



An Evaluation of the Effectiveness of a Self Management Programme

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BACKGROUND

A chronic condition is defined as a condition that lasts longer than six months, non-communicable and involves functional impairment or disability and is usually incurable – requiring treatment in the longer-term. Approximately 40% of the population have at least one chronic condition and 66% of accident and emergency admissions are as a result of a chronic condition (HSE 2009). The care of people with chronic conditions consumes a large proportion of health and social care resources. People with chronic conditions account for 2 out of 3 patients admitted as medical emergencies and are extremely high users of acute services (HSE 2008). With an increasingly aging population and an increase in key risk factors associated with chronic disease- especially among the more disadvantaged sectors of society, there is a real threat of widening of health inequalities in the future (SLAN 2007).

Doorley (2010) stated that in Ireland the provision of existing primary care services is out of line with the epidemiology of chronic disease; that chronic disease presented one of the biggest challenges facing the HSE; and is a pre-requisite for a sustainable solution to the most effective use of hospital resources.

The traditional health and social care model is primarily episodic and demand led. The Health Service Executive (HSE) in Ireland has adopted a Population Health approach where the focus is on addressing health and social inequalities and disease prevention. Part of this is recognising that everyone has a responsibility to promote and protect their own health and the health of others.

The positive impact of self-management programmes on chronic conditions has been widely acknowledged across the globe and the evidence has shown the vast majority of self-management programmes to have an immediate impact on patient care. A strategically applied person-centred self-management programme empowers the individual to better manage their chronic condition. This produces a more confident, competent health-conscious individual (Lorig et al 1998, 2001; Phillips et al 2010, De Silva 2011), as well as reducing unplanned hospital admission, significant reduction in medication, reduced length of stay, urgent care visits and missed appointments.

In recognition of the evidence relating to chronic disease and its effective management, the HSE ‘Transformation Programme (2007)’ outlined a focus on: (1) evidence-based strategies to deal with the management of chronic conditions; (2) the re-orientation of health services to

prioritise self-management programmes on a population basis for people with chronic disease; and (3) the measurement and demonstration of return for investment in health and social care. This report incorporates all three objectives.

This study examines the impact of a self-management programme (The Quality of life Programme), adapted from the hugely influential and successful Chronic Disease Self-Management Programme (CDSMP) on the health and well-being of the participants immediately after completing a programme. A small scale study, it provides quantitative evidence from standardised instruments of changes in perceived mental and physical health as a result of their participation in the programme. The use of standardised instruments allows for benchmarking with other health service providers.

Introduction

Chronic conditions are increasing at an alarming rate and this increase has far-reaching implications and poses predictable and significant threats to all countries (WHO 2003). The main implications relate to the considerable burden that chronic conditions will have over the next 30 years relating to costs to the health and social care system, and the impact the chronic condition will have on the individual and their families and significant others.

The World Health Organisation produced a guidance document titled 'Innovative Care for Chronic Conditions: Building Blocks for Action' to help alert decision-making throughout the world regarding the severity of the problem and the current evidence-based strategies to address the problem. A central tenet of the proposed strategies is Wagner's 'Chronic Care Model', a structured and integrated model of chronic care management.

The Chronic Care Model

The Chronic Care Model is an evidence-based, conceptual framework. The goal of the model is to support the development of informed activated patients and prepared proactive healthcare teams whose interactions become more productive and satisfying around chronic illness (Epping-Jordan et al 2004).

The Chronic Care Model has been implemented to varying degrees of success throughout the USA (Bodenheimer et al 2002a; 2002b), the UK (Leatherman 2003), Sweden (Porea et al 2009) and in the developing world (Sunaert et al 2009). Epping-Jordan et al (2010) report that the model has or is being implemented in over 1000 healthcare organizations, including

approximately 500 community healthcare settings. It has provided the theoretical underpinning of strategies to address chronic conditions such as diabetes, heart disease, depression (Solberg et al 2006), oral anticoagulant therapy (Drewes et al 2011), arthritis (Lorig et al 1986), and cancer (McCorkle et al 2011).

Evidence presented in the academic literature support such whole system changes as having the ability to change care management (McCulloch et al 2000; Wagner et al 1996). However, this change process requires multi-component interventions that challenge and change the prevailing clinical systems of care (Wagner et al 1996). Wagner and Colleagues (1996; 2002; 2007) present a theoretical framework describing a multi-component model that identifies areas where change may be made in order to help practice particularly in primary care.

The Chronic Care Model recommends a combination of multiple strategies to inform primary care practice to improve quality of care and health outcomes. At the core of the model are improved functional and clinical outcomes for patients' disease management resulting from productive interactions between informed, activated patients and prepared, proactive teams of healthcare professionals (Wagner et al 1999; 2001). These productive interactions are deemed to result from the integrated implementation of the six components of the model.

