Rheumatology Nursing
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I would like to thank all the nurses and patients who have shared their knowledge and experience with me over the years, but a few individuals need special thanks.

Firstly, I would like to thank my fellow ‘scribes’ many of whom are renowned experts in their chosen topics and all have been keen to share their knowledge.

Anne Bassett deserves my thanks and a medal for her guidance and unbelievable forbearance.

Helen Greenwood has spent many hours checking references and coordinating changes, all well beyond the call of duty!

Finally, I have to give my love and thanks to my husband Geoff whose unbelievable tolerance is something to behold and whose ‘household management skills’ have improved no end whilst I was editing this second edition.

Acknowledgements
Preface

Musculoskeletal diseases are the most common causes of disability in developed countries throughout the world, and in the United Kingdom, a significant rheumatic disease affects one in seven of the population. They also affect people from all walks of life and of all age groups including babies and the very elderly. Rheumatic diseases are so common that it is inevitable that every nurse will at some time provide care for a rheumatic patient. It is therefore essential that they have some knowledge of rheumatology nursing. Historically this knowledge has been difficult to acquire as there is a paucity of textbooks specifically about rheumatology nursing, and therefore the aim of this book is to fill this gap.

The essence of rheumatology nursing is the ‘Three E’s’; educating, empowering and enabling our patients. This requires the nurse to work in partnership with the patient and their carers and to adopt a holistic approach to care. This approach is acknowledged in each chapter by the seventeen experienced senior nurses who have written this edition.

The book is intended primarily for nurses working at post basic level, but it will also be a useful resource for pre-registered nurses. It is also intended to accommodate continuing nurse education and this is emphasised by the inclusion of aims and intended learning outcomes at the beginning of each chapter, and action points for practice at the end.

The book aims to enhance all aspects of nursing practice and will be particularly helpful to nurses working in the fields of rheumatology, orthopaedic surgery and in general practice. It will also prove useful to nurses caring for patients on geriatric or general medical and surgical wards as rheumatic disease is often a secondary diagnosis. This new edition includes a chapter on the care of children and juveniles with Juvenile Idiopathic Arthritis. This specialist subject was omitted from the first edition but it has been included for completeness.

The book is in four sections. The first sets the scene and comprises four chapters. Chapter one discusses the underlying principles of rheumatology nursing and focuses on the benefits of adopting a therapeutic rather than a purely supportive approach to care delivery. The next two chapters are devoted to the diseases, their diagnoses and their effect on the immune system. Chapter four outlines the various biochemical, haematological, clinical and other assessments used to diagnose and assess the patient’s outcome.
The second section of the book comprises six chapters all of which address the patient’s problems. The chapters include effective interventions that help relieve symptoms such as pain and stiffness, fatigue and sleep disturbance and the psychological and social effects. The effects of rheumatic diseases on the skin are explored and also included is a discussion of the relationship between skin integrity and nutrition and a summary of the effectiveness of dietary supplementation on the rheumatic diseases. Pain, disability and changes in body image can have a profound effect on both sexual function and pregnancy and this is explored in detail. One chapter is devoted to the role of the multidisciplinary team and the care they provide.

The third section of the book focuses on therapeutic interventions. The chapter on medications includes up-to-date information on new developments such as biologic therapies. Other chapters included are complementary therapies and caring for the patient undergoing surgical interventions. Teaching patients about their disease and its treatments is the foundation upon which successful management programmes are built and no book on caring for the rheumatology patient would be complete without a chapter on patient education. Various approaches to patient teaching are discussed and methods of assessing and writing educational material are described.

The fourth section focuses on primary care and paediatric care. Rheumatology as a speciality has often been described as one of the Cinderella Services; it is not seen as a glamorous, emotive or technical branch of nursing. However, to those of us who work in it and love it, nursing the patient with a rheumatic disease is a truly stretching and satisfying experience. Although essential, our nurturing nursing skills alone will not provide the quality of service that our patients deserve. The aim of providing a high quality rheumatology nursing service will be achieved only through great depth and breadth of knowledge; this book represents one step on the road to realising that aim.
I  Setting the Scene
The aim of this chapter is to provide an understanding of the important contribution that therapeutic nursing can make to a patient living with a chronic rheumatological condition. After reading this chapter the reader should be able to:

- describe the key elements of nursing and explain why they are important to a patient with a rheumatological condition;
- discuss the skills and qualities required for the nurse to enter into a therapeutic relationship;
- describe the difference between supportive and therapeutic nursing and provide examples to illustrate this;
- discuss the actual and potential barriers to therapeutic practice;
- outline the components of the nurse consultant role.

