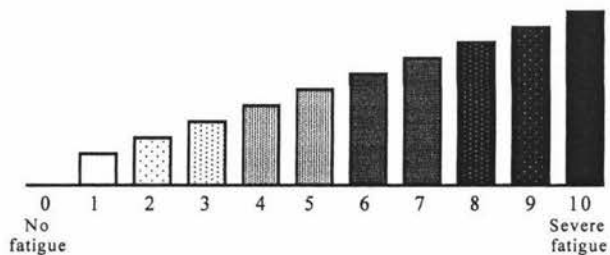
- Excellent.....1
- Very good.....2
- Good.....3
- Fair.....4
- Poor.....5

Symptoms

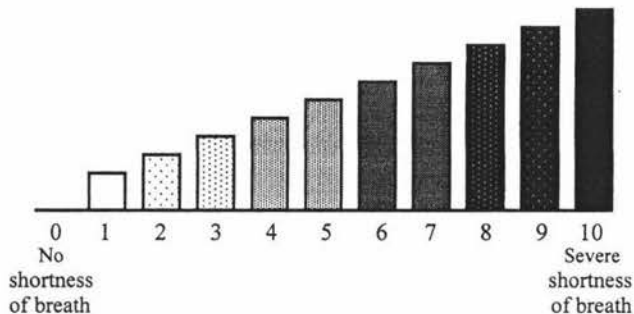
How much time during the past 2 weeks...

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1. Did you feel worn out?.....	0	1	2	3	4	5
2. Were you discouraged by your health problems?.....	0	1	2	3	4	5
3. Did you have a lot of energy?.....	0	1	2	3	4	5
4. Were you fearful about your future health?.....	0	1	2	3	4	5
5. Did you feel tired?.....	0	1	2	3	4	5
6. Was your health a worry in your life?.....	0	1	2	3	4	5
7. Did you feel full of energy?.....	0	1	2	3	4	5
8. Were you frustrated by your health problems?.....	0	1	2	3	4	5
9. Did you have enough energy to do the things you wanted to do?.....	0	1	2	3	4	5

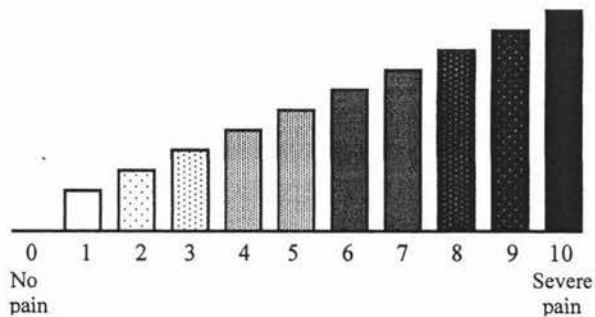
10. We are interested in learning whether or not you are affected by fatigue. Please *circle* the *number* below that describes your **fatigue** in the **past 2 weeks**:



11. We are interested in learning whether or not you are affected by shortness of breath. Please *circle* the *number* below that describes your **shortness of breath** in the **past 2 weeks**:



12. We are interested in learning whether or not you are affected by pain. Please *circle* the *number* below that describes your **pain** in the **past 2 weeks**.



Physical Activities

During the past week, even if it was not a typical week, how much total time (for the entire week) did you spend on each of the following? (Please circle one number for each question.)

	none	less than 30 min/wk	30-60 min/wk	1-3 hrs per week	more than 3 hrs/wk
1. Stretching or strengthening exercises (range of motion, using weights, etc.).....	0	1	2	3	4
2. Walk for exercise	0	1	2	3	4
3. Swimming or aquatic exercise	0	1	2	3	4
4. Bicycling (including stationary exercise bikes).....	0	1	2	3	4
5. Other aerobic exercise equipment (e.g. rower, stairclimber, cross-trainer etc.)	0	1	2	3	4
6. Other aerobic exercise Specify _____	0	1	2	3	4

Coping With Symptoms

When you are feeling down in the dumps, feeling pain or having other unpleasant symptoms, how often do you (Please circle one number for each question):

	Never	Almost never	Some- times	Fairly often	Very often	Always
1. Try to feel distant from the discomfort and pretend that it is not part of your body.....	0	1	2	3	4	5
2. Don't think of it as discomfort but as some other sensation, like a warm, numb feeling.....	0	1	2	3	4	5
3. Play mental games or sing songs to keep your mind off the discomfort.....	0	1	2	3	4	5
4. Practice progressive muscle relaxation	0	1	2	3	4	5
5. Practice visualisation or guided imagery, such as picturing yourself somewhere else	0	1	2	3	4	5
6. Talk to yourself in positive ways	0	1	2	3	4	5

Physical Abilities

Please tick the **one** best answer for your abilities.

