

LONG-TERM OUTCOMES OF AN ARTHRITIS SELF-MANAGEMENT PROGRAMME

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SUMMARY

Objective. A previous UK evaluation of the Arthritis Self-Management Programme (ASMP) demonstrated 4 month improvements in physical and psychological well-being including increased arthritis self-efficacy and increased use of self-management behaviours such as cognitive symptom management, and reductions in pain, fatigue and anxiety. The purpose of this study was to determine whether these effects were maintained at 12 month follow-up.

Methods. Twelve month data were collected via self-administered questionnaires mailed to participants who had previously responded prior to attending the ASMP and at 4 months follow-up.

Results. The sample ($n = 112$) comprised 82% women with a mean age of 59.6 (s.d. 12.4) yr and a mean disease duration of 14.9 (s.d. 11.1) yr. The majority of participants had a general practitioner-recorded diagnosis of either rheumatoid arthritis (46%) or osteoarthritis (44%). Many of the changes noted at 4 months were sustained at the 12 month follow-up.

Conclusion. This first long-term evaluation of a community-based patient education intervention delivered in the UK suggests that after participation in the ASMP, persons with arthritis derive substantial and prolonged benefits in terms of perceived ability to manage arthritis, reduction in pain and improved psychological well-being.

KEY WORDS: Arthritis, Self-management, Patient education.

THE potential advantages of including a psycho-educational intervention in the treatment options for arthritis are being increasingly recognized [1]. Studies have shown that arthritis patient education programmes can be a useful method for enhancing self-care management techniques and improving physical and psychological health outcomes [2–6]. A recent meta-analysis revealed that such interventions provide additional benefits for pain relief 20–30% as great as the effects of non-steroidal anti-inflammatory drug treatments [7]. Lorig [1] has argued that arthritis patient education programmes should be an integral part of treatment and not merely a ‘nice extra’.

The most effective interventions utilize behavioural and cognitive modification techniques, in addition to providing information [1]. One such intervention, designed for people with all forms of mild to moderate arthritis, is the Arthritis Self-Management Programme (ASMP) [8]. This community-based programme is set within the framework of self-efficacy theory [9] and aims to enhance perceived ability to control various aspects of arthritis through skills mastery, modelling, reinterpretation of symptoms and persuasion. The programme is taught by lay leaders, most of whom have arthritis. Lorig emphasizes the importance of lay leaders, suggesting that they act as positive role models for course participants. Interestingly, studies by Cohen *et al.* [10] and Lorig *et al.* [11] found little or no differences in outcome measures between lay- and professional-taught groups.

Randomized controlled trials conducted in North

America have shown that after attending the ASMP, participants reported an increased sense of control, a decrease in pain, a reduction in depressed mood and fewer visits to physicians at 4 month follow-up [8]. In the UK, the first evaluation of the ASMP delivered in community settings to older people (>55 yr of age) indicated that the intervention offered considerable benefits at 4 months in terms of arthritis self-efficacy ($P < 0.0005$), increased use of self-management techniques such as exercise ($P < 0.0005$), a reduction in pain ($P = 0.026$), improved psychological well-being (depression, $P = 0.042$) and fewer visits to general practitioners (GPs) ($P = 0.026$) [6]. Similar short-term benefits were found when recruitment was extended to all adults with arthritis aged 18 and over [12]. For example, after 4 months, participants demonstrated significant increases in arthritis self-efficacy ($P < 0.0005$), cognitive symptom management ($P < 0.0005$), communication with physicians ($P = 0.001$), exercise ($P = 0.0008$) and relaxation ($P < 0.0005$). In addition, significant decreases were found in terms of pain ($P = 0.002$), fatigue ($P = 0.002$) and anxiety ($P = 0.002$).

To be considered worthwhile and attractive to health care purchasers and patients alike, the benefits accruing from self-management programmes should persist over extended periods of time. Nevertheless, according to Lindroth *et al.* [13], long-term evaluations of arthritis patient education are rarely conducted. Of 15 evaluations of psycho-educational interventions included in a meta-analysis, only two studies used follow-up of longer than 20 weeks [14]. Long-term, non-randomized, evaluations of the ASMP in the USA have found that the effects of the intervention remained evident at 20 months [15] and at 4 yr [3]. Thus, despite a slight increase in disability, participants experienced sustained benefits in terms of perceived control, pain and visits to physicians.

