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ABSTRACT

Hill, J. (2003) An overview of education for patients with rheumatic diseases. *Nursing Times*; 99: 19, 26-27.

Patient education is central to enabling patients with rheumatic diseases to manage their lives and live as fully and independently as possible. This education can be provided in a range of formats including individual or group sessions, through an arthritis self-management programme and opportunity education, which is informally taught by health professionals. The format selected should be suitable to the individual patient at the particular time it is delivered, and the education should include both topics that health professionals know are relevant and those that patients have cited as being important to them.

An overview of education for patients with rheumatic diseases

A PRINCIPAL aim of nursing is to help patients to manage their lives and live as fully and independently as possible. In rheumatology, patient education is central to achieving this, as it encourages and helps them develop the positive coping mechanisms that they need if they are to achieve a reasonable quality of life in spite of their condition.

What is patient education?

Lorig (1996) defines patient education as 'any set of planned, educational activities designed to improve patients' health behaviours and/or health status'. This definition emphasises that patients' behavioural changes can improve their health status, and that education is more likely to succeed if it is underpinned by a proven theory such as self-efficacy (Bandura, 1977). Patients who exhibit a high degree of self-efficacy believe that what they do can make a positive difference to their health, and this in turn influences their behaviour and their health outcomes.

Patient education has evolved over the decades. Before the 1970s, doctors provided information about the body and its workings. This model suggests that patients' health is the responsibility of health professionals, and that little or no contribution from the patient is necessary. The recognition in the 1970s that transferring information from professional to patient had many shortcomings led to a change of emphasis to promoting self-care. Since then the process has progressed and modern education programmes incorporate the concepts of extended information transfer and self-responsibility.

Patient education in the rheumatic diseases

Modern therapies such as the biologic agents for rheumatoid arthritis (RA), which are based on knowledge of its pathogenesis, have had a positive impact on the management of rheumatic disease. Researchers identified cytokines as major mediators of immune and inflammatory function. Interleukin-1 (IL-1) and tumour necrosis factor alpha (TNF- α) were found to be particularly important, and IL-1 was the first cytokine to be shown to promote the degradation of cartilage. Drugs such as anakinra that inhibit its biological action are now available by daily injection.

Anti-TNFs are agents that block TNF- α and thus slow the progression of RA. Two new anti-TNFs, etanercept and infliximab, are available and work in different ways.

Soluble proteins in etanercept mimic the receptors that TNF- α normally binds to on particular cells, removing it from circulation, while infliximab produces antibodies that work against TNF- α . Infliximab is a monoclonal antibody to TNF- α , made by combining a human immunoglobulin with a binding region produced in mice.

Although biologic agents appear to be highly effective in slowing the progress of RA, it is still important for patients to undertake self-care activities and, therefore, to receive education. These treatments are not available until the patient has failed to respond to a number of other disease-modifying drugs, and by this time the disease process will probably have damaged the patient's joints. Also, approximately 30 per cent of patients do not respond to biologics and even those with a good response may experience day-to-day variability of symptoms such as pain, stiffness, malaise, and fatigue, which can exacerbate psychological effects such as anxiety and depression.

Social dysfunction remains a common feature of RA, and the condition can have a major impact on the quality of life of patients and those close to them. No matter how effective the treatment, the management of rheumatic diseases depends on patients' ability and willingness to adhere to all their therapies.

Patient teaching

Lorig (1996) has distinguished between patient education and improving knowledge, stating that activities aimed at the latter constitute 'patient teaching'. In clinical practice, many rheumatology nurses believe that teaching patients about their disease and treatments is an integral part of care, indeed many clinical nurse specialists see it as one of their main priorities (Carr, 2001).

Providing information is a fundamental ethical, legal and professional obligation for health professionals - particularly as studies have demonstrated a widespread lack of knowledge about rheumatic diseases and their treatments (Hill et al, 1991). Moreover, patients have expressed their wish to increase their knowledge (Bishop et al, 1997). To perform self-care effectively, patients must be able to vary drug doses according to their symptoms and dissociate their symptoms from the possible side-effects of treatments. Few will acquire the necessary level of knowledge without access to a programme of education that includes information transfer.

