KNOWLEDGE IN PATIENTS WITH RHEUMATOID ARTHRITIS: A LONGER TERM FOLLOW-UP OF A RANDOMIZED CONTROLLED STUDY OF PATIENT EDUCATION LEAFLETS

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SUMMARY

Despite the wide availability of disease-related leaflets, their impact on patients’ knowledge and well-being has rarely been evaluated. A randomized controlled study of a ‘Rheumatoid Arthritis’ leaflet revealed increased knowledge among the intervention group after 3 weeks. In addition, the leaflet was viewed as a source of reassurance. The purpose of the follow-up study was to determine whether the increase in knowledge was maintained in the longer term and to examine psychological well-being. Eighty-four patients (42 intervention and 42 control) completed the 6 month follow-up. There were no significant changes (P > 0.01) in mean outcome measures over the period 3 weeks–6 months for either the intervention or control groups. Patients in the intervention group retained the increase in knowledge observed at 3 weeks. Moreover, there was no evidence of adverse reactions to the leaflet in terms of psychological distress. Leaflets can be effective in promoting longer term increases in knowledge.

Key words: Knowledge, Rheumatoid arthritis, Leaflets.

PROVISION of information is a cardinal feature of clinical encounters. The transfer of information is particularly important in the context of rheumatoid arthritis (RA), where adequate knowledge of the condition may influence patients’ decisions regarding treatment options, compliance with complex regimens and performance of self-care. RA patients are keen to find out more about their disease, although only a proportion (46%) report receiving information from health professionals [1] and many seek further information outside of the clinic setting [2]. The Audit Commission [3] concluded that patients receive neither all the information that they want, nor all the information that they need. Patient education leaflets offer one means of bridging the gap between the amount of information patients desire and the amount they receive and are able to assimilate in medical environments.

Written educational materials are frequently used in clinical settings to supplement verbal information and can increase patients’ knowledge. For example, patients’ knowledge of the side-effects of various drugs, including non-steroidal anti-inflammatories, increased with the use of prescription information leaflets [4, 5]. Furthermore, leaflets have been shown to improve recall of medical facts among osteoarthrosis patients [6] and knowledge among patients with mixed diagnoses of arthritis [7].

Extending this work, a randomized, controlled study examined the effectiveness of leaflets amongst RA outpatients in terms of knowledge, pain and psychological well-being [8]. The study utilized the ‘Rheumatoid Arthritis’ leaflet produced by the Arthritis and Rheumatism Council (ARC). After 3 weeks, the intervention group, who had received the RA leaflet, demonstrated a significant increase in knowledge (F = 21.24, P < 0.0001). There was no evidence of increased psychological distress among patients who received the leaflet. In fact, a trend towards improvement in depressed mood was noted (F = 3.64, P = 0.059). Moreover, qualitative analyses revealed that patients found the leaflet reassuring and believed it helped them ‘come to terms’ with their condition. No changes were evident among the control group.

The purpose of the present study was to determine whether the increased knowledge observed in the intervention group was maintained over a longer period of time (i.e. at 6 months follow-up), and to confirm that receipt of the leaflet did not adversely influence longer term psychological well-being.

PATIENTS AND METHOD

Patients

Ninety-five RA patients who had participated in the earlier study were contacted and agreed to take part in the longer term assessment. The final sample comprised 84 patients (42 control group and 42 intervention group). Patients were lost to follow-up for a range of reasons (e.g. death, serious illness of patient or family member, moved away). Initial recruitment procedures and measures used are detailed elsewhere [8].

Method

The study was a longer term follow-up to an earlier randomized controlled trial. Data were collected by self-administered questionnaires mailed to participants with a stamped addressed envelope for return. Copies of the RA leaflet were mailed to the control group at the end of the study.

Measures. The 6 month assessment comprised: a Knowledge Scale based on the content of the ARC ‘Rheumatoid Arthritis’ leaflet, pain and fatigue visual
analogue scales (VAS), the Hospital Anxiety and Depression Scale (HADS) [9], the Arthritis Self-Efficacy: Pain (ASE: Pain) and the Arthritis Self-Efficacy: Other Symptoms (ASE: Other Symptoms) scales [10] found to be reliable and valid when used amongst British people with arthritis [11].

Analysis. Data were analysed using the Statistics Package for Social Scientists (SPSS) for Windows 6.1 (1994). Differences between baseline characteristics of patients completing the 6 month assessment and patients who did not respond after the baseline or the 3 week assessment were examined using contingency tables, Kruskal–Wallis or analysis of variance, as appropriate. A significance level of 1% was used for all hypothesis tests to restrict the Type I error for the study as a whole.

Repeated measures analyses were used to compare mean scores on study variables at 3 weeks and 6 months, and, at baseline and post-baseline up to 6 months, across the intervention and control groups. The usual assumptions of normality of the errors, homogeneity of variance of the errors and compound symmetry of the variance–covariance matrices were checked through residual plots and Mauchly’s test on compound sphericity. Adjusted F-tests were used when necessary.

The analyses were based on the groups as randomized (i.e. intention-to-treat analyses were performed), as recommended by Altman [12]. Five patients in the control group and 11 patients in the intervention group had read a leaflet (other than the ARC leaflet) between completing the 3 week and 6 month assessments.

RESULTS

With the exception of knowledge, no statistically significant differences (P > 0.01) were found at baseline on any study variable between patients who completed all three assessments and those who did not respond at both 3 week and 6 month follow-ups. With respect to baseline knowledge, the mean score (9.59, s.d. = 6.26) for patients in the control group who did not respond at all three assessments was significantly lower (P = 0.006) than the mean score (17.40, s.d. = 7.21) for patients who responded at 6 months.