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The purpose of the present study was to determine whether the significant improvements observed at 4 months among a cohort of participants attending the ASMP in the UK [12] are maintained over a longer period of time (i.e. at 12 month follow-up).

PARTICIPANTS AND METHOD

Participants

The original sample was recruited by Arthritis Care, the largest voluntary arthritis organization in the UK, utilizing various approaches, including advertising through the Arthritis Care branch network, information placed in GP practices and rheumatology departments, and public service announcements in local media. Entry criteria were: (i) age \geq 18 yr; (ii) ability to complete the questionnaire; (iii) a diagnosis of arthritis from the participant's GP. Of the 176 people who enrolled on the ASMP, 146 completed questionnaires at baseline (prior to attendance at an ASMP), 117 responded at 4 months and 124 responded at 12 months. There was a final sample size of 112 who returned questionnaires at baseline and 4 month and 12 month follow-up. Analysis is restricted to those participants who completed questionnaires at all assessment periods. No statistically significant differences were found on any demographic or study variables between participants who completed all study assessments and those who did not, although responders had their arthritis diagnosed later in life than non-responders (mean ages = 49 and 42 yr, respectively; $P = 0.032$).

Method

The Arthritis Self-Management Programme. The ASMP is delivered over 6 weeks in 2 h weekly sessions and course content is guided by a strict protocol. Course leaders, many of whom have completed the course, are trained by Arthritis Care. Topics include information about arthritis, an overview of self-management principles, exercise, pain management, depression, nutrition, communication with family and health professionals, and contracting. The ASMP was delivered in community settings (e.g. church halls, community centres), on a nationwide basis over a period of 11 months.

The study was a pre-test post-test design with multiple baselines. Data were collected via self-administered questionnaires mailed to participants at three points in time: prior to attending the ASMP (baseline), and 4 months and finally 12 months after completion of a course.

Measures. Many of the standard measuring instruments selected have been used in previous studies of people with arthritis. The primary outcome measure was that of arthritis self-efficacy, defined as the individual's confidence in their perceived ability to control, or manage, various aspects of arthritis (e.g. pain). Secondary outcome measures were physical and psychological well-being, and the use of behavioural and cognitive techniques for coping with arthritis. The questionnaire included the following.

Demographic information and arthritis-related information were collected at baseline only. Two subscales of the Arthritis Self-Efficacy Scale [16], Arthritis Self-Efficacy: Pain (five items) and Arthritis Self-Efficacy: Other Symptoms (six items), validated for use in the UK [17] were used to assess perceived control. In this context, perceived control of arthritis is defined as the individual's confidence in their perceived ability to control, or manage, various aspects of arthritis, with higher scores indicating greater perceived control. Behavioural and cognitive techniques for managing arthritis (e.g. exercise, cognitive symptom management and communication with physicians) were assessed using scales specifically designed for use in evaluations of the ASMP [6, 8]. Exercise was assessed in terms of the range of exercises performed (e.g. flexibility, strengthening, walking, swimming, relaxation) using a simple yes/no response. Cognitive symptom management (five items) and communication with physician (five items) were assessed using scales with each item rated on a six-point scale (0–5) anchored by 'never' and 'always'. Cognitive symptom management assesses how often a person adopts techniques such as visualization to cope with arthritis symptoms. Communication with physician measures perceived effectiveness of the physician/patient consultation; items include: 'How often do you ask questions about the things you don't understand about your treatment?'. Scores for each scale are summed to produce total scores of 0–25. Higher scores indicate greater use of cognitive techniques and improved communication with the physician.

Physical functioning was assessed by the Health Assessment Questionnaire (HAQ), as modified for use in the UK [18]. Scores range from 0 to 3, with higher scores indicating impaired physical functioning. 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' [19].