DEFINITIONS OF NURSING

The most widely known definition of nursing is that of Henderson (1966) who states that ‘the unique function of the nurse is to assist the individual sick or well in the performance of those activities contributing to health or its recovery (or to a peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge, and to do this in such a way as to help him gain independence as rapidly as possible’. Although this definition is not new, it contains the elements relevant to today’s health care with its emphasis on empowerment, rehabilitation, education and self-management.
Health and illness are not static but dynamic entities, fluctuating in response to many internal and external influences. The role that the nurse assumes will be governed by the patient’s perceived need at any particular time. Shaul (1995) in a qualitative study, identified four defined stages that patients encountered as they adjusted to living with rheumatoid arthritis (RA). These included:

- becoming aware (Symptoms became persistent and impacted work, the family and mood.);
- seeking medical help;
- learning to live with it (Through experience, the individual develops different coping strategies that equate with their context.);
- mastery (The individual adapts and lives with the symptoms.).

**CARING**

Caring is one of the most important values of the nursing profession. Although often referred to as a basic requirement, there is nothing basic about high quality nursing care. The term ‘basic care’ has been used and interpreted incorrectly to the detriment of the profession. Nursing requires a combination of:

- knowledge
- understanding
- expertise.

Identifying and meeting the needs of patients who are unable to care fully for themselves involves having regard for people as individuals and being concerned about what happens to them (Malin and Teasdale, 1991). The process of caring comprises elements of both action and emotion. However, in practice the action element frequently dominates, as the nurse concentrates on the patient’s physical needs (May, 1991; Henderson, 1994). This can result in a neglect of the emotional needs that have been shown to be the predominating factor influencing the experience of good or bad care as perceived by patients (Smith, 1992).

An overemphasis on the physical manifestation of rheumatoid arthritis (RA) such as synovitis of the small joints, without consideration of the effects the condition has on the individual's lifestyle, will not provide comprehensive care and may well be harmful. RA can impact on the patient's social activity with over 50% of patients experiencing social isolation (Yelin and Callahan, 1995). If no one has explored the emotional impact of chronic illness with the patient, they may find themselves bewildered, and unsure of where to turn.
for help and advice. It is common for patients with a chronic condition to experience a plethora of emotions including:

- shock
- anger
- grief
- depression.

It is essential that the nurse has the necessary support and education to provide the emotional elements of care; otherwise care will not be holistic, meaningful or relevant to the patient.

**THE ELEMENTS OF NURSING**

The key elements or functions of nursing can be seen in Table 1.1. The main link between the elements is the nature of the relationship between the nurse and the patient.

Once problems have been identified, a plan of care will be formulated which incorporates the patient’s identified needs. Chronic conditions have a global impact on the patient’s life; living with a rheumatological illness will affect not only the individual but also their family and significant others (Ryan, 1996a). The social implications of rheumatological illness are discussed in Chapter 7.

As well as a sound knowledge base, the nurse will require the ability to understand exactly what physical disability means to each individual (Powell, 1991). For instance, a mother with active inflammation in her hands may be prevented from lifting her child, causing feelings of guilt and anxiety. She must be allowed to express her feelings and be given support and advice about practical measures such as lying on the bed to cuddle her child. For others, inflammatory changes in the hands may affect their ability to work, causing depression and poor self-esteem. Counselling will be required to support the individual through this life crisis, but until the nurse is able to appreciate and understand the impact of illness from the patient’s perspective, they will not be able to offer care from a humanistic viewpoint.

**Table 1.1 Nursing functions (Wilson-Barnett 1984)**

- Understanding illness and treatment from the patient’s viewpoint
- Providing continuous psychological care during illness and critical events
- Helping people cope with illness or potential health problems
- Providing comfort
- Coordinating treatment and other events affecting the patient
Essentially, nursing is a social activity. The nurse will need to possess good communication skills and a level of understanding and knowledge about the complex nature of rheumatological illness to be able to offer a complete care package.