At this moment, are you able to:	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do
1. Dress yourself, including tying shoelaces and doing buttons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Get in and out of bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Lift a full cup or glass to your mouth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Walk outdoors on flat ground?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Wash and dry your entire body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Bend down to pick up clothing from the floor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Turn tap on and off?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Get in and out of a car?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How Your Illness Affects Your Life

The following items ask about how much your illness(es) and/or its treatment interfere with your life. **Please circle the one number that best describes your current life situation.** If an item is not applicable, please tick the box to indicate that this aspect of your life is not affected. Please do not leave any item unanswered.

How much does your illness(es) and/or its treatment interfere with:

1. Your feeling of being healthy Not applicable
 Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
2. The things you eat and drink Not applicable
 Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
3. Your work, including job, house work, chores, or errands Not applicable
 Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much

How much does your illness(es) and/or its treatment interfere with :

4. Playing sports, gardening, or other physical recreation or hobbies Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
5. Quiet recreation or hobbies, such as reading, TV, music, knitting, etc. Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
6. Your financial situation Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
7. Your relationship with your spouse or domestic partner Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
8. Your sex life Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
9. Your relationship and social activities with your family Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
10. Social activities with your friends, neighbours, or groups Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
11. Your religious or spiritual activities Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
12. Your involvement in community or civic activities Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much
13. Your self-improvement or self-expression activities Not applicable
Not very much > 1..... 2..... 3..... 4..... 5..... 6..... 7 < Very much

Confidence About Doing Things

For each of the following questions, please *circle* the number that corresponds with your **confidence** that you can do the tasks regularly at the present time.

How confident are you that you can...

- | | | | | | | | | | | | | | | | | | | | | | | | | |
|--|-------------------------|---|---|---|---|---|---|---|----|--|--|--|--|---|---|---|---|---|---|---|---|---|----|----------------------|
| 1. Keep the fatigue caused by your disease from interfering with the things you want to do? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 2. Keep the physical discomfort or pain of your disease from interfering with the things you want to do? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 3. Keep the emotional distress caused by your disease from interfering with the things you want to do? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 4. Keep any other symptoms or health problems you have from interfering with the things you want to do? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 5. Do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |
| 6. Do things other than just taking medication to reduce how much your illness affects your everyday life? | not at all
confident | <table style="margin: auto; border-collapse: collapse;"> <tr> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> <td style="border-top: 1px solid black; border-bottom: 1px solid black; width: 10px;"> </td> </tr> <tr> <td style="text-align: center;">1</td> <td style="text-align: center;">2</td> <td style="text-align: center;">3</td> <td style="text-align: center;">4</td> <td style="text-align: center;">5</td> <td style="text-align: center;">6</td> <td style="text-align: center;">7</td> <td style="text-align: center;">8</td> <td style="text-align: center;">9</td> <td style="text-align: center;">10</td> </tr> </table> | | | | | | | | | | | | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | totally
confident |
| | | | | | | | | | | | | | | | | | | | | | | | | |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | | | | | | | | | |

Daily Activities

During the **past 4 weeks**, how much...

- | | Not
at all | Slightly | Moderately | Quite
a bit | Almost
totally |
|--|---------------|----------|------------|----------------|-------------------|
| 1. Has your health interfered with your normal social activities with family, friends, neighbours or groups..... | 0 | 1 | 2 | 3 | 4 |
| 2. Has your health interfered with your hobbies or recreational activities | 0 | 1 | 2 | 3 | 4 |
- (Circle one)

	Not at all	Slightly	Moderately	Quite a bit	Almost totally
3. Has your health interfered with your household chores	0	1	2	3	4
4. Has your health interfered with your errands and shopping	0	1	2	3	4

Medical Care

1. When you visit your medical doctor (your GP or specialist), how often do you do the following (please circle one number for each question):

	Never	Almost never	Sometimes	Fairly often	Very often	Always
a. Prepare a list of questions for your medical doctor	0	1	2	3	4	5
b. Ask questions about the things you want to know and things you don't understand about your treatment	0	1	2	3	4	5
c. Discuss any personal problems that may be related to your illness	0	1	2	3	4	5

2. In the past 6 months, how many times did you visit a medical doctor?
 Do NOT include visits while in the hospital or to a hospital emergency room visits
 (If you visited two different medical doctors on the same day, for example your GP and medical specialist, count it as two visits.)

