Self-management of rheumatic diseases: State of the art and future perspectives

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Self-Management of Rheumatic Diseases- State of the Art and Future Perspectives

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ABSTRACT

Self-management interventions (SMIs) are patient-centered and designed to foster active participation of patients in order to promote well-being and to manage symptoms. Over the past two decades the role of self-management in chronic diseases has gained momentum. Self-management programs are now acknowledged as a key element of quality care. New modes of delivery allow greater access to information and are tailored to address patient needs. This systematic review presents data from clinical studies of self-management over the past decade, summarizes the evidence for program effectiveness and suggests future research directions.

INTRODUCTION

Self-management is the "individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition" [1]. Whilst often instigated by individuals, health professionals, and patient organizations facilitate self-management in partnership with patients. Traditional patient education offers information and technical skills. In contrast, self-management interventions (SMIs) are problem focused, action–oriented and emphasize patient-generated care plans [2]. SMIs include educational, behavioural and cognitive approaches to influence health knowledge, attitudes, beliefs and behaviours and to promote independence, maintain or adjust life roles and address the psychological impact of disease. SMIs address five skills: problem solving, decision-making, resource utilization, collaborative patient/provider relationships and taking action [3]. SMI success depends upon needs assessments identifying specific groups' concerns.

Importance and meaning of self-management for persons with arthritis

Health professionals view SMIs as structured education to develop patients' illness management skills. However, patients view these differently[4]. A qualitative study[5] reported arthritis patients viewed SMIs as a way to bring order into their lives, helping them recognize boundaries, mobilize resources, cope with change in self-identity and plan, pace and prioritize. This study furthers the understanding of SMIs because it identifies and articulates the value of patient-centered approaches and has implications for SMI evaluation in terms of frequency and methodology. SMI evaluation occurs in stages; pre-, intra- and post-intervention, representing a series of snapshots along a continuum and may miss the full impact on the patient. Additionally, differences in outcome data may occur based on who has asked questions and how questions were asked.

History of self-management programs

In the 1980s, Lorig and associates developed the Arthritis Self-Management Program (ASMP) to enhance well-being and quality of life. The original ASMP was not theory based but considered knowledge leads to behaviour change. During program evaluation participants linked

program satisfaction with an increased sense of disease control [6] thus Bandura's Social Cognitive Theory [7] was selected as a framework for change. As more SMIs developed, researchers recognized the value of peer- as well as professional- led programs [8]. Lorig's ASMP is the most developed and studied of SMIs and is disseminated by patient organizations across the globe.

Most SMI research evaluates group programs delivered face-to-face. Financial constraints, increasing access and technology have driven mailed and internet program development. The ASMP group (Stanford University, USA) leads the way developing new technologies for self-management. However, many SMIs are still delivered one-to-one by health professionals, the least evaluated delivery mode.

EVIDENCE FOR EFFECTIVENESS OF SELF-MANAGEMENT PROGRAMS

Several systematic reviews of arthritis patient education and SMIs have evaluated studies published up to 2002. Reviews of rheumatoid arthritis (RA) SMIs concluded only those using psychobehavioural approaches led to short-term (up to 9 months) significant improvements in functional disability, but effects are not sustained [9,10]. Osteoarthritis (OA) and RA study reviews concluded 40% of SMIs led to improved symptoms and disability [11,12]. Effective programs were more common in OA than RA, possibly because OA SMIs more frequently included exercises and recruited larger samples. Programs based on cognitive-behavioural theory (CBT) or social cognitive theory (SCT) yielded better outcomes. Few studies examined effectiveness for 12 months or more. Two systematic reviews of SMI trials in FM concluded that multimodal interventions yielded better outcomes than single mode interventions but improvements were modest and not maintained [13,14].

Methodological limitations of SMI trials were highlighted such as: insufficient patient-relevant outcomes, lack of consensus for outcomes and patient attributes examined; and low statistical power. Recommendations for future SMI trials included: use of OMERACT core sets; assessment of fatigue and social participation; sufficient power; be disease specific; identify which patient and program characteristics yield beneficial outcomes; explicitly state theoretical basis; publish program protocols /manuals; use leaders trained in group facilitation, problem-

solving, goal-setting and CBT and/or SCT approaches; and use strategies for long-term behavioural change (eg booster sessions) [10,12] .

For this review, Medline, PubMed, EMBASE, CINAHL, AMED, PsychInfo and the Cochrane Library were searched from 2000 for FM, from 2003 for OA and RA and up to November 2009 using key terms of "arthritis," "osteoarthritis, " "rheum$," "fibromyalgia," "self-management," self care " and "patient education." Studies were included if they: were in English; involved randomization; and stated they were SMIs. In total, 30 articles were identified meeting the entry criteria; some were economic evaluations and long-term follow-ups of earlier trials. Studies were excluded if only reporting observational data or long-term follow-up data from previous trials without comparison group data. This review aims to identify whether longer-term (ie >= 12 months) benefits resulted, by diagnosis and if any program or patient characteristics are associated with improvement.

SMIs for individuals with either OA, RA or other arthritic conditions.