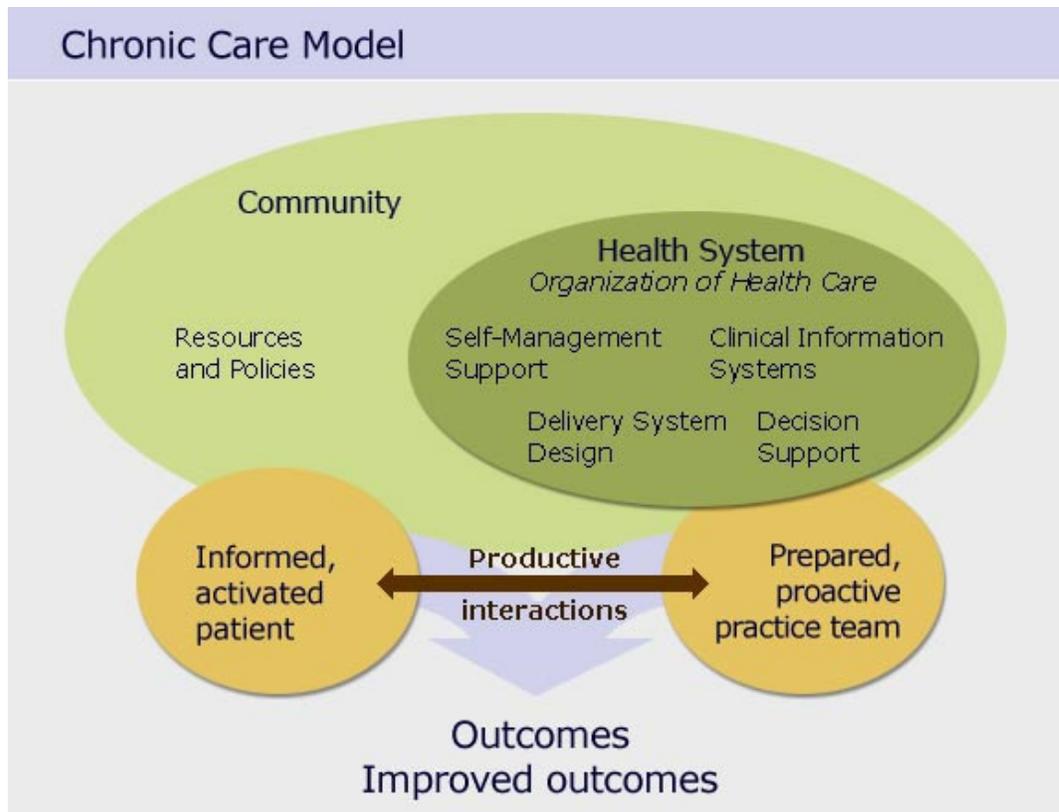


Figure 1 The Chronic Care Model (CCM)

Figure 1 highlights the interacting system components which are essential for providing good chronic illness care.

Health care organization and linkages with community resources and policies are the two top level components that support the next four – delivery system design, decision support, support for self-management, and clinical information systems – on which health care organizations should focus (Epping-Jordan et al 2004; Wagner et al 2002).

A central strand to the Chronic Care Model is the role of self-management programmes. Self-management programmes emphasise a person-centred approach in the management of their illness. The general aim is to help empower the person to manage medication, maintain life roles and manage negative emotions. This is achieved by increasing the person's necessary knowledge, skill and confidence (self-efficacy) to deal with disease related problems (Lorig et al 2001). This transfer of skills is achieved via the establishment and maintenance of a therapeutic relationship between the person, health care professionals and the health care system.

Self-management is defined as follows:

‘self-management is focused upon disease management generally guided at some point by a clinician and often involving the individual in making therapeutic adjustments to a treatment regime’ (Wilson 2008, p45).

Examination of the research relating to the effectiveness of self-management programmes shows the emergence of two strands of development over the last 20 years. In one strand self-management programmes have developed at a broad level where the population at which the intervention is aimed includes all chronic care conditions and the format, mode, location and content of the intervention change. For example, the movement towards peer-led from health professional programmes, or internet-based rather than pen and paper based or delivered in community-based settings rather than in hospitals.

The second strand focused on specific chronic conditions and tailors the self-management material to the condition such as diabetes. In the example in hand, new programmes such as the DESMOND (U.K), D.Net (USA) or the DAFNE (Ireland) have been reported in the literature as having significant impact on the self-management of diabetes.

The research evidence from both strands has helped to inform and refine the development and delivery of successful self-management programmes. However, the focus of this report is related to the impact of self-management programmes delivered to a broad base of chronic conditions.

There have been a number of reviews of self-management programmes: Bury et al 2005; Chodosh et al 2005; Foster et al 2007; De Silva 2011 - these have concluded that self-management programmes have a positive effect on the participants. Evidence presented in peer-reviewed journals has shown that compared to no intervention (i.e. standard care), self-management approaches can provide substantial benefits for participants particularly in terms of knowledge, performance of self-management behaviours, self –efficacy and aspects of health status.

The research literature has examples of a wide variety of examples of self-management interventions; however, Lorig and colleagues extensive work on the Chronic Disease Self-management Programme (CDSMP) is the most widely reported broad range self-management programme and, as a consequence, has the largest evidence base to gauge its success upon. Based on Bandura’s (1986) model of self-efficacy, the individual is viewed as self-reflective

and capable of re-formulating cognitions to control behaviour-event contingencies. The CDSMP emphasises the central role of the person managing the chronic illness. It provides the requisite knowledge and skills to enhance self-confidence and enable self-management of health problems to reduce health distress and illness intrusiveness (Gitlin et al 2008).

In a broad appeal study examining the impact of self-management programmes (CDSMP) Lorig recruited a randomised sample of 831 participants with various chronic conditions (heart disease, lung disease, stroke and arthritis) and this provided quantitative information regarding their self-rated health, disability, social role, activities, limitations, energy/fatigue, health disease, health care utilisation and perceived self-efficacy. In a follow-up study, the researchers reported reduced incidents of hospitalisation and unscheduled hospital visits, and reduced health distress. Self-efficacy improved also. These changes were sustained over a two year period. Lorig et al (2001) concluded that the relatively low cost in implementing such a programme can improve on elements of health care cost, while reducing costs in a population of diverse chronic conditions.

In China, Dongbo et al (2003) reported similar findings to Lorig and colleagues. In their research they reported increased aerobic exercise, cognitive management of symptoms, self-efficacy in disease management and a general sense of well-being among participants in the self-management programme when compared to those who had not participated. The researchers utilised a large sample of randomly assigned participants with a variety of chronic conditions such as hypertension, heart disease, lung disease, arthritis, stroke, or diabetes. These changes in exercise and self-efficacy were accompanied by reduced hospitalisation and improved health in general.

A UK based study conducted by Roger's et al in 2006 used a randomised controlled research design to compare a large sample of participants at baseline and again 6 months later. The intervention sample (n=313) reported increased self-efficacy, greater control over the chronic condition and less impact on the quality of life of the individual. However, the researchers were not able to support previous findings relating to a significant reduction in hospital utilisation. Griffith et al (2005) and Wilson et al (2006) used the same model in the UK and found similar results.

