



Education and Learning for People with Ankylosing Spondylitis

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Thesis submitted in fulfillment of the
regulations for the degree of Doctor of Medicine

Newcastle University

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Institute of Health and Society

January 2011

Abstract

Background: Whilst many isolated educational interventions have been evaluated, less is known about the practical steps patients take to learn about their condition and how to live with it, the factors that influence their learning, or even the ability and inclination of health professionals to provide relevant education. Understanding the experience of education for people with ankylosing spondylitis (AS) will help to develop resources in the future and tailor existing resources for individual patients.

Methods: Focus groups and a survey of UK Rheumatology health professionals were used to describe current practice and professionals' perspectives of education for people with AS. Patients' perspectives of learning were reported through focus groups, serial semi-structured interviews with 10 'new' patients with AS, and further interviews with 12 'review' patients. Finally, consensus methods were employed to review the findings.

Results: A detailed description of education and learning for people with ankylosing spondylitis has been constructed, based on the current provision of education and the perspectives of both patients and relevant health professionals. Analysis of the interviews with patients led to the development of the Established Patient Model, which describes a search for information in four stages. The model indicates that patients do not strive to be experts on their condition, but instead reach a self-defined level of adequate knowledge based on their background and the disruption to their lives caused by AS.

Conclusions: This thesis details how, when and why people with AS learn about their condition, and the content and delivery methods they value and choose. Equally, I have identified variations in the delivery of education by Rheumatology Departments. Understanding these issues allows changes to the provision and organisation of educational resources to be suggested. These potentially complement and facilitate patients' learning, allowing clinicians to recommend educational resources which are likely to be acceptable and useful.

For Laura, Max and Luke

Acknowledgements

I am extremely fortunate to have received the help and support I did in preparing this thesis. I'd particularly like to thank Arthritis Research UK and The Baines Foundation who funded the project and enabled me to take time out of my clinical rheumatology training.

So many people have given their time and expertise, and I am grateful to all of them. I was continually humbled by the willingness of interview participants to invite me into their home and talk openly about their lives. Equally, many members of NASS took part in focus groups or completed surveys, and many health professionals also gave their time and thoughts freely for the same reasons. Thanks to Jane Skerrett and the rest of the team at NASS who helped me to contact members, and to the teams at BSR and BHPR, especially Ross Wilkie, who helped to administer the postal survey. Ann-Marie Smith transcribed my interviews and focus groups, but also (as those who know her will not be surprised to hear) did so much more to help the project run smoothly.

I remain indebted to my clinical colleagues; firstly, the Rheumatologists in the North-East who have helped to recruit participants - especially Matthew Grove and Jennifer Hamilton who helped to set up the study in two of the centres. More recently, I have been grateful to my clinical supervisors, Fraser Birrell and Pam Peterson, who have been understanding and flexible as I have tried to juggle my responsibilities and complete this work. The remainder of my colleagues have also put up with my lack of interesting conversation, and too-frequent moans; I hope both these character flaws will resolve once it has been submitted.

I have been incredibly privileged to be part of such a knowledgeable and encouraging research team. Each of the team – Carl May, Lesley Kay, Wendy Broderick and Tim Rapley – have provided valuable insights and practical help. My guidance from Tim has been unsurpassable, in particular his patient, deliberate and enlightening tutoring in qualitative research, analysis and writing. I cannot envisage what this thesis would have been like without his supervision.

Finally, I hope that in the future I can come close to reciprocating the support and understanding I have received from my family and friends. I think those around me will celebrate its conclusion as much if not more than me. Not least my sons Max and Luke, who were promised they'd get a new bedroom and bunk-beds when I'd finished.

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Chapter 1 – Introduction

1.1 An Introduction to the Thesis

This thesis describes two processes relating to people with ankylosing spondylitis - those of *education* and *learning*. The distinction between the two is subtle but important. While education is defined as ‘the systematic instruction, schooling or training’ of people, in contrast learning reflects the ‘acquisition of knowledge or skills as a result of study, experience or teaching’ (Oxford English Dictionary, 1989). Therefore *learning* is an active response to *education*, but also a response to many other experiences. Learning can take place either as part of, or separate from the prescribed process of education. In this context, patient education is an attempt to influence what and how patients learn, but this influence is variable, and not inevitable.

Within the thesis I describe the process of *education* for people with AS through an analysis of the available educational resources, reflecting current practice, opinion and evidence surrounding the provision of these resources by health professionals and other organisations. My description of *learning* for people with AS has not previously been represented in the literature – a description of *how*, *when* and *why* patients learn about their condition and how to live with it. Analysing these two processes together - education *and* learning – provides a powerful tool when I consider how the resources available to people with AS could be improved. It has allowed me to compare the current provision and organisation of education with what patients want and need to learn about AS, highlighting areas where needs are unmet, and suggesting methods which could improve education for this group.

The research was funded by Arthritis Research UK¹ as a 2 year Educational Research Fellowship. This allowed me to defer my role as a Specialist Registrar in Rheumatology and General Medicine, and instead pursue my interest in education and research.

Throughout my training, and indeed as a medical student, I was interested in patients’ understanding of their health and illness, how this influenced their health, and the extent to which they are able to choose and influence their care. I had also developed an interest in medical education – the training of medical students and junior doctors - and was increasingly involved in this field. I had no practical experience of qualitative research, and

¹ This was known as the Arthritis Research Campaign (arc) at the time; the organisation was rebranded in 2010. It is referred to as Arthritis Research UK throughout the thesis, although for example documents such as those given to patients and professionals included as appendices have not been altered.

while I considered myself to be a ‘socially aware’ doctor, the academic study of sociology was, at the time, similarly unknown to me. For this reason the learning curve was steep, and the literature review contributing to Chapter 2 was a new challenge. There were frequent ‘Eureka!’ moments when I finally grasped the meaning and purpose of an academic paper which had until then proved incomprehensible.

The idea for the study was originally conceived by Lesley Kay; we (the research team) developed this idea into the original protocol used to apply for and secure funding from the Baines Foundation and from Arthritis Research UK, and to obtain the relevant ethical and Trust approval (section 4.1.1). The research team consisted of Dr Tim Rapley, Social Scientist at the Institute of Health and Society, Newcastle University; Professor Carl May, Professor of Medical Sociology at the Institute of Health and Society; Wendy Broderick who has AS herself and is Secretary of the Tyne and Wear NASS Group; and Dr Lesley Kay, Consultant Rheumatologist and Honorary Clinical Senior Lecturer at the Freeman Hospital, Newcastle-upon-Tyne.

The study itself is a broad examination of the topic of patient education for people with AS, using multiple methods and employing multiple data sources. It reflects both patients’ and health professionals’ perspectives, but focuses particularly on patients’ experiences in the year following diagnosis through serial qualitative interviews. A detailed description of the methods used is offered in Chapter 4, including the manner and extent to which they evolved from those originally proposed. The original aims of the study are listed here and were met during the course of the two year project:

- a.* Understand and document the existing literature relating to the design of educational resources for this patient group.
- b.* Describe current practice in patient education for patients with AS in the UK.
- c.* Identify relevant professionals’ (rheumatology consultants, specialist nurses, physiotherapists and pharmacists) views on patients’ educational needs.
- d.* Identify patients’ views on their educational needs at different stages of their disease and lives.
- e.* Formulate key learning outcomes for patients with AS, suggesting optimum methods of learning which would be acceptable for patients; indicate whether further resources are required to meet these outcomes.

Aim *a* is achieved through the literature review within Chapter 3; Chapter 2 is an additional literature review detailing existing knowledge about the experiences of people with AS, which influenced my analysis of the data collected in later phases of the study.

Aim *b* is represented by *two* aspects of current practice. The first relates to the provision of *education* by health professionals and other organisations, described principally in Chapter 6. However, this thesis also reflects current practice in *learning* for people with AS - what they currently do to learn about their condition and how to live with it. This is outlined in Chapters 5 and 7.

Aim *c* is met within Chapters 6 and 8, while aim *d* is achieved within Chapters 5 and 8. Aim *e* remains just one of the implications for future practice and research described in the final results chapter (Chapter 8) and in the conclusion (Chapter 9).

As I will outline in section 1.3, patient education is multi-disciplinary, with interest and contributions from many distinct professional and academic groups, as well as patients themselves. I have tried to write this thesis in a manner and style which is accessible to this wide potential audience. While health professionals involved in the care of people with AS could be considered its primary audience, I hope other groups who are either interested in patient education, in peoples' responses to chronic illness or in qualitative research methodology will find it equally accessible and interesting. At the same time, by attempting to keep medical aspects understandable to readers without medical training and social science aspects understandable to those who do not have this background, I will certainly have irritated or alienated both groups, either by stating the obvious, or by glaring omissions. I hope this doesn't overshadow the remainder of the thesis.

Finally, you will notice the title of the thesis refers to '*people* with AS', rather than '*patients* with AS', or '*AS patients*'. This reflects my recognition that people with AS are individuals who have roles in life beyond those of being a patient. Some commentators believe the term patient should be avoided when describing people with illnesses, suggesting it emphasises, endorses and promotes a profoundly unequal relationship between them and health professionals (Neuberger and Tallis, 1999). However, the term is actually favoured by users of healthcare themselves, who do not find the term offensive (Nair, 1998). Therefore you will find examples of '*patients*' throughout this thesis, not

because I seek to promote the perspectives which Neuberger feared, or because I am unaware of this debate, but because it need not take on these negative connotations, and it remains the best descriptor available.

In the following sections I will introduce first ankylosing spondylitis (1.2) and subsequently patient education (1.3). Both these introductions will be brief, predominantly because the issues relevant to the thesis will be developed further in the literature reviews.

1.2 An Introduction to Ankylosing Spondylitis and the People Who Have It

Ankylosing spondylitis (AS) is an inflammatory arthritis which predominantly affects the spine and sacroiliac joints². ‘Ankylosing’ refers to the fusion between joints which can occur, in particular fusion of the vertebrae resulting in loss of the normal flexibility of the spine. In turn, ‘spondylitis’ reflects the tendency for the spine to be affected. AS is one of several ‘spondyloarthritides’ – that is similar types of arthritis which each tend to affect the spine. The cardinal symptom is of ‘inflammatory back pain’ – pain, associated with stiffness, which is better after exercise and worse after rest, particularly first thing in the morning.

Peripheral joints can also be affected, such as the hips, knees, and shoulders. The inflammation surrounding these joints causes pain, stiffness, and swelling; damage to the joint itself occurs over time, causing loss of range of movement, impairing its normal functions. Fatigue and other constitutional symptoms are very common (Dagfinrud et al., 2005), while other systems can also be affected such as the eye (anterior uveitis), the lungs (pulmonary fibrosis), the heart (valvular and conduction system disease) and bowels (inflammatory bowel disease).

The diagnosis of AS is made clinically, through a combination of the patient’s history and examination findings. According to diagnostic criteria (van der Linden et al., 1984), X-rays of the sacro-iliac joints should also show that significant damage has occurred. This definition is not universally adhered to by clinicians for a number of reasons. Firstly, the definition is primarily intended for research purposes rather than for routine clinical use; secondly, X-ray changes will lag behind symptoms, leading to a perception that X-ray changes would eventually develop, even if not present at this time; finally, the radiation exposure to patients undergoing such X-rays are not insignificant or without risk of harm. However, the need to adhere to this more precise definition of AS has increased because it has been adopted by recommendations governing the availability of anti-TNF³ treatments described below (National Institute for Health and Clinical Excellence, 2008). The effect of

² The sacroiliac joints are at the posterior aspect of the pelvis, and when affected usually cause pain felt in the buttock of the affected side.

³ Anti-TNF = anti-tumour necrosis factor α .

revising these diagnostic criteria to include the results of MRI scans instead is being investigated (O'Shea et al., 2007).

Despite the presence of criteria for the diagnosis of AS, patients describe difficulty getting a diagnosis, and often a considerable delay from the onset of symptoms to being told the cause – a mean of nine years in one study (Feldtkeller et al., 2003). This delay represents both a delay in initial presentation to medical care, but also a delay after this presentation, as many health professionals, including GPs, have difficulty differentiating *inflammatory* back pain from the more common *mechanical* back pain (Jois et al., 2008). One contributing factor to this is its relatively low public profile; despite similar rates of prevalence of the two conditions⁴, rheumatoid arthritis remains the archetypal inflammatory arthritis in public and professional minds.

Ankylosing spondylitis is unusual for a chronic disease in that it predominantly affects men⁵, at least in those with more severe disease (Cruyssen et al., 2007). It also breaks with the public perception of arthritis as a condition which affects the elderly, typically presenting in the early twenties. People with AS therefore form a unique group, and for many men with the condition, AS becomes apparent and begins to cause problems at an important time in their lives. At a time when their peers are concentrating on developing their education, their employment and their social lives, people with AS are forced to adjust their lives and expectations in response to the unforeseen reality of a long-term condition. Unsurprisingly, the diagnosis of AS has been shown to have a significant impact on people's lives, with those with the condition having significantly higher rates of work disability (Ward et al., 2008) and higher rates of depression (Barlow et al., 1993a), and diminished overall quality of life (Ward, 1999). At the same time AS is variable – some individuals experience more aggressive disease than others. Equally, for individuals themselves, the severity of symptoms can range from minimal to severe, the latter during unpredictable disease flares.

⁴ Estimated prevalence of AS in adult Caucasian population in Western Europe is 0.2 – 0.86% compared to an estimated prevalence of rheumatoid arthritis of 0.5-1%. [Khan, M. (1998) 'Ankylosing Spondylitis - clinical aspects', in Calin, A. and Taurog, J.(eds) *The spondyloarthritides*. Oxford: Oxford University Press.] [Creemers, M. and van der Putte, L. (2004) 'Rheumatoid arthritis – the clinical picture', in Isenberg, D., Maddison, P., Woo, P., Glass, D. and Breefveeld, F.(eds) *Oxford Textbook of Rheumatology*. 3rd ed Oxford: Oxford University Press.]

⁵ Ratios range between 8:1 and 1:1 depending on the population and methods chosen. In the referenced study the ratio was 2.1:1 for patients with definite AS in secondary care clinics in the Netherlands.

Qualitative research with people with AS has been limited, although one postal study has focused on patients' perceptions of the impact of AS on their lives (Hamilton-West and Quine, 2009). This study highlighted its effect on work, relationships and family life, the stigma associated with the condition, the resultant withdrawal from social lives, and a general fear of the future. Another study (Mengshoel, 2008) interviewed 12 people with AS in relation to the variability of their disease and symptoms, characterising the changes they made to how they lived their lives as 'ordinary life', 'slowed down life', or 'disrupted life'.

The treatment of AS is multi-disciplinary, involving multiple professionals who normally form part of a rheumatology team. Whilst exercise is increasingly promoted for the management of all chronic illnesses, its role in AS goes beyond routine medical advice to keep fit and active. Exercise is viewed as the cornerstone of management and patients are encouraged to carry out daily stretching exercises designed to maintain and improve spinal mobility and pain. Physiotherapists are often involved in recommending and assessing the effects of these exercises. Similarly, patient education is invariably included as part of guidelines for the optimum management of AS (Zochling et al., 2006), although as I will discuss in Chapter 3, it is not clear what this should entail.

Pharmacological treatment has made significant advances in the last few years with the availability of anti-TNF drugs. Until their introduction, options were limited for those patients for whom non-steroidal anti-inflammatory drugs (NSAIDs) were either contra-indicated or ineffective. Drugs such as infliximab, etanercept and adalimumab have been shown to have positive effects on patients' pain, stiffness, fatigue and overall quality of life (van der Heijde et al., 2006; Davis et al., 2005). Unfortunately, they can also have side effects, including concerns about infection, malignancy and demyelination; due to their novelty, their long-term safety is not fully understood. Their cost is similarly prohibitive, at around £10000 per patient per year, and their use is subject to NICE guidelines (National Institute for Health and Clinical Excellence, 2008). Decisions about whether to use them are challenging for both patients and professionals.

In summary, AS is a long-term, painful and typically progressive disease which is not usually life-threatening, but which appears to have significant differences from other chronic diseases, and indeed other types of arthritis – notably its epidemiology and management strategies. These differences suggest that education may have a particularly

important role to play in the management of AS, perhaps with respect to helping patients to make decisions about their treatment, the use of exercise to improve their health, or to help them cope with the dramatic change from their expected life trajectory. In the next section I will consider the topic of patient education, focusing particularly on its definition and scope.

1.3 An Introduction to Patient Education

Presenting a brief and comprehensive overview of the topic of patient education is not straightforward. The term adopts different meanings in different circumstances, relates to a variety of resources and interventions according to the situation and audience, and aims to achieve broad but ill-defined benefits. There are many different academic and professional groups who either study or provide patient education and each may have a different perspective; such groups include health professionals, psychologists, sociologists and educationalists, a list of interested parties which should also include patients themselves. Equally, patient education overlaps with other concepts which may have similar aims, and I will consider these here as well. Thus this section does not seek to offer a single solution or explanation to this topic, but instead begins the debates which will continue in the remainder of the thesis.

Precise definitions of patient education do not appear frequently in the literature, but such statements provide useful insights into the authors' perspective on its aims and methods. Lorig's definition is the most widely used in the rheumatology literature and is used by the Cochrane Review of education for people with rheumatoid arthritis (Riemsma et al., 2003):

any set of planned, educational activities designed to improve patients' health behaviors and / or health status. ... The purpose is to maintain or improve health, or, in some cases, to slow deterioration. (Lorig, 1996: xiii-xiv)

Even this apparently comprehensive statement leaves some questions. By indicating that only 'planned' activities meet her definition, she appears to exclude much of the learning that patients carry out independently, and also the learning that takes place within the context of clinical care – the information gained through routine consultation with health professionals. Additionally, the emphasis on 'improving' patients' behaviour indicates that optimal behaviours exist, defined by health professionals rather than by patients.

Burckhardt's definition, developed as part of guidelines for future research on patient education within the field of rheumatology, maintains that it should be planned and separate from clinical care, but does acknowledge the role of patients' opinions and choice:

Patient education is planned, organized learning experiences designed to facilitate voluntary adoption of behaviors or beliefs conducive to health. It is a set of planned educational activities that are separate from clinical patient care. The activities of a patient education

programme must be designed to attain the goals the patient has participated in formulating. (Burckhardt et al., 1994: 2)

Similarly, the World Health Organisation (WHO) offers a definition of ‘Therapeutic Patient Education’ which has influenced practice in parts of Europe, but not in the UK (Haute Autorité de Santé, 2007: 1):

Therapeutic Patient Education (TPE) helps patients acquire or maintain the skills they need to manage their life with a chronic disease in the best possible way. It covers organised activities, including psychosocial support, designed to make patients fully aware about their disease and to inform them about care, hospital organisation and procedures, and health- and disease-related behaviours. It helps patients and their families understand and deal with the disease and its treatment together, in order to maintain or even improve quality of life. (originally from WHO - Europe, 1998)

This definition doesn’t limit patient education to processes separate from routine care, and in contrast to Lorig, focuses on *informing* patients about their behaviour rather than *improving* it. It also acknowledges the need for patients’ families to be included in attempts to provide education for people with chronic illnesses.

The aims of patient education deduced from these definitions are therefore not only to increase patients’ knowledge about their condition and treatment, but are also focused on changing their behaviour and ultimately, improving their health. This perspective of education as a ‘therapy’ is supported by examining the outcome measures used in studies of educational interventions, which have included a range of physical, psychological, behavioural and health status measures. The potential of such interventions to reduce societal economic costs by decreasing participants’ utilisation of healthcare resources has not been overlooked by policy makers (Department of Health, 2005).

Whilst these aims for education may be valid, they do not necessarily reflect the aspirations of individual patients who are considering taking part in such a programme. Even if an intervention does ‘improve patients’ behaviour’ by the criteria specified in research studies and reduce societal costs, unless it meets the expectations and needs of the participants it is unlikely to recruit sufficient patients to make it worthwhile. Attempts to incorporate patients’ views into the development of educational and other interventions are encouraged (Richards, 1999), although there is no consensus about the best methods to do this.

As I mentioned at the beginning of this section, there is some overlap between patient education and alternative terms which are sometimes used interchangeably. ‘Health promotion’ and ‘health education’ refer to interventions aimed at primary prevention – maintaining health in the wider population rather than in populations with existing health problems (Caraher, 1998). ‘Counselling’ is a process that gives the patient the ‘opportunity to explore, discover and clarify their situation’ (Hill, 1997: 110), and therefore does not necessarily attempt to increase patients’ knowledge or change their behaviour. The term ‘self-management’ has become widespread since the 1980s, particularly in association with educational programmes based on psychological theories and aiming to change patients’ behaviour, like the ‘Arthritis Self-Management Programme’ (Lorig et al., 1985) which I shall return to in more detail in section 3.3.1.1. The phrase has been used to describe a shift of responsibility for the day-to-day management of their condition from the health care professional to the individual (Newman et al., 2001), and is sometimes used interchangeably with ‘self-care’.

Many of the social, demographic and medical changes during the last century have contributed to the growing interest in and need for high quality patient education. A greater proportion of the population now live for considerable periods with one or more chronic illnesses, and our health system has changed from one focused on the treatment of acute illness to a system in which the majority of health care expenditure is on long-term ‘incurable’ conditions (Department of Health, 2008). The aim of managing these is the ‘maintenance of pleasurable and independent living’ (Holman and Lorig, 2000). This requires an awareness by clinicians of the psychological and social influences on health (Engel, 1977), and increases the scope for patients to participate in decisions about their healthcare, a role in which they require information and appraisal skills. The traditional model of a paternalistic doctor and a compliant patient has to some extent been replaced with ideas of partnership and ‘patient participation’ (Coulter, 1999).

Simultaneously, the concept of ‘patient consumerism’ has become more prevalent – the refusal of patients to accept the ‘medical dominance’ of doctors, and a desire to ‘shop around’ for the best healthcare available (Lupton, 1997: 373). Patients are therefore more inclined to seek out the information on which to base these types of decisions.

However, this demand for information from patients is not universal and a proportion of patients are content not to know about their condition (Kjeken et al., 2006) or do not wish to participate in decisions about their care (May, 1995). Similarly, the idea that education can lead to a fully informed, autonomous patient has been criticised, especially if the aim of the intervention is to increase compliance with medical care (Fahrenfort, 1987) (Wilson et al., 2007). At the same time, some commentators have suggested that ‘patient empowerment’ – the expectation that patients will take control of their illness and treatment - is not necessarily in their interests (Salmon and Hall, 2004).

So patient education is viewed almost exclusively as a *good thing*, and is invariably included in guidelines for the management of AS. However, beyond stating its importance and necessity, there is a lack of clarity regarding its aims, organisation, and how, practically, it should be provided. Suggesting that education should *improve* patients’ behaviour seem to contradict aims of patient empowerment, and its role as a tool to reduce healthcare costs may also be problematic. At the beginning of this chapter I suggested that people with AS experience two interconnected processes - those of *education* and *learning* - and this approach could offer some insight and clarity on this topic.

My introduction to the thesis will continue in the next chapters with literature reviews which first address researchers’ understanding of people with AS (Chapter 2), and subsequently the range and efficacy of educational interventions (Chapter 3). The results chapters, Chapters 5 to 8, offer description and analysis of the processes of education and learning. Finally, in Chapter 9, I consider the implications of the thesis for the future provision of education for people with AS.

Chapter 2 - The Experience of People with AS

2.1 Introduction

In Chapter 1 I highlighted the broad and contentious scope of patient education, principally due to its entwined relationship with concepts such as patient participation and behaviour change, and the involvement and interest of multiple professional and academic disciplines. The task of summarising the relevant literature is therefore arduous, with a significant risk, and a probable inevitability, of overlooking literature which some commentators would consider to be fundamental to the subject. Furthermore, the area does not lend itself well to the techniques of formal systematic review, both because of the volume of literature which could be considered to be relevant, and the difficulty in defining and agreeing criteria with which to select appropriate documents. That is not to say that I haven't used systematic search techniques. Instead, I would suggest that the use of bibliographies, the manual search of the contents pages of relevant journals⁶ and the recommendations of colleagues have ultimately proved more fruitful than the extensive subject heading and keyword search of databases⁷. This is despite my experience in using these databases and the use of additional guidance where I was perhaps less qualified (Wilczynski et al., 2007).

Therefore this review does not seek to 'summarise' the pertinent literature on patient education for people with ankylosing spondylitis, but instead I have used the available literature to answer two distinct but related questions, both of which are central to my overall research question. Firstly, in Chapter 2, I have considered the experience of patients with ankylosing spondylitis through an examination and appraisal of the chronic illness literature, asking: 'What are the consequences of such a diagnosis, and how do people respond?' Thus this section concerns our existing knowledge regarding the effect AS has on peoples' lives - the practical problems they may face, the meaning they may attach to the condition, and the steps they themselves make to counteract its effect. Secondly, in Chapter 3, I have examined the evidence and opinion surrounding the educational resources available to people with AS, with the question: 'Are they effective for this patient group?' Together, these two related reviews provide an historical and academic background for the remainder of the study, beginning to map out the broad areas patients find problematic, and whether the available educational resources are likely to help them. It aims to inform the

⁶ Notably for Chapter 2, *Sociology of Health and Illness and Social Science and Medicine*, and for Chapter 3 *Patient Education and Counseling, Arthritis Care and Research, and Rheumatology*

⁷ Using Medline, CINAHL and PsychINFO accessed online.

reader about what has gone before, introducing themes and ideas that I will return to later in the thesis and providing the context into which I hope my work will fall.

2.2 The Sociology of Chronic Illness

Many doctors have a limited view of this topic, attaching little value to the contribution of sociologists to the advancement of medical knowledge. Thus while doctors may often be the subject of studies, this interest is not always reciprocated; sociologists' work appears only at the periphery of most hospital medicine journals, which limits its effect on these practitioners. However, the diverse body of work on this topic is a uniquely valuable resource with which to understand how people experience illness, and thus how any healthcare system, or any individual practitioner, could seek to address their needs. Within this chapter I have taken an historical approach, tracing the major themes as they have evolved over the decades, and highlighting those areas which are most pertinent to my research.

The term chronic illness is used to describe conditions which are typified by persistent symptoms and impairment, and the absence of a known cure. Examples include multiple sclerosis, diabetes, cardiovascular disease, arthritis, and cancer. Department of Health literature (2008) currently refers to such illnesses as 'long term conditions', using a definition which highlights the effect on a person's life – 'no return to normal' (ibid: 10). A huge volume of literature has accumulated which emphasises those experiences which are common to patients with these conditions rather than the differences which may or may not exist between them. Ankylosing spondylitis has been the unique focus of only a handful of papers in this area: examining the role of NASS (Williams, 1989), the experience of people with AS (Bury, 1978)⁸(Hamilton-West and Quine, 2009; Mengshoel, 2008), and through the quantitative study of psychosocial outcomes, for example (Barlow et al., 1993a). Studies describing and analysing the experiences of people who have a generic 'arthritis', or even 'rheumatoid arthritis' (Shaul, 1995; Bury, 1982) are much more common. Whilst it would be possible to limit this review to a 'Sociology of Arthritis', there are sufficient differences in the demographics, symptoms and management between AS and other forms of arthritis (see section 1.2) that arthritis should not be considered a homogenous condition. Instead, it is more useful to include the wider scope of 'chronic illness' here, but to reflect at each stage on the relevance of particular papers to our specific patient group. This point

⁸ I have not been able to find the text of this paper, referenced by Gareth Williams in 1989, despite searches of relevant libraries and databases, and personal communication with the author.

is also relevant and important to Chapter 3, when we begin to consider the effect of educational interventions.

2.2.1 Parsons' 'Social System'

Talcott Parsons' (1951) work 'The Social System' has offered a reference point and a framework for the further study of the sociology of health and illness, and indeed of chronic illness. Seen by some as the 'founding father' of medical sociology⁹, his concept of the sick role, or more broadly his description of the relationship between doctors, patients and society, remains at the core of teaching and understanding of this subject – in part to illustrate how much has changed since Parsons' work, but equally because many of his arguments and observations still offer useful insights on contemporary issues.

Parsons' structural-functionalist standpoint viewed society as a regulated system, with its members acting subject to regulations which effectively maintained this system, analogous to homeostasis within a biological system. He used 'modern medical practice' as an example 'sub-system' to illustrate this wider theory (1951: 428). The element of Parsons' writing with which he is most closely associated is the 'sick role', a collection of rights and responsibilities which describes society's normative expectations of those people who are ill. The sick role not only moulds the interactions between doctor and patient, but also works to ensure that people return to their functional roles as rapidly as possible and do not pursue any motivation, conscious or unconscious, to remain sick.

⁹ This view often prevails despite other authors describing medicine as a social system before him. [Henderson, L. (1935) 'Physician and Patient as a Social System', *New England Journal of Medicine*, 212, pp. 819-23.]

Figure 1: The Rights and Responsibilities of the 'Sick Role'

- **Right:** To be exempted from normal social responsibilities. This requires legitimation by a physician, and is relative to the nature and severity of the illness.
- **Right:** To be taken care of, because getting well cannot be achieved through decision or will.
- **Responsibility:** To want to get well, because the state of being ill is undesirable
- **Responsibility:** To seek technically competent help (usually a physician), and to cooperate with that help in the process of trying to get well.

Adapted from Parsons 1951: 436-437

There is not the space or the necessity here to trace each of the lines of discussion and criticism which has followed this work, and which Parsons spent his later career responding to - for example (1978; 1975). However, to briefly summarise, it seems less applicable to chronic disease as opposed to acute, with no prospect of the 'complete recovery' which typifies acute disease (Parsons, 1975). Secondly, the process of legitimation described by Parsons was later shown to be dependent on the seriousness of the condition and the degree of stigma attached to it by society, rather than on the prompt diagnosis of the attending physician (Freidson, 1970). Equally, there is little discussion about how the sick role may differ between people of varying age, gender, culture or social class (Young, 2004). It is debates like these that have shaped our understanding of the sociology of chronic illness (Bury, 1991), as authors have first identified deficiencies in his theory, and subsequently sought to describe and explain them empirically. It is this development of ideas and understanding which I will focus on for the remainder of this review. However, I will first examine Parsons' views on patients' knowledge of their illness, and their participation in decisions about their healthcare.

Parsons' description of a patient adopting the sick role does not entirely correspond to the passive person at the whim of the medical professional which has often been suggested (Shilling, 2002). For example, he describes in detail the challenges they face as a result of an insurmountable gap in expertise between doctor and patient. He suggests that:-

the sick person is not, of course competent to help himself [sic], or what he can do is, except for trivial illness, not adequate. He is not only generally not in a position to do what needs to be done, but he does not 'know' what needs to be done or how to do it. (Parsons, 1951: 441)

Parsons therefore indicates that patients have a comprehensive dependence on the expertise of their doctor, both in terms of knowing *how* they might get better and in actually delivering their treatment. Thus the diagnosis of a chronic illness initiates a fundamentally unequal relationship with the medical profession. If we consider patient education in this context, there would be specific limitations to what it could achieve – notably the capacity to be 'fully informed' about their health and the treatments offered, and to participate in decisions about their care. Furthermore, Parsons also suggests that many patients actually overestimate their own technical knowledge, in this case in terms of their ability to assess the competence of their physician:

Laymen do know something in the field, and have some objective bases of judgement. But the evidence is overwhelming that this knowledge is highly limited and that most laymen *think* they know more, and have better bases of judgement than is actually the case. (Parsons, 1951: 441)

Overestimating their knowledge about their illness could have two effects on patients: firstly, it may decrease their motivation to learn more about their condition, because by their assessment they already know enough about their illness and how best to manage it; secondly, it may lead them to make choices about their health independently when, from a health professionals' perspective, they would benefit from following advice.

Finally, when making his concluding remarks about the sick role, Parsons highlights its role in preventing patients forming groups, which contrasts with some of today's commonly used approaches to education (see Chapter 3):

The sick role is a mechanism which in the first instance channels deviance so that the most dangerous potentialities, namely, group formation and successful establishment of the claim to legitimacy, are avoided. The sick are tied up, not with other deviants to form a 'sub-culture' of the sick, but each with a group of non-sick, his personal circle and, above all, physicians. The sick thus become a statistical status class and are deprived of the possibility of forming a solidary collectivity. (Parsons, 1951: 477)

Parsons therefore sees patient groups as a threat to the equilibrium within his 'Social System', and believes they risk patients retaining legitimacy for their exemption from social roles for longer than would be desirable to society as a whole. Ill people are insulated

from each other by their families and doctors in order to prevent societal breakdown. Clearly, any possible benefit to patients from sharing experiences and knowledge within these groups is overlooked or discounted.

In summary, Parsons describes a healthcare system where there are fundamental inequalities between patients and, specifically, doctors. He acknowledges that patients can have ‘a certain amount of knowledge and understanding’ (1951: 438), but he suggests that this may be flawed or overestimated, and can never fully address the imbalance of expertise which characterises the medical consultation. The concept of patient education itself is not acknowledged, and techniques which are now favoured are seen as potentially harmful to the function of society. If we consider the questions I posed at the beginning of this section – regarding the consequences of a diagnosis of AS, and people’s responses – we would conclude from his work that both the consequences and responses were relatively rigid and formulaic (i.e. adopting the sick role), and that the benefits of learning more about one’s health and condition were limited, and also potentially discouraged.

In the sixty years since the publication of the ‘Social System’ much has changed – within the profession of medicine, within our wider society, and with regard to the methods used to study health and healthcare. Considering the extent to which Parsons’ description of the healthcare system can still be applied to today’s patients and practice, it is difficult to determine how far differences between ‘then and now’ should be attributed to changes within each of these three spheres. For example, patients now have greater opportunities to contribute to decisions about their care, and the focus of healthcare itself has broadened from the biomedical focus which typifies Parsons’ description¹⁰. Are these differences due to changes within our wider society, changes within the profession of medicine, or, at least in part, due to the development of our understanding of the relationship between patients and doctors, and the experiences of patients themselves? By modern standards, the methods he used to study ‘medical practice’ are both poorly described, and appear to have omitted

¹⁰ ‘Typifies’ is used deliberately here, as in fact Parsons does at times focus on the detailed experiences of patients, notably pp442-443, where the problem of ‘emotional adjustment’ to illness is considered:

Perhaps the most definite point is that for the normal person illness, the more so its greater severity, constitutes a frustration of expectancies of his normal life pattern. He is cut off from his normal spheres of activity, and many of his normal enjoyments. He is often humiliated by his incapacity to function normally. His social relationships are disrupted to a greater or lesser degree.

These phrases represent a remarkable foretelling of work detailing the ‘illness experience’ which arose decades later (see section 2.2.2.2).

any careful collection of the views of patients¹¹. Since then, the methods used by sociologists and other researchers to gain access to these views have become more directed and specific, and with this evolution our understanding of the experience of chronic illness has deepened. As I focus on these methodological changes in the next section, I will continue my discussion of the consequences of chronic illness, patients' responses to its diagnosis, and the possible role of patient education in this process.

2.2.2 Accounts of Illness

So far we have seen how Parsons' account of illness places little emphasis on the choices made by individual patients, and the factors influencing those choices; it does not illuminate the experience of patients, or explain how they themselves manage their life and illness. Therefore, despite its use and importance as a foundation for the sociology of health and illness, and the occasional observational gem which seems to predict contemporary debates, it clearly has limited use in explaining and predicting the consequences of a diagnosis of ankylosing spondylitis, and the role of education in modifying this process. In the years since Parsons, there has certainly not been an ordered march towards a single explanatory model for chronic illness, and indeed there is an acceptance that such a model would never fully explain the range of patient experiences (Bury, 1991). Instead, there have been overlapping 'shifts in focus', which remain entwined within the ongoing debate in this field. However, with each shift, the literature has moved 'closer to the experiencing subject' (Charmaz, 2000: 278).

2.2.2.1 Illness Behaviour

The study of 'illness behaviour' marked such a shift towards understanding patients' actions. It was first defined as 'the way in which symptoms are perceived, evaluated, and acted upon by a person who recognises some pain, discomfort, or other signs of organic malfunction' (Mechanic and Volkart, 1961: 52). Initially, studies concentrated on patients' decisions to seek medical advice for particular symptoms, or to attend preventative services such as population-wide immunization programmes for polio (Armstrong, 2000). The resultant models sought to explain the behaviour which seemed to disregard current

¹¹ The 'methods' section of *The Social System* (1951) appears as a footnote on pages 428-429. Here he indicates that the book, and Chapter X in particular, have resulted from 'an [incomplete] field study of medical practice in the Boston area several years ago', his 'training in psychoanalysis', and [p429] 'a greater command of the empirical material in this field than in most others'.

medical practice and their ‘best interests’– i.e. why they did not take up help which was offered, or did not present themselves to doctors in a timely fashion.

Examples of these investigations include Rosenstock’s review paper (1966), which proposed a model that was later refined to become the well-known ‘Health Belief Model’, and Mechanic’s studies of students at Wisconsin University (1961), which were ostensibly designed to inform health education at the University, and which referred directly to Parsons’ sick role:

Figure 2: Rosenstock’s Illness Behaviour Model: (Adapted from Dingwall, 2001)

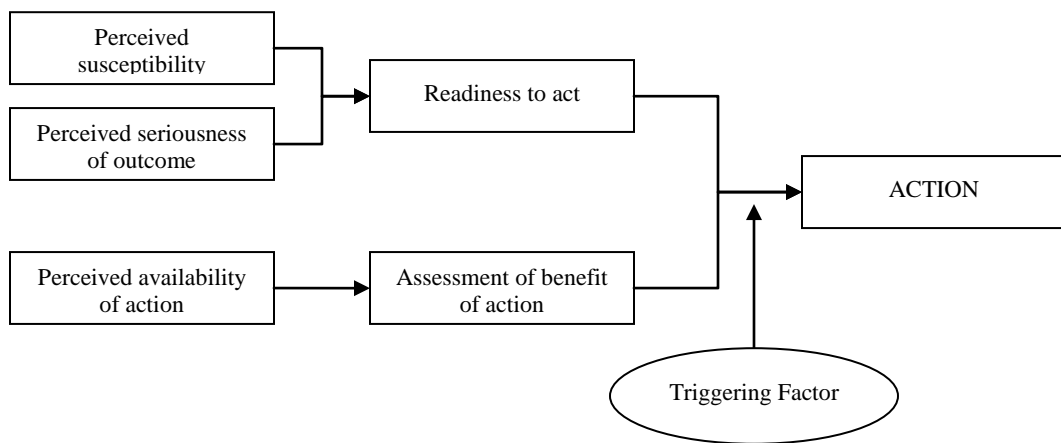
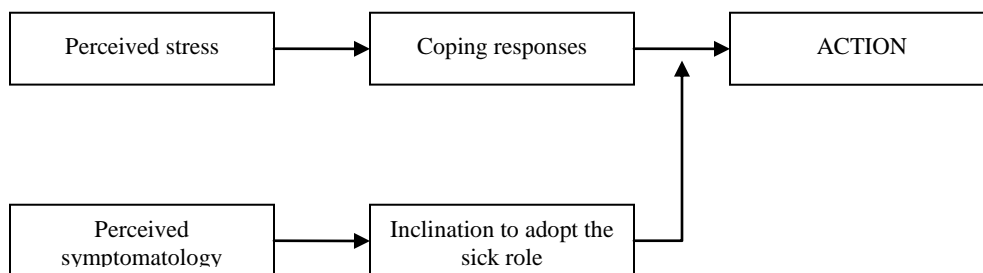


Figure 3: Mechanic’s Illness Behaviour Model: (Adapted from Dingwall, 2001)



Thus in Figure 2, Rosenstock suggested that medical advice would only be sought when there was sufficient psychological ‘readiness’, a perception that the action would be of benefit, and an additional trigger which could either be ‘internal’ (a perception of bodily state), or ‘external’ (an interpersonal, media, or healthcare interaction). Mechanic (Figure 3) saw the sick role as part of a repertoire of coping responses, and that each individual had

a distinct inclination towards adopting it; if that inclination was low, then only very severe or unusual symptoms would lead that individual to seek medical help.

Similar work indicated that patients' cultural background had profound influences on when and how they presented themselves to medical services (Zola, 1973), while some studies extended the concept of the variability of illness behaviour beyond their presentation to doctors to their actions during their illness, and their subsequent recovery or rehabilitation (Suchman, 1965).

I included a section on illness behaviour in this review because it represents a further step towards an understanding of patients' experience of illness - recognising that they make choices and act as 'agents' rather than in accordance with the regulations of an ordered society. It also indicates how researchers considered non-compliance with medical care, and why, in many instances, the provision of information does not have the effect on patients' behaviour which health professionals expect. However the deficiencies and omissions of this work continued to stimulate debate and initiate further study. Firstly, the topic focuses on a single phase of illness: the transition from the perception of symptoms to attending medical care. The assumption appears to be that once an individual has reached medical care, the objective has been achieved; consequently there is little benefit in studying their subsequent experiences and responses in more depth. The methods employed to study the phenomena were also limited to those patients who had reached medical care, or via retrospective cross-sectional population studies which relied on patients' recall of their attendance at clinics, by which time their description of their reason for attendance had been moulded by their subsequent experience of healthcare (McKinlay, 1972).

Quantitative methodology perpetuated the dominant (biomedical) modes of thinking of the time, depicting lay explanations of illness and behaviour as 'flawed', emphasising the superiority of professional accounts (Dingwall, 2001), and excluding those individuals who were not already in contact with medical services. Thus attempts were made to alter illness behaviour when in fact it was only understood in relation to professionals' beliefs about how patients should behave within 'their' healthcare system. By the mid-1970s it was felt to have 'run out of steam'. Attempts to produce a comprehensive model for behaviour which was both explanatory and predictive had been unsuccessful (Armstrong, 2000) and interest instead grew in qualitative studies which could link patients' behaviour with their

own explanations and understanding of illness. A patients' perspective of illness had not yet been described, and thus there was still much to learn about the consequences of chronic illness, and how patients respond to its diagnosis.

