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The effectiveness of group work facilitated by health care professionals in long term conditions. A narrative review Margaret Jackson, Daniel Jones, Judith Dyson and Una Macleod

Background: About 15.4 million people in the UK live with a long-term condition. Seventy percent of health and social care spend is invested caring for this population. Evidence suggests that group work interventions offer patient support, improved outcomes and reduce the costs of care.

Aim: To review the current evidence base examining the effectiveness of group work in chronic physical disease where such groups are facilitated by health care professionals.

Design and setting: Systematic review and narrative synthesis of studies of group-work interventions led by health professionals for adults with specified long-term illnesses.

Method MEDLINE, Embase, PsycINFO and Cochrane databases were systematically searched using terms relating to group work and long term conditions. Studies were included if they were RCTs with a control group that did not include group work.

Results The 14 included studies demonstrate a high degree of heterogeneity in terms of participant characteristics, intervention, and outcome measures and are of varying quality methodologically. Tentatively, there appears to be some statistically significant improvements in psychological outcomes in the intervention groups and more positive than negative outcomes in quality of life measures.

Conclusion There appears to be some benefits resulting from group participation in adults with chronic disease especially in psychological and quality of life parameters. However, results are mixed and some benefits short-lived. Some of the studies are small and the quality of studies is variable. There is a clear need for larger and better quality studies to explore this potentially important area.

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INTRODUCTION

Evidence increasingly demonstrates the value of group work to manage long term conditions (1, 2). Long-term conditions are placing a growing burden on individuals, their families and health care systems. Around 15.4 million people in the UK are currently living with a long-term condition and care of this population accounts for 70% of the health and social care spend in England (3). Group work interventions may be a way to offer effective support, improve outcomes for patients and reduce costs to health and social care services.

In England the Expert Patient Programme (EPP) launched by the Department of Health in 2001 is an adapted version of The Chronic Disease Self-Management Programme (CDSMP), devised by Lorig and colleagues (4). It is based on Bandura's self-efficacy theory (5) and has been used and adapted widely as the basis for many lay-led and some professionally-led group projects. The CDSMP can improve the overall health of patients and reduce the number of hospital admissions (6).

Professionally-led groups can be highly structured. Examples include the 'Group outpatient model' used in the US (see, for example, the work by Sadur (7)) and the UK Pulmonary Rehabilitation programme (8). Other groups are based on the CDSMP and yet others adopt a much more psychological approach (for example, Herschbach (9)).

The aim of this study is to review the current evidence base examining the effectiveness of group work in chronic physical disease with health professional facilitators.

METHOD

The search strategy was designed to identify all relevant literature relating to professional led group work interventions for long-term conditions. Inclusion and exclusion criteria are illustrated in Figure 1. Only RCTs and papers written in English were included. An initial scoping search was undertaken to identify search terms. Following this, MEDLINE, Embase, PsycINFO and Cochrane databases were systematically searched on 29th October 2017. A combination of Medical Subject Headings and keywords were used which focused around 'group work' and 'chronic illness'. These terms were combined using Boolean operators (Appendix 1). Grey literature searches were conducted using OpenGrey. Reference lists of all full text articles were reviewed. No time restrictions were applied. One researcher undertook the search. Titles, abstracts and full text articles (n=91) were then reviewed by two researchers. Where there was disagreement regarding inclusion or exclusion of a paper a third researcher was consulted.

Figure 1. Inclusion criteria

| Participants | Aged 16 years old or over with one or more of following long-term |
|---------------|--|
| | condition: heart disease, diabetes, stroke disease, lung disease, |
| | arthritis |
| Intervention | Health professional led face to face group work, minimum six sessions |
| Control group | Usual care or waiting list control. |
| Outcomes | Patient reported outcome measures (including measures of symptoms- |
| | somatic and psychological; self-efficacy; self-care, quality of life and |
| | health-related knowledge). |

Data extraction

Data extraction involved using a bespoke form based on that used by Cochrane. Data extraction included the age, gender and ethnicity of participants and the location, group work setting, theoretical basis, type of professional leader and number and length of sessions. All primary and secondary outcomes relating to health and wellbeing were extracted.

Results

In total 14 studies from 6 countries including 2578 participants were included (Figure 2).





Risk of bias assessment was conducted for all included papers (11). Studies were judged low, unclear or high risk based on seven methodological quality domains (figure 3). Overall, although the methodological quality of the studies is mixed and there is some absence of reporting, they appear to be reasonably robust in terms of risk of bias. For example, most of the areas of high risk were for blinding. Given the nature of the intervention (a health care practitioner delivered group) and the control (waiting list) it would not be possible to blind either participants or personnel.



KeyLow RiskHigh RiskUnclear
Risk

Figure 3: Methodological Quality of included papers

There was an extensive range of outcome assessment tools used (Appendix 2). Figure 4 gives an overview of the included studies. The studies cover a wide range of patient characteristics and of interventions. Many of the interventions are either loosely or more rigorously based on the CDSMP (14-16, 18, 19, 24). Others offer a range of other psychological interventions. The interventions are presented in accordance with the TIDieR Consort criteria (26).

Figure 4: Summary of included papers

| Study | Sample | Intervention description ¹ (duration) | Theoretical Underpinning ² | Outcomes measured | Significant Findings ³ |
|-------------------------------|---|---|--|---|---|
| Berg 1997 (14) | 55 adults with moderate to severe asthma prescribed inhaled medications (other than "as needed" bronchodilator s) in the USA | Asthma self-management program including education, skills training, relaxation techniques, psychological response and problem-solving skills. Six 2-hour registered nurse led weekly sessions and self-monitoring. No report of intervention fidelity. | Self–efficacy theory | Metered Dose Inhaler (MDI) chronology to assess compliance, self- reported compliance (measured when using inhaler), lung function (Spirometrics and peak- flow meter), self-efficacy using SEAMS and self- management using ASMAT. | There was significantly better compliance in the intervention compared with control group in compliance according to the MDI chronology. There was no significant difference in any other outcome measured. |
| Coleman et al 2012 (15) | 146 primary care patients with osteoarthritis of the knee in Australia | The "OAK" programme (disease specific self-management group) to improve self-efficacy and influence health behaviours. Six, 2.5-hour sessions delivered weekly involving groups of 12 in a community venue and delivered by health care practitioners. A facilitators' manual assured fidelity. | Social Cognitive theory | Pain and function WOMAC, Quality of Life SF-36, pain (Visual Analog Scale, measured weekly). Timed Up and Go test, hamstring and quad strength and knee range of motion (measured at baseline, 8 weeks and 6 months). | There were statistically significant improvements in the intervention compared with control group in pain, quality of life and function at both 8 weeks and 6 months compared with baseline. |
| Elzen et al 2007 (16) | 139 older (>59) people with | Adapted Chronic Disease Self- Management Programme | Self-efficacy theory | Rand-36, Self-efficacy scale (GSES), and Self- | No significant difference in any of the outcome measures between |
| | one or more | (CDSMP) to improve self- | | management behaviour | intervention and control groups. |

