Does patient education in rheumatoid arthritis have therapeutic potential?

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Rheumatoid arthritis (RA), a common and serious condition, can be viewed as a model for chronic disease in general. In addition to its chronic nature, RA is characterised by uncertain disease progression and an unpredictable course of exacerbations and remissions. While there is as yet no cure, there is evidence that various medical interventions may ameliorate its effects. In addition, the management of RA often results in the patient coming into contact with a large number and variety of health professionals and in learning complex physical and medical therapeutic regimens. For many patients their pain, disability, deformity, and reduced quality of life persist in spite of treatment. There is clearly room for new approaches to enhance current treatment effectiveness. Patient education is one such approach that is thought by many to be beneficial in helping patients to cope and cooperate with their disease and its complex management.¹⁻⁴

There has been increasing research in the field of patient education, and major reviews of published studies have been conducted by Mazzuca on the value of education in chronic disease in general⁵ and more recently by Mullen⁶ and Lorig on education in arthritis.⁷ In the current climate of rising health care costs and audit it is important to justify the effectiveness of patient education. Thus it may be useful to distinguish between patients' 'right' to know more about their disease and its management and the health benefit they might receive from increased knowledge. Many would argue that patients do have an inherent right to information, and studies have shown that patients do want to know about their illness,⁸⁻¹⁰ but this in itself does not imply that education should be automatically included in management. Like other interventions it should be viewed in terms of its efficacy and adverse effects. If beneficial effects can be shown then it should be recognised that patients do have a need to know for the sake of their health, and education should be regarded as part of routine management. This paper reviews some published patient education programmes and critically analyses whether patient education in arthritis can yet be justified in therapeutic terms.

Justifying education programmes

Green defines patient education as including all planned educational activities aimed at assisting patients in achieving voluntary health behaviour changes.¹¹ It assumes the acquisition of knowledge, skills, and attitudes in order to effect these changes. Education programmes

Table 1 Questions to ask when assessing a patient education programme

Are the educational objectives appropriate?
Are the educational methods appropriate?
Have the educational objectives been achieved?
Has there been therapeutic benefit?
Are there adverse effects?
What is the resource cost?

can be assessed as outlined in table 1. These assessments relate, firstly, to the internal educational coherence of the objectives of the programme, the methods used to attain them, and their success; and, secondly, to the achievement of the external standard of therapeutic benefit measured in clinical rather than educational terms. This potential effect of education on disease outcome is of prime concern to both patients and health care providers. Trying to discover if there has been improvement in health status and quality of life as a result of taking part in an educational programme has often been beyond the scope of many published reports, partly because the time taken to show such effects is prohibitive and partly because of failure to perceive the need to show explicit therapeutic efficacy. When it is not possible to evaluate therapeutic outcome the attainment of educational objectives which seem appropriate may provide at least some guide to likely efficacy.

A review of some published programmes

ARE THE EDUCATIONAL OBJECTIVES APPROPRIATE? Owing to the complex nature of RA and its management and because no one course of treatment has proved to be consistently effective, the objectives of patient education programmes have shown wide variation. Table 2

Table 2 Knowledge, skills, and attitudes considered in patient education programmes

Knowledge
Disease process and medical management ^{4 14 15 17 28 29}
Drugs ^{4 14 15 17 26 28 29}
Nutrition ^{4 14 15 28 29}
Exercise/joint protection ^{4 14 15 17 28 29}
'Quackery'/alternative treatments ^{4 15 28 29}
Community resources ^{14 15}
Skills
Exercise ^{4 14 28 45-48 57}
Joint protection/energy conservation/work simplification ¹⁴
Relaxation/stress management ^{4 23 24 49 50}
Drugs ^{4 14 15 28}
Sleep ^{4 14 15 28 49}
Communication with doctors and family ^{4 14}
Attitudes
Coping ⁵⁰
Problem solving/goal setting ^{46 50}
Stress management ¹⁴
Self efficacy ⁵⁰
Self esteem ⁶¹