2.2.2.2 The Illness Experience

The next *shift in focus* was towards the detailed description and theorizing about the manner and extent to which illness, and especially chronic illness, affects and becomes part of patients' lives. Commentators have recognised Anselm Strauss and Barney Glaser's work as editors of '*Chronic Illness and the Quality of Life*' (Strauss et al., 1984) as marking a fundamental change in the emphasis of medical sociology (Pierret, 2003; Bury, 1991). Their use of qualitative methods (specifically grounded theory analysis of interviews with patients) enabled them to access patients' worlds in a manner which had not been possible or attempted until then. From this point on, studies could elicit the *meaning* of illness for the patients themselves – the practical *consequences* for the individual and those around them, and the personal and public *significance* of the condition (Anderson and Bury, 1988) – as well as their response to the illness. These methods provided ways to look at patients' understanding of their illness, their reports of interactions with healthcare, and their own explanations and interpretations of their thoughts and actions. However, the representation and analysis of the information obtained through interviews with patients remains a challenge (Kleinman and Seeman, 2000; Armstrong, 1984). What is said must be interpreted with respect to the patients' social and cultural background, and many stories also have a moral purpose (Baruch, 1981). The significance and range of stories that patients tell about their illness, or 'illness narratives', is also included within the scope of this section.

Many of the studies and themes I have referred to here have proved to be useful in the interpretation and analysis of my own data in the later chapters. Thus while many of the descriptions here are necessarily brief, I will return to some in more detail later.

2.2.2.2.1 Biographical Disruption and Loss of Self

Mike Bury's (1982) description of chronic illness as 'biographical disruption' shaped the debate within medical sociology in a manner analogous to Parsons' *Social System* thirty years previously. Based on interviews and observations in clinic with thirty people with

rheumatoid arthritis, he used the data to construct a framework which could predict the experiences and behaviour of patients one might encounter in the future, rather than solely describing the experiences of the patients in this cohort. The paper conceptualised illness as a force which disrupts ‘the structures of everyday life and the forms of knowledge which underpin them’ (1982: 169), and described three aspects of this disruption: 1) the disruption of ‘taken for granted assumptions and behaviours’, 2) the disruption of the ‘explanatory systems normally used by people’, and 3) the response to this disruption involving a ‘mobilisation of resources’.

Tracing the process of becoming someone with a chronic illness, Bury acknowledges the problems patients have in recognising symptoms which health professionals would quickly appreciate as significant, instead dismissing them initially with ‘common sense’ explanations. Much of this early process occurs in private, as patients struggle to work out the most appropriate way to behave in front of family members and medical professionals. The diagnosis is met with relief that they are ‘going to get it sorted out’, but additionally there is a biographical shift towards old age, because until that time they have considered that chronic illness, and particularly arthritis, affect the elderly and not individuals like them. The subsequent realisation that medical explanations for their illness are incomplete, and medical treatments not wholly effective, leads patients to return to their own knowledge and a further search for causation and meaning. Patients’ response to their illness is moulded by their access to resources – notably their own social network of friends, family and acquaintances – on which they increasingly rely, and which often become unequal, dependent relationships.

Thus Bury portrays chronic illness as being disruptive in a variety of complex and disparate ways, highlighting its effect on their previously taken-for-granted self-concept, meaning, and the planned trajectory for their biography, as well as on relationships and other material and practical affairs (Lawton, 2003). However, while Bury attempted to generalise his findings from patients with RA to all people with chronic illnesses, subsequent studies have noted exceptions and suggested modifications (Williams, 2000). For instance, issues of context and timing are important in determining the extent and character of the disruption caused to the patient. Bury recognised this himself in his later work, noting that people had expectations of when and how they would become ill, guided by their own ‘social clock’

(Bury, 1991). This view was influenced by studies of stroke in an elderly population with high-levels of co-morbidity (Pound et al., 1998) indicating that for some, a stroke did not represent the dramatic disruption that many would envisage. The term ‘biographical flow’ was later coined to represent these less disruptive events, as determined by the patient’s age, co-morbidities, or previous knowledge of strokes (Faircloth et al., 2004). Similarly, ‘biographical reinforcement’ was noted to be more appropriate when considering haemophiliac and homosexual men, and describing their experience of being diagnosed as HIV positive (Carricaburu and Pierret, 1995). For the former, being HIV-positive confirmed or ‘reinforced’ their experiences of being ill throughout their lifetime; for gay men, it confirmed their continuing struggle within society.

While Bury considered the process of developing a new chronic illness, at a similar time Kathy Charmaz (1983) was examining the experiences of people with severe chronic illnesses, typified by being ‘housebound’. She interviewed 57 people in California with a range of diagnoses, and her report focuses on the suffering due to illness which goes beyond physical symptoms to include a ‘loss of self’ – ‘a crumbling away of their former self-images without simultaneous development of equally valued new ones’ (1983: 168). Charmaz argues that this suffering is derived from society and its view of illness - notably the value that is attached to independence, individual responsibility and hard work - leading patients to view their dependence negatively and blame themselves for it. Additionally, she identifies four distinct factors which contribute to the *loss of self* for patients who are chronically ill: they live restricted lives, exist in increasing social isolation, they experience discrediting and stigmatizing events, and they resent becoming a burden to others. Therefore people with chronic illnesses have greater dependence on others to define who they are, they need more social contact, and yet they are less able to contribute to, and thus sustain their existing relationships.

It is apparent that neither of these two studies is directly applicable to patients with AS; Bury’s sample was predominantly female and had RA, while the age and reported severity of Charmaz’s patients suggest that their experiences may not be the same. That is not to suggest that these descriptions are irrelevant to patients with AS, or that the studies should necessarily be repeated in our specific population. Instead, we must consider these studies according to what we know about AS, and in the context of individual patients, as

highlighted when discussing the revisions to biographical disruption suggested above. Charmaz's and Bury's studies, amongst others, facilitate an understanding of the range of consequences of chronic illness, which had not been previously been fully described or appreciated; the circumstances of individual patients or cultures should be considered to gain a more comprehensive picture. Simon Williams summarizes these issues, indicating the factors that should be considered:

Prejudging the issue ... cannot ... be justified. Instead, *timing* and *context, norms* and *expectations*, alongside our *commitment* to events, anticipated or otherwise, are crucial to the experience of our lives, healthy or sick, and the meanings with which we endow it. (Williams, 2000: 51-52. emphasis in original)

So, if we consider a young man developing ankylosing spondylitis in his twenties, he may not experience the degree of social isolation and 'loss of self' described in people whose mobility is severely restricted, but his 'biographical disruption' may be considerable, given the alterations he must make to his assumed life trajectory if he had previously been healthy. In addition, we might pay particular attention to 'the process of recognition and of legitimating the illness', given that 'the symptoms of [the] condition coincide with those widely distributed in a population' (Bury, 1982: 170). Thus the fact that the dominant symptom of AS, back pain, is highly prevalent and itself stigmatising (Holloway et al., 2007; Chew-Graham and May, 1999), increase the impact of the condition.

The concept of patient education has, until now, been conspicuously absent from this review of the illness experience; nor is it mentioned in Bury's or Charmaz's paper, or in other comparable works. This is partially because patient education was in its infancy at that time, and in fact grew out of an increased realisation of the views of patients which stemmed from this kind of study¹². Additionally, as Bury himself later suggested, there was a tendency to emphasise the burden of chronic disease for patients, rather than the positive steps people take to counteract the damaging effects of their condition (Bury, 1991). However, it is still possible to trace the role education might play in influencing and moderating the effects described in both these studies, and in particular the effects of lay knowledge about their condition.

¹² Kate Lorig's descriptions of the theoretical origins of her work developing a self-management program for people with chronic illnesses often cite qualitative studies by authors such as Anselm Strauss. See for example: Lorig, K. and Holman, H. (2003) 'Self-management education: history, definition, outcomes and mechanisms', *Annals of Behavioural Medicine*, 26, (1), pp. 1-7.

Bury (1982) considered medical knowledge to be an ‘opportunity to conceptualise the disease as separate from the individual’s self’ (172-3), allowing patients to distance themselves from the disease, and view themselves as ‘victims of external forces’, rather than being to blame for their symptoms and disability. The relationship between patients and medical knowledge is not a simple one however, because as they learn more about the medical perspective and the care available to them, they are often ultimately disappointed by the inadequacy of the explanations and treatment they receive. As a result, patients are forced back to their own lay explanations for their condition, as we will discuss further when we consider illness narratives.

Equally, Charmaz (1983) indicates that knowledge can facilitate a reduction in the sense of loss which accompanies chronic illness, Information about the availability of services could reduce the restriction caused by illness, and reduce the real or perceived burden on those people patients rely on. She also states that ‘knowledge’ can also increase the choices which are open to patients, increasing their sense of freedom and maintaining their self-image. However, she makes little comment about *how* patients should accumulate this knowledge, or the precise information they should acquire.

Moving beyond these discussions of the effect of knowledge on the consequences of chronic illness, we are left with questions rather than answers about the role of education in chronic illness. These questions centre upon the aims and scope of patient education and the extent to which it can modify the effects of chronic illness as described by Bury and Charmaz. For instance, can health professionals (or anyone else) teach patients how to ‘mobilise their resources’, or to modify their reaction to potentially stigmatising or discrediting events, or even to live a less restricted life? I think to some extent they can, but as we shall see, the best ways to achieve these objectives are far from clear.

2.2.2.2.2 A Response to Chronic Illness – ‘Normalization’¹³

Within Bury’s argument for more focus on the *positive actions* people take in response to chronic illness (Bury, 1991: 460), he suggested new terminology to help authors standardise their language, and encourage greater clarity within the debate. *Coping*, he proposed, reflects how patients learn to tolerate or put up with the effects of illness;

¹³ The American spelling is used here to reflect the origin of the term ‘normalization’ in this context, and the continuing convention within the sociology of chronic illness.

strategy is what people do in the face of illness – specifically the actions taken to mobilise resources and maximise favourable outcomes; *style* reflects the way people respond and present features of their disease and treatment to others. Although this nomenclature has not been universally adopted, once again it provides a framework with which to consider this broad topic.

Normalization is one such *strategy*. Used by Strauss in 1975 to describe how people with chronic illnesses manage their lives and their treatment regimes (Strauss et al., 1984) and specifically in relation to RA at the same time (Wiener, 1984), the term ‘normalization’ has numerous other meanings within different historical, social and scientific fields. In chronic illness, it describes patients’ and their families’ attempts to live life ‘as if normal’ (Wiener, 1984: 91) making their illness and its consequences routine, and treating the changes and improvisations they make as ordinary. This process can involve either scaling down activities, in which case the inactivity is often justified to others as ‘normal’, or struggling to maintain previous levels of activity, with the risk of overextending oneself.

Normalization represents a further task for patients: in addition to their aims of staying alive and controlling their symptoms, they also strive to appear normal to the rest of society, covering up their problems and limitations.

If successful, normalization enables patients to increase their capacity and maintain their level of health (Charmaz, 2000), finding ingenious ways to overcome the disruption caused by their illness. However, this success depends upon factors related to the individual, the condition itself, and those around them. Strauss (1984: 79) specifically lists the determinants as:

- 1) the social arrangements the patient can make
- 2) the intrusiveness of the symptoms and treatment regime
- 3) the knowledge others have of the condition
- 4) its potential to be fatal.

If patients are unable to normalize, then they are forced to ‘renormalize’. This occurs in response to new or prolonged disruption which cannot be incorporated into their current strategy and regime, resulting in a lowering of expectations, the development of a ‘new set of norms for action’, and withdrawal from their previous roles (Wiener, 1984: 94).

I will return to the topic of normalization and its implications for patient education when reviewing my interviews with newly diagnosed patients with AS. In the context of this literature review, however, it remains an important response to chronic illness – a patient’s desire to be perceived as normal and maintain a sense of normality, alongside behaviour or ‘work’ which is directed towards achieving this.

2.2.2.2.3 Illness Narratives

Illness narratives are the stories people tell about their illness. Through qualitative interviews, they have provided the principal means by which researchers have accessed and sought to understand patients’ views and experiences. Yet they also remain a topic in their own right - an opportunity to consider the effect on its audience of both the content of the story and the style in which it is told. Reissman (1990: 1195) notes that ‘we are forever composing impressions of ourselves, projecting a definition of who we are, and making claims about ourselves and the world that we test and negotiate in social interaction’. Interviews with patients are a continuation of that social interaction, and the resultant narrative is an impression of that person, a definition that they have projected in those particular circumstances. Thus the interpretation of these narratives needs to consider the ways they have been ‘shaped by motive and context’ (Bury, 2001: 281), in order that we can ‘hear the story that is *really* being told’ (Kleinman and Seeman, 2000: 238). This topic can therefore inform us about how patients talk about their illness, and how this talk can be interpreted; for researchers hoping to understand the patients’ perspective, taking their stories at face value – without considering this additional layer of interpretation - may well be doing them a disservice.

Gareth Williams, in his paper on *narrative reconstruction* (Williams, 1984) viewed illness narratives as having both routine and reconstructed elements. The routine form relates to a commentary on ‘the mundane incidents and events of daily life’ (1984: 178) in which they are ordered within the narrator’s ‘practical consciousness’¹⁴. This narrative appears as ‘an orderly sequence of facts’, with minimal comment or explanation of why the events took place. In contrast, the reconstructed form of the narrative is necessary to account for the disruptions to this order which are so severe that the routine narrative is lost, and can no

¹⁴ Williams credits the term ‘practical consciousness’ and later ‘discursive consciousness’ to ‘A. Giddens (1979). *Central Problems in Social Theory: Action, Structure and Contradiction in Social Analysis*. Pub: London: Macmillan’.

longer be followed. Examples of these ‘severe’ disruptions which could lead to such reconstructions would include a death within the family, redundancy, or of course, the diagnosis of a serious illness. This process of narrative reconstruction can therefore be seen as a response to the loss of the ‘explanatory systems’ within Bury’s description of biographical disruption. In this form, the narrative is used to bridge the gap between these disruptive events and their biography – their sense of who they are, and how they want to be perceived.

Within this study, Williams interviewed thirty patients with RA whom he termed ‘seasoned professionals’ with respect to living with their chronic illness; each had been diagnosed at least five years before the interview. He focuses on three cases, and in each case on their account of why they developed RA. Specifically, he explores why each of the patients chose to explain the onset of their illness in their own particular way, noting that each narrative constitutes ‘an imaginative attempt to find a legitimate and meaningful place for RA in their lives’ (Lawton, 2003: 27). Williams himself saw the process as ‘an attempt to reconstitute and repair ruptures between body, self, and world by linking-up and interpreting different aspects of biography in order to realign past and present and self with society’ (Williams, 1984: 197)

Later commentators have classified narratives according to their overall effect on the listener – the ‘work’ they do as stories – often emphasising their moral, political or religious purpose. That is not to suggest that these narratives represent conscious attempts to manipulate their audience, nor that the whole passage of conversation can be neatly apportioned to a particular narrative class (Radley and Billig, 1996). Instead the classifications offer another framework within which to analyse what patients say, and provide a more sophisticated understanding of how individuals with chronic illnesses interact with society.

Bury suggests that there are three types of illness narrative: *contingent*, *moral*, and *core* (Bury, 2001). Contingent narratives are analogous to Williams’ ‘routine’ narratives, describing events and their ‘proximate’ causes and effects. Moral narratives are closer to those narratives Williams would term ‘reconstructed’: culpability is considered, and the effect is to ‘exonerate the individual from blame, and help to maintain self-worth’ (*ibid*: 275). Reissman’s (1990) description of her interview with a man with multiple sclerosis is

a good example. Despite recently breaking up with his wife, losing his job, and his son leaving home, 'Burt' presents a positive impression of himself as an effective and masculine husband, father and worker. Bury's final category, core narratives, relate the patient's experience to the concept of society's views on illness. The effect of these narratives are conveyed by the manner and style in which they tell their story and their use of specific forms of language, typically without deliberate consideration. Thus narratives become - as examples - 'heroic', 'tragic', 'comic' or 'didactic' (Bury, 2001: 278), broad brush strokes which can tell us more about the relationship between ill people, their self-image and society.

Further narrative categories which Bury would recognise as 'core' are described by Arthur Frank (1995) in his book *The Wounded Storyteller*, in which he recognises *restitution*, *chaos* and *quest* narratives and the concept of *testimony*. Equally, Ian Robinson (1990) views aspects of the written narratives of people with multiple sclerosis as *stable*, *progressive* or *regressive* depending on whether they were moving closer or further away from the goals in life which they set themselves. I will not describe each of these categories in detail here, but instead include them as further examples of how sociologists have examined illness narratives. Such labels are not the final result of any analysis; they are not the final result in an attempt to understand patients' experience and the way in which they communicate it. Instead they allow the 'researcher' or the 'listener' to examine the narrative as a whole, or at least in large sections, consider its effect, and the explanations for that effect.

2.2.3 Lay Understanding of Illness: Knowledge and Expertise

In the previous sections I have considered how specific authors have referred to patients' knowledge about their illness, principally in relation to the transitions which have taken place within the sociology of chronic illness. I noted Parsons' emphasis on the limitations of knowledge in the context of continued reliance on medical professionals, Bury and Charmaz's views of knowledge as a potential mitigating force against the damaging effects of chronic illness, and later Williams's description of the tendency for patients to reconstruct narratives to bridge the gap between medical explanations and their own understanding of aetiology. The process of educating patients attempts to increase various aspects of patients' knowledge about their condition, and yet we have already seen in this

review that there are disparate opinions regarding the extent and effect of such knowledge. In this section, therefore, I will focus on changing concepts of lay knowledge and lay expertise, specifically the nature and limits of such knowledge, and the value which health professionals and researchers have attached to them.

Some sociologists refer to a period, prior to the nineteenth century, when lay knowledge was inseparable from medical knowledge (Jewson, 1976). At this time, illnesses were defined and diagnosed by the descriptions of their sufferers, and ‘new knowledge’ was constructed through observation and collaboration with patients rather than by investigators in laboratories. The development of ‘biomedicine’, with its increasing use of diagnostic tests and technologies, is viewed as causing a further devaluation of patients’ knowledge, and a reduction in its importance to health professionals (Daly, 1989). The argument suggests that without the need to elicit a thorough and consequential history, or even be in the same room as the patient, the opinions and understanding of patients unnecessarily obscures the scientific diagnosis and management plan.

However, in contrast to this movement moulded by the way medicine is practised, two trends have increased the interest in patients’ understanding and interpretation of illness (Prior, 2003). The first is the focus on the ‘patients’ perspective’, and research into the experience of illness I outlined in earlier sections. The second, described as the ‘sociology of scientific knowledge’ (Busby et al., 1997: 81), has considered the nature and production of knowledge itself, and suggested a ‘democratisation of knowledge’ (Prior, 2003: 43). Thus, following these arguments, ‘lay knowledge’ could be considered to be as valuable, though obviously different, to ‘*scientific* knowledge’.

The influence of these sometimes conflicting trends can be outlined through the changing terminology used by researchers over the last three decades. Lay or health ‘beliefs’ have instead become lay ‘knowledge’, perhaps a subtle change in vocabulary, but one which seems to reflect a change in their importance relative to the scientific perspective of medicine. Linguistically, ‘beliefs’ could be considered erroneous and exist without logical grounding; practically they were used to compare patients’ understanding with a ‘gold standard’ of medical fact, or to explain behaviour which appeared illogical in the face of medical wisdom. Thus a change from ‘belief’ to ‘knowledge’ signifies a change from viewing patients’ understanding very much from a medical perspective (Armstrong, 1984),

to one which values their contribution towards an overall understanding of health and illness.

By the 1990s, however, this trend had accelerated to consider patients as ‘experts’. Tuckett (1985) is one of the first to use this phrase, in his book suggesting a new model for the medical consultation - ‘Meetings Between Experts’. Here though, he defines the limits of such ‘expertise’:

We conceive of the consultation as a meeting between one person who has, by his training and experience, access to scarce and specialist knowledge and another person who has, by experience, immersion in his culture and past discussion, a set of ideas about what is happening to him. Both parties form models of what is wrong, what should be done, what are the consequences of the problem, its treatment and so on, based on their own reasoning and background knowledge. These models may involve a degree of inconsistency and uncertainty. (Tuckett, 1985: 217)

Thus Tuckett views patients’ expertise as experiential, and argues that successful consultations between patients and doctors should be based on sharing their respective realms of expertise. Within this description the doctor retains their unique access to ‘specialist biomedical ideas and skills’ (217). However, later this distinction appears less well defined. Initially, this is through the relaxation of technical definitions such as ‘epidemiologist’ (Davison et al., 1991) or ‘pharmacologist’ (Monaghan, 1999) to include lay adaptations of these ‘expert’ professions. Yet some authors blur the distinction further by arguing that lay people can themselves develop the technical skills which define expertise, and can perform the same technical functions.

Epstein (1995), for instance, discusses the ‘construction of lay expertise’, noting how people with AIDS employed a number of tactics to achieve the status of experts – thus becoming capable of creating and moulding medical knowledge, and crossing the divide between public and science. The ‘activists’ adopt the language of biomedicine, establish themselves as representatives of a larger group of patients, combine political, moral and scientific arguments, and take sides in pre-existing debates (417-421). Similarly, Arksey (1994) describes how patients with repetitive strain injury (RSI) became ‘experts’ in their attempts to define RSI as a legitimate medical diagnosis. Having followed these arguments, it appears that in certain circumstances it can be increasingly difficult to split the worlds of expert and lay, and define the nature and extent of their respective knowledge and skills.

Lindsay Prior sought to resolve this confusion and debate in his review for the journal *Sociology of Health and Illness* (Prior, 2003). Whilst recognising that patients could acquire a comprehensive experiential knowledge of their condition, he concluded that they were not experts. He considered expertise to be the ‘use and manipulation of technical knowledge’ (45), and that, within medicine, this should include ‘medical fact gathering and the business of diagnosis’ (54), at which patients are not adept. Furthermore, he indicated that it was necessary to separate the laudable aim of ensuring patient participation in medical decisions from the flawed argument that patients were, or could become, experts.

In this section I have described how commentators have differed both in their interpretation of the potential extent of patients’ knowledge, and how this knowledge is perceived within medicine. I share Prior’s conclusion that patients’ roles within medicine are not limitless, and therefore that the reliance on medical professionals described by Parsons (and in this section by Tuckett) cannot be bypassed by the development of a comparable ‘patient expertise’. Therefore, returning our focus to the topic of patient education, I would conclude that the knowledge and expertise that patients require is not a simplified, ‘watered-down’ version of that acquired by doctors during medical training. Similarly, its aims do not include enabling patients to somehow ‘compete’ with medical professionals to influence a universal medical knowledge. Instead, patients require knowledge and skills which undoubtedly overlap with medical expertise, but which focus more on the impact and experience of illness specific to them, and the practical responses they can initiate.

2.3 Conclusions

Within this chapter, I have described how theorists and researchers have come closer to understanding what happens when someone is diagnosed with a chronic illness such as ankylosing spondylitis: the experience of patients, their response, and to some extent how these topics can be studied most effectively. My approach, somewhat necessarily, has been an historical and methodological one, as I have attempted to sort the mass of writing on these subjects into a concise and purposeful piece. I have introduced topics which I feel are fundamental to the remainder of this thesis and explained how, in most cases, they have grown out of what came before, as a response to the debate surrounding existing research. Illness narrative work, for instance, developed from the increasing use of in-depth interviews to access patients' experiences in the early 1980s, and informs the interpretation of my own interviews by describing the norms and conventions people uphold when talking about their illnesses.

Relating these topics to the practicalities of how health professionals should provide or facilitate patient education is not without difficulty. Sociology, by definition, relates to the study of groups, while clinicians will often be concerned with the individual patient consulting them at a particular time. In this way, the sociology of chronic illness is not a short-cut to determining the experience or needs of an individual patient in clinic, but instead it illustrates a range of possible experiences and their importance. Individual circumstances (as referred to by Simon Williams in section 2.2.2.2.1) remain vital to this consideration, despite efforts to refine theories such as biographical disruption with respect to age and co-morbidities. Furthermore, the capacity of education, or indeed other interventions, to modify the experiences described in these papers is never considered. Patient knowledge and expertise are generally viewed as 'beneficial' – for example by Bury and Charmaz – but the details of how this knowledge could be practically imparted, and the potential role of health professionals in facilitating this learning is absent.

Therefore, the sociology of chronic illness does not provide a solution to the question of education for people with ankylosing spondylitis. It does, however, provide frameworks within which we can consider the consequences of a diagnosis of AS and patients' responses, and which will inform our interpretation of interview data. As we move on to consider the effect of educational interventions in the next chapter, we can also hypothesise

that education which acknowledges these frameworks is more likely to be consistent with patients' existing experience of their illness, and may be more successful than those which seek to alter such frameworks.

Chapter 3 - Educational Interventions

3.1 Introduction

This chapter constitutes the second part of my literature review, which as stated in the introduction to Chapter 2, seeks to answer the question: ‘which educational interventions are effective for patients with ankylosing spondylitis?’. While Chapter 2 examined the literature related to the experiences of patients with AS, I will now critically appraise empirical, primarily quantitative, studies which have assessed the effects of education. I have also included relevant review articles, policy documents and commentaries. The methods employed to compile this search were the same as those used in the first review. Similarly, I have not disregarded articles which were related to the chapter’s principal question of efficacy but do not uniquely refer to patients with AS. Instead I have used the same provisos I discussed in section 2.2 to deal with the articles concerning patients with generic ‘arthritis’ or other related chronic diseases.

The scope of this review, and thus my selection and appraisal of articles, relates to some of the topics I discussed in Chapter 1. The chapter’s principal question makes two important assumptions – firstly that we have a robust definition of what constitutes an educational intervention, and secondly that we have similar clarity in determining which are effective. Unfortunately we have already seen that such consensus does not exist in this field, and that specifically the definition and the aims of patient education suggested by academics may not be consistent with those in practical use by patients and clinicians. Clearly if agreement cannot be reached on the ultimate aim or purpose of an intervention then we will be unable to decide whether it has achieved this aim, and therefore if it should be considered effective. Thus agreeing whether education should alter clinical outcomes such as pain, stiffness or disease activity in AS, or change economic, behavioural, psychological, or knowledge based outcomes, seems crucial to the question I have posed. At this stage of the thesis, however, these fundamental questions stretch beyond its scope, and reaching definitive conclusions risks excluding studies which professionals or patients would consider as educational. Therefore this review remains deliberately broad with respect to interventions and efficacy. Many of the interventions discussed would not meet Lorig’s definition (1996) of patient education for instance (see section 1.3). Equally, in the absence of a clear definition of *effective education* facilitated by widely accepted aims, the results of each study are not compared to a universal standard.

The overall result of this approach is a consideration of the range of educational resources and interventions available to patients with AS, a critical appraisal of studies which investigate their effects, and a discussion regarding the significance of these effects.

3.2 Appraising Patient Education Studies

The literature relating to patient education is extensive, and draws from a number of disciplines. In addition to the sociological literature I have already commented on, educational academics have developed theories relating to adult learning and recommended suitable methods to teach groups and individuals (Knowles et al., 1998). Similarly, psychological theories have influenced educational interventions; the most frequently referenced is that of ‘social learning theory’ (Bandura, 1977b) and the related concept of ‘self-efficacy’ (Marks, 2001; Bandura, 1977a). Self-efficacy refers to an individual’s confidence in their ability to perform a task or specific behaviour successfully, and is fundamental to ‘self-management’ programmes. Other theories, such as Leventhal’s self-regulation model (Pimm and Weinman, 1998) and learned helplessness theory (Gonzalez et al., 1990) have also been applied to rheumatology patient education. Equally, there is considerable academic and political guidance (Bury and Taylor, 2008; Department of Health, 2005) regarding the nature of the relationship between health professionals and the public. These contrasting viewpoints exist alongside those of doctors, nurses, physiotherapists and other health professionals, who not only deliver many of the available educational interventions, but also contribute to the academic debate regarding the optimum methods which should be used. Acknowledging the respective academic and clinical backgrounds of these groups, the variety and lack of coherence between studies of patient education becomes more understandable, and an inclusive description and appraisal appears less achievable.

Despite the diversity of the authors’ backgrounds, educational studies have aspired to the conventions of the ‘gold-standard’ evaluation of pharmaceutical treatments – the double-blind, placebo-controlled, randomized controlled trial. Researchers thus seek to reach a tangible ‘proof’ that education is effective, evidenced by statistically significant differences between patients who have undergone an intervention, and those in a control group. Although education has been compared to therapies like non-steroidal anti-inflammatories (NSAIDs) in terms of importance and efficacy (Lorig, 1995), there are significant differences between the respective interventions which make the design and appraisal of educational studies particularly challenging. These differences contribute to the perception that studies of educational interventions are of lower quality than pharmacological studies, a view which has been upheld by quantitative comparisons (Boutron et al., 2003). In this

section I will identify some of the methodological issues which differentiate studies of education from pharmacological research and consider the extent to which these issues affect the outcome and significance of these studies.

3.2.1 Setting and Participants

For the results of such studies to be generalisable, the study population should be adequately described and be similar to the population to which the results are to be applied. In pharmacological studies, this can usually be achieved by detailing variables which could influence the effect of the drug, such as the age, gender, ethnicity, co-morbidity or even genotype of the participants. While these variables are also likely to be important in deciding whether educational interventions are applicable to a particular population, an additional range of variables may influence the outcome of educational interventions, and less is known about their potential effect. Therefore, consideration should also be given to variables which are less easy to describe, such as participants' level of education, previous experience of patient education, social circumstances, personality, educational needs and expectations. For instance, it is difficult to conclude what the effect of recruiting a high proportion of participants from existing self-help groups would have on the results of a large study of a self-management programme (Bower et al., 2006). It is unlikely that these results could legitimately be applied to the general population, given this recruiting bias. Equally, differences in culture and the organization of the respective healthcare systems make the application of results from an economic evaluation of a US educational intervention in the UK problematic, for example with Kate Lorig's study (1993).

Perhaps more importantly, especially when considering the application of educational interventions for people with AS, there is evidence that patients who are recruited for educational studies are not representative of the wider population with arthritis, with more female, elderly and well-educated patients volunteering (Hawley, 1995). The discrepancy is probably influenced by the significant time commitment required from participants, and thus the need to either sacrifice other activities or to have sufficient leisure time in order to attend. Additionally, these individuals may be more inclined to attend group activities, and may not attach the same negative connotations to activities which are portrayed as 'educational' as individuals who were less successful at school. While this could be seen as making the trials more pragmatic – including only those patients who would volunteer for

educational interventions outside of the research environment – it does reduce the external validity of the research findings. Similarly, as the individuals overrepresented in studies are also those likely to be already informed about their conditions, it is questionable whether these interventions are targeting the patients have the greatest need and would benefit most.

3.2.2 *The Intervention*

Reports of patient education trials are frequently criticised for describing the intervention inadequately (Burckhardt et al., 1994), and therefore an argument exists that it can be misleading to compare even apparently similar studies, especially using techniques like meta-analysis (Newman et al., 2004). Details such as the exact content and delivery of the education can be complex and lengthy to describe in research papers, but do allow studies to be effectively appraised and good practice to be replicated.

The ‘mode of action’ of education is not straightforward, however, and it is not possible to describe it in the manner of a pharmacological effect. Its effect is likely to be modulated by factors such as participants’ motivation and ability to learn, their pre-existing behaviour and beliefs, and through their relationships with other people. Ultimately, the links between knowledge, behaviour and measured health outcomes are complex and the factors influencing these relationships are not (and never will be) fully understood or predictable. Thus, particularly in programmes where there is face-to-face contact, many unseen variables can be influenced by educators, for whom personality and social factors will have significant effects on participants’ outcomes: two apparently identical interventions may have markedly different results when delivered by two different people.

There are also related issues with appropriate blinding and placebos. A true educational ‘placebo’ does not exist, and without an understanding of why and how education exerts any therapeutic effect, it is difficult for researchers to select and deliver an appropriately inert placebo. It is similarly difficult to blind the participants as to whether they have received an intervention or not. Furthermore, while participants in drug trials can have their medication regime strictly controlled, it is less easy to restrict or control the education that patients receive outside of any trial setting – educational activities overlap with other aspects of patients’ lives, and these ‘contamination’ effects are rarely acknowledged, yet these may be important factors in determining the efficacy of an intervention. Many of

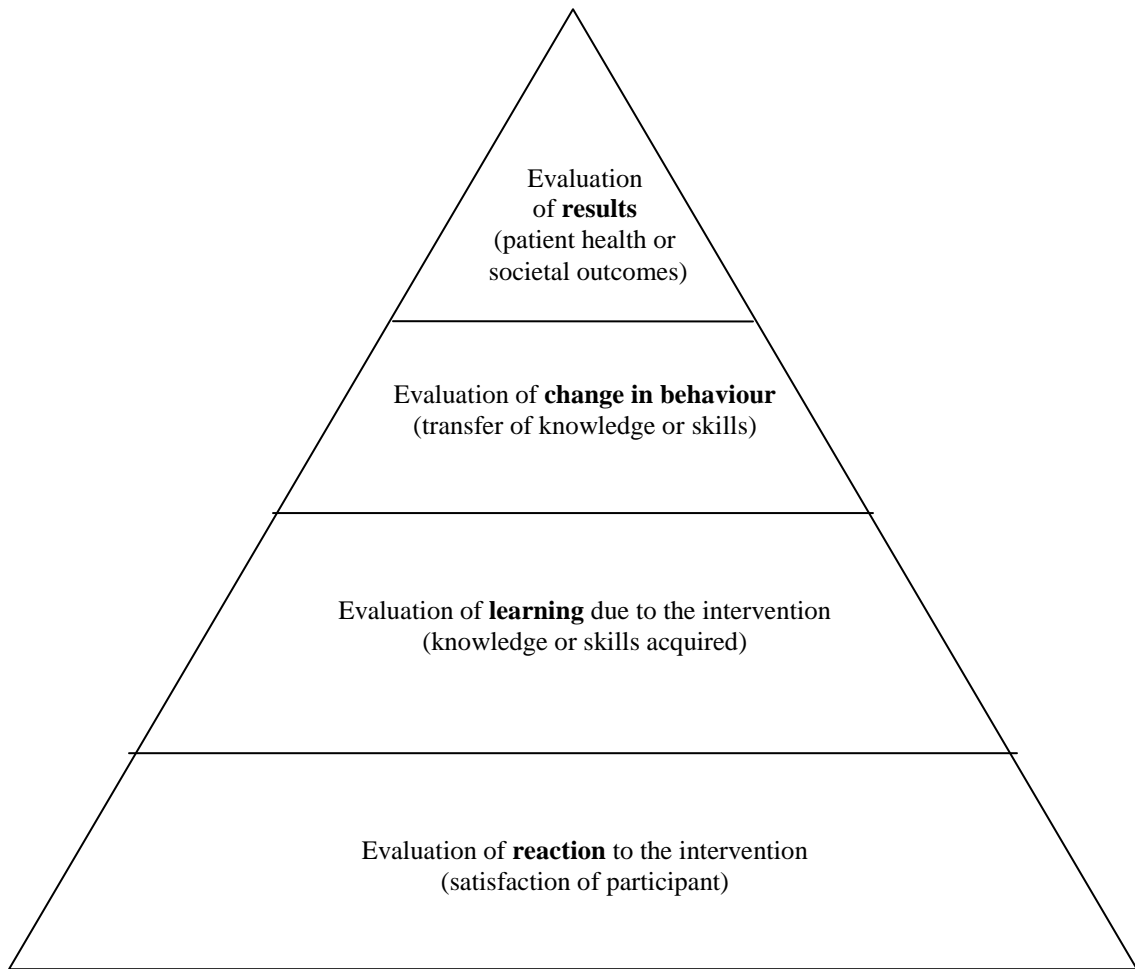
these issues are considered in a broader form in the Medical Research Council's guidance on evaluating complex interventions (2008).

3.2.3 Measuring Outcome

As I discussed in the introduction to this chapter, there is a perception that education can be effective for patients, but little consensus about what exactly it should achieve. Outcome measures chosen range from the simplicity of patients' satisfaction with an intervention to the complexity of economic evaluations from a societal viewpoint, taking account of costs such as hospital admissions and the benefits of improved quality of life. Clearly no-one would disregard an intervention which appeared to have economic benefits, but would the converse be true – should an intervention be deemed ineffective if it does not produce these benefits? Equally, interventions which reduce patients' utilisation of health services may actually be discouraging and reducing useful and appropriate visits to healthcare practitioners. Interviews with patients before and after participation in one educational intervention illustrated the wide range of changes in healthcare utilisation which occurred, and the factors which influenced any change (Gately et al., 2007). The authors highlighted the importance of pre-existing patterns of utilisation and patients' own biography in predicting future behaviour, as opposed to any effect of the intervention itself.

Kirkpatrick's hierarchy is used as a tool to evaluate the effectiveness of educational interventions in the context of professional training (Kirkpatrick and Kirkpatrick, 2006) (Figure 4), but has not previously been applied to patient education. It provides a framework to consider the effect of educational interventions, indicating the level of complexity of change of behaviour required to achieve particular outcomes, and also the increasing risk of confounding factors in measuring these more complex outcomes:

Figure 4: Kirkpatrick's Hierarchy – Evaluating Educational Interventions (Adapted from Kirkpatrick and Kirkpatrick, 2006)



Using this hierarchical model, outcome measures such as disease severity and healthcare costs appear at the apex of triangle. Changes in these outcomes are much more difficult to ascribe specifically to the intervention, as the potential effect of confounding factors increases towards the apex. However, changes in these measures are also most likely to interest those who plan and finance the delivery of healthcare, and also the bodies which fund and publish research.

Where these more 'objective' outcomes are either not measured or not sought, then measures of behaviour change, appearing lower down the hierarchy, are often used. These are usually recorded in the form of self-completed questionnaires which are employed before and after an intervention such as a group education programme. Even when

appropriately validated, such questionnaires remain subject to important confounding effects. Firstly, apparent improvements can be seen simply by repeating the measurement of behaviour or attitudes – the ‘Hawthorne effect’ (Landsberger, 1958). Secondly, reported behaviour is likely to change more than actual behaviour after an intervention which was either ostensibly designed to influence it, or assigned value judgements when discussing it. Thus the effect of educational interventions on behaviour or attitudes (including self-efficacy) may well be exaggerated when measured by these commonly used methods.

Finally, particular problems exist when the long-term outcomes of educational interventions are being studied. The design of randomized controlled trials of group interventions has used ‘waiting list’ patients as a control group. Participants are recruited to a trial on the basis that they will attend an education programme, but half are randomized to enter a waiting list phase, during which time they act as the control group for the other half who take part in the intervention. Using this method, there is clearly a limit to how long patients can ethically and practically remain on a waiting list. However, this time limit is also the effective limit to the duration of long-term follow up in determining the effect of the intervention, because they cannot continue to act as controls after they have undergone the intervention. Alternative methodology has been to recruit a control group separately, but in this case particular care has to be taken to ensure the characteristics of the groups do not differ in the manner discussed in section 3.2.1.

3.2.4 Appraising Patient Education Studies - Summary

In this section I have described some of the methodological difficulties associated with studies of patient education interventions, which not only differentiates this type of research from trials of pharmaceutical agents, but also helps to make sense of the literature concerning this topic. Although I have pointed out a number of potential hazards which exist in interpreting the results of these studies, my objective has not been to disregard their findings. Instead, I have pointed out that evaluating the effect of educational interventions can be extremely challenging, and the potential for confounding factors affecting results appears to be greater than for drug trials. Researchers need to take appropriate care in choosing and reporting the participants, the intervention, and the outcomes of any trial, and explain the decisions they have taken in designing the trial. Readers must be aware of the challenges faced in evaluating educational interventions, and in turn ensure this is reflected

in how trial results influence their practice. The difficulties described using these conventional methods also indicates, by comparison, some of the strengths of employing alternative, qualitative methods to evaluate educational intervention.

3.3 Resources for Patients with Ankylosing Spondylitis

There are many educational resources available to patients with AS, and having already described the difficulties in appraising the efficacy of these resources, I will now consider how these different methods of education have been evaluated, and what conclusions can be drawn with respect to people with AS. Some authors have attempted to provide an overview of the range of educational resources available, trying to determine the most effective way to deliver education to patients, either through meta-analyses calculating comparative effect sizes for different methods of delivery (Theis and Johnson, 1995), or through critical reviews of the literature relating to patients with arthritis (Schrieber and Colley, 2004; Hawley, 1995).

Theis and Johnson (1995) analysed 73 studies which compared educational strategies in adult patient populations, and suggested that structured programmes using multiple methods had the greatest effect (Mean effect size (ES) = 0.54), whilst verbal ‘question and answer’ sessions were least effective (Mean ES = 0.34). However, there is insufficient information to determine the inclusion criteria used for these studies, or the methods used to ascertain the quality of the included studies. Additionally, the validity of combining results from many unspecified outcome measures to give a mean effect size and of including patients with a wide range of acute or chronic medical conditions is not questioned.

In comparison, the latter critical reviews are useful in highlighting the range of interventions available, the studies which the authors associate with these methods and feel are important, the perceived deficiencies in the evidence presented, and recommendations for how researchers should proceed in order to increase our understanding of the topic. However, these reviews do not consider issues of acceptability or uptake by patients, or indeed whether these interventions meet the needs and expectations of the specific patient group we are interested in – people with AS.

For each of the resources in this section I have identified and evaluated literature pertaining to its effect and utility for people with AS, and discussed potentially beneficial and detrimental factors for both patients and health professionals.

3.3.1 Group Education

The promotion of education arranged through groups of patients is based upon the concept of a 'group effect', which can enhance learning through the social organisation, cohesiveness, shared experiences and shared goals common to members (Jacques, 2000). From a practical viewpoint, group education may allow for more efficient use of resources, with a higher ratio of patients to tutors enabling costs to be reduced. The use of lay facilitators has suggested further savings compared to health professionals, with the additional argument that they may act as positive role models for participants, further promoting the adoption of healthy behaviours. (Lorig et al., 1986).