Did you include any visits to a chiropractor, acupuncturist, podiatrist, physiotherapist, or other alternative health provider in the number above? Yes No
 If yes, how many visits did you include in the number above? visits

Did you include any visits to a psychiatrist, psychologist, family counsellor, social worker, or other mental health provider in the number above? Yes No
 If yes, how many visits did you include in the number above? visits

3. In the past 6 months, how many times did you go to a hospital emergency room? visits

4. In the past 6 months, how many TIMES were you hospitalised?
 for one night or longer? times

5. How many total NIGHTS did you spend in the hospital in the past 6 months?
 (do NOT include nights in a nursing home or other minimum care facility) nights

6. How many total NIGHTS did you spend in a nursing home or other minimum care facility in the past 6 months? nights

7. In the past 6 months, how many times did you go to **OTHER** urgent care or after hour care, **NOT** the hospital emergency room? visits

Course Evaluation

Thinking about the "Living a Healthy Life" Self-Management course **how much do you agree or disagree** with the statement. (Please circle **one** number for each question):

1. Overall the course has been worthwhile
Strongly Disagree > 1..... 2..... 3..... 4..... 5..... 6..... 7 <Strongly agree
2. After this course I feel more confident about my ability to cope with my health
Strongly Disagree > 1..... 2..... 3..... 4..... 5..... 6..... 7 <Strongly agree
3. The overall length of the course was satisfactory
Strongly Disagree > 1..... 2..... 3..... 4..... 5..... 6..... 7 <Strongly agree
4. The length of time of each session was just right
Strongly Disagree > 1..... 2..... 3..... 4..... 5..... 6..... 7 <Strongly agree
5. The course venue was satisfactory (e.g. comfortable)
Strongly Disagree > 1..... 2..... 3..... 4..... 5..... 6..... 7 <Strongly agree
- 6 Overall, I was very satisfied with the course leader
Strongly Disagree > 1..... 2..... 3..... 4..... 5..... 6..... 7 <Strongly agree
- 7 I will recommend the course to others, because of its high quality
Strongly Disagree > 1..... 2..... 3..... 4..... 5..... 6..... 7 <Strongly agree
- 8 In your opinion, should the course be taught by (i) health educators, (ii) peer leaders, or (iii) one health educator and one peer leader. *Please circle one.*
9. Thinking back, were there any barriers or obstacles that made it difficult for you to attend the self-management course? Yes No. Please *tick*
10. If you answered **Yes**, name the most important obstacle or barrier that you had to overcome to attend the course (e.g. transport)
11. Thinking back did you have the support of your family, loved ones or significant others to participate in the self-management course? Yes No. Please *tick*
12. Did you attend all 6 sessions of the course? Yes No. Please *tick* If you answered **No**, please **circle** which session **you did not** attend? I did not attend Session 1 2 3 4 5 6.

*Many thanks for taking the time to complete the second
questionnaire!*



Charlene Pretorius

Appendix E Human Ethics Approval



25 July 2002

Ms Charlene Pretorius
101 Braemar Road
Castor Bay
AUCKLAND

Dear Charlene

Re: HEC: PN Protocol – 02/54
An evaluation of the 'Living a Healthy Life' self-management course for
people with chronic disease in New Zealand

Thank you for your correspondence and the amended protocol.

The amendments you have made and explanations you have given now meet the requirements of the Massey University Human Ethics Committee and the ethics of your protocol are approved.

Any departure from the approved protocol will require the researcher to return this project to the Massey University Regional Human Ethics Committee: Palmerston North for further consideration and approval.

A reminder to include the following statement on all public documents "This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/54. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Regional Human Ethics Committee: Palmerston North, telephone 06 350 5249, email S.V.Rumball@massey.ac.nz."

Yours sincerely

A handwritten signature in cursive script that reads "Sylvia Rumball".

Professor Sylvia V Rumball, Chair
Massey University Regional Human Ethics Committee: Palmerston North

cc Dr Christine Stephens
Psychology
TURITEA PN320

Appendix F Information Sheet (Baseline)



"LIVING A HEALTHY LIFE"

SELF-MANAGEMENT FOR CHRONIC CONDITIONS COURSE

Information Sheet

My name is Charlene Pretorius. As part of my Masters degree in Health Psychology I am undertaking a research project under the guidance of Dr Christine Stephens, who is my supervisor. My particular interests are in the area of chronic disease, what impact it has on the individual and how a course in self-management will affect the person. In New Zealand some people have one chronic disease, while others may have several chronic diseases. Some examples of chronic diseases in New Zealand are diabetes, arthritis, high blood pressure, headaches, asthma, heart disease, depression, multiple sclerosis, gout, cancer and many others. You have decided to participate in a self-management course "*Living a Healthy Life*" offered by Arthritis New Zealand. I am interested to know how you felt before and after the course, and how often you visited your doctor or other health professional.

