Factors limiting participation in arthritis self-management programmes: an exploration of barriers and patient preferences within a randomized controlled trial

Ilana N. Ackerman¹, Rachelle Buchbinder²,³ and Richard H. Osborne⁴

Abstract

Objective. To improve understanding of barriers to participation in community-based arthritis self-management programmes and patient preferences for self-management education.

Methods. Individuals with hip or knee OA referred to orthopaedic surgeons or rheumatologists at six public and private hospitals in Victoria, Australia, were recruited for a randomized controlled trial (RCT) of the Stanford Arthritis Self-Management Programme (ASMP). As part of the study design, potential participants were asked during the screening and recruitment process about reasons for being unable to attend the course, reasons for not participating in the study and individual preferences for course scheduling.

Results. Of 1125 individuals assessed, 216 (19%) were unable to attend six ASMP sessions. This was commonly due to physical limitations, including illness, restricted mobility and pain (22%), difficulty getting to or from courses (22%), work commitments (22%), the time commitment required (17%) and family roles (12%). Among those who did not want to participate in the study (n = 258), the overwhelming reason was disinterest (74%). Specific preferences for course scheduling were frequent, confirming the practical challenges faced in organizing courses for the RCT.

Conclusion. Incorporating patients from public and private settings, this study has elicited new insights into barriers to ASMP participation. Many people with hip or knee OA have limited capacity and motivation to attend community-based group programmes. Future self-management programmes and research should include more accessible options for those who cannot attend group-based programmes.

Trial registration. Australian New Zealand Clinical Trials Registry, http://www.anzctr.org.au/, ACTRN12606000174583.

Key words: patient education, health services accessibility, osteoarthritis, patient preference.

Introduction

Arthritis self-management education programmes such as the Stanford Arthritis Self-Management Programme (ASMP) endeavour to teach people to effectively manage their arthritis. ASMPs are recommended as part of OA clinical guidelines [1, 2]; however, uptake of these programmes has been limited [3, 4]. Poor attendance rates are also concerning, as highlighted by a large study from the UK where almost 30% of participants randomized to receive a 6-week ASMP did not attend any sessions [5]. In an Australian study of self-management support for severe arthritis, Crotty et al. [6] reported that only 52% of the intervention group pursued the option of a 6-week self-management programme conducted through the local arthritis foundation. Although ASMPs are commonly available through arthritis organizations and community health centres in Australia, it remains unclear whether the 6-week,
community-based model represents an attractive or feasible option for people with OA.

We recently completed the first Australian randomized, controlled trial (RCT) of the Stanford ASMP for people with hip or knee OA. As described previously [7], slow recruitment and ongoing pragmatic challenges led to the premature closure of recruitment before reaching the target sample size. Based on the literature and anecdotal information, we had anticipated potential recruitment difficulties and planned a priori to systematically investigate reasons for inability to attend or disinterest in attending an ASMP within our RCT [8]. This information could be used to optimize access to effective arthritis self-management programmes and aid the design of new models of education capable of reaching more people with OA. The setting of this study provided an ideal opportunity to examine accessibility given the use of four public and two private hospital sites, including one regional hospital. This meant that the recruitment pool comprised patients from a range of socioeconomic and cultural backgrounds. The aim of this substudy was to explore barriers to participation in a 6-week, community-based ASMP among people with hip or knee OA, and preferences for course scheduling and format.

Methods

Study design

This study was an RCT with 12-month follow-up (Australian New Zealand Clinical Trials Registry ACTRN12606001745883). The protocol has been described previously [8]. The intervention group received the standard 6-week Stanford ASMP and an arthritis self-help book [9]; the control group received the book only. The courses were offered on a range of weekdays, with morning, afternoon and evening courses scheduled. Weekend courses were also initially planned. In scheduling courses, careful consideration was given to potential work commitments and local traffic and parking issues. This study was approved by the Human Research Ethics Committees at each hospital and the University of Melbourne. All data collection was undertaken between 2006 and 2009. The trial outcomes have been reported elsewhere [7]; the current article reports prospective data on barriers to participation in community-based ASMPs and self-management research, and individual preferences.

Participants

People referred to an orthopaedic surgeon or rheumatologist for hip or knee OA were recruited through four public hospital outpatient clinics (Alfred Hospital, Austin Health, Barwon Health and Northern Hospital) and community-based private practices within two private hospital settings (Cabrini Hospital and Epworth Hospital) in Victoria, Australia.