However, there are also arguments against promoting education as a universally collective activity. Opportunities to offer information specific to patients' circumstances are greater in one-to-one sessions (Hill, 1997), and although reasons for non-participation in group education has not been studied in any depth, many patients seem unwilling to attend groups¹⁵. Although there are no shortages of hypotheses, definitive and rigorous explanations are lacking, but could be obtained through qualitative interviews with non-attenders. A lack of confidence and willingness to talk about issues which many people consider deeply personal – health, relationships and finances – may be important. The homogeneity of groups could also influence patients' willingness to join or continue to attend group education; men may find groups with a female majority difficult, and similarly issues of age, social class or disease severity could affect attendance; younger participants may find older group members with the same condition but greater disability difficult to relate to, perhaps leading to an expectation that they too will inevitably deteriorate as they age. Additionally, patients may not wish to join or attend groups associated with their disease because of a desire not to be labelled with that condition, and to try and minimise the perceived impact on their life.

¹⁵ While this is largely anecdotal, there is some empirical data to support this statement. A study in San Francisco compared patients with either OA and RA that had attended a group education programme with those that had not despite having been repeatedly offered the programme. Non-participants were significantly more likely to be male and non-white, while there were no differences in the educational level of the two groups. [Bruce, B., Lorig, K. and Laurent, D. (2007) 'Participation in patient self-management programs', *Arthritis Care & Research*, 57, (5), pp. 851-854.] Conversely, there were no gender differences between participants and non-participants in an individual educational intervention [Blanch, D. C., Rudd, R. E., Wright, E., Gall, V. and Katz, J. N. (2008) 'Predictors of refusal during a multi-step recruitment process for a randomized controlled trial of arthritis education', *Patient Education and Counseling*, 73, (2), pp. 280-285.]

The answers to these questions of preference and acceptability would help providers of education understand patients' priorities and to design alternative interventions which may share some of the potential benefits of group education, and yet be utilised by non-attenders of conventional group education. I will return to these questions in my results chapters.

I have separated the remainder of this section examining group education into literature related to self-management studies, to self-help groups and finally to other group resources.

3.3.1.1 Self-Management Studies

There is substantial literature detailing the application of self-management interventions in chronic illness. Programmes of group education have developed from a number of studies led by Kate Lorig at the Stanford Arthritis Centre since the late 1970s, and mirrored in the UK by research led by Julie Barlow (Barlow et al., 2000). The Chronic Disease Self-Management Programme (CDSMP) (Lorig et al., 1999), has been adapted into UK health policy as the Expert Patients Programme (EPP) (Expert Patients Programme, 2011), which is aimed at people with any self-defined chronic illness. Groups are led by trained patients rather than health professionals. The Arthritis Self Management Programme (ASMP) (Lorig et al., 1993), a predecessor to the CDSMP, is also available to patients in the UK as 'Challenging Arthritis' (Arthritis Care); both are 6 week programmes, at 2 hours per week, and are based on self-efficacy strategies.

Published trials of these programmes have reported improvements in physical (e.g. pain, disability), psychological (e.g. depression, anxiety, self-efficacy) and economic outcomes, the latter through reduced utilisation of healthcare resources. Despite these results and the optimistic discussion which accompanies them, concerns remain about their universal promotion; many of these were raised in Taylor and Bury's critical review (2007). The authors argue that self-efficacy does not represent a 'magic bullet' for chronic disease management, and that there are significant dangers in viewing the construct in this fashion. Importantly, self-efficacy fails to acknowledge the social restrictions on patients' behaviour (for example attempting to improve diet with limited availability of fresh food locally, poor culinary skills, and limited finance), and assumes that all are equally capable of changing their lifestyle. Additionally, the precise relationship between improvements in self-efficacy and improvements in coping with ill-health remains unclear, and therefore focusing efforts

on increasing it may detract from more productive methods of improving patients' lives. It has been suggested that programmes would be more acceptable to participants if they acknowledged or sought to build on their existing self-care mechanisms (Kendall and Rogers, 2007). Other commentators share this concern that encouraging widespread participation in these programmes will not lead to the benefits to patients and society suggested by its proponents (Greenhalgh, 2009; Griffiths et al., 2007)

A systematic review of self-management in chronic disease examined interventions for people with arthritis, diabetes or asthma (Warsi et al., 2004), finding 71 applicable trials, of which 27 related to arthritis. Whilst subsequent reviews have criticised this paper for attempting to combine the results of studies which have extremely variable and poorly documented methods (Newman et al., 2004), the authors found no statistically significant difference between intervention and control groups for pain or disability scores. They also found evidence of publication bias and suggested that the developers of educational programmes should not be involved in their subsequent assessment.

Criticism of the methodology of these trials incorporates many of the challenges faced in studies of educational programmes discussed in section 3.2. Long term outcome data is particularly lacking, as randomized trials have employed the waiting list control design. Lorig's study (1993), is often referenced within arguments suggesting the enduring economic benefits of these groups, with calculated cost savings of \$648 per RA patient, and \$189 per OA patient over four years, made by a reduction in the number of visits made to their physicians. However, the control groups were not recruited for an educational study, and therefore arguably included patients who were less keen to learn about their condition or change their behaviour. Equally no data is provided to indicate whether there were significant differences between the two groups at baseline, and the method used to collect the number of 'physician visits' was different for each group.

Other key discourses in this area include whether the leader of the education group should be a health professional or a 'lay-leader', and how the arthritis-specific courses compares to the 'generic' chronic disease course. A randomized trial (Lorig et al., 1986) compared the outcomes at 4 months of 27 arthritis patients who took part in a lay-led self-management course with 29 similar patients who attended 'professional-led' sessions. They found that the former (lay-led) group gained less knowledge of arthritis self-management, but

performed relaxation behaviours more often. There was no difference in pain or disability scores, but those who attended the professional led course seemed to increase the number of visits to their physician in the months after the intervention, although this isn't commented on in the discussion. The authors' conclusions were that patients could teach the course 'safely', and that the arthritis community should utilise patients more as educators. However, they did not suggest that lay leaders were more effective overall - which seems to be the message some commentators have taken from this paper - and there was no comment on the preferences of potential participants for lay or professional group leaders. Attempts to answer the second question - the effect of the disease specificity on patient outcomes - have indicated better outcomes in global health and activity levels at four months for the disease specific programme, although differences between the two groups were smaller at one year (Lorig et al., 2005)

The REPORT study (Research into Expert Patients – Outcomes in a Randomized Trial) (Kennedy et al., 2007a) is an assessment of the Expert Patients Programme (EPP) in the UK. It randomized 629 patients from across the UK with a self-defined diagnosis of a long-term condition to either immediate enrolment on an EPP course, or to a 6 month waiting list control group. The mean age of participants was 55 years, 70% were female and 95% were of white ethnic background. Whilst it proved impossible to record the total number of people who declined to take part, more than 600 did not start the trial after initially showing interest in it. Reasons included problems with access to the courses, poor current health state, a belief that they were already efficient self-managers, dislike of the group approach, or insufficient motivation for a 6 week course. Primary outcomes were the mean of four self-efficacy scores, energy levels as a measure of health status, and a self-reported measure of healthcare utilisation. Statistically significant improvements were seen in the treatment group at 6 months in self-efficacy (Effect size 0.44, $p=0.000$ to 4sf), and in energy levels (Effect size 0.18, $p=0.004$). Cost analysis showed a small increase in quality of life (QALY improvement 0.02), and a reduction in cost of £27, indicating that if there is a willingness to pay for healthcare interventions at £20000 per QALY, there is a 70% chance that the EPP is cost-effective.

A self-management course designed specifically for patients with AS has been designed and evaluated (Barlow and Barefoot, 1996). It consisted of 12 hours of intensive tuition

spread over two consecutive days; limited information regarding the content of the sessions is available, but it included hydrotherapy and standard exercises, exercise motivation sessions and information about AS and appropriate posture. The study was a non-randomized comparison between the first 30 participants on the programme and matched controls at baseline and 6 months. The control group did not take part in any planned educational activities. Statistically significant differences in self-efficacy scores and depression were seen between the intervention and control groups, but no difference between measured disease severity and function. Increases in exercise frequency seen at 3 weeks in the intervention group did not persist at 6 months. Comments by the authors suggest that the psychological improvements seen were clinically significant, and that ‘booster sessions’ or inviting partners to attend the course may have meant that the changes in exercise behaviour would have persisted. However, when the effect of reinforcement sessions has been assessed elsewhere, the results have been disappointing (Lorig and Holman, 1989).

The interest in this area has been considerable over the past two decades, with an impressive volume and recently, increasing quality of research into this difficult field. While it is clear that for certain participants the programmes have dramatic, positive effects (Ness, 2006), the measured improvements in outcomes at the apex of Kirkpatrick’s hierarchy (see Figure 4) have been small, and limited to short-term evaluations. Equally, although there is some evidence that increases in measures of self-efficacy are valued by patients (Richardson et al., 2009), it remains unclear exactly how this psychological construct relates to patients’ health. There are also doubts about the populations which are likely to both volunteer to attend and subsequently benefit from these interventions. The majority of volunteers are female, middle aged and well educated (Lorig et al., 2005)¹⁶ while it may be those people who are young, poorly educated, and lack self-confidence that benefit most (Reeves et al., 2008). In summary, the evidence examined suggests that many patients with ankylosing spondylitis would not volunteer to take part in such programmes, and certainly do not belong to the populations of patients that have been extensively studied. From a wider perspective, doubts remain about the significance to patients of some of the changes seen in the trials of this intervention, and about the value of the societal

¹⁶ In this trial of patients with generic ‘arthritis’, participants were mainly female (81%), elderly (mean age 65.5 years), and with a high level of education (mean 15.5 years duration). This demographic is highly represented in trials of self-management, as noted in section 3.2.1.

economic benefits which are widely quoted. Practically, the transfer of the EPP in the UK away from the NHS to a Community Interest Company (CIC) may limit the availability of these groups, making the target of 100,000 participants per year by 2012 difficult to achieve (Expert Patients Programme, 2011). The transfer has resulted in a new requirement for individual primary care trusts to purchase programmes from the organisation, and in some regions the EPP is not currently available.

3.3.1.2 Patient Support Groups

The National Ankylosing Spondylitis Society (NASS) is a registered UK charity which aims to improve outcomes for patients with ankylosing spondylitis through a variety of methods. Formed in 1975, it now has more than 8000 members, and views education as one of its principle objectives (Skerrett, 2010). This is achieved through local support and exercise groups, a guidebook for patients, a website, and a bi-annual newsletter, which contains articles on the latest medical research and correspondence from members about problems and solutions related to their condition. Local support groups function differently from the education groups described previously – not as a time-limited programme of education or exercise, but as an informal drop-in for members who choose to attend on that particular evening. They are usually run by interested physiotherapists and patients with AS (Feldtkeller, 2002).

People with AS who are members of NASS are certainly different – they exercise more, are more satisfied with their available support, and have a ‘lower reliance on powerful others’ (Barlow et al., 1993b: 153). However, it is likely that these differences to some extent determine the patients who join NASS, as opposed to being due to the influence of NASS on its members. Gareth Williams (1989), in his study of support groups for people with ankylosing spondylitis, suggests that the make-up and output of NASS in the 1980s encouraged self-reliance rather than mutual aid, and minimised any acknowledgement of the influence of social and psychological factors on members’ health. This type of detailed, independent evaluation of NASS hasn’t been repeated, so it is not clear how far his observations still apply today. Interestingly, Williams concludes that self-help groups provide governments with ‘a ready excuse for dismantling the statutory health services’ (*ibid*: 155). More recently, aggressive marketing of a state-backed self-management

initiative (the EPP) was seen as a threat to services provided by voluntary organisations (Taylor and Bury, 2007).

Evaluation of support groups has not focused on the educational or behavioural outcomes reported in self-management studies, demonstrating the difficulty in comparing the effect of these resources. A randomized controlled trial of 112 patients with arthritis (17% of whom had AS, 55% had rheumatoid arthritis), using a waiting-list control group design, examined the effect of ‘mutual support groups’ (Savelkoul and de Witte, 2004). Patients in the intervention group attended 10 group sessions with 10-12 patients where they were able to exchange information, experiences, feelings and emotions. The methods or rate of recruitment are not specified. While the support groups increased patients’ communication skills and were appreciated by participants, surprisingly they didn’t have any effect on the size of their social network, or measures of loneliness.

Support groups are important for many patients with AS, and NASS is the most important source of information for its members (Rogers, 2005). Evaluating it as an educational resource and disentangling the effects of membership from the characteristics of those who join is more difficult, and has not yet been accomplished.

3.3.1.3 Other Group Education Resources

Cognitive behavioural therapy (CBT) has been assessed as an educational intervention for patients with arthritis, although it attempts to increase patients’ control over pain and other symptoms rather than dealing specifically with the transfer of information and skills.

Participants can learn relaxation, diversion and cognitive restructuring skills in group settings, and subsequently how to transfer these into everyday life (Parker et al., 1993).

Alison Hammond, an academic occupational therapist, combined these techniques with education for patients with RA in a modular course termed ‘Lifestyle Management for Arthritis Programme’ (LMAP) (Hammond et al., 2008). She showed improvements in pain and psychological status which persisted at 1 year, compared to an information-based group programme led by other health professionals.

A comparison between CBT and self-management programmes for patients with osteoarthritis (OA) and rheumatoid arthritis (RA) examined 17 self-management and 9 CBT studies – 8 of the 26 studies were not controlled trials (Hawley, 1995). Using a meta-

analysis design to compare effect sizes, she concludes that both programmes reduce self-reported pain to a similar degree, but that CBT appears to have a more rapid effect, and may be more likely to cause changes which persist beyond 6 months. Effects on psychological measures and function were small or non-existent, though the absence of deterioration in function was noted and raised as a possible marker of efficacy.

Combined physiotherapy and education classes are provided to patients with AS at some centres, and there is evidence that these are more effectively provided in group format. A randomised trial compared a total of 144 patients with AS who either attended group sessions or who exercised at home (Hidding et al., 1993). Those in the group sessions had better spinal mobility measurements and global assessment scores after 9 months, although it is not clear if the measurements were by a blinded assessor, and the difference between the two arms could be explained by the fact that those in the group were supervised exercising, while those at home were simply given the instructions of which exercises to do.

Few controlled studies evaluating group educational interventions have been published which have not been based on self-efficacy theory or CBT. This is consistent with the guidance from commentators who suggest that 'a-theoretical' teaching is less effective (Taal et al., 1997; DeVellis and Blalock, 1993). However, Lindroth et al (1995; 1989) examined the effect of a didactic group teaching programme on 100 patients with OA and RA in Sydney, Australia, using a matched control group recruited from another hospital. Topics discussed were determined by a workshop attended by health professionals and patients, and the overall aim of the programme was to increase patients' knowledge about their condition and teach them skills to help them cope with it. Improvements in knowledge and disability were seen after 12 months; the former persisted at 5 years. Contrary to self-management strategies, patients in the intervention group reported more visits to their physician and other health professionals than members of the control group at 5 years. This may reflect improved access to useful resources for these patients, differences in practice between the two recruiting hospitals, or perhaps a strategic, beneficial increase resulting from increased awareness of their needs.

3.3.2 Individual education

Information delivered on a one-to-one basis is one of the most commonly used forms of education, simply because it occurs as part of routine clinical consultations and care.

Patients ask questions about their condition and its management during consultations, raise individual concerns, and receive advice on physical, psychological and social problems depending on the experience and expertise of the practitioner. In fact, because this process is so ingrained in routine practice, some would not include this within the concept of patient education. Research into patients' views consistently show consultations with health professionals, and physicians in particular, are the most valued source of information about their condition for patients with arthritis (Buckley et al., 1990). Interventions aimed at encouraging question asking and thus addressing patients' information needs during consultations have been evaluated in a meta-analysis of 33 randomized trials (Kinnersley et al., 2008). Written materials and coaching of patients had similar, small effects on the number of questions asked, and patients' overall satisfaction with the consultation.

Nevertheless, research into the effectiveness of one-to-one education has been seen as a much lower priority than examinations of group education (Buckley et al., 1990), because of the resource implications I have already discussed, but also because individual education is often seen as less effective, irrespective of the methods used. For instance, a randomized controlled study investigating education for people with Type II diabetes compared a group intervention designed and delivered by the author with routine care plus extra routine appointments with the patient's normal GP, dietician and practice nurse (Deakin et al., 2006). The additional improvements in HbA_{1C}, diet, physical measurements and behaviours seen with the group programme are assigned to the benefits of group over 1:1 education, yet one can question whether the findings would be replicated if the individual education resources were also delivered by people with the same motivation, specialist knowledge and training as the authors.

One-to-one sessions with a patient trained to educate other patients were investigated in a controlled trial of 108 newly referred patients in Texas (Branch et al., 1999). Each newly-diagnosed patient in the intervention group saw the 'patient educator' immediately after their consultation with the Rheumatologist, and had a follow-up phone call one week later. Patients in this group had better knowledge about their condition, were more satisfied with

their overall care, but there was no impact on health status at 8 weeks; this may have been too early to notice a change, and the study may have been insufficiently powered to show a clinically significant but small change in this measure.

Other controlled studies have shown improvements in adherence to prescribed medications in RA (Hill et al., 2001), and improvements in physical measurements and function for a combined physiotherapy and one-to-one education sessions in AS (Kraag et al., 1990). Telephone interventions in OA and RA have shown benefits in overall health status over nine months (Maisiak et al., 1996).

Much of the discussion around individual education for patients has been centred on who provides it. Although physicians are seen by patients as being the most qualified to teach them about their condition, this may be because patients do not fully understand the role and expertise of other health professionals, or have not had the opportunity to consult them. Similarly, the Consultant Rheumatologist is often the patients' most stable contact with respect to their condition, and may well have informed them of their diagnosis. Additionally, there is no single group of professionals who accept and lead this and other aspects of education (Smith, 2000), although in centres where they are employed and trained, specialist nurses are increasingly taking on this role in rheumatology and other disciplines (Coates, 1999). However, one-to-one education is primarily an important form of learning for patients because it occurs as part of the routine delivery of healthcare, reaching patients without additional resources or motivation to attend a specific resource.

3.3.3 Written Information for Patients

Written information in the form of leaflets is frequently used to offer patients details about their condition, care and treatment choices. Commonly used as an additional resource which people can keep and review at their own convenience, they can be distributed during consultations, put on display in public areas for patients to select, or be provided to patients prior to visits to hospitals. A comprehensive review, funded by the NHS, assessed the quality of resources available for a selection of chronic conditions, and gave guidance on how they should be developed in the future (Coulter et al., 1998). The study used focus group methodology to elicit patients' views and responses to existing literature, and analysed this data with the opinions of chosen experts in each of the specialities the leaflets

represented. The results highlighted the discrepancies between the content and delivery of the information being provided at that time, and the description from patients of what they wanted.

The Arthritis Research UK (formerly the Arthritis Research Campaign (**arc**)) distributes 2.1 million patient information leaflets a year (Arthritis Research UK, 2010) – related both to specific rheumatological conditions, and to more general topics (e.g. ‘Driving and Arthritis’, and ‘A Beginner’s Guide to the Internet’). The charity produces a leaflet relating to Ankylosing Spondylitis (Arthritis Research UK, 2005a). In addition to a similar leaflet produced by NASS, this was read by the majority of people with AS in a survey of patients attending a single secondary care clinic (Vallabh et al., 2008). Arthritis Research UK commissioned a multidisciplinary, multi-centred review of its patient literature materials, addressing the use, content and distribution of its leaflets (Barlow et al., 1995). The review consisted of a number of studies: qualitative research examining how health professionals use and distribute the leaflets, a randomized controlled trial of the effect of the RA leaflet on patients with the condition, and a Delphi survey of interested health professionals and supporters of the charity examining the content and presentation of the booklets.

The qualitative study highlighted differences between rheumatologists and allied health professionals – the former tended to exert more control over the distribution of leaflets, for example preferring to hand them to patients personally rather than allowing them to select their own from a display. Rheumatologists were also more concerned about the effects of information that could be deemed ‘harmful’ – for example a patient who picked up a leaflet about a condition they didn’t have, or information about their prognosis which could increase their anxiety.

The second part of the study (Barlow et al., 1995) analysed the effect of the RA leaflet on 108 patients with rheumatoid arthritis recruited from three hospitals in the Midlands, and used semi-structured interviews and self-report questionnaires before and after the intervention. There was a positive effect on knowledge, pain levels and depression, with no effect on anxiety levels or overall health status. The third study, the Delphi survey titled ‘Improving Patient Publications’, led to the development of new guidelines for the review of existing resources from Arthritis Research UK, and the content and presentation of new leaflets.

Written information is not the most appropriate information resource for all patients; a study of people with rheumatoid arthritis in Glasgow found that 1 in 6 were functionally illiterate (Gordon et al., 2002b), highlighting the importance of using alternative methods to communicate essential information to these people. A number of different tools are available to measure the 'readability' of texts (Friedman and Hoffman-Goetz, 2006), which relate the complexity of the language (i.e. the number of syllables per word and the number of words per sentence) to a 'reading age'; most sources suggest that information for patients should have a reading age below 13 years. However, readability is probably not the most important factor which determines if written information will be understood and retained (Reid et al., 1995). Other less 'easy-to-measure' variables include writing and presentation styles and the influence of the reader's beliefs and experiences are equally, if not more, important (Smith et al., 2008).

Attempts have been made to make the information normally presented in leaflets more accessible to patients with poor reading skills. 'Mind-maps', pictorial representations of rheumatological conditions and their management have been developed (Arthritis Research UK, 2005b). A study into their effectiveness indicated they did not improve the knowledge of functionally illiterate patients more than the standard leaflet alone, and in fact they seemed to aid the understanding of the more educated and literate patients more than the illiterate (Walker et al., 2007).

Written information is therefore relatively efficient to produce and distribute, can reach a large population, and is convenient for many patients to use. Less emphasis is placed on its potential effect on health and economic outcomes than for group education (Murray, 2008), and concern remains about how best to reach patients with poor reading and comprehension skills.

3.3.4 Education via the World Wide Web

Patients can now access more medical information than ever before, largely due to the growth of the internet. In the UK, 65% of households have internet access, and this figure is growing by 7% per year. 71% of people have used the internet within the last 3 months, of whom 34% had used it to search for health-related information (Office for National Statistics, 2008). The continuing growth in access suggests that significantly more than 1 in

4 UK rheumatology patients will use the internet to learn about their condition, the figure indicated in a survey carried out in 2001 (Gordon et al., 2002a). More recently, nearly two-thirds of new referrals to an American Rheumatology clinic had used the internet prior to their first appointment (Hay et al., 2008), although few of them discussed their findings with their doctor.

Nettleton (2005) identified three discourses regarding the effect of the increased availability of health information via the internet. The first, which she labels ‘celebratory’, argues that this change is empowering for patients, ‘recalibrating the power relations between patients and health professionals’ (*ibid*: 973). The second outlook, held mainly by health professionals, is ‘cautionary’, concerned that patients will be misled, and that they are fundamentally unable to appraise sources of information reliably. The third discourse sits between these two opposing arguments, and suggests that patients are usually able to make their own judgements about the suitability and relevance of information they encounter on the web. Additionally, she examines the organisation of information on the internet, and how the use of internet search engines like *Google* has led to many of the traditional sources of information – charities, governments and large companies – dominating the provision of information even within the apparently anarchic world wide web.

Using discourse analysis of qualitative interviews, Nettleton then considered how children with chronic illnesses and their parents obtain information about their conditions from the internet. Her findings are consistent with similar interview studies (Hart et al., 2004), and others which have directly observed patients using the internet in order to describe the methods patients employ to access and appraise the available information (Sillence et al., 2007; Eysenbach and Kohler, 2002). Search engines are generally used, and only the first few sites listed are visited. While few participants actually recalled the names of the websites they had visited, concepts such as the type of organization producing the information, the country of origin, the author’s qualifications and characteristics, and the replication of the same message on other sites were important in determining perceptions of reliability. Great care is usually taken to preserve their relationship with their practitioner, whose expertise is often still required to help make sense of the vast range of information obtained.

Attempts have been made to produce and evaluate educational programmes via the internet for people with arthritis. Lorig's group at Stanford created a web-based version of their Arthritis Self-Management Program (Lorig et al., 2008) and recruited 850 patients with RA, OA or fibromyalgia to a randomized controlled trial via links to the study website. Each virtual 'group' was asked to carry out weekly tasks over a six week period, with online access to the same Arthritis Helpbook used by the conventional programme. Peer moderators led each group, including posting on message board where participants could discuss topics of their choice. The trial showed beneficial effects in pain, disability and self-efficacy at 6 and 12 months, with no change in health care utilisation or exercise rates.

Online support sites like 'KickAS' (KickAS) exist, where patients can post messages sharing personal experience and expertise, or perhaps find reassurance that there are other individuals with similar problems. This can occur away from the influence of the medical profession, and without the face-to-face contact which some patients find inconvenient or intimidating (White and Dorman, 2001). Relevant to the case of AS, there is evidence that online help of this kind is much more likely to be used by men than traditional face-to-face methods (Salem et al., 1997).

A similar resource is provided by DIPEX (personal experiences of health and illness) project (DIPEX, 2008), although there is no facility for visitors to share their own experiences. A team of qualitative researchers based at Oxford University have analysed interviews with around 50 patients with a range of chronic conditions: RA and chronic pain are included, but AS is not. Visitors to the site can access video, audio and written excerpts from the interviews, organised according to the important themes raised by patients. Evaluation of the site has included consideration of how patients who visit the site would use the information they learn there (Ziebland and Herxheimer, 2008).

Patient education therefore appears to be following a seemingly ubiquitous trend towards increasing use of the internet for information and communication. It has considerable potential to provide both technical and experiential data to patients without relying on health professionals. Many of the original fears raised by its lack of regulation have been allayed by the use of search engines which lead people to established, 'conventional' sites, and also users' developing skills of information appraisal. Like written information, there

are concerns about access to education provided in this manner, and the optimum methods for it to be delivered.

3.3.5 Other Educational Resources

Patients with ankylosing spondylitis learn about their condition from a wide variety of resources; these can be ‘planned’, like the majority of examples discussed in the previous sections, or ‘unplanned’ – from friends, relatives, and also different forms of the media. Patients’ families could be particularly important because rates of AS are higher in first-degree relatives than in the general population, so as well as potentially fulfilling a carer role, they may also have experience of the condition itself. Whilst it is difficult to formally evaluate these resources in a research environment, their influence on the knowledge, attitudes and behaviour of patients with AS may be greater than the influence of health professionals and educational literature.

A number of innovative programmes have been evaluated which could lead to insights into new ways to deliver education. A controlled investigation of a cognitive behavioural intervention in rheumatoid arthritis showed greater reduction in pain in the group in which family members were included (Radojevic et al., 1992). However, in other settings there are concerns that the invitation and attendance of family members or carers can disrupt the group dynamics, and they are not usually permitted to attend the EPP (Expert Patients Programme, 2011). Other researchers have shown benefits from integrating education with other interventions in a multidisciplinary program (Hurley et al., 2007) in this case for OA. Elsewhere, audiovisual resources have been used; the addition of a video detailing appropriate exercises for patients with AS increased their self-reported exercise rate (Sweeney et al., 2002). A mail-delivered education programme which tailored information to patient characteristics such as age, educational level, type of arthritis and disability showed benefits in pain, disability and health scores, and those in the intervention group did not consult their doctor as often as controls (Fries et al., 1997).

This latter intervention may indicate an area where more interest and research should be directed. To some extent, patients who use the internet are already tailoring the information they receive through the websites they choose to visit. However, there is now much greater scope to direct people to the information and education that they are likely to want or need,

through interactive resources that patients can access themselves. In the next section I will move from examining the process of providing information and education and its effects, towards the process of deciding what patients would like to learn, and would benefit from learning.

3.3.6 Needs Assessment for Patients with AS

Needs assessment within the wider healthcare setting aims to bring about changes in the provision of care which benefit the population as a whole, usually within the context of finite resources. It not only involves the assessment of non-recipients of interventions (i.e. the unmet need), but also the recipients of ineffective, inefficient or inappropriate healthcare which can lead to the reallocation of resources in order to meet the needs of the population as a whole more effectively (Stevens and Gillam, 1998). Within this concept there is also a philosophical debate about how we assess need: is it the severity of the condition or the potential to benefit from an intervention which is the primary determinant? When considering patient education, this would refer to the decision whether to devote resources to those with lower baseline knowledge and skills (the more severe ‘condition’) or to those with greater potential to increase their skills. This latter concern has not been addressed in the patient education literature, but practitioners and researchers appear to have attempted to balance these two objectives.

Additionally, there may be important differences between the education patients say they would like to receive, and the information and resources which would most effectively benefit their health and psychological well-being. Rephrased, it may be difficult for patients to independently identify their ‘learning needs’, because fundamentally, how can they themselves know or describe the knowledge they do not know.

Educational needs assessment has concentrated on the ‘unmet need’ of patients rather than addressing the inappropriate provision of education and the subsequent reallocation of resources. There is an expectation that education programmes are preceded by an evaluation of the target population, including ‘the problems caused by the rheumatic disease, skills needed to manage the disease, and current level of knowledge and skills’ (Burckhardt et al., 1994: 2). Some authors also indicate the process should include some assessment of the patients’ ‘readiness to learn’ (Coates, 1999), perhaps using a

psychological model such as the ‘transtheoretical’ stages of change model (Prochaska and Diclemente, 1998), and also consider the patients’ family members and carers. The preferred methods of delivery of education are often also included (Buckley et al., 1990). Questionnaires or qualitative methods like observation, focus groups and semi-structured interviews could be used to collect the data.

A needs assessment self-completed questionnaire specifically designed for patients with AS has been produced in Leeds; patients rate a total of 39 statements on a 5-point Likert scale ranging from not at all important to extremely important (Ndosi et al., 2007; Pickles et al., 2006). While these questionnaires are relatively easy to administer and interpret, and indeed can help to describe different trends in desire for information, their results are likely to be dependent on the timing and setting in which the questions are asked, and rely on a shared interpretation of the meaning of the questions between the researcher and the patient. Fundamentally though, these tools act as ‘*want*-assessments’ rather than *need*, as it is patients’ desire for information on various topics which is being measured, rather than a search for topics and skills which are most likely to benefit them.

Needs assessment studies in arthritis have reached a variety of conclusions depending on the methods used and the populations studied. Silvers et al (1985) compared the opinions of patients with rheumatoid arthritis with their physicians in a survey of 101 patients and 28 doctors. Interestingly, doctors overestimated the patients’ desire for information about psychosocial topics, although it is not clear from the paper exactly how these questions were phrased to patients. It is doubtful how many patients would understand the term ‘psychosocial’ for example, and therefore would not be likely to rate this information need highly. Examining a breadth of studies, issues around work, relationships and feelings were seen as important to patients with arthritis, with greater expressed need by females than by males (Adab et al., 2004) including in AS (Ndosi et al., 2007). There also appears to be a greater need for this information for those with shorter duration of illness in AS (Pickles et al., 2006), and in those with more severe disease in RA (Buckley et al., 1990).

Consistently, however, patients request most information about their own condition, its treatment, and their future health (Neville et al., 1999). This usually includes written information, and includes significant input from doctors. Examining the methods used to deliver education, doctors are more confident that group education is beneficial than

patients themselves (85% of physicians rated groups ‘very important’, versus 45% of patients) (Silvers et al., 1985). It also appears that a low proportion of patients consider self-management skills to be important despite the evidence for its efficacy, with only 42% of 201 replies rating this highly, compared to 78.6% for ‘side effects of medication’ (Adab et al., 2004).

Needs assessment can therefore take a variety of forms. Questionnaires are frequently used, yet they rely on the patient and the researcher sharing the same understanding of the meaning of the posed questions. They can provide information about what patients *want* to know more about, but risk overlooking important topics which may improve patients lives, but which patients may not consider to be important at that time. When interpreting the result of such studies we should again take care to consider the population studied, and the effect of when and how the questionnaire was distributed.

3.4 Conclusions

At the beginning of this chapter I posed the question: ‘which educational interventions are effective for patients with ankylosing spondylitis?’. However, having appraised the evidence and opinion related to these interventions there remains no definitive, universally applicable answer. There are four principal reasons which help to explain this apparent failure, and which simultaneously illuminate the difficulties in studying this area and suggest areas which could be addressed in future research.

Firstly, as I discussed in the introduction to this chapter, there remains uncertainty about what constitutes an educational intervention. ‘Unplanned’ education (consisting of routine clinical care, independent searching for information from sources such as the internet, the influence of patients’ social networks, and even sporadic media coverage) may have greater influence on how people cope with and manage their AS than any brief, planned intervention. Yet this unplanned education cannot be evaluated using the methodology favoured in determining the efficacy of educational interventions; equally it is more difficult to influence.

Secondly, the outcome measures used to assess educational interventions attempt to reflect overlapping and potentially contradictory personal, family, health professional and societal *aims* for education. The existence of these separate aims is not defined or articulated in the discourse surrounding the topic, and therefore it is unsurprising that the assessment of outcome in trials of educational interventions seems incomplete. One could hypothesise that *individuals* taking part in education would want to learn how to cope with their AS, and develop strategies to maximise favourable outcomes in the sense described by Bury (1991: 460). *Family* aims may be broadly consistent with those of the individual, but there may be greater emphasis on reducing any negative impact on family members’ lives. In contrast, *health professionals* may want patients to behave in ways which are consistent with their own views of the healthcare system, such that patients’ behaviours do not adversely affect their own priorities. *Societal* aims include the economic outcomes which assess reduction in healthcare or social security costs. If these aims are concordant, and all can be achieved effectively with the same intervention, then this issue need not be significant. However, the existence of these potentially competing priorities has not previously been acknowledged, nor has the best way to resolve conflicts which may arise.

Taking the issue of healthcare utilisation and costs as an example, promoting this as a marker of efficacy may not be concordant with patients' aims, for whom an increase in utilisation may be wise; this may impact on the uptake of the educational intervention by patients themselves.

Thirdly, the overall effectiveness of an intervention must also be related to its uptake, especially because patients must choose to use the resource, making corresponding sacrifices of time and other resources. There is no compulsion to take part in education, thus interventions must not only be effective in terms of improving outcomes, but must also be desirable for patients in order to attract participants. This is rarely addressed in evaluations, and care should also be taken to assess the characteristics of those patients who choose to attend, in order to decide if they reflect those patients who may benefit most from education.

The final reason for the failure to answer the question of efficacy satisfactorily relates to an insufficient understanding of patients with AS – notably the specific characteristics which differentiate them from patients with other forms of arthritis and chronic illness, and the differences which exist between people with AS. There remains a tendency to adopt a 'one-size-fits-all' approach to education for people with chronic illnesses, and yet people may want or need different information at different times, presented in different ways. People with different chronic conditions engage with education in different ways, as discussed in a meta-synthesis of qualitative studies related to self-management interventions (Protheroe et al., 2008). The authors found that patients' use of and response to the resource, and the optimum timing of delivery, were all related to both characteristics of their chronic condition itself, and of the individual. Amongst other issues, the social status and legitimacy of the condition were important, as were perceptions of treatment possibilities, and patients' previous experience of and access to healthcare. Thus, when considering the case of AS, we cannot assume that their needs will be analogous to those people with the frequently studied osteo- or rheumatoid arthritis. Similarly, the needs and optimum delivery methods for individuals with AS will vary greatly, but can, at least to some extent, be predicted by characteristics that could be elucidated by research in this area.

With these difficulties noted, what recommendations should be made with regards current practice for health professionals? Importantly, there is no evidence that isolated self-

management programmes in their current form have more than a small effect on patients' health, and even this may not be sustained (with the caveat that this reflects changes in health which were *measured*). Outside of the populations which have been extensively studied, the results are particularly disappointing (Buszewicz et al., 2006; Griffiths et al., 2005). However, while these types of programmes will be acceptable and useful for some patients with AS, at present we do not know enough about which patients benefit most, and how to assess whether and when a patient should be advised to attend. Qualitative interviews with 'responders' and 'non-responders' may help to unravel these questions.

Considering other forms of education, written information is relatively easy to produce and distribute, and guidance exists with the aim of making it as accessible and useful as possible. One-to-one education, via a Rheumatologist or other health professional during routine consultation, requires little additional commitment from patients and thus can reach all those who attend these services. Patients are likely to do their own research into their condition and treatment, and if necessary, should be able to discuss their findings with a health professional. If a patient is willing to attend group education, then this could be recommended, either in the form of membership of NASS or attendance of self-management or exercise sessions. Inevitably, all this must take place within the restrictions of limited resources.

Although we can make these general, non-specific, recommendations, clearly there is still a great deal to learn in this area. The debate which has followed the implementation of the EPP in the UK has highlighted ways in which current uncertainties could be addressed. Work examining patients' differing responses to the EPP and similar programmes are particularly enlightening (Protheroe et al., 2008; Gatley et al., 2007), as are suggestions that interventions intended to change patients' behaviour need to take a 'whole systems perspective', addressing not only patients, but also the health professionals they consult, and the services available to them (Kennedy et al., 2007b). Practically though, we should avoid viewing patients as a single, homogenous group who will respond to interventions in predictable ways, and instead learn more about the differences between patients. We must seek to understand when, how and why they use different information sources at different times, understanding more about their existing patterns of education and learning, and thus ways in which we can improve this process in a way which is acceptable and beneficial. It

is this latter process which is the focus of the remainder of this thesis, as I initially explore when and why patients seek information and education in Chapter 5, and reflect on current practice for health professionals in Chapter 6.

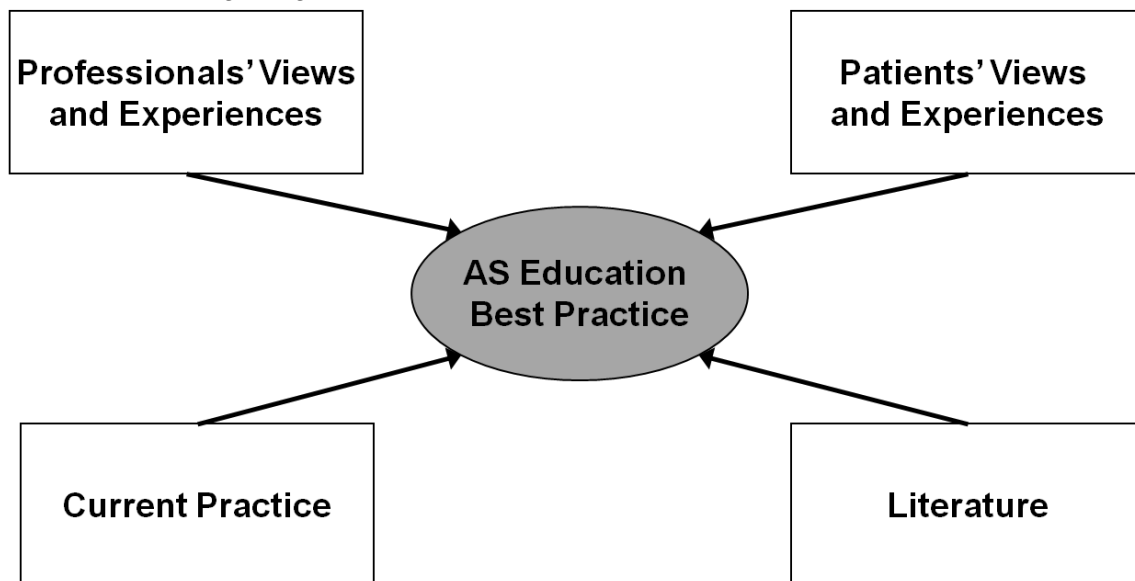
Chapter 4 – Methodology

4.1 Introduction and Overview

My approach to this chapter is broadly practical: it aims to describe the processes that we, as a research team, undertook to collect and interpret the data discussed in the remainder of the thesis. It does not comprise of a mundane description of ‘methods’ which risks offering few insights into the choices and challenges we faced along the way. To facilitate this I have used the first rather than the third person intermittently and offered greater detail about the practical steps I took, following the suggestions of Silverman (2005: 303). In addition I have outlined aspects of the research project such as the events of focus groups and interviews where they complement the reflective discussions here rather than in results chapters.

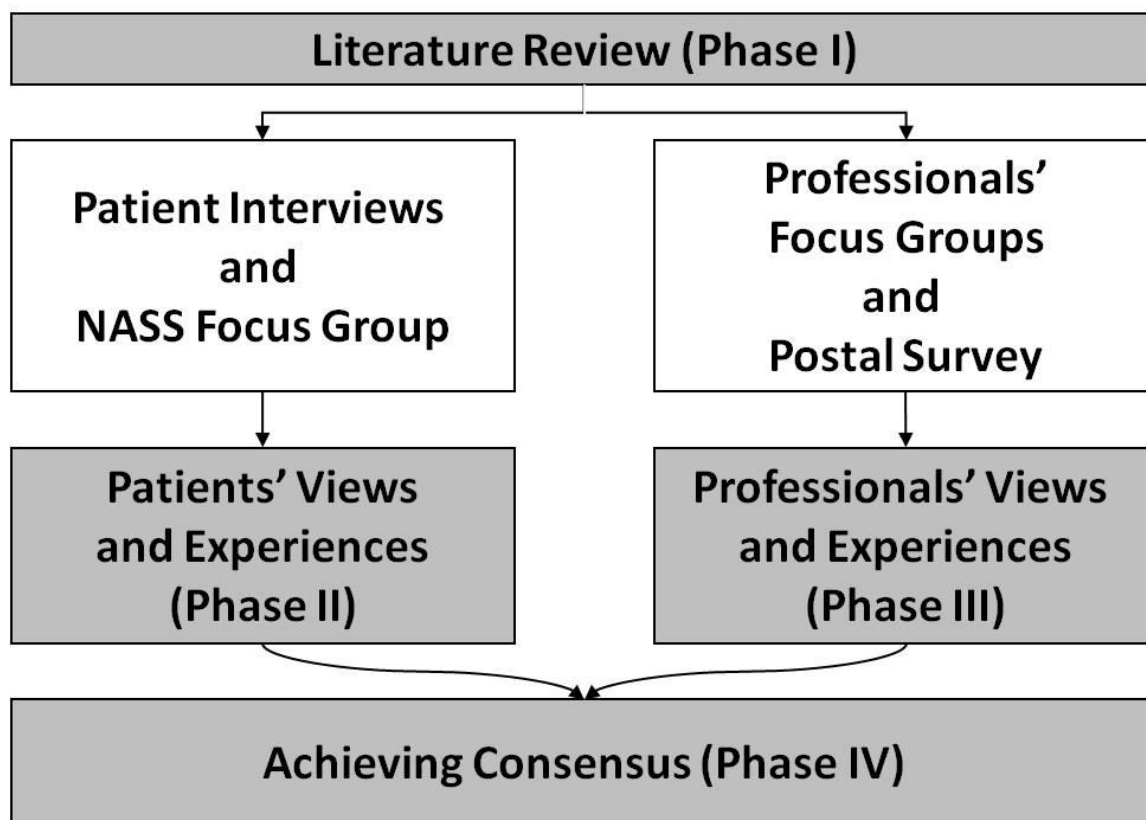
The study employed multiple sources of data and multiple methods, referring to our use of both qualitative and quantitative methods, and the use of different techniques within qualitative research – namely focus groups, interviews and diaries. There has been a great deal of interest in the benefits and pitfalls of such ‘multiple-methods research’ in recent years, particularly with respect to the ability of researchers to triangulate different sources and methods in order to reach an interpretation of a phenomenon which is closer to the full picture. Despite the initial attractiveness of these approaches, aggregating data without consideration of the limitations of each dataset can be problematic and in many cases there are arguments against the validity of such techniques (Brannen, 2004). I will consider these arguments in greater detail in section 4.2.3.3 when I focus on the validity and generalisability of my findings.