I would like to invite you to participate in this study. If you agree to take part, I would appreciate it if you could please fill in a questionnaire at the beginning of your course. If you are Maori, from Pacific People descent, or from a non English speaking country you may wish to have support people when reading or filling in the questionnaire. I will post another information sheet to you after six months to remind you of the study, as well as a second questionnaire, so that we can see how you feel six months after the course and how often you visited the doctor during this time. Both times you will find a self-addressed envelope which you can use to post the questionnaire directly to me. You will have an opportunity to read the questionnaire at home before deciding if you wish to take part. Your identity will be protected throughout the study and afterwards as well. I assure you that no one at Arthritis New Zealand will know if you decided to participate in the study or view any person's responses to the questionnaire. Your anonymity will be protected at all times. Dr Stephens and I will be the only people who will have access to the questionnaires, which will be locked away in a safe. At the end of the study, all the questionnaires will be destroyed in a shredder.

Te Kunenga ki Pūrehuroa

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You do not have to fill in the questionnaire, or answer any questions that you do not want to. I will assume that if you decide to complete the questionnaire, it is your consent to take part in the research. Please note that identification information will be removed from the survey information on receipt by the researcher. It will be kept separately from the research data. Identification information will be issued with a code which will be recorded on the survey information. No attempt will be made to match identification information to survey information. If you wish to obtain a summary of the research results, please tick the appropriate box in the questionnaire. The results will be posted to you once the study has been completed.

You have certain rights as a participant:

- You have the right to decline to take part in the study
- You have the right to refuse to answer any particular questions
- You have the right to withdraw from the study at any time
- You have the right to ask any questions about the study at any time during the time of participation
- You may provide answers with the understanding that it will be held in complete confidence by the researcher and her supervisor, and will only be used for the purposes of the investigation. There will be no way that any person who participated will be identified in any reports of the results.
- You have the right to receive a summary of the results of the study after it has been completed.

There are various ways you can contact me or my supervisor, Dr Christine Stephens, if you have any questions, queries or concerns regarding the research. You could write to us at the School of Psychology, Private Bag 11-222, Massey University, Palmerston North. Alternatively, you could phone me on 09-4108768 or Dr Stephens on 06-350799 extension 2041. If you have access to email, my address is c.pretorius@clear.net.nz and Dr Stephens C.V.Stephens@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/54. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Regional Human Ethics Committee: Palmerston North. Telephone 06-3505249 or email [S.V. Rumball@massey.ac.nz](mailto:S.V.Rumball@massey.ac.nz)

Thank you for giving this information sheet your consideration.

Appendix G Information Sheet (Six Months)



"LIVING A HEALTH LIFE"

SELF-MANAGEMENT FOR CHRONIC CONDITIONS COURSE

Information Sheet

Thank you for completing the first questionnaire. A reminder that this research is being conducted by Charlene Pretorius as part of her Masters degree in Health Psychology under the guidance and supervision of Dr Christine Stephens. The study is in the area of chronic disease, what impact it has on the individual, and how a course in self-management will affect the person. In New Zealand some people have one chronic disease, while others may have more than one chronic disease. Examples of chronic diseases in New Zealand are diabetes, arthritis, high blood pressure, headaches, asthma, heart disease, depression, multiple sclerosis, gout, cancer and many more. You have participated in a Self-Management Course offered by Arthritis New Zealand. I am interested to know how you feel after the course, and how often you visited your doctor or other health professional.

I would like to invite you to participate in the *second* part of the study. The fact that you have participated in the first part of the study, does not mean that you have to take part again. However, if you agree to take part, I would appreciate it if you could please complete the second questionnaire. If you are Maori, from Pacific People descent, or from a non English speaking country you may wish to have support people when reading or filling in the questionnaire. I have included the questionnaire so that you have the opportunity to read it before deciding if you wish to partake again. Your identity will be protected throughout the study and afterwards as well. I assure you that no one at Arthritis New Zealand will know if you decided to participate in the study or view any responses to the questionnaire. Your anonymity will be protected at all times. Dr Stephens and I will be the only people who will have access to the questionnaires, which will be locked away in a safe. At the end of the study, all the questionnaires will be destroyed in a shredder.