TABLE 1. ADVANTAGES AND DISADVANTAGES OF GROUP AND INDIVIDUALISED PATIENT EDUCATION

Type of education	Advantages	Disadvantages
Individual patient education	<ul style="list-style-type: none"> ■ Flexible to each patient's needs ■ Topics can be tailored to the patient ■ Patients can decide the topic order and dictate pace of teaching 	<ul style="list-style-type: none"> ■ Does not facilitate shared experiences or resolutions to problems ■ No interaction with other patients – not a sociable activity
Group patient education	<ul style="list-style-type: none"> ■ Other patients can act as powerful role models ■ Patients can learn from each other ■ Facilitates social interactions ■ Less labour intensive than individual education ■ Relatively cheap ■ Good for teaching generic principles such as: <ul style="list-style-type: none"> - disease process; - families of drugs; - joint protection; - principles of exercise; - relaxation techniques. 	<ul style="list-style-type: none"> ■ Some patients do not want to join groups ■ Patients may have a wide range of knowledge and experience: <ul style="list-style-type: none"> - different rates of learning; - different levels of skill; - fear of criticism. ■ One articulate patient can dominate the group ■ Less advantageous when patients: <ul style="list-style-type: none"> - are starting a new drug treatment; - have learning difficulties; - need individualised exercise or joint protection programmes.

Types of patient education

Patient education can be delivered in many formats:

- Individual education taught, for example, by a specialist nurse through a structured or informal programme;
- Group education taught by a team of health professionals through a structured programme;
- Arthritis self-management programmes taught by lay people and health professionals through a structured programme;
- Opportunity education taught informally by health professionals. The two most common methods used are individual and group education, both of which have their advantages and disadvantages (Table 1).

Individual education

Individual patient education is the format most commonly used by nurses in the UK. Many provide it when patients attend clinics for routine monitoring of disease-modifying anti-rheumatic drugs, a format that is both practical and effective (Hill et al, 2001). One of the most positive aspects of one-to-one patient education is its flexibility. Although the programme needs to be planned, it can be tailored to patients' individual needs by including topics that are important to them at a pace that suits them.

Group education

Group education is epitomised by the Arthritis Self-Management Programme (ASMP), which was devised in the USA (Lorig et al, 1986) and is used extensively in Canada, Australia and Europe, including the UK. It is a community-based programme of six two-hour sessions delivered over a period of months by professionals and people who have arthritis. All programmes should include topics that professionals know are relevant and that patients have cited as being important to them, including: knowledge of disease; symptom management; drug treatments; protecting joints; exercising; diet; sexual life; coping strategies; communicating and goal setting.

Effectiveness of patient education

A number of authors have reviewed the effects of the various types of patient education. Lorig et al (1987) concluded that knowledge increased in 94 per cent of studies reviewed – 77 per cent demonstrated increased practise of beneficial behaviours, 64 per cent showed positive changes in psychological state and 61 per cent demonstrated improvement in health status. Reimsma et al (2002) found that education for patients with RA had a small but significant effect on anxiety and depression, tender joint counts, disability and patients' overall assessment of their condition. Of the three forms of intervention scrutinised (counselling, providing information and behavioural treatments) only behavioural treatments demonstrated significant improvement.

Although these results are interesting, the reviews take no account of the appropriateness of different interventions at different stages of patients' adjustment to their disease. Newly diagnosed patients often go through something akin to grieving, and their initial reaction may be denial. It would be inappropriate to begin an education programme at this stage. Patients need time to come to terms with their situation and at this stage the nurse's role is to support and counsel. Providing information can begin when patients start seeking information, and motivational interviewing will prepare them to undertake behavioural changes to their lifestyles. Once patients are receptive, education can commence.

Conclusion

Patient education aims to maintain or enhance patients' health status by improving their self-efficacy and encouraging positive behavioural changes. The accumulation of knowledge alone cannot do this. Education is a complex process, and maximum effectiveness will only be reached if it is presented to the right patient at the right time in an appropriate format. This means a variety of strategies should be employed at different stages of a patient's illness, taking into account individual needs and preferences. Whatever the format of education, the role of rheumatology nurses is to educate, enable and empower patients so that they can manage their lives, minimise their symptoms and live as fully and independently as possible. Delivering appropriate patient education goes some way to achieving this goal. ■

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