Psychological well-being was assessed in terms of anxiety, depression, positive and negative affect, and acceptance of illness. The Hospital Anxiety and Depression Scale [20] is a brief self-report measure that provides separate scores for anxiety and depression. Scores range from 0 to 21, with higher scores indicating greater anxiety and greater depression. The Positive and Negative Affect Scale [21] consists of 20 adjectives used to describe positive and negative feelings, and emotions. Higher scores indicate greater positive and negative states. The present study included the Acceptance of Illness Scale [22] to measure the degree to which participants were able to accept their illness. Pilot testing revealed that one of the eight items, 'My health does not make me feel inadequate', posed problems for participants. Reliability tests and factor analyses suggested that the psychometric properties could be improved if this item were omitted. The reliability coefficient for the scale comprising the remaining items was 0.887. Subsequently, the mean of these seven items was taken as the measure of

acceptance, with higher values denoting a greater degree of acceptance.

Questions included at baseline and 12 month follow-up assessed health care visits (e.g. visits to GP, GP visits where arthritis was discussed, visits to rheumatologist and visits to other health professionals) using a time frame of 'during the past 4 months'. These questions were not asked at 4 months because it was felt that health care visits should be assessed at comparable times of the year in order to minimize the effects of seasonal bias. Hence, comparison of health care visits was conducted across baseline and 12 months only. Owing to the evidence of positive skewness, a square root transformation was applied to render normality for comparative analyses of visits to GP, GP visits where arthritis was discussed and visits to rheumatologist.

An open question was included in the 12 month follow-up which enabled participants to report their views concerning their experience of the ASMP.

Analysis. The Statistical Package for the Social Scientists (SPSS) for Windows 6.1 (1994) was used to perform all analyses on the quantitative data. Comparisons for all study variables (excluding health care visits) were made across the three points in time, using repeated measures, with emphasis between 4 month and 12 month values to determine whether there had been a significant deterioration in improvements reported at the earlier assessment period. These analyses were repeated with disease duration as a covariate; since no differences were found in the results with and without the covariate, the former analyses are reported here. Paired *t*-tests were used to compare use of health care resources (e.g. visits to GP) across baseline and 12 months.

The proportions of participants who carried out exercise activity during the month prior to the 4 month and 12 month assessment periods were compared using McNemar's test. Similar analytical procedures were used to examine change on visits to other health professionals. Repeated measures analyses and McNemar tests were used, as appropriate, to compare the study variables across the two common types of arthritis [i.e. rheumatoid arthritis (RA) and osteoarthritis (OA)]. The level for interpreting statistical significance was set at 1% throughout to restrict the Type 1 error for the study as a whole.

RESULTS

The sample was predominantly female (82%), with a mean age of 59.6 yr, mean disease duration of 14.9 yr and a relatively high score on the HAQ (mean 1.57), indicating substantial physical disability. The majority of participants had a GP-recorded diagnosis of either RA (46%) or OA (44%). Four participants with OA had an additional rheumatic disease. Fifty-eight per cent reported other health problems (e.g. irritable bowel syndrome, heart complaints). Participants' characteristics are presented in Table I.

Diagnostic concordance between GPs and ASMP participants was evident in the majority of cases (88%).

TABLE I
Participant characteristics at baseline ($n = 112$)

Variable	Mean	S.D.	Range
Age (yr)	59.6	12.4	33–89
Duration of disease (yr)	14.9	11.1	1–49
Health Assessment Questionnaire (HAQ)	1.57	0.77	0–3
Gender: women	82%		
Type of arthritis (GP-recorded diagnosis)	46% RA 44% OA 10% other*		
Co-morbidity	58%		
Registered disabled	40%		
Educational qualifications	50%		
Married/living with partner	54%		

RA, rheumatoid arthritis; OA, osteoarthritis.

*Other types of arthritis include scleroderma and psoriatic arthritis.

Participants were recruited through information distributed in Arthritis Care's branch network (64%), rheumatology departments (17%), GP surgeries (10%) and the general public (9%).

