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# Self management of long term conditions: A literature review

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# **Self-management of long-term conditions: a literature review**

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## Project team

**Nicholas Hardiker RN PhD:** Nick is a Professor and Associate Head (Research & Innovation) of the University of Salford School of Nursing, Midwifery & Social Work. Nick has a background in nursing and has Bachelors, Masters and Doctoral degrees in Computer Science from the University of Manchester, UK. He has nearly 20 years experience of theoretical and applied research, with a particular focus on Health Records and Terminologies, and has been involved in several large literature reviews on topics such as public engagement with eHealth, nursing record systems, and public health interventions. Nick holds an adjunct Chair at the University of Colorado, Denver, USA and is currently Director of the International Council of Nurses eHealth Programme. He has published widely and is asked regularly to speak at conferences and seminars. He is Editor-in-Chief of Informatics for Health and Social Care, he is a member of national and international standards bodies and think tanks, and regularly provides advice to organisations such as the UK Department of Health. Nick acted as principal investigator, project manager and researcher for this review and was jointly responsible for searching, filtering, appraising and synthesising findings. Nick assumed overall editorial control of this final report.

**Maria J Grant MSc BA:** Maria has been a Research Fellow (Information) at the University of Salford since 1998. She is a qualified information scientist with a Masters degree in Health Information Management. She has extensive experience of and expertise in literature searching on a range of health and social care practice and policy topics. Founded in evidence-

based information practice, her research interests include enhancing professional practice and using information technology to access the evidence base in an efficient and meaningful way. This includes the identification of appropriate sources of evidence and investigating optimal database searching, particularly in relation to qualitative research evidence. Maria is Editor-in-Chief of the Health Information and Libraries Journal, an official publication for the Chartered Institute of Library and Information Professionals. Maria provided advice on searching, appraising and synthesising findings, contribute to the thematic analysis and appraisal of the literature, and was jointly responsible for writing the final report.

**Ian Jones RN PhD:** Ian is a senior cardiac nurse and academic with over 20 years clinical experience. He is a former President of the British Association for Nursing in Cardiovascular care, Council Member of the British Cardiovascular society and Nurse Fellow of the European Society of Cardiology. He has published widely in the field and completed a PhD focussing on the clinical outcomes for cardiac patients. He has successfully managed a number of funded research projects which have ranged from the needs of the carers of cardiac patients, the end of life needs of heart failure patients and the users views of cardiac nurses. He has benefited from a number of grants from the British Heart Foundation and other NHS organisations to undertake this important area of work. Ian is an internationally renowned academic who is regularly invited to present at the annual conferences of a number of national cardiac societies. Ian acted as researcher and was jointly responsible

for searching, filtering, appraising and synthesising findings and writing the final report.

### **Advisory team**

In addition to members of the project team, the Turning Point steering group acted as advisors to this review.

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## **Plain language summary**

We looked for information on what mechanisms help people take care of their own health. We found five mechanisms:

- patient education or counselling about their condition
- developing exercise plans with patients
- a combination of education or counselling and exercise plans
- care supported by computers or telephone
- personal health plans

These can help people take care of their own health and some can save money but more work is needed to find out how and why.

## Executive summary

A number of policy documents have been published recently that support the principle of self care and self management and call for 'implementation'. Partners across the north west of England are working together, through the development of a pilot service, to reduce emergency readmissions of patients with long-term conditions while simultaneously improving quality and outcomes. In order to inform this work, this literature review has drawn on published evidence around self-management, with a particular focus on people living with chronic obstructive pulmonary disease and/or heart failure in urban areas of high-deprivation, to allow a comparison between the model that underpins the pilot service and other reported models of self-management, including how these models are delivered, their impact in terms of patient outcomes, and their relative cost-effectiveness.

A total of 79 articles (identified from among 923 abstracts) were included in the literature review. Each article fell into one of five themes. The majority of articles fell within the education or counselling theme, followed by personal plans, education or counselling with exercise, telehealth and exercise only.

The results for all studies of exercise only interventions were positive, demonstrating increased activity/exercise, improved quality of life and self-efficacy, and improved status.

Personal plans appear to have made a positive impact in the majority of studies, particularly in terms of hospitalisations and health care utilisation, status and outcomes and behaviour.

For those studies that described a combination of education or counselling with an exercise programme, the results were largely positive (particularly in terms of status or outcome).

The range of education or counselling interventions (without exercise) appear to have made a modest positive impact in the majority of cases (particularly in terms of behaviour and status and outcomes).

While some studies showed positive effects from the use of telehealth, no difference between control and intervention groups was reported more often.

Only one study included any negative effect – increased exacerbations for the intervention group in a combined educational/counselling and exercise, although the reasons for this are unclear.

In all cases, there was no identifiable predictor for any positive (or negative) effect, although most educational/counselling interventions (with or without exercise) involved human contact and many provided some degree of ongoing support.

The majority of interventions to support self-management appear to make some positive impact in terms of behaviour, status, outcome, use of health services or quality of life; there is also some indication, albeit limited that costs of care can be reduced as a result. However, due to the heterogeneous nature of the interventions in published reports, further primary research is needed to identify common predictors of success and the longevity of success.

The findings from a number of relevant previous literature reviews support the findings from this review.



## Background

### Self care and self management in the UK

Before the introduction of the NHS in 1948 individuals were responsible for the diagnosis and management of their own minor illnesses and injuries [1]. The local pharmacist played a key role in providing advice and support for families as they took responsibility for their own treatment [1]. However the dawn of the NHS, whilst dramatically improving healthcare, also created a change in culture where the Doctor became the focal point of all healthcare provision. But such a model of care is both costly and resource intensive and as such is ultimately unsustainable.

Publication of the Department of Health's Patient and Public Involvement in the New NHS [2] attempted to re-introduce the notion that patients should be placed at the centre of care both in terms of organisation and delivery of care. This sentiment was reinforced and subsequently embedded as health service ambitions [3, 4] in the NHS plan in 2000 [3]. The NHS plan highlighted self care as one of the key building blocks for a person centred health service. The plan recognised that whilst the NHS would continue to provide interventional care there was also a need to develop support mechanisms for people to manage their own illnesses once more. In essence this was an acceptance that professional led care is not warranted in all cases and a move towards self management would not only be clinically but financially welcome. This ideological shift, where patients and carers become involved as partners in care and the growing recognition that health professionals can learn from those under their care led to the

development of expert patient panels in many health care organisations [4].

The need for self care is then woven throughout the numerous Department of Health publications that have been published since. In 2004 the Department of Health published a paper entitled Improving Chronic Disease Management in which they noted that around 17.5 Million people were living with one or more long term conditions in the UK [5]. These patients also accounted for 80% of GP consultations and two thirds of emergency attendances [5]. In the same year they produced the NHS Improvement Plan [6] and *argued that self care was key to improving the well being and quality of life of people with long term conditions.*

Also in 2004 the new GP contract allowed General Practitioners to receive increased financial reward by meeting key quality standards many of which were centred on the management of long term conditions. In 2006 they reinforced the sentiment of the NHS Improvement plan in their publication 'Our health, our care, our say' [7] but argue further in their paper 'Supporting people with long term conditions to self care' that self care can also reduce the need for emergency and inpatient care [7].

In 2007, the publication 'Commissioning framework for health and well-being' [8] emphasises the need to commission services so that self care is supported. This publication therefore highlights the need not just for individual healthcare professionals to value self care but that services should be commissioned to place self care at its very heart. These sentiments are reinforced further in the social care agenda in the publication 'Putting People First: A Shared Vision

and Commitment to Transformation of Adult Social Care' [9].

A number of policy documents have been published since 2007 that all support the principle of self care and self management. High Quality Care for All: NHS Next Stage Review Final Report [10] recommends that a personalised care plan should be available for all those suffering with a long term condition increasing an individual's participation in care. The Quality, Innovation, Productivity and Prevention (QIPP) initiative suggests increasing the pace of movement towards self care and argues that such a change is likely to achieve a net annual cost saving of about £250m through better use of information, support and skills training.

The terms self care and self management are often used interchangeably. De Silva [11] identifies a wide range of initiatives that support self management:

- Care plans
- Patient-held records
- Online courses
- Electronic information
- Written information
- Group education
- Self monitoring
- Telephone coaching
- Active group education
- Goal setting
- Motivational interviewing.

De Silva characterises these approaches according to the degree to which they focus on technical skills (e.g. self monitoring) or on self-efficacy (e.g. care plans), and their emphasis on information provision (e.g. written

information) or on behaviour change (e.g. motivational interviewing).

At the time of writing the Department of Health was developing a cross Government strategy to provide a clear direction and vision of how services for people with long term conditions can work together to help prevent or delay long term conditions where possible and improve the quality of life and independence for people with long term conditions.

### **Motivation for the study**

A number of partners across the north west of England are working together to reduce emergency readmissions of patients with long-term conditions while simultaneously improving quality and outcomes. To this end a pilot service has been established to provide patients with educational support to help them to better understand their condition, to modify their behaviour in order to improve their health and well-being, and to enable them to stay well at home. The aim is to improve their quality of life and to instil confidence, increase knowledge and provide tools and techniques to self-manage. This will allow patients to more effectively self-manage exacerbations, thereby preventing readmission to hospital.

In order to inform this work, this literature review has drawn on published evidence to allow a comparison between the model that underpins the pilot service and other reported models of self-management, including how these models are delivered, their impact in terms of patient outcomes, and their relative cost-effectiveness.

## Aims

The aims of this literature review were:

- to source systematically published and available evidence around self-management, with a particular focus on people living with chronic obstructive pulmonary disease and/or heart failure in urban areas of high-deprivation
- to identify different models of self-management and best existing practice in terms of implementing these models
- to provide recommendations for the most 'successful' and cost-effective approaches to supporting self-management for the target population.

## Ethics and Governance

The literature review was given Ethical consideration by the University of Salford but did not require formal ethical approval as there was minimal or no risk to individuals.

## Method

### Sources and searches

The breadth of the search (and to a lesser extent the depth of analysis) was shaped by resources and timescale. The literature sources considered in this project included national and international academic journal articles available via the bibliographic database MEDLINE.

Other potential bibliographic sources were not consulted due to resource and time constraints and due the large number of abstracts returned on the initial search. Citation tracking was not carried out on included articles for similar reasons.

Free text and MESH heading searches were undertaken on MEDLINE (via

OVID) in July 2012 and were purposefully restricted to English language papers published from the year 2000 to the present day (see Appendix A for search strategy).

Abstracts were independently reviewed by members of the review team. Items were selected for retrieval and further analysis if they met ALL of the review inclusion criteria, which were:

1. Heart Failure/ Chronic Obstructive Pulmonary Diseases
2. Named or identifiable examples of a self care/management programme
3. A comparison either between or within groups was made
4. Measurable outcomes

Where areas of uncertainty existed, discussions were held between two members of the review team.