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shows some of the major areas considered. This list is not exhaustive but represents those objectives most commonly reported in published studies. One of the key components in developing an education programme is that the content should be based on the needs and beliefs of those receiving education,^{7 9 10 12} enabling new information to be built on to and into these existing beliefs. Divergence of opinions between patients and health providers about the importance of various aspects of the disease, its management, and treatment has been clearly shown.^{9 10 13} Formulating an agreed agenda between the patient and the educator is therefore clearly essential. Mazzuca suggests that patients do not need to know about the pathophysiology of their disease,⁵ but in a study by Silvers patients themselves rated pathophysiology and diagnostic procedures as very important.¹⁰ The importance of considering measures to reduce pain and disability is generally accepted as the highest priority, but it is not surprising that there is a variation in needs and beliefs when different cultures, customs, races, and geographical settings are studied. This re-emphasises the importance of recognising these factors when formulating a suitable curriculum. Only Lindroth,¹⁴ Goepinger,¹⁵ and Lorig¹⁶ report that they have assessed patient needs when designing their education programmes.

It is necessary to consider the appropriateness of and justification for the various educational objectives included in the programmes. Poor levels of knowledge have been noted in patients before the start of education.^{14 17} This is often in the face of a long disease history and patient experience of regular contact with health professionals. Williams and Wood suggest that this lack of understanding of the medical model of illness is not ignorance on the part of patients, but rather that they have their own well constructed but non-medical models of illness.¹⁸ The implication here is that knowledge should not only make sense scientifically but should also fit into a valued framework of patients' life events on which is based their own illness explanation. Although many programmes emphasise medical knowledge, there is in fact little evidence to support a causal link between knowledge, behaviour, and health outcome. If a better informed patient is the aim of the programme then almost all are successful in the short term,⁷ with the improvement maintained for up to two and a half years in one long term study.¹⁹ Programmes concentrating on gains in knowledge alone are rarely successful in improving health, however.⁵

Skills and behaviours thought to be beneficial in arthritis are a second major component of education. There are many skills widely held as being of therapeutic value and those most commonly included in programmes are listed in table 2. Evidence from controlled trials to support their therapeutic value is weak and in some cases non-existent.

Exercise is commonly taught and is a routine part of management, yet few studies have been conducted in this field. A recent study did show a reduction in the number of swollen joints with

no adverse effects for patients with moderately active RA undergoing aerobic training.²⁰ An uncontrolled trial on quadriceps exercises for osteoarthritic knees demonstrated improved function,²¹ but whether this is also true for patients with RA is not known.

Relaxation is another common practice and has been shown to produce significant pain relief in patients with osteoarthritis,²² but again evidence that relaxation in RA is consistently efficacious is inconclusive. Many relaxation methods require a person to rest physically in order to practise relaxation, and rest itself has a beneficial effect. Randomised controlled trials by Randich²³ and Shearn²⁴ showed no improvement in pain in patients practising relaxation techniques.

Instruction in joint protection is another intuitively sensible part of management, but here again the evidence for its success is weak. A review by Agnew concludes that the effects of joint protection on pain and stress, inflammation, and the prevention of deformities have yet to be shown.²⁵

The therapeutic effects of drugs are well reported, but it is the question of cooperation or compliance with drug regimens³ which is of importance in education programmes. In one study only six of 32 patients with early RA reported taking the number of tablets prescribed by their general practitioners.⁹ Drug information leaflets combined with verbal advice as a method of improving knowledge and compliance have been tested and gains in knowledge reported.²⁶

Attitudinal objectives have recently attracted more attention and are coming to be regarded by some as important variables in the outcome of disease. Health professionals and patients in general disagree about the importance of the psychosocial content of education. Although depression,^{13 15} fear and anxiety,¹³ self awareness,¹⁴ communication skills,^{10 14} and stress management¹⁴ have all been cited by patients as topics for inclusion in education programmes, they are considered to be of much lower importance than pain and disability.^{10 13} The logic of RA suggests that psychosocial consequences of arthritis are likely to be secondary to the biologically obvious effects of pain and disability. It seems reasonable, therefore, to argue that programmes which focus solely or primarily on psychosocial factors may have inappropriate objectives.