¹ According to TIDieR Consort parts a and b ² According to TIDieR Consort part b ³ Presented according to outcome measure in figure 5

| Study | Sample | Intervention description ¹ (duration) | Theoretical Underpinning ² | Outcomes measured | Significant Findings ³ |
|--------------------------|---|---|---|---|---|
| | chronic disease (angina, heart failure, arthritis, diabetes, COPD or asthma) in the Netherlands | efficacy and thus influence self- management. Six 2.5-hour sessions delivered weekly involving groups of 10-13 delivered by the study's primary investigator. A detailed manual assured intervention fidelity. | | measured at baseline, immediately after the course had finished and at 6 months. | |
| Grady et al 2014 (13) | 902 people with heart failure in USA | A self-management intervention "HART", group counselling that provided coaching in self- management skills and problem solving. Eighteen 2-hour sessions delivered over a year by health professionals with advanced degrees. Intervention fidelity was ensured by audiotaping sessions and reviewing a sample of 5%, monitoring data and monthly group leader meetings. (Powell et al 2010) | No specific theory noted, however the intervention was underpinned with behaviour change techniques such as self- monitoring and cognitive restructuring | Health Related Quality of Life according to QLI, Medical outcomes SF-36 pre and post treatment and depression using GDS. | No significant difference in HRQOL between groups or across time. |
| Henry et al 1997 (17) | 19 people with non-insulin dependent diabetes in Australia | Cognitive Behaviour Therapy (CBT), stress management programme including relaxation and coping skills training. Six weekly 1.15-hour group sessions conducted by a therapist. | CBT | Self-reported scales of depression (BDI), anxiety (STAI) and daily stressors (Hassles scale), glycosylated haemoglobin (HbA ₁) and fasting blood sugar all measured pre | There were statistically significant reductions in the treatment compared with control groups for HbA ₁ , BDI, anxiety, and stress. |

| Study | Sample | Intervention description ¹ (duration) | Theoretical Underpinning ² | Outcomes measured | Significant Findings ³ |
|-------------------------------|---|--|--|---|--|
| | | | | and post treatment | |
| Jonker et al 2015 (18) | 169 older frail people attending a day-care facility in the Netherlands | CDSMP intervention, six weekly 2.5 hourly sessions delivered in the day care facility. | Self-efficacy theory | Mastery (Pearlin Mastery Scale), Self-efficacy (perceived Self-Efficacy Scale), Depressive symptoms (CES-D), life satisfaction (using a two question author designed Likert scale), Value of life (VOL-scale). Pre and post intervention and at 6 months follow-up. | A significant improvement in mastery and depression in the treatment group post intervention but this was not sustained at 6 months follow-up. |
| Kendall et al 2007 (19) | 100 people who had been stroke inpatients at a large hospital in Queensland Australia | CDSMP with the addition of a stroke specific information session. Six weekly 2-hour sessions delivered to groups of 10-15 by health professionals. Fidelity assured by structured course protocol. | Self-efficacy theory | SSQOL and self-efficacy by the SES collected at 3, 6, 9 and 12 months. | There were statistically significant improvements in the quality of family roles, self-care, work productivity and function in daily activities of the intervention compared with control group at time 3 (9 months). |
| Leibing et al 1999 (20) | 55 hospital out-patients with a diagnosis of rheumatoid arthritis in Germany | CBT group treatment. Twelve weekly sessions delivered by instructors with >5 years psychotherapeutic experience. Fidelity was ensured by tape recording and reviewing sessions. | CBT | Disease status (blood values, grip strength, swollen joints, HFAQ and medication use), pain (the affective pain score and a pain diary), psychological variables (STAI, DS, AHI, and BeCoMo). All measured at baseline, 3 and 12 months other | The treatment group showed statistically significant decrease in affective pain and increase in positive acceptance compared with the control group. |

| Study | Sample | Intervention description ¹ (duration) | Theoretical Underpinning ² | Outcomes measured | Significant Findings ³ |
|---------------------------------|---|--|---|---|---|
| | | | | than the pain diary (four times a day for 12 weeks). | |
| Lindroth et al 1997 (21) | 100 people with rheumatoid arthritis in Sweden | The "rheumatoid arthritis school", a version of CDSMP tailored to the needs of the group. 8 weekly 2.5 hour sessions led by health professionals. | Self-efficacy theory | Pain (VAS). Perceived disability attitude towards disease and a list of questions to assess knowledge. Measure before and after the intervention and at 12 months. | There were improvements in knowledge, pain, self-confidence, self- care, and quality of life in the intervention compared with the control group some of which were maintained at follow up. |
| Ruesch et al 2017 (22) | 26 psychology out-patients with long-term conditions and comorbid depressive or adjustment disorders in Germany | STEpS CBT group treatment. Eight weekly sessions of 100 minutes delivered by psychologists. | CBT | Depression (HADS-D) and global psychological distress (BSI) and health related Quality of Life (SF- 12) measured pre and post intervention and at 2 month follow-up. | The treatment group showed a statistically significant reduction in depression and higher quality of life post treatment. Other than subjective physical health there was no sustained difference between groups at follow- up. |
| Rybarczyk et al 1999 (12) | 178 people with at least one long-term condition and a (clinician judged) psychosocial problem in the USA | Eight 2-hour classroom sessions delivered by a clinical psychologist and primary care physician, a 327 page home manual relating to sessions delivered and three relaxation audio tapes. Alternatively, a home course where video tapes of the classes were given along with all other materials. Fidelity was not reported. | Underpinned by behaviour change techniques such as relaxation, cognitive restructuring and problem solving | Medical Symptoms (MSCL), Pain (SF-MPQ), Anxiety (BAI), Depression (CES-D), health locus of control (MHLC), life satisfaction (LSI) | Significant improvements in both intervention groups compared with the control group in MSCL frequency, sleep, pain, anxiety, depression and the multidimensional health locus of control scale. |