Seven studies were identified: two being published within one article and three articles related to one study [15-22]. **See Table 1.** Fifty to 75% of participants had OA, 15 to 35% RA and 15 to 17% other diagnoses. Two studies included between 30-52% of people with FM (who could have other arthritis diagnoses) [17,21]. Six studies evaluated the ASMP or variations thereof, all including weekly exercise practice (stretch, strength and walking). Two evaluated the ASMP [16,21]; two a mailed, individualized version of the ASMP (SMART: provided over 12-18 months) [15]; one an internet- ASMP [17]; and one a "one-time" mailed ASMP version [22]. The seventh evaluated the individually tailored "I'm Taking Charge of My Arthritis" (ITCA) program provided in individual home visits [18-20]. All were community or home-based and all (apart from the ITCA study led by health professionals) led by either peer moderators or self-completed. All programs involving contact lasted 6 weeks (in person or internet) and the other two self-completed at a pace to suit participants. Two studies included booster sessions [15,18,19]. Apart from the ITCA, all programs included similar ASMP content and teaching strategies. Cognitive and behavioural strategies were taught by trained leaders, following the ASMP leader manual, using SCT approaches to

facilitate change.

Methodologically, five studies used intent-to-treat (ITT) analysis [15,16,22] (and only four included control groups [15,17,18,22] .Two conducted a priori sample size analyses and recruited sufficient participants [21,22] and a further four [15-17]recruited between 340-1090 patients suggesting these were large enough to detect differences.

All studies evaluated pain, function, mood, self-efficacy, and health behaviors. (**Table 5)**. Five reported follow-ups of 12 months or longer [15-17,21]. At 12 months, all five demonstrated improvements in self-efficacy; four in function (Lorig et al 2004, 2005, 2008); two in pain [15],[18]; and one in mood [18]. The least effective ASMP recruited predominantly African American participants [21]. Most effective ASMP studies were delivered to predominantly non-Hispanic white participants, either face to face[15] or via the Internet [17]. Most participants (64-75%) had OA. Only one study conducted sub-group analyses by diagnoses, demonstrating the Internet ASMP was most effective in OA, next in RA and not at all in FM [17]. Follow-up longer than 12 months occurred in only one study with a control group comparison. At two years, the SMART programme, including booster materials, reduced perceived arthritis severity and doctor visits but by three years, there were no differences [15].

SMIs for individuals with osteoarthritis

Eight studies were identified [23-30]. Economic analyses were conducted for two studies [31,32]. **See Table 2.** Three studies enrolled only patients with knee OA and five patients with hip and/or knee OA. Three used a cluster RCT approach with medical practices as the unit of analysis [23,24,28]. Most participants, approximately 75%, were women. Three studies evaluated the group-format ASMP [25,29,30]. Five evaluated other SMIs, comparing these to usual care or information booklets [23,24,26-28]. Three studies were group interventions: two combining SMIs with supervised and home exercise practice [24,27]; and two evaluated individual SMIs [26,28]. Most group interventions lasted 12 hours over 6 weeks, apart from one of four hours plus an individual home visit [23]. None included booster sessions. Individual interventions lasted one hour[26] or duration was not stated [28], with both including telephone follow-up. All but one study [29] recruited patients from primary care. All but one [25] were led by a health professional, either GP, nurse and/or physical

therapist, and group SMIs used SCT approaches. Methodologically, five studies used ITT analysis [25,27-30] and a priori power calculations were reported in four. (**See Table 2)**

All studies evaluated pain and function; four also examined health knowledge, behaviors and care use; three measured self-efficacy; but mood and fatigue were infrequently assessed (**See Table 5).** Four studies only reported short-term outcomes (between 4 to 9 months): with three reporting improvements in pain and function [27-29]; and one brief individual SMI reporting no differences[26]. Two studies found no significant differences in outcomes at any follow-up, both having shorter duration interventions of one or five hours [23,26]. Two studies [24,25] included economic analyses. Whilst both had health benefits only one demonstrated cost-effectiveness[32]: a group format being better than individual interventions[27]. Overall, of the four studies evaluating long-term outcomes (ie 12 months or longer) significant, modest effects were found for: pain [24,30]; self-efficacy [25,30]; function [24] and mood[25]. The most effective interventions longer-term were protocolized group SMIs, including six weeks of supervised exercise, using either CBT or SCT approaches led by trained leaders [24,30].

SMIs for individuals diagnosed with inflammatory arthritis

Five studies were identified [33-37] (**Table 3).** Four recruited people with RA only and one, pragmatically, RA (50%), early inflammatory arthritis (35%) and psoriatic arthritis (14%) [37]. Three studies recruited people with well-established disease (average 12-15 years) and two early to established disease [34,37]. Studies showed some similarities: all evaluated small group programs (up to 10 participants), were hospital-based and led by health professionals. All except one[34] had control groups, either usual care, information booklets or attention control (an information program). All used ITT analysis. In other respects studies were diverse. Sample sizes ranged from 59 to 218, with only three reporting sample size analyses and recruiting sufficient participants to detect differences [33,36,37].