ARE THE EDUCATIONAL METHODS APPROPRIATE?
As important as the content of a programme are the various processes and methods by which it is presented. Table 3 lists some of the approaches

Table 3 Teaching methods used for patient education

Small group work
Individual teaching
Computer assisted instruction
Didactic
Interactive
Lay-led groups
Professional-led groups
Home study
Passive instructional (booklets, audio-visual programmes)
Reinforced

used. Work in the field of adult education has shown that an interactive learning approach is more acceptable and successful than a didactic style, particularly when working with mixed ability groups.^{7 27} This has been confirmed in chronic disease⁵ and arthritis.⁷ There is little difference in effectiveness between lay-led groups and professional-led groups.²⁸ Computer based education²⁹ and home study methods³⁰ show promising results but need further investigation. Although an individual approach is an effective method of gaining knowledge,¹⁷ small group work is more effective at changing attitudes and behaviours.¹² Investigations of the routine provision of information leaflets^{26 31 32} have only examined gains in knowledge. Rather surprisingly, a reinforcement programme which provided 'refresher courses' for patients did not show any improvement over the gains made during the initial education programme.³³

HAVE THE EDUCATIONAL OBJECTIVES BEEN ACHIEVED?

In one review 94% of studies measuring changes in knowledge demonstrated improvement,⁷ suggesting that most programmes are competent at teaching patients facts. In most studies changes in skills are evaluated by self report of behaviours, assuming that patients have been using their skills correctly and as frequently as they say. Budesheim *et al* did, however, ask patients to demonstrate their skills.³⁴ Although the actual use of skills is of greater importance than the ability to demonstrate them, unless the skills are checked as part of the assessment method it cannot be assumed that they are performed correctly. Given this reservation, 77% of studies measuring changes in self-reported behaviour showed increased use of skills. Instruments (questionnaires) have been

developed to explore the various psychological aspects of arthritis^{21 35-37} and have been used to assess patients. Success in changing attitudes is less consistent than for knowledge and skills, though more than half of the studies measuring the achievement of attitudinal objectives showed improvement.⁷ Outcomes for coping (managing to continue with life despite the difficulties of illness), anxiety, and self efficacy (belief in the ability personally to do things which improve illness) were more positive than those for depression and loss of control.

HAS THERE BEEN THERAPEUTIC BENEFIT?

Therapeutic benefit shown by an improvement in the 'quality of life' must remain the final arbiter of efficacy. Table 4 outlines one convenient classification of the main effects of RA on different dimensions of a person's quality of life. Although measures of disease activity using a variety of clinical tests are sometimes used to assess the results of education programmes, it is of greater importance to measure the effects on those variables that directly impinge on a person with arthritis. Particular attention should be paid to the aspects which are affected to a greater degree by RA—physical discomfort (pain) and disability.

No attempt has yet been made to measure alterations in mortality in RA as a result of patient education, yet educational achievement has been shown to be a strong predictor of subsequent mortality.³⁸

Pain, joint count, morning stiffness, and global health scores can all be used as measures of physical discomfort, pain being the most important. A number of studies (outlined in table 5) have reported pain reduction after educational intervention. Others have failed to show these improvements,^{14 24 39} including one study²⁸ which was based on the Arthritis Self Management Course,⁴⁰ adopted by the Arthritis Foundation for use throughout the United States. In a study by Parker an increase in pain was reported after traditional patient education.³⁹ These inconsistent findings may in part be explained by the shortcomings of the assessment tools employed,⁴¹ but it has been argued that pain may not be an optimal measure for assessing the effectiveness of patient education.¹⁴

Table 4 Effects of rheumatoid arthritis on quality of life

Dimension	Size of RA effect
Mortality	+
Discomfort	+
Physical	++
Mental	+/-
Disability	++
Physical	++
Mental	-
Costs	+