Figure 5: An Overview of the Project. Four Principal Data Sources Interpreted in Order to Offer Recommendations Regarding Best Practice



I used the strengths of specific research techniques to address particular aspects of the study. In some instances these informed later phases of the research, such as the focus groups which were used to develop both the interview schedule for one-to-one interviews and the survey for health professionals. In other cases they enhanced the data collected, such as the diaries used in the serial interviews with patients (4.2.2.3); later phases were used to verify and reflect on the data already collected. Thus the different sources and methods were used in an integrated and reflexive manner, with an awareness of their influence on the research topic with respect to the risk of aggregating data described above. Figure 5 shows the data sources used; Figure 6 indicates the phases of the research project, illustrating how the results from one phase were utilised by the next.

Figure 6: The Connections between the Research Phases, Illustrating their Temporal Relationship



I have divided the remainder of the chapter into sections reflecting the phases of the research shown in Figure 6. I will first describe the methods used to understand patients' views and experiences (Phase II, section 4.2), then health professionals' views (Phase III, section 4.3), before reviewing the phase we initially termed 'Achieving Consensus' (Phase IV, section 4.4). I used similar techniques to analyse the qualitative data from interviews and focus groups with patients and professionals. These techniques are detailed in section 4.2.3. Where analytical methods differed for specific aspects of the project, this is reflected in the relevant sections. The literature review methods (Phase I) are included in the relevant chapters.

4.1.1 Ethical and other Approvals

Ethical approval was obtained for the project from the Gateshead and South Tyneside Ethics Committee (reference 06/Q0901/80). An amendment was sought and granted in order to carry out the telephone interviews with Gastroenterology and Ophthalmology Consultants described in section 4.3.3. All participants received written information regarding the research project, and gave their consent to participate.

Similarly, research and development approval was granted by the three hospital Trusts from whom the participating patients and health professionals were recruited. Caldicott approval regarding the use of personal data was also granted by the Caldicott Guardian of each Trust. The project was registered with the local Clinical Research Network.

4.2 Phase II - Patients' Views and Experiences

This phase of the project began with a focus group with the Tyne and Wear NASS Group and continued with longitudinal, semi-structured interviews with 10 people newly-diagnosed with AS and single interviews with 12 'review' patients - people who had been diagnosed with AS more than one year ago.

The initial aim of this phase, as described in our research plan, had been to 'identify patients' views regarding their educational needs at different stages of their disease and lives' (*aim d*, section 1.1). However, data emerged during my early interviews relating to the practicalities of *how* patients learnt about AS, leading me to include this as an additional aim for this phase. I became aware that the interviews were more than an instrument to gather patients' views as my understanding of the strengths and scope of qualitative research increased. They could also be analysed more thoroughly – gaining an understanding of how AS impacts on participants' lives, and how this in turn affects their learning about the condition; describing the practical efforts they make to search for information and their experiences of this search; considering the meaning of what interviewees said, and how this relates to our existing knowledge about chronic illness. Therefore my original plan to use the interviews solely to document *patients' views* was an underestimation of the useful data that can be obtained from such interviews. The additional aim of understanding *how* people with AS practically learn about their condition offers valuable information when considering the best methods to deliver education, as presented in Chapters 5 and 7.

4.2.1 Focus Group

I carried out a single focus group with 8 NASS members (4M, 4F, age 28 – 71) which took place after a regular meeting of their group. This was a convenience sample consisting of the members of the support group who attended when I first visited them to introduce the research at their meeting 3 weeks earlier. These patients were not selected to be representative of the range of people with AS; as members of NASS they were likely to be more informed and motivated to learn about AS than most patients, and to have an interest in the subjects we were discussing. I moderated the group and was accompanied by an observer who assisted with the audio-recording and set up of the focus group. I planned and carried out the group with guidance from colleagues who had previously used focus

groups, from training courses at Newcastle University, and having read relevant literature including Morgan (1997) and Krueger and Casey (2000).

The aim of the group was to learn more about the sources of information used by patients, and to discover areas where current education provision may not meet patients' needs. Broadly, it was to identify areas which we could focus on in more depth in the interviews with patients, and if necessary in the survey of health professionals. The topic guide (see Appendix I) was developed by the research team based on our experiences of these areas. In order to stimulate the initial discussion, I asked participants to discuss different sources of information about AS (for example 'information leaflets', 'other people with AS', 'physiotherapist' etc) and rank them according to their usefulness.

The group was recorded and transcribed verbatim; the transcript was analysed using the techniques described below (see section 4.2.3), along with the focus groups with professionals (see section 4.3.1). Some results from these groups are included in this thesis, within Chapter 6. A more extensive analysis was presented as a report for an interim assessment and used to inform the topic guide for the semi-structured interviews and the survey questions for professionals. The themes which emerged were around the content and delivery of education, the additional functions of education beyond increasing knowledge about the condition, prioritisation by professionals and their evaluation by patients.

4.2.2 Semi-Structured Interviews

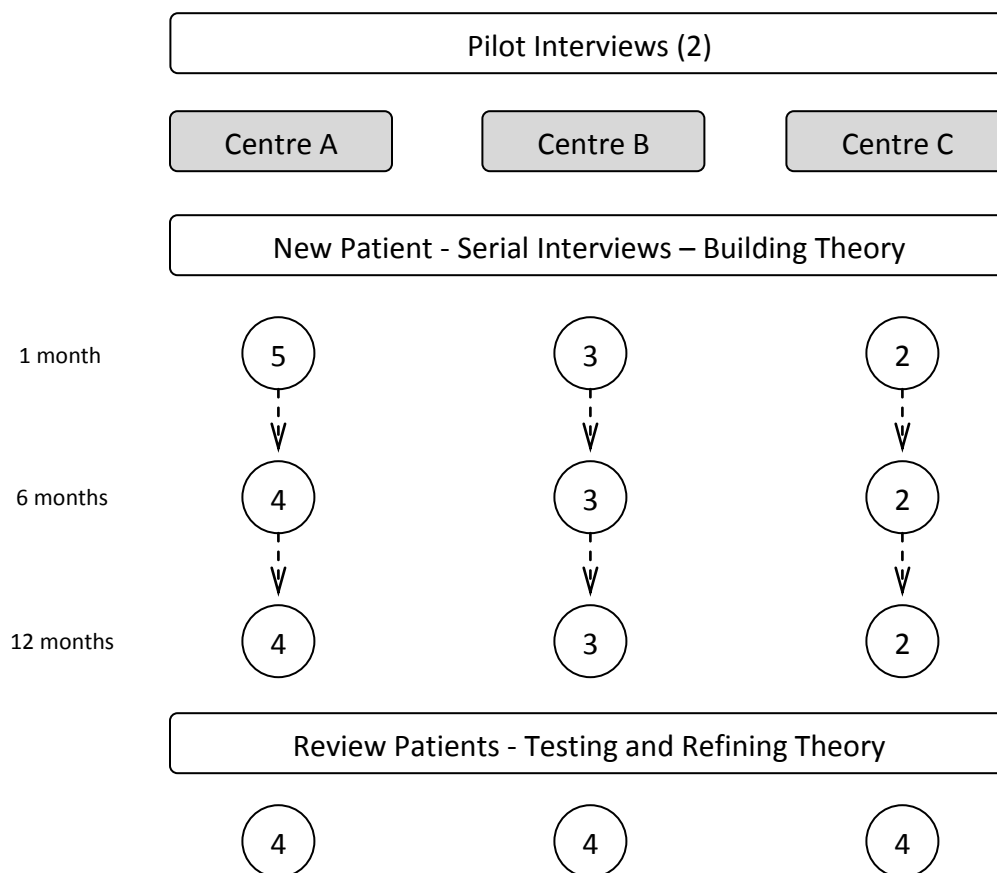
4.2.2.1 Overview

I interviewed ten people who had recently been diagnosed with AS - at 1 month, 6 months and 12 months post-diagnosis. These 'new patient' interviews explored the questions they had about their condition, the problems they faced, and their descriptions of their interactions with health services and educational resources. As discussed above (4.2), my focus for the interviews shifted from simply reporting their views on 'patient education' to gaining a rich description of their experiences, and relating these to their educational needs through my analysis. Having completed my analysis of these 'new patient' interviews, I interviewed 12 people who had been diagnosed with AS at least one year previously and termed these 'review patient' interviews (Figure 7). Again, this represents a shift from our original research plan, where we suggested that these two sets of interviews would run

concurrently rather than in series. This change enabled the theories and findings from the new patient interviews to be challenged and - where necessary - modified, in response to this second phase of interviews. It also enabled us to recruit and interview people with particular characteristics who had either not been represented in the new patient cohort, or who potentially offered further insights into particular topics or themes.

The use of serial (or alternatively 'longitudinal') interviews, employed here with newly-diagnosed patients, is an established technique which has been used to help researchers understand issues which change with time, such as the recovery from stroke (Faircloth et al., 2004) and peoples' response to chronic illness (Conrad, 1990). There are also other benefits to interviewing patients more than once which encouraged us to choose this technique, including the ability to build a relationship with interviewees which can enable topics to be discussed in more depth, as well as those which might otherwise be 'off-limits'. Murray (2009) suggests that serial interviewing is particularly suited to highlighting deficiencies in care, suggesting methods by which care could be improved, and enabling private (as opposed to public) accounts to emerge. He also highlights particular pitfalls of the method – notably those of data-overload and attrition, such that fewer participants complete the study than start it. We recruited ten new patients as oppose to the originally proposed 6 to allow for patients deciding not to complete the 3 interviews, and because we continued to collect novel and useful data as we recruited more patients.

Figure 7: Overview of Semi-structured Interviews. The numbers within the circles refer to the number of patients interviewed at each stage.



4.2.2.2 Participants and Setting

Potential study participants were initially approached by their Rheumatologist and asked whether they would be interested in taking part in the study. In turn, I publicised the project to Rheumatologists at each of the three centres through presentations and email. If people with AS were interested in participating and gave consent for their contact details to be passed to me, I sent out an information sheet regarding the project, and later contacted them by telephone, answered any queries, and arrange a convenient time and place to meet. Written consent was obtained at the time of the first, and if applicable, subsequent interviews.

The three centres from which I recruited patients are all rheumatology departments within hospital trusts in the North East of England. Centre A is an urban hospital offering tertiary services; Centre B is a multi-site district general trust which covers a largely rural community; Centre C is a large district general hospital which covers an urban population.

New patients were initially recruited as a criterion sample, such that I encouraged Rheumatologists to approach everyone they had recently diagnosed with AS. However, my strategy became more stratified as recruitment progressed in order to interview women with AS, who had not been represented amongst the first recruits. This change in strategy was communicated to the consultants by email. Review patients were recruited in order to test and refine the analysis of the new patient interviews, and the sampling was therefore theoretical. This proved more of a challenge, attempting to describe the characteristics of people I would like to recruit to consultants who were more accustomed to the random sampling strategies commonly used with quantitative methods. Indeed, many of the characteristics I was looking to explore were not necessarily easily recognised or described. For instance, I was keen to speak to people who didn't necessarily follow the norms of the healthcare system – those that weren't concordant with treatment plans, and might offer more insight into patients I termed 'vulnerable' (see Chapter 7). Thus the patients I was looking for would not typically have been approached to take part in research projects, and additionally, were not those whom consultants would necessarily think would give a 'good' interview – that is a well-informed, eloquent interview, which would praise the service provided by that consultant! I expressed these thoughts directly in my communication with the consultants to try to reduce the effect of these challenges on recruitment.

Participants were included with a clinical diagnosis of AS rather than stricter diagnostic criteria commonly used in drug trials¹⁷. This approach was chosen to reduce the burden on research participants, ensuring that they wouldn't have to undergo additional tests, and so that I wouldn't need to access their medical records. It is also likely to reflect the thoughts and behaviour of patients, who, once they have been told they have AS by a Rheumatologist, are unlikely to differentiate themselves depending upon whether or not they meet New York criteria. Exclusion criteria were age under 16, severe learning difficulties and ill-health such that their clinician did not consider them well enough to be interviewed. Participants for whom English was not their first language were offered an

¹⁷ The Modified New York Criteria [van der Linden, S., Valkenburg, H. and Cats, A. (1984) 'Evaluation of diagnostic criteria for ankylosing spondylitis. A proposal for modification of the New York criteria', *Arthritis and Rheumatism*, 27, (4), pp. 361-8.] are still the most commonly used, although there is concern about their exclusion of people who have the early stages of AS. These criteria specify that AS should be diagnosed in people with established X-ray changes at their sacro-iliac joints, along with one of three clinical criteria: inflammatory low back pain, reduced lumbar spine movements, and reduced chest expansion.

interview with an interpreter present: in practice this offer was not taken up by the one review patient to whom it was offered.

Using this recruitment strategy it is not possible to count the number of patients who declined to take part in the project. Some may have been approached by their clinician but did not show any initial interest. Of those who gave initial consent to their clinician, 4 withdrew before being interviewed (3 new patients, 1 review); three cited time pressures, the other seemed keen to participate but was out of his house at the times we arranged to meet. Retention of participants through their serial interviews was good, but achieving this did require commitment and flexibility. One participant from Centre A preferred not to have a 6 month interview, but did take part in an interview at 12 months. Another from Centre B had a telephone interview for his third interview at his request. I lost contact with another participant from Centre A who missed his 12 month interview; I later found out he had moved house.

All participants completed a basic demographic questionnaire, usually at the end of their 1st interview. In addition they completed a BASFI questionnaire¹⁸ (Calin et al., 1994) which offers information about the degree of functional impairment resulting from their Ankylosing Spondylitis. This data is tabulated in Appendix II.

4.2.2.3 Interviews

The majority of interviews took place in participants' own homes; one new patient and three review patients instead chose to be interviewed in a hospital setting because it was more convenient for them; another new patient was interviewed at their place of work for similar reasons. Each interview was audiorecorded and transcribed; I checked and amended each transcript with the audiorecording to ensure they represented the interview, and as part of the process of becoming accustomed to the data. The interviews lasted between 35 and 95 minutes.

Until now I have referred to the interviews as 'semi-structured', but this is a broad and inexact term. It does define them as situated between structured interviews, where there is minimal deviation from a set of scripted questions, and depth interviews, where the interviewer asks open questions in an attempt to allow the participant to control the topics

¹⁸ Bath Ankylosing Spondylitis Functional Index.

discussed. We used an interview schedule which was initially developed from the focus groups, the literature and our own experiences, and which was adapted and modified in response to two pilot interviews, and as the interviews and our analysis progressed (see Appendix III). In practice, it was analogous to a checklist, often referred to only at the end of the interview in order to ensure I hadn't overlooked any topics. In the case of the serial interviews, I heavily annotated the schedule guided by my analysis of the previous interviews with that participant, returning to topics we had discussed before and clarifying or expanding on important points. Overall, my style was closer to depth interviewing than to structured interviewing, allowing and encouraging participants to talk about the topics they felt were important, not following a defined order of topics, and yet questioning and prompting with detailed knowledge of the topics and questions I wanted to include.

Similarly, I described the interviews as 'one-to-one'; however, principally as a function of their setting within participants' homes, partners or other family members were sometimes present for part of the interview. A typical scenario was a participant's partner returning from a shopping trip and joining in for the latter part of the interview, or the participant making a statement such as 'my husband / wife might be able to answer that question better than me ... I'll go and ask them'. I did not routinely seek to include partners or family members in the interviews, but when suggested by the participant I encouraged their participation, and obtained their consent. Their contribution was frequently valuable, either by prompting further discussion and interpretation through their own views or description of events, or occasionally waiting until the patient themselves was out of the room, and adding their own, sometimes contradictory perspective on the impact of AS on their lives.

The serial interviews also employed an information diary (see Appendix IV), which was given to participants at their first interview. This had a very simple format through which they were asked to note any questions or problems they had encountered regarding their AS, the steps they had taken to answer or resolve them, and whether they had learnt anything new about AS since we last met. These diaries were not analysed separately, but were instead used as a tool to help participants to consider the topics I would ask them about, and thus to prompt discussion at subsequent interviews. Their use was variable, with some choosing not to complete them, and others regularly recording their thoughts.

4.2.2.4 *Conflicting Roles*

The topic that arose most frequently as I reflected upon the interviews in my research diary was the conflict I felt between my role as a clinician and my role as an interviewer or researcher. I first recognised this during the first focus group, when I felt that my attempts to initiate discussion amongst the NASS members were sometimes met by the presumption that, as a Rheumatologist, I should already know the answers and not need to ask. I felt that by trying to be a competent researcher, I risked appearing as an incompetent clinician.

During the interviews with new patients I felt the conflict more acutely, as I was faced with people whom I sometimes judged could benefit from medical input and advice. However, my priority now was to ask questions rather than answer them – to ‘take’ rather than to ‘give’. My initial approach to this dilemma was to emphasise that, broadly, my role and the aim of the research was to better understand their situation and therefore to try to improve the care and service offered by rheumatology departments, influenced by the experiences of Reventlow (2005). However, within this introduction I also stated that although I normally saw people like themselves, this interview wasn’t part of their standard care, and the purpose was to learn about their thoughts rather than offer my own. I added that I would be happy to answer their questions about AS and their care at the end of the interview, thereby tacitly suggesting that I wasn’t open to questions during the interview itself. On occasions this approach led me to deflect their questions, stating that I would ‘come back to them at the end’. On reflection, this probably made me appear evasive and unhelpful, and potentially reduced participants’ willingness to share their thoughts. Furthermore, the discussions surrounding these questions often yielded valuable data, and yet sometimes occurred after the audio recorder had been switched off. There were also moments when the approach was untenable, when I felt that the interviewee was displaying misunderstandings which I should address immediately, and I shifted, at least temporarily, into a more therapeutic role (discussed in detail in Chapter 7).

This conflict has analogies to the debate about how an interviewer should conduct themselves - the extent to which they offer their own opinion and experience, and the manner in which they interact with the participant (Rapley, 2004). Similarly, it reflects the influence of the professional role of the interviewer discussed by Richards and Emslie (2000). Initially, I orientated to a *neutrality* which attempted to minimise any influence I

had on their care and health, which positivists would describe as ‘contaminating’ the data. As the interviews progressed, I became less reluctant to break this barrier I had created between my roles as researcher and doctor. I still explained the interview was separate from their standard care and that our conversations wouldn’t be included in their medical notes or reported to their clinicians. At the same time, I used my understanding of the information and healthcare which was potentially available to them to produce more detailed and useful conversations. Practically, this meant describing the course of action which might be suggested by their clinician in these circumstances, or offering an explanation I might give to patients I saw with similar problems. This not only enabled a much more natural interaction, but also one which allowed me to gain insights into their responses to such explanations and information.

Thus over the course of the 42 one-to-one interviews I carried out as part of the project, my interviews became focused on ‘just get[ting] on with interacting with that specific person’. (Rapley, 2004: 16). During some interviews I felt that avoiding clinical aspects of the interview as they arose would not be ethical, as well as actually detracting from the data I could collect. Within others, in a more positivist tradition, my questions remained open and I was reticent to offer my own opinions because I felt it would strongly influence theirs. By contrast, in some later interviews I offered the tentative results from aspects of the project and asked for patients’ comments, and was willing to be more adversarial. However, in each instance, when analysing the interviews I tried to remain aware of the influence my own questions and behaviour had on the trajectory of the interview. It is this analysis that I turn to in the next section.

4.2.3 Analysis of Qualitative Data

The separation of this section of writing overlooks the difficulty differentiating the process of analysis from the remainder of the data collection. It is certainly difficult to identify the point at which collection stops and analysis begins. Tasks such as writing reflective research notes after each interview seem to straddle both processes. Similarly, modifications to the interview schedule influenced the data collection as my analysis progressed, breaching any temporal boundaries. I have tried to make this separation for the sake of clarity and will describe the practical steps I took to analyse the qualitative data. However, I have first considered my philosophical standpoint. Together, these two topics

contribute to the generalisability and validity of the research data, which I have considered in the final part of this section.

4.2.3.1 *Philosophical Standpoint*

By stating my view on the nature and meaning of our knowledge about the world I am following the conventions of qualitative research. A researcher's standpoint is commonly seen as fundamental to their work, and introductory teaching and texts often focus on competing philosophies before the methods themselves are discussed. Returning to these discussions¹⁹ having collected my research data and with a broader understanding of qualitative research, I recognise that an awareness of such arguments is vital when making claims about the validity of the results of a research project. At the time however, I found such discussions interesting but struggled to apply them to my work. Arguments tended to be persuasive regarding the legitimacy of the specific standpoint being described, but equally each seemed abstract with respect to the practicalities of my research.

Hammersley (1992) suggests that these debates are not 'foundational' to qualitative research, and do not need to be resolved before engaging in this sort of empirical work. Indeed, he suggests that they can be 'a distraction; a swapping of one set of problems for another, probably even less tractable set' (p43). Similarly, Seale (1999) sees research as a 'craft skill, relatively autonomous from the need to resolve philosophical or epistemological debates' (p31). Both authors reflect that an awareness of different standpoints is vital to understand the scope and limitations of different methodologies and their resultant data. Seale extends the argument to suggest that it is this awareness of the debates, rather than adhering to a particular paradigm, that is essential for high quality research. It is this pragmatism which underlies Hammersley's original description and Seale's subsequent support for 'subtle realism'.

Subtle realism is a philosophical strategy which seeks to reconcile the differences between realism and relativism which could otherwise undermine the findings of qualitative research studies. Realism suggests that there is a single social reality which is observable and describable, and therefore that research is aimed at discovering - or at least getting closer to - this reality. Relativism, in contrast, indicates that such a reality does not exist,

¹⁹ I found Crotty (2003) the clearest and most useful overview.

but that instead ‘‘the way things are’ is really just ‘the sense we make of them’’ (Crotty, 2003: 64). In this way descriptions of objects and social phenomena cannot represent a single reality, but are instead a reflection of the cultural background of the observer. This latter approach becomes more problematic when it is applied in an extreme version to the research process itself, when the only claim that is possible from a research project would be that the results represent the author’s own view of the phenomenon in question, and that this view is no more valid a representation of reality than any other observer’s.

Hammersley describes three key elements to his subtle realism which define it as separate from both realism and relativism (adapted from 1992: 50-1):

- The definition of ‘knowledge’ as beliefs whose validity is known with certainty is not correct. While we cannot be entirely certain, in many cases we can be reasonably confident about its validity, based on judgements about the knowledge claim itself – for example, the evidence for it, its plausibility and credibility, and the assumptions on which it has been based.
- Phenomena can exist independent of our claims about them, and the accuracy of those claims can be judged by the extent to which they represent the phenomena. Thus a description by a researcher of a social phenomenon can be judged as to whether it reflects that reality, in contrast to a relativistic standpoint where its validity would always be equal to the descriptions of others.
- The aim of social research is to represent reality, but it can never reproduce it. There will always be alternative, equally valid and non-contradictory descriptions of the same phenomena from alternative perspectives.

I would therefore describe my philosophical standpoint as subtle realism, suggesting that there is a reality or a ‘truth’ which can be discovered and described through research, but that it comes with some caveats. Firstly it does not represent a certainty and may therefore later be shown to be false. Additionally, other commentators may offer different descriptions which may also be true. Finally, its accuracy and value will be judged according to standards of plausibility, credibility and relevance by a research community such as that described by Seale (*ibid*: 29).

Of course the plausibility and credibility of results and conclusions claiming to be ‘new knowledge’ are dependent on the methods used to reach them. I will therefore return to my description of the analysis of the qualitative data.

4.2.3.2 *Practicalities*

Many published qualitative research studies describe their methods of analysis solely with reference to a particular technique, such as grounded theory, as described by Glaser and Strauss (1967). This reference is used as a shortcut to describe the process of the analysis, when in fact there are a range of practical analytic techniques used to generate and test hypotheses included under this umbrella. Using this shortcut relies on both the reader and the author sharing the same understanding of what the particular technique entails, and can leave doubt about which techniques were actually used. In this section I have attempted the difficult task of unpicking the process which took me from the interviews to the results chapters.

I drew on a range of different analytical practices, as I will explain. It is also worth noting that I began as novice with respect to qualitative analysis, and this was both an educational as well as an analytical journey. This is a record of what I actually did, and doesn’t necessarily represent what I would plan to do with another project in the future.

At the time of the interviews and focus groups I made notes on the setting for the interview, any important events or conversation that occurred before or after the digital recording, and my reflections on the content of the interview. The interviews were transcribed and I subsequently checked through the transcripts in detail with the audio recording to make corrections, remove references to names and places which would reveal their identity, and to begin get to know the interview. I then coded the transcript and my reflections using NVivo software, applying different coding frames for the focus groups and interviews. In the case of the interviews, the frame developed during the first 10 new patient interviews in response to my analysis; subsequently only minor changes were made. Codes ranged from those which could have been considered at the start of the project (eg ‘use of internet’, ‘Rheumatologist’) to those which emerged from the data as a result of my analysis (eg those related to the Established Patient Model, see Figure 8). Despite the coding process, I continued to return to the transcripts to check the context of excerpts I chose, and to look

for meaning I had overlooked in previous readings. The NVivo software served as a reference library for my codes and transcripts rather than as a discrete analytical tool.

My analytical strategies were influenced by authors such as David Silverman (Silverman, 2006) and Clive Seale (2004) as well as those of Strauss and Corbin (1998). Initially, I wrote about the key issues or *categories* which I felt were important from my first interview, and then subsequently ‘built up’ the number of cases I was considering and comparing in this regular analytical writing. The writing was based on careful line-by-line analysis of the transcripts and served as a method of analytic induction, generating and validating hypotheses. Deviant cases – those that were inconsistent with my existing categories and models – were sought and received particular attention, so that these resulted in the modification or rejection of these categories. I met my supervisor and Director of Studies, Tim Rapley, every 2 or 3 weeks to discuss my writing and review the analysis. Having also read and considered the transcripts himself, Tim was able to offer alternative analyses and suggest useful reading. Similarly, the remainder of the research team reviewed the transcripts and my analysis, offering additional interpretations at data analysis workshops.

At the same time I created diagrams using software²⁰, expanding on and testing categories with subsequent interviews, and using transcript excerpts to illustrate my ideas. These diagrams not only offered an opportunity to summarise my ideas, but also facilitated their growth in a logical, accessible manner which could also represent the passage of time during the longitudinal interviews. Examples of these diagrams are included in Appendix V, while Chapter 5 details how the Established Patient Model developed through these methods.

The practicalities of my data analysis therefore consisted of techniques to get to know my data, followed by circuits of coding, analysis, writing, and feedback from other members of the research team.

4.2.3.3 *Validity and Generalisability*

The value and utility of qualitative data is dependent on discussions around the validity or ‘truth status’ of the data and the extent to which it can be applied to other settings. There

²⁰ I used open source mindmap software: initially ‘Freemind’ and later ‘CmapTools’ (<http://cmap.ihmc.us/>)

are some people with a background in quantitative research who would doubt that a study with *so few participants* could influence our thinking about this group and the process of learning about AS. In response, this section deals with the reasons why the findings from an interview study of 22 people with AS – consisting of a total of 30 hours of discussion - could or should be applicable to other patients.

Both Seale (1999) and Silverman (2006) consider these issues with reference to the concepts of internal and external validity²¹ originally proposed by Campbell and Stanley (1966) having first reflected on their application to *qualitative* rather than the original context of *quantitative* research. I will follow the same route as I consider the credibility of the data I have produced.

Data from interviews are relatively easy and efficient to collect, relying only on two people discussing a range of topics. Yet they are not the window into the participant's reality that many seem to consider them, but instead are a product of the interaction between the two people. Put more simply, people say and do different things, and that to treat what people say in interviews as an unquestionable truth is to misuse the data. Instead, I need to consider the effect of the setting of the interview on the data collected, and subsequently, the effect of my own background on the analysis.

As I have already mentioned, my role as both medical professional and interviewer is significant. For instance, participants may have been more likely to portray themselves as 'good patients' who were behaving in ways they thought medical professionals would approve of²². However, this influence may have been present whatever the profession of the interviewer, and I was not the personal Rheumatologist of any of the interviewees, a scenario which would have probably magnified this effect. My profession also provided me with some understanding both of the problems the participants were facing and the workings of the health system they were negotiating, which I think enabled me to be more effective as an interviewer in some respects. When it came to analysing the data, work detailing illness narratives (see Chapter 2) was invaluable when understanding what is

²¹ Seale defines internal validity as 'the extent to which causal propositions are supported in a study of a particular setting' (1999: 38), and external validity as 'the extent to which causal propositions are likely to hold true in other settings' (1999: 40)

²² Some of my early analysis of the interviews looked at how the interview participants portrayed themselves as 'experts' in their condition, and contrasted this with the reality of how they learn about and managed their health. (see Appendix V).

routine when people talk about their health. Similarly, the influence of my own cultural and academic background on the analysis was moderated by the involvement of the rest of the research group.

In the light of these concerns, there is no doubt that if another researcher had done the same project, they are likely to have focused on and reported different results. But that does not detract from the results of this study. Returning to my discussion of Hammersley's subtle realism, there is an understanding that all such studies may later be proved false, and that other perspectives on the data may be equally valid.

In quantitative research the generalisability of study results depend upon the extent to which the population sampled can be shown to represent the wider population. By contrast, I have not attempted to form a *representative* sample of people with AS, and yet I still make claims from the results. How do I justify this? While different authors have described many techniques to improve the generalisability of qualitative research, Seale (1999) describes two particularly strong arguments.

The first is that by providing sufficient detail regarding the phenomenon itself and the context through which it was encountered – the 'thick description' - researchers provide readers with enough information on which to base judgements about its relevance to specific circumstances which they, the reader, may be considering. Applying this to my findings, it would suggest that there is no immediate assumption that these findings would be applicable to other populations - this would be subject to separate, empirical examination - but the reader themselves may reach a conclusion from the data presented here that it may be useful and valid in their setting.

Secondly, I would argue that the sample selected, based on a range of purposive sampling strategies, results in greater external validity than a randomly selected group of patients. Thus by recruiting participants with an aim of *disproving* the theories as they have emerged and by *maximising difference* within the sample I have improved the strength and validity of the findings, such that they can be considered as a valid representation of the range of people with AS. However, it could also be argued that I have not maximised difference in my sample by applying geographical limitations to recruitment, and therefore doubts could be raised regarding its application to populations outside of the North East of England. This

is certainly a valid criticism which could only be tested empirically with patients from other regions; at the same time, with reference to Seale's first point above, readers may feel the setting is sufficiently similar to their own region to take up these findings.

Triangulation and respondent validation are two techniques suggested by some authors as methods of improving the validity of research studies. Whilst I have used them in this project, Silverman suggests both are 'usually *inappropriate* to qualitative research' (2006: 291, emphasis in original). His argument against triangulation arises from its search for an objective truth by means of viewing a phenomenon from multiple perspectives. Whilst this may be beneficial for physical objects, by their nature social objects *are different* from different perspectives, so there is the potential for damaging consequences if the technique is used to label one perspective as 'truth', and another as 'false'. In contrast, and as Silverman concedes, there is still benefit in examining such social phenomenon from multiple perspectives when this limitation of triangulation is understood and instead the aim is to compare and contrast perspectives. This was my approach with my data from focus groups of patients and professionals (see Chapter 6), and when comparing this to my interview data.

Both aspects of the phase we originally termed 'Achieving Consensus' represent examples of respondent validation – the second focus group with NASS members, and the web-based survey of patients and professionals (see Sections 4.4.1 and 4.4.2 respectively). As described in the relevant results chapter (see Chapter 8) I did encounter some of the problems Silverman describes in relation to this technique. In particular, it was difficult to convey both methodological issues and results to patient groups and health professionals, and where participants were asked to rate our findings according to importance, it was those that were consistent with their self-image which were viewed more favourably. Therefore I would share his view, put most succinctly by Fielding and Fielding (1986: 43) that:

there is no reason to assume that members have privileged status as commentators on their actions such feedback cannot be taken as direct validation or refutation of the observer's inferences. Rather such processes of so-called 'validation' should be treated as yet another source of data and insight. (from Silverman, 2006: 293)

In summary, I have employed techniques in the design and implementation of this research project which I hope make the results and conclusions credible. At the same time my

claims are within the boundaries of subtle realism, such that they may be overtaken by the research of others in the future, and they are a result of *my* interpretation of the data, influenced by the input of the rest of the research group. I will return to issues of validity and its influence on my findings and recommendations in the final chapter.

4.3 Phase III - Professionals' Views and Experiences

This phase ran concurrently with Phase II (see Figure 6) and consisted of two focus groups and a postal survey. The focus groups were with Rheumatology Consultants and Rheumatology Health Professionals from the North East of England, and were used to inform the subsequent survey. The survey sought to establish a UK perspective on current educational provision for people with AS, describing the resources provided to patients and issues relevant to the delivery of education. The results of this phase are presented and discussed in Chapter 6.

4.3.1 Focus Groups

The focus groups followed similar methods to those described in section 4.2.1 with respect to the NASS focus group. The first group consisted of Rheumatology Allied Health Professionals who were involved in the care of people with AS. The latter were Rheumatology Consultants. Participants were recruited from the three Rheumatology departments from which we also recruited patients (Centres A, B and C). Potential participants were approached by email with a purposive strategy designed to ensure maximum differences with regards to profession, gender, experience and hospital. The participants' details are shown in Table 2 and Table 3, Chapter 6.

Like the NASS group, I moderated each discussion; Tim Rapley observed and made additional research notes and occasional interjections. Topic guides were devised to encourage discussion about the local provision of education for people with AS and participants' experiences of providing education for this group (see Appendix VI). The discussions were recorded and transcribed. Analysis followed the methods already detailed in section 4.2.3.

4.3.2 Survey of Health Professionals

The principal output of the focus groups was a questionnaire which was distributed to all Consultant members of the BSR (British Society for Rheumatology) and all members of the BHPR (British Health Professionals in Rheumatology) (see Appendix VII for a copy). The aim of the questionnaire was two-fold:

- To describe the educational resources provided by Rheumatology departments in the UK for patients with AS
- To document the views and experiences of the Rheumatologists and Rheumatology health professionals who provide these resources.

The BSR is the national professional organisation for Rheumatologists, Rheumatology trainees and scientists working within musculoskeletal health; its activities range from organising an annual conference to campaigning for sound health policies in the field of rheumatology. The BHPR is an equivalent organisation whose membership is made up of members of the rheumatology multi-disciplinary team, for example nursing, physiotherapy and occupational therapy.²³ Both organisations co-operated with the survey – the BSR provided the professional addresses of its consultant members, the BHPR itself distributed our questionnaires because it did not want to pass members’ details to us for Data Protection reasons. In both instances responses could not be matched to individuals, and therefore we could not identify non-responders or send targeted reminders. In order to maximise response rates the survey was publicised on the website of both organisations, and in relevant newsletters. In addition, a letter explaining the purpose of the survey including the Arthritis Research UK logo was included with each questionnaire (Appendix VII) and a single email reminder was sent to each potential respondent two weeks after it was originally distributed.

The survey itself was developed to address the themes which arose from the three focus groups which preceded it – with NASS members, Consultant Rheumatologists, and health professionals respectively. Data regarding respondents’ professional background, the organisation and provision of education within their department, their opinion regarding the aims of patient education and which patients benefit most from education was collected. Its layout and content was developed with reference to training in questionnaire design through Newcastle University, and relevant literature (Dillman, 2007; Fowler, 1995). Final versions of the survey were reviewed by the research group and piloted with local Rheumatologists and health professionals who had taken part in the original focus groups. We employed two forms of piloting. Questionnaires were either completed with me

²³ See www.rheumatology.org.uk for further details about the BSR, and www.rheumatology.org.uk/BHPR/ for further details about the BHPR.

observing and discussing the process in order to review questions which were unclear (n=4), or alternatively participants completed the survey independently, but returned the questionnaire with comments about the clarity and appropriateness of each question (n=6).

The results of the questionnaire were compiled and analysed using SPSS software version 15.0.1. All data were held anonymously; the results are presented in Chapter 6 within this thesis. Free-text comments were analysed and grouped in order to quantify responses.

The survey therefore provided information about the educational resources which rheumatology departments offer patients. A high proportion of Rheumatologists are members of the BSR, and similarly many allied health professionals with an interest in rheumatology are members of the BHPR. Hence we would expect that the majority of rheumatology departments would have been represented in the survey, and the sample was appropriate for the aims of the survey. The design provided a wide distribution, but many of those who received the questionnaire would not have had a particular interest in either ankylosing spondylitis or patient education. Those that did return the survey were likely to be those with a specific interest in these areas, and were therefore more likely to provide additional resources as part of their normal practice. Therefore we expected the results to be an overestimate of the provision of resources.

4.3.3 Telephone Interviews

The telephone interviews were employed as a method of rapidly verifying the information which rheumatology departments offer patients regarding conditions which are routinely managed by other medical specialities. More specifically, they concerned the information offered to people with ankylosing spondylitis regarding the risk and subsequent management of eye and bowel complications – iritis and inflammatory bowel disease. These topics were identified during the new patient interviews as confusing and incomplete in the existing patient literature.

Three local gastroenterology consultants and three ophthalmologists were recruited, initially via an email explaining the purpose of the interview and offering some background to the project. In total 5 gastroenterologists and 3 ophthalmologists were approached; 2 gastroenterologists did not answer initial email correspondence. The consultants were recruited from the three centres through which patients were also recruited, and were

approached because they were the specialists to whom participating rheumatology teams would routinely refer patients.

An interview schedule was devised to determine the information relevant and appropriate for people with a new diagnosis of AS. A specific time was agreed for the telephone interview, and the conversation was digitally recorded using computer software. These interviews were not transcribed; instead I repeatedly listened to the recordings and made analytical notes in relation to the themes outlined during the interviews with patients. The results from one interview were used to inform the subsequent one; inconsistencies were explored, and patients' views expressed to me during interviews were used to illustrate the difficulties patients faced in understanding the available information. This approach was more time-efficient than those used elsewhere in the project. This was because these interviews were designed solely to add information to existing themes, not to develop new ones.

The results from the telephone interviews are presented in Chapter 8.

4.4 Phase IV - Achieving Consensus

I have kept the original title for this phase despite making a definite break from the concept of a consensus process as the research project progressed. Thus the initial plan to ‘bring it all together’ is maintained, but the idea of ‘achieving consensus’ became both unachievable and less useful as the analysis of the interviews evolved. This realisation that the envisaged consensus was unrealistic follows the arguments I have already outlined regarding the limitations of triangulation and respondent validation (see section 4.2.3.3). By feeding back our results to stakeholders we were not going to be able to resolve the differences between their respective perspectives to create a single ‘true’ perspective. Yet there is still merit in carrying out this process. This phase therefore offered the NASS members who had taken part in our first focus group and a sample of Rheumatology health professionals and NASS members from across the UK the opportunity to review our findings and comment on their relevance and utility. We therefore collected this additional data not as a means to achieve consensus, but to gain further insights regarding stakeholders’ perspectives, the differences between these perspectives, and indeed how our results contrast with them. In turn, this phase offered further information about how education should be provided to people with AS, and how any changes could be implemented.

In this section I will therefore report how first the focus group and subsequently the web-based survey of NASS members and professionals were carried out.

4.4.1 NASS Focus Group

This focus group took place after I had analysed the interviews with people with AS, and after the survey of health professionals. I had also presented many aspects of the project to different audiences, so in this respect was accustomed to talking about my results. The participants were recruited in the same manner as the previous NASS focus group: I agreed a date when the focus group would take place with the secretary of the group, and publicised it three weeks in advance. The focus group took place after their normal weekly meeting; all the individuals present at the meeting took part. It was audiorecorded, transcribed and subject to the same analytical techniques described in previous sections.

However, the focus group itself had a different structure to the previous groups. I used PowerPoint slides to illustrate different aspects of the project and to stimulate discussion

amongst the group. Typically, I would talk about one aspect of the study for 1-2 minutes, and then ask questions of the group related to this. My principal aim was to discover the extent to which my findings reflected their experience of patient education and whether they had experiences or opinions which might contradict these findings; my questions reflected this aim. Similar to the ways in which I used the topic guides within the interviews, I did not attempt to adhere rigidly to the structure provided by my prepared presentation, and followed a conversational style which was led by the participants.

The results are presented in Chapter 8, along with a discussion of their validity and implications for the rest of the project.

