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## **‘Instilling the strength to fight the pain and get on with life’: learning to become an arthritis self-manager through an adult education programme**

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### **Abstract**

The aim of this study was to determine whether the Arthritis Self-Management Programme (ASMP) is effective in promoting perceived control and self-management ability when delivered in an adult education setting. The study was a pre-test–post-test design based on a sample of 89 people attending an ASMP. Data were collected by self-administered questionnaires prior to the intervention and after the intervention, 4 months from baseline. The sample comprised 80% women, with a mean age of 57 years and a mean disease duration of 13 years. Most participants had either osteoarthritis or rheumatoid arthritis. After 4 months, participants demonstrated significant increases in arthritis self-efficacy ( $P < 0.0005$ ), cognitive symptom management ( $P < 0.0005$ ), communication with doctors ( $P = 0.018$ ), exercise ( $P = 0.003$ ) and relaxation ( $P < 0.00005$ ). In addition, significant decreases were found in terms of pain ( $P = 0.034$ ) and visits to other health professionals ( $P = 0.004$ ). The first evaluation of the ASMP, delivered within the context of adult education, suggests that this form of community health education programme can offer substantial benefits for participants, particularly in terms of perceived ability to control various aspects of arthritis and in greater utilization of cognitive-behavioural techniques.

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### **Introduction**

Arthritis is a generic label used for over 200 different types of musculoskeletal, connective tissue and non-articular conditions with the most prevalent being rheumatoid arthritis, osteoarthritis and ankylosing spondylitis (Taal *et al.*, 1993). Disease concomitants (e.g. pain, fatigue, stiffness, inflammation and limited physical functioning) follow an unpredictable pattern of exacerbation and remission. Since there is no cure for most forms of arthritis, treatment is ameliorative, aiming to reduce pain and inflammation, and to maintain physical functioning. The individual is expected to assume responsibility for day-to-day management of their condition in their home environment for long periods of time. However, despite arthritis being the leading cause of physical disability in the UK (Badley and Tenant, 1993), very few receive assistance with the non-medical aspects of disease management, such as adopting a healthy life-style.

Health education programmes for people with arthritis in the UK have tended to be limited to specific hospital populations (i.e. people recently diagnosed with rheumatoid arthritis) and availability has been dependent upon geographical location. Although such programmes are becoming more common place, community-based health education for wider audiences (i.e. not restricted to a specific type of arthritis) is rare. One notable exception is the Arthritis Self-Management Programme (ASMP) organized and delivered by Arthritis Care, a voluntary organization in the UK. The ASMP is a health education programme designed for people with mild to moderate arthritis by Lorig and

colleagues at Stanford University, USA (Lorig and Holman, 1993) and is delivered in community settings (e.g. village halls, school halls). It is a 12 h course, comprising six weekly sessions of approximately 2 h each. The course is delivered by pairs of lay leaders most of whom have arthritis and in accordance with a comprehensive set of guidelines (Lorig and Gonzalez, 1992). Topics include an overview of self-help principles, information on the disease process, exercise, cognitive pain management, depression, communication with health professionals and realistic, self-driven, goal accomplishment. The interactive nature of the course places emphasis on brainstorming ideas, modelling, problem solving and skills mastery. The course is accompanied by *The Arthritis Helpbook* written specifically as a reference text for the ASMP (Lorig and Fries, 1995).

The programme is set within the theoretical framework of self-efficacy (Lorig and Gonzalez, 1992). Bandura [(Bandura, 1991), p. 229] defined self-efficacy as:

...belief in one's capabilities to mobilize the motivation, cognitive resources and courses of action needed to meet given situation demands.

Self-efficacy beliefs not only influence the course of action pursued but also the effort expended, perseverance in the face of difficulties, the nature of thought patterns (i.e. encouraging or self-deprecating) and the amount of stress experienced in demanding situations (Bandura, 1994). Strategies that enhance self-efficacy beliefs (i.e. mastery experience, role modelling, persuasion and reinterpretation of physiological state) are incorporated into the ASMP. Thus, participants are encouraged to become active agents in the context of arthritis, perceiving themselves as capable of successfully enacting the self-management strategies that best suit their needs in a given situation and at a given point in time. The aim is to help people move away from the traditional passive patient role associated with the medical model of care and to regain a sense of control in their lives.