Mean scores on variables at baseline, 4 months and 12 months are presented in Table II. Compared with baseline values, significant positive effects were reported both at 4 months and at 12 months, with no significant deterioration between 4 months and 12 months, on Arthritis Self-Efficacy: Other Symptoms ($P < 0.0005$, $P < 0.0005$, $P = 0.685$), Arthritis Self-Efficacy: Pain ($P < 0.0005$, $P < 0.0005$, $P = 0.788$) and Cognitive Symptom Management ($P < 0.0005$, $P < 0.0005$, $P = 0.731$). Continuous improvement was seen on Communication with Physician ($P = 0.002$, $P < 0.0005$, $P = 0.031$). The proportion of participants continuing to perform relaxation and flexibility exercises remained stable at 12 months, although a trend towards fewer participants carrying out strengthening exercises at 12 months (70% compared to 86% at 4 months; $P = 0.039$) was noted. A trend towards increased scores on the HAQ between 4 and 12 months was observed (means = 1.52 and 1.59, respectively; $P = 0.016$). Significant mean decreases at 4 months compared with baseline, with no significant change between 4 months and 12 months, were found on Pain ($P = 0.006$, $P = 0.868$), Fatigue ($P = 0.003$, $P = 0.477$) and Anxiety ($P = 0.004$, $P = 0.406$). Further, a significant decrease between baseline and 12 months was found on Anxiety ($P = 0.002$). Use of formal health care resources remained unchanged throughout the 12 month study period. The mean number of GP visits and rheumatology visits were similar at baseline (2.7, 0.71) and 12 months (2.5, 0.72).

A comparison of changes from baseline to 4 months and baseline to 12 months, with respect to participants reporting/not reporting co-morbidity, showed no significant differences on any study variable. A similar comparison with respect to participants with/without formal education revealed one significant difference in terms of change on mean physical disability score.

TABLE II
Comparison of study variables at three time points and between 4 months and 12 months

Study variables (range)	Baseline Mean (S.D.)	4 months Mean (S.D.)	12 months Mean (S.D.)	P values Repeated measures analysis 4 months–12 months
Arthritis Self-Efficacy:	32.56	37.32	36.94	0.685
Other Symptoms (6–60)	(12.15)	(10.79)***	(11.09)***	
Arthritis Self-Efficacy: Pain (5–50)	22.95 (10.31)	28.01 (9.19)***	28.21 (9.66)***	0.788
Cognitive symptom management (0–25)	7.25 (4.07)	10.24 (4.28)***	10.30 (5.39)***	0.731
Communication with physician (0–25)	12.92 (5.46)	14.06 (5.86)**	15.05 (6.29)***	0.031
Health Assessment Questionnaire (0–3)	1.57 (0.77)	1.52 (0.72)	1.59 (0.74)	0.016
Pain (0–10)	6.42 (2.60)	5.80 (2.49)**	5.84 (2.74)*	0.868
Fatigue (0–10)	6.61 (2.61)	5.93 (2.72)**	6.10 (2.69)	0.477
Acceptance (1–5)	2.91 (1.06)	3.05 (0.94)*	3.08 (1.0)*	0.680
Anxiety (0–21)	9.37 (4.44)	8.84 (4.58)**	8.51 (4.21)**	0.406
Depression (0–21)	6.77 (3.83)	6.35 (3.52)*	5.95 (3.52)**	0.113
Negative affect (10–50)	19.60 (9.07)	19.51 (8.76)	18.56 (7.85)	0.208
Positive affect (10–50)	29.72 (7.55)	30.13 (7.53)	31.04 (7.86)	0.388

Significant improvements compared to baseline: * $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

Participants with no formal education reported a slight decrease on physical disability from baseline to 12 months, whereas participants with formal education reported a slight increase (mean change scores -0.0842 , 0.1250 , respectively; $P = 0.002$).