4.4.2 Web-Based Survey

This survey offered 100 Rheumatology health professionals and 100 NASS members the opportunity to select which of our findings they felt were most important to the topic of education for people with AS. The health professionals (HPs) were selected purposively from those who volunteered as part of the postal survey to help with a later phase of the study. Respondents were therefore selected to represent different professions and different regions of the UK, in proportion to the number of responses to the postal surveys. 40 Rheumatology consultants, 25 Rheumatology nurse specialists, 25 Rheumatology physiotherapists, 5 podiatrists, 2 occupational therapists, 1 psychologist, 1 dietician and 1 pharmacist were therefore approached. The 100 NASS members were approached by their central office staff from a database of members with AS who had stated they were willing to help with research projects.

The survey was developed and distributed using a web-based survey tool²⁴. Participants were invited to take part via a personalised email which included a link to the survey. The findings of the research project were presented to the participants in the form of 30 statements or propositions; these are listed in Table 11, Chapter 8. The statements were initially developed by Tim Rapley and I, and aimed to summarise the findings of the project in short, accessible phrases. These were reviewed and modified by other members of the research team before being included in the survey. In addition, the introduction to the

²⁴ www.surveymonkey.com

survey included a very brief overview of our methods, and an example of one of our results in more detail – the Established Patient Model.

The survey itself consisted of two discrete rounds. The same 200 people were invited to participate in each round. In Round 1, participants were asked to select 10 of the 30 statements to *reject* on the basis of being, in their opinion, our *least important* findings. The analysis of Round 1 resulted in the original 30 statements being reduced to 20 by discarding the 10 statements which most participants had rejected. In Round 2, participants were asked to select the 10 *most important* statements. The analysis of Round 2 resulted in a final 10 statements being selected as the *most important* findings of the research project.

The responses remained anonymous but the survey tool allowed a single reminder to be sent to those who had not yet responded. Simple demographic questions were included in the survey for NASS members. Opportunities for free-text comments were available to both patients and professionals regarding the research project and the survey itself. I performed thematic analysis with these comments, using Excel spreadsheets to analyse both this and the quantitative data. Differences between the propositions selected by patients and professionals were reviewed. The results are included in Chapter 8, along with a discussion of the survey method.

4.5 Conclusions

In this chapter I have offered a description of how the data presented in the remainder of the thesis was assembled, in sufficient detail - I hope - for the reader to reach their own conclusions regarding its validity and its application to other settings. There are likely to be additional details which I have omitted but which some readers would appreciate and find useful, or even feel are essential to the interpretation of the results. I hope these are few and not considered too significant.

Additionally, this chapter offers information about how and why the project has evolved from its original proposal and plan. In some cases this evolution has resulted from my own deeper understanding of qualitative research; in others it has come about because of the data we have collected and the directions our analysis has taken us; the responses of different audiences when I have discussed or presented my findings have also had an effect. Positivists might argue that to deviate from the original protocol represents weakness within a research project, an opportunity for bias which should be avoided. I would suggest that such deviation is to some extent inevitable, as one cannot accurately predict all the eventualities of research when it is commenced. In addition, failure to follow the leads and opportunities which are encountered during a research project does a disservice to the participants, and is likely to detract from the outcome. Therefore, the distinction between 'good' and 'bad' practice with respect to changes to the protocol is not whether or not it occurs, but instead whether it can be justified, and whether the author identifies and explains the reasons and implications of such changes.

The next chapter, Chapter 5, is the first of the results chapters, and therefore signifies a shift from the description of methods - 'what we did', to the outcomes - 'what we found out'. It begins with an overview of the results chapters, before explaining how the Established Patient Model was constructed, a model which describes the process through which people with AS learn about their condition.

Chapter 5 – Patients’ Perspectives: Becoming Established

5.1 Introduction to the Results Chapters

In Chapter 4, I described and considered the techniques employed in this study of education and learning for people with AS, making particular distinction between the perspectives of patients and health professionals. This separation continues into the first two results chapters. Chapter 5 uses data from the interviews with patients to examine the *timing* of patients' learning, outlining a model which will be applied to specific aspects of education in the subsequent chapters. Chapter 6 returns to health professionals' perspectives, considering the *current practice* for AS patient education in the UK, primarily via data from the focus groups and the survey. In Chapter 7 I have considered the *content* and *delivery* of education, focusing on how patients use the resources which are currently available, and how these individual resources and the organisation of education could be improved as a result of our increased understanding of the experiences, practice and opinions of both patients and health professionals. Finally, in Chapter 8 I will report on the response of patients and professionals to our findings, and begin to summarise the results.

5.1.1 Nomenclature with Respect to Interview Participants

All references to the interview participants in the thesis have been anonymised. Each is referred to by a letter; their demographic characteristics are tabulated in Appendix II. Within the text, particularly in relation to excerpts from interview transcripts, each interview is also referred to by a code. Thus 'Anew1.3' refers to the third (or 12 month) interview with 'new' patient 1 from Centre A, while 'Crev3' is an interview with 'review' patient 3 from Centre C. While the participants are referred to by an initial, the interviewer is referred to as 'I'.

5.2 The Established Patient Model

5.2.1 Development of the Model

The Established Patient model describes the process by which patients with ankylosing spondylitis *learn about their condition* and *learn how to live with it*. It demonstrates the temporal relationship between receiving a diagnosis and the practical steps patients take to learn about AS, as well as their objectives when searching for information within the four distinct stages of the model (see Figure 8).

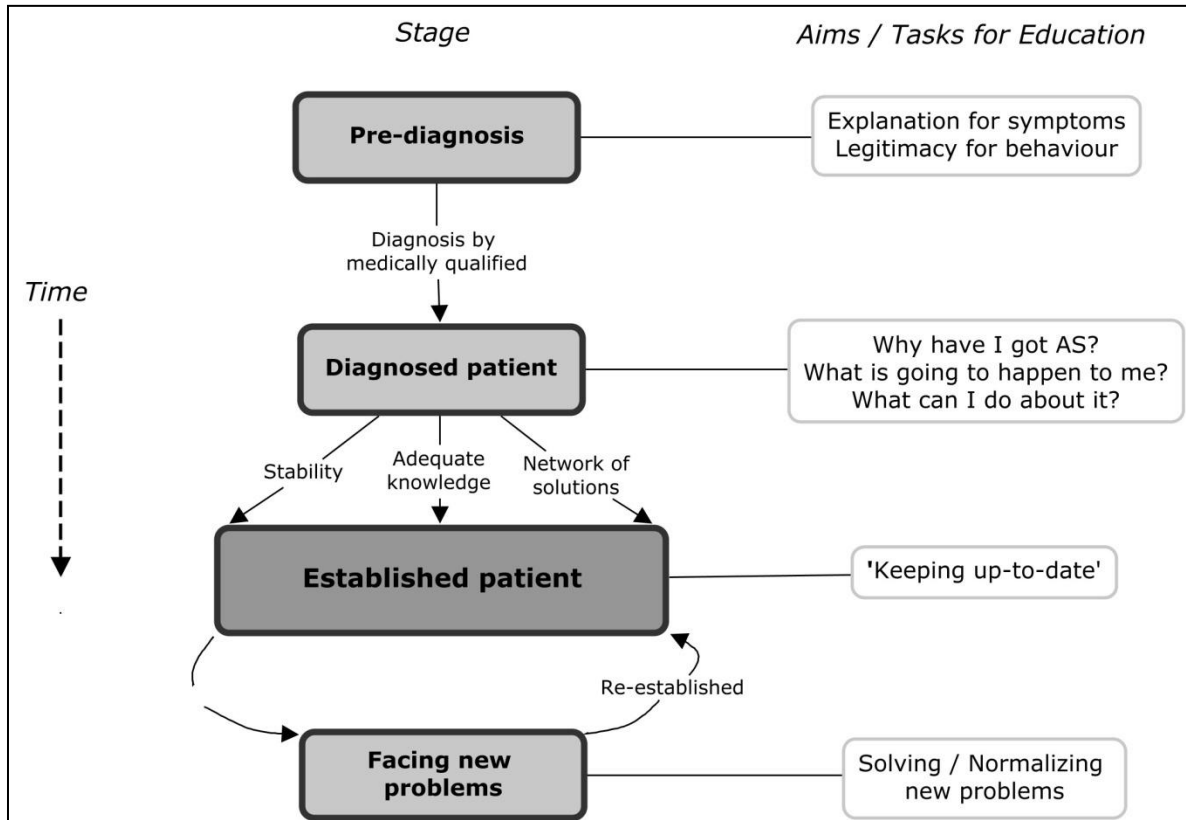
It was not our intention at the outset of the project to develop such a model, but instead it emerged and evolved as the analysis of the interviews with newly-diagnosed patients progressed. Initially, my analysis focused on the differences between patients who - using crude descriptive terms - appeared to be ‘coping’ or to have ‘come to terms’ with their AS (e.g. P (Anew4), J (Bnew1)), and those who were struggling with their new diagnosis (e.g. C (Anew1), W (Anew3)). This line of investigation led to the development of a concept I termed ‘expertise’, which I considered to be a potential aim for patient education, and which was related to a number of different characteristics²⁵. However, the term ‘expertise’, and to a degree the concept itself, is problematic. Firstly, it echoes the well-practiced debates regarding the differences between professional and lay knowledge and expertise within medicine, which I described in Chapter 3. Secondly, there is a moral element to the term which implies an additional obligation on patients ‘to be an expert’ on their illness, indicating an extension of Parsons’ description of patients’ responsibilities ‘to want be well’ and ‘to seek technically competent help’ (1951: 436-437). Using ‘expertise’ in this context thus risks judging and ostracising those patients who choose not to engage with education and decision making in health (Kjeken et al., 2006; May, 1995), potentially resulting in a society which considers them less worthy of treatment. Finally, ‘expertise’ is now strongly associated with the Expert Patients Programme (EPP) and thus repeating the term in this context would make it difficult to delineate the differences between this

²⁵ Appendix V includes a diagram illustrating this concept, including relevant transcript excerpts. I felt that there were two important aspects of patient expertise – the ‘reality’ and the ‘image’ of expertise. Whilst the former reflected the development of knowledge, skills and experience which would help patients deal with the health and social problems arising due to their condition, the latter influenced whether these characteristics were apparent when they were interviewed – i.e. whether they *appeared* to be an expert.

concept of expertise as an outcome of education, and the outcomes which the EPP hopes to achieve.

The next important analytical step was the identification of patients who had stopped the rapid search for information which occurred after their diagnosis – patients for whom the process of learning about ankylosing spondylitis had become less important. I made this observation during my second phase of interviews with newly-diagnosed patients, when participants were six months post-diagnosis, and I was therefore able to witness and consider the changes which had occurred since their first interview. This breakthrough not only enabled me to begin to describe these *established patients* and their characteristics in detail, but also facilitated a new temporal approach to my analysis of patient education. This approach led to conceptualising learning about AS as occurring over four distinct stages: *pre-diagnosis*, *diagnosed*, *established*, and *facing new problems* (see Figure 8). Each of these represents a separate stage in the process of learning about the condition, particularly with respect to patients' aims for education, but also to the methods they use. It results in a model which attempts to reflect the reality of when, why and how the interviewees in this research project search for information and education concerning AS, and also relates to the literature discussed in Chapter 2 regarding the experiences of patients with AS. However, it does not specify or suggest a status to which patients should aspire to: unlike the expert patient ideal, the Established Patient Model does not expect patients to be knowledgeable or to be efficient 'self-managers'. Instead, it recognises and possibly predicts the learning needs of individuals with AS, and can indicate suitable content of education and methods of delivery.

Figure 8: The Established Patient Model: Four Stages of Learning About AS



In the remainder of this chapter, I will focus on my interviews with people with AS in order to illustrate the model further. I will use excerpts from the transcripts to describe each of the stages in more detail and also the circumstances leading to patients moving from one stage to the next.

5.2.2 Pre-diagnosis

The pre-diagnosis stage begins with the development of unexplained symptoms, and consists of a search for the explanation and degree of legitimacy which is provided by a medical diagnosis. Until patients obtain a diagnosis from a suitably qualified person²⁶, fundamental questions related to their symptoms and condition are unanswerable, and they remain cut-off from other patients with AS with whom they could potentially share their

²⁶ In this study the 'suitably qualified person' was universally a hospital-based Rheumatology Consultant. Diagnoses were sometimes *suggested* by other health professionals – physiotherapists, general practitioners or chiropractors for instance – but the diagnosis, at least in the patients' mind, remained provisional until it had been confirmed or made by the Rheumatologist to which they had been referred. This may reflect our recruitment of participants through these same Consultants, although our wider experience also reflects this situation.

experiences. Medical knowledge and information is routinely organised with respect to discrete diagnoses, leaving those people with symptoms which remain ‘unlabelled’ with few useful, or certainly specific, educational resources to consult.

Of course it is impossible to effectively define or study prospectively a group of people who have ‘pre-diagnosis ankylosing spondylitis’. If this period is prolonged, and if their symptoms are not recognised by a number of health professionals, their experiences may become analogous to those with ‘medically unexplained symptoms’ (Hatcher and Arroll, 2008). However, despite these difficulties, this time between the onset of symptoms and receiving a diagnosis remains an important period when considering education for people with ankylosing spondylitis, both because it aids our understanding of patients’ knowledge about the condition at the moment they are informed of the diagnosis, and because their experiences during this period can shape their relationship with health services after diagnosis.

Ankylosing spondylitis is *unknown* to patients at the time they are given the diagnosis. They may have heard of the diagnosis - although this was rare in this cohort - but irrespective of patients’ background, their existing knowledge is not useful and thus the search for information described in relation to the ‘Diagnosed Patient’ (see 5.2.3 below) is universal. AS remains unknown until this time because of four inter-related factors - and I will examine these in turn.

Firstly, as I have already intimated, the term itself is alien to most of the general public - ‘it is basically unheard of around here.’ (Anew1.1: 288). Excerpt 1 illustrates this point further:

Excerpt 1: Anew5.1

- 37 I ... going back to before you were told that you had this condition, ankylosing spondylitis, had you heard about it before?
- 38 K Never heard about it.
- 39 I Or anything similar?
- 40 K Never. I had heard of spondylitis but it is just like you know it is because you haven’t got it you don’t really look into it, do you know what I mean? It is like me looking into lung cancer or whatever on the internet now, you know. I haven’t got it so, that I am aware of, so I wouldn’t go and look at it, you know.

Here, K initially describes his comprehensive lack of knowledge about AS prior to his diagnosis, and then (38) the principal factor determining this ignorance – that he hadn't been told he was suffering from it. Like other participants, he recognised and attached meaning to some related terms, such as 'spondylitis', or 'arthritis', but associated these with images of an almost inevitable, irreversible decline with age. Furthermore, his analogy to searching for information about lung cancer probably overestimates his pre-existing knowledge about AS; it is more plausible that prior to his own diagnosis with AS, he understood more about the causes, symptoms and likely prognosis for people with a lung malignancy than he did about AS, especially given the diffusion of cancer-related talk and experiences in contemporary life and the media.

This leads to my second reason why AS is unknown, which is that prior to diagnosis, people are unaware of those around them who have the condition, as shown here:-

Excerpt 2: Bnew3.1

43 I ... when you saw [consultant], ankylosing spondylitis, this thing, AS, wasn't something that you had heard of before?

44 T Never before.

45 I No and you don't know anyone with it or know?

46 T Well actually since I have been told I have it one of my mam's friends, her husband had it, has it sorry.

47 I Oh right?

48 T Eh, but I never knew. I knew he had a bad back but he was a gardener and I just thought it was all those years of bending down and digging holes and stuff like that, you know.

This narrative is repeated by other interviewees, with descriptions of relatives, friends or associates whose diagnosis, although longstanding, only became apparent after their own condition was confirmed. Similarly, there are descriptions of older family members whose appearance and symptoms were consistent with AS, but which were perhaps unrecognised by health professionals, or alternatively not discussed within the family unit. These descriptions suggest that existing patients with AS experience either a reluctance or difficulty in discussing and divulging their diagnosis to others. This lack of communication results in pre-diagnosis patients being 'cut off' from a potential source of background

knowledge of the condition, and the opportunity to compare their own symptoms and experiences with such a person.

P (Anew4) is a general practitioner and therefore would be assumed by many people, based on his medical training and experience, to have a greater understanding of ankylosing spondylitis than a lay person:

Excerpt 3: Anew4.1

- 39 I And did you have a sort of image or sort of an idea about what it [AS] was [prior to your diagnosis]?
- 40 P Well you know it is different when you are learning it from a medical point of view and then you find out that you have it. It is; you don't; you are thinking about it medically, you don't really think about how it is going to affect you personally or how it is going to; I suppose if you are seeing a patient you try and go through from a personal point of view how it is going to affect them but when you haven't seen patients before with it on a regular basis you look at things in a medical way, and as soon as kind of I had some inclination of what it was I was more worried about how it was going to affect me long-term, whether it was going to get better, how worse was it going to get, what could I do to stop it or first things like that really.

He has met or cared for people with ankylosing spondylitis, and read about it in textbooks, but sees this as the '*medical point of view*' (40), separate from the '*personal point of view*' (40). This latter view, encompassing specific information about *his* future rather than *the* prognosis, and how it is going to affect *him*, illustrates the specific aspects of his understanding of AS which he lacked before his diagnosis. Now that AS was a condition which affected him rather than the patients he was caring for, significant gaps in his knowledge became apparent, and it was this information, this personal view - or perhaps more appropriately, *personalised* view - which had been lacking. This separation of professional and personal understanding of AS and a renewed sense of ignorance about the condition was also evident on interviewing U (Crev2), a physiotherapist who developed symptoms in her late teens.

Finally, it appears that people do not apply their knowledge about AS to their own health unless the diagnosis is confirmed by a medical practitioner:

Excerpt 4: Bnew1.1

- 16 J I didn't really know much about the disease because ... I didn't think about researching it because I thought it would have been identified earlier.
- 17 I You didn't think it reflected, sort of, what you had at that time?
- 18 J Em and my friend has ankylosing spondylitis and I didn't seem to have the same sort of complaint. I had one or two similar complaints but not the same. I thought it would all be the same sort of diagnosis you know. He has problem with his neck, he has restricted movement, he gets a lot of pain and although I was in a lot of pain and I had the iritis like he has em ... em I had the plantar fasciitis which was different, I had the sciatic pains which were different so I didn't associate the two together.

In this excerpt, J has heard of AS, has a friend who has already been diagnosed with it, but doesn't associate his condition with his friends' because he thought doctors would have identified it earlier. He had presented himself to the medical profession: if he had AS he assumes they would have told him, appearing to discount the possibility that they could have 'missed' the diagnosis. In addition, he notes the differences between the individual symptoms experienced by him and his friend, effectively explaining why he hadn't made the connection, and thus the diagnosis, himself. Three years after the onset of troublesome symptoms, after he was diagnosed, he was able to begin 'researching' (16) and learning about AS.

So far in this section on pre-diagnosis patients I have described and explained patients' lack of knowledge about AS at the time of diagnosis, thus beginning to explore why patients feel unprepared for the diagnosis, and why they 'rush' for information after their diagnosis in an attempt to address this. However, our model indicates that during this stage patients are searching for the *explanation for their symptoms* and *legitimacy for their behaviour* which is provided and facilitated by a medical diagnosis. This search for a diagnosis takes different forms, and it is these which I will turn to now. L (Cnew2) describes a two year period when she was searching for a diagnosis. Her symptoms were initially attributed to 'the type of exercise I was doing because I was going to the gym' (26 – not shown), having consulted both her GP and a chiropractor. Not convinced by this explanation, L did her own 'research'²⁷:

²⁷ During the interview, it is L who initially uses this term to describe her use of the internet and other information sources. In Excerpt 5 it appears I use the term first, when in fact I am echoing her earlier use.

Excerpt 5: Cnew2:1

- 11 I OK so before you spoke to the hospital and before you spoke to the doctor there you sound, you said you had done some research?
- 12 L Yeah.
- 13 I Researched yourself? Can you tell me a bit more about that?
- 14 L I just went on the internet and typed in like the symptoms I had and stuff. And I know the internet, I do, I have a science background (SMILING) so I know you are not meant to look into em too much on the internet because it is a lot of freehold stuff that nobody rules and regulations but em. As I say rheumatoid arthritis and ankylosing spondylitis were the two things that met up with all of my symptoms and they had. But this special em even tests like if you give yourself a specific score for each symptom you had and how long like you wake up on the morning and if you have had pain for less than an hour, more than an hour can mean this or this and then I looked in a few books and that was it really. So it wasn't a shock when he [her Rheumatologist] said because I had already kind of looked at it and I was glad in the end that it was something and not just, nothing. That,
- 15 I Yeah.
- 16 L You know for so long they had been saying they didn't know what it was so it was better to know what it was.

I will return to patients' use of the internet in Chapter 7. However, in the present context it is worthwhile pointing out that given L's familiarity with the internet, her awareness of its uses and limitations, along with her particular skills resulting from her 'science background' (14), it would seem more remarkable if she did not use this resource.

Secondly, L uses the information she receives from the self-diagnosis website²⁸, along with the rest of the internet content, as contingent to information she receives from the medical profession. She reports that 'looking into it and hearing about it *in detail* was through the doctor' (10, not shown, my emphasis), and it is not until she is given the diagnosis by a Rheumatologist that she considers herself to have AS.

The search for a diagnosis depicted so far, described by L, is not universal amongst the interviewees. In contrast, T (Bnew3) tells another story:

²⁸ Neither L nor I were sure which website she had used, and since then I have not been able to find a website which exactly fits her description given here. However, websites such as www.diagnose-me.com, and www.healthline.com offer similar services to the public.

Excerpt 6: Bnew3:1

- 37 I Yeah, yeah, OK. And did you have any ideas? I mean obviously you said your GP had said it was perhaps sciatica?
- 38 T Ah ha.
- 39 I Is that what you thought it was or had you thought it was anything else?
- 40 T I just went with the GP. I was sort of, I mean people were, and before I had been to see the GP other people said, 'oh it may be sciatica' and so when I, it was sort of in my head anyway when I went to see the GP. I didn't say anything to the GP, I just left her to do her job and tell me what was the matter with us and she said 'sciatica' which apparently it is easily mistaken for.
- 41 I COUGH Mmm.
- 42 T And so. I mean my grandmother has had sciatica and the symptoms she had are quite similar to the symptoms I had so just went along with it.

T had experienced symptoms attributable to AS for more than three years before he received a diagnosis, and was equally familiar with the internet. Unlike L though, T seems to abdicate responsibility for his health – or rather his diagnosis - to his GP (40), although this may be because her explanation for his symptoms was consistent with his understanding of them, influenced by his grandmother's experience (42). For some patients then, it would seem that the search for a diagnosis, even in this internet age, remains limited to visits to their GP.

L's statement in Excerpt 5 that she was glad 'it was something and not just nothing' (14) indicates her relief at the diagnosis, at least in part. By this time, L had already adjusted her social role – by taking time off work for physiotherapy appointments, requesting and receiving a new chair at work, by changing her car to one which she could access more easily, and even by describing her symptoms to her partner, friends and work colleagues. Her relief therefore reflects the legitimacy which accompanies a medical diagnosis, and with it an adequate explanation to those around her for why she has been behaving in this way. Conversely, without a diagnosis, her behaviour, motivation and even her symptoms would remain questionable to those around her.

This need for the legitimacy of a medical diagnosis is acknowledged by Parsons (1951) within his description of the sick role, and later by Bury (1982), who stated that:

where symptoms of a condition coincide with those widely distributed in a population ... the processes of recognition and legitimating the illness are particularly problematic. (Bury *ibid*: 170)

This observation reflects the experiences of ‘pre-diagnosis’ patients with AS for whom distinguishing themselves from people with ‘*just a bad-back*’ (Anew5.1: 30, my emphasis) becomes important. For K (Anew5), this was to avoid the stigma associated with low back pain, and its status as a common reason for absenteeism: ‘one of the biggest excuses probably used in Britain’ (Anew5.1: 202). Similarly, J (Bnew1) compares his own health with that of people with mechanical back pain, minimising their symptoms and asking: ‘what’s wrong with them? It’s only a bit of an ache in the back.’ (Bnew1.3: 65). However, this example, from my third interview with J, shows that this search for legitimacy continues even after diagnosis, now suggesting a need to effectively explain the diagnosis to others in order to sustain legitimacy.

In summary, prior to its diagnosis AS is *unknown* – either *unheard of*, or alternatively any existing understanding of AS is not applied or is considered irrelevant to their current health. Learning about AS for many people ‘pre-diagnosis’ involves ‘just [going] through the processes’ (Anew1.1: 19) - that is visiting their GP or another health professional repeatedly until it is recognised and diagnosed. Thoughts that professionals’ assessments may be inaccurate are at least temporarily suppressed because of a perception of superior, perhaps unchallengeable knowledge and training. Meanwhile, sources of information which are independent of the formal healthcare system are predominantly the reserve of those with a diagnosis of AS, inaccessible to those who only have the symptoms of the condition. Practically, this is because of the organisation of medical information: it is impractical to search for information without an appropriate name or medical label, exaggerated in the case of AS because of the lack of lay awareness of the condition. Additionally, there are difficulties accessing other patients and their experiences when one doesn’t have the same medical, legitimised diagnosis, and these other patients tend not to communicate their own diagnosis widely or effectively.

5.2.3 Diagnosed Patients

The diagnosed patient is characterised by a rush for new information, a search to answer three key questions - ‘Why have I got AS?’, ‘What is going to happen to me?’, and ‘What

can I do about it?’ - and a relative willingness to consider new educational opportunities. The stage begins with confirmation of the diagnosis of AS and ends when the patient becomes ‘established’, when this rush for information which characterises diagnosed patients comes to an end.

T (Bnew3) illustrates the transition that occurs when, in response to his diagnosis of AS, he thinks: ‘Right, at least I have got a diagnosis now, I can go away and have a look at it’ (Bnew3.1: 60). There is a sense of relief, particularly at the prospect of an explanation and further information. The term ‘go away’ is particularly pertinent, because although patients rated the approach of their diagnosing consultant highly, the information gained directly from this initial consultation appeared limited:

Excerpt 7: Anew1.1

- 6 I ... So I mean what do you understand that [consultant] told you about ... about the sort of diagnosis? What can you remember about that?
- 7 C Not very much.
-
- 24 I Yeah. So do you remember much about talking to her [Rheumatology consultant] then? Was it, ?
- 25 C No
- 26 I Lots of people say that actually, you know.
- 27 C I was just in shock I think.
- 28 I ... you know you go and see the doctor and they are completely in shock and they don't really take things in.
- 29 C No (SIGH OF AGREEMENT)
- 30 I Do you think that is what applies to you?
- 31 C Aye, I just couldn't believe that I had something like that at my age.

In the context of the rest of this interview, C is downgrading his understanding of AS. At this point, he is positioning himself as having only minimal knowledge. If, later in the interview, he is shown to misunderstand specific issues, such identity work could reduce his risk of embarrassment. However, the sense of shock C describes at receiving the diagnosis, along with its effect on his uptake and retention of new knowledge, is shared by other participants. For example, W describes the experience as ‘like someone had just whacked you in the face with a baseball bat’ (Anew3.1: 116), and that, unsurprisingly, his

‘mind sort of went just blank’ (84). In contrast J (Bnew1), like T, was more positive, feeling ‘*relief* that I could identify the problem ... and take a step forward’ (Bnew1.1: 58 – my emphasis).

In fact, patients’ emotional reaction to their diagnosis was, to varying degrees, either *shock* or *relief*, and this reaction in turn influenced their subsequent search for information. Patients who had been through a prolonged or difficult pre-diagnosis phase, involving multiple visits to health professionals, or a perception that their symptoms had not been fully recognised, experienced relief that they would now be taken seriously, and hope that their problems could be resolved. These patients began their rush for information immediately. Conversely, patients who experienced significant shock at the time of diagnosis did not describe the same prior *search* for a diagnosis, and in some cases had either attributed them to an alternative cause (e.g. Anew5 – a car accident) or had thought their symptoms would resolve spontaneously (e.g. Anew1). For these patients, the diagnosis was unexpected and immediately linked with ideas and images of ongoing, deteriorating pain and disability. There was no prior contemplation of chronic illness as a possible cause for the symptoms, and these patients struggled to search for or absorb information immediately.

Information provision in the setting of this initial consultation therefore appears problematic, especially when the diagnosis is unexpected or is viewed by the patient as particularly dangerous or severe. Only in one instance (F, Cnew1.1: 130 *not shown*) does verbal explanation of the condition appear to be the primary purpose of this consultation. In this case, the diagnosis had already been suggested by an ophthalmologist following recurrent episodes of iritis, and F had already been able to search for information about AS independently. Instead, this first consultation fulfils different functions, offering patients new ideas and resources with which to learn about AS away from the clinic room.

The rush for information begins with a patient information leaflet²⁹ provided by the Consultant Rheumatologist at the time of diagnosis. Contrary to views expressed at the consultants’ focus group, there was evidence these were read by patients at the first

²⁹ Participants recalled receiving either or both of the two leaflets on AS provided by rheumatology units – one produced by NASS, the other by Arthritis Research UK. It was initially difficult to deduce exactly which leaflet the patient had read, so I began to take the leaflets themselves to the interviews in order to remind participants and stimulate discussion.

opportunity and generally well-received. For example, the leaflets were read while waiting for an X-ray (P, Anew4), on the bus on the way home (T, Bnew3), or during their next break at work (F, Cnew1). They were also used to help explain the diagnosis to those around them, either by reading the booklets together, or simply passing them to others to read.

Similarly, the internet was also used as an information resource in the time shortly after diagnosis. Patients' use of the internet in this context was linked to its use during their everyday life, and represented an attempt to discover the type and extent of information available, rather than to answer specific questions. Broad searches for the term 'ankylosing spondylitis' with search engines were described, and this pattern follows the conventions for patients' internet use studied elsewhere (see section 3.3.4). Interviewees struggled to name the sites they had visited or found useful. Where specific sites were sought, these had been recommended by their Rheumatologist or were associated with the leaflets they had also received through the hospital.

In Chapter 7 I will consider in more detail the role of both information leaflets and the internet in education for people with AS. In addition, I will examine the precise part the Rheumatologist and other health professionals play in the process. However, before we move on from the resources available to patients, it is worth noting that few potential learning resources are dismissed at this time. Ostensibly at least, patients are initially willing to consider the resources offered or described, including group education resources. For instance, W (Anew3), thought that meeting other people with AS in this setting would be 'helpful' (Anew3.1: 238), and that he would gain 'positive feedback' and 'encouragement to do more [exercise]' (242). Similarly, L (Cnew2) views the opportunity as 'interesting', particularly '[meeting] somebody who has gone through what you have gone through, with the pain and the lethargy' (Cnew2.1: 140). Neither W nor L ultimately participates in these activities, despite their initial enthusiasm (see also Table 8, Chapter 7). This may indicate that these statements were influenced by the interview scenario – the knowledge that I, as the interviewer, was interested in education - and thus a tendency for interviewees to concur with this interest. An alternative explanation is that, at this stage, patients are unwilling to dismiss potential sources of help and education because the situation is new and uncertain, and thus they are unsure what help they will need.

Currently, there is little comprehension of how AS will affect their lives, and therefore only limited ability to appraise potential sources of information regarding their utility. Without an understanding of the problems, there is a reluctance to dismiss possible solutions.

Returning again to the defining characteristics of the ‘diagnosed patient’, I explained that there were three key questions that patients searched for answers to: ‘Why have I got AS?’, ‘What is going to happen to me?’, and ‘What can I do about it?’. In Excerpt 8, P succinctly describes the questions that were foremost in his mind:

Excerpt 8: Anew4.1

86 P I know it is hard to predict what is going to happen in the future so I didn’t really ask any of that. I wanted to know what I can do now and what I can do now to prevent it getting any worse. That was my main ... my main concern I suppose.

.....

120 P You don’t kind of want to know the ins and outs of it and the fine details of it. I suppose from the patient point of view you want to know how it is going to affect you now, what you can do, what it is going to stop you from doing, how you maybe want to change your life according to what you have found out and what the future holds really. ...

P does not list ‘explanatory’ questions here – the queries analogous to ‘why me?’ - while he also states that the ‘fine details’ (120) are not necessary. This contrasts with patients who have not received medical training, who view these as important areas to learn about. This is related to differences between lay and professional concepts of disease. P understands the limits of medical science, its inadequacy when explaining why one person will develop a condition such as AS, and another won’t. P therefore knows that searches for an explanation will be unhelpful, and like questions about the future (86), regards these topics perhaps not as *unimportant*, but more as *unfeasible*.

The other patients, without this complex, medical vision, have difficulty rationalising the uncertainty and unpredictability of this chronic condition. Examples of logical questions from the patient’s perspective, but verging on the unanswerable from the medical perspective include: ‘How have you got this disease, but nobody knows?’ (Anew2.1: 92) and ‘She [the Rheumatologist] says it is hereditary but no-one in my family has had it before?’ (Anew1.1: 23). Excerpt 9 illustrates the practical difficulties in answering these types of question:

Excerpt 9: Anew3.1

- 248 W Like I said I am ... I used to do seventy-five mile on a pushbike you know what I mean. I used to be fit as a fiddle like I said I cannot understand how I have ended up getting AS. I just, I cannot. I cannot. That's, at the minute that is what is going round through my head, I cannot understand how I have got it.
- 249 I You want a reason, sort of an explanation?
- 250 W Yeah well I am just ... I want to know how I have actually got it.
- 251 I Yeah, yeah.
- 252 W Like I say you are sitting there exactly the same as me but I have got AS and obviously you haven't do you know what I mean or you haven't been diagnosed with it but
- 253 I I know it is ..
- 254 W What is different between us?
- 255 I I know, it is difficult because it is a condition that does just sort of arise out of the blue; there is no sort of explanation. It is not like you have got lung cancer and you have been smoking all your life. You can say that lung cancer has almost been caused by it. There is nothing like that for ankylosing spondylitis, it is sort of 'chance'. It is, it is a fluke, it is unpredictable to a certain extent and that. It is not really a great explanation is it?
- 256 LAUGHING

Fundamentally, W expects a straightforward, definitive explanation to why he has developed AS, and health professionals can only offer 'risk factors'. In his case these are his age and gender, and the fact that he is HLA-B27 positive. These differences between patients' expectations and the information available are also evident when considering prognosis:

Excerpt 10: Anew1.1:

- 85 I OK. I mean do you think ... do you think you needed or wanted to know anything that was in the booklets about the other things that can happen to you?
- 86 C Well it is good to know about them, that they could happen but it doesn't tell you how likely they are to happen or nowt and whether they are going to happen.
- 87 I Yeah so it is about uncertainty without, sort of plans?
- 88 C It is knowing that you could get them but not knowing if you are going to get them.
- 89 I Yeah, so it worries you?

Leaflets such as the Arthritis Research UK or NASS publications which C is referring to here, list the possible ‘extra-articular’ complications of AS, but do not inform patients of how likely they are to develop these problems. This is probably because of the authors’ perceptions that identifying patients at greater risk of these complications will cause anxiety amongst these groups. However, there is a demand for this type of information by patients and a denial that it would cause additional anxiety. Later in the interview, C states that ‘I just wanted to know what was going to happen to me basically. What is the worst case scenario?’ (Anew1.1: 146). It is of course difficult to predict how he would react if he was, at this early stage in the disease course, told he was at risk of severe disease and future disability.

Within the question about what will happen to *me* are questions about the future impact on their *family*. These are expressed very early, both through concern about the inheritance of AS, but also regarding their continued ability to care for and provide for their dependents. Similarly, questions about the future were usually accompanied by what, practically, patients could do to influence their outcome and improve their symptoms, as shown in Excerpt 8. The impression gained by C is that ‘there is not much you can really do for it [AS] apart from exercising.’ (Anew1.1: 41). No patients seemed aware of newer treatments such as the biologic therapies, despite their recent search for information on this condition and my questions concerning ‘other treatments they knew about’. J tells of his friend with AS, who ‘at the minute is fighting for a treatment which costs £10,000 a year’ (Bnew1.1: 191), but did not think this would ever be available to him. At the same time, these patients were trying out the exercises suggested by their Rheumatologists, physiotherapists and diverse sources of information, and discovering their limitations as a therapy, both in terms of carrying them out in the manner suggested, and benefits for their symptoms. For some, these limitations to the treatments currently offered, combined with a lack of hope for better treatment in the future, seemed to exacerbate their low mood and frustration.

Another key question concerning ‘what can I do about it?’ was how to avoid making their condition worse. This ranged from whether the exercise they currently did was suitable, to more detailed questions relating to the strength of their ‘new’ bodies:

Excerpt 11: Anew5.1

- 256 I ... it was a while ago that you first heard this term ankylosing spondylitis, is there anything that you think you should have been told at the time that you now know?
- 257 K Just what, you know, really what (SIGH) [3 sec pause] I am trying to think how to say it. Em (SIGH) so what strain can you put on your back before you are likely to damage it, you know, by lifting heavy things, falling off kerbs or whatever, or is it just going to be the way you fall? How much, like to what degree is it, is it more likely, is your back more likely to fracture with this than what it is when you are eh? You know because that is a fear, it's a big fear that. Eh when you get out the bath and you slip you know are you going to end up in a wheelchair for the rest of your life?
- 258 I Sort of how much can you do?
- 259 K Yeah how much can you do? You know what exercise can you do? I mean well my consultant is telling me to like ... to try and straighten up but is that not going against the curvature like the natural, which is now natural curvature, of my spine.

In K's case, a lot of this fear of damaging his back seemed to stem from when his GP first raised the possibility of AS. It was suggested that his back was now fragile and at risk of fracture after quite minimal trauma (Anew5.1: 50 – not shown). While K represents an extreme case, the concept of avoiding damage and potentially harmful activities is an important question for patients. There is powerful imagery associated with a 'broken back', which as K suggests (257), is associated with paralysis and long term immobility. Being informed that your back is diseased raises the possibility of an increased susceptibility to this, and patients want to ensure they receive the most appropriate advice.

During this stage, patients adjust their view of the future for themselves and those around them, and learn to cope with their symptoms. They must also learn to navigate the healthcare system which they have now, inadvertently, become part of. For some patients without prior experience of this system, this is a daunting task, ranging from understanding the precise roles of different health professionals to where to seek help from with queries or problems. I will return to this topic in the later section on vulnerable patients in Chapter 7.

I have now examined the process of learning about AS from diagnosis until becoming 'established', a term I will explain in the next section. There is a rush for information which begins and is guided by the diagnosing Rheumatologist. Although only limited information may be retained from the consultation itself, those resources provided and

recommended by the Rheumatologist are highly valued as definitive and trustworthy. It is difficult for patients at this stage to determine the *scope* of their learning needs – there is no curriculum available for them to follow, and no boundaries to information available through web resources. Instead their learning is shaped initially by their emotional response to the diagnosis, ranging from *relief* to profound *shock*, and subsequently by their social background – their familiarity with and access to resources such as the internet, family support, and other people with AS. Patients want answers to the broad questions I have discussed, but may be searching for definitive accounts which are beyond the current limits of medical science and may therefore be dissatisfied with the explanations they receive.

5.2.4 Established Patients

Established patients are those who have stopped the rapid search for information which characterises diagnosed patients; the steep learning curve which began at the moment of diagnosis flattens, and their priorities switch from learning about the condition to ‘learning to get on with it’ (Anew1.3: 371). Importantly, there are no pre-requisites with respect to knowledge, skills, behaviour or time after diagnosis for a patient to be described as established. The term is not a description of patients who are particularly adept at managing their own health, or who know more than other patients about the condition itself. Instead ‘becoming established’ marks a shift in patients’ perceived need for education and information, occurring at a time and for reasons I will explore further.

The analysis of the new patient interviews revealed three distinct descriptions of established patients – those that had normalized their AS, those that perceived no benefit from participating in further patient education, and those that had disruption to their lives due to other social or health factors which took priority. Those patients who had normalized their AS had each achieved three pre-requisites which determined when this moment occurred – they had a self-defined level of *adequate knowledge* about AS, *stability* within their health, healthcare and social lives, and had built a *network of solutions* to potential problems related to AS which they may encounter in the future. The following subsections consider these six factors which determine when and why patients become established. These results were subsequently corroborated by the review patient interviews, gaining additional evidence that the initial analysis and model were valid, and failing to

produce new narratives despite the recruitment strategy aiming to maximise potential differences around these themes.

5.2.4.1 They have normalized their AS

In Chapter 2, I discussed Strauss and colleague's work on normalization (1984), describing the strategies people with chronic illnesses employ in order to live life 'as if normal' (ibid: p91). This process is certainly evident in these interviews, particularly regarding the extent to which the disruption caused by AS is increasingly viewed as routine, and the condition becomes an integral part of patients' lives. In fact, there are important similarities between our concept of established patients and those patients who have 'normalized' their AS. The patients we have considered so far in this section have reached their level of adequate knowledge at a time when their physical symptoms have been reduced or made 'less intrusive' by treatment (e.g. NSAIDs or anti-TNF) and because they have made the 'social arrangements' (ibid: p79) necessary to adapt their lives. As such, this group of established patients are those that have successfully normalized their AS, inasmuch as they have incorporated the condition and any ongoing disruption due to AS into their own and their families' lives. As F states, in the context of ongoing, stable symptoms: 'I don't even think of it [AS] as a condition, to me it is just sort of normal to me now.' (Cnew1.3: 246).