Using a data extraction tool developed, piloted (on 3 articles) and refined by the project team the content of all included studies was summarised and emergent themes confirmed (see Appendix B for data extraction tool).

Relevant review articles were reserved for cross-validation of the final results of this review.

Disagreements over which items to include were resolved through face-to-face negotiation.

Agreed included items were obtained, allocated arbitrarily to the three team members and subjected to further review.

## Thematic analysis

The data extraction tool allowed the team to analyse articles into the following categories:

- Bibliographic details
- COPD or Heart Failure
- Self-management programme
- Study design
- Measurable outcomes
- Findings
- Reviewer and review date

Emergent themes that were common across different studies were identified through email discussion.

## Results

### Bibliographic searches

Nine hundred and twenty three abstracts were independently reviewed by members of the review team.

One hundred and twelve articles readily and freely available online were obtained for closer examination. Seventy-nine of these were identified as meeting the review inclusion criteria and were subjected to detailed analysis.

Thirty-two additional literature reviews were obtained for post-analysis comparison.

### Emergent themes

The main themes to emerge from the analysis concerned the type of self-management programme. Five themes emerged (reflecting the underlying model of self-management):

1. Education or counselling, individual or group, with or without follow up (44 articles fell within this theme)
2. Exercise (5 articles)

3. Education or counselling with exercise (12 articles)
4. Telehealth (6 articles)
5. Personal plans (12 articles)

These overarching themes are used in this report to structure the remainder of the analysis.

### *Education/counselling*

A study of a nurse-led primary health care clinic in Sweden examined the effectiveness of providing two structured personalised education interventions to increase participants' knowledge of COPD and quality of life [12]. Sixty-two patients were invited to join the study with 52 agreed to participate; mean age 66 years. No change was noted in the control group though **self-report of having stopped smoking and improved quality of life scores were noted in the intervention group**. This may be accounted for by participants being motivated to make lifestyle changes as a result of the educational intervention. However, one of the researchers facilitated the intervention, which may have beneficially influenced the project outcomes.

A Spanish nurse education intervention to improve self-care behaviour was provided to heart failure patients and, where possible, their families a minimum of once every three months; participants (111 men, 40 women, mean age 65.4 years) were also visited by their doctor every three months [13]. Although limited detail is provided of the intervention content, the before and after measures signalled **significant improvements in self-care activity**, primarily in contacting health professionals when symptoms appeared or worsened.

A randomised controlled trial in Norwich, UK, investigated the

effectiveness of pharmacists providing two home based visits to 293 heart failure patients; mean age 77.6 years for the intervention group, 76.4 years for the control group. The visits were completed within two and eight weeks of discharge from hospital and coupled drug reviews with self-management and lifestyle advice within the home setting [14]. Although quality of life (QoL) scores favoured the intervention group there was **no statistically significant difference in QoL or mortality outcomes**.

Worth et al [15] undertook an evaluation of a structured COPD education programme. Eighty patients (mean age 63 years) with mild to moderate COPD participated in four small group sessions (4-5 patients) each lasting two hours. Data was collected six months before and after the programme. Although **no significant effect was measured in terms of lung function or quality of life scores, proper adaptation of medication during exacerbations and a significant reduction in exacerbations and hospital days due to COPD** were observed in the education group after six months.

Forty participants (mean age 66.6 for the intervention group, 65.0 for the control group) in the USA were recruited to a single site 3 month randomised controlled clinical trial of a COPD self-management education programme with proactive remote disease monitoring [16]. Participants were taught self-management techniques upon enrolment in the trial, participated in a 20 minute telecommunication education intervention each weekday morning and had enhanced communication with the study coordinators. The study coordinator assessed risk of exacerbation on a daily basis through

home monitoring and contacted the patient if considered high risk. Each participant recorded **dramatic improvements in their quality of life** scores than the comparison group. The intervention uncovered 9 exacerbations, 7 of which went unreported by study participants. Although not statistically significant, healthcare costs also declined for the intervention group (down by \$1,401) compared with an increase for the control group (\$1,709).

A nurse-directed approach to individualised patient education and weekly telephone follow-up was the focus of a prospective quasi-experimental multi-centred research study undertaken with 23 participants with heart failure (aged 18-75 years) in a community-based hospital in the USA [17]. **Functional capacity was not significantly impacted** by the intervention, though **statistically significant improvement was noted in the 'health and function' and the 'psychological and spiritual' domains of total quality of life**.

A three month randomised controlled trial was undertaken with 111 patients (mean age 63 years) with heart failure in Porto Alegre, Brazil to evaluate an educational nursing intervention during hospitalisation (3-5 visits) compared with the educational intervention followed by telephone monitoring [18]. Each visit lasted approximately 30-40 minutes and consisted of reading a heart failure manual with participants, reinforcing instructions and answering questions. Telephone contact was initiated with the intervention group within seven days of discharge; once a week for one month reducing to every 15 days in the second and third month. **Both groups significantly improved their heart failure awareness and self-care knowledge scores**

**regardless of telephone contact after discharge.** Although not statistically significant, the intervention group had 34% less visits to the emergency care unit and were 10% less likely to be re-hospitalised or die.

Following an educational programme (3 x 3 hours) delivered to primary health care nurses (29/30) and physicians (10/23), a cluster randomised study was undertaken in eight Swedish primary health care centres with 153 participants with heart failure (54% male, mean age 79 years) [19]. Two-hour education and counselling sessions were facilitated by a nurse in the participants' homes, supported by written, verbal and interactive (multimedia program on CD-ROM) information focused on the patients' needs and skills. Telephone follow-ups were undertaken on a monthly basis, with the appearance of new or worsening symptoms increasing the frequency of telephone contacts or visits. Although **there were limited effects between groups**, the intervention group **retained their physical and mental status better during the 12 month follow-up**. Within groups, the intervention group had **significantly maintained their health related quality of life and experienced greater control over levels of depression** than the control group, particularly amongst women at 3 and 12 months follow-up.

A double blind randomised clinical trial explored the effects of a protocol-based 45 minute education programme provided to individuals by a pulmonary nurse in a Netherlands-based respiratory outpatient clinic (asthma and COPD) in addition to usual care [20]. Eight hundred and five patients were screen for eligibility from which 191 participants were included in the study; mean age 60 years in the

intervention group, 61 years in the control group; women comprised 47% in the intervention group, 39% of the control group. The intervention group suffered statistically significant **fewer exacerbations** per 1000 observation days; 1.5 compared with 3.6 in the control group. Significantly higher increases in knowledge of their condition were also shown though multiple linear regression analysis did not reveal a significant treatment effect.

A Japanese study randomised 102 patients with COPD (mean age 71.7 years) to receive either usual care of a six-month programme of educational sessions or usual care followed by tailored education [21]. The educational sessions were interactive and lasted at least 30 minutes. The tailored education sessions constituted an integrated educational programme and included individualised treatment and healthcare plans based on participants' domains scores for the Lung Information Needs Questionnaire. At six months, the intervention group had **significantly improved activities of daily living scores**; at 12 months both **dyspnoea and BODE index scores were significantly improved**. The intervention group experienced **significantly fewer hospitalisations** during the integrated education period when compared with the control group.

A pilot study using a randomized experimental design with 36 mostly white, mostly male participants was conducted in rural Northern California, with a follow up after 3 months [22]. The intervention was administered by a trained, non-cardiac-trained registered nurse. In addition to usual care, patients in the control group received a printed brochure on heart failure published by the American

Heart Association. Patients in the intervention group were given a one-on-one education and counselling session by a non-cardiac-trained registered nurse in the physician's office (n = 8) or patient's home (n = 12). The intervention group also received a phone call at 1 month to reinforce the content of the education program. **Knowledge about heart failure was significantly improved** by the intervention. The intervention **positively influenced patients' monitoring of their weight each day** but that **positive behaviour change did not translate to improved self-reported behaviours** related to seeking help from physicians. At 3 months, heart failure severity was non-significantly lower in the intervention group compared with the control group.

The results of a randomized, controlled trial of 223 systolic heart failure patients in Michigan, USA were published in the same year [23]. The study compared the effects of a 1-hour one-on-one teaching session before discharge with a nurse educator to the standard discharge process. The nurse educator discussed information specific to heart failure, instruction was given to reduce daily dietary sodium and fluid intake unless otherwise specified by the patient's physician, and the session contained the rationale for self-care behaviours: daily weight monitoring, smoking cessation, avoidance of heavy alcohol intake and non steroidal anti inflammatory drugs, and what to do if symptoms worsened. Patients in the education arm of the study were also given a copy of the treatment guidelines for heart failure treatment written in layman's terms. Subjects were contacted by telephone at 30, 90, and 180 days to collect information about clinical events, symptoms, and self-care practices.

Subjects randomized to receive the teaching session had **fewer days hospitalized or dead** in the follow-up period than did controls. Patients receiving the education intervention had a **lower risk of re-hospitalisation or death. Costs of care, including the cost of the intervention, were lower in patients** receiving the education intervention than in control subjects by \$2823 per patient.

A randomized controlled trial in the Netherlands involved a 12-month follow-up of 317 heart failure patients with a slight to marked limitation of physical activity [24, 25]. Control patients received usual care including regular checkups at an outpatient clinic. Intervention group patients also participated in the 'Chronic Disease Self-Management Programme' (CDSMP) which emphasizes patients' responsibility for the day-to-day management of their condition(s). The CDSMP is a structured self-management programme and consists of six-weekly group sessions of two and a half hours each led by a cardiac nurse specialist ('professional leader') and a CHF patient ('peer leader'). The programme incorporates skills mastery (goal-setting and action-planning), reinterpretation of symptoms, modelling, and social persuasion to enhance self-efficacy expectancies. Patients are supported in action-planning through telephone calls with co-participants. In one report of the study [24] **there were favourable effects on walking for exercise and other physical activities such as aerobic, stretching, and strength exercises, sports, and gardening were reported in the intervention group immediately after completion of the programme.** The effect of the programme on other physical activities extended to 6 months of follow-up. However there were **no significant**

**differences found at 12 months of follow-up and no favourable effects were found for the other outcomes – drinking or smoking behaviour, body mass or healthcare utilization.** The authors concluded: 'Therefore, our results seem to be in line with previous studies, showing limited evidence of a beneficial effect of the CDSMP on health behaviour and healthcare utilization' In a second report of the same study [26], statistically significant effects were found directly after the programme for cognitive symptom management, self-care behaviour and cardiac-specific quality of life (although **no effects were found at 6- and 12-month follow-up**).