In the UK, the ASMP was first introduced and

evaluated as part of a community project delivered in seven regions of the UK targeting older adults within the Arthritis Care branch network. Results showed that 10 weeks post-ASMP, the benefits were commensurate with those found in previous studies in the US. That is, older adults over the age of 55 years demonstrated enhanced arthritis self-efficacy, improvements in psychological well-being, cognitive pain management (e.g. distraction), communication with doctors, and participation in exercise activities and relaxation techniques. Furthermore, reductions in pain and visits to GPs were also identified (Barlow *et al.*, 1997a).

The underlying philosophy of the ASMP is similar to that of community health education. That is, it places much emphasis on positive health behaviours among a population at risk. For example, community health education has addressed smoking intentions, beliefs and behaviours among women (Secker-Walker *et al.*, 1996); and knowledge, attitudes, beliefs and behaviours about HIV and AIDS among Asian and Pacific Islander populations in the US (Yep, 1993). In addition, community health education programmes have been effective in changing knowledge, attitudes and behaviour with respect to cardiovascular disease (Farquhar, 1991).

One form of community education within the UK, supported by public funding, is that of Adult Education. Adult Education is a flexible, accessible public service that provides learning opportunities to all persons over the statutory school leaving age (i.e. 16 years and above) who are no longer in full-time education (Organization for Economic Cooperation and Development, 1977). Adult Education aims to facilitate individual, personal development and fulfilment (Fieldhouse, 1996), and advocates 'participatory learning' over 'taught learning' (Tight, 1996). In essence, adult education provides a unique forum for knowledge enhancement, skills acquisition, attainment of technical and professional qualifications, fulfilment of personal challenges, and the promotion of attitudinal and behavioural changes (Kidd and Titmus, 1989). For the majority, enrolment is driven by three

motivational factors: goal orientation (e.g. qualification attainment, promotion and problem solving), activity orientation (e.g. need for group identity and enjoyment being with similar others) and learning orientation (e.g. desire for knowledge and skills enhancement) (Houle, 1961). Thus the basic tenets of Adult Education suggest that it could be an appropriate vehicle for the delivery of health education programmes. However, the potential for improving health-related factors through Adult Education has received little attention from researchers. Rather, the predominant emphasis has been to evaluate programme planning, theory and practice (Fisher, 1993; Cervero and Wilson, 1994; Courtenay, 1994), adult literacy (Lysynchuk *et al.*, 1992), and education, distance and self-directed learning in older adults (Harold, 1992; Percy and Withnall, 1992).

As part of Arthritis Care's commitment to people with arthritis, they worked in partnership with the Adult Education Service of Northamptonshire to offer the ASMP to all adults with arthritis over the age of 18 years. This innovative project provided a unique opportunity to examine the effects of a community health education programme that has proven to be successful among older adults in the UK and in other parts of the world, such as the US (Lorig and Holman, 1993) and Australia (Simeoni *et al.*, 1995), within a new setting. As such, the study represents the first evaluation of the ASMP delivered through Adult Education within the UK. Thus, together with courses such as French for Beginners and Pottery, people in Northamptonshire were given the opportunity to enrol on a course to learn more about managing a common chronic condition, that of arthritis. The aims of the study were to determine whether attending the ASMP delivered within the framework of Adult Education in the UK influenced: arthritis self-efficacy; physical, psychological well-being; the use of behavioural and cognitive techniques for managing arthritis; and the utilization of formal health care resources.

Specific research hypotheses were:

- Participation in the ASMP increases arthritis self-efficacy.

- Participation in the ASMP improves health status (e.g. psychological well-being, pain, fatigue).
- Participation in the ASMP increases the use of behavioural (e.g. exercise) and cognitive techniques (e.g. cognitive symptom management).
- Participation in the ASMP influences the use of health care resources (e.g. visits to GPs).
- Change in pain is mediated by change in cognitive symptom management and change in arthritis self-efficacy.