5.2.4.2 Adequate knowledge has been achieved

In Excerpt 12, L (Cnew2) describes her own 'educational journey', reflecting on the six months since she was diagnosed with AS:

Excerpt 12: Cnew2.2

- 98 L ... When I first found out about it I went on the internet and searched for it. I read all the leaflets, all the booklets but since then I really haven't even looked at anything.
- 99 I Yeah so you have not gone back onto the ... the internet?
- 100 L No - it just feels like 'I know what it is, I know what happens, that's it'.
- 101 I Yeah.
- 102 L I don't feel like I need to look into it any more. I might change my mind but at the minute I just feel like I don't need to know anything else, which probably I should maybe look into it more but I just feel like ... [tails off]

Here, L explains her thorough search for information when *diagnosed*, but then a shift occurs, such that she doesn't feel she needs 'to look into it [AS] any more' (102). There is an element of surprise to L's tone and description, suggesting that she hadn't recognised this shift in her own priorities until this interview. She indicates she now possesses a self-defined *adequate* level of knowledge about AS which is probably temporary ('I might change my mind' (102)), and perhaps morally inferior to her period of fervent searching ('I should maybe look into it more' (102)). Comparable statements were apparent throughout my early interviews, encouraging me to focus on how this *adequate* level of knowledge is determined by their circumstances, led by a belief that it would influence how patient education could be organised and delivered. Other examples include T's report that: 'I don't obviously know everything about it [AS] but I know what I need to know - as far as I know that might just be ignorance' (Bnew3.1:186). Similarly P highlights the danger of reading 'too much' about AS, causing one to become 'preoccupied with it' rather than allowing it to 'blend in' to your life. For P, adequate knowledge was 'what I need to do most days to prevent it getting any worse' (From Anew4.1: 297-301).

So far in this section, we have seen how patients' search for information about AS slows or stops when they consider themselves to have adequate knowledge – that is sufficient information to get on with their lives and prevent deterioration of their symptoms. I will now suggest that this occurs when patients reach *stability* within their health, healthcare and social lives, and when they are aware of sources of help or information they could turn to if they encounter further problems related to their condition – having created their own *network of solutions*.

5.2.4.3 There is stability within health, healthcare and social lives

In this excerpt F (Cnew1) relates his need for information to his current symptoms:

Excerpt 13: Cnew1.1

- 192 F ...For now I am quite happy. Not happy with my condition but I am happy with you know my knowledge of it, if you get what I mean and it is. I am very rarely in pain with it now.
- 193 I Yeah.
- 194 F It is only now and again, where, as I say as things progress, and if some. To meet up with someone who has already been at that stage of it, it may

be useful but at this precise moment in time I have, I don't think it would be, I wouldn't do anything different if you get what I?

F had started a non-steroidal anti-inflammatory medication at the time of diagnosis, and had noticed a significant improvement in his level of pain and functional impairment, reducing them to what he considers manageable levels. He describes a degree of satisfaction with his knowledge of AS, which he relates to his current, improved symptoms – being ‘rarely in pain with it now’ (192). This improvement and new stability of symptoms, coinciding with a reduced need and search for information, is also seen in patients who respond to anti-TNF medication. H (Brev1), together with her husband, had been very active looking for different treatments for her AS, but had entered what she termed her ‘comfort zone’ (Brev1: 512) with regard to education shortly after starting etanercept six years earlier. Similarly, N (Brev4) no longer asked questions during consultations with health professionals, and in fact would forget to attend his appointments such was the reduced priority he now assigned to his AS care and knowledge. In section 5.2.5 I will describe how the converse is also true – that a change in symptoms, or indeed in healthcare or social situation, restarts the search, utilising the sources of information they now have access to.

5.2.4.4 A network of solutions has been built

During the diagnosed stage, as well as learning about AS, patients were also learning about the sources of information and help available to them. Patients were discovering the presence, strengths, limitations and relevance of different health and education resources, and importantly, how to access them. These ranged from more formal providers such as Rheumatologists, physiotherapists and specific information booklets, to less well defined sources such as family members, other patients, and the internet. The extent to which this occurred and the conscious deliberation employed in the task of ‘appraisal’ varied between patients. However, this process of learning how to navigate the healthcare system was an essential part of the education process, as each patient ascertained the potential utility of each source in addressing both their present and future needs. During the interviews, I was able to examine this topic by asking participants what action they would take should they run into various problems related to their AS, such as a deterioration in their symptoms. Of course, answers were dependent on individual circumstances and experiences, but by the

time they had stopped their rapid search for information, patients could suggest potential sources of information, and how they would access them. For some, this was returning to their GP, while others could describe a more complex network of solutions, dependent on the exact nature of the problem and potentially utilising a range of formal and informal resources.

5.2.4.5 Lack of perceived benefit of further education

The first explanation of *why* learning slows or stops is therefore that the patient has ‘normalized’ their ankylosing spondylitis. I suggested there were three such explanations, and I will now examine the second. K (Anew5), as shown in Excerpt 14, does not think learning more about ankylosing spondylitis will reduce the disruption it is causing to his life, and has therefore stopped looking for further information:

Excerpt 14: Anew5.1

- 154 K And em and ways of helping myself but everything that you read or about, about ways of helping yourself, it doesn't work. It doesn't take the pain away you know, nothing will take the pain away. Nothing will bring your confidence back and em in the end you think well what the hell you know I might as well just get on as normal you know and that is what I have been doing probably for the last 3 or 4 months. Just going to work, coming back when I have been bad, going back but it is my partner that I feel sorry for because she is having to do like loads more in the house. I can't decorate you know I can't ... I can Hoover and do things like that but I can't stretch or anything like that. Like stand ... I am frightened to stand on anything in case I fall off it. So I can do little bits around the house. I can't even clean a bath out. I can't bend. I have to go on my hands and knees to clean my bath out after I have been in the bath because I can't bend to do a simple task like that.
- 155 I So I mean it sounds to me to a certain extent you know you started off by finding out everything about that you could, mainly from the internet but then now you almost feel that you have learnt as much as you can and it is not really helping?
- 156 K It is not helping in my case. I am not saying it won't help everyone, but it is not helping in my case.
- 157 I And your motivations for sort of finding out more is?
- 158 K It has gone now aye.
- 159 I It is dropping off, a wee bit?
- 160 K Mmm.

161 I And that's ultimately what ... why do you think you have stopped looking?

162 K Because I have never found anything that helps me.

K has participated in the rush for information characterising the 'diagnosed patient'. However, he now realises the limitations of the knowledge and skills he can acquire through these means, and has 'stopped looking' (161). Initially, he was attempting to understand the condition, answering the sorts of questions discussed in section 5.2.3. Now though, he cannot envisage getting the practical, tangible benefits he wants through education. He is established, but has not normalized his AS, at least in terms of making his illness and its consequences routine and ordinary³⁰. The concept of adequate knowledge remains valid, but rather than this being related to a lack of perceived *need* as in the case of those who have normalized their AS, in this example K feels he knows enough because he perceives that learning more won't have an impact on his life. Similarly, C states that 'I tried to learn as much as I could, but none of it really seems to help' (Anew1.3: 42) and had therefore stopped his search for new information, while J found that he was no longer learning any new, useful information when searching, so had also stopped (Bnew1.3: not shown).

5.2.4.6 Competing disruption to health or social lives

The third explanation relates to the priority assigned by patients to the disruption caused by AS to their lives, relative to their other health or social problems. As patients' focus switches to other priorities the search for information about AS slows or stops, irrespective of the normalization process, or their perception of the utility of such information. B (Bnew2), at 26 years-old, found out his wife had ovarian cancer at the time their first baby was born. Immediately, the priority he gave AS and its associated symptoms declined as he took on the role of caring for his wife and child, and stopped working as she received chemotherapy and her health declined. He continued to experience symptoms of AS, and indeed they interfered with his ability to fulfil these new roles. However, his time and personal resources were now devoted to these new priorities, and he struggled to make time

³⁰ However, other aspects of normalization include the attempts to appear normal to other members of society, which by continuing to work despite his symptoms, he was attempting to achieve.

for medical appointments, or to consider learning more about his condition and how to cope with it.

Finally, when referring to the effect of becoming established on patients' learning, until now I have indicated only that their search for information 'slows or stops'. In fact, patients looking for information at this time of adequate knowledge and stability seem to do so for one specific reason – to *keep up-to-date*. To a degree, this represents a method of verifying the standard of their healthcare – by checking if there are any new developments in treatment which could improve their lives. Some patients have an expectation that their consultant would routinely inform them if there were any such advances (Arev1: 169 not shown), but others describe an occasional internet search 'to see if there is any new stuff ... if there is any new medication' (Anew1.3: 301-303).

Established patients have stopped their rapid search for information about AS, and any continuing education is centred upon verifying their standard of healthcare. Their search has stopped because they have either normalized their AS, do not perceive further education as a useful way of improving their lives, or have altered their priorities in response to new health or social problems which outweigh the disruption caused by their AS. For people who have normalized their AS, becoming established occurs at a time when they consider they have adequate knowledge of AS and how to live with it, have stability within the spheres of health, healthcare and their social lives, and have created their own network of potential solution to problems. In the following section I will consider how this network is put into practice, as I examine the circumstances in which patients' search for information restarts.

5.2.5 Facing New Problems: Re-establishing Oneself

The established stage represents a period of stability, the duration of which is determined by the nature of each individual's disease and social circumstances. If these remain constant and unchanged, there is little practical reason to return to searching for information. However, in the context of a chronic illness, this scenario is unlikely to persist indefinitely, and thus a search for information will restart when patients face new problems. Strauss describes the range of problems they are likely to face, which were also borne out in these interviews:

even when their normalization tactics are working well, various ups and downs of symptoms, new/additional regimens, and the hazards of the trajectory itself, combined with any changes to relevant social contingencies, all potentially threaten whatever arrangements have been established for maintaining a near normal life and social relationships. (Strauss et al., 1984: 79)

I was able to examine this topic using the information diaries newly-diagnosed participants completed between interviews, which detailed the problems and questions they had encountered during this intervening period. These prompts provided the opportunity to trace the route chosen by patients to address these problems, or to attempt to obtain answers to these questions. During the review patient interviews, when these diaries were not used, similar discussions followed my questions about the last occasion patients had a problem related to their AS, or sought information about it. To this extent I tried to focus on real problems they had encountered rather than rely on their responses to hypothetical scenarios (i.e. ‘what would you do *if* this happened?’), which provided interesting data, but which was also more susceptible to bias towards what participants felt they *should* do in these circumstances, rather than what they actually did.

Table 1 illustrates some of the problems and questions described during the interviews with new patients, giving some indication of the range of difficulties encountered, and the practical steps the patients took to resolve them. Unsurprisingly, the resources consulted by patients are those they found useful during their initial search for information – they are employing the network of solutions built until this moment. With each cycle of problem and solution, the network is modified to better reflect their experience of ‘what works for them’. There is a variety of outcomes as well – from rapid, successful solutions in the case of F’s disease flare, to problems that dissipated without complete resolution in the case of T’s query about osteoporosis and L’s lack of physiotherapy appointments. These problems are discounted when presumably more pressing matters, perhaps unrelated to AS, resume priority in their lives.

Table 1: Examples of Problems Faced by Established Patients

Patient	Reference	Summary of Problem	Disruption caused	Resources Used	Notes
S	Anew2.2:40	'me son lives with me now'	'Everything centres on me son'. Lower priority for own health and healthcare, little room in the house	Family members – his brother and son's mother. Social services to apply for new housing	Healthcare appointments need more planning, unable to attend group education
P	Anew4.2:10	'I had a few episodes of iritis'	Symptoms, attending multiple appointments, forced to discuss his health at work	Rang on-call ophthalmology dr himself to discuss his problem	As a GP, he was aware of urgency of situation and referral routes. Was still shocked by difficulty of obtaining treatment
T	Bnew3.2:116	'Have I got brittle bones?'	Concerned because of recent metatarsal fracture	Identified this as a potential problem, but hadn't taken any action.	Didn't think the query was valid because he hadn't read about it elsewhere. Unlikely to resolve this without a further trigger e.g. encountering information by chance or being questioned by an HP
F	Cnew1.2:2	'I had a few weeks when I was in more pain'	Symptoms corresponded with arrival of new baby – difficulty performing paternal tasks	None. Recognised symptoms as a flare of AS. Had already discussed scenario with his consultant and so increased his frequency of treatment.	He checked his actions had been appropriate at his next appointment.
F	Cnew1.2:137	'I wondered if it would be OK for me to donate blood' (in view of medication and HLA-B27)	AS threatened benevolent social role as a regular blood donor	Internet search, booklet, and rang blood donor centre – not resolved.	Frustration at lack of answers despite investment of time and resources
L	Cnew2.2:22	Confusion about physio appointments. They said I was missing them, I hadn't received any	Missed out on planned care, felt that she had been labelled a difficult patient who DNA'd.	Had phoned secretary to explain her perspective.	Not satisfied with response. Was going to discuss with Rheumatologist at next appointment (but then forgot)

During his third interview, F (Cnew1) describes an episode which highlights the limitations of information alone as a solution to patients' problems. Like his earlier problem tabulated

above, F experienced a flare of his AS, on this occasion associated with severe buttock pain which was causing him to struggle to walk. Initially, he performed an internet search for ‘pain relief’ and ‘spondylitis’, and also visited the NASS message board, searching for suggestions (Cnew1.3: 74). He found that the medications that were suggested were ‘anti-inflammatories that can only be given by the GP’ (ibid: 80) or were ‘Americanised’ (80). These treatments therefore required a visit to his GP irrespective of this independent search for information. He then went to his pharmacist, who suggested another medication which was available without prescription³¹, but this proved to be ineffective. Ultimately, despite attempts to solve this problem independently, he still required a GP appointment to obtain effective treatment (in this case Tramadol). Although he knew the names of a number of treatments which may have been effective, this information alone was insufficient without the authority to obtain it, and F recognized that in many ways his renewed search for information had been fruitless. Assuming that each cycle, with the additional experience it brings, alters the resources patients employ in their search for information, he may be less likely to consult these independent sources again in the future.

Other patients were also unsuccessful at translating the information available to answers to their specific questions. When B (Bnew2) discovered his wife was pregnant, he searched on the internet to find out ‘if it was hereditary or not’ (Bnew2.2: 20). He found what he described as ‘good information, but it still didn’t answer my question’ (ibid: 28). Despite an extensive search which revealed that ‘they weren’t sure how ... it [AS] came about’, and that it was linked to ‘a gene in the blood’ (ibid: 30), at the end he felt better informed generally, but still unable to state how likely his unborn child was to develop AS. In this instance, the information wasn’t in a format which answered B’s specific query, and B couldn’t apply what was available to his own circumstances. Again, in order to answer this question adequately, he required additional help, probably from a health professional who could personalise any information, answer specific questions in the detail required, and address any pre-existing misunderstandings.

I will return to these issues again in Chapter 7 when I consider how patients use the internet and other resources to answer questions regarding their health, and how the organisation of information for patients with AS could be improved in relation to its content and delivery

³¹ He was offered Paramol, which is paracetamol and low-dose dihydrocodeine available over-the-counter.

methods. In this section, however, I have described how the search for information about AS restarts when established patients encounter new problems. From a patient's perspectives education at this stage is no longer about gaining a broad understanding of the condition, but is instead aimed at finding solutions to their own specific problems. These vary considerably in their gravity, from potentially life-threatening problems to less significant examples which are resolved by the patient shifting their priorities rather than finding a solution. Similarly, patients vary in the choices they make about how to attempt to resolve their problems, predominantly based on their access to and previous experience of a range of different resources – their developing *network of solutions*. Thus different patients will draw on different resources to solve the same problems. For example, one may seek advice on the internet, one will see their GP, another may arrange to see a physiotherapist, whilst another will phone their consultant's secretary, or ask a friend or family member they consider has particular expertise in that area. For many problems though, information needs to lead to *practical help*, such as physiotherapy treatment, the prescription of a drug, or perhaps the provision of disability benefits, and this may limit the utility of particular resources if used in isolation. Whatever the problem, once it has been resolved, or *normalized* in the appropriate circumstances, patients will once again be established, and their need for more information decline once again.

5.3 Conclusions

Within the field of patient education there has been a continuing struggle to identify what information should be offered to which patients, at what time. This reflects the uncertainty, which has been largely overlooked, about which resources *patients* themselves consider to be useful, and which they *choose* to use. So far, attempts to address this problem have used needs assessment methods to determine the information patients would like to receive, or considered ideas such as Lichtenthal's 'readiness to learn' checklist (from Bastable, 2006) or Prochaska and Diclemente's 'Transtheoretical (stages of change) model' (1998). These latter examples suggest explanations why certain patients are not receptive to education at certain times, but overall have considerable limitations in their application to this topic.

Bastable offers a list of considerations to practitioners deciding whether an individual is 'ready to learn', using the acronym 'PEEK' (physical, emotional, experiential and knowledge factors). It remains unclear how a practitioner could practically and reliably gather the answers to this extensive list in an interview, how they would subsequently apply the set of disparate information to the provision of education, and whether it would improve the experience for the individual patient or the practitioner themselves.

Additionally, such information dealing with the assessment of the optimum timing for education for *individuals*, and which does not elucidate the needs of populations, is of only limited use when designing educational resources.

The 'stages of change' model was originally used in the field of psychotherapy and alcohol addiction to target interventions at those who are most likely to change their behaviour. Patients are considered to be within either pre-contemplation, contemplation, preparation, action, or maintenance phases with respect to changing specific behaviours. The model has also been applied to the uptake and effect of arthritis education (Keefe et al., 2000). Self-completed questionnaires are used to determine which stage patients are in, and interventions can be devised and applied for each stage. Its particular relevance to patient education depends upon the precise aim and nature of the resource – if its aim goes beyond 'behaviour change' then it would seem to be unhelpful. Additionally, Bunton et al (2000) have summarized a number of concerns about the internal and external validity of the stages of change model, challenging its widespread adoption as a tool to explain and predict behaviour.

This chapter presents a model which describes the relationship between patients' health, healthcare and social lives and the information they would like, need and practically use. Fundamentally, it reflects the practicalities of how - and to some extent why - patients use and interact with educational resources, including health professionals themselves. By conducting repeated interviews with patients over their first year with the condition, I was able to describe patients' experiences and opinions with reasonable proximity, avoiding as far as possible the danger that events and emotions would be coloured by long lapses of time, as well as documenting changes over time. Verifying the model with purposively recruited review patients broadened the external validity of the model, providing opportunities to test the model on more diverse populations. Nonetheless, it requires testing on a larger, geographically and ethnically diverse sample of patients. Its application to people with other chronic illnesses, despite a degree of face validity, also remains an empirical question.

In some aspects, our model also reflects, extends and corroborates the work of others who have studied chronic illnesses. Bury (1982) for example, when conceptualising chronic illness as biographical disruption, describes the challenges patients face when they initially develop symptoms of a disease, notably recognising the significance of their symptoms, and deciding how to present themselves to family and friends, and later, to medical care. He sees medical diagnosis as the culmination of this phase, which resembles the 'pre-diagnosis' stage of our model. Using the data from the interviews, we have been able to describe not only the range of practical responses to this situation, but also begun to explore why AS patients find it difficult to access information at this stage, and why they can feel so unprepared for the diagnosis when they receive it.

Similarly, as I discussed in section 5.2.4.1, Strauss's 'normalization' model (Strauss et al., 1984) reflects the experiences of a subset of patients described as established using this model. He also describes the process of 'renormalization' in the face of 'routine disruption', indicating that this reflects patients 'lowering expectations and developing a new set of norms' (ibid: 94). Our data on 'facing new problems' suggests an additional, more positive outcome, where AS patients avoid the shrinking physical and social role suggested by Strauss.

Using these two concepts as examples, I would argue that the Established Patient Model reflects important existing work related to patients' experiences of chronic illness. Like that work, it only focuses on the experiences and needs of patients themselves rather than of the family and carers surrounding them. However, given its emphasis on education, it provides a different (and complementary) understanding of patients' practical responses to their circumstances. It also facilitates a structured assessment of the resources available to them, to enable us to begin to explore ways to improve the experience of patients with AS. It enables the design and organisation of resources for patients to be considered, taking into account how they could be made available or promoted to different 'stages', and whether each stage is adequately catered for. It reaches beyond simply asking what patients 'want', acknowledging that such accounts may not be a comprehensive reflection of the information they may find useful, and are likely to be influenced considerably by the framing of such questions. It utilises the sort of information about patients that health professionals already know or routinely ask – such as whether there have been significant changes in their health or healthcare or social life - to help make sense of the education they may be seeking, rather than relying on separate psychological assessments of uncertain relevance.

In this chapter I have sought to describe patients' perspectives of learning about and adapting to a diagnosis of ankylosing spondylitis, and its ongoing effects on their lives. Patients' decisions to search for information, and the methods they employ, are primarily determined by their current circumstances, and subsequently by their previous experiences of searching for information. The content of the information they seek, and their broad aims for education, are described in relation to whether they are pre-diagnosis, diagnosed, established or facing a new problem according to the Established Patient Model, and again in relation to their current circumstances. Patients' inclination to learn more about their condition does not remain constant, and for significant periods of time - when they are established – this assumes minimal priority within their life. In the following results chapters I will relate these findings to the other aspects of this study: examining how far professionals' perspectives of education correspond to patients' perspectives, whether current practice in this area reflects the reality of how patients learn described here, and what improvements to the delivery and organisation of education for this group could be adopted.

Chapter 6 – Professionals’ Perspectives and Current Practice

6.1 Introduction

The Established Patient Model outlined in Chapter 5 was developed through the analysis of interviews with people with ankylosing spondylitis. Naturally, in view of the sources employed in constructing the model, it describes the process of learning about ankylosing spondylitis from the patients' perspective. While it acknowledges the critical role of health professionals at several stages in the process, it fails to provide a detailed examination of the process from their particular perspective. Many health professionals³² within rheumatology will have considerable experience of consultations with people with AS, understanding the problems patients frequently describe with respect to their AS, and the methods of education which may be most successful. Potentially, they may also have developed a particular interest in education for patients, or have received training regarding this aspect of their work. However, even for those health professionals with a particular interest in this area, education for people with AS will remain one of a number of roles, taking place within the structure provided by the organisation in which they work.

This chapter provides an overview of education for people with AS from the perspective of health professionals, who not only provide much of this education, but may also influence the other resources patients use through their recommendation and referral. It considers the extent to which the literature pertaining to this topic - as discussed in Chapter 3 - appears to influence or reflect the routine practice of health professionals, as well as their aims and priorities in delivering education, and the challenges they face in this process. Health professionals' perspectives provide an account of current practice which can be compared to patients' accounts of what they want and need, and also valuable opinions about how the process can be successfully and practically improved. Finally, considering the critical role they play in the education and overall care of patients with AS, an understanding of health professionals' views and experiences is essential if any changes or new resources in this area are to be implemented.

The data presented in this chapter are the results of Phase III of the study: the focus groups I carried out with Consultant Rheumatologists and Rheumatology Allied Health

³² When I use the term 'health professional' I include doctors, nurses, physiotherapists, pharmacists, occupational therapists, dieticians, psychologists and other similar health-related professions. I specify this here because the phrase is sometimes used interchangeably with '*allied* health professionals' elsewhere. I would consider this latter term to include those professions *allied* to medicine - that is the above list of professionals, but excluding doctors. I have used these two related terms in this way throughout the thesis.

Professionals, and the subsequent survey of BSR (British Society for Rheumatology) Consultant members and BHPR (British Health Professionals in Rheumatology) members. The related methodology is described in detail in Chapter 4, and a copy of the BSR/BHPR survey is included as Appendix VII.

Each section of this chapter addresses a theme which arose during the focus groups, and which I returned to when designing the specific questions for the survey. In this respect the chapter offers a combination of qualitative and quantitative data; the focus groups were used to identify and explore the important topics, while the survey determined the variety of opinion and experience related to these topics, and widened the geographical scope of the project beyond the North-East of England.

6.2 Participants

The focus group participants are described in Table 2 and Table 3. All the participants had contact with patients with AS as part of their professional role. The Allied Health Professional (AHP) Group members each worked within or alongside their respective secondary-care rheumatology departments, and had experience of delivering group or one-to-one education to AS patients. A total of fourteen AHPs were approached to take part; initially, eight invitations were made by email, and sequential invitations were made in response to negative replies to ensure an appropriate number ultimately attended. A Rheumatology Pharmacist from Centre C was unable to attend at short notice and instead provided an annotated topic guide. Similarly, twelve consultants in total were invited to attend their focus group, but five were unable to attend because of other commitments.

Table 2: Allied Health Professional Focus Group Participants

Code	Profession	Centre	Gender
SpN1	Specialist Nurse	A	F
SpN2	Specialist Nurse	A	F
SpN3	Specialist Nurse	B	F
Physio1	Physiotherapist	B	F
Physio2	Physiotherapist	B	F
Physio3	Physiotherapist	A	F
OT	Occupational Therapist	A	F

Table 3: Consultant Rheumatologist Focus Group Participants

Code	Centre	Gender
AB	A	M
CD	A	M
EF	C	F
GH	A	M
IJ	B	M
KL	C	F
MN	A	F

Table 4 describes the characteristics of the survey respondents. The response rate of 40% is at the upper end expected for similar surveys (Hill, 2008). It is likely to reflect the relatively low response rates expected from health professionals, but also our inability to target reminders due to Data Protection Act (1998) issues³³, and the fact that both organisations include members who are either retired or do not see patients with AS. The denominator for the response rate may also have been increased by members working at more than one hospital, thus some people were sent multiple copies of the questionnaire. Equally, some Consultant Rheumatologists are members of both BSR and BHPR, and therefore will have received two copies of the survey, presumably returning only one. Despite these limitations, these two organisations provided the best opportunity to access and survey the professionals involved and interested in our topic.

While the geographical spread reflects the membership of both the BSR and the BHPR (see Figure 9), the response rates of the separate professions within the BHPR survey reflects their relative interest in the topic area. The organisation has a total of 100 members who are physiotherapists, from which 67 replies were received. This response rate of 67% compares to 38% for nurses (102/269), and 39% for occupational therapists (OTs) (18/46), suggesting that more physiotherapists found the topic area relevant to their professional role, and in turn indicates their central role in this area.

³³ The databases containing the names and addresses for both surveys were held by the British Society for Rheumatology, and were not passed to us because of their duty to protect this data. We were therefore unable to identify non-responders in order to direct reminders and improve the response rate.

Figure 9: Survey Response by Geographical Region

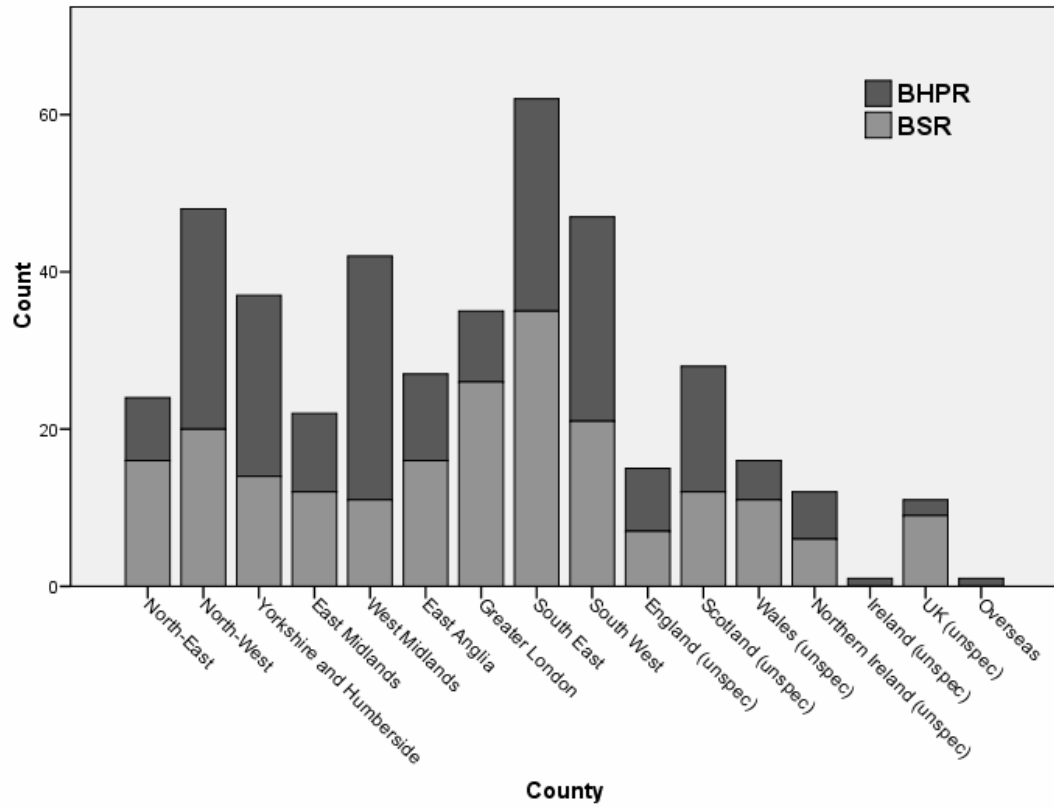


Table 4: Characteristics of Survey Respondents

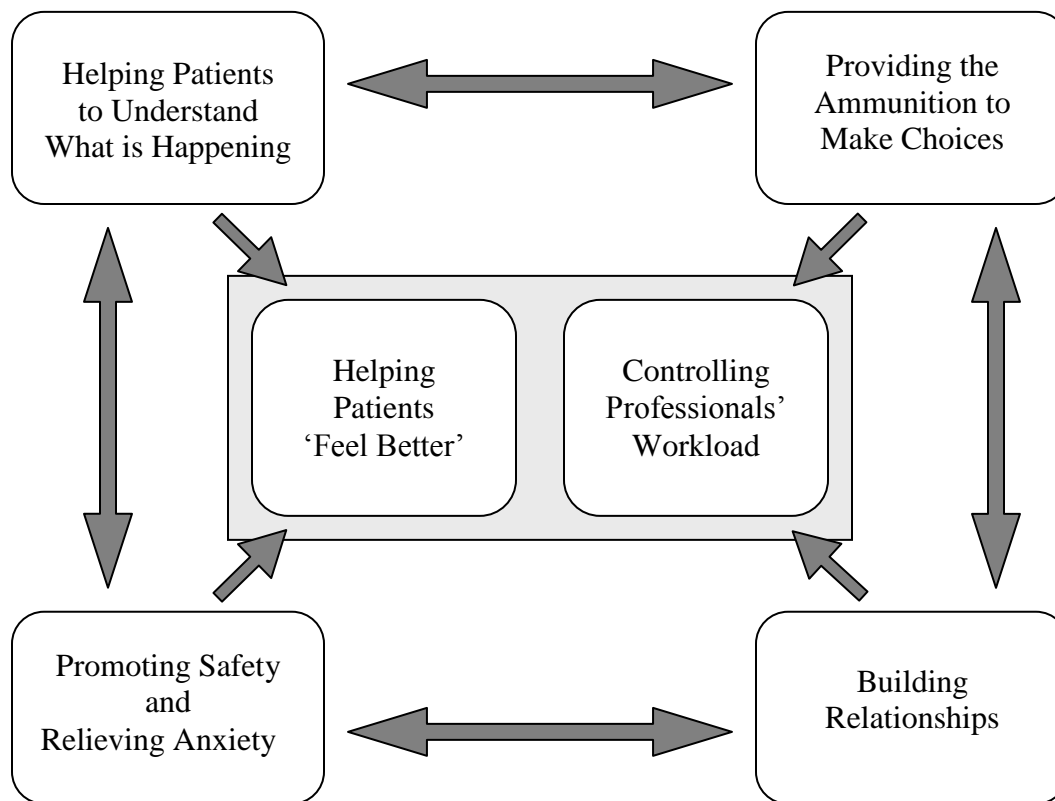
	BSR (Consultants)	BHPR (Health Professionals)
Response Rate (Total 443 / 1107 = 40%)	222 / 571 = 39%	221 / 536 = 41%
Professional Role (% of total responses)	Consultant Rheumatologist 222 (50%)	Nursing 102 (23%) Physiotherapy 67 (15%) Occupational Therapy 18 (4%) Podiatry 24 (5%) Medical 4 (1%) Psychology 2 (0.5%) Dietician 1 (0.2%) Incomplete 3 (0.7%)
Type and Place of Work (% of Consultants and Health Professionals, respectively)	Clinical 179 (81%) Academic 4 (2%) Both Clinical and Academic 33 (15%) Missing 6 (3%)	Clinical - Hospital 162 (73%) Clinical - Community 25 (11%) Academic 17 (8%) Both Clinical and Academic 14 (6%) Missing 3 (1%)
Involved in AS Education (% of Consultants and Health Professionals, respectively)	Yes 70 (32%) No 146 (66%) Missing 6 (3%)	Yes 106 (48%) No 111 (50%) Missing 4 (2%)
AS Caseload (Patients per week)	Median 2.5 Minimum 0 Maximum 15	Median 1.5 Minimum 0 Maximum 25

6.3 Aims and Functions of Education

In Chapter 3, I highlighted the difficulty in appraising educational studies with respect to their efficacy in the absence of clearly defined, universal aims for patient education. The range of ‘positive’ outcomes for such studies includes increased knowledge about their condition, changes in psychological measures, changes in behaviour and societal economic benefits. The focus groups explored this complex theme by asking participants what they considered were the *aims* of education in the context of ankylosing spondylitis, and how they thought the patients they encountered had *benefited* from patient education. When analyzing the transcripts we were also able to identify further *functions* or ‘work’ that education performs in practice, which although not necessarily expressed explicitly by the participants, instead emerged when reflecting on what was said. These functions are important products of education, but may not be recognised by more superficial evaluation of the process.

In this section, therefore, I will describe the potential benefits of education for people with AS, from the perspective of the health professionals who deliver and organise their education. We have also identified the ‘work’ patient education does for health professionals, an aspect which has not previously been examined. This analysis is based on only two focus groups, and we have not had the opportunity to verify these findings with further qualitative interviews in the same way as the patient data described in Chapter 5. Accordingly, Figure 10 is included here not as a substantive or definitive theory, but primarily as an overview of how these functions of education appeared to inter-relate during these specific focus groups. The central functions of education were two-fold – firstly to help patients ‘feel better’ physically and emotionally (Consultants Group: 518 – see Excerpt 2), and secondly to control the workload of health professionals, which in the absence of patient education would potentially spiral out of control. These central functions were achieved via the four peripheral functions in the diagram, which I shall examine in turn.

Figure 10: Aims and Functions of Patient Education – Health Professionals’ Perspectives



Excerpt 1 illustrates the benefits for patients from education stated by the participants of the AHP Group in response to my initial question:

Excerpt 1: Allied Health Professionals Focus Group

163 I Can we just sort of talk generally about what we think that patients should be getting, what benefits they get from education, just in general terms?

164 SpN2 I think education has got a number of roles and the main one is for, to help them understand their disease and what is happening to them and also the fact that a vital role is to help them manage their disease.

165 I Right

166 SpN2 Whether that is through medication or sort of non-pharmaceutical type of intervention, em and be that from advice from members of the allied health professional team like physio/OT.

167 SpN3 You are offering that level of support at the same time though aren't you because you are getting the education as a blanket kind of education thing but the undercurrent is the support.

168 SpN2 Yes

169 SpN3 And that is what they come back for. You know they don't come back and say 'Can I have some education?', they come back for the

support and it is part and parcel of the same thing. I think if they don't get the education they don't get the support.

170 GENERAL YEAH

SpN2's reply is that education's main role is to help patients to '*understand* their disease and what is happening to them' (14 – my emphasis). While the phrase is not fully explained in this setting, I think she is conveying a very broad sense of the term 'understand', which was actually discussed more thoroughly within the NASS Focus Group (not shown). The specific aspects of *understanding* AS which arose during the patients' discussion were the recognition of symptoms as related or unrelated to AS, a level of understanding of the pathophysiology of AS which offers an explanation of symptoms and treatment with face validity for patients, and an understanding of prognosis in order to facilitate some planning for the future.

Similarly, the initial response to a question about the aims of patient education from the Consultants' Group is shown in Excerpt 2:

Excerpt 2: Consultants' Focus Group

- 518 AB Well you are trying to give patients information so that they can handle their disease more logically, more appropriately and feel better for it.
- 519 MN Know when to contact us.
- 520 IJ Yes.
- 521 Tim So how would ... what would the aims be? Is it changing behaviour, is it changing disease ... is it changing psychosocial issues what is it or is it all of the above and more?
- 522 AB As far as drugs is concerned, it is about safety. Giving them enough information so they can take those drugs safely and appropriately. I mean as far as their behaviour is concerned I think they all behave so differently I think it is about having giving them enough information to encourage them in the right direction. Preferably they know where they can get more information from or how they can get back to you.
- 523 GH At least you are pointing them in the right direction. All you can do is offer advice and em get the message over that the right thing to do is be physically active but if they don't want to do that there is nothing you can sa ... you know you just sort of ... personally I shrug my shoulders and say you know clearly they are not going to do that and you just manage the best you can.

In this example, AB states that information is given to patients to help them ‘handle their disease more *logically*, more *appropriately*’ (518 – my emphasis), echoing the comments of SpN2 in Excerpt 1 who uses the term ‘manage’ (14) in place of ‘handle’. Again, the precise components of patients ‘managing their disease’ are not elucidated, but the concept returns to the arguments I outlined in Chapter 2 regarding the limitations of lay expertise. Health professionals consider ‘managing’ a condition would include making decisions about the most appropriate investigations to carry out, and choosing the optimum treatment; such decisions would be beyond the knowledge and expertise of those patients who have not had medical training. Instead, it seems that health professionals recognise a separate concept of ‘managing ill-health’ which does not require medical training, but which can and should be influenced by education. Additionally, by using the terms ‘more logically’ and ‘more appropriately’ (518) to describe the changes which education should bring about, AB is suggesting that education is used by health professionals to influence the way patients think about their AS – to align patients’ aims and knowledge more closely to their own, or at least ‘to encourage them in the right direction’ (522). These issues relate to the comparison between a *logical* medical understanding of a condition, and potentially *erroneous* lay health beliefs which I also explored in Chapter 2 (see section 2.2.3). While this process of alignment is beneficent – the health professionals believe they are acting in their patients’ best interests – the underlying sentiment is that patients need guidance from health professionals in order to make ‘correct’ decisions about their health. Excerpt 3 shows more of the characteristics of this guidance, which I have referred to as ‘Providing the Ammunition to Make Choices’ in Figure 10:

Excerpt 3: Consultant’s Focus Group

546 CD Sometimes the trouble ... sometimes we are a bit dishonest aren't we. I mean if you think for this patient the right drug is methotrexate because they are starting to sort of 'rot' the peripheral joints and the patient is extremely anxious about side-effects you will probably sell the drug and down-play the side-effects because you think that is right for the patient. So sometimes we do sort of ... we are economical with the truth sometimes aren't we?

.....

550 AB But that is also good medicine because you are actually personalising it for them. You are doing an individual risk benefit analysis in your head and of course there will still be patients like that that you can't persuade to take it even though you really think they should.

- 551 CD Yes.
- 552 GH Absolutely.
- 553 KL I think it is all about as well allow ... giving patients the ammunition or the knowledge to make choices for themselves.
- 554 AB Yes, to have enough to be involved in their own management.
- 555 KL Yep.
- 556 AB And make the decisions that need ... need making.

Here, the Consultants are describing how they change the emphasis of the information they provide in order to increase the likelihood of the patient making the ‘correct’ decision, in this instance regarding starting a disease-modifying drug like methotrexate. Many patients are reluctant to take this medication, which is often effective but also potentially toxic. This reluctance can be exacerbated rather than relieved by the provision of more information, which can focus on the relatively rare but severe side-effects of such treatments. The Consultants’ approach may be employed because they believe that the patient can never *fully* understand the relative risks and benefits of the drugs, and perhaps as a short-cut because they don’t have the time necessary to fully explain the risks and benefits of taking it. Thus ‘giving patients the ammunition to make choices’ as a function of education reflects a careful, beneficent presentation of information which can lead patients towards a particular decision. The *ammunition* (Consultants’ Group: 553) is therefore information which leads to patients making decisions more aligned to professionals’ rather than the patient’s pre-existing understanding of AS.

So far in this section I have discussed how education can, from the perspective of health professionals, be used to increase patients’ understanding of AS, and to inform, but perhaps more subtly *influence* the decisions patients make about their health. I will now explain the third and fourth functions of education referred to in Figure 10 – notably how it can be used to build relationships and relieve anxiety.

In Excerpt 1, SpN3 suggests that patients appreciate ‘the support’ provided by education most highly (AHP Group: 17-20). In the case of group education this is from the other patients who attend - ‘support for each other’ (AHP: 22) – but there is also substantial support from the health professionals who deliver education (AHP: 31 – not shown). When asked to expand on the meaning of support in this context, similarities begin to emerge

between health professionals' concept of support and the concept of patients building a network of solutions described in the 'diagnosed' stage of the Established Patient Model. Education introduces patients to other members of the rheumatology multidisciplinary team, perhaps most importantly providing 'a face and a name and a contact' (AHP: 31 - not shown) which they could return to if they encounter new problems in the future. By offering education, these health professionals felt that they increased patients' awareness of both their role as health professionals, and more specifically, the services they offered. At a personal level, through meeting them and demonstrating their expertise, they felt that they increased patients' confidence in their ability to help them, and increased the likelihood they would return to them for help in the future.

Returning to Excerpt 2, AB's initial comments about the aims of patient education refer to the importance of ensuring that patients take their medications 'safely and appropriately' (Consultants: 522). As I mentioned earlier, drugs such as methotrexate and anti-TNFs, can have severe and potentially fatal adverse effects, and therefore there is considerable focus on teaching patients how to take these drugs, how to prevent and recognise these adverse effects, and the appropriate action to take if they actually occur. This information provision not only serves to promote patient safety in attempting to reduce the risk of these adverse events occurring, but also appears to have an additional function for health professionals:

Excerpt 4: Consultants' Group

539 KL I think if you take it on a very cynical point of view, patient education is about us covering our backs as well. So that you know if something does go wrong we have got some kind of proof to say 'well we did actually tell you that that might happen'.