You do not have to fill in the second questionnaire, or answer any questions that you do not want to. I will assume that if you decide to complete the questionnaire, it is your consent to take part in the research. Please note that identification information will be removed from the survey information on receipt by the researcher. It will be kept

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separately from the research data. Identification information will be issued with a code which will be recorded on the survey information. No attempt will be made to match identification information to survey information. If you wish to obtain a summary of the research results, please tick the appropriate box in the questionnaire. The results will be posted to you once the study has been completed.

You have certain rights as a participant:

- You have the right to decline to take part in the study
- You have the right to refuse to answer any particular questions
- You have the right to withdraw from the study at any time
- You have the right to ask any questions about the study at any time during the time of participation
- You may provide answers with the understanding that it will be held in complete confidence by the researcher and her supervisor, and will only be used for the purposes of the investigation. There will be no way that any person who participated will be identified in any reports of the results.
- You have the right to receive a summary of the results of the study after it has been completed.

There are various ways you can contact me or my supervisor, Dr Christine Stephens, if you have any questions, queries or concerns regarding the study. You could write to us at the School of Psychology, Private Bag 11-222, Massey University, Palmerston North. Alternatively you could phone me on 09-4108768 or Dr Stephens on 06-350799 extension 2041. If you have access to email, my address is c.pretorius@clear.net.nz and Dr Stephens C.V.Stephens@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol 02/54. If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Regional Human Ethics Committee: Palmerston North. Telephone 06-3505249 or email S.V.Rumball@massey.ac.nz

Thank you for giving this second information sheet your consideration.

Appendix H Independent t-tests

Appendix H1

Independent t-test comparisons between Women and Men with regard to Health Status, Self-Efficacy and Health Behaviour Variables at T1 and T2.

<u>Scale</u>	<u>n</u>	<u>Mean</u>	<u>SD</u>	<u>n</u>	<u>Mean</u>	<u>SD</u>	<u>t</u>	<u>df</u>
		<u>Women</u>			<u>Men</u>			
Health Status								
Self-Rated Health T1	75	3.23	0.82	17	3.35	0.70	-0.59	90
Self-Rated Health T2	54	3.31	0.72	11	3.55	0.93	-0.92	63
Energy/Fatigue T1	71	1.89	0.76	16	2.46	0.70	-2.73**	85
Energy/Fatigue T2	53	1.97	0.83	11	2.29	0.74	-1.17	62
Health Distress T1	73	2.10	1.14	15	2.07	1.16	0.10	86
Health Distress T2	53	1.90	1.15	11	2.07	1.29	-0.43	62
Fatigue Visual Numeric T1	73	5.14	2.10	17	4.18	1.85	1.88	27
Fatigue Visual Numeric T2	52	5.33	2.11	9	5.00	3.12	0.40	59
Shortness of Breath Visual Numeric T1	74	1.88	2.15	17	2.53	2.88	-0.88	20
Shortness of Breath Visual Numeric T2	53	2.60	2.66	9	3.00	3.35	-0.40	60
Pain Visual Numeric T1	75	5.16	2.80	17	4.24	2.95	1.22	90
Pain Visual Numeric T2	53	5.11	2.67	9	4.78	3.15	0.34	60
Physical Abilities (Disability) T1	74	0.52	0.46	16	0.37	0.35	1.26	88
Physical Abilities (Disability) T2	54	0.53	0.48	11	0.27	0.33	1.69	63
Activities Limitations T1	73	1.82	0.95	16	1.52	1.10	1.13	87
Activities Limitations T2	53	1.92	1.05	11	1.77	1.15	0.42	62

 $p < .01^{**}$

Appendix H1 (cont.)

Independent t-test comparisons between Women and Men with regard to Health Status, Self-Efficacy and Health Behaviour Variables at T1 and T2.