One study, reported in three articles [27-29] comprised a randomised control trial involving 78 participants with asthma and 62 with COPD, with a one year follow up, to explore a patient education programme - one 4 hour group session, followed by one to two individual nurse and physiotherapist sessions. Self-management was emphasised following a stepwise treatment plan. In one article describing the study, the authors reported that during the 12-month follow-up, **approximately two and three times as many uneducated asthmatics and COPD patients, respectively, visited their general practitioner (GP) compared with educated, and there was higher levels of absenteeism** [27]. In a second article the authors reported that the control and intervention groups induced mean total costs of NOK19 900 and 10 600 per patient, respectively but that for every NOK put into patient education, there was a saving of 4.8. A reduced need of 100DDD of rescue medication was associated with a concomitant saving of NOK 5600. The authors concluded that 'patient education of patients with

COPD in a 12-month follow up **improved patient outcomes and reduced costs**' [28]. In the third article the authors reported patient education **reduced the need for GP visits by 85%** (from 3.4 to 0.5) and **kept a greater proportion independent of their GP during the 12-month follow-up**, compared with no education (73% versus 15%, respectively) [29].

Another study, a randomised trial with 142 patients (of an initial 153) in the Netherlands, also involved group face-to-face education/counselling programme with follow up [30]. All patients attended four 2-hour self-management sessions. In addition the intervention group (n = 74) participated in the COPE-active programme offered by physiotherapists of private practices, consisting of a 6-month 'compulsory' period (3 sessions/week) and subsequently a 5-month 'optional' period (2 sessions/week). Because COPE-active was intended to change behaviour with regard to exercise, one session/week in both periods consisted of unsupervised home-based exercise training. Of 153 patients, 74 intervention and 68 control patients completed the one-year follow-up. Statistically significant between-group differences in incremental shuttle walk test-distance (35.1m) and daily activity (1190 steps/day) were found in favour of the intervention group. Over the 12-month period a significant difference of the chronic respiratory questionnaire (CRQ) dyspnoea-score (0.33 points) and a non-significant difference of the endurance shuttle walk test (135 m) were found. No differences were found in the other CRQ-components, anxiety and depression scores and percentage of fat-free mass. The COPE-active group showed an **improvement of daily activity** (steps/day) after 7



months that increased further during the second period. Daily activity of the control group decreased progressively. The mean between group difference over the whole period was 877 steps/day, the between-group difference at 12 months was even higher (1190 steps/day).

Effing et al [31] recruited 159 COPD patients from a total of 421 eligible from an outpatient department in the Netherlands. The mean age of the group was 63 years and consisted of mainly men (59%). The participants all received COPE active which was a physiotherapist led exercise programme. The participants were then randomised to either self management which included self treatment to self management alone. All patients received smoking cessation advice if appropriate. They also participated in 4 weekly information sessions which lasted 2 hours per session. In addition, the intervention group received training in the treatment of exacerbations. This training was delivered via telephone. Patients were asked to record their daily symptoms in a diary along with any exacerbation of their disease. Those in the intervention group also recorded any self treatment that they had initiated. There was **no difference between the mean frequency of exacerbations or severity score** between the two groups. However there was a **statistical difference between the two groups in the highest percentile i.e. those experiencing the most exacerbations with those in the control group experiencing more exacerbation days per year.** In addition **self reported antibiotic use was significantly higher in the intervention group.** When exploring the cost effectiveness of the intervention the authors discovered

that when considering factors such as exacerbation days, use of medication, health care contacts and admissions that there was a **cost saving of 154 Euro per patient.**

A 12-week, prospective, randomized controlled trial including 192 participants in an urban teaching hospital in Ottawa was conducted of the effect of transitional care on health-related quality of life (disease-specific and generic measures), rates of readmission, and emergency room use [32]. The nurse-led intervention which included education for heart failure self management focused on the transition from hospital to home and supportive care for self-management 2 weeks after hospital discharge. At 6 weeks after hospital discharge, the overall Minnesota Living with Heart Failure Questionnaire (MLHFQ) score was better among the transitional care patients than among the usual care patients. Similar results were found at 12 weeks post-discharge for the overall MLHFQ and at 6 and 12 weeks post-discharge for the MLHFQ's Physical Dimension and Emotional Dimension subscales. Differences in generic quality life, as assessed by the SF-36 Physical component, Mental Component, and General Health subscales, were not significantly different between the transition and usual care groups. At 12 weeks post-discharge, 31% of the usual care patients had been readmitted compared with 23% of the transitional care patients, and 46% of the usual care group visited the emergency department compared with 29% in the transitional care group. The authors concluded: 'There were **significant improvements in health-related quality of life (HRQL) associated with Transitional Care and less use of emergency rooms.**'

Hermitz et al [33] undertook a randomised controlled trial with 177 recently discharged COPD patients from two acute hospitals in Sydney, Australia. One hundred and seventy seven patients were randomised to either intervention (84) or control group (93). The group consisted of marginally more women (52%), and ages ranged from 30-80 years. The patients in the control group received normal care i.e. discharged to the GP with or without specialist follow up. Those in the intervention group were visited by a community nurse one week after discharge and once again one month later. The initial visit focussed on providing the patient with advice regarding their activities of daily living, exercise, symptom recognition and smoking cessation. The patient also received a physical assessment with a recommended care plan posted to the patient's GP. The second visit was used to reinforce the messages previously delivered. The researchers used either telephone or face to face interviews at baseline and at 3 month follow up to elicit the patients' responses. The authors discovered, at follow up, that the patients in the intervention group had statistically significantly **more knowledge about the importance of vaccination and the factors that prevent worsening of the condition** but there was **no statistically significant difference in relation to help seeking knowledge**. In addition there was **no difference between the two groups in relation to hospital readmission or GP attendance**. When exploring behaviour the researchers also found **no difference in relation to smoking and vaccination rates or quality of life at follow up**.

Lemmens et al [34] carried out a complex study involving 150 patients (259 eligible and 189 recruited) in

Holland over a 12 month period to explore the impact of a multi factorial intervention on the management of patients with COPD. The group consisted of marginally more males (66%) with the mean age of the group being 66years. The respondents were mostly married (80%) with an educational level **lower than diploma level** (75%). All of the patients completed a range of surveys designed to assess their quality of life, satisfaction with care, compliance with treatment, self management abilities and knowledge. The participants also undertook spirometry tests at baseline to assess lung function. The process of providing care was also assessed by the health professionals using the assessing chronic illness care survey. All participants then received a 15 minute education session. An education programme was also delivered to the health professionals with GPs attending 3 courses that focussed on treatment options and practice nurses attending 6 study days that focussed on management and care. Finally case management was introduced and a more collaborative working model. A number of outcomes were explored as outline above. The patients' **objective and subjective knowledge of the disease and compliance with treatment improved**. However there was **no difference in the prevalence of smoking habits or exercise levels**. **Neither was there any change in the patients perceived quality of life but an improvement in dyspnoea symptoms was noted** in both surveys focussing on this area. **The lung function worsened over the 12 month follow up period**. When exploring patient satisfaction the authors noted that whilst there was **no improvement in the satisfaction with GP care** the patients were **more**

**satisfied with the care delivered by the practice nurse.** The process of care was also evaluated and the delivery system and the clinical information systems were considered to be more efficient.

In the Irish Republic Lawlor et al [35] carried out a retrospective review of all 246 patients (mean age 68 years) who had been included in an early discharge programme in order to investigate readmission rates. Those in the intervention group were discharged with a prescription and a GP letter explaining the study. They were visited by the Physiotherapist and nurse the day after discharge with subsequent visits as appropriate, over a fourteen day period. The participants were also provided with a contact telephone number if further support was needed. A further care package included outpatient follow up at 6 weeks and 3 months, clinical assessment and examination, education regarding their condition and medications, exercise regime, chest physiotherapy and self management plans. A sub group of 60 patients from the intervention arm received additional advice regarding self management which included more information about the disease and its effects. They also received advice regarding the recognition of symptoms and were provided with steroids and antibiotics to be used as part of an early management strategy. The patients in the control group i.e. those patients who had not been accepted onto the early discharge programme, received normal care. The intervention appeared to **reduce the readmission and emergency presentation rates** by 51% and 48% respectively compared to the rates of the same patients for the 12 months prior to the intervention. The same effect was also discovered in the **sub**

**group but with even greater reductions in readmission and emergency presentation** although not statistically significant. There was **no change in the readmission rates for the patients who had received normal care.**

In a Dutch study Jaarsma et al [36] recruited 186 heart failure patients from an acute hospital in the Netherlands. Of these patients 132 had full follow up data. The patients were randomised to receive either routine care (74) or intensive education (58). The mean age of the group was 72 years, consisted of mainly men (60%) and 55% of the participants were married. The patients were randomised to receive either routine care or intensive education sessions. The education sessions focussed on issues such as recognition of symptoms, fluid balance and compliance. Individual problems were also considered such as social interaction, sexual function and access to GPs. Most patients received 4 visits while in hospital plus 1 telephone call and 1 home visit. The patients were interviewed at 1, 3 and 9 months. There was **no statistical difference between the two groups in relation to self care abilities or quality of life but self care behaviour was statistically higher in the intervention group at one month and 3 months, although this effect was diminished by 9 months.**

In an American study, Baker et al [37] carried out a randomised controlled trial to compare two methods of delivering education for heart failure patients. The authors identified 2848 patients who appeared eligible. 1006 were never approached, 555 patients either refused or the physician refused and 682 were found not to be eligible. 605 patients agreed to participate. 302

of these patients were recruited to the control group and 303 to the intervention group. The mean age of the sample was found to be 60 years with 39% of participants considering themselves to be white non Hispanic, 38% African American and 16% Hispanic. The educational level of participants was equally divided across quartiles but over half (52%) of respondents were **earning less than \$15,000 per annum**. The control group received a one-off education session whereas the intervention group, who received the same education session, also received subsequent telephone education and counselling. The intervention group had a **significantly greater comparative increase in knowledge, self-efficacy and self care behaviours** to the control group. **Health related quality of life at one month remained relatively stable for the control group but increased in the intervention group.** The difference between the two groups was statistically significant.

In a British study Sridhar et al [38] conducted a randomised controlled trial to compare a routine 4 week pulmonary rehabilitation programme with the same programme but augmented with 3 home visits and monthly telephone follow up. During telephone and home visits, nurses reinforced advice regarding treatments, smoking cessation if relevant and the need to continue their exercise therapy, they discussed and reinforced the self management education that had been given and they offered encouragement for successful self-treatment. The patients were also given a full physical assessment and a written action plan about the treatment of COPD. There were 1247 COPD patients admitted to the hospital in the study period. Five

hundred and seven of these patients died, 166 lived outside the area, and 277 were thought not to be suitable for additional clinical reasons such as co-morbidity. Of the 297 that were deemed suitable for inclusion in the study, 120 declined an invitation to participate and 55 did not reply. This resulted in 122 patients being recruited to the study who were randomised equally to each group. The group consisted of an approximately equal gender distribution with 49% of participants being male. The mean age of the sample was 69 years with no statistical difference between the two study groups. There was **no difference in the exacerbation or hospital admission rates** between the two groups. However the **rate of deaths due to COPD was statistically significant with 16.7% (1/6) in the intervention group compared to 66.6% (8/12) in the control group.** In addition the way in which exacerbations were treated also differed with **patients in the intervention group more likely to initiate treatment, producing fewer GP consultations.**

There were several reports within the included studies of education or counselling programmes using different modalities.

