Patient education in rheumatoid arthritis: the effectiveness of the ARC booklet and the mind map

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Objective. To determine the effectiveness of a pictorial 'mind map' together with the Arthritis Research Campaign (ARC) booklet for imparting knowledge to participants with rheumatoid arthritis (RA). Also, we wished to relate this to their reading ability.

Methods. We studied 363 participants with RA. Reading ability was assessed using the REALM, and knowledge was assessed using the Knowledge Scale Questionnaire (KSQ). Information on educational attainment, disease state and levels of anxiety and depression was also collected. Participants were randomly assigned to receive either the ARC booklet alone or the booklet and the mind map together.

Results. A significant minority (15%) of participants were functionally illiterate. There was a statistically significant increase in knowledge across both groups from baseline to reassessment after they were given the literature, but there was no difference in attainment between the groups. The more literate participants gained more knowledge regardless of the information they were given. They were also significantly less anxious and less depressed.

Conclusions. The ARC booklet with or without the mind map was associated with a significant increase in knowledge. Poor readers had poor educational attainment and poor knowledge acquisition. The information on the mind map was not more accessible to them. Different educational strategies will be necessary to educate these patients.

Introduction

Patient education has become an integral part of the therapeutic approach to helping patients with rheumatoid arthritis (RA) to self-manage their arthritis. It is also integral to the promotion of both adherence and safety in relation to what are now complex treatment regimes. A variety of evidence indicates that educational attainment is associated with better disease outcomes in RA [1–3]. The accessibility of educational material is, however, key to successful knowledge transfer and low levels of literacy may limit understanding of traditional forms of patient information [4, 5].

The Arthritis Research Campaign (ARC) has produced patient information on a variety of musculoskeletal conditions. This literature is written for patients and contains information on the diseases, coping strategies and answers to common questions. This information has traditionally been in the form of booklets, which, although illustrated, contain a lot of dense typescript. While this is appropriate and accessible for patients with good literacy skills and educational attainment, it may not be so good for those with lower literacy skills. A recent study in Glasgow [6] showed that one in six of their RA patients were functionally illiterate. A booklet format may not, therefore, be useful to a substantial minority of patients.

A recent innovation at the ARC has been the production of more pictorial 'Mind Maps' based on some of the booklets. The concept of mind mapping is a technique developed by Buzan et al. [7] in which information is presented diagrammatically using key words and images exploded from a central idea in a format that aids cognitive processing. Mind maps focus on meaning rather than being concerned with grammar and semantics, hence the expectation that they may be more accessible to less able readers. Thus far though, the main use for mind maps has been as a study technique in educational settings to aid revision. Mind maps have been shown to improve the recall of factual knowledge by 10–15% in a randomized study of medical students with follow-up at 1 week [8]. However, in a study of the effect of three different patient education methods on recall in orthodontic patients, small but significant advantages in recall gained through the use of mind maps were not maintained at 6 weeks [9]. In this study, patients who did not speak English as their first language were excluded, and the relationship between literacy and improvements in recall were not examined. One expectation of the production of these was that they might be more accessible to less able readers.

This study was designed to test the effectiveness of both the booklet and the mind map in transferring knowledge to patients and to relate this to their reading ability.

Methods

Full ethical approval for this study was obtained at all participating sites. Participants with RA were recruited in three hospital Rheumatology departments. They were consecutive patients diagnosed by their treating Rheumatologist as having rheumatoid arthritis and willing to take part in the study. Fully informed and written consent was taken.

Participants performed the REALM reading test [10] followed by a HAQ [11], the HAD [12] and the Knowledge Scale Questionnaire (KSQ) [13]. The KSQ was adapted from an existing RA knowledge questionnaire for use in clinical settings. The eight sections comprised 40 statements completed by a true or false response. The scoring system was +1 if correct, 0 if not completed or don’t know, and −1 if incorrect. Possible scores ranged from −40 to +40. Participants were also asked about their highest educational achievement, what their first language was and from whom they had received information about their disease.

The REALM is a test of reading fluency where subjects are asked to read a list of medically relevant words and score one point for each word correctly read. Pronunciation and hesitance and inability to read a word mean that that point is lost. Scores range from 0 to 66. Raw scores on the realm roughly correspond to US school grades: 61–66 9th grade, should read most educational material; 45–60 7th–8th grade, may struggle with
available educational material: 19–44 4th–6th grades, need low literacy material; <18 3rd grade, illiterate.

The KSQ is in the nature of multipart questions that are scored true or false. It is negatively marked with a range of score from 0 to 40.

Participants were then randomly allocated to receive the booklet alone or the booklet and the mind map. An arrangement was made to contact the participant after a week to allow time for them to read the ARC booklet and look at the mind map where applicable. The KSQ was repeated over the telephone unless the participant indicated that they had not had time to look at the materials, in which case a further telephone call was made a week later. At the end of the study those participants who had not received the mind map were sent a copy.