Individuals were eligible to participate if they were aged ≥ 18 years, had a diagnosis of hip or knee OA (from radiology reports or able to be classified according to ACR criteria [10, 11]), were referred to an orthopaedic surgeon or rheumatologist, had sufficient English language skills and vision to self-complete questionnaires and a reasonable expectation of attending the six sessions of the ASMP if randomized to the intervention group. Exclusion criteria included cognitive dysfunction, previous participation in an ASMP or similar education programme, placement on an orthopaedic waiting list for joint replacement surgery or scheduled joint replacement surgery.

Screening and recruitment

After identification and preliminary screening, patients from the public hospitals were sent an introductory letter. Private patients were given an introductory letter by their specialist. Research staff then telephoned potentially eligible individuals to provide detailed information about the study and complete the screening process.

A standardized script for screening and recruitment was developed (see supplementary data, available at Rheumatology Online) and used consistently by the team. This included information about the randomization process and the time commitment associated with the intervention and assessment procedures. Training was provided to all recruitment staff. A standardized screening proforma was used to summarize and record all information obtained during the telephone conversation, which was then entered into the study electronic database. If verbal consent was obtained, eligible individuals were mailed a consent form and baseline questionnaire. Written informed consent was obtained from all participants prior to randomization.

Data collection

Detailed information about barriers to participation and patient preferences were captured as part of the telephone screening and recruitment process, according to the following steps.

Screening

Individuals who were excluded based on their inability to attend the ASMP, if randomized to the intervention group, were asked about specific reasons for this ($n = 216$). Individuals for whom the screening process could not be completed due to disinterest ($n = 197$) were asked about specific reasons for this, where possible.

Recruitment

Eligible individuals who chose not to participate in the study ($n = 4$) were asked about specific reasons for this decision. Eligible individuals who gave verbal consent and were subsequently mailed a consent form and baseline questionnaire ($n = 183$) were asked about their preferences for course venue, course scheduling and course format (either 6-week course or mailed self-help book). Although a web-based ASMP is available [12], this format was not offered to study participants as part of the RCT and was therefore not included in the course format question.

Follow-up

Prior to the cessation of recruitment, attempts were made to contact eligible individuals who provided initial verbal
consent but did not return their written consent form and those who revoked their verbal consent (n = 57), to enquire about reasons for not participating in the study.

Statistical analyses

Similar to the methods reported by Blanch et al. [13], individuals were classified according to their eligibility and consent status during the multi-stage screening and recruitment process (Fig. 1). Those for whom telephone screening could not be completed (predominantly due to disinterest) were classified as the early refusal group. Individuals who were considered eligible but did not provide verbal consent for the mailing of study documents were classified as the eligible, early non-consent group. Those who were considered eligible but either revoked their verbal consent or did not provide written consent were classified as the eligible, late non-consent group. Finally, those who were considered eligible and provided verbal and written consent were classified as study participants.

Demographic characteristics were compared between groups using Kruskal-Wallis and \( \chi^2 \) tests (IBM SPSS Statistics 20, Armonk, NY, USA). Reasons for not being able to attend an ASMP were categorized into main themes for descriptive analysis, as were reasons for not participating in the study. Course scheduling and format preferences were also analysed descriptively. Course venue preferences were not considered to be of interest beyond the local geographical area and are not reported in this article. Examples refer to comments made by individuals during the screening and recruitment process, and are presented exactly as recorded and/or summarized in the study electronic database.

Results

Participants and reasons for exclusion

Figure 1 shows the number of individuals screened and summarizes the reasons for exclusion. Data on the flow of participants through the study and completion rates have been reported previously [7].

Demographics

There were some demographic differences for the early refusal group compared with the eligible, non-consent and study participant groups. The early refusal group was older and had a higher proportion of patients from public hospital sites (Table 1); as such, this group was more likely to be waiting for an appointment with an orthopaedic surgeon.

Inability to attend an ASMP

According to our eligibility criteria [8], individuals who were unable to attend a 6-week ASMP were considered ineligible to participate in the RCT (n = 216, Fig. 1). The barriers to attendance reported by this group are presented in Table 2. Physical limitations, including illness, limited mobility and recent falls, were commonly considered to be barriers to attendance (n = 47, 22%), as highlighted by the following examples: about to have surgery, OA not a priority, too unwell to attend course, due to hip OA and cannot get out of house without assistance; difficulties walking due to OA; not very mobile, unable to get to course; and falling down a lot. This category also included pain; some individuals reported that their primary interest at this point was pain relief, or they were unable to attend ASMP due to pain or in too much pain to be able to attend.

