An 8-yr follow-up of Arthritis Self-Management Programme participants

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Objectives. To examine the pattern of scores on self-efficacy, health status and use of self-management techniques among a group of Arthritis Self-Management Programme (ASMP) participants over an 8-yr period, and to describe participants’ perspectives of the ASMP and current use of self-management.

Methods. Data from 125 participants who attended the ASMP as part of a randomized controlled trial and completed assessments at baseline, 4-month and 8-yr follow-ups were entered into the analysis. A sub-sample of 10 participants (five high- and five low self-efficacy) was interviewed.

Results. The sample was 87% female; mean age 65 (s.d. 12) yrs; mean disease duration 19 (s.d. 11) yrs; 48% RA; 48% OA. The overall pattern of scores showed improvements between baseline and 4 months, which appeared to be maintained at 8-yr follow-up on self-efficacy, positive and negative affect, anxious and depressed moods, pain and fatigue, cognitive symptom management and communication with physician. The exception was HAQ, which was stable from baseline to 4 months (as expected), but had increased at 8 yrs indicating a decline in physical functioning. Sub-group analyses by RA and OA showed similar patterns of results. Interviews revealed that some participants continued to have problems with disease acceptance and highlighted the importance of pre-course expectations.

Conclusions. Long-term maintenance of self-efficacy, psychological well-being and self-management techniques may be possible following attendance on the ASMP. The need for additional psychological support for those who are having difficulty adjusting to their condition and its consequences is highlighted.

Key words: Arthritis, Self-efficacy, Self-management, Psycho-educational intervention.

Introduction

The potential advantages of including psycho-educational interventions in treatment options for arthritis have been recognized [1]. Psycho-educational programmes can be a useful method for enhancing self-management techniques and improving physical and psychological health outcomes among people with arthritis [2–7]. A Cochrane review of patient education for people with RA reports small but statistically significant short-term effects on disability, joint counts, patients’ global assessment and psychological well-being [8]. A comprehensive review of self-management education programmes in chronic disease (e.g. diabetes, asthma) found trends towards reductions in pain and disability for arthritis education programmes [9]. However, self-efficacy and psychological outcomes were not examined as these variables were rarely assessed in the original studies. A meta-analysis of exercise and self-management for patients with knee OA found that benefits were mostly in the psychosocial domain [10].

One lay-led, community-based intervention designed for people at the mild to moderate end of the disease spectrum is the Arthritis Self-Management Programme (ASMP) [11]. The ASMP has been delivered in a number of countries and aims to enhance participants’ sense of confidence in their ability to employ appropriate self-management skills to meet their needs. The ASMP consists of six sessions of 2-h durations every week delivered in community settings by pairs of lay leaders who have arthritis themselves. Topics covered include an overview of self-management principles, information about arthritis, exercise, cognitive symptom management, depression, communication with health professionals and goal setting. The ASMP is based on the theory of self-efficacy [12] and incorporates self-efficacy-enhancing strategies including mastery experience, modelling, persuasion and re-interpretation of physiological state.

In the UK, the ASMP has been delivered by a voluntary organization (Arthritis Care). Randomized controlled trials (RCTs) have shown the ASMP to be effective at 4 and 12 months in terms of self-efficacy, self-management behaviours and psychological well-being [6, 7]. However, in contrast to studies conducted in the USA [11], there is little or no change in use of healthcare resources. Qualitative studies have revealed that the ASMP provides participants with the ‘tools’ to make changes in the way they manage their condition [13], which may have important implications for health-related quality of life, and ability to maintain employment or independent living, for example, in the longer term.

In order for interventions to be perceived to be beneficial, effects need to be sustained over time. However, few studies have investigated long-term impact. One difficulty with longitudinal studies is finding a suitable control group. Thus, long-term follow-up studies tend to be uncontrolled or focus on intervention group participants of previously conducted RCTs. A long-term, non-randomized, evaluation of the ASMP in the United States found that the positive effects on pain and depression remained evident at 4 yrs despite an increase in disability [3]. A 2-yr translational study of the ASMP conducted in Australia [14] reported sustained improvements in health status (e.g. reduced levels of pain, fatigue and health distress). A 5-yr controlled follow-up study of a different approach (i.e. a professionally led arthritis education programme) in Australia found that disability remained stable and perceptions of control improved between 1-yr and 5-yr follow-up among the intervention group [15]. Thus, there are indications of potential longer term effects for the ASMP and similar programmes.

