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## Introduction

Arthritis is a topic worthy of attention and one in which psychology and psychologists have crucial roles to play. For example, psychological theories may enable greater understanding of this painful, long-term condition and can be used to inform development of psychological interventions aiming to aid adaptation. Such interventions may be delivered by psychologists or psychologists may design and provide tutor training for interventions that can be delivered by others, including health and social care professionals, voluntary organisations or lay people living with arthritis who take on the role of peer educators.

Arthritis is a generic label used for over 100 different types of musculoskeletal, connective tissue and non-articular conditions, the most prevalent forms being osteoarthritis (OA), rheumatoid arthritis (RA) and ankylosing spondylitis (AS) in adults (Taal, Seydel *et al.*, 1993) and juvenile idiopathic arthritis (JIA) in children. Other forms of arthritis (e.g. systemic lupus erythematosus, Scleroderma, Sjogren's syndrome, psoriatic arthritis, and gout) are less common. Most forms of arthritis follow an unpredictable course of exacerbations and remissions, resulting in varying degrees of physical disability. Prognosis is uncertain, and, since there is no cure, treatment is ameliorative, aiming to alleviate inflammation, reduce pain and preserve or improve function. Medication remains the mainstay of medical management and can improve disease outcomes for many. However, medication can be associated with adverse side effects (Kean *et al.*, 1997; Thompson *et al.*, 1985), which are often a cause of concern for patients and their carers (J. Barlow, Harrison & Shaw, 1998). Other treatments that may be offered include physiotherapy, occupational therapy and podiatry. People with arthritis often require long-term monitoring and care by general practitioners (GPs) and/or hospital-based rheumatology

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clinics for more severe cases and conditions (e.g. RA). Despite regular treatment, many patients experience severe functional disability after 20 years of living with the disease (Fries *et al.*, 1996). Indeed, a recent community-based, UK study reports the rates of work disability among people with RA at 1, 2, 5 and 10 years after symptom onset as 14 per cent, 26 per cent, 33 per cent and 39 per cent respectively (Barrett *et al.*, 2000). The authors conclude that the move to earlier, more aggressive medical treatment has failed to influence the rates of work disability among this patient group. Thus, it is not surprising to find that many people with arthritis turn to complementary medicine (Resch *et al.*, 1997), express a strong desire to learn 'something I can do myself' (J. Barlow, Pennington & Bishop, 1997) and participate in psycho-educational interventions.

Arthritis is one of the most common, long-term conditions affecting millions of people worldwide. In the US, prevalence rates of self-reported arthritis are projected to increase from 15 per cent (37.9 million) in 1990 to 18.2 per cent (59.4 million) by 2020 (Helmick *et al.*, 1995) with older people, women, and those with less education or lower incomes being at greater risk. In the UK, diseases of the musculoskeletal system account for 46 per cent of all disability reported by adults living in private households (Martin *et al.*, 1988). The burden of rheumatic diseases is related to treatment and outcomes, described by Fries and Spitz (1980) as death, discomfort, disability, drug toxicity, dollars and dissatisfaction, mainly associated with current treatment. To this can be added quality of life for individuals living with arthritis, and their families. The burden of disease from a societal perspective is measured in monetary terms. Data from the US, Canada, the UK, France and Australia suggests that the cost of rheumatic diseases accounts for 1 to 2.5 per cent of the gross national product (March & Bachmeier, 1997). Until 1999 arthritis was not considered a major public health problem anywhere in the world, despite being the largest single cause of physical disability (Badley & Tenant, 1993) and being associated with increased rates of mortality (Pincus & Callahan, 1993). The US is the only country to have recognised that arthritis demands a public health approach. Following publication of the *National Arthritis Action Plan: A Public Health Strategy* (NAAP), the Centers for Diseases Control and Prevention (CDC) initiated a major programme in 1999 to both measure and reduce the impact of arthritis. The programme involves three core strategies:

1. fostering development of state arthritis programmes;
2. strengthening public health science;
3. developing health communication, health education, and health system quality improvement activities to reduce the burden of arthritis.

The last of these involves the development of tools and strategies to be used by state health departments and other partners. One strategy under development is a health communication campaign to increase physical activity among people with arthritis. In addition, the CDC has developed an online training programme for state health departments and others interested in a public health approach to arthritis. The CDC is also attempting to improve the clinical care received by people with arthritis by piloting system changes such as routine monitoring of functional status, ongoing self-management support and easy access to physical and occupational therapy in primary care.

At an international level and with the support of the World Health Organization, the period 2000–2010 has been designated the Bone and Joint Decade by health professionals from different specialities, scientific and patient organisations and governments. The overall purpose is to mobilise an offensive against diseases affecting the musculoskeletal system, particularly in terms of the development and promotion of improved therapeutic options.