**THE PHILOSOPHY OF NURSING**

A philosophy of practice is essential. It should provide a clear outline of what nurses perceive to be important and central to their practice. This ensures a continuity of approach and can unify the team and ensure that care is practised from a shared understanding with an identified purpose. If nurses working within a clinical area do not share a common purpose, disunity and fragmentation of care can occur. To be meaningful, the philosophy should be derived from those working in both primary and secondary care. Each clinical area will need to determine and develop the beliefs that shape present practice. A philosophy imposed by the wider organisation without the necessary consultation will probably fail in its objective. A rheumatology philosophy of care can be divided into four interlinked and complementary areas (Figure 1.1). Underpinning each area is the patient as the central focus of care delivery.

**BELIEFS RELATING TO HEALTH**

Health is the state in which the individual has adapted to physical, psychological and/or social imbalances and is able to cope with their arthritis in a positive and constructive manner. In the context of rheumatological conditions, health does not mean the removal of all symptoms, as this would be an unre-

![Figure 1.1 The rheumatology philosophy of care.](image-url)
alistic outcome and an unfair burden to place on patients. Health and illness are not static entities, many rheumatological conditions are characterised by flares and remissions and the patient will require advice, support, guidance, motivation and education to deal with problems presented by each new phase of their illness.

BELIEFS RELATING TO THE ENVIRONMENT

The hospital

The hospital environment is alien to most people and can cause anxiety and loss of confidence. To counter this, a person needs to believe that they can influence care management (Tones, 1991) even if the belief is illusory, and participate actively at all levels. Neglect of the patient’s individual concerns and perceptions can lead to isolation and the adoption of poor coping mechanisms. Nursing must create a positive atmosphere that will address both internal and external issues. If the orientation of the ward is committed to task delivery with little emphasis on interpersonal communication, the patient will be unable to explore their emotions to the detriment of their health and acceptance of their condition. Work by Edwards et al. (2001) has demonstrated that when patients are nursed on specialist rheumatology wards they report increased confidence in the nurses’ ability and knowledge, whilst patients nursed on non-specialist wards reported a lack of understanding regarding their arthritis.

The community

As resources are increasingly diverted to the community, a person with arthritis may have reduced access to the specialist multidisciplinary hospital team. It is therefore necessary that nursing expertise moves into the community. A community rheumatology nurse can act as the interface between primary and secondary care. The rheumatology nurse can liaise with practice nurses and other community workers to promote a greater understanding of the needs of the patients and to ensure continuity of care. Practice nurses are conducting assessment clinics (Dargie and Proctor, 1994) and monitoring second line disease-modifying drugs. It is important that primary care is supported by the secondary care service, and that community nursing staff have easy access to their hospital colleagues. In this way, the patient can be given ready access to whichever service best matches their need. Aspects of seamless care are discussed in Chapter 16.

BELIEFS RELATING TO THE INDIVIDUAL PATIENT

The beliefs that the rheumatology nurse holds toward the patient have important impact on the care provided. Viewing patients according to the following beliefs is essential to underpinning quality care provision.
The individual is a person with an ongoing health related problem. The individual should not be depowered, but encouraged to share their own valuable knowledge store, which is essential to their care.

The individual will bring their own lay beliefs and life experience to all situations. These are usually consistent over time and pertinent to the individual concerned (Donovan, 1991). They need to be shared with the nurse, as they will influence the success and acceptance of care management. For instance, if a patient believes that exercise damages the joints, this needs discussing so that the patient can incorporate new information into their existing knowledge. In this instance, advice will be required about the type and amount of exercise needed and the anticipated outcome, enabling the patient to make an informed choice and contribute to the decision-making process.

Patient autonomy should be the overriding principle that guides nursing practice. Paternalism is based on the principle of beneficence (i.e. the professional knows best) and is frequently used to justify actions such as forcing treatment on the individual for the individual’s supposed good. Use of the principle of autonomy to guide nursing decision-making will remove the passivity and dependency implicit in paternalism. A heavy reliance on professional beneficence can unintentionally remove the rights or abilities of patients to participate in their own care.

