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Autoimmune diseases

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Rheumatoid arthritis

Rheumatoid arthritis (RA) is an autoimmune symmetrical inflammatory arthritis of unknown cause. It is hypothesised that various factors, including infection, stress and trauma might act as initiating factors in people with a genetic disposition (Arthur 1998). RA is characterised by inflammation of the synovium (a substance that lines the joints and tendon sheaths of the body) and increased synovial exudate, which result in thickening of the synovium and joint swelling. The condition is characterised by a symmetrical small joint polyarthritis involving the hands and feet, but larger joints can also be affected.

The autoimmune response initiates an immune complex, which activates the inflammatory process. Inflammation is usually a self-limiting event, which continues until the antigen is destroyed. However, in RA, the immune complexes are not deactivated and the continuation of the inflammatory response can result in severe joint destruction. In RA the immune reaction commences in the joint, where the synovial lining of the capsule becomes inflamed and congested with T lymphocytes, B cells, macrophages and plasma cells (Firestein 1994). This causes proliferation of the synovial membrane, which erodes the bone, resulting in altered function. Local signs of inflammation include redness, heat, swelling and pain. The systemic nature of inflammation can result in extra-articular features, such as fatigue, anaemia and weight loss. Systemic manifestations of RA are outlined in Box 1.

Patterns of presentation

The most common form of presentation occurs typically in the fourth or fifth decade of life and manifests as an insidious onset until the antigen is destroyed. However, in RA, the immune complexes are not deactivated and the continuation of the inflammatory response can result in severe joint destruction. In RA the immune reaction commences in the joint, where the synovial lining of the capsule becomes inflamed and congested with T lymphocytes, B cells, macrophages and plasma cells (Firestein 1994). This causes proliferation of the synovial membrane, which erodes the bone, resulting in altered function. Local signs of inflammation include redness, heat, swelling and pain. The systemic nature of inflammation can result in extra-articular features, such as fatigue, anaemia and weight loss. Systemic manifestations of RA are outlined in Box 1.

Epidemiology

RA affects approximately one million people in the UK (Hill and Ryan 2000). The prevalence is 1:200 women and 1:600 men (Le Gallez 1996), although the distribution among the sexes is more even over the age of 60. RA occurs globally, with severe presentations evident in Northern Europe (Lawrence 1994).

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In brief

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Summary
Rheumatoid arthritis is the most common form of inflammatory joint disease in the UK, affecting about one million people (Hill and Ryan 2000). The authors discuss the patterns of presentation, clinical features and nursing management of this condition.

Key words
Arthritis and rheumatism
Multidisciplinary teams
Nursing: care
Nursing: role

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onset of symmetrical small joint polyarthritis, affecting the metacarpophalangeal (MCP) and proximal interphalangeal (PIP) joints in the hands and the metatarsophalangeal (MTP) joints in the feet (Cushnaghan and McDowell 1999). As the disease progresses, other joints might also be affected, including the wrists, elbows, shoulders, cervical spine, ribs, temporomandibular joints, knees and ankles. An initial presentation and diffuse swelling is more commonly seen in older persons. RA can also present in a monoarticular form affecting larger joints such as the shoulders or knees. The symptoms might be confined to these areas or become more generalised affecting other joints.

**Clinical features** The American Rheumatism Association’s revised criteria for the classification of RA provide guidance on diagnosis (Box 2). Common clinical features include:

- Pain – often the first symptom experienced by the patient, it can vary in its intensity and location on a daily basis. Pain is often accompanied by early morning stiffness, which can range from a few minutes to several hours and is an indicator of disease activity. Joint pain is assessed by direct palpation of the joints and can assist in the assessment of disease activity.
- Joint inflammation – can be periarticular (in the area around a joint) or intra-articular (within a joint). Symmetrical swelling of the MCPs and PIPs is typical of RA. The features displayed in the hands are often a reflection of the patient’s overall condition, which could be early, late or progressive. Tendons are also sheathed with synovium and in extensor tenosynovitis swelling occurs over the dorsum of the wrist. Rupture occurs more commonly in extensor tendons than flexor tendons.
- Reduced joint function.
- Muscle weakness – can be an early feature of RA and might lead to marked muscular atrophy.
- Extra-articular features including subcutaneous nodules.