The research literature is consistent in the impact of the self-management programmes on the person's well-being (Lorig et al, 1998, 2001; Dongbo et al 2003; Roger's et al 2006 and De Silva 2011). However, inconsistent evidence is reported when the impact of the programme

is measured in economic terms such as reduced hospitalisation, reduced visits to the GP, A&E, and a reduction in unscheduled hospital visits. Lorig et al (2001) reported these reductions to be present 2 years post intervention but this dissipated thereafter. However, Rogers (2006) failed to find such an effect. These discrepancies were found to be a product of sampling methods. Phillips et al (2010) found that when the sample was self-referring and as a result of an open call for participants to avail of the intervention, this attracted highly motivated and already successful self-managing participants who found the psychological benefits to be very effective. These participants provided little opportunity to reduce economic cost such as hospitalisation. Contrary to this, in samples from poor economic backgrounds and those most in need of assistance, the economic impact was very pronounced.

Phillips et al (2010) reported that participation in the CDSMP offers an overall saving of £1,800 per person per year. The researchers cited the UK based Wanless Report (2002) that the 'dividend created by a [health care provider] that promotes health, self-care and early interventions, and that integrated services around patients is potentially sizeable, amounting to billions of pounds' (1, 32). The US centre for disease control concurred with these sentiments and concluded that there was a very high certainty that self-management programmes reduce health utilisation and the CDSMP in particular results in reductions in healthcare expenditure.

Phillips et al further elaborated on the full economic impact of the CDSMP in society. In a review of the social return on investment relating to the positive physical and mental health changes associated with participating in the intervention, an effect was noticed on the participant's ability to positively contribute to society. This contribution was in the form of increased positive relationships, increased job-related activities, volunteering and a reduction on the likelihood to be a burden on society. This positive contribution was determined to be a £3:£1 benefit to cost ratio. For every pound spent it produced a saving of £3. The authors determined that these figures were conservative.

An ever growing evidence base continues to support the intervention internationally and with various populations with chronic conditions. Internationally the CDSMP had been successfully implemented across the world (see <http://patienteducation.stanford.edu/organ/cdsites.html#ire>): for example in the UK (Wilson et al 2008), Holland (Elzen et al 2007), and China (Dongbo et al 2003). In the UK, the

CDSMP was re-titled the 'Expert Patient Programme' and became an intricate part of the healthcare system in 2002. It continues to expand into all areas of health and social care (see <http://www.expertpatients.co.uk/course-participants/courses>). In the USA Lorig and colleagues continue to expand the CDSMP in a similar vein and have provided many of the resources and literature derived from the studies that they have conducted as free resources to encourage self-management (<http://patienteducation.stanford.edu/>).

The focus of the CDSMP has moved to include areas of the health care population considered to be 'difficult' to reach such as those with learning disabilities (Wilson et al 2008), older people (Elzen et al 2007), addiction problems (Phillips et al 2007), cancer patients (Wilson 2008) and those with literacy difficulties (Gitlin et al 2008). Examination of the various aspects of the interventions applied in each of these various settings show minor modifications to a generic CDSMP programme.

In Ireland the CDSMP was introduced in the North West region under the title 'Quality of Life Programme' and as part of this process the policy-makers felt that the impact of the intervention should be measured. This study provides evidence of the impact of the 'Quality of life Programme' on health and well-being of a sample of participants.

METHODOLOGY

The Quality of Life programme was delivered across a number of practice settings in the North West Region as part of a strategic self-management programme for people living with chronic conditions. A test re-test survey methodology was used to measure the impact of the programme across the two time points with a set of standardised questionnaires completed at both time points to measure the overall impact of change.

Aims and objectives

The overall aim of the study was to measure the impact of the Quality of Life Programme on participants' knowledge, attitudes and behaviour.

Sample

Participants in the intervention were self-referring and recruited via adverts in local GP practices and hospitals; referred from health professionals. In three of the 'Quality of life' Programmes, a purposive sample of participants were invited to complete a questionnaire prior to commencing in the programme. The researcher explained to participants the nature

of the study, the overall aims and objectives and that each participant would be asked to complete a similar questionnaire on completion of the programme. All participants were told of the voluntary nature of their participation and that they would still be able to take part in the programme regardless of whether they decided to participate in study or not.

Instrumentation

A number of standardised tools that focused on the implementation of self-management programmes in people living with chronic conditions were identified from the Stanford Patient Education Research Centre – Self-Management Programme Evaluation Tools Battery (<http://patienteducation.stanford.edu/research/> Sourced May 2011). The tools had established psychometric properties and have been used in many international studies across the world. They breakdown into four broader categories: health behaviour; health status; health care utilisation and self-efficacy. Lorig and colleagues (1996) state that there is “no hard and fast rule” to instrument selection. The selection depends of the aspects of health care the self-management programme is focused on addressing. In this study these included:

Health Behaviours

Exercise: This is a six item scale measured on a five point score. Scores are rated in minutes per week spent performing both aerobic and stretching strengthening exercises. Scores range from zero to more than 3 hours per week. Higher scores indicate higher levels of time spent performing exercise.

Communication with Doctors: The focus of this scale is to see if key behaviours taught during the programme concerning communicating with health care providers have changed. This scale comprises three items rated on a six point Likert scale ranging from ‘Never’ to ‘Always’. Higher scores indicate greater levels of communication with the doctor. It is reported to have an internal consistency score of 0.73 (Lorig et al 1996) and a test retest reliability of 0.89.

Health Status

Self-rated Health: This single item scale is derived from the National Health Interview Schedule. It has been found to be an excellent predictor of future health. Higher scores indicate poorer health rating. Scores range from 1 – excellent to 5 – Poor. Lower scores

indicated a greater sense of healthiness. Test re-test reliability of the item is 0.92 (Lorig et al 1996).

Fatigue/Pain/Shortness of breath Visual Numeric: The three scales are all single item visual analogue scales that address the specific characteristic of its title. Each visual analogue scale is scored 1 – 10 with increasing scores indicating the greater severity of fatigue, pain or shortness of breath.