<u>Scale</u>	<u>n</u>	<u>Mean</u> <u>Women</u>	<u>SD</u>	<u>n</u>	<u>Mean</u> <u>Men</u>	<u>SD</u>	<u>t</u>	<u>df</u>
Health Status								
Intrusiveness: Physical Wellbeing & Diet T1	75	3.35	1.65	17	3.03	1.93	0.70	90
Intrusiveness: Physical Wellbeing & Diet T2	54	3.21	1.46	11	3.23	1.71	-0.03	63
Intrusiveness: Work & Finances T1	74	3.83	1.77	17	3.41	2.16	0.84	89
Intrusiveness: Work & Finances T2	54	4.15	1.68	11	3.82	1.94	0.60	63
Intrusiveness: Marital, Sexual, Family Relations T1	73	2.53	1.61	15	2.73	1.60	-0.46	86
Intrusiveness: Marital, Sexual, Family Relations T2	50	2.84	1.96	11	3.76	2.19	-1.38	59
Intrusiveness: Recreational & Social Relations T1	74	3.55	1.51	17	3.08	1.33	1.18	89
Intrusiveness: Recreational & Social Relations T2	54	3.79	1.55	11	3.70	1.85	0.17	63
Intrusiveness: Other Aspects Of Life T1	73	2.54	1.32	17	2.94	1.91	-0.83	20
Intrusiveness: Other Aspects Of Life T2	53	2.75	1.53	11	3.79	1.90	-1.95	62
Intrusiveness : Illness (summed) T1	72	3.07	1.26	15	2.87	1.54	0.60	85
Intrusiveness : Illness (summed) T2	50	3.25	1.37	11	3.68	1.84	0.38	59
Self-Efficacy								
Self-Efficacy For Managing Chronic Disease T1	69	5.32	1.99	16	5.96	2.69	-0.89	19
Self-Efficacy For Managing Chronic Disease T2	52	5.77	1.98	11	5.82	2.39	-0.07	61
Self-Management Behaviour								
Cognitive Symptom Management T1	67	1.46	0.92	14	1.27	1.06	0.68	79
Cognitive Symptom Management T2	51	1.92	1.05	10	1.85	0.84	0.19	59
Communication With Physician T1	73	2.70	1.29	16	2.19	1.17	1.46	87
Communication With Physician T2	52	3.12	1.24	11	2.42	1.30	1.66	61

Appendix H2

Independent t-test comparisons of between Age Groups with regard to Health Status, Self-Efficacy and Health Behaviour Variables at T1 and T2.

<u>Scale</u>	<u>n</u>	<u>Mean</u>	<u>SD</u>	<u>n</u>	<u>Mean</u>	<u>SD</u>	<u>t</u>	<u>df</u>
		<u>Over Fifty years old</u>			<u>Under fifty years old</u>			
Health Status								
Self-Rated Health T1	63	3.06	0.67	27	3.59	0.93	-2.67*	38
Self-Rated Health T2	45	3.29	0.70	20	3.45	0.89	-0.79	63
Energy/Fatigue T1	58	2.11	0.70	27	1.72	0.88	2.23*	83
Energy/Fatigue T2	44	2.05	0.76	20	1.97	0.95	0.36	62
Health Distress T1	60	1.88	1.09	26	2.35	1.08	-1.81	84
Health Distress T2	44	1.86	1.18	20	2.06	1.16	-0.63	62
Fatigue Visual Numeric T1	62	4.55	1.99	26	5.69	2.13	-2.41*	86
Fatigue Visual Numeric T2	41	5.05	2.17	20	5.85	2.35	-1.32	59
Shortness of Breath Visual Numeric T1	62	2.11	2.44	27	1.74	1.85	0.71	87
Shortness of Breath Visual Numeric T2	42	3.00	2.85	20	2.20	2.57	1.07	60
Pain Visual Numeric T1	63	4.86	2.83	27	4.96	2.77	-0.16	88
Pain Visual Numeric T2	42	4.90	2.86	20	5.35	2.43	-0.60	60
Physical Abilities (Disability) T1	61	0.49	0.46	27	0.41	0.34	0.83	86
Physical Abilities (Disability) T2	45	0.52	0.50	20	0.36	0.38	1.28	63
Activities Limitations T1	62	1.73	1.00	26	1.81	0.96	-0.32	86
Activities Limitations T2	44	1.89	1.07	20	1.80	1.05	0.32	62

 $p < .05^*$

Appendix H2 (cont.)

Independent t-test comparisons of between Age Groups with regard to Health Status, Self-Efficacy and Health Behaviour Variables at T1 and T2.