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## Method

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### Participants

The sample was recruited by Northamptonshire Adult Education Service through advertisements placed within health service-based networks, the Arthritis Care network, local media and community resources. Participation in the evaluation was not mandatory for attendance on the ASMP. The entry criteria for the study were (1) age  $\geq$  18 years and (2) an ability to complete the questionnaire. Of the 142 people who attended the ASMP during the 2 year research phase, 131 completed questionnaires prior to attendance (Time 1 or baseline). Nine people failed to meet the entry criteria (i.e. did not fully complete the questionnaire) and were excluded from the analysis. Thirty-three did not complete the follow-up assessment, yielding a final sample size of 89. Failure to complete the ASMP was attributed to a flare of disease activity in eight cases and transport difficulties in five cases.

### Method

The mode of recruitment, set within the rules and regulations of Adult Education, prevented randomization for research purposes. Northamptonshire Adult Education operates a system whereby enrolment entitles the student to immediate access to a given course, therefore randomization to a waiting list control group was prohibited. Thus, the evaluation of the project followed a pre-test-post-test design. Data were collected by self-administered questionnaires mailed to participants at two points in time: prior

to attending the ASMP (Time 1) and 4 months from baseline (Time 2). Outcome measures comprised: arthritis self-efficacy (defined as the individual's confidence in their perceived ability to control, or manage, various aspects of arthritis such as pain); physical well-being; psychological well-being; the use of behavioural and cognitive techniques to manage arthritis; and the utilization of formal health care resources.

### Measuring instruments

The questionnaire was tested for comprehensibility and acceptability to ensure a 'user friendly' format (i.e. minimum of writing) among the first 10 participants. Many of the standard measuring instruments selected have been used in previous studies of people with arthritis, and have established reliability and validity. The questionnaire assessed the following dimensions.

Demographic information (e.g. age, gender and education) and arthritis-related information (e.g. specific type and disease duration) were only collected at baseline.

Physical functioning was measured by the modified Health Assessment Questionnaire (HAQ) (Kirwan and Reeback, 1986), which has been adapted for use in the UK. The HAQ assesses ability to perform daily activities including: dressing and grooming, walking, eating, and reaching. Scores range from 0 to 3; with higher scores indicating impaired physical functioning. No change was expected on this dimension over a period of 4 months. The HAQ was included to provide an indication of the level of physical functioning among participants.

Pain and Fatigue were measured separately with standard 10 cm horizontal visual analogue scales (VAS) anchored by 'no pain/fatigue' and 'pain/fatigue as bad as it could be' (Huskisson, 1983).

Depression was measured using the 20-item Centre for Epidemiological Studies—Depression (CES-D) Scale (Radloff, 1977). The CES-D showed evidence of positive skewness. A square root transformation was conducted, which rendered greater symmetry for comparative analyses.

The Arthritis Self-Efficacy scale (Lorig *et al.*,

1989) was used as a measure of the strength of a person's belief in their ability to control, or manage, various aspects of their arthritis and comprises two sub-scales: Arthritis Self-Efficacy for Pain (five items) and Arthritis Self-Efficacy for Other Symptoms (six items). This scale has been validated for use among British people with arthritis recruited through community sources (Barlow *et al.*, 1997b).

Behavioural and cognitive techniques for managing arthritis were assessed using the scales developed to evaluate the ASMP by Lorig *et al.* (Lorig *et al.*, 1989) at the Stanford Arthritis Centre (e.g. exercise, cognitive symptom management and communication with physicians).

Use of formal health care facilities was assessed in terms of visits to GPs, the number of these visits to GPs during which arthritis was discussed, visits to rheumatologists and visits to other health professionals. These assessments used a time frame of 'during the past 4 months'. The number of visits to GPs and the number of visits to GPs where arthritis was discussed showed evidence of positive skewness. Square root transformations were applied to render symmetry for comparative analyses.

An open question was included in the assessment at Time 2, enabling participants to report their views concerning the ASMP and the associated research.