The characteristics of patients remaining in the study at 6 months are presented in Table I. The recommended cut-off point for detecting mood disorder on the HADS is a score of ≥8 [9]. At the 6 month follow-up, 57% of the sample scored ≥8 on the anxiety subscale of the HADS compared with 43% who scored ≥8 on the depression subscale.

Mean scores on the outcome variables at the 3 week assessment and the ensuing change scores over 3 weeks–6 months of the outcome variables are presented in Table II. There were no statistically significant changes (P > 0.01) on any outcome variables over the post-baseline period 3 weeks–6 months for either the intervention or the control group. Comparing mean scores post-baseline (i.e. 3 weeks–6 months) with baseline mean scores, there is a significant increase in mean total knowledge score (mean increase = 5.61) for the intervention group and no significant change (mean decrease = 0.25) for the control group (P < 0.0005). There was a decrease in mean depression score (mean decrease = 0.69) for the intervention group compared with an increase for the control group (mean increase = 0.93), producing a significant difference (P < 0.0005) in the pattern for depression scores across these two groups over the baseline to post-baseline time period. There was a significant decrease in pain scores (P = 0.004) from baseline to the post-baseline period for both the intervention and control groups.

DISCUSSION

This study has demonstrated that a short-term change in knowledge following the receipt of a diseaserelated leaflet can be maintained over a period of months rather than weeks. However, it should be noted that all patients in the intervention group were interviewed by telephone following completion of the 3 week assessment. Thus, the maintenance of change at 6 months could derive from the effects of the leaflet or from the combined effects of leaflet and interview. During the interview, patients were not questioned about their knowledge, rather their views were sought on leaflet content, style, format and the feelings experienced when reading the leaflet. Whether the interview served to embed patients’ knowledge more firmly is an issue to be explored in future studies. Nevertheless, the results indicate the potential of using a low-level, low-cost intervention to increase patients’ knowledge of their condition over time. The precise role played by knowledge in relation to compliance with treatment regimens remains to be elucidated.

### Table I

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intervention group (n = 42)</th>
<th>Control group (n = 42)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yr)</td>
<td>58.3 (11.3, 37–78)</td>
<td>58.3 (10.7, 26–75)</td>
</tr>
<tr>
<td>Gender</td>
<td>85.7% women</td>
<td>76.2% women</td>
</tr>
<tr>
<td>Duration of disease</td>
<td>16.0 (11.7, 0–47)</td>
<td>18.6 (12.5, 1–52)</td>
</tr>
<tr>
<td>Health Assessment Questionnaire</td>
<td>2.18 (0.92, 0–3.00)</td>
<td>1.92 (0.84, 0.13–3.00)</td>
</tr>
<tr>
<td>No formal educational qualifications</td>
<td>64.3%</td>
<td>76.2%</td>
</tr>
<tr>
<td>Married/living with partner</td>
<td>66.7%</td>
<td>71.4%</td>
</tr>
</tbody>
</table>

Values are means (s.d., range) or percentages.
A point worth noting is the relative stability of anxiety and depression scores in the intervention group. Concern had been expressed in the early stages of the original study [13] that giving people disease-related information might generate psychological distress. However, there was no evidence that receipt of this specific leaflet was the cause of negative psychological reactions, as indicated by standard measuring instruments. These findings add to the growing body of evidence suggesting that controlled provision of information does no harm [14, 15] and may, in fact, do good.

Limitations of the study include the focus on one specific leaflet and patients with one diagnosis: RA. Further research is necessary to determine whether these findings generalize across other forms of rheumatic disease (e.g., osteoarthritis), and to other patient education leaflets. A further limitation was the tendency for drop-outs in the control group to have lower knowledge at baseline. This could not be accounted for by differences in terms of educational level, co-morbidity, age, duration of the disease or pain scores, although there was some evidence ($P = 0.036$) of milder physical disability in these patients. Such patients might feel that they do not need to be well informed about RA and therefore might lack the motivation to participate in a study. Participation among the control group might have been biased towards patients who felt sufficiently competent to complete the Knowledge Scale. However, the consistency of knowledge across baseline, 3 week and 6 month assessments for the control group emphasizes the changing pattern of knowledge in the intervention group (see Fig. 1). There was no evidence that this pattern of results was due to regression towards the mean.

The most effective mode of leaflet distribution has yet to be identified. For example, the positive effects of information provision might be enhanced when leaflets are distributed in the more realistic scenario of a one-to-one consultation with doctors or rheumatology nurse practitioners, rather than when leaflets are mailed to patients by researchers. The timing (e.g. at diagnosis, after several years, or regularly throughout the disease course), the content and the format of information provision are further important issues that need to be addressed in greater depth. Patients in the early stages of their disease might benefit from staged information, gradually building up to a comprehensive account of their condition and its treatment. This strategy would make full use of the fact that patients’ interest in learning more about RA does not decrease over time [1] and that increased knowledge following receipt of written materials appears to be independent of disease duration [8]. Finally, the selection of alternative educational media now available (e.g. audiotapes, videos, the Internet or computer multimedia programs) offers additional methods of information transfer. Thus, the written word should not be viewed as a universally acceptable medium for communicating patient-oriented information.

### CONCLUSION

In conclusion, leaflets can be an effective means of increasing knowledge amongst patients with RA and appear to generate a sense of reassurance. Moreover, change in knowledge can be maintained over periods of months rather than weeks. The successful transfer of knowledge is an important aspect of overall disease management and represents but a small step in the complex process of adjusting to life with an incurable, painful, disabling condition. The challenge for the future is to clarify how gain in knowledge can be harnessed to improve compliance, increase self-care and facilitate adjustment.
ACKNOWLEDGEMENTS

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REFERENCES