| Study | Sample | Intervention description ¹ (duration) | Theoretical Underpinning ² | Outcomes measured | Significant Findings ³ |
|---------------------------------------|--|---|--|--|--|
| Scott et al 2004 (23) Smeulders | 294 adults with one or more self- reported long term conditions in the USA 317 hospital | Cooperative Health Care Clinic (CHCC). Monthly 90-minute group meetings held over a year that included health related topics and the opportunity for one to one 5-10 minute meetings with their physician. Led by a primary care physician and a nurse. Intervention fidelity was not reported. CDSMP, six weekly group | Not explicitly reported. Self-efficacy | Numbers of clinic visits, in-patient admissions emergency department visits, hospital, professional or home services (all recorded monthly), quality of life, self-efficacy and activities of daily living (at 24 months). Self-efficacy (GSES and | There was statistically significant difference in cost for fewer ED visits by interventions patients. QOL was significantly greater in intervention compared with control patients, as was confidence in communicating with a physician. |
| et al 2010 (24) | out-patients with congestive heart failure (CHF) in the Netherlands | sessions of 2.5 hours held by a cardiac nurse specialist and a patient with CHF. Fidelity was ensured by following the CDSMP protocol. | theory | CSSE), perceived control (CSS), self-care behaviour and quality of life (EHFScBS, RAND, KCCQ), anxiety and depression (HADS) at baseline, directly after the intervention, 6 and 12 months. | were found in the intervention compared with control group for cognitive symptom management and cardiac specific quality of life. Neither was sustained at 6 or 12 months. |
| Zangi et al 2011 (25) | 78 people with inflammatory rheumatic joint disease in Norway | The vitality training programme, a mindfulness based group intervention delivered in 10 4.5- hour sessions over 15 weeks with a booster session 6 months after the end of the course. Delivered by health professionals trained in mindfulness. A facilitation manual supported intervention | No specific theory noted, however the intervention was underpinned by mindfulness | Psychological distress (GHQ-20), self-efficacy (Arthritis SES), emotion focused coping (EAC), pain, fatigue and disease activity (numerical rating scales from 0-10). | Significant effects in favour of the intervention group were found post treatment and at 12 months for psychological distress, self-efficacy, pain, symptoms and emotional processing. |

| Study | Sample | Intervention description ¹ (duration) | Theoretical Underpinning ² | Outcomes measured | Significant Findings ³ |
|-------|--------|---|--|-------------------|-----------------------------------|
| | | fidelity. | | | |

Analysis

A narrative approach was taken to synthesis as recommended in circumstances of heterogeneity of the methods, interventions and outcome measures of the included papers (27) (Figure 5). This process comprises five stages: i) problem identification; ii) literature search; iii) data evaluation; iv) data analysis and v) presentation (28).

| TIRGIE J. THEITES I - SLAUSULATIV SIRTITILATIL OULLOTTE - TO SLAUSULATIV SIRTITILATIL OULLOTTE | Figure 5. Themes (| = statistically significant outcome = | = no statistically significant outcome) |
|--|--------------------|---------------------------------------|---|
|--|--------------------|---------------------------------------|---|

| | 1. Somatic Symptoms & Physical Functioning | 2. Psychological Symptoms | 3. Self-Efficacy | 4. Self-Care | 5. Quality of Life | 6. Knowledge (about illness/health) |
|------------------------------|---|------------------------------|------------------|--|--------------------|-------------------------------------|
| Berg 1997 (14) Coleman | journal of daily asthma concerns including wheeze, cough, shortness of breath and chest tightness | | - (SEAMS) | post-treatment inhaler use (observed) (ASMAT) ability to make good decisions in a variety of clinical scenarios (e.g. severe asthma attack) | | |
| 2012 (15) | Pain: WOMAC at 8 weeks, not maintained at 6 months SF36- body pain maintained at 6 months (TUG), Hamstring strength and range of motion test (small improvements) | | | | | |

| | 1. Somatic Symptoms & Physical Functioning | 2. Psychological Symptoms | 3. Self-Efficacy | 4. Self-Care | 5. Quality of Life | 6. Knowledge (about illness/health) |
|---------------------|---|--|----------------------------|---|---------------------|--|
| | months | | | | | |
| Elzen 2007 (16) | (RAND-36- physical component summary scale of the Dutch version)- | (RAND-36- mental component summary scale of the Dutch version | - (GSES- Dutch version) | Self-management behaviour using scales developed by Lorig for the CDSMP- frequency of exercise, cognitive symptom-management (coping with symptoms scale) and (quality of) communication with a physician (self-reported scale) | | |
| Grady 2014 (13) | (SF-36 Physical Functioning scores) | | | | - (QLI) | |
| Henry 1997 (17) | | Anxiety (STAI), & Perceived Stress (Hassles scale) Depression (BDI) Coping ability frequency of hassles & perceived coping ability (Hassles scale) | | | | |
| Jonker 2015 (18) | | + (CES-D) | + (12-item version | | + (Dutch version of | |

| | 1. Somatic Symptoms & Physical Functioning | 2. Psychological Symptoms | 3. Self-Efficacy | 4. Self-Care | 5. Quality of Life | 6. Knowledge (about illness/health) |
|----------------------|---|---|---|--------------|---|-------------------------------------|
| | | depression scores at 6 months – Positive affect (CES-D- assessed separately using a specific subscale of the CES-D) | of the perceived self- efficacy scale) | | VOL-scale) at 6 weeks and 6 months | |
| Kendall 2007 (19) | | | - (Lorig SES) | | (SSQOL-which includes domains measuring physical, psychological and social wellbeing) at time 3 (9 months) for family roles and fine motor tasks A trend towards significance (p= 0.05) in relation to work productivity and self- care Physical, psychological and social domains of the SSQOL | |

| | 1. Somatic Symptoms & Physical Functioning | 2. Psychological Symptoms | 3. Self-Efficacy | 4. Self-Care | 5. Quality of Life | 6. Knowledge (about illness/health) |
|-----------------------|---|---|---|--|---|---|
| Leibing 1999 (20) | Disease activity (VAS) Pain at nine months follow-up Affective Pain Score | (STAI, DS, AHI) anxiety anxiety depression and helplessness Coping (adapted BeCoMo) positive acceptance and resignation | | | | |
| Lindroth 1997 (21) | + (VAS) pain at 3 months, not maintained at 12 months | (single question) | (Swedish version of the AHI) perceived helplessness did not change (single question)- self-confidence at 3 and 12 months | (interview) joint protection behaviours at 3 and 12 months and more home exercises at 3 months (single question) capacity to ease pain at 3 and 12 months | (Swedish version of the Stanford HAQ) perceived disability at 3 months, not maintained at 12 months | (assessed on 5 key questions with yes or no answer options) at 3 and 12 months. Change in knowledge about inflammation and different arthritis treatments correlated positively with a reduction in helplessness. The intervention group reported fewer problems due to lack of knowledge about disease diet and |

