PATIENT EDUCATION

Advances in patient education in rheumatic disease*

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Health or patient education has been defined as 'any combination of learning experiences designed to facilitate voluntary adaptations of behaviour conducive to health'.¹ In this definition we would broaden 'behaviour' to include beliefs as there is growing evidence that beliefs, for instance, about one's ability to control one's health or life, can have both direct and indirect effects on health.²⁻³ This definition does not presuppose specific methods as health education draws on a number of fields, such as communication theory, group theory, learning theory and instructional design, counselling, psychology, and community organisation. Many educational approaches to patient education claimed by one discipline are claimed by another, albeit with differing theoretical justification or labels. The most effective programmes usually combine methods.

The goals of patient education in chronic disease are similar to those of traditional medical care: to improve function, relieve pain, enhance psychological wellbeing, maintain satisfactory social interaction and employment, and control disease activity. Securing informed consent for management options is an ethical obligation of medicine that is most effectively carried out by application of educational principles.⁴ This paper reviews recurrent research advances in aspects of patient education in North America.

Patient educators, especially in arthritis, have only recently come to view health outcomes as legitimate goals for their efforts and as reasonable standards for performance. Patient educators historically have concentrated on intermediate outcomes, such as knowledge and skill acquisition and alteration of behaviour, which were thought to lead to better health. Recent work, however, casts doubt on the assumptions about how education works and has opened up new possibilities. Newly considered intermediate variables may be grouped as sense of control, coping skills, and disease management skills. It now seems likely that many of the positive effects of educational programmes may be wrought, not so much through knowledge and behaviour change directly, but through enhancement of a general sense of control or efficacy and skill in coping with variability of the disease and its sequelae.

Review of current knowledge of patient education in arthritis

The volume of arthritis education research has expanded in the 1980s. Since 1982 there have

been three reviews of compliance with arthritis regimens,⁵⁻⁷ two reviews of psychological aspects of arthritis,⁸⁻⁹ two reviews of published work on education and research methodology,¹⁰⁻¹¹ and two meta-analyses of the impact on pain, disability, and depression of educational programmes.¹²⁻¹³ A recent article presents 'Research priorities for arthritis professional education'.¹⁴ We will review the published reports on arthritis education for effects on knowledge, behaviour, and health outcomes. Although most programmes have been tested on patients with rheumatoid and osteoarthritis, much is still applicable to less common rheumatic conditions.

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Dr Lorig and colleagues found 34 arthritis education studies measuring the effects of educational interventions on knowledge about the disease process and treatment; 32 (94%) of them found increases in knowledge.¹⁰ Thus educational programmes do increase patient knowledge. Although the transfer of knowledge is often not sufficient to bring about desirable intermediate outcomes and improvement in health, it is fundamental to all patient education efforts, and a cornerstone on which other methods must build. We also have ethical and legal obligations to inform patients about their disease and treatments so that they may make informed decisions. Studies of informed consent¹⁵ and doctor-patient communication¹⁶ indicate that patients are often poorly informed about their disease and treatment. Two surveys of patients with arthritis receiving active care also showed a surprising ignorance: 65% of patients in one study could not correctly name their arthritis diagnosis,¹⁷ and the other study found that 11% of patients with rheumatoid arthritis and 55% of patients with osteoarthritis could not identify correctly the type of arthritis they had.¹⁸

A striking observation in the majority of patient education studies in arthritis is that most subjects are 'experienced' patients and still seem able to learn things about their illness or treatment. That organised programmes consistently increase knowledge underlines the fact that room exists for improvement in the way we currently deliver information. Care givers, generally well meaning, may not recognise patients' desire for information¹⁵ or may lack the time or skills for patient education.¹⁶ Patients may be distraught and not ready to

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learn when the information is first given. Thus it seems that organised efforts, set aside for times when patients are ready to learn, may be consistently successful in improving the transfer of information.

We are past the point when tests of education *v* usual care are useful or newsworthy. We recommend that greater effort be devoted to setting standards, and comparing different educational approaches for effectiveness and efficiency—for example, classes *v* mailed lessons,¹⁹ computers,²⁰ individualised learning,²¹ and lay *v* professional teachers.²² We should also increase our efforts to develop ways of helping groups at high risk, such as patients with low literacy or who are non-English-speaking, and to improve doctor-patient communication and enhancement of patient question-asking. The rationale behind the last approach is that instead of determining what information patients need and spoon-feeding it, one teaches patients skills in determining what information they want and how to go about getting it. This skill might have more lasting impact than knowledge imparted in a discrete programme, as the information needs of patients can be predicted to change a number of times over the course of a lifetime with the disease.

BEHAVIOUR

Exercise, relaxation, joint protection, and adherence to medical regimens may affect patient health and psychological status. Lorig and colleagues¹⁰ found 48 arthritis education studies measuring attempts to change such behaviour. Of these, 37 (77%) showed increased practice of desired behaviour, which is consistent with findings from other chronic diseases,¹³ and indicates that behaviour can be changed, sometimes with longlasting effects.

Long term compliance with arthritis prescriptions for drugs, physical therapy, and physical modalities is about 50%, however, similar to compliance with regimens for other chronic diseases.^{5,6} This is not a failure of education itself, rather it is an indication that reinforcement may be necessary, just as repeated drugs or physical therapy are necessary to help manage a disease.