Although courses were scheduled in hospital and community-based locations, many individuals reported they were unable to attend due to distance or transport difficulties (n = 47, 22%). Work commitments were also commonly reported (n = 47, 22%). Other reasons (n = 43, 20%) included upcoming travel or specific preferences for the day, time or venue of a course. This category also included perceptions of the course, satisfaction with current self-management and use of other therapies: also ‘does not feel her OA is bad enough for [the] course’; also ‘thinks she might become depressed from talking and thinking too much about OA’; ‘discussed with GP, decided not appropriate candidate given age and frail’; ‘is already managing OA through exercise and diet’; ‘feels already doing as much as she can’; and ‘does hydro and physio, not interested in more commitments, i.e. course’. A number of people expressed concern regarding the time commitment required (n = 37, 17%) or were unable to attend due to family commitments including carer roles (n = 25, 12%).

Reasons for not participating in the study

As there were no clear differences between subgroups in terms of reasons for not participating in the study, these data were pooled for analysis (n = 258). The most frequent reason for non-participation was disinterest (n = 190, 74%). Other reasons (n = 56, 22%) for not participating included a range of themes, such as satisfaction with current status or self-management: ‘not interested as feels is managing well’, ‘feels like she has her OA under control’ and ‘has read a lot and does a lot to manage the arthritis already’. Some individuals expressed doubts about the potential personal benefits of participation: ‘does not feel she will get much out of [the] course’; ‘does not feel they would gain anything’; ‘too old - won’t get any benefit at her age’ and ‘does not feel the study will be of any benefit to her’. Others reported a lack of support from their GP: ‘his doctor told him the course wouldn’t help him’ and ‘GP suggested that (name omitted) was not suited for the project and that it did not relate to his condition’, despite a diagnosis of knee OA. A number of individuals were seeking more definitive treatment: ‘wants something to fix knee’; ‘was seeking therapy’; ‘just wants something to get rid of the pain’ and ‘not interested in self-management, wants surgery’. Others expressed concern about the content of the study questionnaire, for example: ‘does not feel the questions asked are appropriate’; ‘felt the questions did not relate to him’; ‘questionnaire is very comprehensive and off-putting’.
**Fig. 1** Patient screening and recruitment.

- 1125 individuals were assessed for eligibility
- 623 not eligible
- 118 unable to contact to complete screening
- 197 unable to complete screening as not interested (early refusal group)
- 187 eligible

**TABLE 1** Comparison of demographic characteristics

| Characteristic                                      | Early refusal group (n = 197) | Eligible, non-consent group (n = 61) | Study participants (n = 126) | P     |
|-----------------------------------------------------|-------------------------------|--------------------------------------|-----------------------------|-------|
| Age, median (interquartile range), years            | 70 (61–77)                    | 67 (57–72)                           | 67 (57–73)                  | <0.01 |
| Female, n (%)                                       | 115 (63)                      | 36 (61)                              | 76 (60)                     | 0.92  |
| Public hospital, n (%)                              | 196 (99)                      | 53 (87)                              | 111 (88)                    | <0.01 |
| Type of medical specialist, n (%)                   | 0.02                          |                                      |                             |       |
| Seen by orthopaedic surgeon                        | 28 (14)                       | 19 (31)                              | 29 (23)                     |       |
| Referred to orthopaedic surgeon, waiting to be seen | 164 (83)                      | 39 (64)                              | 95 (75)                     |       |
| Seen by rheumatologist                              | 5 (3)                         | 3 (5)                                | 2 (2)                       |       |
| Diagnosis, n (%)                                    | 0.13                          |                                      |                             |       |
| Hip OA                                              | 51 (29)                       | 11 (18)                              | 39 (31)                     |       |
| Knee OA                                             | 119 (68)                      | 49 (80)                              | 79 (63)                     |       |
| Hip and knee OA                                     | 6 (3)                         | 1 (2)                                | 8 (6)                       |       |

*Sub-categories total more than 623 as some individuals were excluded based on more than one criterion.*
Many individuals did not want to participate because of physical limitations, illness or perceptions that the course might be too demanding (n = 48, 19%). Specific examples include ‘feels it would be too strenuous to get to and from the ASMP sessions if allocated to the intervention group’, ‘having trouble with his health and is unable to concentrate’, ‘feels too unwell to take part’ and ‘no energy to participate’.

While reasons for non-participation were not specified for some individuals (n = 26, 10%), others expressed concern about the potential time commitment required (n = 20, 8%), with comments such as ‘does not have time to participate (looks after grandchildren and managing exercise routine)’ and ‘read through [the] CF [consent form] and did not want to make the time commitment possibly required’. Some individuals also cited family (n = 11, 4%), transport or distance issues (n = 6, 2%) and work commitments (n = 2, <1%) as reasons for not participating in the study.