| | 1. Somatic Symptoms & Physical Functioning | 2. Psychological Symptoms | 3. Self-Efficacy | 4. Self-Care | 5. Quality of Life | 6. Knowledge (about illness/health) |
|------------------------|--|--|--|-------------------|--|--|
| | | | | | | physical therapy at 3 and 12 months |
| Ruesch 2017 (22) | | (depression subscale of the German version of the HADS) immediately post intervention but not maintained Global psychological distress (German version of the BSI- The Global Severity Index calculated the means of all items) | | | Health-related quality of life (German version of SF-12): on mental composite scores immediately post intervention but not maintained On physical composite scores treatment group significantly improved at post-treatment and follow- | |
| Rybarczyk 1999 (12) | (MSCL) in frequency of medical symptoms (SF-MPQ & MSCL sleep, pain) | (BAI, CES-D) significant decrease in anxiety and depression symptoms those defined as having clinical levels of anxiety | (MHLC)-belief that chance factors influence health internality, powerful others | Health behaviours | | |

| | 1. Somatic Symptoms & Physical Functioning | 2. Psychological Symptoms | 3. Self-Efficacy | 4. Self-Care | 5. Quality of Life | 6. Knowledge (about illness/health) |
|------------------------|--|---|---|--|--|--|
| | | those defined as having clinical depression | | | | |
| Scott 2004 (23) | functional outcomes (advanced, household and basic ADLs- a composite measure derived from two established tools) | | communicating with physicians (scales drawn from Lorig) managing their disease, doing chores, participating in social/recreational activities, and controlling/ managing depression(scales drawn from Lorig) | | 10-point self- reported quality of life scale (QOL score) at 24 months | |
| Smeulders 2010 (24) | | - (HADS) | psychosocial attributes (GSES- Dutch version Cardiac Self-Efficacy Questionnaire, perceived control (Pearlin Mastery scale), The Coping With | self-care (EHFSCBS) short term effect not maintained at 6 and 12 months | (Rand-36, KCCQ, Perceived autonomy VAS and HADS) short-term effect not maintained at 6-month | |

| | 1. Somatic Symptoms & Physical Functioning | 2. Psychological Symptoms | 3. Self-Efficacy | 4. Self-Care | 5. Quality of Life | 6. Knowledge (about illness/health) |
|--------------------|---|--|---|--|--------------------|--|
| 7 | | | Symptoms Scale (Lorig) cognitive symptom management not maintained at 6 and 12 months follow-up | | | |
| Zangi 2011 (25) | Fatigue (assessed using Numerical Rating Scales) post- treatment that improved at 12 months Effects in pain and the patient global assessment of disease activity | (GHQ-20, EAC) psychological distress at 12 months. In the intervention group⁴ Emotional processing emotional expression | (pain and symptoms subscales from the Arthritis SES) self-efficacy pain (indicating better ability to manage pain) despite the lack of a significant improvement in symptoms. Self-efficacy (general, cardiac, symptom management) | self-care ability and overall well-being (10- point NRS) maintained at 12 months | | |

⁴ The number of subjects exceeding the GHQ-20 threshold of 23 (indicating significant psychological distress) was reduced from 13 (36%) at baseline to 2 (6%) at 12 months compared with 10 (29%) at baseline to 8 (24%) at 12 months in the control group

RESULTS

- 1. Somatic symptoms: In studies that measured pain as an outcome (12, 15, 20, 21), all except Zangi (25) demonstrate statistical improvement in the intervention group compared with control. In some studies this effect is short-lived (eight weeks (15), three months (21)) whereas in others it persists(nine months (20)). In people with osteoarthritis of the knee functional parameters improved and were maintained at six months (15). A reduction in fatigue, maintained at nine months is observed in people with inflammatory joint disease (25). There were no changes in asthma symptoms (14), physical components of the Rand-36 and SF-36 measure (13, 16), 'disease activity' (20, 25) and activities of daily living (23).
- 2. Psychological symptoms: Most studies that evaluated this found statistically significant improvements in some psychological outcomes following group participation (12, 17, 18, 20, 22, 25). Henry (17) found improvement in anxiety and perceived stress, but not depression and coping ability. Jonker (18) reported improvement in depression but not in 'positive affect'.Ruesch (22) found improvements in depression scores immediately post-intervention, not maintained at 2 months and no effect on 'global psychological distress'. Zangi (25) found improvement in psychological distress and 'emotional processing', maintained at 12 months, but not in 'emotional expression'. Leibing (20) found positive effects in anxiety, depression, feelings of helplessness and some aspects of coping. Rybarczyk (28) improvement in anxiety and depression scores. Three studies found no positive psychological effect (16, 21, 24).
- 3. Self-efficacy: Self-efficacy is a key foundation of the CDSMP (29, 30). Therefore it is not surprising that several studies have looked at the effect of their intervention upon self-efficacy. Six studies found some positive effect on self-efficacy following group intervention (12, 18, 21, 23-25). Jonker (18) found improvements in self-efficacy and mastery maintained at six months. This effect was seen in those with less high school education, but not in those with more education. Zangi (25) found improvements which improved between immediate post treatment analysis and 12

months. Other studies (12, 21, 23, 24) reached mixed conclusions on self-efficacy parameters, three (14, 16, 19) found no significant changes in self-efficacy measures.

- 4. Self-Care: Six studies report the effect of group work on patient self-care (12, 14, 16, 21, 24, 25). Improvements were seen in inhaler use (14), joint protection and exercise (21), capacity to ease pain (21), self-care in heart failure (24) and overall self-care and well-being (maintained at 12 months) (25). Three studies, however, found no significant effect on self-care in some or all of the parameters measured (12, 14, 16).
- 5. Quality of Life: Six studies demonstrate statistically significant improvements in quality of life measures (15, 18, 19, 21-24). In some of these studies improvements are maintained at six months (15, 18) and 24 months (23). One paper did not find statistically significant QOL effects (13) but the control group had information and some telephone contacts with health professionals and improvement was seen in both treatment and control groups.
- Knowledge: Only one paper specifically measured changes in participants' knowledge (about rheumatoid arthritis) (21). There was significant improvement at three and 12 months and a correlation was seen between knowledge increase and reduction in helplessness.

Duration of effects: six studies demonstrated most or all of their statistically significant effects at or beyond six months post-intervention (15, 18, 20, 22, 23, 25). There are both short-term (<six months) and longer term effects seen in Lindoth's study (21) whereas Smeulders (24) demonstrated predominantly short term effects only. The remaining studies either did not demonstrate any significant effects (13, 14, 16) or did not clearly specify time points of data collection (12, 17). Zangi's (25) study demonstrates further improvement from immediately post-treatment to 12 months on several parameters. There were no adverse events reported.

