Patient education in rheumatic disease

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This review looks at the various facets, pros, cons and developments in patient education for people with rheumatic diseases.

One in seven of the population suffers from a significant rheumatic disease. This accounts for one third of all severely disabled people in the country. Many of the disabling systemic forms of arthritis are painful, debilitating, life altering and incurable.

Disease management attempts to control the inflammatory process, relieve pain, prevent joint destruction and deformity and minimise physical, social and psychological dysfunction. Even the best management programme can be thwarted, however, by the unpredictability of a disease such as rheumatoid arthritis (RA), in which symptoms can vary dramatically from day to day.

A woman with severe RA described her own recent experience. She had just undergone a severe 'flare'; her morning stiffness had lasted about five hours and she described her pain as 'excruciating'. After what she depicted as 'living in hell' for a week, she woke one morning with no stiffness and little or no pain. This state continued for a further week before her symptoms gradually started to reappear. She asked the question: 'How do I cope with that?'

Clearly, treatment programmes must be tailored to the individual patient's day-to-day disease activity. This means he or she must have the knowledge to regulate daily exercise programmes, plan rest/activity periods and adjust drug regimes accordingly; few patients acquire this knowledge without some professional assistance (1). Patient education (PE) is therefore an important consideration in their care.

Patient education Educating patients about arthritis and its treatments is accepted by the majority of health professionals as an essential component in the management of rheumatic disease, but to be successful, programmes must be planned and systematic with clearly defined, achievable objectives.

Over the years, both formal and informal group and one-to-one programmes have been developed for people with arthritis. The majority originated in the United States, but more recently programmes have also been designed in Australia (2).

Regardless of the format of the patient education programme, the aims are essentially to enable patients to participate effectively in their own management, develop coping skills, make informed choices about their treatments and weigh up the consequences of their own actions or inactions (3). In essence, PE provides them with choice.

Access to PE. PE programmes have been developed for patients who are admitted to hospital. One such programme is held at Chapel Allerton Hospital in Leeds. Here, groups of patients are
PE programmes aim to enable patients to participate in their management and develop their day-to-day activities. Taught by members of the multidisciplinary team in one-hour blocks. A different topic is discussed at each session and the programme lasts for 10 days. The PE programme is then repeated so patients can join at any point in time.

This type of PE programme is held in a number of hospitals throughout the country. Each hospital has developed its own programme, but most would include some core topics (Fig. 1).

Only a minority of patients with rheumatic disease are admitted to hospital. The majority are treated in outpatient clinics or by their GPs. Outpatient PE programmes, such as those provided in nurse-led clinics (Fig. 2), have shown to be as effective as in-patient programmes in increasing knowledge (4, 5), promoting self-care activities (6) and improving outcomes (5).

A small but growing number of nurses are also providing a link between hospital and community, co-ordinating an effective extended team approach to PE (7). Yet only a minority have access to a systematic PE programme (8).

Until recently, PE programmes have been taught almost exclusively by health professionals. In the US, however, Lorig has pioneered the use of trained lay teachers. They work in pairs, teaching an arthritis self-management course, a 12-hour community based programme.

A series of studies has shown that lay teachers are well accepted by professionals and patients in the US, and are as effective as health professionals in their teaching (9, 10). This method of PE has become commonplace in Australia and New Zealand, and a similar programme is now being assessed by Arthritis Care in the UK.

**Methods of providing information** A number of studies have looked at different types of educational material and alternative methods of imparting knowledge. In a controlled study of five styles of illustration presented in a booklet for patients with osteoarthritis, Moll concluded that pictures in booklets enhance communication, and certain picture-text interactions appear to increase comprehension (11).

Written information is often provided in booklet form. A comparative study of two booklets about RA found that the one which contained more comprehensive information was more effective in improving knowledge (12).

Computer-based education lessons have been advocated as one solution for patients with learning difficulties, and a PE computer programme for patients with RA proved to be very successful (13). Patients have expressed a preference for information about their drug treatments to be in the form of leaflets, and the effectiveness of this method has been evaluated and shown to be successful (14). More recently, video tapes backed up by booklets have been shown to be useful additions to PE in the UK (15).