### Analysis

Quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS, 1993). Comparisons were drawn between baseline values and post-intervention values to determine whether attending the ASMP delivered in the context of adult education led to changes among people with arthritis. Mean values on health status outcome measures (HAQ, pain, fatigue and depression) were compared across Time 1 and Time 2 using paired *t*-tests. Similarly, paired *t*-tests were used to test for significant differences between Time 1 and Time 2 mean values on arthritis self-efficacy and behavioural outcome measures (number of visits to GPs, number of visits to GPs where arthritis was discussed, communication with doctors and

cognitive symptom management). The proportions of participants who carried out exercise activity (i.e. stretching and strengthening exercises, relaxation, walking for half a mile or more, and swimming) during the month prior to Times 1 and 2 were compared using McNemar's test. Similar analytic procedures were used to examine change on visits to rheumatologists and other health professionals. Multiple regression analyses were used to examine the potential mediating effects of cognitive symptom management and arthritis self-efficacy on change in pain, as suggested in Baron and Kenny (Baron and Kenny, 1986). To examine whether the findings differed for people with different types of arthritis, a series of repeated measures analyses were conducted with time and type of arthritis as the factors. The most common types of arthritis found in the sample were used (i.e. osteoarthritis and rheumatoid arthritis).

Effect sizes were calculated using the following formula: effect size =  $(x_2 - x_1)/SD_1$ , where  $x_2$  is the mean score at Time 2,  $x_1$  is the mean score at Time 1 and  $SD_1$  is the standard deviation at Time 1. The boundaries used to determine small, moderate and large changes in study variables (0.2, 0.5 and 0.8, respectively) are in accordance with Kazis *et al.* (Kazis *et al.*, 1989).

Qualitative data derived from the open questions were subjected to content analysis thus enabling themes, contrasts and similarities to emerge from within the data.

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## Results

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The majority of the sample were women, with a mean age of 57 years and a mean disease duration of 13 years. The main types of arthritis were osteoarthritis and rheumatoid arthritis. The mean HAQ score was 1.17, indicating moderate impairment of physical functioning among this group of people. In addition, participants reported moderate levels of pain and fatigue with means of 5.63 and 5.36, respectively. Fifty-five per cent reported comorbidity (e.g. depression, angina, hiatus hernias, gastric problems). Scores on depression showed that 39% of the sample were at risk of clinical

depression (i.e. scores  $\geq 16$  on the CES-D) at Time 1. Participant characteristics are presented in Table I.

No statistically significant differences were found on any of the study variables between participants who completed the study assessments (Time 1 and Time 2) and those who did not complete an assessment at Time 2 (see Table II). However, there was a trend towards higher pain among those who completed the Time 1 assessment only.

### Self-efficacy

Analyses revealed that participants significantly increased their arthritis self-efficacy beliefs both in relation to pain and in relation to other symptoms ( $P < 0.0005$  in both cases). These increases were associated with small to moderate effect sizes (0.45 and 0.35, respectively). Thus after attending an ASMP, participants felt more confident in their ability to manage their arthritis (see Figure 1 and Table III).

### Health status

With respect to health status, only a small, though statistically significant, decrease in pain was found ( $P = 0.034$ ) giving a small effect size of  $-0.21$  (see Figure 1 and Table III). As expected, scores on the HAQ remained fairly stable over time and there was no evidence of significant change in fatigue or depression (see Table III).

### Cognitive and behavioural techniques for managing arthritis

Cognitive symptom management refers to cognitive techniques such as distraction, relaxation and guided imagery that can help individuals to cope with pain. A significant, moderate improvement on cognitive symptom management ( $P < 0.0005$ , effect size 0.47) was revealed, thus indicating that participants increased utilization of these techniques, in order to manage their arthritis (see Figure 1 and Table III).

The number of participants carrying out stretching and strengthening exercises had significantly increased from 66% at Time 1 to 84% at Time 2 ( $P = 0.003$ ). Similarly, the number of people

**Table I.** *Participant characteristics*

Variable	Time 1 ( <i>N</i> = 89)		
	Mean	SD	Range
Age (years)	57.3	12.8	26–82
Duration of disease (years)	13.4	10.9	0–50
Health Assessment Questionnaire (HAQ)	1.17	0.69	0–3
Pain	5.63	2.76	1–10
Fatigue	5.36	3.06	0–10
Depression	15.04	11.13	0–54
Gender: women	80%		
Type of arthritis (% of cases)	45% RA	48% OA	42% other (e.g. AS, SLE)
Registered disabled	27%		
Other health problems	55%		
Some formal educational qualifications	56%		
Married/living with partner	66%		

RA, rheumatoid arthritis; OA, osteoarthritis; AS, ankylosing spondylitis; SLE, systemic lupus erythematosus.