Health Distress: This is a modified version of the Medical Outcomes Study distress scale. It uses 4 items that provide an accurate indication of distress caused by illness. Scoring ranges from 0 – None of the Time to 5 – All of the time. Higher scores indicate a greater level of distress caused by the chronic condition. The Health Distress Scale correlates with the MOS Depressive symptoms scale (0.61) and CES – D scale (0.63). It has internal consistency in scoring of 0.87 and a test-retest reliability of 0.87.

Social/Role Activities Limitations: This questionnaire is adapted from the Medical Outcomes Study. It measures to what extent illness interferes with role activity. It is sensitive to change, and has proven measures of internal consistency (0.91) and test-retest 0.68 (Lorig et al 1996).

Health Care Utilisation

Visits to care providers: Four single item questions examined the frequency of service use for various health care services in the past 6-months. These cover visits to the doctor; hospital emergency room; nights spent in hospital; and time spent in hospital by the participant. Each of the four items has acceptable test-retest reliability.

Self Efficacy

Chronic Disease Self-Efficacy: This scale covers several areas that are common across many chronic conditions such as symptom control, role function, emotional functioning and communication with doctors. It contains 6 items and each item is scored from 1 – not confident at all to 10 – totally confident. It is reported to have an internal consistency score of 0.91 (Lorig et al 2001).

Impact on Quality of Life Measure

A sub-scale was included that examined the impact a chronic condition has on eight areas of quality of life. These included: health; mobility; ability to do tasks; pain; anxiety; relationships with family and friends; confidence and fatigue. Each area was measured on a five point Likert scale ranging from 1 – does not affect my quality of life to 5 – totally affects my quality of life and I am not coping. Each area was measured using a single item and higher scores reflected a greater impact of the chronic condition on quality of life.

Questionnaire Title	No. Of items	Range	Mean	SD	Sample (n)
Communication with doctors	3	0 - 5	3.08	1.20	1130
Self-efficacy for managing chronic disease	6	1 - 10	5.17	2.22	605
Self-rated Health	1	1 - 5	3.29	0.91	1129
Shortness of breath Scale	1	0-10	2.43	2.60	122
Pain Visual Numeric	1	0-10	4.36	3.03	122
Fatigue Visual Numeric Scale	1	0-10	4.89	2.71	122
Health Distress	4	0-5	2.04	1.16	1130
Social/Role Activities Limitation Scale	4	0-4	1.70	1.11	1130
Exercise (Stretching/Strengthening)	1	0 – 180	40.1	54.8	1127
Exercise (Aerobic)	5	0 - 540	90.6	90.9	1130
Visits to doctor	1	open	5.33	5.23	1128
Visit to A & E	1	open	0.40	0.93	1129
Times hospitalised	1	open	0.23	0.76	1129
Nights in hospital	1	open	1.31	5.53	1130

Impact on Quality of Life Measure	8	1 - 5	--	--	--
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Table 1. Questionnaire and scoring details of the instruments drawn from the Stanford Patient Education Research Centre

Intervention

The CDSMP consists of a structured programme based on the premise that people with different chronic conditions present common needs. It consists of a 6 session programme, with each programme lasting 2.5 hrs. The programme aims to empower patients to assume active roles in maintaining their health. Each session uses didactic learning and group discussions to teach strategies for managing common symptoms and engaging in healthy behaviours. Session 1 provides an overview of self-management and chronic conditions. Session 2 through to 5 focus on physical symptoms and emotional challenges such as frustration, fatigue, pain and isolation. The programme introduces easy-to-use symptom management techniques, including stretching, strengthening and aerobic exercise, nutrition, managing medications and stress reduction practices. Open communication with family and friends, advanced care planning, and partnering with health care providers is also covered. Participants establish their own goals and action plans and receive support to accomplish them.

Procedure

Participants were invited to engage in the Quality of Life Programme as an integrated part of normal medical care. The evaluation of the impact of the programme was coordinated by the trainers providing the programme.

Prior to commencing the programme, each participant was given a written and verbal explanation of the aims and objectives of the study, what they would be required to do, and their ethical rights. Those who were willing to participate were provided with a questionnaire pack containing the questionnaire, participant information sheet and consent form. Once completed, the questionnaire was returned in a sealed envelope to the trainer. The process was repeated a second time post-intervention.

Data Analysis

The data was analysed in two formats to maximise the information gathered. An unequal number of participants completed the questionnaire pre-intervention and post- intervention.

Within this, a core of 13 participants completed it on both occasions. Analysis of the data was conducted where the scores for the two time points were considered independent and an independent T-Test was used to examine differences in mean score across the two occasions. In the second method of analysis the emphasis is on examining how individuals changed over time. A paired sample T-Test was used to measure the impact of change for the individual and the pattern of consistency of change in the sample.

Ethical Issues

The participants were informed of their right of refusal without detriment to their further participation in the Quality of Life Programme. The principles of the Helsinki declaration on ethics in research were used as guidelines for the evaluation process and full ethical approval was sought and gained prior to commencing the evaluation. Anonymity and confidentiality of the participants were guaranteed throughout.

RESULTS SECTION

Demographic Details

A total of 37 participants completed either the pre or post intervention questionnaire. A total of 33 participants completed the pre-intervention questionnaire; a total of 17 completed the post-intervention questionnaire. Of the total samples, 13 participants completed both the pre and post intervention questionnaire.

Table 2 shows the demographic details at pre-intervention.

		Percent	Condition	Percent
Gender	Male	24.2%	Diabetes	36.4%
	Female	75.8%	Heart Disease	9.1%
Marital Status	Married	59.4%	Asthma	3.0%
	Single	21.9%	Arthritis	18.2%
	Widowed	9.4%	Other	33.3%
	Separated	3.1%		
	Divorced	6.3%	Mean Age	54.9 years old

Table 2. Demographic Details of respondents

The majority of participants were married females. The most represented group with a chronic disease were diabetics. The average age of participants was 54.9 years old.

Reasons to attend the programme

Participants were given an opportunity to identify reasons for wanting to attend the Quality of Life Programme. Thirteen broad ranging options were offered. The top three identified reasons are shown in table 3. The main three reasons for attending the course were to gain information (47.7%); develop a positive attitude (32.7%); and to help with lifestyle changes (27.9%).