This book aims to provide an overview of arthritis that is grounded in the realities of living with a long-term condition often characterised by pain, fatigue, physical limitations and psychological sequela such as anxiety and depression. Life with arthritis involves a continual process of adjustment, which is a useful illustration of how the human spirit can survive, maintain a sense of hope and even flourish in the face of adversity.

As well as the growing body of literature in psychosocial rheumatology, the book draws on my own research and research conducted with colleagues based in the Self-Management Programme, Applied Research Centre in Health & Lifestyle Interventions, Coventry University and in healthcare provision. I view the person with the condition as central to my research and have learned a great deal by simply listening to the stories of people with different types of arthritis covering the full age span – from young children to 90-year-olds. The lessons learned and the rich depth of understanding offered by qualitative approaches is

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used to complement quantitative investigations of pertinent issues. Thus, qualitative studies and associated quotes from such studies are used extensively in many sections of the text. A substantial section of the book is devoted to interventions with a psychological basis. Anything that promotes a positive change is of vital importance in the search to assist people with arthritis make the adjustments needed to attain a satisfactory quality of life. Indeed, psycho-educational interventions, especially those involving lay people as tutors, are well established in psychosocial rheumatology. One could speculate that this development has occurred in the face of the inability of medicine to offer a cure or successful alleviation of symptoms with no associated adverse side effects.

In Chapter 2, the disease characteristics of the main types of arthritis are described, along with epidemiological data, risk factors and disease management strategies that are typically employed. The book will focus on four main types of arthritis (i.e. RA, OA, AS in adults and JIA in children), allowing perspectives from across the age span (e.g. childhood to the older elderly) to be considered and, in the case of JIA, the perspectives of close family members. The chapter concludes by considering metaphysical explanations for arthritis and the use of complementary medicine.

Chapter 3 adopts a historical approach by reviewing early attempts to link personality characteristics with the onset of arthritis, particularly RA and AS. The difficulties of identifying causal links between personality and arthritis and links between stressful events and disease onset are discussed. The problems that can arise in obtaining a diagnostic label for the specific type of arthritis and the overlap between physiological and psychological symptomatology are reviewed. Finally, the relationship between disease duration and wellbeing, particularly depressed mood, is examined.

Chapter 4 describes the experience of living with arthritis from the perspectives of children through to older adults, and includes insight into the perspectives of carers (partners or parents). The chapter draws on the growing body of qualitative studies that aim to provide a picture of arthritis grounded in lived experiences and to generate rather than to test theory. An increasing number of such studies are appearing in the literature, a trend that reflects the increasing emphasis on patient-centred approaches to health care, and the need to listen to the voices of consumers (users) of services. This focus is in keeping with a number of

White Papers published in the UK (e.g. *Saving Lives: Our Healthier Nation*). Key areas perceived as problematic by people with arthritis and their carers are developed. For example, the essential task of managing persistent pain, chronic fatigue and feelings of loss of control are presented. This chapter sets the scene for later discussions of coping and self-management.

The psychological and social aspects of life with arthritis are intertwined. However, for the purpose of presentation, they are dealt with in Chapters 5 and 6 under the broad headings of psychological impact and social impact. The theme of considering both the people with arthritis and their carers is continued. In contrast to Chapter 4, most studies of psychological impact are based on quantitative methods, with many aiming to test psychological models. Reflecting the focus of the majority of psychological studies, the increased vulnerability to depression will be discussed in depth, including the relationship between pain, disability and depression. Other issues covered include the concept of control that emerges as a salient issue for people living with the disease.

Chapter 6 focuses on the way that arthritis can interfere with social relationships, and gives particular emphasis to studies of social support, spouses and other family members. The social model of disability is explored and issues connected with working life, resultant economic impact and the visibility of arthritis are discussed. The notion of visibility is examined in relation to children, adolescents and the myths about arthritis that are present in society (e.g. that arthritis is a disease of old age).

Chapter 7 discusses healthcare issues in arthritis, such as understanding more about the relationship between patient and healthcare professional, particularly in terms of encouraging individuals to play a role in their disease management. The issue of disease duration in relation to the amount of knowledge and coping skills attained by people with arthritis is reviewed. This leads to consideration of arthritis patient education focusing on the use of informational strategies and written materials as simple interventions that can be widely distributed at relatively low cost.

Chapter 8 covers the use of more complex psychological interventions in arthritis, many of which draw on social cognitive theory in their guiding principles. The most common interventions are based around cognitive-behavioural techniques and lifestyle management (e.g. exercise, diet). Self-management is well established in the field of arthritis, and

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encompasses lay-led interventions delivered in community settings. Given that people with arthritis spend the majority of the time managing their condition in the home environment, becoming a successful self-manager is of paramount importance. Interventions for children with JIA are included, although there are few studies published in this area.

Key issues covered are summarised in Chapter 10 and the way forward for psychosocial rheumatology is identified in the form of a research agenda.