**Table II.** *Comparisons between people who completed the two study assessments (Times 1 and 2) and those who only completed the assessment at Time 1*

Variable	Completed at Time 1 only ( <i>N</i> = 33)	Completed at Times 1 and 2 ( <i>N</i> = 89)	Mean difference	<i>P</i>
Arthritis self-efficacy: pain	26.56 (9.69)	26.64 (10.17)	–0.08	0.998
Arthritis self-efficacy: other symptoms	32.97 (11.93)	35.06 (11.20)	–2.09	0.514
Communication with doctor	9.79 (6.15)	11.76 (6.30)	–1.97	0.136
Cognitive symptom management	7.16 (4.85)	7.74 (5.39)	–0.58	0.618
Pain	6.66 (2.38)	5.63 (2.76)	1.03	0.060
Fatigue	5.79 (3.02)	5.36 (3.06)	0.43	0.458
HAQ	1.02 (0.66)	1.17 (0.69)	–0.15	0.247
Depression <sup>a</sup>	3.78 (1.29)	3.58 (1.49)	0.20	0.497

<sup>a</sup>Square root transformed. Figures are mean (SD).

practising relaxation had increased from 34% at Time 1 to 63% at Time 2. This difference was significant at  $P < 0.00005$ . The numbers of participants walking half a mile or more and swimming remained stable.

### Visits to GPs, rheumatologists and other health care professionals

Significant decreases in visits to other health professionals were identified between Time 1 and Time 2 ( $P = 0.004$ ). During the 4 months prior to the ASMP, 45% of participants visited other health

professionals. This figure dropped to 26% during the subsequent 4 months.

Visits to the GP and visits to the GP to discuss arthritis remained stable over the two time points. During the 4 months prior to attending the ASMP and the subsequent 4 months, participants visited their GP once on average to discuss their arthritis. In addition, visits to rheumatologists also remained stable during both 4 month assessment periods. A significant, but small, improvement on communication with doctors ( $P = 0.018$ , effect size 0.21) was revealed (see Figure 1). After attending the ASMP,

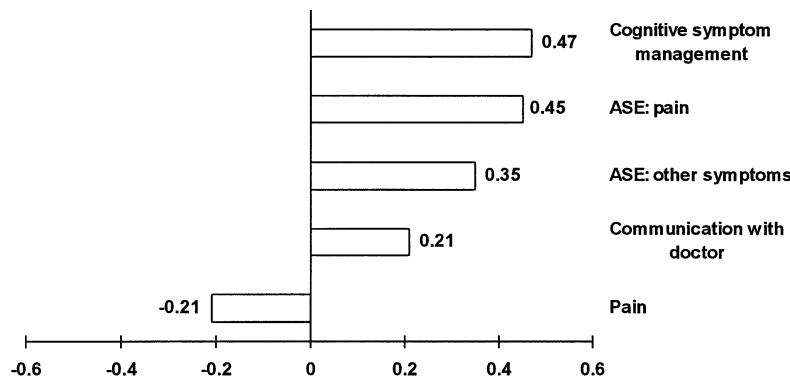


Fig. 1. Effect sizes (Time 1 to Time 2): significant changes only.

Table III. Comparisons of mean values at Times 1 and 2, and effect sizes

Variable	Time 1	Time 2	Mean difference	P	Effect size
Arthritis self-efficacy: pain	26.47 (10.10)	31.05 (9.10)	4.58	<0.0005	0.45
Arthritis self-efficacy: other symptoms	34.91 (11.18)	38.77 (10.31)	3.86	<0.0005	0.35
Communication with doctor	11.70 (6.30)	13.00 (6.38)	1.30	0.018	0.21
Cognitive symptom management	7.70 (5.44)	10.25 (5.11)	2.55	<0.0005	0.47
Pain	5.63 (2.77)	5.06 (2.57)	-0.57	0.034	-0.21
Fatigue	5.36 (3.07)	5.27 (2.89)	-0.09	0.760	-
HAQ	1.17 (0.69)	1.12 (0.72)	-0.05	0.138	-
Depression <sup>a</sup>	3.63 (1.48)	3.63 (1.51)	0.00	0.997	-

<sup>a</sup>Square root transformed.

participants felt better able to discuss their arthritis with doctors.