Scale	n	Mean	SD	Over Fifty years old		Under fifty years old		t	df
				n	Mean	SD	n		
Health Status									
Intrusiveness: Physical Wellbeing & Diet T1	63	2.92	1.61	27	4.11	1.71	-3.16**	88	
Intrusiveness: Physical Wellbeing & Diet T2	45	2.93	1.46	20	3.88	1.35	-2.45*	63	
Intrusiveness: Work & Finances T1	62	3.31	1.72	27	4.56	1.85	-3.066**	87	
Intrusiveness: Work & Finances T2	45	3.76	1.62	20	4.68	1.77	-2.05*	63	
Intrusiveness: Marital, Sexual, Family Relations T1	60	2.06	1.22	27	3.48	1.70	-3.94***	39	
Intrusiveness: Marital, Sexual, Family Relations T2	41	2.60	1.91	20	3.70	1.93	-2.10*	59	
Intrusiveness: Recreational & Social Relations T1	62	3.13	1.51	27	3.99	1.16	-2.89**	63	
Intrusiveness: Recreational & Social Relations T2	45	3.60	1.66	20	3.93	1.39	-0.78	63	
Intrusiveness: Other Aspects Of Life T1	61	2.47	1.41	27	2.69	1.35	-0.68	86	
Intrusiveness: Other Aspects Of Life T2	44	2.87	1.56	20	2.98	1.86	-0.25	62	
Intrusiveness : Illness (summed) T1	59	2.68	1.20	27	3.67	1.18	0.01***	84	
Intrusiveness : Illness (summed) T2	41	3.05	1.41	20	3.77	1.43	0.07	59	
Self-Efficacy									
Self-Efficacy For Managing Chronic Disease T1	57	5.51	2.24	26	5.42	1.62	0.18	81	
Self-Efficacy For Managing Chronic Disease T2	43	5.82	2.12	20	5.76	1.80	0.11	61	
Self-Management Behaviour									
Cognitive Symptom Management T1	54	1.59	1.00	26	1.19	0.68	2.06*	69	
Cognitive Symptom Management T2	41	2.07	1.14	20	1.59	0.56	2.19*	59	
Communication With Physician T1	62	2.61	1.33	26	2.55	1.28	0.20	86	
Communication With Physician T2	43	2.95	1.36	20	2.95	1.28	-0.01	61	

$p < .05^*$

$p < .01^{**}$

$p < .001^{***}$

Appendix H3

Independent t-test comparisons between the North and South Islands with regard to Health Status, Self-Efficacy and Health Behaviour Variables at T1 and T2.

<u>Scale</u>	<u>n</u>	<u>Mean</u>	<u>SD</u>	<u>n</u>	<u>Mean</u>	<u>SD</u>	<u>t</u>	<u>df</u>
		<u>North Island</u>			<u>South Island</u>			
Health Status								
Self-Rated Health T1	38	3.13	0.70	56	3.30	0.85	-1.03	92
Self-Rated Health T2	26	3.50	0.76	41	3.27	0.74	1.23	65
Energy/Fatigue T1	34	2.01	0.83	55	1.95	0.78	0.31	87
Energy/Fatigue T2	26	1.85	0.92	40	2.09	0.77	-1.12	64
Health Distress T1	34	2.23	1.16	56	2.02	1.13	0.85	88
Health Distress T2	26	2.26	1.38	40	1.73	0.96	1.71	41
Fatigue Visual Numeric T1	36	4.39	2.21	56	5.36	1.98	-2.19*	90
Fatigue Visual Numeric T2	25	5.32	2.53	38	5.37	2.17	-0.81	61
Shortness of Breath Visual Numeric T1	37	2.22	2.30	56	1.95	2.34	0.55	91
Shortness of Breath Visual Numeric T2	25	3.08	2.93	39	2.49	2.60	0.85	62
Pain Visual Numeric T1	38	5.11	3.26	56	4.98	2.57	0.20	67
Pain Visual Numeric T2	25	5.44	2.92	39	4.87	2.57	0.82	62
Physical Abilities (Disability) T1	37	0.37	0.42	55	0.57	0.44	-2.12*	90
Physical Abilities (Disability) T2	25	0.42	0.39	41	0.52	0.51	-0.80	64
Activities Limitations T1	38	1.78	1.02	53	1.76	0.95	0.08	89
Activities Limitations T2	26	1.90	1.25	40	1.92	0.98	-0.05	64

 $p < .05^*$

Appendix H3 (cont.)

Independent t-test comparisons between the North and South Islands with regard to Health Status, Self-Efficacy and Health Behaviour Variables at T1 and T2.