Preferences for course scheduling and format

The logistical challenges faced in scheduling courses for the RCT [7] were confirmed by the course preference data provided by the eligible, late non-consent and study participant groups (n = 183). Of these individuals, half (n = 92) preferred the course to be held on a particular day (or days) or were unable to attend if scheduled on a particular day. Only one-quarter (n = 46) had no specific preference or were flexible in terms of course scheduling. Many preferred to attend a course held during the day (38%), with few people favouring evening or weekend courses (3% each). Most people (n = 103, 56%) preferred to attend a 6-week course, while similar proportions preferred to receive the self-help book only or had no preference (19% each).

Discussion

Improving access to self-management education programmes has long been a goal for many [3, 14], but this objective will be difficult to achieve until the barriers to participation are understood. This study is the first to systematically investigate barriers to participation in ASMPs among people with hip or knee OA. While our data indicate that the traditional, group-based format is desirable to some people, for many, attendance at weekly community-based sessions is clearly not feasible. This research has elicited comprehensive information about reasons for non-participation in ASMPs, providing a practical resource that can be used by health policy makers and clinicians to maximize patient engagement in self-management education.

Although several personal factors have been hypothesized to limit the uptake of community-based ASMPs [15], there has been little empirical research to guide health policy. In an Australian pilot study of the Stanford Chronic Disease Self-Management (CDSM) course for people with chronic conditions (including arthritis), the most common reasons for not participating included illness, difficulty in committing to the course and a perception of the course being unsuitable [16]. As part of their study, Buszewicz et al. [5] interviewed a sample of participants with hip or knee OA who did not attend any sessions of the allocated 6-week arthritis education programme. The most common reasons for non-attendance were timing and access issues, although these were not further defined. More recently, researchers in the USA investigating individualized arthritis education for people with inflammatory arthritis identified the main reasons for not participating in their study as disinterest, previous research participation, health issues, insufficient time, dislike of the study and transport issues [13].

Building on previous work, our study has generated new and important findings about barriers to participation

| Reason provided                      | n (category %) |
|--------------------------------------|----------------|
| Physical limitations                 | 47 (22)        |
| Illness/physical condition/having surgery | 25             |
| Limited mobility/disability/falls/frailty | 11             |
| Pain                                 | 7              |
| Hearing impairment                    | 3              |
| Easily fatigued                       | 1              |
| Distance/transport difficulties       | 47 (22)        |
| Course venue too far from home       | 31             |
| Does not drive or have access to transport/unable to get to course | 12 |
| Cannot travel                        | 2              |
| Transport difficulty not specified   | 2              |
| Work commitments                     | 47 (22)        |
| Works full time                      | 19             |
| Work arrangements unclear/looking to return to work | 18 |
| Shift worker/on call                 | 5              |
| Self-employed                        | 2              |
| Work-related travel                  | 2              |
| Works part time                      | 1              |
| Other                                | 43 (20)        |
| Specific preferences for course      |                |
| scheduling and/or venue              | 20             |
| Travel or moving away                | 15             |
| Other reasons                        | 7              |
| Will not go to course                | 1              |
| Time commitment required             | 37 (17)        |
| Unable or unwilling to commit to the course | 18 |
| Too busy                             | 12             |
| Too much time commitment involved    | 7              |
| Family commitments/carer role       | 25 (12)        |
| Family commitments or carer role    |                |
| not specified                        | 7              |
| Carer for grandchildren              | 7              |
| Carer for spouse/unwell spouse       | 6              |
| Carer for children                   | 4              |
| Carer for parent                     | 1              |
| Not interested                       | 8 (4)          |
| No reason given                      | 4 (2)          |

*Based on 216 individuals considered ineligible due to inability to attend six sessions. Percentages total >100% as some individuals provided more than one reason.
in community-based programmes specific to people with hip or knee OA. Perhaps the most important (and potentially modifiable) barriers to emerge were physical limitations, including reduced mobility, pain and fear of falling. Although these are intuitive given the underlying diagnosis and its associated impairments, this finding highlights the profound impact that OA can have on daily life and access to services. Our research also shows that concurrent illness and co-morbidities among people with OA can further restrict the ability to attend community-based sessions. By integrating self-management courses with clinic-based or home-based physiotherapy and rehabilitation services, it may be possible to manage pain, improve mobility and address balance deficits while providing structured education. This could potentially be achieved through additional training of health professionals and the development of new education programmes designed to fit within a treatment delivery model. Given the challenges faced in organizing group-based programmes, it may be simplest to offer self-management education on an individual basis in these settings, for example, as a short additional session following a physiotherapy treatment session. Each session could focus on a specific aspect of arthritis self-management, meaning that comprehensive education could be provided over the course of a 6-week treatment programme.