**Mediation of change in pain**

Results of the multiple regression analyses showed that change in pain was not mediated by change in cognitive symptom management (see Table IV). However, change in pain was partially mediated by change in arthritis self-efficacy for pain and other symptoms, the strongest mediational effect being through arthritis self-efficacy for pain.

**Comparison between people with osteoarthritis and rheumatoid arthritis**

The outcome measures at Times 1 and 2 were compared across two common types of arthritis, rheumatoid arthritis (N = 40) and osteoarthritis (N = 42). Where participants reported a diagnosis

of both rheumatoid arthritis and osteoarthritis, the primary diagnosis was taken to be rheumatoid arthritis. The only statistically significant differences across osteoarthritis and rheumatoid arthritis on demographic variables was age (P = 0.006). Participants with osteoarthritis were on average 7.5 years older than participants with rheumatoid arthritis. Significant differences were found on two study variables: the HAQ (P = 0.007) and visits to rheumatologists (P = < 0.00005). At both Time 1 and Time 2, participants with rheumatoid arthritis had significantly higher mean scores on the HAQ (0.39 units higher than osteoarthritis), indicating greater physical disability and reported more visits to rheumatologists. At Time 1, 29 people with rheumatoid arthritis reported visiting a rheumatologist compared to eight people with osteoarthritis.

**Table IV.** Regression analyses examining potential mediating effects of cognitive symptom management and arthritis self-efficacy on pain

Variables	Step 1		Step 2	
	$\beta$	<i>P</i>	$\beta$	<i>P</i>
<b>Regression 1</b>				
pain at Time 1	0.60	0.00001		
cognitive symptom management at Time 1	-0.02	0.7923		
pain at Time 1			0.56	0.00001
cognitive symptom management at Time 1			0.04	0.6989
cognitive symptom management at Time 2			-0.12	0.2846
Adjusted $R^2$ for final equation = 0.27, $F = 11.75$ , $P < 0.00001$				
<b>Regression 2</b>				
pain at Time 1	0.44	0.00001		
arthritis self-efficacy: pain at Time 1	-0.37	0.01		
arthritis self-efficacy: other symptoms at Time 1	0.14	0.3118		
pain at Time 1			0.39	0.0001
arthritis self-efficacy: pain at Time 1			-0.18	0.2017
arthritis self-efficacy: other symptoms at Time 1			0.05	0.7279
arthritis self-efficacy: pain at Time 2			-0.52	0.0005
arthritis self-efficacy: other symptoms at Time 2			0.30	0.0459
Adjusted $R^2$ for final equation = 0.42, $F = 13.34$ , $P < 0.00001$				

A similar finding was demonstrated at Time 2, with 24 people with rheumatoid arthritis visiting a rheumatologist compared to only three people with osteoarthritis.

With respect to change over time, all of the study variables were independent of arthritis type. Thus people with osteoarthritis and rheumatoid arthritis demonstrated similar improvements after attending the ASMP.

**Qualitative findings**

The ASMP helped people with arthritis in a number of ways. Participants reported gains in their knowledge, awareness and understanding about arthritis, particularly in terms of how to manage their condition on a daily basis. Some participants referred to improvements in their general health and psychosocial well-being. For example, one participant had experienced an improvement in her mobility as a result of setting herself goals with respect to exercise. Others felt more positive, more confident, hopeful about the future and expressed intentions to seek out further courses or activities (e.g. ‘Taster’ days offered by Northamptonshire

Adult Education). However, several participants expressed concern that there were few opportunities to meet with others after the end of the ASMP. It was clear that one of the main benefits deriving from attending the ASMP was the opportunity to meet and share concerns with similar others in a non-threatening environment. Meeting other people with arthritis, making new friends and ‘feeling part of a group’ not only promoted positive thinking but also helped participants to realize that they were not alone. Moreover, knowing that the trainers also had arthritis was an important aspect of the course experience. The trainers were looked upon not only as positive role models but also as people who really understand the needs of people with arthritis. The following quotes eloquently epitomise the course experience:

The course gave me the strength to fight the pain and get on with life.