Two studies used telephone counselling. Brandon et al [39] described a study employing a pre-test post-test experimental design involving 20 participants from rural Alabama randomly assigned to either the experimental group, or a control group, who would receive the usual care provided by their cardiologist. The participants were predominantly African American, most of who had not graduated from high school, and were earning less than \$20000. The experimental programme comprised

seven Advanced Practice Nurse telephone appointments, from 5 to 30 minutes, including education about the pathophysiology of heart failure, a low sodium diet, smoking cessation, flu/pneumonia vaccinations, when to call the physician with symptoms of exacerbation, and medication adherence. The intervention group had **significantly fewer hospital readmissions** over time. There was an **improvement in the mean self care behaviour scores** for the intervention group, whereas the control group's self care behaviour mean score did not change. The intervention group reported more improvement in overall quality of life, and the control group reported a decrease in overall quality of life. Although no significant differences between age, race, income, marital status, or education and the independent variables of the study were detected, there was a significant difference between gender and quality of life at pretesting (quality of life for women was lower than for men).

A randomised controlled study was undertaken in Hong Kong with 60 participants (**on low incomes**, mean age 73 years) to determine if a nurse-initiated telephone follow-up programme could improve self-efficacy among patients with COPD [40]; 12 patients declined to take part in the study. Thirty-three per cent of participants had no education and more than 68% were not receiving any form of government financial support. The telephone calls lasted between 10 and 20 minutes and were made on days 3-7 and days 14-20 following discharge. The telephone calls followed a protocol covering assessment, management options and evaluation. Participant outcomes were evaluated in days 29-35 and demonstrated **improved self-efficacy**

**scores** compared with the control group. There was **no significant difference between healthcare service use or hospitalisation rates** at one and three months, though a **significant difference was found in the reduced number of visits to accident and emergency departments** by the intervention group participants.

Another programme used videotapes [41]. A pilot study in the USA used pre-test post-test questionnaires and assessment of re-hospitalization rates for 10 participants (on low incomes) during a 60-day period involving 10 participants. Four videotapes provided practical guidance on daily weight tracking, medication adherence, low-sodium diet management, exercise, stress reduction, smoking cessation, detection of fluid retention, maintenance of prescribed exercise, and recognition and reporting of symptoms that precede heart failure exacerbation. Videotape content was based on national guidelines for heart failure discharge education. Each of the four videotapes features older heart failure patients' visually modelling health behaviours and discussing their challenges and successes in managing heart failure. A nurse administered pre-test questionnaires and the first videotape in person prior to hospital discharge. The nurse telephoned patients after the viewing of each remaining tape (at home weekly) to reinforce key concepts and, after 2 months, to collect post-test questionnaire data. After viewing the tapes, data indicated participants had a **clinically relevant improvement in heart failure knowledge, and improved or maintained heart failure health status**. None were re-hospitalized during the 60-day follow-up period. One patient contacted his/her

physician to report weight gain, as prompted by the videotapes. The cost data indicated that patients paid \$177 out of pocket monthly for medications. No data was presented on whether use of weight logs increased – half of patients used them.

One study evaluated an Internet-based approach [42]. The randomized study involved 50 participants on the US West Coast with moderate to severe COPD who were current Internet users. Participants returned to one of two academic clinical sites for evaluation at 3 and 6 months. There was no control – also the study had to be abandoned due to technical challenges. The content of the two 6-month self-management programs (Internet-based (eDSMP) and face-to-face (fDSMP)) was similar, focusing on education, skills training, and ongoing support for dyspnoea self-management, including independent exercise. The only difference was the mode (Internet/personal digital assistant (PDA) or face-to-face) in which the education sessions, reinforcement contacts, and peer interactions took place. The fDSMP and eDSMP showed similar clinically meaningful changes in dyspnoea with ADL from baseline to 3 months and sustained these improvements at 6 months. Self-reported endurance exercise time, physical functioning, and self-efficacy for managing dyspnoea also showed positive improvements over time in both groups with **no significant differences with respect to program modality**. Participants who completed the study (data was available for 39 participants) reported favourable satisfaction with the programs.

Another study evaluated a computer-assisted learning programme [43] using a quasi-experimental design,

with a convenience sample of 37 in-hospital heart failure patients in the Netherlands. The computer-assisted learning (CAL) program consisted of a CD-ROM with 8 modules and the study compared this with standard education (brochures and oral information from nurses) on knowledge and self-care in hospitalized heart failure patients. **No significant differences in knowledge or self-care could be found** between the groups. However, **both variables improved significantly over time in both groups**.

Copeland et al [44] reported the results of a USA-based randomised controlled trial (45-95 years) of scheduled telephone-based educational interventions around participant-specific self management plans for chronic heart failure. Frequency of calls was determined by the risk category each participant with heart failure was assigned to. The overall frequency of calls related to the intervention decreased over time. The related and total cost of delivering the service varied according to risk level: high risk - \$8,845 / \$17,989; medium risk - \$14,320 / \$18,312; low risk - \$4,621 / \$3,294. The authors concluded that while there is potential for behavioural improvements, there was **no demonstrable improvement in survival rates**.

Jovicic et al [45] explored the effect of a web-based education tool for 31 middle aged patients (mean =50 years) with heart failure in Canada. 3 patients withdrew prior to completion of the study. The group consisted of 7 people who had a high school degree or less, 21 people who had attended University or College and 3 who had undertaken a Post Graduate course. This randomised controlled trial compared two methods of self care

education. The web group had access to a website with educational content and email access to a cardiac nurse. The 'live' group had access to the website and the cardiac nurse but were also supported with 4 telephone calls. The authors then assessed the participants' knowledge base at baseline and post intervention. **The post intervention mean scores of the live group and the control group were significantly higher than the baseline. The post-intervention scores when compared to pre-intervention scores were also significantly higher in the live group compared to the control group.**

Albert et al [46] undertook a single-centre randomised controlled trial to compare a standard heart failure patient education programme with the same programme augmented with a heart failure education video. In this urban American study 112 hospitalised patients were approached and recruited to participate. The mean age of participants was 60 years. There was a statistical difference in gender between the two groups with the standard education group consisting of an increased number of females (17% v 9%,  $p=0.04$ ) and almost half the group had studied beyond high school. Patients who viewed the video **required less telephone advice, less diuretic therapy, fewer symptoms and increased self care behaviour** during the 90-day follow up. However there was **no difference between the groups in relation hospitalisation, emergency care or laboratory tests.**

Holst et al [47] performed a sub group analysis of a randomised controlled trial in Sweden. The pre and post test study compared quality of life and self care behaviour of 60 heart failure patients (mean age 79 years) who were provided with a one-off intensive

education and counselling session in their home at the beginning of the study. They were also provided with a CD-ROM which contained a multimedia programme that focussed on heart failure management. The patients subsequently participated in monthly telephone interviews for one year. There was **no statistically significant difference in quality of life at 1 year.**

A heart failure study was also undertaken by Powell et al [48] in the USA. This randomised controlled trial recruited 902 patients from out-patient settings and followed them up for 2-3 years. Patients randomized to the education group received tip sheets in the mail and telephone calls to check comprehension. Those in the intervention group were offered, in addition to the tip sheet, 18 meetings lasting 2 hours. Each meeting involved around 10 patients was spread over a year. The sessions focussed on standard heart failure education, plus counselling, to develop mastery in problem solving skills. The sample consisted of mainly men (52.7%) and unmarried individuals (56.3%). The mean age of the group was 63 years and 40.1% of the total population described themselves as descending from a minority ethnic race. 43% studied beyond high school and 51.6% earned less than \$30,000. There were **no differences between the groups in relation to death, heart failure hospitalisation or quality of life** during the mean follow up period of 2.5 years.

Dewalt et al [49] carried out a 2-phase study in which they developed an information booklet for people with low literacy levels and then piloted the use of the document in pre and post test study. The sample were mainly men (60%) and aged between 35-74

(mean=60). 67% of the participants were married with 60% of the respondents considering themselves to be African American. 74% of the sample earned **less than \$15,000 per annum** and recorded a mean education of 9.6 years. The report focused only on the second phase of the study which lasted 3 months. The patients were only suitable if they had a reading age of 9<sup>th</sup> grade or below as measured by the REALM scoring system. All 25 patients received a 1-hour education session, the content of the booklet was discussed and they were contacted via telephone 7 times over a 12-week period. The telephone sessions lasted 5-15 minutes and were used to reinforce the content of the booklet. Patients were **more likely to measure their weight** at follow up compared to baseline. The **use of diuretics was also improved. There was a small improvement in self-efficacy.**

Another heart failure study undertaken by Dewalt et al [50] compared the impact of an information pamphlet distributed to patients in a control group with the effect of an education session and pamphlet being used in conjunction with follow up telephone calls for those in an intervention group. This 12 month long randomised controlled trial recruited 123 patients from University of North Carolina hospitals in the USA. The pamphlet was deliberately written at 6<sup>th</sup> grade level to maximise understanding of those with low literacy levels. Outcomes were assessed at 6 and 12 months. The sample were mainly men (60%) and aged between 35-74 (mean=60). 67% of the participants were married with 60% of the respondents considering themselves to be African American. 74% of the sample earned **less than \$15,000 per annum and recorded a mean**

**education of 9.6 years. In total there were 68 hospitalisations or deaths in the intervention group compared to 111 in the control group. After adjusting for possible confounding variables the difference noted between the two groups was not found to be statistically significant. Neither was there any statistically significant difference in their quality of life.**

Five studies evaluated programmes that included some aspect of motivational interviewing/counselling.

Riegel et al [51] used a mixed method, pre-test post-test design with 15 participants in the USA to evaluate the proportion of patients for whom the intervention was beneficial and the mechanism of effectiveness. Participants received home visits over a three-month period from an advanced practice nurse trained in motivational interviewing and family counselling. There was **quantitative evidence of improvement in self-care in 12 of 15 and qualitative evidence of behavioural change or change talk in 12 of 14 participants** (one tape malfunctioned). Congruence between quantitative and qualitative judgments of improved self-care revealed that **71.4% of participants improved in self-care** after receiving the intervention. Analysis of transcribed intervention sessions revealed themes of 1) communication (reflective listening, empathy); 2) making it fit (acknowledging cultural beliefs, overcoming barriers and constraints, negotiating an action plan); and, 3) bridging the transition from hospital to home (providing information, building skills, activating support resources).