Scale	n	North Island		n	South Island		t	df
		Mean	SD		Mean	SD		
Health Status								
Intrusiveness: Physical Wellbeing & Diet T1	38	3.33	1.66	56	3.29	1.74	0.09	92
Intrusiveness: Physical Wellbeing & Diet T2	26	3.40	1.62	41	3.17	1.50	0.60	65
Intrusiveness: Work & Finances T1	37	3.54	1.79	56	3.91	1.88	-0.94	91
Intrusiveness: Work & Finances T2	26	4.21	1.88	41	4.05	1.66	0.37	65
Intrusiveness: Marital, Sexual, Family Relations T1	36	2.38	1.50	54	2.67	1.66	-0.85	88
Intrusiveness: Marital, Sexual, Family Relations T2	24	3.19	2.09	39	2.91	1.93	0.55	61
Intrusiveness: Recreational & Social Relations T1	37	3.51	1.51	56	3.43	1.47	0.25	91
Intrusiveness: Recreational & Social Relations T2	26	3.68	1.75	41	3.85	1.55	-0.40	65
Intrusiveness: Other Aspects Of Life T1	37	2.29	1.11	55	2.81	1.60	-1.83	90
Intrusiveness: Other Aspects Of Life T2	25	2.81	1.45	41	3.02	1.76	-0.48	64
Intrusiveness : Illness (summed) T1	36	2.90	1.22	53	3.10	1.34	0.41	87
Intrusiveness : Illness (summed) T2	24	3.34	1.51	39	3.35	1.45	0.97	61
Self-Efficacy								
Self-Efficacy For Managing Chronic Disease T1	35	5.69	2.08	52	5.25	2.14	0.95	85
Self-Efficacy For Managing Chronic Disease T2	26	5.37	2.03	39	5.90	2.11	-1.01	63
Self-Management Behaviour								
Cognitive Symptom Management T1	33	1.68	1.06	50	1.26	0.81	2.05*	81
Cognitive Symptom Management T2	24	2.01	1.21	39	1.82	0.86	0.69	37
Communication With Physician T1	38	2.50	1.29	53	2.65	1.30	-0.54	89
Communication With Physician T2	26	2.51	1.47	39	3.23	1.11	-2.24*	63

 $p < .05^*$

Appendix I International Studies

Appendix I

Change Outcomes for Health Status, Health Behaviours, Self-Efficacy and Doctors' Visits for NZ, Canada, China, UK and USA at T2

	NZ T1	Canada T1	China T1	UK T1	USA T1	NZ Δ T2	Canada Δ T2	China Δ T2	UK Δ T2	USA Δ T2
Design	Pre-Post	Pre-Post	Random Control	Pre-Post	Pre-Post					
Time (months)	6	6	6	4	12					
Sample (at T2)	94	105	430	185	489					
Age (Mean)	59	67	64	53	62					
Gender (Women) (%)	82	80	73	72						
Marital Status (Married) (%)	56	36	82	58	64					
Health Status										
Self-Rated Health \downarrow = better	3.23	3.30	3.93		3.30	0.13	-0.28	-0.28		0.04
Energy/Fatigue \uparrow = better	1.97	2.31	2.56	5.81	5.81	0.03	0.03	-0.03		
Health Distress \downarrow = better	2.10	1.94	0.90	2.33	2.30	-0.16	-0.22	-0.24	-0.28	-0.30
Fatigue Visual Numeric \downarrow = better	4.98	4.69	3.53			0.37	-0.46	-0.35	-0.68	-0.30
Shortness of Breath Visual Numeric \downarrow = better	2.05	2.93	2.18	2.34	3.30	0.67	-0.39	-0.05	-0.37	-0.30
Pain Visual Numeric \downarrow = better	5.03	4.04	2.36	3.73	5.20	0.06	-0.57	-0.04	-0.27	-0.30
Physical Abilities \downarrow = better	0.49	0.29	0.12			-0.01	0.06	-0.07		
Activities Limitations \downarrow = better	1.77	1.36	0.75		2.00	0.14	0.10	-0.09		-0.20
Perceived Illness Intrusiveness \downarrow = better	39.54	30.37	25.48		3.30	0.92	0.74	0.07		-0.20
Self Efficacy										
Self-Efficacy for Managing Chronic Disease \uparrow = better	5.42				5.20	0.27				0.50
Self-Efficacy for Managing Symptoms \uparrow = better		5.19	7.08	17.17			1.04	0.52	2.82	
Self-Efficacy for Managing Disease in General \uparrow = better		6.43	7.36	22.01			1.00	0.22	2.73	
Self Management Behaviour										
Cognitive Symptom Management \uparrow = better	1.43	1.68	1.19	6.49	1.30	0.46	0.22	0.37	2.05	0.40
Communication with Doctor \uparrow = better	2.59		1.48	13.26	2.90	0.35		0.04	1.93	0.20
Health Care Utilisation										
Doctors Visits \downarrow = better	4.62	3.03	8.05	2.59	5.5	-1.12	0.14	-1.01	-0.11	-0.4

Note. Δ = T2 minus T1; SD and China Control Group Data not included. Table limited to outcomes measured for respective studies.

Data obtained from: NZ (Pretorius & Stephens, 2004) (In progress); China (Dongbo et al., 2003); Canada (McGowan, 2001);

UK (Wright, Barlow, Turner, & Bancroft, 2003); US (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001).