**Investigations**

Laboratory investigations can inform the diagnosis and progression of RA, although the diagnosis is often established from the clinical history and examination.

**Rheumatoid factor** The rheumatoid factor (RF) is an immunoglobulin complex of immunoglobulin G (IgG) and immunoglobulin M (IgM). It is present in approximately 70-90 per cent of patients with RA and can be absent in the first three to six months following diagnosis (Hill and Ryan 2000). Patients with RA who have this complex are classified as being seropositive. A titre of 1:32 is classified as weakly positive and a ratio of 1:64 and above indicates more active disease (Hill and Ryan 2000). RF is present in at least 1 per cent of the normal UK population and is not diagnostic of RA when other clinical features of the condition are absent (Hill and Ryan 2000).

**Acute phase reactants** Non-specific indicators of inflammation include the erythrocyte sedimentation rate (ESR) and the C-reactive protein (CRP). Both markers can be used to monitor disease activity in RA. The normal range of ESR is 4-20mm/h for males and 10-25mm/h for females. Infection, myeloma and age can raise the ESR. The normal range of a CRP is 0-9mg/l. A consistently raised CRP is associated with severe disease.

**Radiographs** X-rays of the hands and feet often reveal evidence of the condition, including soft tissue swelling around an affected joint and enlargement of the joint cavity. As the condition progresses, periarticular osteoporosis and articular erosions with loss of joint space can occur. The presence of erosions is an indicator of poor prognostic outcome. Factors associated with severe disease and subsequent poor outcome include:

- Presence of extra-articular features.
- Radiological evidence of erosions.
- Rheumatoid factor positive.
- Uncontrolled polyarthritis.

**Synovial fluid examination** The synovial membrane secretes synovial fluid. The aspiration and subsequent examination of the fluid can aid diagnosis. The number of white blood cells present can indicate whether it is a non-inflammatory, inflammatory or infective condition.

**Management**

The management of RA is focused on relieving pain, modifying the level of disease activity and maintaining optimal functional ability for each individual. A dedicated multidisciplinary team can provide a wide range of support for patients, their families and the primary healthcare teams (Box 3), resulting in an effective ‘triangle of care’ (Fig. 1). All members of the team are actively involved in education to enhance care for RA patients.

Specialist knowledge and skills are required to identify the key issues arising from each individual’s needs and perceptions of RA. The patient’s initial needs might vary depending on:

- The length of illness before attending the department.
- Severity of the disease.
- Previous knowledge of RA.
- Perceptions of ‘illness’.
- The individual’s normal coping strategies.
Patient education

Patient education and self-management programmes provide a framework for patients to become the key decision makers in their care. The aim of patient education is to empower patients and improve their health status by changing negative health behaviours (Hill 1998). Patient education should be the earliest intervention as there is little point in prescribing medication, advocating changes in lifestyle, or suggesting other interventions if patients have no concept of the disease process and how a team approach can promote rehabilitation. Initially, this should be undertaken on a one-to-one basis, tailoring information and support to the patients’ needs, health status and the level of pain control at diagnosis, as well as their ability to assimilate information. With the patient’s consent, partners and carers should be included in the educational programme.

Research has highlighted difficulties in providing information for patients and identified that information recall immediately after a clinic appointment is limited (Cameron 1996). It is essential that written information should always support any advice given. Providing written information (or the use of audiovisual aids) means that relatives are able to review the information and gain a better understanding of the consequences of the disease process. Patient education programmes (PEPs) should be provided in tandem with the regular support and education each patient receives. PEPs involve small groups of between five and ten patients, who attend regular sessions over a period of one or two weeks. These programmes should include information on:

- The disease process – aetiology, symptoms, blood tests and investigations.
- Medication – disease modifying antirheumatic drugs (DMARDs), steroids and biologics.
- Pain management – analgesia, non-steroidal anti-inflammatory drugs (NSAIDs), joint injections, as well as managing fatigue and promoting relaxation.
- Exercise and joint protection.
- Complementary therapies.
- Nutrition.
- Goal-setting, self-help support groups and managing a flare (an increase in physical symptomatology, for example, pain, swelling and fatigue).
- Podiatry.