The course was extremely helpful, informative, enjoyable (particularly class discussion and involvement) and created a very positive approach to arthritis.



I found the course very enlightening. It let you discuss your problems with people who know exactly what you are suffering. I was relieved that I was not the only one... The course opened me up and I blossomed from it.

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### Discussion

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People with arthritis reported significantly increased levels of arthritis self-efficacy after attending the ASMP delivered in the context of adult education. They felt more confident in their own abilities to manage the pain and other symptoms of arthritis such as fatigue. For example, people reported that the course enhanced self-confidence and instilled the strength to fight the pain. These findings are in accordance with those reported in previous evaluations of the ASMP amongst older people recruited from the Arthritis Care Branch Network in the UK (Barlow *et al.*, 1997a) and the US (Lorig and Holman, 1993).

As expected, levels of physical functioning remained stable over time. Most forms of arthritis are progressive in nature, therefore maintenance of physical functioning over time can be regarded as a positive outcome. Longitudinal studies are needed to fully examine the impact of increased utilization of self-management strategies over longer periods of time.

Following the ASMP, participants demonstrated a significant though moderate improvement on pain. Moreover, this improvement appeared to be partially mediated through arthritis self-efficacy confirming the importance of enhancing control-related beliefs among people with this chronic condition. Disappointingly, no improvement was noted on either fatigue or depression. With respect to depression, failure to detect change was in contrast to the content of qualitative findings suggesting that participants experienced enhanced psychosocial well-being (e.g. positive mood) after attending the ASMP. Although the CES-D scale has been shown to be appropriate for use in evaluation of the ASMP in the US (Lorig and Gonzalez, 1992), it may not be sensitive enough to detect change amongst the present sample attending

the ASMP in an Adult Education setting and against the backdrop of the UK system of health care. Alternatively, change on depression may take longer than 10 weeks to manifest, therefore longer-term assessment may be warranted. Inclusion of a wider range of psychological measures (e.g. anxiety) and direct assessment of positive well-being *per se* (rather than reduction of negative mood) may serve to illuminate the impact of the ASMP on psychological well-being.

Participants reported increased utilization of cognitive symptom management (e.g. distraction), following the ASMP. The failure of change in the use of this cognitive-behavioural technique to mediate change in pain replicates the results reported by Lorig and Holman (Lorig and Holman, 1993) and may be partly accounted for by the relatively small change in absolute levels of pain reported by participants. A small change in the dependent variable may hinder attempts to demonstrate mediational effects. Improvements in the use of stretching and strengthening exercises and relaxation were noted, suggesting that the techniques incorporated in the ASMP (e.g. realistic goal setting, feedback and problem solving) may be useful in changing behaviour among this chronic disease population. Further studies are necessary to determine whether this pattern of exercise is maintained over longer periods of time and to examine the impact of exercise on health status.

Use of health care resources was evaluated in terms of visits to GPs, rheumatologists and other health professionals. Since participants only visited their GPs to discuss arthritis once (on average) during the 4 month period preceding both assessment points, it is not too surprising that no change was detected over time. In contrast, a significant decrease in visits to other health professionals was identified between Times 1 and 2. As the research was conducted over a 2 year period, the decreased number of visits cannot be accounted for by seasonal variation. Therefore, the benefits of attending an ASMP may have influenced perceived need for help from other health professionals. Although participants did not make fewer visits to their GPs, they believed that the nature of their

communication with doctors had significantly improved following the course; they felt better equipped to discuss their arthritis when they did visit their doctors.

As may be expected, prior to attending the ASMP, people with rheumatoid arthritis were found to have a higher degree of physical disability. However, this was the only significant health status difference between people with these two main types of arthritis (e.g. levels of reported pain were very similar). No differences were identified in terms of change over time after attending the ASMP. For many health professionals, the notion of providing health education programmes for a 'mix' of people with different diagnoses, albeit under the same 'umbrella' of arthritis, is often viewed with a degree of scepticism. This view may derive from the prevalence of the medical model that focuses on pathological disease parameters rather than the subjective experience of patients as they attempt to manage their condition in the home environment. The findings from this study suggest that participants derive similar benefits from the ASMP, regardless of their diagnostic type of arthritis, thus challenging the scepticism fuelled by the medical model.