Programme duration varied from 12 -52 hours, over 6 weeks to 9 months, with three including booster sessions (between 3 to 9 months post-programme). Programs also varied in content and delivery. All provided information about the disease and medications. Four explicitly used SCT

and/or CBT approaches. Two were led by clinical psychologists using CBT combined with education from multidisciplinary team members using "more traditional didactic approaches" for physical strategies [34,35]. Two described use of leader manuals, staff training in SCT/CBT approaches and applying these throughout programs [33,37]. One study did not explicitly describe its theoretical framework [36]. Only two included regular exercise [36,37].

All studies evaluated pain, function and mood. Disease status and self-efficacy were measured in four and fatigue in three studies (**Table 5**). Short-term benefits were found in four studies. Three had longer-term follow-up at 12 months but only two showed benefits [33,37]. Both used SCT/CBT approaches throughout the programs, specially trained health professionals and longer-term booster sessions. Riemsma et al [33] identified improved self-efficacy and fatigue in people attending a primarily cognitive strategy SMP without their partner, whilst those attending with partners showed no sustained benefits. Hammond et al [37] (2008) showed significant improvements in pain, self-efficacy, perceived control and health behaviours. This was the only program consistently enabling both cognitive and behavioural strategies using SCT/CBT approaches with substantial skills practice. Patients also had shorter disease duration (average 7 compared to 12-15 years).

SMIs for individuals diagnosed with fibromyalgia

Seven studies were identified [38-44] (**Table 4**). Five recruited people from secondary care diagnosed with FM by rheumatologists using ACR criteria and two recruited patients from primary care diagnosed by General Practitioner [38,42]. Programs were similar with respect to group size (up to 12 participants) and leadership (health professionals). Additionally, an eighth study (Internet- ASMP) reported FM results separately [17](**Table 1**). Most studies included a control group of usual care, wait list control, information leaflets or an attention control (relaxation) group. Only one had no control group, comparing exercise, SMI or combined exercise and SMI [44]. Sample sizes ranged from 53 to 207, with all but two [38,40] including sample size calculations and recruiting sufficient numbers to potentially demonstrate differences. Only four included ITT analysis[17,39,42,43]. Program duration varied between 18 – 50 hours, with four being wholly or

partially community based (e.g. leisure centres, YMCAs). Four programs lasted between 2.5 to 6 weeks and four between 10-16 weeks. None included booster sessions.

All programs included information about FM and its management. Nine different SMIs were evaluated, as one study evaluated two styles of SMI [38]. Of these, six explicitly used SCT and/or CBT approaches with four reporting use of trained leaders experienced in these (CBT group only[38]); [17,43,44]. All included cognitive components (e.g. managing pain, relaxation) and six included supervised exercise practice. A systematic review identified supervised moderate intensity aerobic exercise (minimum 12 weeks, 3x/week) is effective in FM [45]. However, only two programs combined SMIs with this exercise intensity [39,44], with only one showing short-term improvements [44]. Three studies included at least 10 sessions of supervised exercise spread over 6– 10 weeks [40,42,43] .

All studies evaluated pain, function, perceived health and mood. Fatigue was measured in seven, self-efficacy and social role/support in four, health behaviours in three and health care use in only two (see **Table 5**). Considering studies using either case-completer or ITT analysis, short-term benefits were found for 4-6 months in three studies for three or more outcomes [40,43,44]. Three had controlled follow-ups between 8-12 months [17,41,43] but only two showed minimal continued benefits: in fitness [41] and self-reported improvement [43]. In summary, no FM studies showed SMIs, with or without exercise, sustained benefits across a range of outcomes for more than 6 months.

SUMMARY OF THE EVIDENCE

Previous reviews have identified psychobehavioural SMIs lead to short-term benefits (ie 6-9 months) but that longer-term benefits are infrequently evaluated and rarely sustained [12,33]. In this updated review we aimed to identify whether recent SMI trials identify any longer-term benefits and whether any program, diagnostic or patient characteristics are associated with improved outcomes.

Of the 30 studies identified, only 14 had follow-ups of 12 months or longer, seven of which (two of the same SMART ASMP) led to sustained benefits in pain and/ or function. All were methodologically sound. Little is known about benefits beyond 12 months as only two had longer-term follow-ups, although both demonstrated some continuing benefits [15,24]. The ASMP

leads to sustained benefits over four years and is cost-effective [46], but more research is needed in other SMIs. We recommend SMI studies demonstrating benefits at 6-12 months seek funding to extend follow-up and evaluate cost-effectiveness, to provide data for service development decisions.

In terms of program characteristics, the seven effective SMIs were either the group ASMP, a variant (SMART or internet versions) [15-17,30] or acknowledged ASMP influence on structure and format [24,37]. Thus, common program features were: duration of at least six weeks; explicit use of SCT and/or CBT approaches; individualized weekly action plans with progress review; highly protocolized with participant handbooks; and led by the same trained leaders. All face-to-face programs included weekly supervised exercise and graded home aerobic exercise (eg walking, Tai Chi). Three included aerobic exercise within programs [25,30,37] and the mailed/ internet ASMPs strongly promoted exercise action-planning with clear details about exercise performance. We recommend these strategies be incorporated into clinical programs and in research trials. Evidence-based guidelines should include studies meeting SMI criteria [3] and not treat all interventions equally. Whilst eight studies used boosters [15,18,19,20,28,33,35-37] only three showed significant benefits [15,28,37]. Further evaluation of the timing, delivery (phone, mailing or group) and effectiveness of booster sessions is warranted.