The individual has the right to be an active rather than passive recipient of care if they wish. However, to assume that all patients wish to be empowered is not adopting an individualized approach. Research by Waterworth and Luker (1990) showed that some patients were ‘reluctant collaborators in care’. They wished to leave decision-making to the nurse, regarding their own involvement as neglect of care. By carrying out an individual assessment, the nurse will recognise the patient’s perceived needs and plan care accordingly. Some patients may prefer a partial involvement rather than a full contributing and participating role. This should be respected and reflected in care management. It will take time for patients to learn about their condition, and reliance on the nurse at a time of crisis, may be necessary for adaptation. As the therapeutic relationship develops, the patient may feel more able to contribute to care decisions. Nevertheless, the emergence of a new stressor such as a reduction in mobility may return the patients to a heightened state of dependency.

The patient is not an isolated being but lives as part of a social network. Any decisions concerning their care should incorporate the needs, values and expectations of these significant others. The individual has many social and occupational roles and the effects of illness must be addressed in a holistic manner.

The individual’s values, perceptions and expectations will be central to care planning and the success of care interventions.
BELIEFS RELATING TO NURSING

Carr (2001) defined the following beliefs:

- Nursing enables the patient to manage their condition, lead as full a life as possible and make informed choices.
- Nursing makes a difference to the patient.
- Nursing supports, enables, cares for and educates the patient.
- Nursing provides a high quality service.

EMPOWERMENT

The concept of empowerment is central to the provision of patient-focused care. Tones (1991) defines empowerment as the 'process whereby an individual or community of individuals acquires power' (i.e., the capacity to control other people and resources). An empowerment approach to health recognises the rights of individuals and communities to identify their own health needs, to make their own health choices and to take action to achieve them (Wallerstein and Bernstein, 1988). This is a rather utopian viewpoint, as the ability to make health choices necessitates active participation in the nurse/patient relationship and equality of access to the possible intervention, which may not always be possible. For example, a young mother with rheumatoid arthritis may not be able to attend a pain management programme because of her inability to use public transport. However, there is some merit in Wallerstein’s contribution, as it challenges the traditional view of the passive patient, placing the patient (in this definition) in a more active role. Empowerment necessitates a relinquishing of the power held by the health care professional or a sharing of power on a more equal basis.

Empowerment is a complicated subject, so much so that some authors (Gibson, 1991) have found it easier to define it by the consequences of its absence, namely:

- powerlessness
- helplessness
- hopelessness
- alienation.

The combination of an internal locus of control and a belief in powerful others can be of benefit (Wallston, 1995). For instance, the patient may respect the information offered by the nurse, but will judge its relevance against what is meaningful to them. If the nurse recommends an increase in exercise, they will experiment and balance the perceived benefits against time that could be spent on other activities. A person who believes only in powerful others, will
preclude individual judgement and prevent an individual assessment of whether the situation is within their personal control.

Empowerment comprises three elements:

- responsibility
- accountability
- risk taking.

Responsibility can be allocated to a person, but unless the person accepts the responsibility they are powerless to act. It may also be the case that an individual is willing to take responsibility, but social and political constraints prevent this. Tones (1991) states that acceptance of responsibility will be determined by the extent to which an individual possesses competence, skills and/or the belief that they are capable of controlling central aspects of their lives and overcoming environmental barriers.

**THERAPEUTIC NURSING**

Therapeutic nursing has been defined as ‘that practice where the nurse has made a positive difference to a patient or client’s health state, and where he or she is aware of how and why this positive health difference has occurred’ (Powell, 1991). Four main areas (Table 1.2) in which nursing can be seen to be therapeutic have been highlighted by MacMahon and Pearson (1991).

Rheumatoid arthritis is an incurable condition but the goal of well-being remains realistic. Supportive nursing has a role to play as the aim of many of the interventions (both medical and nursing) is to limit the potential for further deformity and disability. One example is disease-modifying drug therapy such as methotrexate or gold injections. However, to adopt an exclusively supportive approach would be detrimental to the patient, as it does not allow the patient to participate in the control of their management. Control is retained by the nurse, stifling any attempt by the patient to take an active part in their care.