Table 5 Studies showing pain reduction by patient education

Author	Study design	Measure	Intervention
Bradley <i>et al</i> ⁴²	Randomised and controlled with testing before and after	Visual analogue scale (VAS)	Biofeedback. Cognitive-behavioural group therapy Arthritis self-management course
Lorig <i>et al</i> ⁴	Randomised and longitudinal (20 months)	Ordinal scale	Arthritis self-management course
Lorig <i>et al</i> ⁴⁵	Randomised, controlled, longitudinal (4 months)	VAS and ordinal scale	Arthritis self-management course
Minor <i>et al</i> ⁴⁵	Randomised, controlled, longitudinal (12 weeks)	Not known	Physical conditioning, exercise
O'Leary <i>et al</i> ⁴⁰	Randomised, controlled, testing before and after	Not known	Cognitive behavioural training in coping techniques, relaxation, pain strategies, and goal setting
Perlman <i>et al</i> ⁴⁶	Test of 3 groups before and after	AIMS*	Low impact aerobic dance/exercise and problem solving education
Goeppinger <i>et al</i> ¹⁵	Randomised, controlled, longitudinal (12 months)	Composite score using VAS, ordinal scale, and Gracely pain scale	Small group lay-led arthritis self-care intervention

*AIMS=arthritis impact measurement scales.

Pain may act as the limiting factor to normal daily activities, so that the final result of a programme might be to increase function within the same pain threshold. Although there may be many beneficial outcomes from an educational programme other than pain relief, it remains the most important concern of patients with arthritis.^{7 9 14} Thus it should surely be assessed either in terms of a person's perception of pain or their ability to control pain.

Results of studies of the impact of RA on a person's psychological status (mental discomfort) are not consistent^{51 58-60} and caution is required when judging the success of patient education interventions in affecting these variables. When studies do measure psychological status an improvement is often shown. More recent results suggest that there is little difference in psychological status between patients with RA and those with other chronic diseases,⁴² but factors such as perceived helplessness, social support, and self efficacy are important mediators in patient education and predictors of future disability and pain.^{30 43 44} Physical disability measures include functional assessments, physical assessments, walking time, and grip strength. In the 76 programmes reviewed by Lorig^{7 45} measures of physical disability were reported, of which 27 showed improvement. In an additional study patients reported increased functional ability one year after completing an education programme.¹⁴ Programmes emphasising exercise and physical training have consistently shown improvements in physical health status.⁴⁵⁻⁴⁸ Only one study by Achterberg *et al* reported negative findings after education.⁴⁹ Other characteristics of programmes successful in improving function were those emphasising problem solving,⁴⁸ self-management activities,^{14 16} coping,⁵⁰ and self efficacy.⁵⁰ Other studies have, however, failed to show positive outcomes for physical status.^{15 24 28 39 57} It might be further argued that given the progressive nature of RA, the absence of a decline in function may be interpreted as evidence of programme success.^{7 30} Furthermore, reports have not yet considered the possibility that although potential function remains unchanged, actual function—that is, the degree to which patients use their potential, might have improved.

ARE THERE ADVERSE EFFECTS?

Possible adverse effects after education have not been well reported. It has been suggested that for patients with a recent onset of chronic illness information may lead to increased depression.⁹ Heightened levels of helplessness and fear are other potential reactions.⁵³ Where the content of a programme does not relate to the beliefs of the group or individual confusion may result.⁹ Fostering a misplaced sense of personal responsibility for the development and care of their arthritis may be potentially harmful, and education as a substitute for standard medical care should be avoided.⁵³ Attempts to encourage changes in lifestyle, work practices, and psychosocial variables may also have detrimental effects on both personal and work relationships.

WHAT IS THE RESOURCE COST?