One problem highlighted in this study is that there is often no formal means through which participants can continue to meet after the end of the 6 week course. A similar finding was identified in the context of older adults (Barlow *et al.*, 1997a) and is an inherent aspect of many short courses (Barlow and Barefoot, 1996). Meeting with similar others and the exchange of information (e.g. experiences and coping strategies) is a valuable, but often overlooked, aspect of many courses. For example, an evaluation of a cognitive-educational programme for people with fibromyalgia included an education/discussion programme as an 'attention placebo' for cognitive therapy (Goosens *et al.*, 1996). There were no significant differences between the groups on quality of life measures and the authors concluded that the intended placebo was in reality an active therapy. As recommended by Barlow *et al.* (Barlow *et al.*, 1997c), a measuring instrument closely linked to the concept of sharing

and the type of support experienced in a group educational setting may be needed to tap changes on this dimension.

A limitation of the study was the inability to randomize participants into two groups: an intervention and a control group. The nature of the project, set within the confines of an adult education department, prohibited such an approach. A randomized controlled study is needed to confirm that the positive benefits identified derive from ASMP attendance and longer-term follow up assessments will be necessary to determine whether the changes are maintained over time. Furthermore, demand characteristics may have influenced the changes identified. For example, people on the programme were volunteers who may have been motivated to improve regardless of attendance on the ASMP. Further studies are needed to identify the causal mechanisms leading to change. The initial decision to enrol on a programme may be one such mechanism. However, given that people cannot be forced to participate in any form of health education and cannot be blinded to the intervention, the reality is that programmes will always comprise volunteers. One solution, not available in the present study, is to randomize people to an intervention and waiting list control group, thus controlling for motivational factors. Reliance on recruitment through community sources may constrain the generalizability of findings and may be viewed as a weakness. However, the programme was designed for people with mild to moderate arthritis in community settings, since the programme developers felt that people attending hospital clinics were already well catered for (Lorig and Holman, 1993). Recruitment through community sources has been justified in research focusing on the psychological aspects of chronic disease (Glasgow and Hampson, 1995). Nonetheless, future evaluations of the ASMP could benefit from obtaining confirmation of each participant's primary diagnosis from a medical practitioner. In this respect, a high concordance rate (87%) between self-report and clinical diagnoses among participants enrolling on the ASMP delivered outside of Adult Education has been noted (Barlow *et al.*, 1999). One further limitation is the delivery of the

ASMP through one single local authority as there is great disparity with respect to policies, structure, resources and practices between local authorities (Wilson, unpublished).

A strength of the study was that once involved with the ASMP, very few people dropped out of the programme. In fact, people who completed both assessments looked forward to enrolling on further courses and activities in the Arthritis Care Initiative, Adult Education and elsewhere (e.g. yoga, assertiveness training). Failure to complete the course was attributed to ill health or transport difficulties rather than dissatisfaction with the programme itself. The trend towards higher pain in those failing to complete the study adds weight to the suggestion that ill-health was a factor influencing attrition. People experiencing a 'flare up' of disease activity may have found it difficult to attend each of the six weekly sessions or to complete the assessment. Clearly, it will be important to target those with high pain levels in future studies since the ASMP may provide them with useful strategies for managing the fluctuations that are so characteristic of most forms of arthritis. With respect to our evaluation, the attrition may be explained by the fact that completion of questionnaires was not mandatory for course attendance. Furthermore, in addition to our questionnaires, participants completed evaluation forms distributed by the Adult Education Service after each of the six weekly sessions. Thus the exhaustive use of questionnaires may partially explain attrition over time.

In conclusion, the first evaluation of the ASMP delivered within the context of adult education in the UK suggests that this form of health education programme is not only acceptable to people with arthritis, but can offer substantial benefits in terms of an enhanced sense of control, a reduction in pain, increased use of cognitive and behavioural techniques, and perceived ability to discuss arthritis in health care settings. The ASMP was viewed as a welcome step forward that helped to create a 'positive' approach to arthritis and is in accordance with the basic tenets of adult education.

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## Dedication

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This article is dedicated to Gwenda Ridge. Her valuable contribution to this important initiative will always be remembered.

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