In terms of patient characteristics, there is little research regarding who benefits most from SMIs. The majority of ASMP trials recruited community or online volunteers, who may be more motivated to change. In ASMP studies recruiting from primary or hospital settings (all with OA) there is conflicting evidence, as two studies (with enhanced exercise) were effective [29,30] but a third, was not [25], supporting an earlier study's findings [47]. Only one ASMP trial has evaluated whether different diagnostic groups fare better, concluding the internet version is more effective in OA, less so in RA and not in FM [17]. Another study [33] reported patients with RA attending without their partner fared better, as they could openly discuss problems without loved ones present. Additionally, those not benefitting seemed less motivated to participate and change, had poorer heath and more stressful life events [4]. In an FM study, patients with initially higher self-efficacy

reported greater improvements [43]. Further research is needed to appropriately target interventions and/or modify SMIs to meet the needs of specific patient groups.

FUTURE DIRECTIONS

To best address the needs of patients with arthritis, we recommend researchers demonstrating positive outcomes from SMIs with sufficient sample sizes, undertake secondary analyses to investigate whether any baseline characteristics may predict better outcomes. We also recommend evaluating longer-term (12 months or more) benefits of SMIs, using protocolised SCT/CBT based programs of sufficient duration, incorporating exercise for 6 sessions or more, (longer for FM, including twice-weekly supervised graded aerobic exercise), led by either specially trained health professionals or peer leaders and which incorporate assessment of patient-relevant outcome. Increased use of qualitative methods integrated into clinical trials (eg patient dairies (written or audiorecorded), focus groups or interviews) are suggested to promote participants' expression of any perceived benefits on overall well-being, and to explore their perspectives on SMI effectiveness, as opposed to the sole use of questionnaires using standard validated tools which may not be detecting meaningful differences to the patients. For example, a woman attending a SMI course reported walking to her local shops for the first time in 12 years. Taking over two hours to make the 200 yard trip was entirely irrelevant to her. Such change is not captured in outcome measures. Her ability to control to her life was her relevant outcome. Use of such qualitative approaches will help investigate the full impact of SMIs on individuals, determine the most patient-relevant outcomes for future trials, investigate the process of change and shed light on what patient attributes influence benefits (or lack of) to better target and time SMIs. **See Table 6.**

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Table 1: Studies of Self-Management in Persons with Arthritis (Osteoarthritis, Rheumatoid Arthritis, Fibromyalgia and other arthritic conditions

Author (yr)	Design and Sample (n): Diagnoses (%); Mean age (y); % women; arthritis duration (y)	Recruitment source % Drop out	Intervention, Duration, Booster, Comparison Group	Facilitator; Training provided (Y/N)	Theory	Follow-up	Significant Outcomes: Improved
Lorig et al (2004) [15]	RCT n=1090 OA (40%); RA (60%); 62 y; 77 % women Duration - not stated	CV Drop-out: 12m: 10% 24m: 9% 36m: 15%	(a) SMART (individually tailored print materials based on the ASMP) plus the Arthritis Helpbook. Booster: follow-up materials every 4 months for 12 to 18 months. (b) usual care	Self-completed	SCT	12, 24 and 36m	CC and ITT analysis 12m: SMART: function, role function, self-efficacy 24m: global severity, doctor visits 36m: no difference
Lorig et al (2004) [15]	Randomized parallel group trial n=341 OA (70%); RA (30%); 65 y; 75% women Duration- not stated	CV Drop-out: 12m: 5% 24m: 7% 34m: 21%	(a) SMART (as above) (b) 6 x 2h/ wk ASMP (6 x 2h/week: action-planning, problem solving, decision-making; exercise, cognitive symptom, pain, fatigue, sleep management; nutrition, communication plus Arthritis Handbook. No booster. **No control group**	PM (Y)	SCT	12 ,24 and 36m	ITT analysis 12m: SMART: function, social role function, self-efficacy 24m: no differences 36m: ASMP: social role function, doctor visits
Lorig et al (2005) [16]	Randomized parallel group trial n=355 OA (75%); RA (15%); Other (15%) 65y; 85% women; Duration – not stated	CV Drop-out: 4m: 9% 12m: 15%	(a) ASMP 6 x2h/wk (see above) (b) CDSMP 6 x2h/wk (content similar to ASMP (No booster either group) **No control group**	PM (Y)	SCT	4 and 12m	ITT analysis: 12m: Within group: ASMP pain, fatigue, self-efficacy, health distress, activity limitation, exercise. CDSMP: global health, activity limitation, exercise. 12 m: Between group: ASMP fatigue, global health
Nour et al	RCT n=125 housebound	CHC	(a) Self-management	HP (Y)	CBT	1w and	CC analysis