DISCUSSION:

Our review included 14 papers that considered the effectiveness of group work facilitated by health care professionals for patients with long term conditions. The included studies

covered a range of interventions and outcome measures. Even when a specific outcome was measured (e.g. self-efficacy) a range of tools were used. It is not possible to draw any conclusions about what specific intervention may be effective. The four studies that demonstrated the most improvements are those by Coleman (15), Leibing (20), Scott (23) and Zangi (25). These interventions are each very different: CDSMP, mindfulness, CBT and the US Group outpatient model.

Our review was comprehensive in terms of no date limit on included papers but key words may not have been failsafe in procuring all the papers. However, our citation searching was thorough and a significant number of the final papers were found this way. The studies in this review are varied in terms of participant characteristics and intervention delivered which meant that meta-analysis was not possible. The results of some included studies (12, 14, 17) should be considered with caution due to the small number of participants, short length of follow up (seven weeks in one case(17)) and numbers of group hours offered (as few as nine hours(17)). In some cases instruments used lacked validity (14). Quality of included papers was of marked variability. Some studies had areas of uncertain and some, high (12, 13, 18), risk of bias. The Cochrane review of lay led group work (1) experienced many of the above limitations and in particularly noted short term assessment of outcomes, mostly only up to 6 months.

As the CDSMP is such a widespread intervention it is worth considering the results of the five CDSMP studies (14-16, 19, 24). Improvements were found in treatment concordance (14), quality of life (15, 19, 24) and other outcomes such as somatic symptoms (15) and self-care and self-efficacy (24). This is consistent with findings from a RCT of a lay led CDSMP intervention (30) which showed improvements at six months in health behaviours (e.g. exercise), self-reported health, social/role activities, and fewer hospitalizations and days in hospital. The Cochrane review of lay led group work (1) demonstrated improvements in self-efficacy, self-rated health, cognitive symptom management and frequency of aerobic exercise.

In terms of non-CDSMP interventions one of the most effective interventions appears to have been Zangi (25) which is a study based on mindfulness. The improvements were

sustained and improved at 12 months post intervention. However in this study, perhaps significantly, there were many more hours of group time (45 hours) than the other studies (most were less than20 hours) suggesting a potential dose-response effect.

Some interventions were theoretically underpinned and included theories such as Self-Efficacy/social cognitive theory (29) and Cognitive Behavioural Therapy (CBT) (31). Both these approaches include constructs such as cognition, emotion, self-beliefs and mastery, personal and environmental factors. Social Cognitive theory incorporates the concept of self-efficacy as a key component. Self-efficacy is 'the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations' (29). A systematic review demonstrated that the CDSMP (underpinned by self-efficacy) led to increased physical exercise, less health distress, improved self-care and self-efficacy (18). There is some systematic review evidence of efficacy of CBT in long term physical illness (32). Our included studies demonstrated CBT to impact pain and psychological but not functional outcomes (20, 22). It is feasible that whilst self-efficacy and cognitive constructs are useful, there may be additional determinants at play such as attitudes, social influences, and motivation (33). This possibility is supported by Elzen's study (16) where, despite there being no statistically significant findings the intervention was very popular amongst participants with very high attendance rates suggesting that the patient gains may not have been identified by the outcome measures used. There is also evidence that interventions that are tailored according to assessed determinants are more effective than those that are not (34).

Overall we recommend professionally led group-based interventions to support people with long term conditions. There were many positive outcomes reported. However, based on the dearth of literature and the quality of included papers this recommendation is made tentatively. Not all included papers underpinned their interventions with theory and we recommend this approach should be taken in the future in accordance with the NICE guidelines (35) and the guidelines for complex interventions development (36).

Future research could usefully examine which specific elements of group interventions are useful, perhaps by comparing different group approaches in a similar population, and more

rigorous analysis of long term outcomes. Other questions to address are what qualities in facilitators produce greater impact on outcomes.

To be able to evaluate group work with greater clarity (including meta-analysis) consistency in use of outcome tools is essential. There should be some evaluation of the relative merits of professional versus lay-led group work to include economic evaluation. We found only two studies that make comparisons between these (12,13). They both studied the same intervention (the CDSMP) in people with arthritis and therefore cannot be generalised. Further consideration, including the economic impacts, of a possible 'dose-response' effect would also be relevant.

Conclusion

We set out to address the hypothesis that by enhancing an individual's self-care skills within the context of a group facilitated by health professionals, their capacity to cope with and manage their health issues is enhanced. This review supports the case that such groups can be beneficial for people with long term illness in improving pain, psychological symptoms and quality of life. But results are mixed and some benefits short-lived. These results are potentially of interest to policy makers and providers. Were we to be able to better demonstrate the effectiveness of group work in long term conditions and to determine what specific elements are effective and at what 'dose' then such a format could become an important intervention in LTCs.

References

1. Foster G, Taylor S, Eldridge S, Ramsay J, Griffiths CJ. Self-management education programmes by lay leaders for people with chronic conditions. 2007.

2. Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. The Lancet. 2004;364(9444):1523-37.

3. Department of Health, NHS Outcomes Framework 2015 to 2016. London: Department of Health 2015.

4. Lorig K, Chastain RL, Ung E, Shoor S, Holman HR. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis & Rheumatism: Official Journal of the American College of Rheumatology. 1989;32(1):37-44.

5. Bandura A. Self-Efficacy: toward a unifying theory of behavioural change. Psychological Review. 1977;84(2):191.

6. National primary Care Research and Development Centre 2018 [Available from: http://www.ihi.org/resources/Pages/OtherWebsites/NationalPrimaryCareResearchDevelopmentCentre.aspx.

7. Sadur CN MN, Costa M, Michalik D, Mendlowitz D, Roller SH, Watson RA, Swain BE, Selby JV, Javorski WC. Diabetes management in a health maintenance organization. Efficacy of care management using cluster visits. . Diabetes care 1999;1(22):2011-7.

8. ZuWallack R, & Hedges, H. Primary care of the patient with chronic obstructive pulmonary disease-part 3: pulmonary rehabilitation and comprehensive care for the patient with chronic obstructive pulmonary disease. American Journal of Medicine 2008;121(7 Supplement):S25-32.

9. Herschbach P, Book, K., Dinkel, A., Berg, P., Waadt, S., Duran, G., Engst-Hastreiter, U. and Henrich, G. Evaluation of two group therapies to reduce fear of progression in cancer patients. Supportive Care in Cancer. 2010;1(18):471-9.