Another important theme to arise was the role of primary care providers in supporting self-management education. Several potential participants received advice from their doctor that the programme (or study) was not suitable or would not benefit them. This supports earlier research showing that a health professional’s recommendation is the strongest predictor of taking part in an ASMP [17] and that general practitioners can be wary of the clinical benefits of self-management programmes [18]. Given the perceived lack of benefit also reported by some patients, efforts to improve the uptake of self-management education should include garnering the support of trusted health professionals. Initiatives to promote programmes to primary care practices are being designed in the USA [19], but we are not aware of similar strategies in Australia. In an era of evidence-based health care, efforts to enhance clinician endorsement should focus on highlighting the available evidence that supports the effectiveness (and cost-effectiveness) of education programmes and the potential benefits that patients may receive as a result of their participation. It has been previously noted that the evaluation of self-management interventions requires a stronger focus on patient-centred measures that are robust and meaningful to clinicians and funders [8, 15, 20]. Future research should make greater efforts to capture relevant outcomes that better inform clinicians on the potential benefits of self-management interventions [21].

Our findings have implications for the design of new self-management models and future studies in this area. Despite embedding several enablers into our study design (for example, offering transport or parking reimbursement and utilizing local venues), many potential participants remained reluctant or unable to attend an ASMP. Many individuals reported multiple demands on their time, indicating that no single self-management model can meet the varied needs of this patient group. Careful preparatory work with typical patients in specific settings would be valuable for determining the most convenient locations and scheduling preferences for education courses before embarking on future studies. Similarly, in clinical and community settings, feasibility studies could be used to establish whether proposed programmes are acceptable to prospective participants prior to implementation. More intensive courses conducted over a shorter time period (for example, 2–3 weeks) may be less onerous on patients, but the development of sustainable self-management skills is likely to be greatest over longer periods with between-session tasks and booster sessions. Future programmes are likely to have greater uptake and impact if they are carefully tailored to the patient’s needs and lifestyle. As with good clinical practice, self-management programmes could be based more specifically on a patient’s identified needs and then structured around identified barriers. To improve equity of access, future studies should offer alternative education formats, and these could include telephone, mailed and Internet versions. Promising web-based programmes are being developed to support patients with musculoskeletal conditions (for example, www.steppingup.org.au), which are responsive to the challenges reported in this study, including mobility restrictions and work and family commitments. There is also scope to develop state-of-the-art applications for mobile phones and hand-held devices to enable education to be accessed when convenient. This is particularly relevant for younger people who increasingly access social media and other information through portable devices. From a clinical perspective, the findings of this study could also be used to develop criteria for appropriate referral to self-management education. Based on our data, patients who are experiencing few symptoms or are already coping well are less likely to participate, as are those who prefer to receive treatment.

A strength of this research was the use of standardized scripts for recruitment and screening, which should have reduced potential variation in the marketing of the course between staff. Also, patients with a range of OA severity from six public and private health care settings were screened for this study, increasing the external validity. There are also several limitations to acknowledge. As recruitment was limited to patients fluent in English, our findings do not incorporate the views of people from non-English-speaking backgrounds. It is also possible that recruitment from other settings, including primary care, may have produced different results. Our recruitment strategy focused on secondary care, as we believed these patients would have a significant capacity to benefit from self-management education. However, it is likely that patients presenting to medical specialists experience more severe symptoms or limitations and may have different expectations regarding their OA management.
Another limitation is that beyond lack of interest, we have little information from the early refusal group (Fig. 1) about specific reasons for not wanting to participate. This is similar to previous research [13] and reflects the difficulty in obtaining detailed information from individuals who were often quick to end the telephone call with research staff. Finally, data collection was undertaken by research staff within the context of an RCT. It is possible that patients’ views regarding ASMPs might differ if obtained in a purely clinical setting, for example, as part of a medical consultation.

Capturing the patient’s perspective, this study has generated detailed information about barriers to ASMP participation. While the programme was accessible for some patients, many reported barriers, including severe pain, functional limitations, transport difficulties, employment responsibilities and carer roles. It is evident that a range of models is required to meet the individual needs and preferences of people with OA. An ongoing challenge is to translate these findings into policy to enable more people to receive appropriate self-management education in a format that is acceptable to them.

**Rheumatology key messages**
- Group-based self-management programmes are inaccessible for many people with hip or knee OA.
- Barriers to participation in self-management programmes for people with OA included physical limitations, travel difficulties and work commitments.
- The development of effective self-management models capable of reaching more people with OA is warranted.

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**Supplementary data**

Supplementary data are available at Rheumatology Online.

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