Medication

A range of pharmacological interventions is used in the management of RA. Patients might be prescribed medication for pain control, DMARDs, which are sometimes referred to as slow-acting antirheumatic drugs (SAARDs), biologics, such as anti-tumour necrosis factor alpha treatments, and intravenous, oral or depot injections of corticosteroids.

The management of patients with RA receiving long-term treatment for their disease relies on the principles of informed consent (Dimond 2001a and b). Patients should have an opportunity to discuss their medication and the potential risks and benefits of treatment. This advice should be supported with written information. Research has identified drug treatment and side effects as an area of significant concern for patients with RA (Bath et al 1999).

**Fig. 1. Triangle of care**

- Patient and family
- Primary care team
- Rheumatology team
- Enhances patient and family empowerment
- Provides a seamless service

**TIME OUT 2**

Write notes on how you would explain the disease process to a patient with RA. Imagine a patient who has been newly diagnosed with RA, how would you begin to assess his or her education needs?

**TIME OUT 3**

Write down the information and advice you would give to a patient who is experiencing moderate systemic and local pain due to RA.

**Box 3. Multidisciplinary roles**

- **Medical**
  - Diagnosis
  - Prescribe pharmacological treatments
  - Physical assessment
  - Referral to other members of team or specialist support
  - Review – general medical and functional
- **Nursing**
  - Education
  - Advice on pain management
  - Drug information
  - Treatment monitoring
  - Review of functional ability
  - Social/psychological support
- **Physiotherapy**
  - Functional assessment: range of movements, gait analysis
  - Exercise regimens – water and land-based
  - Pain relief
  - Improving mobility using goal setting
  - Walking aids
- **Occupational therapy**
  - Joint assessment, protection and splinting
  - Assessment and advice on need for energy-saving aids
  - Home assessment, assessment of daily activities of living
  - Pain management, relaxation
  - Work assessment and redeployment advice
- **Psychologist**
  - Psychological assessment
  - Support in coping with grief, denial, poor self-esteem and pain management
  - Theoretical expertise in psychological aspects of chronic disease
- **Podiatry**
  - Assessment of foot function and deformities that restrict gait
  - Pain relief
  - Adaptation of shoes
  - General chiropody advice
- **Dietician**
  - Assessment of nutritional need and intake
  - Improving nutritional intake
Autoimmune diseases

Pain is a cardinal feature of RA and is the most significant symptom of the disease. Most patients with RA need to rely on regular pain relief. Chronic uncontrolled pain can quickly lead to a cycle of sleeplessness, fatigue, loss of appetite and depression (Hill and Ryan 2000). This can result in a loss of perceived control over the disease and the ability to adequately control pain. However, analgesia alone is not the answer and the psychological aspects of pain management should be considered simultaneously with pharmacological preparations. Health professionals should spend time learning to understand the patient’s perspective on health, illness and any other social issues that might reduce his or her ability to focus on pain control. Distraction and relaxation techniques can be used to support the pharmacological interventions and help patients to explore the multifaceted aspects of pain management.

Pain management Regular non-opioid analgesia can be advocated for the relief of mild to moderate pain. Pharmacological options for pain relief are outlined in Box 4. It is important to ensure that patients receive adequate education to enable them to use a step-up or step-down approach to pain relief.

The anti-inflammatory, antipyretic and analgesic properties of NSAIDs can help to reduce pain and early morning stiffness. Once the disease is being managed and pain management is well established, the dose of analgesia and NSAIDs can sometimes be reduced. There are moderate risks associated with the long-term use of NSAIDs and patients need to be fully assessed on a regular basis. The development of a class of NSAID called Cox II has demonstrated an ability to reduce significantly the risk of gastrointestinal side effects in some patients (Emery et al 1999). The National Institute for Clinical Excellence (NICE 2001) advocates the use of Cox II for patients at high risk of developing serious gastrointestinal complications.

Local pain control can be achieved in some joints with the use of:
- Ice packs on hot and painful joints.
- Topical application of NSAIDs creams.
- Hot baths to reduce pain and joint stiffness, especially in the morning.
- Splinting to protect the joints.