10. Moher D LA, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Annals of internal medicine 2009;18(151):264-9.

11. Higgins JP, Altman, D.G., Gøtzsche, P.C., Jüni, P., Moher, D., Oxman, A.D., Savović, J., Schulz, K.F., Weeks, L. Sterne, J.A. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. The British Medical Jouranl 2011;343:d5928.

12. Rybarczyk B D, G., DeLaCruz, M. and Lapidos, S. Comparing mind–body wellness interventions for older adults with chronic illness: Classroom versus home instruction. . Behavioural Medicine. 1999;24(4):181-90.

13. Grady KL DLC, Kozak AT, Cursio JF, Richardson D, Avery E, Calvin JE, Powell LH. Does selfmanagement counseling in patients with heart failure improve quality of life? Findings from the Heart Failure Adherence and Retention Trial (HART). Quality of life research. 2014;1(23):31-8.

14. Berg J D-JJ, Sereika SM. An evaluation of a self-management program for adults with asthma. Clinical Nursing Research. 1997;6(3):225-38.

15. Coleman S, Briffa, N.K., Carroll, G., Inderjeeth, C., Cook, N. and McQuade, J., . A randomised controlled trial of a self-management education program for osteoarthritis of the knee delivered by health care professionals. Arthritis research and therapy. 2012;14(1):21.

16. Elzen H SJ, Snijders TA, Steverink N. Evaluation of the chronic disease self-management program (CDSMP) among chronically ill older people in the Netherlands. Social Science and Medicine. 2007;1:64(9):1832-41.

17. Henry JL WP, Bruce DG, Chisholm DJ, Rawling PJ. Cognitive-behavioural stress management for patients with non-insulin dependent diabetes mellitus. Psychology, Health and Medicine 1997;1(2):109-18.

18. Jonker AA, Comijs HC, Knipscheer KC, Deeg DJ. Benefits for elders with vulnerable health from the Chronic Disease Self-management Program (CDSMP) at short and longer term. BMC geriatrics. 2015;15(1):101.

19. Kendall E CT, Kuipers P, Posner N, Buys N, Charker J. Recovery following stroke: the role of self-management education. Social Science and Midicine. 2007;64(3):735-46.

20. Leibing E, Pfingsten, M., Bartmann, U., Rueger, U. and Schuessler, G. Cognitive-behavioral treatment in unselected rheumatoid arthritis outpatients. The Clinical Journal of Pain 1999;1(15):58-66.

21. Lindroth Y, Brattström M, Bellman I, Ekestaf G, Olofsson Y, Strömbeck B, et al. A problembased education program for patients with rheumatoid arthritis: evaluation after three and twelve months. Arthritis & Rheumatism: Official Journal of the American College of Rheumatology. 1997;10(5):325-32.

22. Ruesch M, Helmes A, Bengel J. Cognitive behavioral group therapy for patients with physical diseases and comorbid depressive or adjustment disorders on a waiting list for individual therapy: results from a randomized controlled trial. BMC psychiatry. 2017;17(1):340.

23. Scott JC CD, Venohr I, Gade G, McKenzie M, Kramer AM, Bryant L, Beck A. Effectiveness of a group outpatient visit model for chronically ill older health maintenance organization members: a 2-year randomized trial of the cooperative health care clinic. Journal of the American Geriatrics Society. 2004;52(9):1463-70.

24. Smeulders ES VHJ, Ambergen T, Uszko-Lencer NH, Janssen-Boyne JJ, Gorgels AP, Stoffers HE, Lodewijks-van der Bolt CL, Van Eijk JT, Kempen GI. Nurse-led self-management group programme for patients with congestive heart failure: randomized controlled trial. Journal of Advanced Nursing. 2010;66(7):1487-99.

25. Zangi HA MP, Finset A, Eriksson LR, Høystad TØ, Lunde AK, Hagen KB. A mindfulness-based group intervention to reduce psychological distress and fatigue in patients with inflammatory rheumatic joint diseases: a randomised controlled trial. Annals of the rheumatic diseases 2011;1.

26. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. Bmj. 2014;348:g1687.

27. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme Version. 2006;1:b92.

28. Rybarczyk B, DeMarco, G., DeLaCruz, M. and Lapidos, S. Comparing mind–body wellness interventions for older adults with chronic illness: Classroom versus home instruction. Behavioral Medicine 1999;24(4):181-90.

29. A B. Self-efficacy: toward a unifying theory of behavioral change. . Psychological review. 1977;84(2):191.

30. Lorig KR SD, Stewart AL, Brown Jr BW, Bandura A, Ritter P, Gonzalez VM, Laurent DD, Holman HR. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Medical Care. 1999;1:5-11.

31. Beck AT. Nature and relation to behaviour therapy. Behaviour Therapy. 1970;1(1):184-200.

32. Cuijpers P VSA, Andersson G. Internet-administered cognitive behavior therapy for health problems: a systematic review. Journal of Behavioural Medicine 2008;31(2):169-77.

33. M. F. The role of theory in HIV prevention. AIDS care. AIDS care. 2000;1(12):273-8.

34. Baker R C-SJ, Gillies C, Shaw EJ, Cheater F, Flottorp S, Robertson N. Tailored interventions to overcome identified barriers to change: effects on professional practice and health care outcomes. Cochrane database of systematic reviews. 2010;CD005470.

35. National Institute for Heatlh and Care excellence, 2014 Behaviour Change: Individual Approaches [Available from: <u>https://www.nice.org.uk/guidance/PH49</u>.

36. Craig P DP, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. . British Medical Journal. 2008;29(337).

37. Nicassio PM, Wallston, K.A., Callahan, L.F., Herbert, M.A. and Pincus, T. The measurement of helplessness in rheumatoid arthritis. The development of the arthritis helplessness index. Journal of Rhumatology. 1985;12(3):462-7.

38. Taylor GH, Rea, H.H., McNaughton, S., Smith, L., Mulder, J., Asher, M.I., Mitchell, E.A., Seelve, E. and Stewart, A.W., . A tool for measuring the asthma self-management competency of families. Journal of Psychosomatic research. 1991;35(4):483-91.

39. Steer RA, Beck AT. Beck Anxiety Inventory. 1997.

40. Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. Archives of general psychiatry. 1961;4(6):561-71.

41. Heim E, Valach L, Schaffner L. Coping and psychosocial adaptation: longitudinal effects over time and stages in breast cancer. Psychosomatic Medicine. 1997;59(4):408-18.

42. Franke G. Brief symptom inventory-deutsche Fassung. Göttingen: Hogrefe. 2000.

43. Sullivan MD, LaCroix, A.Z., Russo, J. and Katon, W.J., . Self-efficacy and self-reported functional status in coronary heart disease: a six-month prospective study. Psychosomatic Medicine. 1998;60(4):473-91.