Reason	1st	2nd	3rd	Total
Gain information	26.9%	8.3%	12.5%	47.7%
Develop a positive attitude	7.7%	20.8%	4.2%	32.7%
Change lifestyle	15.4%		12.5%	27.9%
Increase mobility	3.8%	12.5%	8.3%	24.6%
Deal with Depression	7.7%	4.2%	12.5%	24.4%
Cope with pain	7.7%	16.7%		24.4%
Improve self-confidence	19.2%	4.2%		23.4%
Prevent deterioration			16.7%	16.7%
Learn about exercise		16.7%		16.7%
Improve flexibility		4.2%	12.5%	16.7%
Meet others	3.8%	4.2%	8.3%	16.3%
Develop hope for the future	7.7%		4.2%	11.9%
Manage fatigue		4.2%	4.2%	8.4%
Reduce medication			4.2%	4.2%
	100%	100%	100%	300%

Table 3. Reasons for attending the Quality of Life Programme

General Health of Respondents

The general health of the participants indicated that over half of the sample (59.4%) rated their health as only fair or poor. No participants scored their health as excellent and only 9.4% rated it as very good (See figure 2).

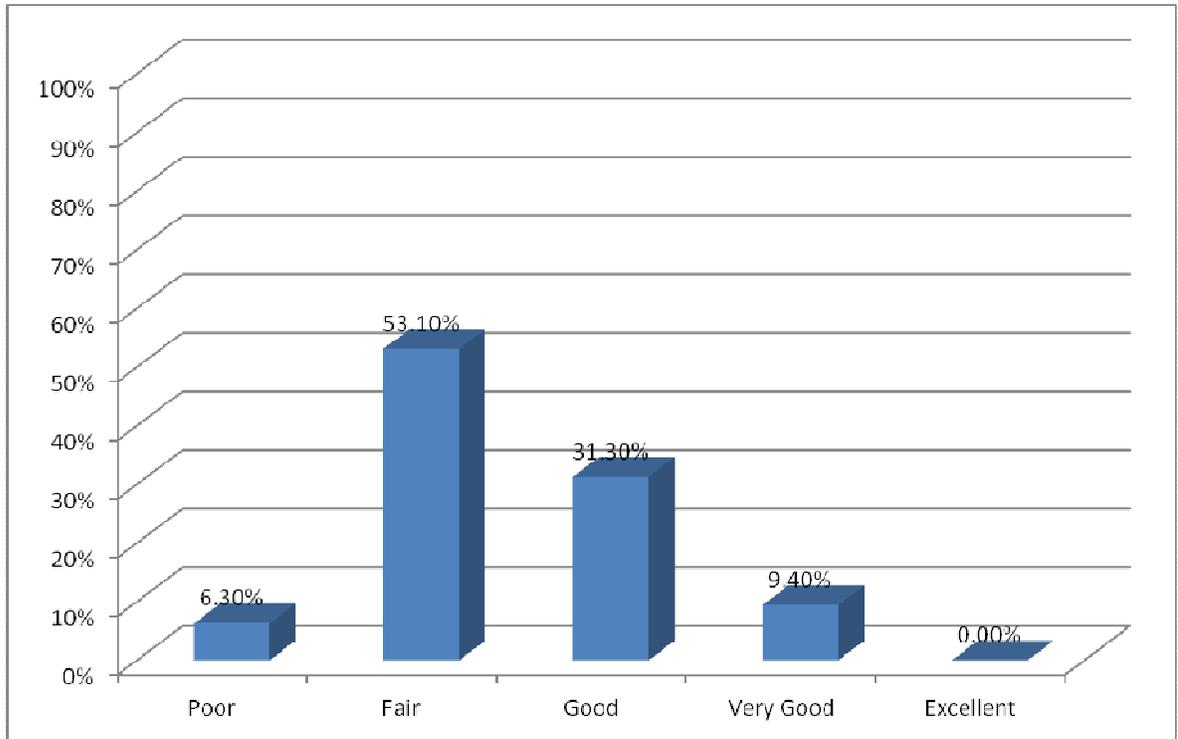


Figure 2. The General Health of the Respondents

The statistical analysis of the data incorporated two approaches. In approach 1 analysis was based on the complete sample scores at the pre and post intervention stages of the programme. Independent Sample T-Tests were used to compare the mean scores across both time points. The mean scores and significant of the differences are reported accordingly. In approach 2 a paired sample means test was used with the sub-sample of respondents that completed both questionnaires. The use of both methods helped to maximise use of the data set and increase accuracy in the findings. Table 4 highlights the mean scores of all questionnaire measures pre and post intervention for both methods. A shaded row indicates statistically significant differences in scores.

Factor	Independent T-Test			Paired-Sample T-Test		
	(Pre) Mean	(Post) Mean	Statistically Significance	(Pre) Mean	(Post) Mean	Statistically Significance
Health Distress	2.4	1.2	0.01	1.7	1.3	0.21
Communication with Doctors	2.0	2.5	0.28	2.0	2.4	0.34
Self-efficacy	5.9	7.9	0.00	6.6	7.7	0.04
Stretching and Strengthening	23	42	0.14	26.5	34.6	0.24
Aerobic Exercise	117	117	0.99	113	113	1.0
Level of fatigue (last two weeks)	6.0	3.9	0.01	5.2	3.5	0.02
Level of shortness of breath (last two weeks)	3.5	2.2	0.10	1.9	2.1	0.71
Level of pain (last two weeks)	5.3	4.7	0.49	6.5	6.0	0.17
Social/Role activities Limitations Scale	1.6	0.9	0.03	1.4	1.1	0.03
QUALITY OF LIFE						
Health	2.8	2.4	0.12	2.8	2.4	0.17
Mobility	2.6	1.9	0.05	2.7	2.0	0.04
Ability to do tasks at home	2.8	1.9	0.01	2.7	2.2	0.11
Pain	2.7	2.6	0.83	2.9	2.8	0.68
Anxiety	2.8	1.9	0.03	2.5	2.3	0.28
Relationship with family/friends	2.5	2.1	0.25	2.4	2.3	0.17
Confidence	2.5	1.8	0.01	2.3	1.8	0.28
Fatigue	3.2	2.3	0.01	3.0	2.3	0.08

Table 4. Mean scores and statistical significance of differences in mean scores

Health Distress (scored 0-5). A mean score of 2.4 reflected that the participants felt distressed ‘some of the time’. This score decreased to 1.2 that reflected a score of ‘a little of the time’. An identical scoring pattern was reported for both the independent and paired T-Test sample.