540 CD That is certainly true of the drugs isn't it.

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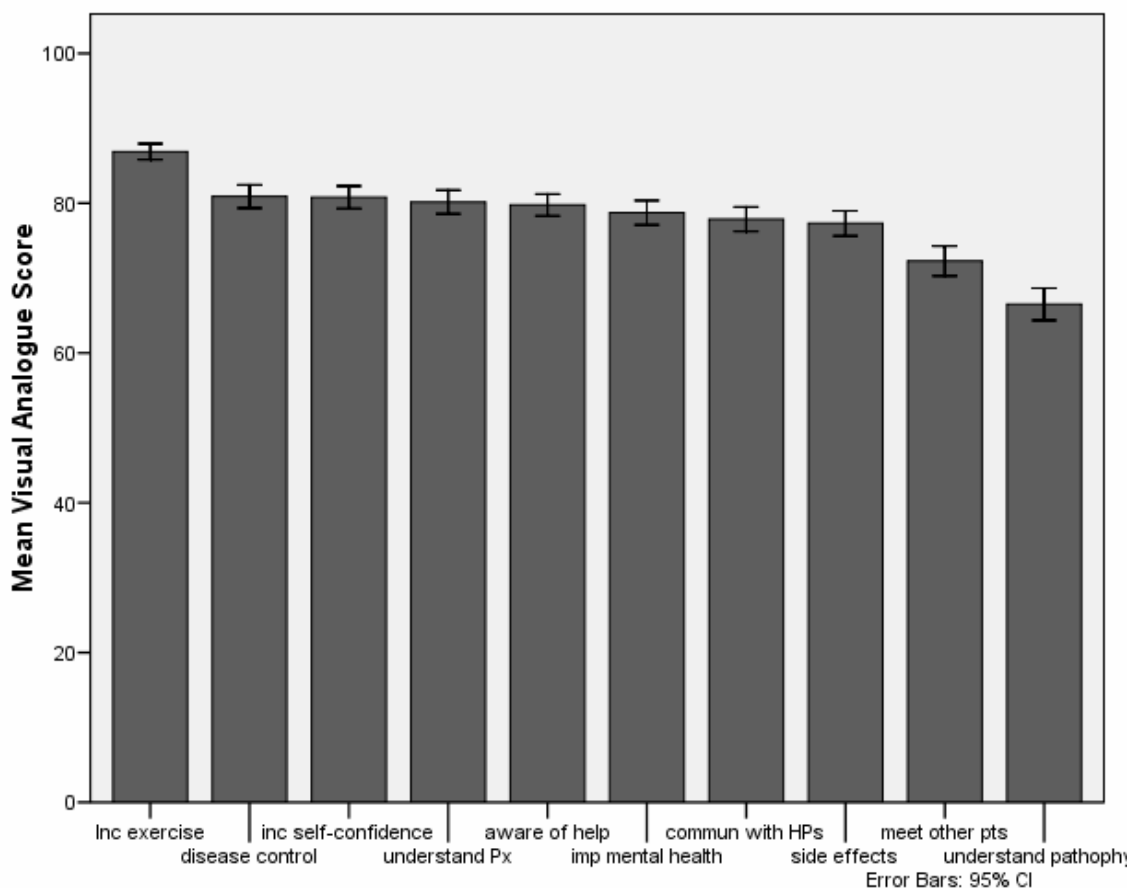
In this excerpt, KL recognizes that health professionals want to know that they have made sufficient attempts to prevent iatrogenic illness, and also that they are protected from litigation in the event that an adverse event occurs, on the basis that the patient was advised of the potential effects and therefore had made an informed choice to receive the treatment. In this respect, education relieves the anxiety not only of patients, but also of the health professionals caring for them. The former were described as being reassured through a better understanding of what is happening to them (AHP: 72-76 – not shown), while for the

latter education serves to reduce the likelihood of adverse events occurring due to prescribed drugs, and also the likelihood they will experience litigation if such events occur.

I have now briefly described the four peripheral functions of education displayed in Figure 10, and given examples from the focus groups. There is some overlap and interaction between the functions, illustrated by the two-directional arrows in the diagram. For example, explaining the process of spinal fusion or ‘ankylosis’ to patients with AS will help to explain the associated pain, stiffness and restricted movement, but equally it provides the ammunition to choose to exercise and adhere to medication regimes in order to prevent ankylosis occurring. Equally, building trusting therapeutic relationships between patients and members of the rheumatology team is likely to further influence the decisions patients make, and the extent to which they follow the advice they receive. However, the core aims of education to which these four functions contribute towards are firstly to help patients feel better – in a broad sense which incorporates long term physical and emotional health – and also to control the workload of health professionals. This second core aim is typified by the comment that education aims to help patients ‘know when to contact us’ (Consultants’ Group: 519, Excerpt 2). It recognizes the limited resources which are available to health professionals, notably their time, and includes areas of education which promote reduced consultation rates, and time efficient methods of delivering information such as group education or web based resources. I shall return to the topic of limited resources in section 6.5.

The aims of education were also addressed in the survey, by asking respondents to rate potential aims using a visual analogue scale with extremes of ‘not at all important’ (0mm) and ‘very important’ (10mm) (see Appendix VII, Question 3.1). The statements were devised from outcome measures used by existing trials of educational interventions and from the initial analysis of the focus groups. The survey did not seek to validate the model as shown in Figure 10, because this was the product of further analysis which I completed at a later date. The results of this survey question are shown in Figure 11.

Figure 11: Aims of Education – Mean Visual Analogue Score of Importance by Rheumatology Consultants and Rheumatology Health Professionals



Thus health professionals rated ‘increasing the frequency of exercise’ as the most important aim of education for people with AS ($p < 0.0005$, Wilcoxon Signed Ranks Test), and ‘increasing the understanding of the pathophysiology of AS’ as the least important ($p < 0.0005$). It is interesting to compare these results with those of patients completing the same survey, as there may be some important differences. For example, patients may not associate education with exercise in the same way as it appears health professionals do – it may be factors other than education which are more important in influencing whether or not they carry out an exercise routine (see section 7.2.5). Equally, health professionals appear to rate understanding the pathophysiology of AS as less important, while patients themselves find such information useful in order to obtain valid explanations of what is happening to their bodies.

In summary, the focus groups revealed professionals’ perspectives regarding the aims of patient education for patients, but also the functions it performs for health professionals

themselves. These functions reflect the reasons why health professionals deliver education, and encourage their patients to learn more about their condition, but are not necessarily the same aims as patients. In the subsequent section, I will address the range of educational resources provided or recommended by health professionals for their patients.

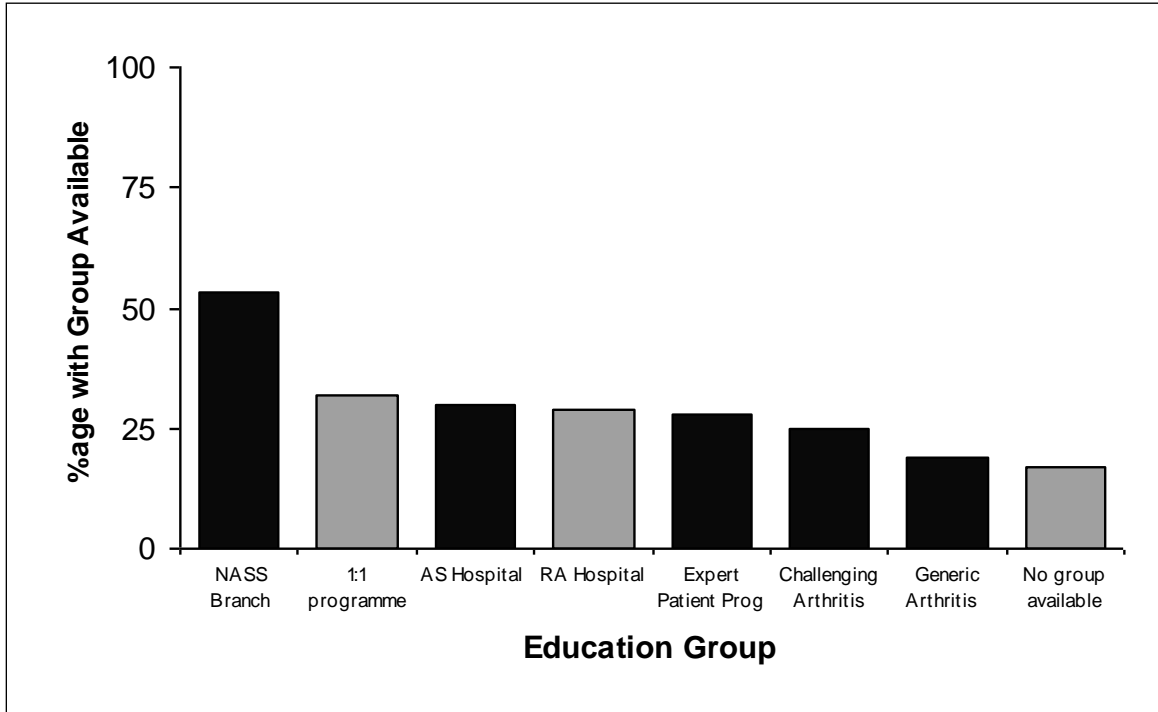
6.4 The Provision and Availability of Education

The interviews and focus groups with patients and professionals in the North-East of England revealed significant variability in the provision of educational resources. For instance, one rheumatology department offered a group education programme to all newly-diagnosed patients with AS, another had links with a local NASS group, and the organisation of physiotherapy services also differed between departments and was discussed during the AHP focus group (295–341 – not shown)³⁴. In response to the variation in services evident within this region, the survey sought to determine how far this variation was apparent across the UK, and learn more about the factors which influenced the availability of education to people with AS. This would be useful when considering how far the findings from the remainder of the project were applicable to the rest of the UK, providing information about current practice which would be essential if we were to suggest changes, while perhaps also highlighting examples of good practice.

Figure 12 shows the percentage of respondents who reported that the patients attending their service could access the specified educational groups (Q2.1 Appendix VII). Data for one-to-one education programmes and for rheumatoid arthritis (RA) groups are included as comparators; their data is in pale grey:

³⁴ Two physiotherapists, both of whom offered patients the opportunity to attend an annual review clinic, discussed their services. While one physio reported that no patients actually took them up on this offer, the other reported that patients appreciated and used this service. The apparent differences between the two services were the continuity of professionals in the unit with higher attendance, and the physiotherapy input into an initial group education programme.

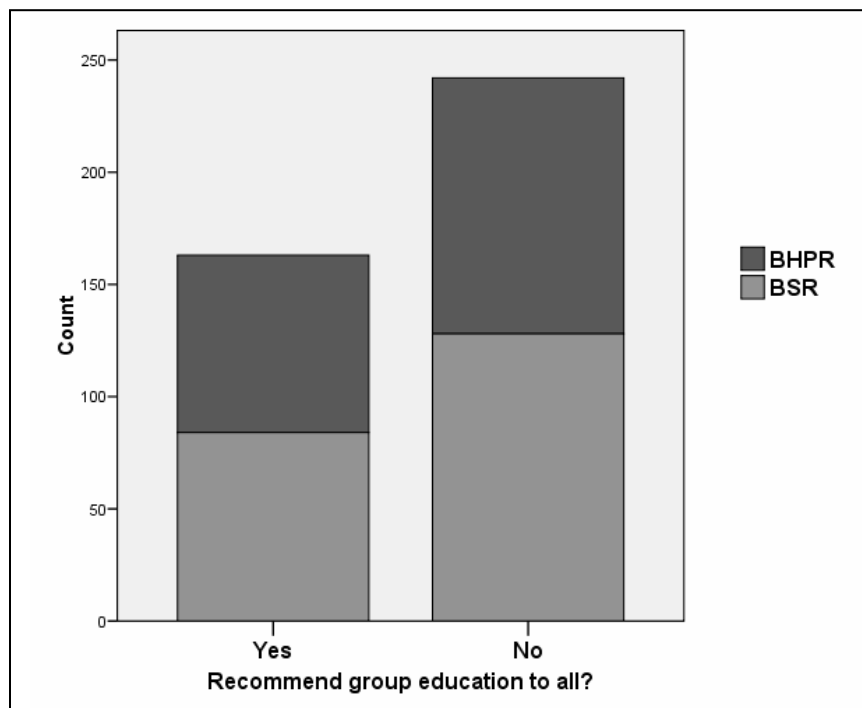
Figure 12: Availability of Group Education for Patients Attending the Service of Respondents



More than half of respondents ($225/422 = 53.3\%$) reported that their patients could attend a NASS group, although comments elsewhere in the survey indicated that this figure included groups where patients would have to travel significant distances in order to attend. 30% of respondents had a specific AS group organised by their own hospital team; a similar number reported RA groups. One-to-one education programmes were available to 32%, although we didn't find out the length and format of these programmes. 16% reported that there was no education group which their patients could attend.

Figure 13 shows that group education is not recommended to all patients with AS:

Figure 13: Numbers of Rheumatology Health Professionals who Recommend Group Education to All Patients with AS

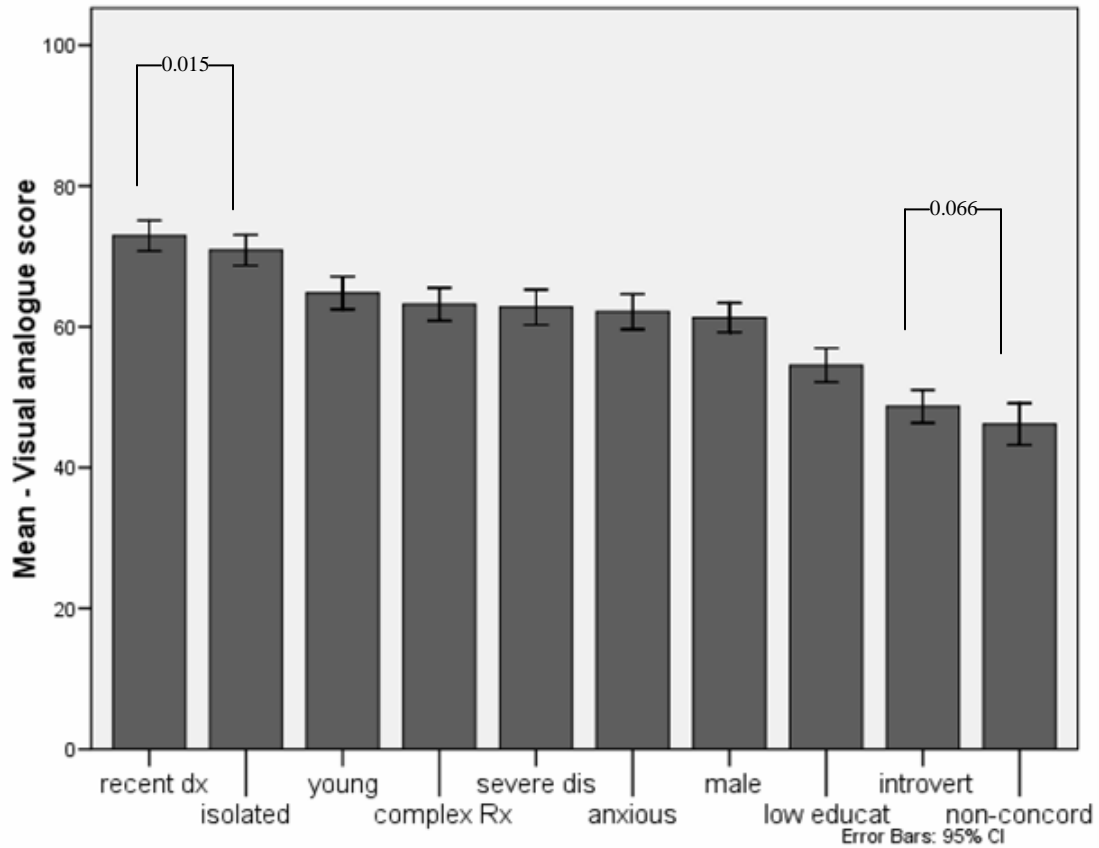


Free text comments were invited to allow respondents to explain their answer to this question (see Q2.3, Appendix VII). Those health professionals who made universal recommendations commented on the benefits of group education, for example ‘promotes exercise’, ‘support’, and ‘better adherence’. Where comments were made to explain a negative answer to this question, these usually referred to lack of local availability (64 of 123 comments to explain an answer ‘No’). 34 / 123 comments referred to *offering* education, but falling short of recommending it if the patient was unwilling to attend. 10 respondents (6 consultants, 4 AHPs) indicated that it was not their role to recommend group education, and that it was dealt with by other members of the multidisciplinary team. 11 comments reported that they made recommendations based on an individual assessment of the patient, using judgements, for example, about patients’ duration and severity of disease, their coping strategies, and the impact of AS on the rest of their lives.

Q2.4 of the survey asked participants to rate how likely patients with certain characteristics were to benefit from group education, using another 10cm visual analogue scale, ranging from ‘not at all likely’ to ‘very likely’. This question sought to address health professionals’ beliefs and experience around which patients were most suited to group

education, and thus which patients this should be recommended to, and perhaps discovering any existing consensus. The results are presented in Figure 14:

Figure 14: Likelihood of Benefiting From Group Education - Mean Visual Analogue Scores by Rheumatology Health Professionals



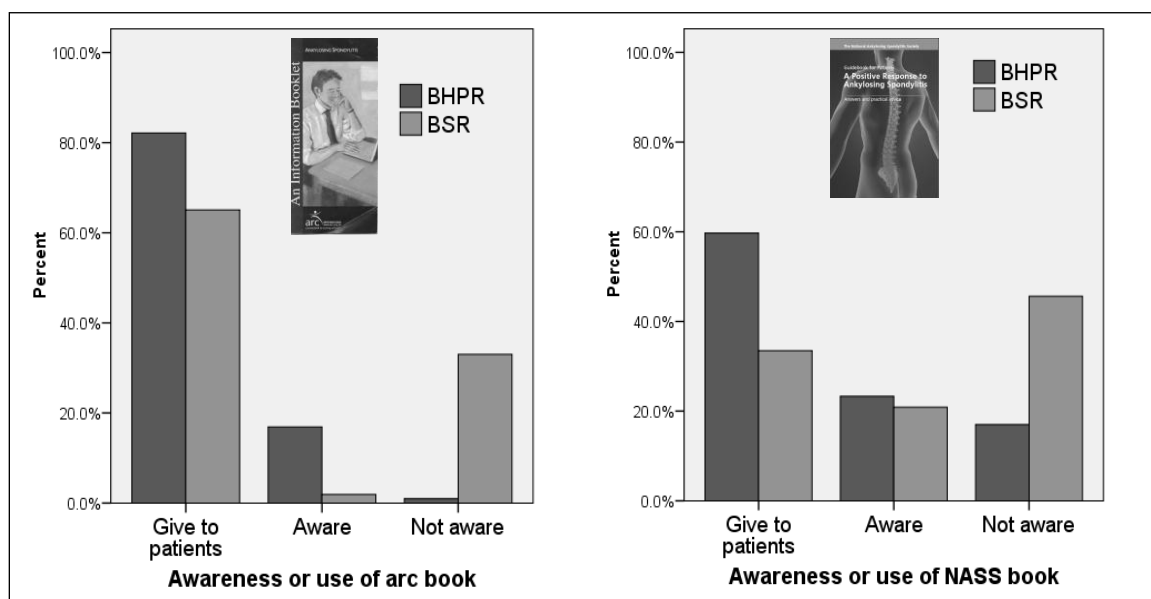
Those patients with a recent diagnosis of AS were judged most likely to benefit from group education ($p = 0.015$, Wilcoxon Signed Rank, see Figure 14), while those patients who were ‘not concordant with treatment, including exercise’ were thought to be least likely to benefit. It is difficult to deduce the extent to which respondents considered whether patients would actually attend the group education programme when considering whether individuals would benefit – the particularly low scores for non-concordant and introverted patients, and those with low educational achievements may be due to a combination of perceived poor attendance *and* poor outcomes for those that actually attend. These patients, who in fact may be those that are most in need of education, are considered those least likely to benefit.

Information leaflets about AS are produced by both Arthritis Research UK and NASS and were easily recognised by participants in both the AHP and Consultants’ focus groups.

There was little distinction made between the two leaflets in terms of usefulness, although one consultant voiced the view that the NASS one ‘is actually better ... it has a bit more information in it’ (Consultants’ Group: 144 – not shown). Instead, it was the availability of the booklets which determined which were given to patients: ‘the arc ones are the ones in the cupboard, so I give that out.’ (Consultants’ Group: 195 – not shown). There was, however, significant uncertainty about *how* patients used them, and whether they were actually read: ‘I can’t remember anyone commenting on the ankylosing spondylitis one ... so we don’t know what they do with them’ (Consultants’ Group: 209-211 – not shown).

Figure 15 represents the results from Q2.6, illustrating the use and awareness of the respective information leaflets amongst respondents. In addition to the data shown here, 18% also reported giving patients written information which had been produced locally.

Figure 15: Awareness and Provision by Rheumatology Health Professionals of the arc and NASS Information Booklets about AS

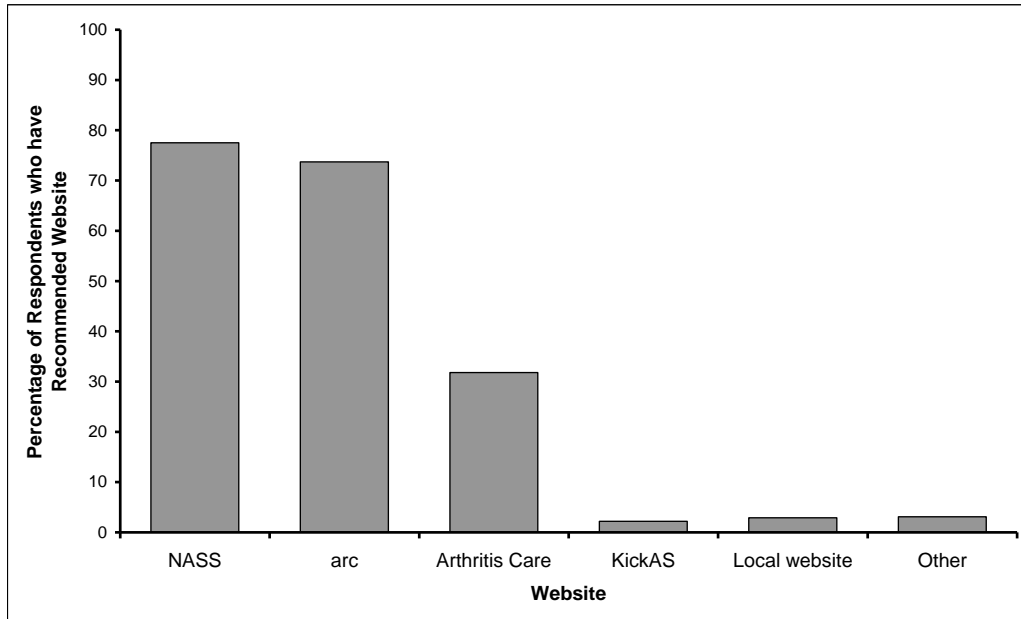


A significant proportion of respondents were not aware of the booklets, and this was more common amongst the Consultants than the other health professionals: 68 Consultants unaware versus 2 AHPs for the arc booklet ($p < 0.0001$, Fisher’s exact test) and 94 versus 35 for the NASS booklet ($p < 0.0001$, Fisher’s exact test). There were no significant regional differences in the use of the leaflets, and it is not clear if those patients who

attended the practitioners who were ‘not aware’ of the leaflets were in fact able to obtain them from another member of the rheumatology team.

54% (225 / 414) of respondents *routinely* gave patients advice about using the internet, while 12% (48 / 414) had not given advice on this topic. Figure 16 displays the websites that respondents had previously recommended to patients:

Figure 16: Websites Recommended to Patients with AS by Rheumatology Health Professionals



The arc and NASS websites had each been recommended by approximately three-quarters of respondents. The most popular message-board website, KickAS.com, had only been recommended by 2% (9 / 418).

In this section I have outlined some of the variability in education offered to patients with AS across the UK. Group education, despite the relative frequency of trials to examine its effect, is not universally available to patients with AS. Where it is available, it is most frequently provided by NASS rather than through NHS organisations such as hospital departments or primary care trusts. Along with other key educational resources such as information booklets and websites, there is a reliance on charitable organisations like NASS and Arthritis Research UK to provide patient education. While 30% of respondents reported that their patients could attend a hospital-based group, this is likely to be an overestimation of the figure for the UK as a whole, as there is likely to be a response bias in favour of those who have an interest in AS education and are more likely to provide such

groups. Additionally, some education groups are likely to have been represented in our figures more than once because of multiple responses from the same department.

Health professionals' opinions about which patients are most likely to benefit from group education are intriguing, although it is difficult to comment about the extent to which these opinions guide professionals' practice in terms of recommending group education. The results do suggest that there is at least an awareness that group education is more appropriate for some patients than for others, although it does little to confirm whether these opinions are valid or useful. I will return to the judgements that health professionals make in the next section, as I consider the role of limited resources in the provision of education.

6.5 Limited Resources and Unmet Need

In section 6.3 I considered the functions of patient education, indicating that through promoting safety and increasing patients' understanding of their disease, health professionals were able to reduce, or at least attempt to control their own workload. In this section I will continue this theme, recognising that health professionals' role as educators is not independent of their other roles – it co-exists, and often competes, within an environment of limited time and resources.

Excerpt 5 illustrates the response of the AHP focus group to the description of a resource which patients had requested as part of a consultation exercise about patient education:

Excerpt 5: AHP Group

- 146 Physio2 Most people wanted specific information leaflets that are handed out in clinic but specific to that Trust. 'This is what we can offer, this is the general information you need about the drugs protection, stretches and that kind of thing.'
- 147 I Right
- 148 SpN3 Right, interesting.
- 149 Physio2 But they wanted it specifically given to them in clinic but not you know something off the shelf something specifically written by the team and 'this is who to contact if you need help in the future' but 'this is all ... everything you wanted'. All the information together. These are all the stretches, this is all the pain relieving advice, this is all the drug protection advice, kind of all in a pack really.
- 150 SpN3 A bit mind-blowing isn't it!
- 151 Physio2 Exactly.
- 152 SpN1 I suppose they can go and read it at their own pace then can't they.
- 153 Physio2 Yeah.
- 154 SpN3 But would they, would they?

Until now in this chapter, my focus has been on the topics *health professionals* consider are important for patients to learn about. In response to a clear description of what *patients want*, SpN3 suggests that such a resource is 'a bit mind-blowing' (150), and it appears that this opinion is shared by the rest of the group. The phrase 'mind-blowing' seems to refer to the quantity of the information they want, and, because it was 'specific to that Trust' (146), the work required to produce this. Furthermore, SpN3 expresses significant doubt that such

investment of time would be worthwhile, for despite the fact that the information has been requested by patients, there is uncertainty about whether it would actually be used (154). In this example, it seems unlikely that this resource will be made available for patients because it has not been assigned sufficient priority; there is limited time and other resources available to produce it, and the investment required is not judged to be appropriate by health professionals.

This *prioritisation*, specifically an awareness of both the resources required to provide education and the alternative ways those resources could be employed, is also evident elsewhere in the focus groups, and in the survey. In Excerpt 6, the difficulties in choosing who to invite to group education are described, because of the risk that the cost will be ‘wasted’ if the patient doesn’t attend. In Excerpt 7, a scenario is described in which the resources required for group education are also ‘wasted’, in this case because of the characteristics of the patients who actually attend:

Excerpt 6: AHP Group

144 SpN3 And there is a huge outlay in group education as well. You know staff time, accommodation and food and all the rest of it but if you had wasted it - that is a horrible way of putting it but you know - you have wasted it on that person are you going to invite them again next year?

Excerpt 7: AHP Group

42 Physio3 We do ours all individually because we found the uptake in groups wasn't very good and I think you end up with ... there are two types of people, the people who want the information and then ‘thank you very much if I am in trouble I will come and get you’, and the others who kind of grab onto a group and like that support. And when you run these things you inevitably find out of the ten who turn up, one will come to your regular group and then you get this little core who come all the time

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44 Physio3 and then the other people who are off there with I don't know terrible back pain because their AS has flared just getting on with it because that is what they like and other ones who use the service but perhaps don't ... I am not saying that they don't need it but you know they are [YEAH] and so we just went for an individual and ‘if you need any help here I am’ and ‘here is some stuff that you can use’. Measurement scores and things that are simple/functional, ‘if you notice there is a deterioration then just give us a ring and we can see you and help you out’.

This second example (Excerpt 7) is more subtle than the first, describing groups where the physiotherapist judges that inappropriate patients were attending – those who ‘grab onto a group and like that support’ (42), as oppose to those with ‘terrible back pain’ (44). This view of which patients *should* be attending group education (seemingly held by most of the focus group members from their response (43)) may have been shaped by a practical experience of which patients seem to benefit from education and therefore should be encouraged to go, but also a *moral evaluation* of how patients should behave in response to their AS. There is thus acceptance that group education can provide support for those patients that want it, but a sense that this function alone is not of sufficient priority to justify the resources required to sustain these groups.

Further examples of the difficulties in providing group education were indicated in the free-text comment areas of the survey. In total 14 respondents reported groups at their hospital ‘failing’; in 6 cases, the explanation was related to a reduction in the resources available, for example funding being reduced, or an interested professional leaving their post. Another 6 respondents explained that their groups had failed because of issues related to patients themselves; of these, 3 reported simply that there was insufficient numbers of patients attending, while for the other three the group was said to be failing because the existing attendees were ‘too cliquey’, or were ‘older patients with established disease, which put younger patients off’ (BSR Survey, Response Number 70). For the remaining 2 of the 14 failing groups, there was either no indication specified regarding why it had failed, or it was felt that the recruitment for the groups had not been sufficiently ‘targeted’, resulting in groups which were too ‘heterogeneous’ (BSR Survey, 73).

At the end of the survey (Section 5, Appendix VII), we asked respondents about the educational resources they felt would be useful for patients with AS, and why they felt they were not already available. We also asked them specifically about resources which patients had suggested themselves (Q5.2). The responses to these questions were coded and displayed here as Table 5 and Table 6.

Table 5: Coded Responses from BSR / BHPR Survey (Q5.1a and 5.2) – Educational Resources Suggested by Health Professionals and Patients. Note only categories suggested by more than one respondent are included here.

Suggested Education: 'Useful, but Not Available'	Counts		
	BHPR	BSR (Consultants)	Reported from Patients
Group Education / Exercise / Support	21	20	6
DVD / Video	18	21	1
Physio / Nurse Dedicated To AS	6	5	0
Improve / Update Literature	4	5	0
One-To-One Education	3	4	0
Multidisciplinary Education Sessions	3	4	0
Online Resources	3	3	0
Education For Primary Care Staff	3	0	0
Education Specific For Newly Diagnosed	2	4	0
Psychology Input	2	2	0
Research To Determine What Patients Want	2	0	0
Resources Available In Other Languages	1	2	0
For Patients With Children	1	0	1
For Late Diagnoses	1	0	1
Better Exercise Tuition	0	4	0
Information For Undifferentiated. Spondyloarthritis	0	2	0
Improve Patient 'Networking'	0	2	1
More Input From NASS	0	2	0
Hydrotherapy	0	0	7
Working / Employment Issues	0	0	2
Time With An IT Literate Patient	0	0	2

Table 6: Coded Responses from BSR / BHPR Survey (Q5.1b) – Explanations for why education considered useful is not available. Note only explanations suggested by more than one respondent are listed here.

Reason Why Suggested Education is Not Available	Counts	
	BHPR	BSR (Consultants)
Resources - Financial	29	37
Resources - Time	24	13
Resources - Human (Expertise)	24	12
Low Priority Compared to Other Conditions eg RA, SLE, cardiovascular disease	11	7
Resources – ‘Space’	9	3
Resources (not specified)	6	12
Ability / Willingness of Patients to Attend	3	5
Organisation / Motivation / Interest in Topic	2	15
Awareness of Resources Available	2	8
Lack of lay person to lead / become involved	2	1

Clearly a significant proportion of those health professionals without access to group education for their patients think it would be useful, and the barriers to provide this and other resources are most frequently perceived to be the lack of necessary finance, expertise, time and space. Additionally, there also appear to be issues with the perceived priority of AS compared to other health problems, and levels of interest in the topic of patient education itself, especially amongst consultants. The interest of patients is also required, both to attend education groups and act as lay-leaders in some instances. As we have already discussed, some patients may be more likely to attend than others, and judgements can be made about how useful their attendance is. Very few respondents added comments about educational resources which patients had requested; hydrotherapy was most frequently mentioned, a treatment which although not an educational resource, is valued by many people with AS and is not universally available.

In this section I have discussed some of the areas which health professionals find difficult in the field of patient education for people with AS. Initially, I showed that decisions about the education provided for patients are made within an environment of limited resources, and a desire to use those resources in appropriate ways which benefit patients. There is

concern that education programmes will not be attended (Excerpt 6), or that less 'appropriate' patients will attend (Excerpt 7). The judgements which health professionals make about which patients are appropriate seem complex, especially when it is difficult to predict which patients will actually attend if invited (AHP Group: 85 – 100, not shown), and there don't seem to be reliable methods to persuade people to attend (AHP Group: 131 – 139, not shown). The moral evaluation of patients seems to have an influence: those patients who attend to increase their knowledge and skills, or have more severe disease, are considered to be more appropriate than those who have mild disease or attend purely for the less tangible benefit of support (Excerpt 7). In some cases though, groups can fail to fulfil the task they were started for, if a core of patients dominate an existing group and result in it becoming irrelevant or inaccessible for newcomers. When commenting on whether such groups are truly 'failing' though, health professionals must weigh up the benefits to those patients who consistently attend, with the potential to benefit other patients if the resources were used elsewhere.

6.6 Health Professionals' Roles

The focus groups and survey sampled a range of the health professionals involved in the care and education of people with AS (see Table 2, Table 3 and Table 4). In this section I have considered the role of these different professional groups in the process of education, focussing on how the professions perceive their own role in education, and whether their perception is shared by other professionals, or indeed patients. Within this theme I have examined leadership roles within education, and how tasks and topic areas are distributed between the professional groups involved. This information provides a clearer picture of the role of each profession and the relationship between professions which exist when providing education - both vital in understanding how education is currently provided.

During the NASS Focus Group at the beginning of the project the participants carried out a ranking task, discussing and rating potential sources of information about AS in terms of their usefulness and strengths. The most useful sources of information were 'Other patients with AS' and 'Rheumatology Consultants', closely followed by physiotherapists. The response of the Consultants' Focus Group to my statement that they had been rated so highly by patients is shown in Excerpt 8:

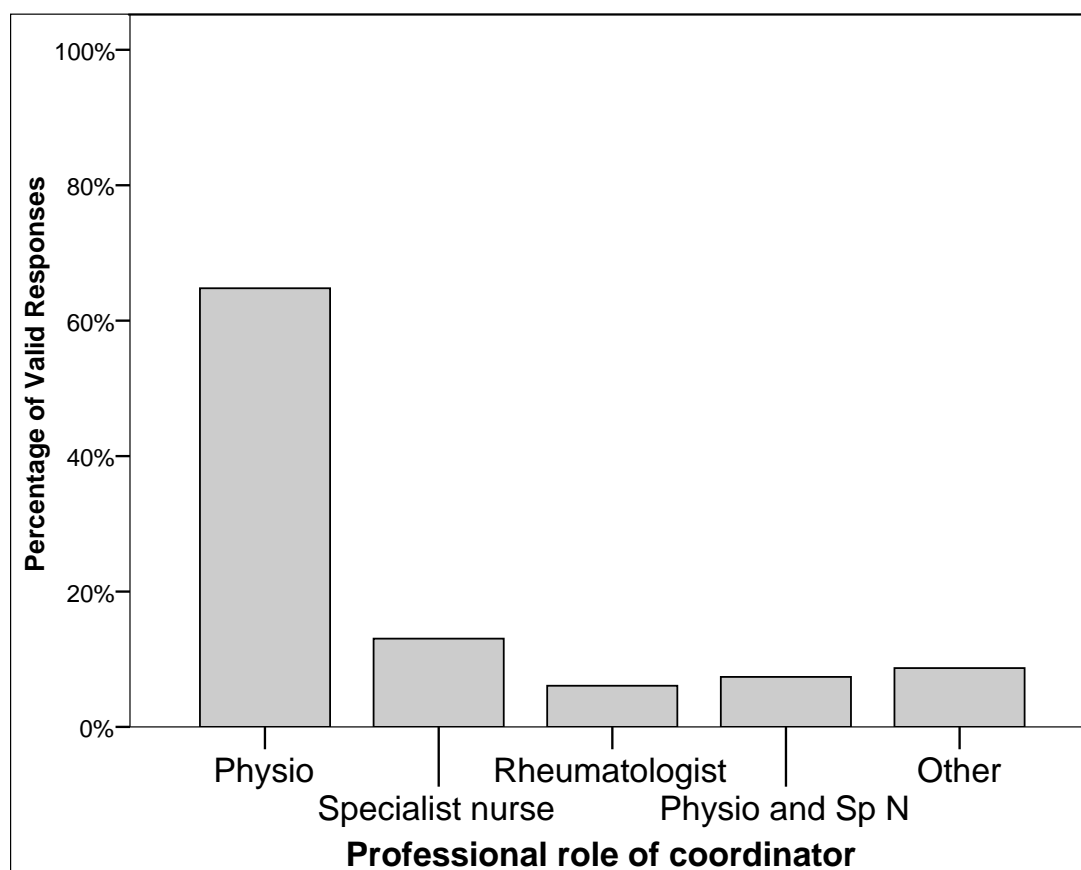
Excerpt 8: Consultants' Group

- 14 AB Well we are their access to health care and they recognise that and, I guess they still look up to us, don't they.
- 15 IJ We are usually the people to make diagnosis aren't we?
- 16 [YEP – more than one person indicating agreement]
- 17 GH We are frequently their first sort of contact in the hospital. Obviously they have gone through the sort of primary care but they, very often don't perceive their GP's as being somebody that knows very much about it in this area, so I think we are often perceived as the first person they hit who, recognises what they have got and er, actually has a bit of information about it.
- 18 KL I think also because, whilst they may be, patients may see us as being the main source of information, we would probably see physiotherapists and the nurse practitioners as perhaps being more involved in patient education ...
- 19 I Yeah.
- 20 KL ... and I think at first contact they possibly don't appreciate the role that allied health professionals actually have in their care.

In this excerpt, the Consultants list potential explanations why they are perceived as the most important source of information, particularly highlighting their role in initially diagnosing ankylosing spondylitis and thus offering an explanation of the symptoms patients have been experiencing. However, they also display some reluctance to fulfil this role, indicating that they would consider other health professionals to be better placed to provide education (18), and that patients may rate doctors highly because they don't understand the role AHPs can fulfil (20). This difference between patients' perceptions of the most useful sources of information and Consultants' ideas of who should be providing it not only represents a mismatch likely to cause problems in the delivery of education, but also reflects another example of prioritisation by health professionals. In this instance, Rheumatology Consultants may be assigning a lower priority to education and information provision than to other, unspecified, aspects of their work.

Instead, physiotherapists are more likely to adopt the role of educators for these patients. From the survey, 230/418 responders (55%) reported that there was an individual within their service who co-ordinated education for people with AS (See Q4.1) Figure 17 shows the professional role of these co-ordinators; of the 230 responses where there was a 'co-ordinator' for education, in 149 cases (64.8%) this was a physiotherapist:

Figure 17: Professional Role of Co-ordinators of Ankylosing Spondylitis Patient Education within Rheumatology Departments

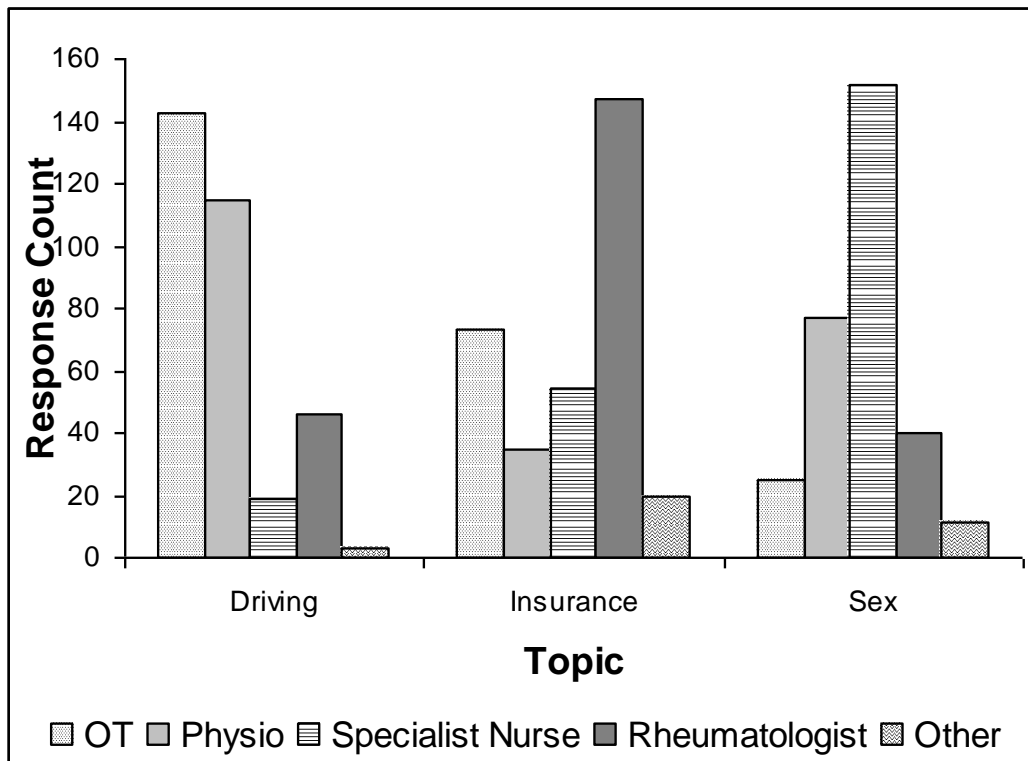


The roles of different health professionals were also considered in relation to questions and education about specific topics. Information regarding driving, insurance and sex was identified during the NASS Focus Group as being difficult to access. However, when these topics were discussed during the AHP and the Consultant Focus Groups, there was disagreement about *who* should be addressing these topics. During the Consultants' Group, participants expressed the view that nurses dealt with questions about sex most appropriately because their consulting style was different and they had greater privacy during consultations (Consultants' Group: 49-59 – not shown). In turn, the AHP group indicated that they also found these topics difficult to address satisfactorily, raising the same concerns about privacy during their consultations, but also additional issues of embarrassment and appropriate training regarding how to deal with such sensitive topics. (AHP Group: 439 – 478 – not shown). These topics seemed to be equally difficult to address for each of the professions involved in their care, whilst each believed others were more capable of addressing these difficult areas. There was an impression that these topics

were being overlooked not only because they were inherently difficult to address effectively, but also because of assumptions that they were being effectively dealt with by other professions.