The present study is an 8-yr follow-up of a group of participants who attended the ASMP as part of an earlier RCT [6]. The aim was to examine the pattern of scores on self-efficacy, health status, use of self-management techniques and use of healthcare resources from baseline (before attending the ASMP) and 4-month and 8-yr follow-ups. An additional aim was to...
describe participants’ perspectives of the ASMP and current use of self-management via interviews 8 yrs after attendance.

Sample and method

Multi-centre ethics committee approval was obtained. Twenty-nine of the original 311 RCT Intervention Group participants were traced as deceased; thus, 282 questionnaire packs containing a consent form, patient information sheet, a follow-up questionnaire and stamped addressed envelope were distributed by post. A total of 125 respondents provided written consent and returned completed questionnaires; 47 packs were returned as ‘addressee unknown’; 19 declined; and no response was received from 91 giving a response rate of 44%. Data were collected by self-administered postal questionnaires at each assessment.

Measuring instruments

Self-efficacy. This was assessed using two subscales of the Arthritis Self-Efficacy Scale (ASE) [16] [i.e. ASE: Pain (5 items) and ASE: Other Symptoms (6 items)], validated for use in the United Kingdom [17]. Each item is rated on a 10-point scale (1–10), scores are summed and higher scores indicate greater perceived ability to control various aspects of arthritis.

Use of self-management techniques. Self-management techniques were assessed using scales developed at the Stanford Arthritis Centre [18] and covered cognitive symptom management, communication with physicians and exercise. Exercise-related activities (e.g. walking) were assessed on a four-item scale by asking how many days each activity was performed in the past week. ‘Cognitive symptom management’ (CSM) assesses how often a person adopts techniques, such as visualization, to cope with arthritis symptoms. ‘Communication with physician’ (CWP) measures perceived effectiveness of the physician–patient consultation. Both are five-item scales with each item rated on a six-point scale (0–5) anchored by ‘never’ and ‘always’. Scores for each scale are summed, with higher scores indicating greater use of cognitive techniques and more effective communication.

Health status. The HAQ [19] was used to assess physical functioning. This short scale covers performance of daily activities, including dressing, walking and eating. Scores range from 0 to 3, with higher scores indicating impaired physical functioning. Scores of 0–1 are generally considered to represent mild to moderate difficulty, 1–2 moderate to severe disability and 2–3 severe to very severe disability [20]. This was included in the original RCT as an indicator of physical functioning only; no change was expected in the short time period of the original RCT. Pain and fatigue were measured separately with standard 10 cm horizontal visual analogue scales (VAS) [21].

Psychological well-being. This was assessed using the Hospital Anxiety and Depression Scale (HADS) [22] and the Positive and Negative Affect Scale (PANAS) [23]. The HADS is a brief self-report measure that provides separate scores for anxiety and depression and severity of relatively mild degrees of mood disorder in non-psychiatric, hospital outpatients. Scores range from 0 to 21, with higher scores indicating greater anxiety and greater depression. The PANAS comprises 20 adjectives used to describe positive and negative feelings and emotions. Each item is rated on a five-point scale (1–5) and relevant scores are summed to give separate total scores (range 10–50) for positive and negative affect. Higher scores indicate greater positive affect and greater negative affect.

Use of healthcare resources. ‘Visits to the GP’ and ‘GP visits where arthritis was discussed’ were assessed using a time frame of ‘during the past 4 months’. Number of visits to a rheumatologist and allied health professional visits within this time frame were also assessed.

Interviews

The 11 ASE items were summed and percentiles calculated. Purposive selection of a sub-sample of 10 participants aimed to achieve a mix of males and females, RA and OA, and variation in age from among those within the lowest and highest self-efficacy percentiles. Five participants from the lowest and five from the highest percentiles were identified and agreed to be interviewed by telephone. Interviews were tape-recorded, subject to the permission of each participant, and the content was transcribed verbatim. An interview schedule was developed based on that used previously in a similar study [13]. Topics covered included the experience of attending the ASMP with reference to current practice of self-management and perceived benefits.