Disease-modifying anti-rheumatic drugs DMARDs are used to suppress the disease process and prevent the development of erosions and deformities. Current opinion supports early and aggressive treatment with DMARDs (Brooks 1998). These drugs are toxic and require frequent monitoring to reduce the risk of toxicity (Box 5). Research has demonstrated the benefits of using combination therapy (two or more DMARDs), and there is little evidence of any additional toxicity as a result of using combination treatments (O’Dell and Scott 1999). The role of the nurse in supporting patients on DMARD treatment involves providing advice and literature on the risks and potential benefits of specific drug treatments. Nurses also need to ensure that patients are assessed and reviewed before and after treatment, and all assessments and advice should be carefully documented. Regular blood monitoring is required to assess the safety and efficacy of the new treatment alongside ongoing support and education of the patient, especially as it takes several months before the benefits of the treatment become apparent. Primary health-care teams need to be informed of the patient’s treatment plan so that they can monitor the effectiveness of treatment, assess side effects and monitor any changes in drug regimens.

Biologics During the past decade, new therapeutic options termed ‘biologics’ have become available. These drugs act on altering the normal immune response by blocking the normal inflammatory process. Biologics block tumour necrosis factor alpha, a cytokine that is implicated in launching an inflammatory response.

These drugs are now being administered in intravenous (infliximab) and subcutaneous treatments.
(etanercept). The management of patients receiving these drugs requires specialist nursing expertise to ensure thorough screening of patients for infection before treatment and to monitor the benefits of treatment. Patients need to be screened for infection as there is the potential for the new biologic agents to increase the risk of infection – it is not advisable to commence this treatment in patients with co-existing infection.

Research in this field is ongoing and knowledge gained has informed researchers targeting other potent cytokines implicated in the inflammatory cascade.

**Corticosteroids**

Corticosteroids have the potential to reduce pain as a result of their anti-inflammatory effect, however, long-term treatment with steroids in RA remains controversial (Hill and Ryan 2000). Therefore, corticosteroids are used mainly to achieve remission and symptom relief during exacerbations of the disease.

**Management of functional ability**

Maintaining functional ability requires a multidisciplinary approach to assessment and recognition of deterioration in a range of movements. The role of the physiotherapist in assessing patients and advising them on appropriate exercise regimens is crucial. Hydrotherapy – the use of warm water for exercise – is an important part of physiotherapy for patients with RA. Patients generally find exercising in water relaxing and rewarding (Hill and Ryan 2000). Hydrotherapy programmes should be supported by the patient’s own regular exercise regimen. The benefits of exercise need to be reinforced regularly as patients might find exercising time-consuming and boring. Exercise helps to maintain general body endurance and muscle strength, and reduces the risk of a decreased range of movement and functional limitation.

The role of the occupational therapist in assessing the needs of patients is paramount in enhancing their independence and quality of life. Joints that are painful, hot and inflamed are vulnerable to damage, and movement increases pain. A thorough assessment of hand function, general mobility and the activities of daily living (ADL) will provide information to guide the changes needed to enhance the ability of the patient to maintain these activities. Using simple aids can often result in a significant reduction in pain and time taken to undertake tasks, and this can boost self-esteem. The occupational therapist provides:

- Splints for the protection of damaged and vulnerable joints.
- Practical skills on energy conservation, for example sitting down to do the ironing, and pacing (achieving a balance between exercise and rest).
- Assessment of the home environment for safety and practical aspects of daily living, for example, safe access to bathing and the use of kitchen equipment and stair lifts.
- Information on positive coping strategies.
- Educational advice and support on the work environment or redeployment.
- Review and regular assessment of ADL.

**TIME OUT 4**

Reflect on how you might feel if you had RA. Think about the effect this diagnosis would have on your psychological and social functioning, and aspects of wellbeing. Discuss with a colleague what you think the nurse’s role should be in enabling patients to address and manage this aspect of their condition.

**General wellbeing**

Patients with poor nutrition are at increased risk of tissue damage, muscle wasting and weight loss. This can sometimes be attributed to an exacerbation of the disease. Many aspects of general wellbeing are interconnected to other areas discussed in this article, including pain, function and psychological status. In addition to these issues, patients should have access to:

- Psychological support from a trained psychologist.