Self-efficacy Scale (scored 0-10). The respondents reported significant changes in self-efficacy scores across the intervention period. Self-efficacy scores increased from a moderate position of 5.9 out of 10 to 7.9 out of 10 representing a 20% rise across the two time points. Similar significant scores were reported for both the independent and paired T-Test sample.

Exercise was measured using a scale with two sub-scales (Stretching/Strengthening and Aerobic Exercise). Each subscale was measured and represented as an average of time spent performing each of the two types of exercise over a typical period of one week. The sample spent an average of almost 25 minutes engaging in Stretching/Strengthening exercises. This increased to almost 45 minutes post intervention. No differences were noted in aerobic exercise.

Levels of Fatigue/Shortness of breath and Pain. Decreases in fatigue, shortness of breath and pain were reported by participants as a result of the intervention. Levels of fatigue were scored as 6 out of 10 pre-intervention. This decreased by 2.1 points to 3.9 out of 10 post-intervention. Participants’ shortness of breath was lowered from a score of 3.5 out of 10 to 2.2. Likewise, levels of pain decreased from 5.3 out of 10 to 4.7. Statistically significant differences were noted on the measures of fatigue only. Similar significant scores were reported for both the independent and paired T-Test sample.

Social/Role Activities Limitations (scored 0 – 4). Four items measured the impact of chronic conditions on the participants’ ability to participate in social and family events. Aggregated scores on the factor indicated higher levels of interference on the participants’ lives. Scoring levels decreased from a position of ‘moderate’ levels of interference to a ‘slight’ level of interference. Similar significant scores were reported for both the independent and paired T-Test sample.

Impact on Quality of Life. The impact of a chronic condition on the participant’s quality of life was measured using an instrument that covered eight areas of life. Scoring ranged from 1 – 5 with increasing scores reflecting a greater negative impact on the person’s quality of

life. All items were scored as having been impacted on by the chronic condition and that the person was coping. This scoring bracket was the same on both pre and post intervention. Decreases were observed on all eight of the items with large decreases observed in the areas of anxiety, confidence and fatigue. Statistically significant differences were noted on four of the eight items.

Communication with Doctors (Scored 0 – 5). A mean score of 2 indicated ‘sometimes’ being comfortable in asking the doctor questions regarding their condition. This level of confidence increased slightly but not at a statistically significant level.

Nine of the changes on mean scores were at a statistically significant level. Examination of the shaded areas of the left hand columns Table 3 show that the intervention had a significant impact on self-efficacy of the participants, the impact the chronic condition has on their social and health life and the levels of fatigue they experienced. The intervention also helped to reduce the impact of the chronic condition on five of the 8 quality of Life measures indicating an improvement in quality of life among participants.

Hospital Utilisation.

	Mean	Range
In the past 6-month how many times did you visit a doctor?	6.2	1 - 21
In the past 6-month how many times did you visit a hospital accident and emergency department?	0.84	0 - 10
In the past 6-month how many times were you hospitalised?	0.5	0 - 3
In the past 6-month how many nights did you spend in hospital?	2.7	0 - 30

Table 5. Hospital utilisation among participants at pre intervention data collection point

The participants’ pattern of hospital utilisation was collected at the pre-intervention stage as this provided the largest sample of participants. Over the last 6 months participants made an average of 1 visit per month. The range scored that the higher number of visits over this period was 21. The participants made at least one visit to the accident and emergency department in the 6-month period as a result of their chronic condition and this score ranged from 0 to 10 visits. Participants were hospitalised an average of 0.5 times in the 6 month

period (or once a year if you wish to deal in whole numbers!). Nights spent in hospital averaged out at 2.7 nights over a six month period. Nights spent in hospital varied from 0 – 30.

The Impact of the Programme

The participants were asked to rate the helpfulness of the Quality of Life Programme. Rating was on a four point Likert scale ranging from poor to Excellent. All participants rated the scale as being at least good. Almost half (47.1) rated it as being excellent. Figure 3 shows the percentage scores.