For patient education to justify its place as a routine part of patient management requires proof of its cost effectiveness. Although many studies suggest beneficial therapeutic and subjective improvements, they are presented in a way which makes it difficult to quantify their financial balance. The cost of providing an education programme is often omitted from reports and a subsequent reduction in the demand for health service resources has yet to be shown. Measures that might be assessed include: the number of visits to doctors; hospital admissions; paramedic treatment; and drug use. In addition, changes in lost income or in social support might be included. In one study the number of visits to a doctor was reduced by 35% over 20 months of follow up.³³ Although outcome cost savings are difficult to measure, input costs can be estimated. For most programmes the major cost is health professional time per patient and of those studies that report either time or number of patients in each group, the average cost is about 12 hours per programme or one and a half hours per patient. In the United Kingdom this is about £12 per patient based on current senior paramedic/nurse salary scales. This figure rises when programmes are individualised to two and a half hours per patient (£20). Where programmes concentrate on objectives such as stress and pain management, coping strategies, and relaxation there is a further increase ranging from 10 to 80 hours per programme, but information on group size has not been provided and comparative costs cannot be calculated. In some programmes costs can be reduced by the use of trained lay leaders^{28 30} and home study methods. Although capital costs may be high, computer based education subsequently requires little input from professionals. At present the cost of providing education must be viewed as additional expenditure but when placed in the context of other medical expenses, even minor therapeutic benefit would make it cost effective.

Summary of review

Rheumatoid arthritis is associated with a severe negative health status having major adverse effects on individual patients and society as a whole.⁴² Although the therapeutic efficacy of many currently used treatments still needs to be better established, patient education has been shown to enhance these treatments, as judged by improved knowledge and behaviour. Improvements in pain and function are less consistent. The mechanisms by which education works are still not fully understood.⁵⁵ Those programmes which have been shown to have beneficial outcomes in influencing health status^{14-16 46-48 50 54 55} have the following characteristics:

- They are related to the needs and beliefs of the patients taking part
- They emphasise the relief of pain and disability
- They use interactive teaching methods in group settings

Table 6 Information required to assess reports about patient education

Aims and objectives of programme
Teaching methods used
Overall study design
Patient population
Evaluation instruments
Sample size
Concurrent treatments
Resource costs
Adverse effects

- They develop self-management techniques, problem solving, and self efficacy
- They employ exercise training.

Clearly many of the reports reviewed above do not include sufficient information on which to base an adequate assessment of the utility of the education programmes which they advocate. Table 6 lists the main areas which should be included in future reports. A randomised, controlled, longitudinal trial is probably the best overall study design, though alternatives have been proposed.⁷ About one third of the 64 RA education studies reviewed by Lorig were controlled and randomised. In view of the relation between patients' background and their educational needs, patient selection is an important aspect of programme assessment. The best patient sample will be representative for sex, disease duration, functional status, socio-economic status, and education level. Non-representative groups have often been used—for example, one sample comprised low income male veterans who had had their arthritis for 14 years and were of a low education level,⁵⁶ while another was predominantly female with a disease duration of less than five years and high educational achievement.²⁹ The use of validated assessment instruments is particularly important when measuring psychosocial variables as many scales are not designed to be used in the presence of somatic complaints such as those of arthritis. Sample size should be appropriate to that required to detect clinically useful effects, and few reports include details of concurrent treatments. When education is only one part of a multidisciplinary team management any changes in drugs, use of paramedical services,

and other treatments for both control and experimental groups should be reported. In short, to justify the therapeutic benefit of new innovations in education the same standards should apply as those used for other therapeutic manoeuvres. Many researchers in this field are now aware of these problems and randomised controlled studies are being adopted.^{15 16 24 28 39 47 50} Work on refining measurements of such variables as pain, disability, self efficacy, helplessness, coping, and social support is continuing.

Current attempts to promote patient education in the United Kingdom

Most reports on the education of patients with arthritis have been published by workers in the United States and, more recently, in Australia. Because of differing cultural and social circumstances, health care systems, and patient ascertainment it is difficult to apply these findings directly to a United Kingdom population or to use some of the available educational materials appropriately. Only two of the studies reviewed were conducted in the United Kingdom^{26 31} and both had limited and specific objectives. This does not, however, indicate a lack of interest or activity in the United Kingdom, but rather a failure to evaluate, record, and publish those projects which have been undertaken. Our own (far from exhaustive) personal inquiries have disclosed developing or operating programmes soundly based on the assessment of patient needs and the use of appropriate adult education methods in four cities (Salisbury, Bath, Leeds, and Newcastle), all directed towards the alleviation of symptoms. The development of a patient education programme in Bristol illustrates one approach.