Results

A total of 363 RA patients (256 female) were enrolled (Newcastle 185; Barnsley 107; Bradford 71). Of these 188 were allocated the booklet only and 175 were allocated the booklet and the mind map. There were no significant differences between the two groups for age; gender; disease duration; HAQ; baseline KSQ or REALM score (Table 1).

The majority of participants (85%) had an educational history including high school or equivalent. Approximately 11% had an educational level of 7th–8th US grade, and just <4% had an educational grade of less than 7th grade. The range of REALM scores for each group is illustrated in Fig. 1. Reading ability was mostly good, but 15% scored <60 and a few <48. There was a relationship between educational attainments and reading ability, however, there were only small numbers in the lower ability groups (Fig. 2).

The majority of participants (97%) reported that English was their first language for speaking and reading. When asked who provided the most information about their disease the replies were as follows: consultant (37%), rheumatology department (19%), Nurse specialist (8.5%), ARC leaflet (8%), GP (5%) and a long list of others.

Pre- to post-intervention KSQ results are shown for both groups in Fig. 3. The booklet only group showed a mean increase in knowledge of 6.56 (CI 3.36–8.75). The group that received both booklet and mind map increased by a mean of 6.45 (CI 3.78–10). There was, therefore, a significant increase in knowledge over the study in both groups, but there was no significant difference between the two groups in terms of change in PKQ score (Mann-Whitney U-statistic z = −0.91, P > 0.3).

We were also interested in any relationship between reading ability and the effectiveness of the information provided to the two groups. This showed a trend in the direction of the better readers getting more information from the combination of the booklet and the mind map than the poor readers. We performed a univariate analysis of variance model with difference between scores as the dependent variable and REALM score, age, intervention group, depression and anxiety as the independent variables (Table 2). The only significant predictor variable was reading ability. However, the model fit was not good, with an adjusted R-squared of 0.2 (this estimate did not change with the omission of anxiety and depression from the model).

Figure 4 shows the change in knowledge plotted against educational attainment and shows that those with better educational attainment had greater increase in knowledge. These results suggest that the poor readers who were also the people with poor educational attainment had poor knowledge acquisition regardless of the information given. The better readers tended to benefit from having two types of literature. The mind map did not solve problems for the poor readers and other strategies will need to be employed.

We also investigated the difference in anxiety and depression between the good (REALM > 59) and poor (REALM < 60) readers. The results with 95% CI are shown in Fig. 5. The poor readers were significantly more anxious (P = 0.03) and more depressed (P = 0.01). The same relationship was seen between knowledge scores pre intervention and anxiety (P = 0.01) and depression (P = 0.006) with the less knowledgeable being more anxious and more depressed. The data suggest that poor reading leads to poor knowledge, which associates with more anxiety and depression.

Discussion

The rate of illiteracy in our study was similar to the study from Glasgow [6] and a rheumatology service in Australia [16].
We found the same significant minority of people who have literacy problems, with 4% of our participants having educational achievement of 7th grade or below and 15% scoring <60 on the REALM. We suspect than several potential participants who may have had low ability avoided the test with excuses such as ‘I haven’t got my reading glasses’. This level of reading would make the conventional booklet inaccessible. There is, therefore, clearly a need to provide more accessible information or alternative forms of education for such people.

We had thought that the more pictorial mind map would have been more accessible to poor readers, but in the event we were unable to show any such effect. Indeed, any effect of the map seemed to be greater for the better readers. It appeared that the poor readers, who also had poor educational attainment, were unable to improve their knowledge with either format of information. This may relate more to understanding than simply literacy. We are unable to test this, as we have no information on one related to the person’s ability to read [15].

For those with poor literacy and poor educational attainment it may be that simply giving information may not be adequate. Other educational strategies may be necessary, such as individual or small group tutorials. It may even be that some patients are unable to achieve an understanding of their disease and treatment, and are likely to require more intense supervision. This whole area requires further research. Initially, a qualitative study of this group to ascertain their views would be appropriate. Exploration of preferred learning styles and accessibility of information could lead to a study aimed at altering behaviour.

Completing the KSQ with participants, it became clear that many were relating the questions directly to themselves rather than to RA in a more generic way. ‘Yes that happened to me’, or ‘no, I haven’t had that so it does not happen in RA’. Another perceived problem was with the drugs, where knowledge seemed to be good if they had had the drug rather than if they had not. A previous study of the ARC literature [16], which predated the mind map, showed a similar increase in knowledge from use of the booklet. It also showed increased knowledge gain in younger people with better educational achievement but did not include any measure of reading ability. Use of the leaflet also improved depression supporting the view that information could have general benefits.
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References