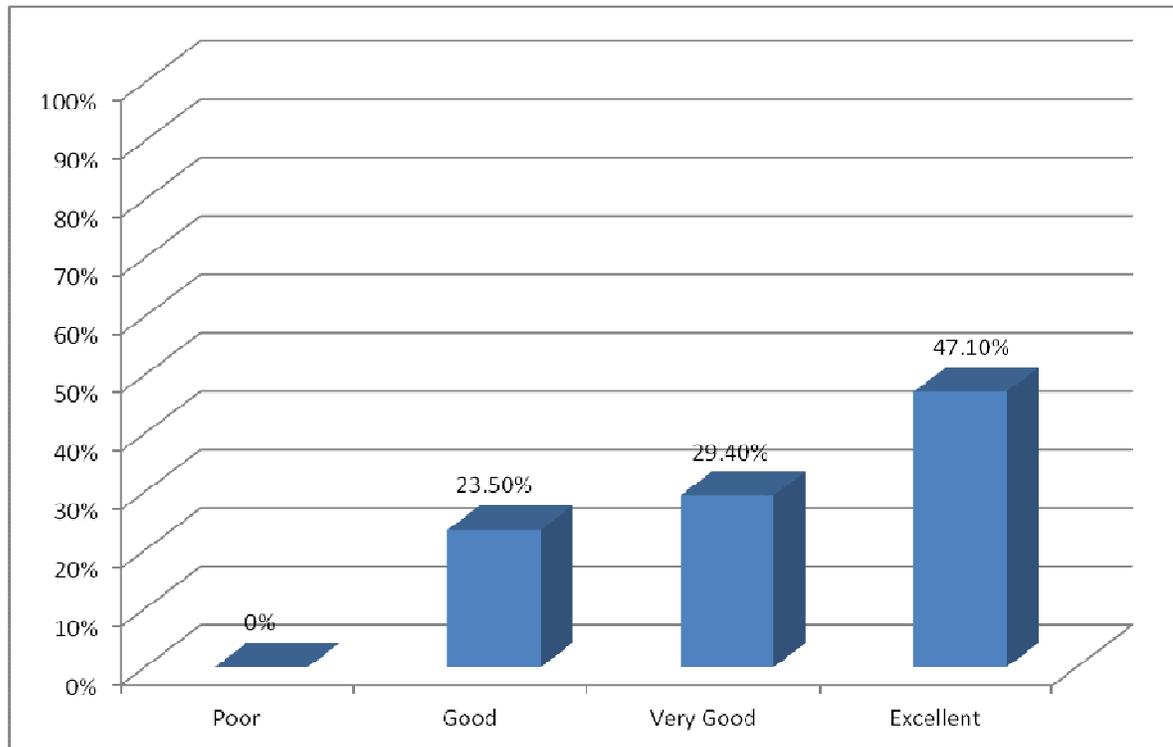


Figure 3. Participant rated helpfulness of the Quality of life Programme

Benefit	1st	2nd	3rd	4th	5th	Total Percent
Positive thinking	6.3	12.5	25.0	25.0	12.5	81.3
Action setting/ goal planning	56.3	6.3	6.3		6.3	75.2
Develop a positive attitude	12.5	31.3	25.0			68.8
Relaxation techniques	6.3	18.8	6.3	6.3	6.3	44.0
Coping with pain	6.3		6.3	6.3	18.8	37.7
Information about exercise	6.3	12.5	6.3	6.3	6.3	37.7
Dealing with difficult emotions			6.3	12.5	12.5	31.3
Depression management		12.5	6.3	6.3		25.1
Working with your health professional				12.5	12.5	25.0
Information about healthy eating			12.5	6.3		18.8
Distraction techniques				12.5	6.3	18.8
Information about medications				6.3	12.5	18.8
Information about my condition	6.3	6.3				12.6
Other					6.3	6.3
TOTALS	100%	100%	100%	100%	100%	500%

Table 6. Benefits derived from the Quality of life Programme

There was considerable variability in scoring of the benefits derived from attending the course. The most consistently reported benefits rated by the participants were the development of a positive attitude and action setting/goal planning and positive thinking. Other positive benefits were derived in relation to relaxation techniques, depression management and working with health professionals (see table 6).

Positive changes		Positive changes	
Increase exercise	76.5%	Able to do more	29.4%
Positive attitude	64.7%	No longer feeling alone	29.4%
Eating more healthily	58.8%	Deterioration prevented	11.8%
Less fatigued	47.1%	Increased knowledge of condition	11.8%
Better at communicating with health professionals	41.2%	Reduced medication	5.9%
Increased ability to cope with pain	35.3%	Other	5.9%
Increase self-confidence	35.3%	Increased mobility	2.35%
Reduced depression	29.4%		

Table 7. Participant identified positive change as a result of the intervention

Participants were asked to indicate if they felt that their involvement on the programme had resulted in changes on a variety of areas of their lives. Participants were free to highlight as many areas as required. The most positive changes were noted as increased exercise, a more positive attitude and healthy eating. Half of the participants reported less fatigue as a result of the programme. Interestingly, almost a third (29.4%) felt less depressed as a result of their involvement in the study. Surprisingly, only 11.8% of the participants felt that they were more knowledgeable about their condition post-intervention than when they commenced the programme.

The impact of the Quality of Life programme was measured shortly after completion and found to overwhelmingly recommend the programme to other people with chronic conditions (94.1%) All participants stated that ‘it would be helpful if this course was routinely prescribed to people with chronic conditions’. The participants were asked if they wished to participate in a follow-up in 6 months’ time. Almost all (94.1%) stated that they wished to do so.

DISCUSSION

There is a need for real change in how chronic care conditions are addressed in Ireland. The changing demographics and the associated change in lifestyle activities such as increased smoking prevalence, a more sedentary lifestyle and the increase in obesity means that a

reactive, acute sector focused health system will not be able to cope with the increased demand it faces. People with chronic conditions currently consume vast amounts of health care resources (HSE 2008). As part of a proactive approach, the HSE has highlighted the need for evidence based, self-management programmes that can provide evidence of effectiveness in producing change. This study addresses all three strands by using a strong evidence base to inform the research literature. The intervention is one of the most widely utilised self-management programmes as it has a strong database to support its selection. The study also draws on a strong evidence base to measure and evaluate the effectiveness of the self-management programme.

Benchmarking the Sample Scores

The findings show that when compared to a large sample from the USA the typical participant was similar across both settings with only minor differences when compared to the pre-intervention scores. Examination of table 8 shows the typical individual with a chronic condition to have average levels of self-efficacy, in moderate levels of pain, and to be moderately hindered by their condition in conducting their social and recreational activities. The participants in Ireland tend to engage in more aerobic activities and less stretching and strengthening. The Irish sample was considerably less likely to actively communicate with their doctor, had more frequent visits to their doctor, were more likely to be hospitalised and spent longer in hospital.