44. LS R. Scale: A self-report depression scale for research in the general population. J Clin Exp Neuropsychol. 1997;19:340-56.

45. Regan CA LK, Thoresen CE. Arthritis appraisal and ways of coping. Scale development.
Arthritis & Rheumatism. Official Journal of the American College of Rheumatology. 1988;1(3):139-50.
46. D vZ. Clinical self-rating scales (CSRS) of the Munich psychiatric information system (PSYCHIS München). Assessment of depression 1986:270-303.

47. Jaarsma T, Årestedt KF, Mårtensson J, Dracup K, Strömberg A. The European Heart Failure Self-care Behaviour scale revised into a nine-item scale (EHFScB-9): a reliable and valid international instrument. European Journal of Heart Failure. 2009;11(1):99-105.

48. Bosscher RJ SJ. Confirmatory factor analysis of the general self-efficacy scale. Behaviour research and therapy 1998;1(36):339-43.

49. Goldberg DP, Hillier VF. A scaled version of the General Health Questionnaire. Psychological medicine. 1979;9(1):139-45.

50. Kanner AD, Coyne JC, Schaefer C, Lazarus RS. Comparison of two modes of stress measurement: Daily hassles and uplifts versus major life events. Journal of behavioral medicine. 1981;4(1):1-39.

51. Kohlmann T, Raspe H. Hannover Functional Questionnaire in ambulatory diagnosis of functional disability caused by backache. Die Rehabilitation. 1996;35(1):I-VIII.

52. NJ WSSKP. The Health-Promoting Lifestyle Profile: Development and Psychometric Characteristics. . Nurse Research. 1987;36:76-81.

53. Zigmond ASaS, R.P. The hospital anxiety and depression scale. Acta psychiatrica Scandinavica 1983;67(6):361-70.

54. Bigot A. The relevance of American life satisfaction indices for research on British subjects before and after retirement. Age and Ageing. 1974;3(2):113-21.

55. Hellman CJ, Budd M, Borysenko J, McClelland DC, Benson H. A study of the effectiveness of two group behavioral medicine interventions for patients with psychosomatic complaints. Behavioral Medicine. 1990;16(4):165-73.

56. Wallston KA, Strudler Wallston, B. and DeVellis, R. Development of the multidimensional health locus of control (MHLC) scales. Health education monographs. 1978;6(1):160-70.

57. Pearlin LI, Schooler C. The structure of coping. Journal of health and social behavior. 1978:2-21.

58. Sherer M, Maddux JE, Mercandante B, Prentice-Dunn S, Jacobs B, Rogers RW. The selfefficacy scale: Construction and validation. Psychological reports. 1982;51(2):663-71.

59. Ferrans CE, Powers MJ. Quality of life index: development and psychometric properties. Advances in nursing science. 1985.

60. Van der Zee KaS, R. RAND-36. Groningen: Northern Centre for Health Care Research, University of Groningen, the Netherlands 1993;28.

61. Williams LS, Weinberger, M., Harris, L. E., Clark, D. O., & Biller, J. Development of a stroke-specific quality of life scale. Stroke. 1999;30(1361-1369).

62. Lorig K, Stewart A, Ritter P, Lynch J, Gonzalez V, Laurent D. Outcome measures for health education and other health care interventions: Sage; 1996.

63. Spielberger CD, Gonzalez-Reigosa F, Martinez-Urrutia A, Natalicio LF, Natalicio DS. The statetrait anxiety inventory. Revista Interamericana de Psicologia/Interamerican Journal of Psychology. 2017;5(3 & 4).

64. Melzack R. The McGill Pain Questionnaire: major properties and scoring methods. Pain. 1975;1(3):277-99.

65. Bullinger M, Kirchberger I. Fragebogen zum Gesundheitszustand: SF-36: Hogrefe, Verlag für Psychologie; 1998.

66. Ware JE, Kosinski, M., Gandek, B., Aaronson, N.K., Apolone, G., Bech, P., Brazier, J., Bullinger, M., Kaasa, S., Leplège, A. and Prieto, L. The factor structure of the SF-36 Health Survey in 10 countries: Results from the IQOLA Project. Journal of Clinical Epidemiology. 1998;51(11):1159-65.

67. Ekdahl C, Eberhardt K, Andersson S, Svensson B. Assessing disability in patients with rheumatoid arthritis: use of a Swedish version of the Stanford Health Assessment Questionnaire. Scandinavian journal of rheumatology. 1988;17(4):263-71.

68. Podsiadlo D, Richardson S. The timed "Up & Go": a test of basic functional mobility for frail elderly persons. Journal of the American geriatrics Society. 1991;39(2):142-8.

69. Knipscheer K, van Schoor N, Penninx B, Smit J. Levenswaardering bij ouderen (LWO): de validering van een meetinstrument. Tijdschrift voor gerontologie en geriatrie. 2008;39(4):133-45.

70. Bellamy N. The WOMAC knee and hip osteoarthritis indices: development, validation, globalization and influence on the development of the AUSCAN hand OA indices. Clinical and experimental rheumatology. 2005;23(5):S148.

APPENDIX 1: Search strategy

- 1 group work.ti,ab. (1063)
- 2 patient support group*.ti,ab. (485)
- 3 patient support program*.ti,ab. (183)
- 4 ;peer support group*.ti,ab. (406)
- 5 peer support program*.ti,ab. (310)
- 6 group therapy.ti,ab. (3468)
- 7 expert patient program*.ti,ab. (37)
- 8 chronic disease self management.ti,ab. (474)
- 9 self management program*.ti,ab. (1753)
- 10 self management group*.ti,ab. (138)
- 11 psychotherapy group*.ti,ab. (309)
- 12 group processes.ti,ab. (368)
- 13 self help group*.ti,ab. (1347)
- 14 patient care team*.ti,ab. (336)
- 15 online support group*.ti,ab. (299)
- 16 voluntary group*.ti,ab. (115)
- 17 online support program*.ti,ab. (12)
- 18 health community.ti,ab. (1577)
- 19 care meeting.ti,ab. (138)
- 20 1 or 2 or 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 or 16 or 17 or 18 or 19 (12236)
- 21 exp SELF-HELP GROUPS/ (8721)
- 22 exp PSYCHOTHERAPY, GROUP/ (10932)
- 23 20 or 21 or 22 (27489)
- 24 long term illness*.ti,ab. (564)
- 25 long term condition*.ti,ab. (1636)
- 26 chronic disease.ti,ab. (33628)
- 27 chronic illness*.ti,ab. (15077)
- 28 self care.ti,ab. (16541)
- 29 self management.ti,ab. (18169)
- 30 multiple conditions.ti,ab. (838)
- 31 multimorbidity.ti,ab. (2673)
- 32 chronic care.ti,ab. (2714)
- 33 exp CHRONIC DISEASE/ (120160)
- 34 exp SELF CARE/ (55472)
- 35 exp LONG-TERM CARE/ (1316115)
- 36 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 (1500269)
- 37 23 and 36 (13812)
- 38 limit 37 to last 2 years (2294)