Analysis

Data were analysed using the Statistical Package for the Social Sciences version 15.0 [24]. The level for interpreting statistical significance was set at 1% to allow for Type I errors, and two-tailed tests were used. Ninety-nine per cent CIs were computed for mean scores at each time point, and change in scores between 4-month and 8-yr follow-ups were compared using repeated measures analysis of covariance (ANCOVA), with baseline values and communication with physician used as covariates, as there was a statistically significant difference (P < 0.001) in this last variable between responders and non-responders at baseline [25, 26]. Visits to the GP and health professionals, and how many times arthritis was discussed were described by median and range. Exercise activities were explored over the three time periods and changes compared using Cochran’s Q-test. Analyses were performed to compare the consistency of findings across responders with RA and OA.

Interview data were analysed using thematic content analysis. Researcher bias was minimized through regular cross-checking of data and findings. Transcripts were identified by code numbers. Analysis was conducted without knowledge of scores on study variables including self-efficacy.

Results

The sample was mainly female (87%), married/living with partner, had a comorbid condition (80%), with a mean age of 65 (S.D. = 12) yrs, disease duration 19 (S.D. = 11) yrs and the majority of participants had either RA (48%) or OA (48%) (Table 1). The overall pattern for self-efficacy, health status and use of self-management behaviours showed an improvement between baseline and 4 months followed by maintenance of improvements at 8-yr follow-up (Table 2), although at 8 yrs improvements on

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some variables were attenuated. Statistically significant improvements at 8 yrs were increased for anxiety \((P = 0.004)\). However, HAQ scores showed maintenance from baseline to 4 months, but were increased at 8 yrs \((P < 0.001)\), indicating a decline in physical functioning in the longer term.

Exercise activities were recoded to indicate taking part in walking, swimming, cycling or relaxing on some, or on three or more days in a week. There was an overall increase in walking over the three time points, with 71% of the participants reporting walking on \(>3\) days/week for exercise at 8 yrs \((P = 0.013)\). The increased use of relaxation techniques on \(>3\) days in a week from 22% at baseline to 34% at 4-month follow-up was not maintained by the 8-yr follow-up \((P < 0.001)\), although it was still higher at 28% than at baseline. The proportion of participants cycling and swimming was low at all time points (Fig. 1).

There were no significant changes in visits to GP (median = 2, range 0–17) or health professionals (median = 0, range 0–11) in the previous 4 months over the three time periods. At baseline, participants discussed arthritis at these GP visits twice on average (median = 2, range 0–12). At subsequent time points, this average reduced to once (range 0–17).

There was a statistically significant difference at baseline in HAQ \((P < 0.001)\) between participants with RA and OA, mean (s.d.) for RA being 1.7 (0.7) and 1.2 (0.7) for OA. Sub-group analyses showed a similar pattern of results as for the main analyses.

**Interviews**

**High- and low self-efficacy.** Two researchers blinded to participants’ SE status correctly identified high and low self-efficacy participants from interview transcripts. The main difference between high and low SE participants concerned pre-course expectations: three low SE participants were ‘disappointed’ as they had expected the ASMP to provide a ‘quick fix’, medical solution to their arthritis or a treatment.

But it wasn’t what I was looking for at that time. They didn’t say “take this pink pill once a day and you won’t HAVE arthritis any more”. I wanted it desperately to be like that.

—Low SE 3

Two low SE participants had enjoyed meeting similar others and at 8-yr follow-up were using some of the techniques learned on the ASMP. In contrast, three low SE participants felt they had not learned anything new as they were already using a number of self-management techniques, such as pacing, deep breathing, relaxation and exercise. Two low SE participants felt the positive, upbeat atmosphere of the course invalidated ‘real’ problems that they felt could not be overcome and they continued to have problems accepting their condition.

I found the upbeat optimism irritating. It seemed as though they didn’t want to acknowledge that we’ve had our lives ruined by this (arthritis).

—Low SE 5

It still makes me quite, angry is too strong a word now, but I still feel very distressed by the fact that it’s there . . . my perception of self as a disabled person makes me grind my teeth with fury, and the stigma that’s attached to it.