(2006, 2007); [18, 19] Laforest et al (2008) [20]	113 randomized OA 65%; RA 35% 78y; 90% women Duration- not stated	Drop-out: 8m 22%	programme: "I'm Taking Charge of my Arthritis." (ITCA: exercise; relaxation; everyday coping behaviours; leisure activities; social networking) Individually tailored 6 x 1h/wk home visits by health care practitioner; Booster: 42% monthly telephone calls for 6m (b) one year wait list control			8m	1w: ITCA: function, helplessness, behaviours (exercise, relaxation) 8m: exercise
Goeppinger et al (2007) [21]	Randomized parallel group trial n= 416 (predominantly African Americans) Diagnosis: "arthritis" 64y; 82% women; Duration – not stated	CV Drop-out 4m: 23% 12m: 60% (but only 40% contacted)	(a) ASMP 6 x2h/wk (b) CDSMP 6 x2h/wk (No booster either group) **No control group**	PM (Y)	SCT	4 and 12m	CC analysis: 4m: Both groups: self-efficacy, global health. ASMP group: exercise use CDSMP: pain. 12m: ASMP only: self-efficacy
Lorig et al (2008) [17]	RCT n= 855 OA 64%; RA 28%; FM 52%; Other 14% 52y; 60% women; duration – not stated	CV OV Drop-out: 6m 25% 12m 24%	(a) Internet –based ASMP log-on 1-2h >=3x/wk for 6 wks: self-tests; read information; post action plans, participate in discussion board; tailored exercise programme; Arthritis Helpbook. No booster. (b) Usual care	PM (Y)	SCT	6 and 12m	ITT analysis: 12m: IASMP: pain, activity limitation, global health, self-efficacy, health distress. OA only (n=292): as above + function, fatigue RA only (n=144): pain, activity limitation, global health only. FM only (n=86): no differences.
Goeppinger et al (2009)	RCT n= 921 three ethnic/racial	CV (90%)	(a) Mailed ASMP-based Tool Kit (TK): self-test to	Self-completed	SCT	4 and 9m	ITT analysis:

[22]	categories. OA 51%; RA 33%; FM 30%; Other 17%. 54y; 86% women; duration – not stated	Rheum. (10%) Drop-out: 4m 16% 9m 30%	evaluate arthritis impact and tailoring selected information; information sheets for e.g. exercise, dealing with emotions, fatigue/ pain management, HP communication; how to action plan, problem solve, decide what to try, individualize exercise; Arthritis Helpbook and relaxation/exercise CDs. No booster. (b) 4m wait list control group.				4m: TK: pain, fatigue, function, global health, self-efficacy, depression, health distress, exercise, doctor communication. 9m: (No control group comparison). Benefits sustained.

Table 2: Studies of Self-Management in Persons with Osteoarthritis Only

Author (yr)	Design and Sample (n): Mean age (y); % women; arthritis duration (y)	Recruitment source % Drop out	Intervention, Duration, Comparison Group	Facilitator Training provided (Y/N)	Theory	Follow-up	Significant Outcomes: Improved
Victor et al (2005) [23]	Cluster RCT of 22 practices for n=193 patients with knee OA 63.5 y ; 69% women Duration – 55% had OA for more than 3 years	PC Drop out: 12m 35%	(a) Home visit to review goals, educational booklet and 4 x1 h group teaching sessions (6 to 8 participants) led nurse educator at GP office (b) Educational leaflet about arthritis only	RN (NS)	Not stated	1, 3, 6 and 12m	CC analysis 1 and 12m: No differences
Heuts et al (2005) [24]	RCT n=297 Hip and/or knee OA aged 40-60 years. 51.5y; 60 % women Duration – not stated	PC Drop out: 3m: 9% 21m: NS	(a) SMP: 6 x 2h (goal-setting, exercise (resistance), relaxation, problem-solving, communication, emotions, assistive devices, action plans and feedback) plus participant handbook. No booster. 12h. (b) usual care	PT (Y)	CBT	3m 21m	ITT analysis: 3m: SMP: pain, function 21m: SMP: pain, function
Buszewicz et al (2006) [25] Patel et al (2006) [31]	RCT n= 812 > 50y with hip and/or knee OA 68y; 63% women Duration – not stated	PC Drop out: 4m: 20% 12m: 24%	(a) ASMP: 6 x 2h plus information booklet. No booster. 12h. (b) Information booklet	PM (Y)	SCT	4 and 12m	ITT analysis: 4m: ASMP: self-efficacy, anxiety, depression 12 m: ASMP: self-efficacy, anxiety
Hurley et al (2007a and b) [27,32]	Cluster RCT n=418 >50y; chronic knee pain > 6m 66y; 70% women Median Duration - 6y	PC Drop-out: 7.5m: 20%	(a) Exercise and SMP (ESCAPE): group: 12 sessions 2x/week for 6 weeks (goal-setting, action plans, pain, pacing, healthy eating, relaxation, graded class and home exercise programmes). No booster. 12h. (b) ESCAPE: individual (as	PT (not stated)	SCT	7.5m	ITT analysis: 7.5m: both ESCAPE groups: pain, function, anxiety. Group more cost-effective than individual.