A second study [52] involved 30 patients in Quebec, who were recruited from a heart failure clinic and



randomly assigned to an experimental or control group (n = 15 for each group). Data were collected at baseline and at 1 month after randomization. The motivational interviewing programme comprised 3 interventions (1 in person and 2 on the phone). During the initial encounter, patients were invited to identify one behaviour that they would like to change among the 5 behaviours proposed: fluid restriction, low-salt diet, daily weights measurement, exercise, and medication. Using an algorithm to evaluate the stages of change and the conviction and confidence level (ALEGrO), the nurse evaluated the patients and then selected a stage-specific intervention from the list of nursing interventions specific to the conviction and confidence level and the stages of change (INOVA). During the second and third encounters, which were done on the phone, the nurse started the encounter by going through the ALEGrO algorithm again to evaluate the level of conviction and confidence and the stage of change. There was no need for the patient to identify a new behaviour to change because the same behaviour was targeted for all 3 encounters. The nurse then used the INOVA list to direct the encounter. Patients in the experimental group obtained significantly higher scores than those of the control group patients in terms of **confidence to perform self-care behaviours specific to heart failure**. The results of the other hypotheses were not statistically significant.

Brodie et al [53] undertook a 5 month controlled physical activity lifestyle intervention study with 60 patients with chronic heart failure. Mean ages were 76 years for participants receiving usual care (a heart failure specialist nurse advising patients to participate in a structured exercise programme

including details of local amenities), 78 years for the group receiving the intervention (eight 1-hour home-based motivational interviews delivered weekly with the aim of assisting decision making and promoting physical activity) and 79 years for those participants receiving both usual care and the study intervention. All three groups demonstrated increased self-efficacy and motivation scores. The intervention group recorded the highest positive changes in health related quality of life; disease related quality of life scores improved most in the usual care group, with **statistically significant differences** recorded between those receiving just motivational interviewing and the **group receiving motivational interviewing in addition to usual care**.

One further study [54] in the Netherlands used a pre-test post-test design. Twenty-one COPD patients were randomized to an experimental group that followed a regular rehabilitation program plus a counselling intervention or to a control group that only followed rehabilitation; with feedback from a pedometer for both groups (itself used also as a motivational tool). The lifestyle physical activity (e.g. walking, cycling, stair climbing and gardening) counselling program comprised 4 x 30 minutes sessions of motivational interviewing. **The experimental group showed an increase of 1430 steps/day (+69% from baseline), whereas the control group showed an increase of 455 steps/day (+19%)**. Secondary outcomes showed no differences.

Finally, in a Japanese study [55] 104 patients with chronic heart failure were recruited from an outpatient setting and randomised to either routine care

or access to an educational intervention (based on principles of cognitive behaviour therapy and motivational interviewing). Ninety four patients completed the programme. The participants were mainly male (63%), and not currently employed (80%) which is unsurprising as the mean age of the sample was 73 years. The intervention was delivered monthly on a 1:1 basis over a six month period followed by a six month follow up. The educational sessions were facilitated by a nurse and lasted around 30 minutes. The content focussed on both disease management (medication, diet, exercise, smoking cessation etc) and the importance of adopting self care behaviours. Participants in the intervention group had statistically **significant lower BNP levels at 6 months and BP levels at 12 months. The control group were found to have higher levels of dyspnoea at 3, 9 and 12 months. There was no difference between the two groups when other symptoms were explored. Emotional, physical and social quality of life scores were higher** for the intervention group than the control group at 6, 9 and 12 months. Patients in the intervention group were also found to have made a **statistically significant change in their behaviour in relation to exercise, medication and weight monitoring. There was no statistical difference between the two groups when their mortality rates, readmission rates or NYHA class were compared.**

### **Exercise**

Two studies looked at the use of pedometers in encouraging a more active lifestyle. Following a 2 week run-in period, 17 COPD participants (mean age 68 years) were randomly assigned to either the MOBILE-Coach

or MOBILE-Self-Monitored group in Seattle, USA [56]. Individualised exercise plans were developed for all participants who were also issued with a pedometer and an exercise booklet including tips on strengthening and stretching exercises and a list of local resources. All participants were encouraged to keep a daily log of exercise and symptoms and to exercise 3-5 times a week up to a total of 150 minutes of moderate intensity endurance exercise. Participants reported that **keeping track of their exercise helped them remain active. The self-monitored participants increased their total step rate over the six-month study period.** This was not the case for the MOBILE-Coached participants who logged fewer steps despite receiving weekly text messages.

In a second study, Hospes et al [57] randomly assigned 35 COPD outpatients (mean age 62 years, 21 males) to a pedometer-based exercise-counselling project. Based in Assen, Netherlands, participants participated in 5 x 30 minute individually-tailored exercise counselling sessions, one every three weeks over the 12 weeks of the project. The intervention group showed **significant improvements in their exercise rates** compared with the usual group (7087 steps increasing to 7872 vs. 7539 decreasing to 6172) as well as demonstrating **significant differences in terms of arm and leg strength, health related quality of life and motivation to be physically active.**

Another study [58], a randomised trial involving 27 male subjects, included a 12-week programme of cardiopulmonary training. Exercise sessions were 3 times per week and included a 5- to 10-minute warm up

followed by PoleStriding and/or treadmill walking, and 5-minute active cool down. **Oxygen uptake improved** over the 6 and 12 weeks, respectively, in the exercising group, whereas the non-exercising group declined. Additional fitness gains were observed in those subjects who continued to exercise at 24 and 36 weeks. When the exercising group was compared with the control group, there was a significant improvement in the perceived physical function subscale change score of the SF-36. The perception of physical functioning in the exercising group increased from baseline to 12 weeks, whereas the control group declined during the 12 weeks. No other significant differences were observed between the groups. Subjects who continued to exercise maintained significant improvements in perceived physical function at 24 weeks. Self-efficacy for exercise was higher in the exercising group when compared with the control group (but the change score was not significant). The overall activity level was not significantly increased although subjects' compliance with completing the activity diaries was poor. Both groups reported no change in difficulty living with their symptoms from HF.

In an American study Donesky-Cuenca et al [59] explored the effect of yoga therapy on patients with COPD. 41 patients were randomised to either usual care or to a 12-week yoga training programme. 210 patients were assessed for eligibility. 169 of these patients were excluded, 123 were not eligible and 46 refused to participate. 41 patients were subsequently randomised to either usual care (21) or a 12 week yoga training programme (20). At the 12 week point 12 patients had dropped out of the programme due to illness (10), death (1) or transportation (1). This resulted in the

data for 29 people being recorded. The sample consisted of 21 females and 8 males. The mean age of those in the yoga group was 72 years compared to 67 years in the control group. 23 of the group were Caucasian and only 6 were employed. 12 of the participants had studied at college or higher. The programme included a wide range of techniques as advised by an expert panel. Those in the yoga group were **able to walk further in 6 minutes** compared to the control group.

Duncan et al [60] used a repeated measures design (in a 2-phase approach) to explore self-efficacy and adherence to exercise for 22 heart failure patients participating in a 24-week exercise programme. The sample consisted of 11 males (55%) and 21 of the participants were Caucasian (95%). The mean age of the group was 60 years. The programme involved a range of strategies including exercise logs, heart rate monitors, support sessions, goal setting with graphic feedback and an internet site. The first 12 sessions were structured; the remaining 12 focussed on self management of exercise. The participants **attended fewer aerobic exercise sessions per week** (statistically significant) and were **less likely to attain the target goal in phase 2 compared to phase 1**. However, the **exercise self-efficacy increased over the 24 weeks**.

**Education/counselling and exercise**  
A before and after trial of a skills-orientated education and near-home fitness programme for 248 participants with COPD (aged 40-75 years) was conducted in Enschede, The Netherlands [61]. The education programme was facilitated by a respiratory nurse and consisted of five 2-hour group sessions of

approximately 8 participants; four at weekly intervals with the final feedback session occurring 3 months after the fourth session. Participation in a 1-hour small group weekly fitness programme was facilitated by a physiotherapist trained in COPD care with individualised training goals devised between a physiotherapist and participant. Training performance and goals were recorded in a training log, symptoms were recorded in a diary and health status graded 1-10 in a weekly report. **No difference was noted in the symptom scores or six minute walking distance between groups, though the intervention group reported more exacerbations;** 69% of these exacerbations were treated at home.

A three-month longitudinal study of outcomes for 100 COPD participants (of 136 patients invited to participate) following an outpatient multidisciplinary pulmonary rehabilitation (PR) programme was conducted in Norway [62]. The PR programme was held 2-3 days per weeks over a six-week period and included group education sessions (45 minutes), group training and psychological support (60 minutes) and individual sessions (30 minutes) with a nurse and physiotherapist. Participants were divided into two groups, dependant on exercise capacity. Those who could walk more than or equal to 250m were given an additional 4 physical sessions with longer walks and three additional psychosocial support sessions. Project findings suggest that higher levels of self-efficacy were an important factor in improving both the health status and quality of life during PR, with participants reporting a **significantly reduced psychosocial impact of COPD immediately following the PR programme.**

A longitudinal study was carried out in Norway to investigate the impact after a one-year hospital based multidisciplinary self-management programme [63]; 30 participants, 46.7% women, mean age 67.2 years. The self-management programme comprised 30 hours of group education and 16 exercise sessions. Twenty-four of the 30 educational sessions were provided in the first six weeks of the programme to groups of between 5-7 participants and included setting personal short-term goals and learning how to self treat with oral antibiotics and prednisolone. Twelve of the 16 exercise programmes were carried out during the first six weeks of the programme and lasted one hour. Exercises were tailored to the individual but performed in groups. A list of local exercise and leisure facilities was provided at the end of the intervention. **Five years after the start of the intervention, two out of three participants self reported that they had continued to exercise regularly** and health related quality of life ratings were similar to baseline values.

A multi-centred randomised clinical trial was undertaken of the 'Living Well with COPD' self-management programme in Canada [64]. Of 469 eligible patients, 191 COPD patients, aged 50 years or more, participated in the study which consisted of: 7-8 one-hour weekly skills-orientated teaching, advice on home exercise, an action plan with customised prescriptions for antibiotics and prednisolone, monthly telephone assessment and access to the case manager during office hours. It was noted that most of the participants were **not highly educated**. Following the intervention **statistically significant reductions were recorded for all causes of emergency visits (down 21%) and hospital admissions (down 26.9%).**

A USA experimental controlled repeated measures study was carried out with 42 participants with heart failure, aged 21 years and over, participated in the exercise training intervention 'Heart Failure Exercise And Training Camp' (HEART CAMP); the eligible patient population was 139 [65]. The first three weeks of the intervention included hospital-based aerobic exercise three times a week, home-based resistance training twice a week and a group meeting. Weeks 4-12 saw participants' self-schedule exercise three times a week and group meetings became bi-weekly. Quality of life increased significantly for the control and intervention groups, the latter group reporting a **31% increase in cardiac exercise self-efficacy over the control group and significantly fewer symptoms.**

In another study, participants in an English COPD home exercise video programme received an individual consultation with a physiotherapist and were given an educational booklet on exercise [66]. Of 40 patients assessed for eligibility, 27 were recruited to the study; mean age 70 years. The intervention group watched a video on the benefits of exercise (a physiotherapist was on hand to answer questions), were shown how to do the exercises in a 30-minute exercise video/DVD and were advised to do the exercises at home four times a week for six weeks. All participants experiencing exacerbations during the life time of the project were advised to telephone the physiotherapist and were excluded from the study. Following the exercise programme the intervention group **scores significantly improved in terms of breathlessness** and showed significant improvements in the Chronic Respiratory Questionnaire for emotion and fatigue but not mastery.