Mazzuca noted that adding a behavioural component to an education programme significantly increases its effectiveness.¹³ This may be due to the simple effects of repetition and reinforcement, known to increase efficacy, but is also likely to be due to the specific contributions of behavioural psychology. Information by itself often fails to bring about behavioural change, not because patients lack the will to change or ability to follow the desired behaviour, but because they lack the skills to overcome habit or forces in their environment. Behavioural psychology provides skills that enable subjects to modify their environment, and reinforcements so that they can successfully change intransigent behaviour.²³

Recently, there has been interest in whether behaviour acts directly to affect health outcomes. Controlled studies of health education have shown that although experimental groups conform more to the desired behaviour, and

show greater improvements in health outcome, the link between subjects' adherence to such behaviour and their health outcome has not always been clear.^{24,25} If this finding is confirmed it is of great importance. One possible explanation for this phenomenon is that training in behavioural skills enhances the patient's sense of control, which has been shown in health psychology publications²⁶ and in arthritis²⁷ to be widely associated with both physiological and psychological health benefits.

HEALTH OUTCOMES—PAIN, DISABILITY, AND DEPRESSION

Lorig's review of 76 health education studies found 46 (61%) showing improved health outcome,¹⁰ which was consistent with Mazzuca's¹³ rigorous meta-analysis of this field. Mullen's meta-analysis of 15 controlled educational interventions for rheumatoid arthritis and osteoarthritis¹² found that educational interventions significantly reduced pain, disability, and depression. On average, the improvement of treatment groups over controls for pain was 16%, for depression 22%, and for disability 8%. Although only about one fourth as effective as non-steroidal anti-inflammatory drugs for reducing pain and about half as effective for reducing disability, the improvement achieved by educational programmes is nevertheless clinically significant. The improvements are all the more impressive when one considers that most patients receiving education were already taking drugs, so that the educational effect was additive. One may conclude, then, that well organised, multifaceted educational programmes of a great variety of types can be effective in achieving clinically significant health outcomes over and above usual medical care and office based education.

Training in patient education for doctors

It has been shown repeatedly that doctors' communication skills and manner of giving information significantly affect patients' outcomes, including their knowledge, satisfaction, compliance, function, and health.²⁸ There is as yet little research specific to doctors and patients with arthritis. A two week preceptorship in arthritis management for primary care practitioners²⁹ resulted in significant improvements in doctors' use of diagnostic tests and corticosteroids, doctors' responsiveness to patients' requests for information, and patients' functional outcomes. Studies by investigators at the University of California, Los Angeles, and the Multipurpose Arthritis Center at the Robert B Brigham Arthritis Center, Boston, are currently evaluating interventions to improve doctor-patient communication in the management of rheumatic conditions.

Most doctors believe that patient education is an important part of their clinical practice. Surveys of community based internists³⁰ and primary care residents,³¹ however, indicate that although many practitioners attempt patient education, for most topics the majority of practitioners provide little education; many feel unprepared or uncomfortable, and doubt the effectiveness of their efforts. Doctors often

underestimate patients' desire for information, and overestimate patients' knowledge about their medical problems, whereas patients often feel intimidated and ask fewer questions than they would like to ask.¹⁵ In the absence of other evidence we infer that rheumatologists' patient education practices are similar to those of other internal medicine specialists.

Although doctors are receptive to the need for improved training in the skills of counselling patients, there is little time devoted to this area in medical education. A survey of United States internal medicine residency programmes accredited in 1985–86 found that only 191 (44%) of 434 responding programmes offered mandatory training, and only 78 (18%) offered elective training in areas related to patient education.³² Obstacles cited by residency directors included insufficient curriculum time (51%), lack of trained faculty (44%), and pressures to reduce both training costs (40%) and patient care costs (37%).

Summary

Education of patients with arthritis began with an emphasis on conveying knowledge, grew to include behaviour change, compliance, and more general coping and management of disease and then progressed to consider physical and psychosocial health outcomes. Research continues in all these areas. Control, in many forms (locus of control, self perceived efficacy, learned helplessness), is now suggested to be a central mediating variable.

Evaluation of programmes is moving away from programme *v* usual care towards comparison of alternative methods of delivery and matching of method to learner. The first generation of researchers in arthritis education tended to be care givers with little formal education in behavioural sciences and evaluation methodology; the programmes they designed were often empirically based. The current generation, nurtured in large part by funds from the Arthritis Foundation and the National Institutes of Health, is better trained in designing programmes grounded in behavioural sciences and educational theory. In the long run, collaborations with care givers and patients will considerably strengthen the effectiveness of education programmes for patients. A variety of educational strategies have been shown to change the knowledge, behaviour, and health of patients with arthritis for the better. Many methods seem to work, so long as the programme is planned, has a goal, and is accountable. There is much work still to be done to teach care givers to be better teachers, and patients to be better managers of their diseases, in concert with their doctors, and to focus on high risk groups. Although most work has been done with patients with rheumatoid arthritis and osteoarthritis, many of these findings can and should be safely generalised to less studied rheumatic diseases. Finally, we need to consider the patient first as a person, and to provide education through all avenues, not just the medical care system.

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