			above). (c) Usual care				
Yip et al (2007) [29]	RCT n=182 Knee OA 65y; 75% women Duration: 8 y	Ortho Drop out: 1w: 18% 4m: 34%	(a) Modified ASMP: 6 x 2h/wk plus exercise (inc. increased exercise: 30 mins Tai Chi/week, stretching, home walking + pedometer). Arthritis Handbook. No booster. 12h. (b) usual care only	RN (Y)	SCT	1w and 4m	ITT analysis: 1w: ASMP: pain, function, self-efficacy, health behaviors 4m: ASMP: pain, function, self-efficacy, health behaviors (hot/cold packs, joint protection, exercise),
Rosemann et al (2007) [28]	Cluster RCT n = 75 practices; 1021 patients knee or hip OA 66y; 66% women Duration: not stated	PC Drop-out: 6m 22%	(a) GP delivered SMI: individual; motivating patients, evidence based self-management information; audio exercise CD; information leaflet. Duration not stated. (b) GP-SMI plus RN monthly structured telephone case management over 6m. (c) Usual care	GPs (Y); RN (Y)	NS	9m	ITT analysis 9m: GP-SMI: fewer X-ray referrals and increased acetaminophen prescriptions. GP-SMI + case management: pain, mobility, social support; fewer X-ray, orthopedic referrals, increased acetaminophen prescriptions.
Yip et al (2008) [30]	RCT n=95 Knee OA 63y; 85% female Duration: 7y	PC Drop Out: 1w: 19% 4m: 22% 12m: 44%	(a) Modified ASMP: 6 x 2h/wk plus exercise (inc. increased exercise: 30 mins Tai Chi/week, stretching, home walking + pedometer). Arthritis Handbook. No booster. 12h. (b) Usual care only	RN (Y)	SCT	1w, 4 and 12m	ITT Analysis 12m: ASMP: pain (overall, at night, when walking), global health, self-efficacy, unplanned doctor visits for arthritis.

Wetzels et al (2008) [26]	RCT n=104; mild hip or knee OA 74y; 76% women Duration – not stated	PC Dropout 6m: 14%	(a) Individual SMP: OA booklet; self-identification of problems; 30 min home visit x 1; agree to change 1 of 4 behaviours (exercise, weight loss, walk aid use, medication); 3m telephone follow-up. Approx. 1h (b) OA booklet	RN (N)	NS	6m	CC analysis: 6m: no difference

Table 3: Studies of Self-Management in Persons with Inflammatory Arthritis only

Author (yr)	Design and Sample (n): Mean age (y); % women; arthritis duration (y)	Recruitment source % Drop out	Intervention, Duration, Comparison Group	Facilitator	Theory	Follow-up	Significant Outcomes: Improved
Riemsma et al (2003) [33]	RCT n= 218 RA 56y; 62% women Duration: 12 y	Rheum Drop-out: 12m 17%	(a) self-management programme (SMP) 5 x 2h/wk (pain management, relaxation, coping with depression, communication, exercise *advice*) plus 3 x 2h booster: 3, 6 and 9 months + partner. 16h (b) as above without partner; (c) self-help guide only	2x RN (Y)	SCT	6 and 12m	ITT analysis: 6m: Both SMP groups: exercise. 12m: SMP *without* partner: self-efficacy, fatigue.
Van Lankveld et al (2004) [34]	RCT n=59 RA 50y; 65% women Duration: 7.2y	Rheum Drop-out: 6m 3%	(a) Education and rational emotive therapy programme (ED-RET) 8 x 1.5h/wk for 4 wks (ED x4: information; "encourage practice of active coping skills" ; 4 = RET) + partner. No booster. 12h. (b) as above without partner. **No control group**	7 MDT members (not stated) & CP (Y)	CBT & RET	2w and 6m	ITT analysis: 6m: Both ED-RET groups: pain, function, mobility, dexterity.
Kirwan et al (2005) [35]	RCT (Zelen design) n=79 RA 54y; 61% women Duration 15y	Rheum Drop-out: 6m 14%	(a) education (ED) and CBT 4 x 2.5h/week + 1 x 2.5h booster at 8w (ED: joint protection, heat and cold; CBT: managing mood, pain, relaxation, sleep, communication, coping). 12.5h. (b) usual care	5 MDT members (not stated) + CP & RN (Y)	CBT	2 and 6m	ITT and CC analysis: CC only at 2m: ED-CBT: self-efficacy 6m: no differences.
Giraudet-le Quintrec et al (2007) [36]	RCT n=208 RA 55y; 89% women	Rheum Drop-out:	(a) education and self-management programme (ED-SMP: ED = 3 sessions (RA,	10 MDT members (not stated)	SCT? CBT?	6 and 12m	ITT analysis: 12m: ED-SMP coping

	Duration 13y	12m 9%	treatment, diet); SMP = 5 sessions (1= pain and stress management; 4 = exercise, relaxation, joint protection, foot care, social advice); 8 x 6h/wk plus 4h booster at 6m. 52h. (b) information booklets				
Hammond et al (2008) [37]	RCT n=167 (RA 50%; EIA 35% PsA 15%) 55y; 65% women; Duration 7y	Rheum Drop-out: 12m 17%	(a) Lifestyle Management for Arthritis Programme (LMAP): 2 modules: 4x 2.5h/wk; 1 x 2h booster (joint protection, fatigue management, exercise, foot care, managing pain and mood; communication, maintaining change); self-paced over 4-6 months. 22h. (b) attention control group: information programme 5 x 2h/week. 10h.	2 OTs & 1 PT (Y) 6 MDT members (N)	SCT CBT None	6 and 12m	ITT analysis 6m: LMAP: pain, fatigue, function, global health, self-efficacy, mood, helplessness, perceived control, behaviours (exercise, joint protection), health care use 12m: LMAP: pain, self-efficacy, perceived control, behaviours (joint protection, fatigue management)