—Low SE 3

The youngest participant struggled to accept his arthritis and felt that the symptoms and resultant emotional distress prevented him from fulfilling his role within the family.

I suppose at that age I was thinking ‘oh I’ll be all right, it won’t get any worse.’ It was just one of those things that
I had to come to terms with and accept, and now, with it getting worse I can’t accept. I’m still only 42 and I’m going through this.

—Low SE 4

The other main themes to emerge were consistent across both high and low SE participants and are presented below.

Recall of ASMP attendance. Despite the 8-yr period since attending the ASMP, participants found it easy to recall their experiences of the course. They had valued being with similar others, which reduced their sense of isolation, enabled reciprocal encouragement, support and practical tips, and led to increased acceptance of the limitations and problems associated with arthritis.

I thought the course was absolutely wonderful ... It helped me to get out of the house. What I found about other people was that most of them had had arthritis much longer than I had and they were great at giving tips. Not only did you learn from the people who were doing the official course, there was a lot of interaction between people.

—High SE 10

Probably meeting people that were in the same boat as I was ... I suppose when you’re in one room with other people that suffer from it you don’t feel quite so bad.

—Low SE 4

Participants not only gained a renewed sense of hope and purpose in their lives but also learned some practical self-management techniques. For example, goal setting was instrumental in helping participants to make small, sustained improvements in exercise, healthy eating, relaxation, depression management and the pacing of activities.

Because before you didn’t have any future. It was blank. Automatically, I use quite a lot of them (self-management techniques) now. I still get depressed but I realize why now, and I know that if I don’t get myself motivated then I’m going into the pain cycle. It gave me a set of goals. I’d never set myself goals in my life before.

—Low SE 2

I try to ensure that I do some exercise, eat more healthily. I know my medication, I have a better rapport with my GP. I mean he regards me as an expert on arthritis as opposed to him being an expert.

—High SE 6

Several participants felt more in control of their condition and life after attending the course. Some acknowledged that there were things that they could not do; however, they no longer felt like victims.

Don’t let arthritis decide what you’re going to do. YOU decide, you take control. I came away thinking “right, get on with it, let’s sort it” and I do to the best I can.

—High SE 8

Many participants valued the fact that the tutors had arthritis themselves, which gave tutors ‘authority’, credibility and ‘real understanding’. However, the two male participants found it hard to empathise with others on the course whose conditions were viewed as ‘very different’ from their own. One male was considerably younger than other course attendees and at 8-yr follow-up and he speculated that he may gain more from attending the course now that his condition had worsened.

I suffer from it a lot more now and I’m in a lot more pain. I can probably empathise with other sufferers a lot more than I could then.

—Low SE 4

Social comparison

Social comparison with tutors and other participants by witnessing others who were worse off and seeing others worse off but coping well emerged as a key factor in the group process that had helped participants to re-evaluate their situation and to shift the focus from their own problems and to something more positive such as exercise.

... the two ladies that run the courses—one was in a wheelchair and the other had quite severe disabilities with the rheumatoid. And you think ‘well, I’ve got to snap out of this’. They’re doing this and look at the state of them and yet they’re having a life.

—Low SE 2

When you go to a group that’s suffering from the same illness then you can compare notes and you can see that things do get better ... it makes you look towards other people rather than inwardly all the time.

—High SE 7

Acceptance. Some participants found that the information and support provided on the course enabled them to more readily accept their condition and they were better able to cope.

It really gave you an insight into the condition you were suffering and you could understand it a bit so, therefore you were more likely to accept it ... and that’s a very hard thing to accept, because it’s a major change in your life.

—Low SE 2

I don’t get so upset about it now. At first I was really cross and upset, angry more than anything ... but yes, it helps you to cope with that.

—High SE 7

Discussion

The overall pattern of scores across the 8-yr period suggest that short-term improvements on self-efficacy, use of some self-management techniques and psychological well-being (i.e. anxiety and depression) appeared to be sustained in the longer term among this sample of ASMP attendees despite a decline in physical functioning. Similar findings were noted in a 4-yr follow-up of the ASMP, which reported improvements on pain and depression despite an increase in disability [3]. A decline in physical functioning over an 8-yr period among a sample of people with a mean age of 65 yrs may be expected and is consistent with other longitudinal studies of people with RA [27, 28] and OA [29]. For example, a 5-yr study of people with RA [30] starting on DMARDs reported a baseline mean score of 1.64 with improvements at 1 yr followed by a gradual return to baseline after 5 yrs. Similarly, an RCT of RA patients randomized to receive adequate symptom control/shared care setting or aggressive hospital treatment [31] found a significant deterioration in HAQ score (i.e. 1.28–1.43) in both arms of the trial after 3 yrs.