The study variables were compared across the two common types of arthritis: RA and OA. At baseline, participants with OA were significantly older than participants with RA (mean ages = 65 and 56 yr, respectively; $P < 0.0005$) and were older when diagnosed (mean ages = 54 and 45 yr, respectively; $P = 0.002$). Statistically significant differences were found on only two study variables: the HAQ and visits to rheumatologist. Participants with RA had significantly higher mean scores on the HAQ compared to participants with OA (mean scores 1.88 and 1.29, respectively; $P < 0.0005$), indicating greater physical disability, and reported more visits to rheumatologists during the 4 months prior to baseline (mean number of visits 1.14 and 0.233; $P < 0.0005$). There were trends towards participants with OA having improved scores on disease acceptance ($P = 0.018$) and positive affect ($P = 0.026$). Change over time was not significantly differentiated by type of arthritis, although there was a weak trend towards a decrease in negative affect between 4 months and 12 months for RA only; scores for OA participants remained stable [$F(1, 92) = 4.06$, $P = 0.047$].

Analysis of the open question confirmed that many participants felt that the ASMP was instrumental in helping them regain some degree of control over their lives. A quote from one of the participants highlights the need for the course to be made available to newly diagnosed patients: 'I strongly believe that if I had undertaken such a course at the onset of my illness then I might have been able to cope better, both emotionally and physically'.

DISCUSSION

The findings from this first long-term evaluation of the ASMP delivered in the UK have demonstrated

that the positive benefits of the intervention can be sustained over an extended period: many of the improvements reported at 4 months [12] remained evident at 12 months.

Although a trend towards an increase in mean scores on the HAQ between 4 months and 12 months was noted, the 12 month score did not differ significantly from baseline. Physical disability, as indicated by the HAQ, is generally considered to increase with age and disease duration; consequently, a relatively stable HAQ score, over the 12 month assessment period, arguably indicates a therapeutic effect. The fact that the HAQ was the only study variable to be influenced by education was intriguing and warrants further investigation.

A major concern for people with arthritis is the presence of chronic and acute pain [23]. The results from this study show that the small but significant reduction in pain reported at 4 months remained evident at 12 months, and is consistent with other long-term ASMP evaluations [3, 13]. Randomized controlled studies of arthritis patient education programmes similar in content to the ASMP have reported no significant reduction in pain in the intervention group compared to the control group after 12 months [2] and 14 months [4]. It should be noted that both Lindroth *et al.* [2] and Taal *et al.* [4] modified the original ASMP, using health professionals rather than lay tutors, and limited recruitment to medical settings. Further, Taal *et al.* recruited only RA patients, and Lindroth *et al.* held separate classes for RA and OA patients. These structural differences may lead to variation in outcomes. The underlying reasons for the difference in long-term effects of patient education on pain remain to be elucidated.

In a 20 month study of the ASMP in the US, Lorig and Holman [15] found that participants reduced physician visits by 35%. Similarly, older adults in the UK made fewer visits to their GP after attending an ASMP, at least in the short term [6]. The results from this study show that the mean numbers of GP and rheumatology visits were similar at baseline and 12

months. It is not clear whether this difference in findings results from the differing health care systems operating in the US and UK, the latter being free at the point of delivery. Nonetheless, participants felt better able to communicate effectively with health care practitioners. Further studies are needed to determine whether the nature of visits changes (i.e. in terms of fewer prescriptions) after attending the ASMP.

Neither disease duration nor co-morbidity appeared to influence outcomes. Equally, participants with RA did not differ significantly from participants with OA on any study variable in terms of change following the ASMP, suggesting that participants derive similar benefits from the course irrespective of their type of arthritis. These findings confirm that introducing general techniques and skills in the context of a group programme can cross diagnostic boundaries. Common denominators and key targets of the programme are managing chronic pain (through other means than medication), fatigue and symptoms of depression rather than management of pathological disease parameters.

A number of caveats need mentioning. Given the lack of a randomized control group, the positive results reported here should be viewed with caution. Although the greater proportion of women in the sample is in accordance with the higher incidence of most types of arthritis amongst women, the combination of a predominantly female sample who were recruited mainly from Arthritis Care's branch network limits generalizability. Nevertheless, the findings are broadly consistent with other ASMP evaluations [8] and add to the growing body of evidence suggesting that people with arthritis derive considerable long-term benefits from the community-based programme.

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