Two groups totalling 16 participants participated in the USA Internet-based Dyspnoea Self-Management Program (iDSMP). The program included weekly nurse-moderated group educational discussions delivered 8 times (30-45 minutes – facilitated at two times during the week to accommodate participants' schedules) and individualised home-based exercise plans [67]. All participants had a diagnosis of COPD and were asked to log onto the study web site at least three times a week to record exercise in an e-diary. Participants received structured supportive emails on a weekly basis. In weeks 9-12 of the program, weekly unstructured chat sessions were provided for continued peer and nurse support. Evaluations were made at baseline and at three months after completing the iDSMP. **No difference was found between the intervention and control groups in terms of perceived support or exercise behaviour.** However, **significant improvements were noted in terms of activities of daily living and self-efficacy when managing symptoms.** Increased confidence in managing dyspnoea was attributed to the education modules by 94% of participants and to the weekly chats by 88% of participants.

One US study explored the effects of shared medical visits in 52 patients with heart failure; 34 completed the study (mean age 67.3 years, 41% female [68]. Control group members had a one-to-one 30-minute visit with a nurse practitioner and a physical examination. The intervention group had a ten-minute physical examination plus a one-hour semi-structured education and support group with six other participants accompanied by either a friend or family member. **No difference was recorded in Self-Care Heart Failure Index scores**

**between groups though the intervention group scores for the Heart Failure Knowledge Test improved from baseline to eight weeks.**

One study described a combined exercise and education/counselling programme (a one-group longitudinal pre-test post-test design with 29 participants) [69]. A 12-month home-based pulmonary maintenance program involved: strength retraining exercises; collaborative goal setting; regular telephone calls; and home visits. **Most participants showed a maintained or improved respiratory function. Most showed no difference or a decline in functional exercise capacity. There was no difference in quality of life and no difference in self-efficacy.**

In another prospective, randomized, parallel group study conducted with 38 participants in France [70], participants were randomly assigned either to usual care without any practical intervention (control group) or to a 4-week standardized, comprehensive, self-management programme comprising education and exercise sessions. After the 4-week intervention, participants were encouraged to continue exercising at home, and were followed-up for 48 weeks. During the maintenance phase (1-12 months), contact with study personnel was limited (for both groups) to telephone interviews to reinforce the importance of exercise and to ask about adverse events. Participants from both groups were assessed at inclusion and at 1 year. For programme participants, a health professional gave 8 lectures to small groups of 4-8 participants at a rate of 2 sessions (i.e. 2 hours per session) per week for 4 weeks. The programme emphasized the acquisition of self-

management skills. After each educational session within the same group, participants performed the usual exercise program used in our laboratory (i.e. cycling at the level of the ventilatory threshold for 30-45 min under the supervision of a qualified exercise trainer). After 12 months, **statistically significant between-group differences were found in favour of the intervention group in 6MWD, in two domains of NHP (energy, emotional reaction) in SGRQ-symptoms, and in cost of COPD medication (480.7 Euro less per patient per year).** Regarding healthcare utilization, **the number of days spent in the hospital for respiratory problems and for all causes, as well as the associated cost per patient and per year did not differ between groups after 12 months.**

In an American study, Lomundal et al [71] recruited 60 patients with COPD to participate in a one-year self management programme. Eleven patients were recruited from hospital and 49 from primary care. The self management programme consisted of small group educational sessions made up of between 5-7 patients. All patients were also given the opportunity to participate in a pulmonary rehabilitation programme that would be run alongside the self management programme in the first year but would also continue for a second year. The two groups were self selective; the control group comprised those who chose not to participate in the additional programme. The patients in the self management group were predominantly male (56%) with the mean age being 67 years. The majority (53%) studied at only secondary school with 6 patients (20%) studying at University. The pulmonary rehabilitation group

consisted of more females (56.3%), was slightly younger (mean = 62.8 years) and more educated with fewer people studying solely at high school (30%) and more studying at University (36.7%). Patients in the self management group were found to have **an improved quality of life at the 6 month point and this was maintained over the 2 year period.** They were also found to be more able to cope whilst accessing the self management programme but their coping levels returned to normal once the intervention ceased. There was **no improvement in functional ability** with the distance travelled during a six minute walk test being stable throughout but **lung function showed a small but significant worsening after 2 years.**

Those who opted to participate in the additional pulmonary rehabilitation sessions were found to have an **immediate improvement in quality of life which continued to improve over the 2 year study period** This group also demonstrated an **improvement in the distance they were able to travel in a six minute period in the first year and this outcome was maintained over the 2 year period.** In addition there was a small but statistically significant **improvement in the Lung function over the first year but this was not maintained over a 2 year period.**

In another American study, Donesky et al [72] carried out a secondary analysis of a previously undertaken randomised controlled trial. The previous year-long trial had compared three groups. These consisted of a dyspnoea management alone group (DM), a dyspnoea management plus 4 additional exercise sessions (DME) and thirdly a dyspnoea management group plus 24 additional supervised

exercise sessions (DMT). All participants in the study were also advised to walk 4 times a week for at least 20 minutes.. The 103 participants were all long term but stable COPD patients. 55% of the group were women and the mean age of the sample was 66.3 years. 101 patients completed the 6 month assessment, 100 completed the 8 months assessment, 94 completed the 10 month assessment and 92 completed the 12 month assessment. The participants were asked to record their walks in a log and this was further discussed during twice-monthly telephone calls by the nurse. There was a **reduction in walking per week throughout the study. Those who exercised prior to starting the programme were more likely to exercise more frequently during the programme. Those who lived with others were more likely to exercise more than those who lived alone, and those with depressive symptoms were less likely to exercise. Participants in the dyspnoea management training group (DMT) walked more than those in the dyspnoea management (DM) alone group.**

### ***Telehealth***

A randomised controlled trial with 60 participants (aged 40 years or older) of a telenursing intervention to reduce hospitalisation for patients with heart failure was undertaken in the USA [73]. The trial compared usual care of home visits with either scheduled telephone calls or scheduled video-based home telecare visits. In addition to emergency contact details for all, the intervention groups also had access to the study nurse via their allocated medium (telephone or video link) between 8am and 5pm, Monday – Friday. Home visits typically took 176 minutes; telecare visits took 52

minutes; telephone calls took 32 minutes. No significant difference was noted between groups in terms of self-care adherence, medication, health status or satisfaction though **heart failure readmissions for the intervention group were significantly reduced (>80% lower).**

In another study in Canada [74] one hundred patients were recruited from a heart function clinic and randomized into telemonitoring and control groups. Telemonitoring participants took daily weight and blood pressure readings and weekly single-lead ECGs, and answered daily symptom questions on a mobile phone over 6 months. Readings were automatically transmitted wirelessly to the mobile phone and then to data servers. Instructions were sent to the patients' mobile phones and alerts to a cardiologist's mobile phone as required. About 70% of telemonitoring patients completed at least 80% of their possible daily readings. **The change in quality of life was significantly greater** from baseline to post-study, as measured with the Minnesota Living with Heart Failure Questionnaire, for the telemonitoring group compared to the control group. A between-group analysis also found **greater post-study self-care maintenance** (measured with the Self-Care of Heart Failure Index) for the telemonitoring group. Brain natriuretic peptide (BNP) levels, self-care management, and left ventricular ejection fraction (LVEF) improved significantly for both groups from baseline to post-study, but did not show a between-group difference. However, a subgroup within-group analysis using the data from the 63 patients who had attended the heart function clinic for more than 6 months revealed the telemonitoring group had significant improvements from baseline

to post-study in BNP (decreased by 150 pg/mL), LVEF (increased by 7.4%) and self-care maintenance (increased by 7 points) and management (increased by 14 points), while the control group did not. **No differences were found between the telemonitoring and control groups in terms of hospitalization, mortality, or emergency department visits**, but the trial was underpowered to detect differences in these metrics.

A further randomized controlled trial [75] with 121 participants (of a pool of 249 that included also angina) compared usual care with home telemonitoring - 3 months of video conferencing with a nurse, daily transmission of weight and blood pressure, and periodic transmission of 12-lead electrocardiogram. There was **no significant difference between patients with heart failure receiving home telemonitoring or usual care in the number of readmissions to hospital within the first year of discharge or in the number of days they spent in the hospital in the first year post-discharge.** Home telemonitored patients with heart failure spent **28% fewer days in the hospital than usual care patients with heart failure within the first 3 months of discharge, but this difference was not statistically significant.** There were no significant differences between randomized groups in the number of emergency department visits made in the first month, 3 months, or 1 year after hospital discharge (the time of study enrolment) for all patients combined or for patients with heart failure (unlike for angina). There were no differences between the intervention and usual care groups in the numbers of visits made to health professionals or number of home visits. However, quality of life was better in home



telemonitored patients with heart failure than in usual care patients on five of the eight SF-36 subscales at 3 months.

In a prospective, multi-centre, randomised study involving 214 patients with chronic heart failure in Netherlands [76], patients in the intervention group received a MOTIVA system, in addition to their scheduled visits to the cardiologist. The system included a secured broad band home TV-channel providing educational material, reminders of medication, health related surveys and motivational messages to encourage the prescribed lifestyle regimen. A subgroup of patients (Intervention-plus), who had been in hospital for heart failure treatment in the year preceding enrolment, were also given automated devices for daily measurements of blood pressure and weight. **No differences between the two groups were found for the number of days in hospital, days alive and out of hospital, quality of life or self care behaviour.** However, **increase in knowledge about heart failure was significantly higher in the intervention group** than it was in the control group. With no decrease in hospital days or health care consumption and with the extra costs of the MOTIVA system and the Medical Service Centre, **overall costs were higher in the intervention group** than the control group.