**Box 5. Disease-modifying antirheumatic drugs and main side effects**

- Hydroxychloroquine
- Azathioprine
- Cyclosporin
- Cyclophosphamide
- Leflunomide
- Methotrexate
- Gold salt (sodium aurothiomalate)
- Penicillamine
- Sulphasalazine
- Biologics

**Side effects of all DMARDs**

- Bone marrow suppression
- Increased risk of infection due to immunosuppression
- Renal dysfunction
- Gastrointestinal effects – diarrhoea and nausea
- Pulmonary – pneumonitis
- Cytotoxic cautions – infertility or potential damage to unborn child/breastfeeding infant
- Skin reactions
- Loss of hair
Box 6. Management of altered body image

- Focus on positive aspects of adaptation to improve the patient’s confidence and reinforce that the patient has successfully adopted coping strategies in other areas of care management
- Adapted equipment can be used to improve independence (for example, a long-handled comb)
- Meet with other patients to learn how they have overcome similar problems
- Understand how the manipulation of drug treatment can influence body image (for example, methotrexate-induced alopecia is often related to the dose)
- Involve patients in an education programme to improve self-efficacy
   - Educational sessions facilitated by a psychologist where the patient has the opportunity to ask questions
   - Education programme to improve self-efficacy in managing the condition
- Involve patients in an education programme to improve self-efficacy in managing the condition
- Equipment to enhance independence and reduce fatigue, such as utensils, chair raisers and bath aids
- Information on support groups, agencies and benefits available
- A telephone helpline service

Complementary therapies

The responsibility of the multidisciplinary team is to provide an open and caring environment for individuals to discuss and seek guidance on various complementary therapy options. There is inadequate research evidence to support the long-term benefits of complementary therapies or possible interactions with other medication. However, the therapeutic benefit of touch together with the patient’s perception of regaining ‘control’ over their disease using complementary therapies has been recognised as having a positive effect (Enser 1995). It is essential that the therapy is provided by a competent practitioner (Rankin-Box 1995).

Psychological and social factors

People with RA experience alterations in their social and occupational roles. Patients have reported lost relationships, disrupted leisure activities and limitations in employment (Yelin et al 1987). The unpredictability of symptoms in terms of pain, stiffness and fatigue, and the consequences of ongoing disease places a psychological burden on individual patients and their families. Maycock (1988) refers to living with RA as ‘a tightrope between freedom and a life sentence’. Nurses involved in the management of patients with RA need to address psychological and social function within a holistic care assessment to provide a comprehensive management plan for each patient.

Altered body image

Body image refers to the way in which an individual feels about his or her body in terms of appearance and function, and how he or she believes others regard his or her body (Pigg et al 1985). Altered body image exists when coping strategies (individual or social) to address changes in body reality, ideal or presentation are overwhelmed by injury, disease, disability or social stigma (Price 1998).

There are many reasons why a person living with RA might experience alterations to his or her body image. The disease process has adverse effects on the structure and function of joints, muscles, tendons and ligaments. Most patients will experience a certain degree of muscle wasting. Severe disease is accompanied by the presence of subcutaneous nodules often affecting the upper limbs and ulna deviation of the finger joints. Such changes to the structure of the joints and muscles will affect the range of movement and function. Patients might also be affected by the visibility of the treatment regimen, including the use of oral steroids, which alter the distribution of body fat. Even the use of a wrist splint to support functional activity might confer to patients that they are different and thus influence their perceptions of their body image.

During assessment the nurse needs to take note of how patients refer to and use their body. If negative terminology is used, for example: ‘...these hands are no good for anything’ then further exploration will be required to assess the impact on psychological and social function. Negative perceptions of body image can lead to social withdrawal and subsequent isolation. The management of body image problems is outlined in Box 6.

Sexuality

Sexuality is an under-researched area. Blake et al (1987) found that feelings of unattractiveness, loss of partner interest and absence of sexual drive were as prevalent among people without illness as they were in patients with RA. Where patients with RA differed was that they experienced a greater loss of sexual satisfaction over time; physical symptomatology cited as causative factors included joint pain and fatigue. In an audit of RA outpatients, Ryan et al (1996) found that 69 per cent of patients with RA perceived that their condition had adversely affected their sexual relationship and they attributed this to pain, reduced joint function and the effects of medication. Le Gallez (1996) found that patients reported fewer opportunities to engage in sexual activity and found fatigue a prohibiting factor. Many patients have expressed a desire to discuss sexuality with health professionals (Blake et al 1987, Ryan et al 1996).