Some nurses do not wish to develop a therapeutic relationship with patients (Salvage, 1990) and others do not value working with patients whose conditions are not amenable to cure (Nolan and Nolan, 1995).

**Table 1.2 Areas of therapeutic nursing**

- Nurse/patient relationship
- Conventional nursing interventions, *e.g.*, pressure-area care
- Unconventional nursing interventions, *e.g.*, practices taken from therapies
- Patient teaching
In order to improve the patient’s well-being the nurse must play the roles of:

- educator
- guide
- motivator
- supporter.

The satisfaction obtained when the patient and the nurse grow together, will help to remove some of the negative perceptions that nurses sometimes acquire when caring for patients with long-term needs.

**THE NURSE/PATIENT RELATIONSHIP**

Salvage (1990) has questioned whether patients desire a close relationship if their immediate concern is relief from pain and discomfort. This may be relevant to patients experiencing acute illness, but in chronic conditions it takes time and close cooperation to cope with pain that cannot be alleviated. This is where individual patient assessment is so important. It should be remembered that some patients may not perceive benefits from developing a relationship, and so long as the patient is aware of how to renew or establish contact should a problem occur, this view must be respected.

**PATIENT PERCEPTIONS**

Some patients with rheumatoid arthritis have a negative concept of the future that persists even after their condition is in remission (Hewlett, 1994). The nurse should identify and address any problems perceived by the patient in the initial assessment. If the patient is convinced that the future means a wheelchair existence, it is not helpful to be told that only 5% of people with rheumatoid arthritis require a wheelchair. Patients require acknowledgement of their problems and explanations provided within their own context (Donovan and Blake, 2000).

The concept of shared care, where the patients take responsibility for their condition with support and guidance of a named nurse, offers the best way forward. Patients who believe they can influence their condition will report fewer physical problems and enhanced well-being (Newman, 1993).

Adopting a holistic humanistic approach to care requires a change from the supportive role of doing for the patient, to a therapeutic approach which necessitates enabling the patient to feel in control (Chapter 5). For instance, if the patient’s main problem is that of pain, the nurse can have a therapeutic input by establishing in conjunction with the patient, the pattern, type and severity of the discomfort, whether or not it is related to activity, and the apprehensions and anxieties associated with it. This is a two way process,
first achieving clarification of the problems from the patient’s perspective and then working in partnership to minimise the stressor. By the use of empathy, respect and trust nurses enable patients to believe in their decisions.

It is also essential to encourage those who have value in the patient’s life to participate in care management. For example, rest is an important part of the treatment for a patient with a systemic condition such as rheumatoid arthritis in which both physical and emotional fatigue can occur. If the family is unaware of this, pressure may be placed on the patient to abandon resting. This can be avoided if the family learns the role of rest in the management of the condition. If there is an absence of shared understanding within the family, the patient may try to disguise their limitations resulting in increased symptoms and a reduced quality of life.

BARRIERS TO THERAPEUTIC PRACTICE

THE VIEW OF NURSING

Some nursing activities, such as assisting a patient to bathe, are often considered to be basic or menial where in fact they are essential to a patient’s well-being. Technical skills are associated with greater status and are therefore deemed to be more important than basic care skills. Therapeutic nursing will include technical skills, but at its core is the realisation of the value of expressive skills (Wright, 1991) which include the ability to:

- be with the patient
- provide comfort
- provide education
- provide the emotional element of care.

Within the framework of therapeutic practice, no act of care having relevance to the patient can be described as menial. Indeed high technology skills without the addition of high touch skills have little meaning for the patient concerned (Wright, 1991). The importance of these expressive skills must be emphasised and should therefore be taught at both basic and post-basic level. A nurse engaged in therapeutic practice will relate to the patient as an individual, adopting a combination of skills that are perceived to be beneficial and to solve the patient’s problems. Nursing should not be embarrassed by this caring element, but should strongly endorse it as the component which the patient directly relates to the success of their nursing care (Smith, 1992). The challenge to nurses is to combine both technical and comprehensive skills into a healing whole which serves the patient (Wright, 1991).