Table 4: Studies of Self-Management in Persons with Fibromyalgia only

Author (yr)	Design and Sample (n): Mean age (y); % women; arthritis duration (y)	Recruitment source % Drop out	Intervention, Duration, Comparison Group	Facilitator Training (Y/N)	Theory	Follow-up	Significant Outcomes: Improved
Soares et al (2002) [38]	RCT n= 53 45y: 100% women Duration symptoms 3.6y	PC Drop-out: Not stated	Hospital-based: (a) Education: individual sessions (2x2h) + 15 x 2h group sessions over 10w (pain, sleep, stress, fatigue/ergonomics, medication, body awareness). No booster. 34h. (b) CBT: 5 x1h individual sessions and 15 x 2h group CBT sessions over 10w (relaxation, biofeedback, pain and stress management, negative thinking, problem-solving); no booster. 35h. (c) wait list control	1OT, 1PT (not stated) CP (Y)	NS CBT	2.5 and 6m	CC analysis: 2.5m: CBT: pain, function, pain coping, self-efficacy, sleep quality 6m: sleep quality
King et al (2002) [39]	RCT n=152 46y; 100% women Duration 9y	Rheum Drop-out: 38%	Community based: (a) supervised aerobic exercise (AE) 12 weeks (up to 40 mins. 3 x /wk 60-75% max. heart-rate). 36h. (b) SMP: 12 x 1.5-2h/wk: pain, fatigue, pacing, exercise benefits, alternate therapies, barriers to change). 24h. (c) AE-SMP (combined as above). 50h. (d) Information leaflets	MDT (not stated) & CP MDT (not stated) & CP (Y)	SCT	3 and 6m	ITT, CC and PP analyses: ITT and CC no differences 3 and 6m: PP analysis only: AE-SMP: self-efficacy, fitness

Cedraschi et al (2004) [40]	RCT n=129 49y; 76% women Duration symptoms 9y	Rheum Drop-out 21%	Hospital based: (a) SMP and exercise: 12 x 1.5h sessions for 6 wks: land (x2) and warm-water (x8) exercise, managing daily activities, relaxation, personal relationships. No booster. 18h. (b) wait list control.	MDT (not stated) & CP	NS	6m	CC analysis: 6m: SMP: Fibromyalgia Impact Questionnaire (FIQ), pain, fatigue, psychological status; satisfaction with symptom control, stress reduction, memory
Ziljstra et al (2005) [41]	RCT (Zelen design) n= 134 48y; 93% women Duration symptoms 9y	Rheum CV Drop-out: 12m 5%	Tunisia- hotel spa: (a) 2.5 weeks spa programme (SPA): 7 x 3hs thalassotherapy 7x 1h exercise (stretch, aerobic), 7 x 1.5h education (role of emotions, pacing, stress handling, coping, medications and alternate therapies). No booster. 38.5h. (b) Usual care	HP (not stated)	SCT	3, 6 and 12m	CC analysis: 3m: SPA: Fibromyalgia Impact Questionnaire (FIQ: includes pain and function), fatigue, physical health, tender points, sleep 6m: SPA: fatigue 12m: SPA: walk time.
Lemstra et al (2005) [42]	RCT n = 79 49y; 85% women; Duration 10y	PC Drop-out: 3m 9% 15m 56%	Community based: (a) SMP and exercise (SMP-EX). Exercise: 18 x 3 1h/week group exercise; SMP (6 weeks): FM information (3h), pain and stress management (2x3h); nutrition(3h); 2 x 20 mins individual massage. 28.7h. (b) Usual care	MDT (not stated) & CP (cognitive sessions)	NS	6w and 15m (uncontrolled)	ITT analysis: 6w: pain, function, global health, mood 15m (uncontrolled): pain, function, mood
Hammond et al (2006) [43]	RCT n= 183 90% female, 48.5 y; 90% women Duration: 2.7y (symptoms 6.5y)	Rheum Drop-out: 8m 24%	Community based: (a) SMP (pain, fatigue and stress management, pacing, sleep, relaxation, exercise (Tai Chi, home walking programme, postural training, strengthening)	1OT, 1 PT (Y)	SCT; CBT	4 and 8m	ITT analysis: 4m: SMP: Fibromyalgia Impact Questionnaire (FIQ), self-efficacy; perceived control;