**The effects of PE** Formal PE programmes for arthritis were founded in the US in the early 1970s, and subsequent research has shown many positive effects: they increase knowledge, improve compliance, change behaviour and decrease a variety of disease symptoms.

**Comparable effect** A meta-analysis of 15 PE studies showed the effects of these programmes to be comparable with non-steroidal anti-inflammatory drugs (16). In a comprehensive review by Lorig, the results from 76 PE studies were analysed. Positive improvement was demonstrated in patient knowledge, self-care behaviours, medication adjustment and compliance, and psychosocial characteristics such as anxiety, depression, self-esteem, locus of control and health status (17).

**Changes in knowledge** Studies have shown that people with RA know little about vital subjects such as their medication (18). PE increases patient knowledge of these topics.

In 1976, Vignos and colleagues carried out
pre- and post-testing on 20 RA patients who had attended lectures and been supplied with literature. Patients increased their knowledge after reading the booklet, but their knowledge was significantly greater when literature was combined with lectures (19). A study on audio-visual teaching, consultation with a health educator and printed take-home material also resulted in significant improvement in knowledge (20). A more recent study from the UK which compared knowledge in patients attending a nurse practitioner or a consultant rheumatologist in an out-patient clinic showed highly significant differences and improvement in those attending the nursing clinic (21).

Many other researchers have established significant knowledge gains in patients with RA (22, 23), but programmes for other diseases have also been studied. A controlled study of patients with ankylosing spondylitis showed that PE increased knowledge and adherence to exercise programmes (24).

In a two year pre- and post-test study of 63 gout sufferers, knowledge scores increased over time (25), and a research project on osteoarthritic patients resulted in improved knowledge and ability to perform exercises (26).

**Self-care** Increases in knowledge are probably of little use unless they lead to improvements in outcomes. In rheumatic diseases, self-care activities such as exercise and joint protection techniques are considered to reduce pain, disability and depression. PE related to these activities leads to an increase in their practice (17).

In 1978, Swartz et al showed that 14 patients attending weekly teaching sessions given by a multidisciplinary team experienced fewer flares, enhanced their communications and improved compliance and clinic attendances (27). A controlled study in patients with systemic lupus erythematosus undertaking a PE class demonstrated that depression was significantly dispelled (28). This is in keeping with Lorig's findings which showed depression was reduced in none of the 17 studies in which it was measured (17).

Energy depletion, resulting in reduced physical activity, is a symptom commonly experienced by patients with inflammatory diseases. Results from a PE programme to teach energy conservation behaviours suggest such strategies can increase physical activity in RA patients (29).
by Donovan et al, it has been suggested that giving information soon after the onset of disease increases depression (59).

Conclusion The literature, mostly from the US, supplies abundant evidence that teaching patients with arthritis about their disease brings many benefits. Although a number of centres in the UK are undertaking programmes of PE, with a few exceptions (1, 33, 36), there is little research into efficacy in this country.

Perhaps this will change as the government is now providing some much needed encouragement through The Patient's Charter and The Health of the Nation. Clearly, these offer an inherent right to information, which studies suggest patients want (14). Nevertheless, some still argue that at a time of rising healthcare costs, PE entitlement must be weighted against health benefit (40), making further UK research into the efficacy and adverse effects essential.

One area which could prove the worth of PE in both financial and therapeutic terms is that of adherence to drug therapy. Non-compliance has been shown to be a major problem in RA and is thought to be one of the most important causes of treatment failure (41). Many believe that non-compliance with drug therapy could be reduced through patient teaching, but the link with PE remains unproven (42). A new randomised controlled study is now being undertaken using a biochemical marker as its primary measure of drug compliance.

There is no doubt that teaching patients is time consuming and therefore expensive, and as yet the debate on the most effective method of teaching is unresolved. Patients are individuals with a variety of beliefs, living in differing cultural and social networks. Each will have different needs and may learn in different ways. What has been shown is that there is a wide variation in knowledge among patients with rheumatic diseases (43), and whichever method of imparting knowledge is used, it is important to assess what the patient knows beforehand by use of a validated tool. This ensures time and resources are not wasted.

References

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