The programme was designed for patients with acute flares of their RA who were admitted to a small eight-bedded rheumatology ward for bed rest, assessment, re-evaluation of treatment, physiotherapy, and occupational therapy review. Pilot studies were performed to gauge the knowledge, skills, and attitudes of these patients, and showed their preoccupation with pain relief by drugs, their low level of 'medical' knowledge, and their feelings of anxiety, depression, and loss of control of their lives. Based on the published material available (reviewed above), the advice of experts in mental health and adult education, and the results of the pilot studies, a patient education programme was devised considering the objectives shown in table 7. The aim of the programme is to provide basic knowledge, practical skills, and appropriate attitudes which will help patients with RA to improve their function, reduce their pain, reduce their use of health service resources, and take greater control over their lives. It is hoped that these benefits will manifest themselves over the months and years after the education programme. The course consists of seven group sessions, many individual patient interview or instruction sessions, and the ward self-medication scheme. It accommodates the need for many patients to rest in bed during their first week in hospital, and

Table 7 Objectives of the Bristol patient education programme

By the end of the programme the patient will:

Knowledge

- 1 Describe the variable nature of rheumatoid arthritis
- 2 Explain the effects, side effects, and regimens of the drugs they are taking for arthritis
- 3 Explain the simple principles of exercise for mobility and strength
- 4 Understand that people with arthritis get anxious and depressed, that this is variable, and that there are ways of coping with these feelings
- 5 Explain the simple principles of joint protection
- 6 Know that there is a list of agencies/individuals to contact for help for their arthritis and related problems
- 7 Know the basic principles of relaxation and of hot/cold treatment
- 8 Describe the features of a chair most appropriate for their condition

Skills

- 9 Demonstrate the use of hot/cold treatment safely
- 10 Demonstrate principles of joint protection using a tap, and other everyday objects
- 11 Demonstrate exercises for mobility and strength in the knee and one other appropriate joint
- 12 Design a daily programme which incorporates rest and activity
- 13 Demonstrate correct self medication

Attitudes

- 14 Believe they can reduce their pain by adopting self help techniques
- 15 Believe that adopting changes in their lifestyle and environment will be beneficial
- 16 Feel less anxious and depressed
- 17 Feel more in control

allows a number of topics to be introduced on a personal basis before they are dealt with in group sessions. It requires a commitment of 11 hours a week from the programme organiser but has almost no other resource requirements.

The programme has been implemented as part of a separately funded research project which aims to test if the patient education programme fulfils its educational objectives in the short term; to test the feasibility and practicality of running the programme successfully as part of routine inpatient management; to discover if it is acceptable to both patients and staff; and to assess the resources that would be required for continuing implementation of the programme. To evaluate the effectiveness of the programme the ability of patients to meet the objectives is tested at the beginning and end. The tests include a multiple choice questionnaire, interviews, the demonstration of skills, the Hospital Anxiety and Depression (HAD) Scale, and the Arthritis Helplessness Index.

Although this is a small uncontrolled study, preliminary results are encouraging and suggest that moderate but definite improvements occur in most patients' knowledge, skills, and attitudes. Should the final results confirm this impression then the patient education programme should be subject to a controlled trial.

Moving forward

In addition to the general need for evaluation of implemented or proposed education programmes, there are a number of specific issues which need to be considered. Is it possible to identify those patients most likely to benefit from education? At what stage in the disease process should we intervene—would too much education too early in the disease be counter-productive? What setting—for example, inpatients with a flare up or outpatients in a community setting when they are in less pain—is most conducive or practical? Can we provide more clear cut evidence from controlled trials to establish which exercises and joint protection practices have greatest therapeutic value? What are the most cost effective methods of delivering patient education?

We expect that as the enthusiastic specific interest groups for nursing and the paramedical professions in rheumatology develop and the medical profession offers increasing recognition and support for patient education these questions will be considered, and education will be able to make an effective contribution to the management of people with arthritis.

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