			10x 2hr/wk (over 12 weeks). No booster. 20h (b) attention control group: relaxation programme 10 x 1 hr/wk for 10 weeks. 10h.				health care use 8 m: exercise; self-reported "improved" status
Rooks et al (2007) [44]	Randomized parallel group study n= 207 50y; 100% women; Duration 6y	Rheum Drop-out: 35%	Community and hospital based: (a) aerobic exercise (AE: walking) 16 x 2x1h/wk + home programme 1x/wk; 32h. (b) strength and aerobic exercise (STAE) 16 x 2x1h/wk; 32h. (c) Fibromyalgia Self-Help Course (FHSC) 7 x 2h/fortnight (pain, relaxation, exercise, communication, fatigue, depression (FM specific version of ASMP); no booster. 14h. (d) combined STAE and FHSC; no booster. 46h. **No control group.**	PM/HP? (Y)	SCT	6m	CC analysis: 6m: STAE-FHSC: Fibromyalgia Impact Questionnaire (FIQ), pain, fatigue, function, AE: fatigue, mood; STAE: FIQ; pain, fatigue, mood All groups: self-efficacy

Key:

Diagnosis: OA = osteoarthritis; RA = rheumatoid arthritis; EIA = early inflammatory arthritis; PsA = psoriatic arthritis; FM = fibromyalgia

Recruitment: CV = community volunteers; OV = online volunteers; ORTHO= Orthopedic clinic; PC = Primary Care; Rheum = Rheumatology out-patient departments; CHC = Community Health Centers.

Intervention: SMP = self management programme; ASMP = the Arthritis Self-Management Programme; SMART = Mail delivered Arthritis Self-Management Programme; CDSMP: Chronic Disease Self Management Programme

Programme facilitator: PM = trained peer/ lay moderator; HP = Health Professionals; RN = registered nurse; MDT: multidisciplinary team (nurse, physiotherapist (PT), occupational therapist (OT) (+/- rheumatologist, pharmacist); CP = clinical psychologist

Training: NS = not stated.

Theory: SCT = Social Cognitive Theory; CBT = cognitive-behavioural theory; NS = not stated

Analysis: ITT = all cases included, imputation of missing values; CC = case completers only

Table 5: Outcome Measures Assessed In Clinical Trials of Self Management Interventions in Arthritis

Paper	Disease status	Pain	Fatigue	Function /Disability	Global health	Self-efficacy	Mood	Perceived control	Coping	Social support/ role	Health behaviors	Health care use/costs
Arthritis: combined												
Lorig et al 2004	✓*	✓		✓		✓	✓			✓		✓
Lorig et al 2005		✓	✓	✓	✓	✓	✓			✓	✓	✓
Goeppinger et al 2007		✓	✓	✓	✓	✓	✓				✓	✓
Laforest et al (2008; Nour et al (2006,2007)		✓	✓	✓		✓	✓		✓	✓	✓	
Lorig et al 2008		✓	✓	✓	✓	✓	✓			✓	✓	✓
Goeppinger et al 2009		✓	✓	✓	✓	✓	✓				✓	✓
Osteoarthritis:												
Victor et al 2005		✓		✓	✓		✓	✓	✓		✓	
Heuts et al 2005		✓		✓	✓	✓						
Buszewicz et al 2006; Patel et al 2006		✓		✓		✓	✓					✓
Hurley et al 2007a and b		✓		✓	✓		✓				✓	✓
Rosemann et al (2007)		✓		✓			✓			✓		✓
Yip et al 2007		✓		✓		✓					✓	
Yip et al 2008		✓	✓	✓	✓	✓						✓
Wetzels et al 2008		✓		✓		✓				✓	✓	✓
Inflammatory												

Arthritis:												
Riemsma et al 2003	✓	✓	✓	✓		✓	✓		✓	✓	✓	
Van Lankveld et al 2004	✓	✓		✓			✓		✓			
Kirwan et al 2005	✓	✓		✓		✓	✓	✓	✓			
Girardet-leQuintrec et al 2007	✓	✓	✓	✓			✓	✓			✓	
Hammond et al 2008	**EMS only**	✓	✓	✓	✓	✓	✓	✓			✓	✓
Fibromyalgia only	**(Tender points)**											
Soares et al 2002		✓	✓	✓	✓	✓	✓		✓	✓		
King et al 2002	✓	✓	✓	✓	✓	✓	✓					
Cedraschi et al 2004		✓	✓	✓	✓		✓			✓	✓	
Ziljstra et al 2005	✓	✓	✓	✓	✓		✓					
Lemstra et al 2005		✓		✓	✓		✓					
Hammond et al 2006		✓	✓	✓	✓	✓	✓	✓			✓	✓
Rooks et al 2007		✓	✓	✓	✓	✓	✓			✓		
Lorig et al 2008		✓	✓	✓	✓		✓			✓	✓	✓

*** global severity of disease**

TABLE 6: Patient Perspectives on Self-Management Programs and Future Directions

- Researchers demonstrating positive outcomes from SMIs with sufficient sample sizes, should undertake secondary analyses to investigate further whether any patient attributes are associated with better outcomes.
- Examine longer-term (12 months and longer) benefits of SMIs
- Standardize implementation using protocols and participant handbooks. Ensure programs are SCT/CBT based, use trained peer leaders or health professionals, are of sufficient duration and incorporate exercise
- Patient dairies, creative writing or interviews are recommended to explore participants' overall well-being, processes of change and ascertain patient relevant outcomes
- Researchers should include patient-relevant outcomes. If using questionnaires, more frequent measures of outcomes may be useful in tracking the full impact of SMIs than longer intervals (baseline, 3 months and one year)