APPENDIX 2. Outcome Assessment Tools

| Outcome Assessment tool | Abbreviation | Used by | Notes |
|--|---------------|------------|--|
| Arthritis Helplessness Index (37) | AHI | (20) | A 15 item scale measuring perceived loss of control |
| Arthritis Self-Efficacy Scale (4) | Arthritis SES | (25) | Three subscales: i) Pain related Self-Efficacy (PSE), ii) function related Self- |
| | | | Efficacy (FSE), iii) Other Self-Efficacy related factors (OSE) |
| Asthma Self-Management Assessment tool | ASMAT | (14) | Developed from Asthma Self- management Competency tool (38) |
| Beck Anxiety Inventory (39) | BAI | (28) | 21 item scale designed to measure the severity of anxiety |
| Beck Depression Inventory (40) | BDI | (17) | 7-item self-report instrument composed of cognitive and affective symptoms of |
| | | | depression |
| Bernese Coping Modes Tool (41) | BeCoMo | (20) | Well validated instrument that assesses 30 coping modes using a structured |
| | | | interview. |
| Brief Symptom Inventory (German version) | BSI | (22) | 53-item psychological self-report symptom scale developed from a longer |
| (42) | | | instrument. Psychometric evaluation shows it to be robust. |
| Cardiac Self-Efficacy Questionnaire (43) | | (24) | A scale with high level of validity measuring function and control symptoms |
| Centre for Epidemiologic Studies | CES-D | (12, 24) | Widely used 20 item, self-report depression scale. Tests well for validity and |
| Depression Scale (44) | | | reliability. |
| Coping with Symptoms Scale (45) | | (16, 24) | Based on the Lazarus-Folkman model of stress and coping, it assesses primary |
| | | | appraisal (perception of harm/loss) and coping thoughts and actions. |
| Depression Scale, The (46) | DS | (20) | Well validated 16 item instrument to asses depression |
| European Heart Failure Self-care Behaviour | EHFScBS | (24) | A valid and reliable self-care behaviour 12 item rating scale |
| Scale (47) | | | |
| Emotional Approach to Coping Scale (EAC) | EAC | (25) | Validated measure to assess ability to acknowledge and express emotions |
| (Stanton 2000) | | | |
| General Self-Efficacy Scale (48) | GSES | (16, 24) | A 10-item psychometric scale designed to assess optimistic self-beliefs to cope |
| | | | with a variety of difficult demands in life |
| General Health Questionnaire (49) | GHQ-20 | (25) | A psychometric screening tool to identify common psychiatric conditions |
| Hassles Scale (50) | | (17) | Validated predictor of concurrent and subsequent psychological |
| | | | symptoms |
| Hannover Functional Ability Questionnaire | HFAQ | (20) | Well validated German 12 item instrument to assess functional capacity |
| (51) | | | |

| Outcome Assessment tool | Abbreviation | Used | Notes |
|--|--------------|----------|---|
| | | by | |
| Health Promoting Lifestyle Profile | HPLP | (28) | 48-item measure of health behaviours |
| (modified) (52) | | | |
| Hospital Anxiety and Depression Scale (53) | HADS | (22, 24) | Validated scale measuring anxiety and depression |
| Kansas City Cariomyopathy Questionnaire | KCCQ | (24) | Valid and reliable health status measure for patients with heart disease |
| (49) | | | |
| Life Satisfaction Index Short form (54) | LSI | (28) | An 8-item version of the original instrument that has been shown to be reliable |
| | | | and valid in measuring subjective well-being. |
| Medical Symptoms CheckList (55) | MSCL | (28) | Includes 25 common physical symptoms (e.g. headache, numbness) |
| Multidimensional Heath Locus of Control | MHLC | (28) | 18 item instrument measuring scores for internality, powerful others and |
| Scale (56) | | | chance locus of control. Good criterion and concurrent validity and reliability. |
| Pearlin Mastery scale (57) | | (18, 24) | Seven-item instrument that assesses the extent to which a person perceives |
| | | | themselves to be in control of events and their perceived ability to manage |
| | | | them |
| Perceived Self-Efficacy Scale (58) | | (18) | A well validated measure of general self-efficacy (17 items) and social self- |
| | | | efficacy (six items) |
| Quality of Life Index (cardiac version) (59) | QLI | (13) | Well validated measure of satisfaction with various aspects of life- in this case |
| | | | 1. health and functioning and 2. psychological and spiritual well-being. |
| RAND (60) | Rand-36 | (16, 24) | 36 item health survey |
| Stroke Specific Quality of Life Scale (61) | SSQoL | (19) | 49-item tool assessing HRQoL in Stroke patients |
| Self-Efficacy scale (62) | SES | (19) | Self-Efficacy for managing chronic disease |
| Spielberger State-Trait anxiety scale (63) | STAI | (17, 20) | Well validated 20 item instrument to assess anxiety. |
| Short-Form McGill Pain Questionnaire (64) | SF-MPQ | (12, 20) | 12 item Likert style instrument measuring affective elements of pain. |
| Self-efficacy for Asthma Management | SEAMS | (14) | Developed for the purpose of this study |
| Scale | | | |
| Short Form (12 item) Health Survey, | SF-12 | (22) | A shorter version of the SF-36, shown to be comparably valid |
| German version (65) | | | |
| Short Form (36 item) Health Survey, The | SF-36 | (13, 15) | Patient reported survey of general health status |
| (66) | | | |
| Swedish version of the Stanford Health | HAQ | (21) | A valuable, effective, and sensitive tool for measurement of patient-centred |
| Assessment Questionnaire (67) | | | health status. |

| Outcome Assessment tool | Abbreviation | Used | Notes |
|---|--------------|------|--|
| | | by | |
| Timed "Up and Go" test (68) | TUG | (15) | A test of basic functional mobility for frail elderly persons |
| Value of Life scale (69) | VOL-scale | (18) | 12-item assessment of a person's self-rating of their valuation of life |
| Western Ontario and McMaster | WOMAC | (15) | Widely used, proprietary set of standardised questionnaires used by health |
| Universities Osteoarthritis Index, The (70) | | | professionals to evaluate the condition of patients with osteoarthritis of the |
| | | | knee and hip (including pain, stiffness and physical functioning of the joints). |