Maintenance of improvements cannot be attributed to the ASMP given the lack of a control group at 8-yr follow-up. In addition, the sample will have received healthcare over the 8-yr period. Nonetheless, there were indications that the ASMP may be of value to some participants in the longer term. For example, some interview participants reported using the techniques learned on the ASMP to help manage their condition (e.g. goal setting, walking for exercise).

Interview participants were able to easily recall their experience of ASMP attendance despite the gap of 8 yrs. Such recall has been linked to emotionally salient events [32] suggesting that for some, ASMP attendance was a significant event and was indicated in the
data where some participants talked about not having a future before the ASMP, for example. The main difference between high and low self-efficacy interview participants concerned pre-course expectations with low self-efficacy participants expressing disappointment that the ASMP was not a medical treatment or instant cure. The latter unrealistic expectation is consistent with wishful thinking (a type of passive, emotion-focused coping) and accords with the difficulties in accepting their condition and its psychosocial consequences reported by several low self-efficacy participants. This suggests that there may be a need to address illness representations before some participants are able to fully engage with the ASMP and also that some people with arthritis need more psychological support than can be provided in a short, lay-led intervention. Longitudinal studies of people with early RA have reported that a minority remain at risk for adjustment problems in terms of depression and anxiety [33] and emotional distress [34].

Regardless of the level of self-efficacy, most interview participants reported benefits that accord with other studies of the ASMP [13] and the related generic Chronic Disease Self-Management Course [35] including renewed hope, an increased sense of control, meeting similar others and reduced isolation. Many felt that the ASMP had benefited them in ways that may not be reflected in the typical outcome variables used in quantitative studies. For example, inspirational modelling, social validation, social connectedness and social comparison appeared to assist participants in accepting their condition and development of a positive attitude. However, three low self-efficacy participants had not learned anything new on the ASMP as they were already using a number of self-management techniques prior to course attendance. This finding has been reported in the context of the Chronic Disease Self-Management Programme [35]. A strengths-based approach building on existing self-management capacity may be an appropriate alternative style of intervention worthy of exploration.

Regarding exercise, data from 21 countries have shown that only a minority (i.e. 13.8%) of the patients with RA participate in physical activity on three or more days a week [36]. However, a 16-yr longitudinal study has shown that older adults who take up exercise even in later life can experience benefits in terms of postponement of disability [37]. In the study reported here, walking for exercise showed an overall increase, although few participants made use of cycling or swimming at any of the three time points. The ASMP encourages participants to take up appropriate exercise in order to maintain and improve strength, flexibility and endurance and to seek professional advice if they have concerns over the suitability of exercise activities for their own condition. An additional module focusing on appropriate exercise activities may be needed and is likely to benefit from professional input combined with the goal-setting strategies used on the ASMP.

Limitations of the study include the lack of a control group and the potential bias towards those who may have been keen to report and discuss their ASMP experience. Although the response rate was as may be expected in an 8-yr follow-up, a more systematic way of obtaining long-term follow-up data of past ASMP participants would be welcome but difficult to establish where course delivery is via community-based organizations rather than the relative stability of a hospital outpatient clinic. Implementation studies that follow participants over time and are not limited by the rigorous criteria of RCTs may be useful in this regard and would enable regular assessment of a cohort of participants over time.

In conclusion, long-term maintenance of self-efficacy, psychological well-being and self-management techniques may be possible following attendance on the ASMP. There may be a need for additional psychological support for those who are having difficulty accepting their condition and its consequences.

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### Rheumatology key messages

- Attendance on ASMP may lead to long-term maintenance of changes in health beliefs, psychological well-being and self-management techniques.
- Additional psychological support may be required for some arthritis patients.

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### Disclosure statement

The authors have declared no conflicts of interest.

### References

Follow-up of ASMP participants