All aspects of sexuality must be addressed on an individual patient basis. Following an initial assessment, a management plan should be devised. This might include advice on planning sexual activity, using pillows to support joints, having a hot bath and taking analgesia before commencing sexual activity. Aromatherapy oils can promote relaxation and different positions can be adopted to

TIME OUT 5

Before reading on, write down what information and guidance you would give to a patient who asked for your help regarding difficulties with sexual intercourse as a result of pain and limitation of movement in the joints.
avoid unnecessary strain on the joints. Patients should be encouraged to attend an education programme to learn how to cope with reduced self-esteem, the effects of medication on body image, and so on. Appropriate patient literature can be obtained from the Arthritis Research Campaign and referral to specialist organisations should be accessible for all patients.

**Depression** It has been estimated that depression affects between 21 and 34 per cent of patients with RA (Creed et al. 1990), although the true incidence might be a lot higher. Depression can impair psychological, social and vocational function (Parker and Wright 1995). Features of depression include alteration in appetite and sleep pattern, loss of interest and enjoyment in life, lack of drive and motivation, and agitation and restlessness (Hill and Ryan 2000). Patients will often require a combination of antidepressant therapy and counselling.

**Work** Many patients with RA discontinue work within ten years of developing the condition (Meenan et al. 1981). Both the patient and his or her family will require psychological support through this period of adaptation. Appropriate agencies, such as the disability employment adviser, can provide information regarding retraining and financial assistance.

**Family** When a family member has a chronic illness such as RA, the family unit can be affected – it might become stronger, or the pressure might have a negative impact on the roles taken within the unit (Affleck et al. 1988). It is important to involve the family in the patient’s care assessment and management, so that family members can learn to recognise and interpret the clinical symptoms and support the individual in self-management. For example, undertaking regular exercise can become a social activity for all the family. This can also provide a useful opportunity to discuss the level and type of support the family is willing and able to provide, and to ensure that it is in accordance with the patient’s perceived needs.

**Professional (UKCC 1992) and political agendas (DoH 1999, 2001)** support nurses in using their expertise to enhance care and improve service provision. Rheumatology specialist nurses have led the way in providing nurse-led clinics (Hill 1992). The nurse-led service promotes independence and empowers patients to manage their condition effectively (McCabe et al. 2000) (Fig. 2).

The role of nurses at these clinics includes:
- Assessing disease activity and functional ability.
- Recording evidence-based assessments.
- Reviewing pain management.
- Providing ongoing education.
- Administering soft tissue or intra-articular joint injections.
- Providing an opportunity to review patients’ and relatives’ anxieties.
- Implementing a patient-focused plan to address problems identified.
- Monitoring drug efficacy and side effects.
- Reducing the need for emergency admissions.
- Liaising with other healthcare professionals, including primary healthcare teams.
- Supporting patients with changes in treatment and offering advice.
- Offering education and research opportunities in collaboration with other healthcare professionals.
- Providing additional support through a telephone helpline service.
- Offering psychosocial support, advice and referral to other agencies.
- Providing information on coping styles.

The assessment of disease activity and functional ability is often undertaken in nurse-led clinics, although there is an element of overlap with other team members. This assessment process must be a valid and reliable method of recording changes. There are various validating assessment tools for measuring swollen and tender joints, functional
ability and activities of daily living for patients with RA (Box 7). It is vital that nurses have an in-depth knowledge of the assessment tools used, including information on the strengths and weaknesses of data collected, and whether they reflect the patient’s perceptions of change (Oliver 2000).

The holistic nature of nurse clinics enables patients to receive a wide range of support. In recent years, nurses have extended their expertise to administer joint injections. This role might enhance the therapeutic relationship between nurses and patients, reducing the need for further outpatient clinic appointments and promoting earlier pain relief. However, administering joint injections must be considered in the context of enhancing patient care (Wright 1995). The provision of a telephone helpline service acts as an additional ‘safety net’ for patients and health professionals. The service provides access, support and guidance on disease problems, drug treatments and psychological needs.

**Conclusion**

Patients with RA require access to a team of health professionals who can guide, support and empower patients to manage their condition effectively within a negotiated care framework. By working in partnership with patients the main objective of maintaining physical and psychological function and independence can be addressed.

**REFERENCES**