In an American study Artinian et al [77] studied the effect of introducing a web-based compliance device for patients with heart failure. This non random sample of 18 patients (94% male) who were aged between 50 and 87 years (mean = 68) were recruited from a heart failure clinic. The patients were mainly black (65%) with a **mean educational level of 13 years**. 78% of

the group were unmarried and 61% lived alone. The patients were randomised to either routine care or to the web-based intervention. The web-based intervention patients all received a Med eMonitor. The device retains a supply of up to 5 medications and uses an alarm to remind patients when the medications are due. The device contains a further 25 virtual compartments in which pre programmed reminders were stored. These included information regarding symptoms, daily weights and other educational material. The reminders were tailored to the patient's history. The device was connected to a telephone line and the data regarding the patient's responses to the reminders and the compliance of medication was downloaded on a daily basis by the researchers. There was **no statistically significant difference between the two groups in relation to self care behaviour or quality of life.**

One final randomised controlled trial [78] compared the impact of using telemonitoring in heart failure patients in the USA. 284 patients (mean age = 77 years) were randomised to either telehealth or routine care. The intervention group was then further subdivided into telehealth with or without video support. **Confidence for those using the video telehealth increased more** than for those in the control group or in the standard telehealth group. **Moreover confidence was associated with increased self care behaviours in some routine care (low salt diet, exercise) and symptomatic care (low salt diet, fluid intake, diuretic use and calling a physician).**

#### ***Personal plans***

An experimental repeated measure study in the USA compared the

efficacy of mutual goal setting between heart failure patients and nursing staff with a supportive educational intervention [79]. Ninety-four percent of the 88 participants (44% men, mean age 75 years) had an annual household **income of less than \$30,000**. Over a six-month period mutual goal setting significantly supported **improved quality of life and the mental health** of participants.

Trappenberg et al [80] undertook a Netherlands-based multi-centred randomised controlled trial with 233 participants (mean age 65 years) of an individualised action plan with ongoing case management support of COPD. Usual care included pharmaceutical and non-pharmaceutical care according to evidence-based guidelines, and participants were encouraged to contact the case manager if a need for information arose. In addition to usual care, the intervention group were required to complete a daily diary of symptoms and received an individualised treatment prescription/action plan (AP) graded according to symptom status; it was optional for the case manager (in consultation with a physician) to provide self-treatment. To evaluate patient understanding and adherence to the AP, two standardised telephone reinforcement sessions were held at one and four months. During the six-month follow up period there was **no difference in the rates of exacerbation or healthcare usage**. However, the **length of exacerbations and recovery times were both reduced**.

In a randomised controlled trial in Scotland, 464 participants with COPD (mean age 69.1 years, 37% male) were allocated to usual care or a supported self-management intervention group [81]. The

intervention included completing daily diary cards, four 40-minute fortnightly-individualised home-based training sessions to detect and treat exacerbations promptly, and home visits by a nurse every six weeks (more if required) for a total of 12 months. Although **no effect was noted on time to first readmission or death**, sub-group analysis suggested that **younger participants and those living with others learned to self manage more effectively and had a significantly reduced risk of COPD related readmissions**. The researchers noted that those who agreed to join the study were less likely to come from deprived areas of residence.

Rice et al [82] undertook a one-year randomised adjudicator-blinded controlled trial of a disease management program with 743 participants with severe COPD in the USA. The mean age of the intervention group was 69.1 years, the mean age of the usual care group was 70.7 years; 97.8% of the participants were male. The management programme consisted of a single education session lasting between 60 and 90 minutes, a self-treatment action plan including capacity for refillable prescriptions, monthly follow-up calls from a case manager. Usual care comprised a one page handout summarising the principles of COPD care and telephone number to a 24hr nursing help line. The intervention saw a **49% reduction in hospitalisation as a result of COPD**, a **28% reduction in hospitalisation for all causes** and a **27% reduction in ED visits for all causes**.

A randomised controlled single-centre study of an integrated heart failure out-patient management program involved 197 participants with heart failure in

Auckland, New Zealand [83]. Patients in the usual care group received routine clinical care, mainly from general practitioners. Patients in the intervention group kept a heart failure diary for the recording of daily weights, attended a heart failure clinic and were encouraged to attend three education sessions. Of the 100 patients in the management group, 76 patients used the diary. Of these, 51 weighed themselves regularly. More of these owned scales at home; they were also more likely to attend the education sessions, and experienced fewer hospital admissions than those patients who did not weigh themselves regularly. Variables independently associated with regular self-weighing included the presence of scales at home, left ventricular ejection fraction >30%, and attendance at the education session(s). At 12 months **level of education on self-management was significantly higher** in the management group than the control group.

In a retrospective non-randomised descriptive study conducted in Houston, USA [84] all patients enrolling in an outpatient heart failure clinic were given a Heart Health Diary to record weight, vital signs and symptoms. Seventy patients used the diary and 54 did not. A review of these 124 patients (82 men and 42 women) was completed 6 months after enrolment to compare the clinical and hospital outcomes. Those using the diary had 35% and 47% more contacts via telephone and clinic, respectively. Both the telephone and clinic groups had **significant functional and B-type natriuretic peptide improvement**. If hospitalized after enrolment in the heart failure clinic, **the average length of stay for all hospital admissions for diary users decreased by 58% and average cost**

**per case decreased by 56%**. Length of stay and cost per case did not significantly change for those not using diaries.

Another study, a prospective, randomised study with 106 participants and a 12-month follow-up, carried out in Sweden, involved a nurse-led heart failure clinic that provided individualised plans for patients [85]. The first follow-up visit was 2–3 weeks after discharge. During the visit the nurse evaluated the heart failure status and the treatment, gave education about heart failure and social support to the patient and his family. There were **fewer patients with events (deaths or admissions) after 12 months** in the intervention group compared to the control group. The intervention group had **fewer admissions and days in hospital during the first 3 months and after 12 months** compared to the control group. The intervention group had **significantly higher self-care scores at 3 and 12 months** compared to the control group. The single items with the largest difference between the intervention and control group after 3 and 12 months were self-care behaviours such as daily weighing, alerting health care professionals at weight gain and restricting fluid intake.

A further study, a randomized clinical trial in San Diego, USA involving 116 participants 95% male and 75% Caucasian with a mean age of 67 years), evaluated a 15-week programme of behavioural management through individualised goal setting [86]. The control group received usual care for patients with heart failure. The intervention group received usual care plus the behavioural management program. Outcomes were assessed at baseline, 4, 10 and 16 months. Intervention

patients showed significantly **improved self-reported disease-specific health-related quality of life** over time compared to control patients. There were **no group differences in exercise performance, physical functioning, mental functioning or general health perceptions.**

In a study conducted in Barcelona, Spain, Garcia-Aymerich et al [87] recruited a total of 113 exacerbated COPD patients after hospital discharge, and randomly assigned them to integrated care or usual care. The intervention consisted of an individually-tailored care plan at discharge shared with the primary care team, and access to a specialized case manager nurse through a web-based call centre. After 1 year of intervention, subjects **improved body mass index** by 1.34 kg/m<sup>2</sup>. Additionally, they **scored better in self-management items: COPD knowledge, exacerbation identification, exacerbation early treatment, inhaler adherence, and inhaler correctness.** There were **no differences in terms of dyspnoea, lung function, quality of life scores, lifestyle factors, or medical treatment.**

Sethares and Elliott [88] described a randomized control trial involving 70 participants in the USA that evaluated the effect of a tailored message intervention on readmission rates, quality of life, and perceived benefit and barrier beliefs in an elderly sample of subjects with heart failure. **Heart failure readmission rates and quality of life did not significantly differ between the treatment and control groups.** However **health beliefs, except for benefits of medications, significantly changed from baseline in the treatment**

**group** in directions posited by the Health Belief Model.

Khdour et al [89] evaluated a programme that included a tailored action plan through a randomized, controlled, longitudinal, prospective clinical trial involving 173 participants in Belfast. Patients were followed up at 6 and 12 months during a scheduled visit. The action plan (e.g. antibiotic and oral steroid to be initiated promptly by patients for exacerbations) was part of a complex clinical pharmacy-led intervention, delivered after assessment of individual need. The intervention included education on disease state, medications and breathing techniques. Patients were also given educational booklets. Over the 12-month period in the intervention group, **emergency department visits decreased by 50% and hospitalization by approximately 60%.** There was a **significant difference between the intervention and usual care groups regarding knowledge scores and good adherence to medication.** There was **no significant difference regarding smoking** between study groups.

Kimmelstiel et al [90] evaluated a complex nurse-driven disease management programme (Specialized Primary and Networked Care in HF (SPAN-CHF)) that included among other things individualised plans and access to support via telephone. This was a prospective randomized assessment, with control, of the effectiveness of the delivery of the programme over 90 days across a diverse provider network in a heterogeneous population of 200 patients with high baseline use of approved heart failure pharmacotherapy. A nurse-manager, experienced in heart failure management, conducted a home visit,

meeting with the patient and the respective spouse/partner/caregiver. Depending on patient knowledge and interest, this visit lasted 45 to 90 minutes and focused on dietary and medical compliance, daily weights, self-monitoring, and early reporting of changes in weight or clinical status. At this session, patients and family received a pre-printed Patient and Family Handbook. After the teaching was complete, the nurse performed a cardiovascular examination and a symptom assessment. Depending on clinical status, the nurse-manager telephoned patients weekly or biweekly, focusing on identifying changes in clinical condition and education reinforcement. At each follow-up phone call, the information discussed during the home visit was reinforced. Nurse-managers were available at any time by telephone. Patients were instructed to report clinical status changes, including any change in weight >2 lb. Nurse-managers received support and weekly management teleconferences with heart failure physician specialists. After 90 days, stable patients received passive surveillance, during which the nurse-manager remained available for incoming calls but did not place regularly scheduled calls. During a 90-day follow-up, patients randomized to disease management experienced **fewer hospitalizations for heart failure. Intervention patients experienced reductions in hospital days** related to a primary diagnosis of heart failure, cardiovascular hospitalizations, and days in hospital per patient-year alive for cardiovascular cause. Intervention patients showed a trend toward reduced all-cause hospitalizations and total hospital days. **On long-term follow-up, there was substantial attrition of the 3-month gain in**

**outcomes**, with sustained significant reduction only in days in hospital for cardiac cause.

## Summary of findings

This literature review included 79 relevant articles (identified from among 923 abstracts). Each of these articles fell into one of 5 themes:

1. Education or counselling,
2. Exercise
3. Education or counselling with exercise
4. Telehealth
5. Personal plans

While these are not necessarily definitive categories, there was a strong degree of consistency between the three reviewers.

Thirty one literature reviews, both narrative and systematic, were returned from the search. These were reserved for cross-validation of the findings of this review. Fourteen reviews relevant to this review and are referred to in the following summary.

### *Education or counselling*

The majority of articles (n = 44) fell within the educational or counselling theme. The interventions reported in these studies involved either individuals or groups of individuals, most involved some form of follow up although some did not, and they used a wide range of modalities: counselling, motivational interviewing, face-to-face, telephone, video, CD-ROM, booklet, computer-assisted learning, the Internet, or a combination of approaches.