Questionnaire Title	Indicator of score	Range	USA	IRE	IRE
			Mean	Mean (Pre)	Mean (Post)
Communication with doctors	Higher score Positive	0 - 5	3.08	2.0	2.5
Self-efficacy for managing chronic disease	Higher score Positive	1 - 10	5.17	5.9	7.9
Shortness of breath Scale	Lower score Positive	0-10	2.43	3.5	2.2
Pain Visual Numeric	Lower score Positive	0-10	4.36	5.3	4.7
Fatigue Visual Numeric Scale	Lower score Positive	0-10	4.89	6.0	3.9

Health Distress	Lower score Positive	0-5	2.04	2.4	1.2
Social/Role Activities Limitation Scale	Lower score Positive	0-4	1.70	1.6	0.9
Exercise (Stretching/Strengthening)	Higher score Positive	0 – 180	40.1	23	42
Exercise (Aerobic)	Higher score Positive	0 - 540	90.6	117	117
Visits to doctor		open	5.33	6.2	--
Visit to A & E		open	0.40	0.84	--
Times hospitalised		open	0.23	0.5	--
Nights in hospital		open	1.31	2.7	--

Table 8. Benchmarking the Sample (IRE) scores against the USA Data Findings

The similarity in findings between Lorig’s original study in 1998 and this study’s sample indicate that there is no difference in point of commencement organisationally between the two studies other than points in time. Both systems commenced from a position where their participants had no previous experience of self-management and as a result significant improvements in care could be achieved.

Overall, the impact of the Quality of Life programme on participants was very positive. Almost all participants stated that they would recommend the programme and all participants felt that the programme should be part of a prescribed programme for all people with chronic conditions. All participants rated the programme as being ‘good’ at the very least with almost half rating the programme as ‘excellent’. The study found an increased sense of general well-being and control of the condition; more social involvement and involvement in low-level exercise. Higher energy levels were also reported. Many of the findings reported with this sample are a replication of the findings outlined in the literature (for example Lorig et al 1998; Dongbo et al 2003; and Rogers et al 2006). Early research into the Expert Patient Programme reported similar findings shortly after implementation.

Interestingly, Dongbo and colleagues had found an increase in aerobic exercise, yet this study found no such change. However, this may be caused by the high ceiling effect that this study reported (participants were involved on an average of 117 minutes of aerobic exercise a week). Inversely, the participants in this study reported significant changes in the amount of time spent doing stretching and strengthening exercise and likewise this significant increase

may be due to a low floor effect on stretching and strengthening. Cultural differences in the perception of doing various types of exercise may account for these differences.

The findings reported in this study replicate those reported in The U.K. based Expert Patient Programme (Roger's et al 2006; Griffith et al 2005; Wilson 2008). Very similar versions of the programme were used in each study and the evaluation instruments were sourced from the same evidence base. The body of evidence to support the findings of the Expert Patient Programme is substantially larger than that of this study. However, if the findings reported by Phillips et al (2010) in relation to the economic and social impact of the Expert Patient Programme in the U.K. were to apply in this study then the HSE would see significant decreases in the cost of caring for the individual with a chronic condition. This would be achieved by reductions in the number of GP visits, reduced medication, admissions to A&E and hospital stays. The social impact would also be significant. The health, social and economic gains would be increased with increased application to a wider population, a finding supported by Lorig and colleagues in 2001.

Phillips et al (2010) states that if these gains are to be achieved and sustained, it is very dependent on the establishment of a support structure such as outlined in the Chronic Care Model (Wagner et al 1996). This model integrates self-management as an intricate person-centred strand within an inter-linked and supporting health system. A supporting system would be defined by clear and directive policies; a facilitating environment such as adequate and consistent staffing; appropriate funding; educational opportunities; and community engagement. The research literature confirms the importance of embedding the self-management programme in a facilitative health system (Lorig et al 2001; Roger's et al 2006; Phillips et al 2010). De Silva (2011) recommends that self-management be implemented as part of a wider initiative to improve care through education of practitioners, applying best evidence, and using technology, decision aids and community partnerships effectively.

Additionally, an examination of the programme would help ensure that it is appropriate and up-to-date. The programme must be based on evidence-based research and the programme leader appropriately trained in the best techniques. In self management there are a variety of techniques and some interventions are more effective than others (De Silva 2001). For example, recent research into self-management techniques have found that the introduction of 'Motivational Interviewing' techniques, as part of the programme, can have the greatest impact on increasing self-efficacy and behaviour change (De Silva 2011). The Quality of

Life Programme works on the promotion of self-efficacy and behaviour change. When complemented with ‘Motivational Interviewing’ techniques it helps produce a highly motivated and empowered patient, encouraging active partnership in the therapeutic relationship (De Silva 2011). The training of staff in the most up-to-date techniques, such as motivational interviewing, would help maximise the programmes potential.

The identification of expectations and desires of the participants prior to and following the programme would help identify areas that the programme currently does not address and areas of potential follow-up. These would help provide effective person-centred care relevant to an Irish setting.

The researchers are cognisant of the limitations of the study. The data presented here was from a relatively small sample of participants and this may limit generality of the results. However, the vast body of evidence that this study contributes to also found very similar results when measuring participants upon completion of the programme. A greater sample size would allow for more in-depth analysis of the data set to help identify the effect of the Quality of Life Programme on sub-populations. To embed an evaluation element in the programme would increase the sample size and evidence-base without burdening the participants.

The evidence presented here may have been influenced by “feel good factors” associated with having completed the programme and given that the information was collected so soon afterwards may detract from the strength of the impact. A follow-up study 6-months or a year post completion to assess how much change has been maintained would help measure the true impact of the intervention. Almost all participants stated that they would be willing to participate in such a follow-up study. At the 6 month follow-up point, the full impact of the programme on self-management and hospitalisation utilisation could be collected from patient records and properly targeted evaluation instruments. This would allow for an assessment of the full economic impact of the intervention.

Conclusion

The Quality of Life Programme had a significant impact on the physical and emotional health of individuals who participated in it. This was particularly noted in the areas of self-efficacy, fatigue and the impact of the chronic condition on the individual’s daily life. Participants felt that it was a very useful programme and it has had a significant impact in the short term on

participants' positive thinking and in generating action plans and goal setting. Participants would recommend participation to other individuals with chronic conditions.

The positive benefits to be gained from the implementation of the Quality of Life Programme on the health of the individual are significant. This positive health has been proven to lower costs to the care provider whilst providing a person-centred, empowered individual with a chronic condition.

The gains are greatly facilitated by a supporting healthcare system and proper targeting of interventions at the various populations that would benefit more; the mastery of the most up-to-date intervention techniques; and integrated community linkage. This targeted approach could address the social inequalities that are present and set to diverge over the coming decades.

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