The results from the educational/counselling interventions were mixed. While no significant negative effects were found for the range of interventions, the results from the majority of studies were equivocal between positive effects and no significant difference between control

and intervention groups. Many studies (n = 16) reported positive effects in behaviour, including self care behaviours such as exercise and carrying out activities of daily living. However 5 studies reported no difference between control and intervention groups and 2 studies found that the positive effects did not last over time. Positive effects on status or outcome were reported in 12 studies, with no difference reported in 6. Seven studies reported improvements in quality of life scores, while 6 reported no difference. Positive results were reported for both beliefs (including self-efficacy) (n = 5) and reduced costs (n = 3). Four studies reported improvements in knowledge as a result of the interventions with 2 reporting no difference. Finally, six studies reported a decrease in hospitalisations and utilisation of health services, although a greater number (n = 8) reported no difference.

Overall the range of education or counselling interventions appears to have made a modest positive impact in the majority of cases (particularly in terms of behaviour and status and outcomes). No one modality, or range of modalities, appeared to be more effective than others, although all but one study within this theme involved human contact and most appear to have involved some degree of ongoing support. In total for this theme, there were at least 53 reports of positive effects with 25 reports of no significant difference.

These results are in line with the results from other related literature reviews. In one review [91], the authors were unable to make recommendations due to the range of outcome measures used. However the authors concluded that while self-management education had no effect

on the use of health services or on outcomes, it appeared to reduce the need for rescue medication and led to increased use of oral steroids and antibiotics for respiratory symptoms. In a further Cochrane review, an update of Monnikhof et al [91], Effing et al [92] concluded 'It is likely that self-management education is associated with a reduction in hospital admissions with no indications for detrimental effects in other outcome parameters. This would in itself already be enough reason for recommending self-management education in COPD' (p 2). However, Effing et al were once again unable to make recommendations due to the heterogeneity of included studies.

A further review by Barnason et al [93] concluded that augmentation, using cognitive behavioural strategies, of patient education for heart failure results in improved patient outcomes.

In terms of the amount of education needed for self-management, Yehle et al [94] suggested that factors (as yet unknown) other than the number and length of educational sessions actually serve to improve self-efficacy.

While Fredericks et al [95] argued for the redesign of heart failure educational programmes, concluding that the 'the most effective means for delivery heart failure patient education is through the individualization of content, the use of combined mediums for delivery, provision of education on a one-on-one basis, and in multiple sessions'(p 30). Harris et al [96] also call for the redesign of both educational programmes and their evaluation.

This view is held more widely. For example Bourbeau and Johnson [97] called for further research around self-management in general. While Ditewig [98] found that methodological

shortcomings make it difficult to assess the effectiveness of self-management interventions.

### *Exercise*

Five articles fell within the exercise theme. Interventions included the use of pedometers to encourage more active lifestyles, structured exercise programmes and yoga therapy.

The results for all studies were positive, demonstrating increased activity/ exercise, improved quality of life and self-efficacy and improved status – ability to walk, oxygen uptake and leg strength. One study showed a drop-off upon moving to a self-management approach. There were at least 8 reports of positive effects.

In one related external review, Hwang et al. [99] concluded that while home-based exercise programme benefit people with heart failure in the short term, further research is required to investigate long-term effects of home exercise.

### *Education or counselling with exercise*

Twelve studies involved a combination of education/counselling with an exercise programme. Only one study reported a negative effect – an intervention group reported increased exacerbations.

Seven studies reported improved status or outcome and one study reported reduced cost. Four studies reported improved belief or self-effect, 2 reported improved quality of life and 1 study reported decreased hospitalisations. However in each case, one study also showed no difference between the control and intervention groups. For behaviour, 4 studies reported positive effects (in one case the difference was still evident after 5 years; in another the

effect was not lasting). However, 3 studies reported no difference.

Overall, for those studies that described a combination of education or counselling with an exercise programme, the results were largely positive (particularly in terms of status or outcome). Two of the studies appeared to describe one-off activities, with the majority being planned ongoing support or reinforcement for the duration of the programme. However, there was no clear predictor for positive effect. In total for this theme, there were at least 19 reports of positive effects with 1 report of a negative effect and 6 reports of no significant difference.

### *Telehealth*

Six studies involved some form of telehealth application as part of the intervention – 2 studies involved video consultation, 1 involved mobile phone telemonitoring, 1 involved a multi-purpose television-based telehealth application, and 1 involved a multi-function telehealth device.

Two studies reported improved quality of life for individuals within the interventions group and 2 reported positive effects in terms of behaviour. In both cases, 2 further studies reported no difference between control and intervention groups. One study reported increased knowledge and 1 reported positive effects on beliefs. In terms of status or outcome, 2 studies reported no difference between control and intervention groups. Only one study reported decreased use of health services while 3 studies found no significant difference between control and intervention groups.

Overall, while some studies showed positive effects from the use of telehealth, no difference between control and intervention groups was

reported more often. Once again, there appear to be no clear predictors. In total for this theme, there were at least 6 reports of positive effects with 9 reports of no significant difference (a greater proportion of 'no difference' to 'positive effect' than all other themes).

In an external Cochrane review, Inglis et al [100] found that structured telephone support and telemonitoring appear to be effective in reducing the risk of mortality and hospitalisations in patients with heart failure, also improving quality of life, reducing costs, and promoting evidence-based prescribing.

Interestingly, Ward et al [101] argued that the components of self-monitoring interventions remain ill-defined, despite guidelines for self-monitoring in cardiovascular disease management.

In a third literature review, Pare et al [102] found that while patients with asthma (and diabetes) who self-monitored had positive outcomes in terms of symptom management and quality of life, the results for home monitoring patients with heart failure were equivocal.

### *Personal plans*

Twelve studies fell within the personal plans theme. Interventions within the theme included mutual goal-setting, individualised action-planning, daily diaries, individualised training sessions, individualised care planning, tailored messages and disease management.

Five studies reported a decrease in hospitalisations and the utilisation of healthcare services, while 3 reported no difference between control and intervention groups. Four studies reported positive effects in terms of behaviour with one reporting no difference. A further 4 studies reported



positive effects in terms of status, while 3 studies reported no difference. Two studies reported improvements in quality of life with 1 reporting no difference. Two studies reported improved knowledge. 1 reported improved beliefs and 1 reported decreased costs. One study reported no difference in activity between the control and intervention groups. Finally 1 study reported no difference in attitude.

Overall, personal plans appear to have made a positive impact in the majority of studies, particularly in terms of hospitalisations and health care utilisation, status and outcomes and behaviour. However, there was no identifiable predictor for any positive effect. In total for this theme, there were at least 20 reports of positive effects with 10 reports of no significant difference.

Two external Cochrane reviews ([103] and its update [104]) both reached the same conclusion: that while they cannot be recommended, and while there is no evidence of reduced healthcare resources utilisation or improved health-related quality of life, action plans with limited COPD education can aid recognition of, and response to, exacerbations.

#### *Best practice*

Because there were no identifiable predictors of success across any of the themes, it would not be possible to identify best practice for the implementation of any specific model or approach. This is the case also for the external literature reviews. A common characteristic of many studies was the ongoing nature of interventions, enacted through visits, telephone calls, group meetings, etc. Almost all studies described interventions that required direct human interaction, albeit through a

variety of media. However, this should not be taken to mean that direct human interaction is a prerequisite to success. Approaches that do not rely on human interaction may be under-researched or under-reported. Also almost all studies presented results that were exclusively positive or demonstrated no significant difference between control and intervention groups (telehealth applications were the least successful in terms of demonstrating positive effects over no difference, while exercise programmes were the most successful). While it is likely that the models used did not cause actual harm, the paucity of studies with negative results may be in part explained by publishing bias.

#### *Participants*

While it is not possible to identify from the studies people who may live in deprived or urban areas (people in affluent areas also attend urban hospitals), across the themes, several studies involved and identified people on low incomes or with low educational attainment.

In terms of studies that involved and identified participants on a low income, none of the studies compared the results with those for participants on a higher income. One study used group meetings with no significant difference between control and intervention groups. One study used mutual goal setting with a positive effect on mental health and quality of life. One study used video tapes with positive effects on knowledge and status. The remaining studies that included people on a low income involved ongoing telephone support (all but one also involved an initial educational session). The results of these 5 studies were largely positive across a wide range of variables. However, it is not possible to infer from this that the approaches

used are particularly relevant to those on low incomes.

There was a similar picture for studies that involved and identified participants with low educational attainment. The results for a pulmonary rehabilitation programme were positive, while they were more mixed for another disease management programme. For a web-based compliance device, there were no significant differences between control and intervention groups. One study augmented an educational programme with video with positive results across a number of variables. The remaining studies involved telephone support with some positive effects.

### *Costs*

Costs of care were lower in intervention groups than control groups in 6 studies (an educational programme with remote self monitoring, a one-off education session, a combined group session with individual follow up sessions, an exercise programme, a combined education and exercise programme, use of a daily diary). One study estimated that the costs of the intervention were higher than any savings that resulted from the intervention (telehealth). None of the external reviews examined demonstrated any impact on costs of care.

## **Conclusion**

The majority of interventions to support self-management appear to make some positive impact in terms of behaviour, status, outcome, use of health services or quality of life; there is also some indication, albeit limited that costs of care can be reduced as a result. However, due to the heterogeneous nature of the interventions in published reports,

further primary research is needed to identify common predictors of success and the longevity of success.

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## Appendix A: MEDLINE (OVID) Search Strategy

- 1 Self Care/
- 2 Self-efficacy/
- 3 exp Pulmonary Disease, Chronic Obstructive/
- 4 exp Heart Failure/
- 5 Lung Diseases, Obstructive/
- 6 copd.mp.
- 7 chronic obstructive pulmonary disease.mp.
- 8 chronic airflow obstruction.mp.
- 9 chronic obstructive airway disease.mp
- 10 chronic obstructive lung disease.mp.
- 11 congestive heart failure.mp.
- 12 cardiac failure.mp.
- 13 coad.mp.
- 14 myocardial failure.mp
- 15 chronic bronchitis.mp.
- 16 selfcare.mp.
- 17 self care.mp.
- 18 self-care.mp.
- 19 self management.mp.
- 20 self-management.mp.
- 21 self-efficacy.mp.
- 22 self-efficacy.mp.
- 23 expert patient\*.mp.
- 24 expert-patient\*.mp.
- 25 1 or 2 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
- 26 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
- 27 25 and 26
- 28 limit 27 to yr="2000 -Current"
- 29 limit 28 to english

## Appendix B: Self Care Review Data Collection Tool

Bibliographic details:	
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HD/COPD		Identifiable pgm <sup>1</sup>		Comparison		Measurable outcome	
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If all 4 are ticked then fill out the following (name and date regardless)

Chronic bronchitis/COPD		Heart failure	
Description of self-care/ self-management programme?			
Description of study design (design, location, participants) – highlight if urban/deprived			
Measurable outcome?			
Cost effectiveness		Quality of life	Readmission/re-attendance
Other			
Findings			
Other comments:			
Reviewer:			
Review date:			

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<sup>1</sup> Self care/mgmt examples include: Self-management of medications, self monitoring, exercising, self-management of exacerbations, stopping smoking, etc. NOT intention to do these but actual behaviours