Continuing this theme, the survey asked respondents who they felt were most effective at answering questions about these three topics (Q4.2). Figure 18 displays the results, showing that OTs were thought to be best placed to answer questions about driving, doctors questions about insurance, and specialist nurses questions about sex. However, in each case the most popular profession received a minority of the total number of responses, indicating a lack of consensus. Similarly, a third of the OTs did not agree that they were the experts on driving (4/12), while 98/192 (51%) of consultants felt others could deal with questions about insurance more effectively, and 55/92 (60%) of specialist nurses had the same opinion regarding questions about sex.

Figure 18: Professional Group That Best Deals with Questions around the Topics of 'Driving', 'Insurance' and 'Sex'



This section illustrates a number of points about the organisation and provision of patient education. Firstly, the role of different professionals within the multidisciplinary team is not clearly defined, allowing flexibility - but possibly also *uncertainty* – regarding who

delivers education or deals with specific topics. In some instances this flexible approach may be necessary, for example if the service does not include an OT or a physiotherapist, and could also enable individuals to develop an interest in education whilst allowing others to follow alternative interests. However, this lack of specificity of professional roles, especially in the absence of an individual who acts as a co-ordinator for education, may contribute to an attitude that others in the team will provide the necessary explanations and education, resulting in omissions and less inclination to provide this information themselves. Equally, this situation may also leave patients uncertain about where to go for help, especially because while they view consultants as important sources of information, consultants themselves may not give education such high priority.

6.7 Conclusions

When I discussed the aims of patient education in Chapter 3 in relation to difficulties determining its efficacy, the aims focused on benefits for patients and potential health-related cost savings. An examination of education which relies solely on these outcomes will not reflect all the effects of education – potentially both positive and negative dependent on the perspective chosen. This chapter has highlighted some of its broader functions, principally from the viewpoint of health professionals involved in its delivery. Figure 10 summarises these functions: to a great extent they remain beneficent – aiming to help patients feel better and understand and explain their own experiences. However, education also has a role in controlling the workload of health professionals, shifting responsibility for patients' health away from professionals and onto patients themselves, promoting a view of illness and its treatment which is more consistent with health professionals' views and the way 'their' health system works. The functions of education therefore promote gravitation towards a 'good' patient, as well as an 'informed' one – a patient who makes decisions which health professionals believe are the right ones. The results of these decisions may improve a patient's future health, but may not be the *fully informed* decisions based on the patient's *own* beliefs and priorities which health professionals may imagine. The fact that health professionals rated 'increasing the amount of exercise' the most important aim of education for people with AS (see Figure 11), perhaps at the expense of understanding why they needed to exercise, is a typical example of the conflict I have described. In turn, this conflict has been noted previously; Mary Dixon-Woods (2001) noted two discourses within patient information leaflets. Firstly those of the biomedical model, viewing patients as passive objects and analogous here to attempts to increase exercise through education; in contrast the second discourse was of patient empowerment and aiming to increase patients' participation in decision making.

Similarly, these functions of education are not consistent with the Established Patient Model described in Chapter 5. Specifically, the concept that patients reach a stage when they feel they know enough about ankylosing spondylitis is only recognised on one

occasion during the focus groups³⁵, and does not seem to influence the survey responses. Instead, there is a pervasive view that patients ought to learn more about their condition – that the ‘good’ patient acting in accordance with health professionals’ ideas about health and illness will attend education classes and read the available literature, and that this will continue consistently throughout their disease course. Those patients who choose not to attend or engage with education are viewed with some incomprehension and with a degree of negative moral evaluation, when they may be established and judge themselves not to be in need of education at this time.

Health professionals’ sense of incomprehension is not limited to those patients who do not engage with education, but in fact extends to judgements about which patients are most likely to benefit from education, and therefore to whom and how strongly they should be recommending different forms of education. I discussed the concept of prioritisation in section 6.5, with respect to the choices health professionals make about the allocation of their own and their department’s limited resources. This lack of understanding regarding who should be offered education, and indeed the benefits they will gain makes this process of prioritisation more difficult, and probably inhibits the availability of resources for patients.

The data from the survey offers an indication of the current provision of resources for people with AS across the UK. The variability is striking, ranging from the lack of any group education for 16% of responders, to a lack of awareness of written resources amongst about 1/3 of Rheumatology Consultants. Where educational resources are available, there is a reliance on organisations such as NASS and Arthritis Research UK to provide them in the form of group education, written information and popular websites. The principal explanation for why rheumatology departments cannot provide more education ‘in-house’ is a lack of resources – the time, finance, interest and expertise required to develop and sustain them. If more of these resources were available to departments, then Table 5 would suggest that offering more group education would be a priority. However, some of those departments that do invest the necessary resources to

³⁵ During the AHP Focus Group (Line 139), SpN3 states that ‘[There] is this particular group of people people who just don't need that [education]. They are quite happy, they have got their head around what they want to get their head round and do they actually not need that level of education or level of support or whatever.’ In fact though, this is seen as an unpredictable stage, which others in the group relate to ‘not being ready’ to learn (SpN2, 141) rather than a rational choice related to their health and social circumstances.

provide group education aren't satisfied with how they function in practice, with health professionals concerned that the patients who actually attended the groups are not those judged to *need* education.

Within this thesis I first considered the experience of people with AS and then the effect of educational interventions in the two literature review chapters. Within the results chapters I explored *how* and *why* patients learn about their ankylosing spondylitis through the Established Patient Model, and have now examined patient education from health professionals' perspectives – specifically considering the aims and functions of education for this group who both deliver education and play an important role in directing patients to other sources. Clearly, there are areas where health professionals' aims are not necessarily aligned with the aims of patients, for instance when information is used selectively to influence patients' choices, or when the aim is to control professionals' workload by influencing their consultation patterns. In these examples, the education may still be beneficent, but the aims of health professionals may remain 'covert' - not apparent to the patients involved. Additionally, these aims and functions should be considered when new educational resources are designed or implemented, as health professionals may be more likely to use and implement resources that also acknowledge their needs and aims, and also so that the effects can be evaluated explicitly.

The final results chapters moves towards more practical suggestions regarding how patient education can be improved for this group. Building on what I have learnt so far about patients' and professionals' perspectives of education and how it is currently delivered, I will focus on the important topic areas for patients and the delivery methods which may be successful. Returning to the interviews with patients, I will focus on those patients who may need different approaches to education. Finally, in Chapter 8. I will report the responses of patients and professionals to my results.

Chapter 7 – Patients’ Use of Educational Resources

7.1 Introduction

In this chapter my focus returns to the interviews with new and review patients, and a study of the educational resources they chose to use, and how they used them. In Chapter 6, I discussed these resources from the perspective of health professionals, considering their availability and the priorities of HPs. This chapter draws on patients' descriptions of these resources, examining the particular role each plays as they learn about AS, and the strengths and limitations of each method. This not only aids our understanding of the practicalities and variation of patients' learning, but also offers valuable information about how the design and provision of these resources could be improved in the future.

The data for this chapter was collected by discussing which resources patients had used, the circumstances which had led to this use, and their evaluation of the experience. Similarly, if patients hadn't used a particular resource, for example if they had declined an invitation to attend an education group, then their explanation for this was also explored. This process was assisted by the diaries completed by newly-diagnosed patients prior to their 6 month and 12 month interviews (Appendix IV), with which they recorded their questions about AS and the resources they had consulted since their last interview. Finally, I also asked interviewees about which resources they would use in some hypothetical situations, such as a new flare of their arthritis.

I have concentrated on the resources which are widely available and either delivered or influenced by health professionals – namely information booklets, the internet, group education, and health professionals themselves. I have not discussed other important resources, such as family and friends or media sources, which can profoundly affect patients' learning, but which are less easily modified by health professionals. Also within this chapter, I have explored patients' experiences of learning about exercise in the context of AS, because of the importance attached to this topic by health professionals. Finally, within the section on 'Vulnerable Patients' I will discuss patients who do not use resources in the manner that health professionals would expect, and may benefit from different approaches to patient education.

7.2 Use of Resources

7.2.1 Information Booklets

Arthritis Research UK³⁶ and NASS produce patient information leaflets which were universally recognised by the interviewees. Only one (Crev3) reported that she had not received a leaflet, either when she was initially diagnosed with AS thirty years previously, or while she attended secondary care follow up and the local NASS group. This experience contrasts with the survey results (see Figure 15) which indicate that the booklets are not universally distributed by health professionals. This discrepancy suggests either a geographical bias – that health professionals in the North-east of England are more likely to hand them out - or a selection bias, such that those professionals who are aware of and use the booklet are more likely both to recruit patients, and remember to give them the booklet. Alternatively, those who were not handed one by their consultant may have been able to obtain them from elsewhere – clinic waiting rooms, other health professionals, or direct from the organisations themselves.

The two booklets were viewed very similarly, with no patients describing important differences, or indeed having spent time comparing the two. Excerpt 1 illustrates an exchange I repeated with many of the patients:

Excerpt 1: Bnew3.3

- 21 I OK and I know you had ... you had a booklet. Are either of these the booklet? [showing both the arc and NASS booklets] I think that's ... you can get that in a different cover now. Have you seen either of those before?
- 22 T I have got both of them. I got eh this one [indicates the arc booklet] when I first found out I got AS, I got this one off [consultant] and I got that one [NASS booklet] when I went for the course eh for my physio.
- 23 I I mean are there any things that you would change, any sort of strong opinions about them or any that you?
- 24 T Eh this one I did [the arc one]. I read this over and over when I first eh got it. Eh that was eh dead helpful. That one I didn't really read because by the time I had gotten it, I got that on the last day of the course, and because I had already been on the internet, read this, had the course I had a quick

³⁶ As noted already, at the time the interviews were carried out, Arthritis Research UK was known as the Arthritis Research Campaign or 'arc'.

flick through it but I didn't really look at it in any detail because I, everything I quickly checked I had more or less known about anyway.

Like T in this example, the interviewees tended to view the leaflets as interchangeable, receiving the first at the time of diagnosis and gaining significant benefit from this, but finding little new information from a second leaflet they may have read later. Similarly, there was no strong recognition or knowledge of the organisations producing the leaflets, especially for Arthritis Research UK. I had to show examples of each in order to identify which leaflet each person had received (232) because they didn't recognise them by name. However, there was wider recognition of NASS, perhaps resulting from their additional activities - offering membership, newsletters and organising exercise groups

Despite these apparent problems identifying the authorship of the booklets, leaflets offered a highly valued introduction to the condition during the diagnosed phase of the Established Patient Model, and usually marked the start of patients' rush for information. They were a trusted source of information for the individuals themselves, and also for those around them. The booklets were often used to explain the condition and its effects to family members, friends and employers, and even to health professionals who were less familiar with AS. Handing the booklet to others provided legitimacy to their symptoms and diagnosis (and the change in their behaviour which had occurred as a result) which wasn't available from a personal description.

The trust and authority held by the booklets, in the absence of significant understanding of the authorship, results not only from their content and appearance, but also from their connection to health professionals. Each interviewee was handed the booklet by their Rheumatologist at the time of diagnosis, and thus explicitly or not, the booklets were recommended and verified by them. I will return to the crucial role played by health professionals in recommending and suggesting other educational resources in section 7.2.4.

The diversity of patients' opinions around the content of the information booklets makes it difficult to envisage a booklet which would meet the expectations of all patients, at all stages of their illness. Given the diversity of patients' backgrounds, this may be unsurprising; however it emphasises the difficulties faced by the authors of these booklets. For some patients the leaflets were indecipherable at the time of diagnosis, containing

medical jargon and statistics which was initially overwhelming. In contrast others who had already learnt the basics from another source were disappointed by the lack of detail, or by the lack of new medical terms which could be learnt. There was another apparently irreconcilable conflict between contrasting views on the tone of the leaflets. For some the leaflets were too negative, causing anxiety about the future which seemed unnecessary; for others the tone was too positive, ignoring a need for 'shock and awe' (Bnew1.3:121) which would motivate patients to exercise appropriately and take their health seriously.

More specifically, patients often praised the practical advice offered by the booklets. For example the list of contacts which had enabled S (Anew2) to get appropriate mirrors for his car, the daily exercise programme which some patients followed, or suggestions like having a bath each morning to improve joint stiffness. The case studies of patients with AS which detailed what had happened to them over a number of years were also commended. However, some patients found it difficult to relate this type of information to their own health, querying when the case studies were written and whether treatments had changed since that time, and whether they too would follow this disease course. Similarly, lists of the potential extra-articular effects of AS such as lung or heart disease were met with concern that the specific risk to their own health remained unclear. Other criticisms included that there was too much focus on AS as a condition affecting young men, and that older patients, or those with disease that had already caused significant spinal deformity, were disregarded. Additional material such as lists of questions patients might want to ask their Rheumatologist, and where to go for help with particular problems were also suggested.

When patients were established or facing new problems the utility of the booklets diminished, as patients' educational needs changed. In most cases the booklets themselves remain valued possessions, with one participant, M (Arev1), producing a NASS booklet she had received 25 years earlier during her interview, and others keeping them in a drawer, or on a bookshelf. As could be predicted from the Established Patient Model, review patients reported picking up new versions of the booklets where available, in order to 'keep up-to-date' and check if there had been any changes since the last version they had read. However, as the review interviews progressed it became clear that the booklets were

now rarely consulted, and on the occasions they were, the information they obtained did not add to patients' existing knowledge, or solve the problems they were experiencing.

The data from these interviews indicate that in their present form the booklets function as a highly-valued introduction to the condition, which in most cases offers readers the reassurance they are seeking. The trust and authority attached to them is because they are distributed by health professionals, and does not necessarily emanate from the author organisations such as NASS and Arthritis Research UK. They have to be generic – as applicable as possible to all potential recipients - which at present should be all newly-diagnosed patients. Being generic is particularly challenging because of the range of medical and demographic differences between these patients. Additionally, the conflict between a preference for greater or lesser detail and between a positive or negative tone not only seems difficult to resolve, but it also seems impossible to predict which patients would prefer particular styles using easily 'measurable' attributes such as previous educational attainment or age. This would make it particularly difficult to tailor the written information handed out by professionals in an attempt to address this problem.

7.2.2 Internet Resources

Within the literature review (section 3.3.4) I described the trend towards increasing access to the internet for patients and the evidence for its use in the context of patient education. In particular, I highlighted its potential to provide information independently of health professionals, and to allow patients to share their experiences without meeting face-to-face. In Chapter 5, when illustrating the stages of the Established Patient Model, I related a number of examples of patients using the internet to their stage of learning about AS. In this section I will focus on this use in more detail, explaining which patients chose to use the internet to learn about AS, how they used this resource, and some of the potential problems they faced.

In Chapter 5, I described how L (Cnew2) had used the internet before seeing a Rheumatologist to try to find out her diagnosis (see Excerpt 5, Chapter 5). As part of her explanation, she stated that she 'knew the internet' (Cnew2.1:14) and used it extensively as part of her work, and therefore it was natural for her to search the web in this manner. This precedent is also followed in the other interviews: it is those people who already regularly

use the internet who seek further information from this source. There are exceptions, for instance M (Arev1) reported that she hadn't used the internet in relation to her AS, despite using it for other purposes. She was influenced by her son who 'scares himself to death' (Arev1:234) when he searches for information related to his own ME³⁷, and therefore she felt searching the internet risked causing herself unnecessary anxiety.

Most of the interviewees had access to the internet at home; those that did not were able to describe real or potential routes of access. In the case of S (Anew2) this was through his brother or daughter; A's wife (Arev3) had used the internet for him through her work. Thus all the interviewees had *some* access to internet, and these examples are part of the continuum of collaborative use of the internet evident from the new and review interviews. H (Brev1) relied upon her husband to carry out detailed research on the issue of anti-TNF treatment principally because she was 'not very good on the internet' (Brev1: 151), and equally it was B's wife who instigated searches on the internet because she was 'a worrier' (Bnew2.1:60) who was more interested and proactive around issues of health.

Returning now to the Established Patient Model in Chapter 5, there are examples of internet use within each of the four stages. *Prediagnosis* there is an unsuccessful search for a diagnosis on the web. Using their symptoms (often 'back pain') as a starting point, patients would try to find a condition which matched and explained their symptoms. Many of the research participants were accustomed to internet searches, and also had significant understanding of health information, therefore it seems remarkable that only one (L, Cnew2) recalled reading about or relating ankylosing spondylitis to their own case. Their experience indicates that information about AS on the web is relatively inaccessible for those without prior knowledge and understanding of the phrase itself; it does not appear to have been prominent when searches for 'back pain' or 'joint pain' are carried out, instead it is just one of many potential causes for these symptoms.

When *diagnosed*, internet searches were broad and limitless – a search to understand the scope of the information and resources available via this source. Participants spent a long time carrying out searches, following interesting links, and reading about the experiences of other patients, usually with only limited recall of the sites they had visited. In some cases

³⁷ ME = myalgic encephalitis. People with ME experience severe and long term symptoms of fatigue, the aetiology of which is poorly understood.

this search was initiated by a health professional suggesting that useful information was available on the web; for others it was a routine step to take given their familiarity with the internet.

During the *established* phase internet use declined, but in some cases it remained relatively frequent. G (Arev4) described an extreme example of *keeping up-to-date*. He still searched for topics related to AS approximately once a week, despite it 'all being the same kind of stuff' (260), and stating that he hadn't learnt anything new for about 6 months. He explained these regular searches as 'going onto autopilot, wanting to read everything just the sort of person I am' (270). However, it was more typical to hear that participants whose health, healthcare and social disruption due to AS was now minimal had ceased their search of the internet, even when their use when diagnosed had been substantial.

The internet was a popular first source of information when *facing a new problem*. By this stage the participants sometimes chose to visit a particular site they had used previously, such as the NASS website or message board, although search engines also remained a popular starting point. Internet use during this stage occasionally included achieving practical benefits like cheaper motorbike insurance through NASS, or reading about exercises they could do independently. However, in most cases information gained from the internet in these settings acted as preparation for a consultation with a health professional. When Y (Brev3) developed severe headaches whilst taking anti-TNF he searched the internet for information and discovered that headaches were a *potential* side effect of the treatment, but it was only through investigations arranged by his Rheumatologist that alternative explanations were excluded and a definitive explanation offered. Similarly, C (Anew1) was able to surprise his consultant by his knowledge of anti-TNF drugs when she suggested them as a possible treatment, and G (Arev4) researched sacro-iliac joint injections on the web when they were suggested by a clinician as a possible treatment. Thus, even when patients are established with their condition and accustomed to using the internet as a source of health information and education, transforming their knowledge about AS into practical benefits is normally reliant on health professionals and other people they come into contact with. Its use is in partnership with normal consultations and sources of help and education, and doesn't replace them.

The major theme which ran through the discussions about the internet was the difficulties patients had in appraising the information they gained from the internet. This was evident from the first interview I undertook, when J (Bnew1), described his uncertainty when faced with contradictory information on websites, asking ‘who is the better accredited site?’ (Bnew1.1: 150). Later, he questions the use of information from the internet produced either by pharmaceutical companies who are ‘pushing their own products’ or doctors who similarly have ‘endorsed’ certain treatments (ibid: 199). He had most confidence in the views of those ‘who have got the condition’ (ibid: 205), and yet other participants felt such testimonies were unreliable, reflecting ‘just personal experience’, and lacking any ‘medical background’ (Cnew2.1: 196). However, it was often these experiences from patients which were most powerful in shaping participants’ views of AS, especially when newly diagnosed. In other fields, the value of this online ‘*collective expertise*’ (Moreira, 2006: 59) is also recognised, in this instance in relation to sharing of experiences in relation to non-invasive ventilation at home.

During the 6- and 12-month interviews, and the ‘reviews’, some participants were able to reflect on the effect of these testimonies of people with AS on their own perception of their disease and future when they were first diagnosed. There was a feeling that using the internet at this stage gave an unnecessarily poor outlook, and it was American sites which were reported as the worst. Testimonies were interpreted as depicting a ‘terminal illness’ (Cnew1.3:372), while there was an absence of hope typified by messages that ‘everything was going to seize up’, and that the available drug treatments ‘caused cancer’ (Arev2: 154). Later in the course of their learning, patients were able to put these messages into the context of other, more positive, information they had received from other sources. However, the impact of these testimonies and images on patients’ understanding of AS in the first few month of their illness was significant, increasing their distress regarding their new diagnosis, and potentially reducing their ability to take active steps to manage their condition.

In summary, the internet is used by patients collaboratively with their significant others in their search for information about ankylosing spondylitis. The aims of patients and the search techniques they employ vary according to the Established Patient Model. In this sample, access to the internet in some form was universal, although obtaining information

through an intermediary could be problematic. The information available to patients is limitless, and advice from health professionals about where to look is appreciated and followed by patients, especially shortly after diagnosis. Later, the internet is used as preparation for consultations with health professionals, or to find out more about treatments suggested by health professionals. However its limitation remains in transforming the information gained by patients from the internet into practical benefits. For this they were still dependent on health professionals to offer definitive interpretation of the information, or, for example, the referral or prescription they had learnt about.

7.2.3 Group Education and Learning from Other Patients

Group education, as I discussed when reviewing the relevant literature in Chapter 3, is promoted as a cost-effective method of providing education to patients with conditions like AS. However, well-designed evaluation of these methods has not shown that participation in these programmes leads to persistent changes in important health outcomes, while recruitment to studies is challenging and not representative of patients who are most in need of education. In Chapter 6 I examined health professionals' experiences of providing group education, highlighting the variable provision of group education for people with AS within the UK, the difficulties sustaining groups given a shortage of resources, and the desire of those HPs who are unable to offer groups to provide them in the future.

This section returns to the topic of group education, focusing now on the benefits and problems patients perceive and experience when they attend, or consider attending, such programmes. I have also broadened the scope of this section to include other methods the interview participants of this project employed to share experiences with other patients. These are shown in Table 7:

Table 7: Methods of Sharing Experiences and Learning from Other Patients Used by Interview Participants

Ongoing support groups for patients with AS (i.e. NASS group)
AS group education courses (run by Rheumatology department, typically over 6 weeks)
One-off education events – for example to discuss a new treatment such as anti-TNF
Meeting or talking to another (more experienced) patient with AS
Internet message boards / chat rooms
Group activities where education is not the primary focus (physio sessions, receiving intravenous treatment at the same time as other patients)
Informal discussion with friends or family who also have AS
Case studies – web-based or within patient information leaflets

The methods shown in Table 7 therefore range from those organised by health professionals to approaches which are independent of healthcare providers; from methods which require face-to-face contact with other patients to less interactive examples such as case studies. I will explore these in more detail below, particularly focusing on the choices patients make about whether to use them, and their subsequent evaluation of them.

There was a high level of interest in opportunities to meet and talk to other patients with AS when patients were first diagnosed. This is consistent with the Established Patient Model, which suggests a willingness to consider educational opportunities at this stage, and a reluctance to dismiss potential solutions to problems they do not yet fully understand. Participants hoped to learn more about the condition itself, particularly gaining an insight into their own future, and learning practical ways to deal with their problems and symptoms from someone who had been through it before. Additionally, there was a feeling that another person with AS could offer an understanding that people without AS couldn't, irrespective of the efforts those people made. This *understanding* is illustrated in Excerpt 2 below, where J discusses the conversations he has with a friend who also has AS:

Excerpt 2: Bnew1.3

61 J I suppose as long as there is someone there to get it off your chest. What I don't like is eh, I mean my girlfriend is, 'Oh yeah, oh you're sore today. Come here and sit down. Come over and we'll just relax.' And

you know it's not what I want. I don't want someone's pity you know. I look at myself and I look fit and healthy. Other people look at me, look fit and healthy and then they complain because ah 'are you whinging about something else again', so well ... you know 'I have this disease and it hasn't just gone away' you know. And it is the understand so ... I don't tend to talk to people because they tend to give you a bit of pity.

62 I Yeah.

63 J And there is no empathy there unless someone else has got the condition or suffered similar.

64 I And is that the same sort of thing that you get if you sort of went to your GP or to a nurse at the hospital, you feel that you get ... would you get anything different from them, do you think?

65 J Em it is more clinical eh and I think the doctors, although they know about the disease and they know about the aches and pains and different aspects of the disease, it is like if you have never had a bad back and you hear someone going on about their back all the time you think well 'what's wrong with them? It is only a bit of an ache in your back you know.'

J uses his friend with AS as an outlet for some of his frustrations about his health and his healthcare, conversations which would risk pity or irritation if attempted with his girlfriend or with healthcare professionals. This issue also arises in other interviews as an important motive when patients seek to meet others with AS. Another advantage, linked to the empathy described here, is the fact that the shared diagnosis provides a short-cut which negates the need for explanations and justification which can pervade conversations with others about AS.

Despite the envisaged benefits of meeting others with AS, clearly and repeatedly stated by six of the ten newly diagnosed patients in their first interview, only one had attended an education group or a NASS group by the time of their last interview. Table 8 illustrates the changing views of patients, using verbatim quotes where they offer clarity:

Table 8: Initial Thoughts about Group Education, Related to Actual Attendance and Reasoning in later Interviews

Participant	Initial thoughts	Attends Group Education?	Reasoning and reflection
Anew1	[It would be good to] to talk to someone who has got the same thing to see what ... how it affects them. To see if they have got any ways to help you and stuff like that. (Anew1.1: 176)	No	Imagines it would be like AA. I couldn't do it, I would make a fool of myself. I wouldn't get anything out of it. I have got other people to talk to. (Anew1.3: 355)
Anew2	It hasn't been suggested yet, but it would be interesting. People would have different views, but all in the same boat (Anew2.1: 324)	No – but does attend a group discussion about anti-TNF drugs.	I'd have no problem getting there [to the NASS group], but now me son lives with us – I obviously can't take me son as well. (Anew2.2: 318)
Anew3	It would be nice to meet up with other patients in local community centre. Encourage each other to do more, find out what helps. Why wouldn't I – I've got nothing to hide. Anew3.1: 240	No	He was told by a podiatrist there was a group locally, and she would get in contact with more details. She didn't, and he didn't chase it up.
Anew4	From a personal point of view I don't really like doing that sort of thing. I can get the information elsewhere. Anew4.1: 191	No	Never considered it; didn't feel it was appropriate as a GP either.
Anew5	He would go to get some confidence back, to learn what others have done in the same situation, and would give him something to work towards.	No	Comments about NASS – it's a self-help group, I want pain relief. If there was going to be a consultant there discussing pain relief he would go. (Anew5.2)
Bnew1	I don't feel I need a support group, I'm independent, I don't need help, I don't want to be around sick people. (Bnew1.1: 176). Although he does exchange symptoms and 'a moan' with a friend who also has AS	No	He would go to a group now to pass on his own knowledge, (Bnew1.2: 285). In retrospect he feels he would have benefited from going when first diagnosed, and would have gone had he not been given the choice – if it was routine (Bnew1.3: 188)
Bnew2	A good idea for those with less background knowledge than him I don't mix well with people – I couldn't talk to people I had just met. (Bnew2.1: 112 and 160)	No	Couldn't attend the physio group sessions because of shift work
Bnew3	I would be happy to go along – learn from people who were there, how they solve problems, more about what AS is. (Bnew3.1: 138)	Yes	Had to wait for a place on a group course – had to phone up to remind them when not offered a place. Enjoyed the sessions, useful, and better than he envisaged.
Cnew1	Its not for me – I'm not discounting it totally, but I'm happy with my knowledge at the moment. I keep myself to myself. I don't talk about my problems. (Cnew1.1:177)	No	Joined NASS, but didn't go to any groups, and hasn't met or talked to any other people with AS.

Cnew2	Would be interested to meet up and do exercises with other patients – so long as it wasn't too far to travel. (Cnew2.1:200)	No	I don't have symptoms now [on NSAIDs], so if I went to a group it would feel like I was talking about a condition I didn't have. Doesn't want to meet others with severe disease – would become emotionally involved and wouldn't be able to assess or learn objectively. (Cnew2.3:290)
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The four participants who initially state they wouldn't attend a group give reasons relating to their particular personality, indicating a level of privacy or uneasiness when speaking to others in those circumstances. J (Bnew1) and P (Anew4) also make an assessment of their own need for such groups, suggesting that they either wouldn't benefit from attending, or can access the resources offered by other means. Interestingly, J later states that in retrospect he regrets not attending a group, suggesting that he should have been *told* to attend, rather than invited. He compares the situation to that of an alcoholic being treated for his addiction, when attendance at meetings is part of the treatment rather than an optional extra which is not part of the routine (Bnew1.3: 176-200 *not shown*).

T (Bnew3) attended a group organised by the rheumatology department (primarily the physiotherapists) of the hospital he attended. He was originally offered a place when he was first diagnosed, but this never materialised. Later, when his symptoms flared after a fracture of his ankle left him immobile, both he and his GP contacted the department to ask to be included in the group. Although other men were invited to his particular sessions, he was the only one who attended, leaving him to cope with the 'typical women chat' (Bnew3.3: 132) of the other participants during the more informal periods between sessions. Overall, he found the course useful, particularly the opportunities to go through exercises with the physiotherapists, and listening to the questions which other patients asked.

The participants who were initially keen to attend group education but ultimately didn't may offer some insight into the reasons why attendance rates can disappoint health professionals, as described in Chapter 6. The practical issues, such as being unable to attend sessions because of family commitments (e.g. Anew2) are well-recognised. Equally, the circumstances of the interviews may have encouraged the participants to appear more eager to meet other patients with AS, perhaps believing that this would be concordant with

my own views as the interviewer, or even that dismissing these opportunities would be morally unfavourable – suggesting either unsociability or a reluctance to learn³⁸. These concerns may have had less effect in subsequent interviews, allowing patients to speak more openly.

However, issues related to the *timing* of group education in patients' disease course are also evident when considering why patients did not attend. Initially, C (Anew1) states that he is not ready to talk to other patients with AS yet, because he is 'still just getting used to it' (Anew1.1:238) and that he 'only know[s] the basics' (ibid: 242). He suggests that he'll look for the support that comes from other patients only when he's more experienced, perhaps feeling self-conscious and not wanting to display his lack of knowledge to others. Later, during his interview 12 months after his diagnosis, he argues that he 'wouldn't get anything out of it', and that 'he has learnt to get on with it now' (Anew1.3: 371). With reference to the Established Patient Model, C feels *unqualified* to share his experiences with other patients when in the diagnosed phase; later, when established, he judges that he doesn't need to attend.

Thus group education for patients with AS is problematic, and taking a wider perspective, so is the concept of sharing experiences face-to-face with other patients. While many patients will initially express an interest in the idea, this expression of interest may be influenced by the tendency to adhere to social norms, as outlined above. It is the optimum timing of any offer group education that causes particular problems: at each stage of the Established Patient Model, there are powerful reasons why many patients would not attend. When diagnosed, patients feel *unqualified* and, similar to the effect of internet horror stories on their perception of AS, they struggle to decide if others' experiences are relevant to their own problems. When established, they do not consider that they *need* group education, or alternatively they can access help through other resources which have less emotional and time cost. Clearly some patients will attend when newly-diagnosed, overcoming the feeling of being unqualified, but it is likely these will be patients who have better social skills. Equally, the groups could be comprised only of newly-diagnosed patients, but this would diminish the potential for learning from other, more experienced

³⁸ In both these cases, however, I would expect any perceived 'coercion' in the setting of these interviews to be less evident than in the clinical setting – where patients are arguably under greater pressure to accept education which is offered.

patients. Those participants who continued to attend ongoing groups such as the NASS group did so for reasons other than education. Both E (Crev3) and V (Crev4) had been attending the group for many years. The group was part of their regular social lives, a chance to meet friends, and a protected time to do the exercises that were part of their weekly routine.

Finally, I would like to address the *image* of group education – what patients envisage attending a session will be like. J (Bnew1) reports that he won't attend because he 'doesn't want to be around sick people' (Bnew1.1: 176) and, rather than people who complain about their problems, he would prefer to be around 'people who are going to help him to progress on' (ibid: 178). Similarly, he feels attending these groups will identify him as someone in need of help, at odds with his own image of self-reliance. Others, like L (Cnew2) and C (Anew1) envisage meetings like 'Alcoholics Anonymous', finding the idea of sitting in circles and discussing their problems unappealing. In contrast it is the tangible, practical benefits which seem to appeal – the opportunity to discuss treatments with a Rheumatologist or to discuss exercises with a physiotherapist. I would suggest that it is these constituents of education programmes that should be emphasised when encouraging patients to attend.

In summary there is a desire to share experiences with other patients, but for people with AS, this desire alone is not sufficient to persuade them to meet face-to-face with other patients whom they haven't met before. I would hypothesise that it is alternative methods to share experiences that are likely to be of greatest benefit to the greatest number of patients. This could be by utilising the internet or by encouraging group interaction during more routine activities like learning exercises, or discussing possible treatments, timed when this is relevant to the individual patients' needs.

7.2.4 Health Professionals

As I discussed in the Introduction, some commentators would not consider the interactions which take place between patients and health professionals as part of routine clinical care to be *patient education*, yet health professionals can significantly influence patients' learning about AS, using methods which overlap with routine patient care. However, their role in this process is not straightforward: there is considerable variation in practice

between professionals and their views of what education should achieve are not necessarily concordant with patients' (see Chapter 6). Within this section I will describe the role of health professionals in patients' learning about AS from the patients' perspective. I will focus on the extent of HPs' influence on patients' education, and on patients' expectations and judgements regarding HPs' practice. Through this analysis, I hope to highlight important areas of health professionals' practice which impact on patients' learning.

The three health professionals which were consistently involved in the care of the patients I interviewed were a Consultant Rheumatologist, a Physiotherapist and a General Practitioner (GP). Other professional groups mentioned were Occupational Therapists, Specialist Nurses, Podiatrists, Osteopaths, Chiropractors, Orthopaedic Surgeons and Disability Advisers. An in-depth study of the role of each of these professions in the care of people with AS, or indeed of patient-professional interactions, is not possible using the research methods I chose. However, there were issues which arose during my analysis of the interviews which are worth commenting on in the context of this study.

In Chapter 5 I described the diagnosed phase of the Established Patient Model as consisting of a rush for information, guided by the diagnosing Rheumatologist. This guidance begins during this first consultation, when the diagnosis of AS is explained to the patient, and further information about the condition usually offered. Immediately, the consultant becomes the definitive source of information about AS. While information gained elsewhere requires verification from other sources, at this stage the guidance offered by the consultant is not questioned. They are viewed by patients in this way because they are a nominated expert on AS, but also because for many they represent the culmination of their search for a diagnosis, and their opportunity to get better. They are thus fulfilling the doctors' role in Parson's sick role discussed in Chapter 2 (Parsons, 1951). Excerpt 3 illustrates further the influence of the diagnosing consultant:

Excerpt 3: Anew1.1

- 131 I OK. You also mentioned, C, that you have sort of been on the internet and had a look around. Why did you do that? Why did you think about going on the internet?
- 132 C The doctor says there is some websites that you can look at and that and there is a group that you can send off to and get newsletters and that sent off them and stuff.

- 133 I Yeah.
- 134 C I have never joined up to that like but I thought I would check on the internet and see if there is owt on it.
- 135 I Yeah.
- 136 C She says there will be websites saying they can sell you pills and stuff and health things to help you and that but she says don't get 'em because most of it is just crap.

In this example C reports that he looked at information on the internet because this was suggested by his consultant, and then (136) that he has followed her advice not to buy the dubious cures marketed to people with AS. Thus even his use of the internet, often viewed as an independent and potentially empowering source of information for patients, is significantly influenced by his consultant. In addition, the excerpt also illustrates consultants' role in increasing patients' awareness of sources of information, suggesting places to search for information rather than providing the information themselves. As already described in section 7.2.1 regarding information booklets, when consultants recommend information sources in this way the likelihood that they will be used increases and they take on additional legitimacy.

The diagnosing consultant has a role not only to provide and signpost sources of information which would be useful to patients, but also to involve other professionals. In this cohort only T (Bnew3) was initially seen by a Rheumatology physiotherapist rather than a consultant, therefore in the remainder of cases it was only through referral that patients had the opportunity to see these professionals. Like information sources, patients were more willing to consult other health professionals if they were recommended by the consultant, and the rationale for seeing them explained. In particular, there was little understanding of the existence or role of OTs and disability advisers by those patients who subsequently greatly appreciated their input and advice. Misunderstandings about the roles of allied health professionals occurred, contributing to patients not attending appointments which might have helped them; I will discuss this further in section 7.3 on vulnerable patients. Similarly I will return to the role of physiotherapists in the next section when I address the topic of exercise.

There were other key roles of health professionals, beyond those of providing definitive information, and of signposting and explaining the relevance of educational resources.

Firstly, health professionals had a unique position in applying generic information about AS to the individual circumstances of the patient. Examples of this arose commonly during the interviews, and included advice about whether particular exercises or sports were safe or advisable for them, how likely they were to develop complications of AS such as heart or lung disease, the best painkiller to take for a flare, or whether their baby would develop AS in the future. In each of these examples, the interview participants had searched unsuccessfully using sources like the internet and information booklets. Often, they had found relevant information, but the answer they found was incomplete – it did not address their precise question; the information didn't relate to their own circumstances.

Health professionals are also important in the process of 'keeping up-to-date' when patients are *established*. For M (Arev1), her annual follow-up with her Rheumatologist was her opportunity to find out if there had been any improvements in the treatment of AS relevant to her. For others, review appointments kept them informed about their own condition – whether their mobility, clinical scores, or radiological appearances had declined, and therefore whether they had new learning needs in relation to this *new problem*.

Patients made judgements about the health professionals they saw, based on their own experience and expectations. Consultants' communication and personal skills were normally commented on, but not their medical knowledge. Some patients were conscious of the pressures on their time such that they did not want to 'bother them with their problems' (Anew4.1: 277), while others felt, retrospectively, they would have benefited from more time with their consultant at the time of diagnosis. Other professions were judged regarding their knowledge about AS and their ability to offer advice which was specific to the patients' individual circumstances. Those professionals whom they had consulted prior to their diagnosis of AS and were perceived as having ignored their symptoms or 'missed' the diagnosis were particularly criticised. Overall, there was an understanding that GPs dealt with a large numbers of conditions, and wouldn't have in depth knowledge about all of them. For a minority, GPs remained their first point of contact in the event of problems; for the majority the hospital rheumatology department fulfilled this role, either through a specialist nurse, physiotherapist or consultant's secretary.

Health professionals' role is therefore vital for patients' learning about AS. Uniquely, they can offer information which takes into account the personal and clinical background of the patient. In the case of the Rheumatology consultant, this information is usually considered definitive information, as a result of the trust relating to their status as an expert and their role in reaching a diagnosis. When *diagnosed*, patients rely on HPs to inform them of resources which they may find useful, to help them avoid common pitfalls of those resources, and to apply the information they find to their own circumstances. At this stage they are also important because of their ability to set the overall *tone* for the management of a patients' condition, maintaining hope and relaying messages about the importance of keeping as active as possible, the availability of effective treatments, and the low probability of severe disability. Later, when *established*, they help keep patients up-to-date with their own health and with the management of AS. They also remain part of the solution to many of the problems patients face.

Until now this chapter has dealt with the sources of education available to patients, focusing on the practicalities of their use. Now, I will move from the resources to one of the topics considered most important by health professionals.

7.2.5 Learning about Exercise

Health professionals viewed education as a method of increasing the amount of exercise people with AS performed, and in fact rated this as their most important aim of education (see Chapter 6). This could be explained by their belief that both the symptoms and long term disability due to AS are modifiable by exercise and that education may change exercise behaviour. This section seeks to explore the link between education and exercise for people with AS, particularly the amount and type of exercise they report, and to consider the factors which influence this, including the education they had received.

All the interview participants were aware that exercise was an important aspect of the management of ankylosing spondylitis; this had been explained by health professionals, at or close to the time of diagnosis. No-one had been given any other opinion or advice, and resources on the internet and information leaflets reinforced this message. Physiotherapists were recognised as the key individuals in the process of learning about exercise, although some participants initially considered them to be involved in the recognition and treatment

of sporting injuries rather than chronic joint conditions such as AS. All the interviewees had been referred for physiotherapy at least once; K (Anew5) was the only new patient who did not attend any appointments. He explained that he had ‘nearly been killed by a physiotherapist’ (Anew5.1: 218) when he had attended as part of his treatment following a car accident, and that he couldn’t risk further pain given his current health. K discussed his reasoning for not engaging with physiotherapy with me, but didn’t discuss his thoughts with his Rheumatology team, instead choosing not to attend the appointments he was offered. I consider K to be a vulnerable patient, and will discuss the ways in which he interacts with healthcare further in section 7.3.

Patients described a range of experiences at their appointments with physiotherapists. The newly diagnosed patients waited until seeing a physiotherapist before commencing or changing any exercise routine, preferring not to use written information alone. Some described being measured, referring to the metrology indices³⁹ used to assess range of movement of the spine and other joints. The exercises described and recommended in the information booklets were referred to; some also described other exercises they could carry out. However, there was some variation in the degree to which they were demonstrated and the patients’ technique assessed. Like other health professionals, physiotherapists were judged by patients according to their perceived knowledge of AS, their personal and communication skills, and their ability to offer expert, tailored advice.

There was variation in the extent to which patients followed advice to exercise, in terms of both the *form* of exercise they did, and the *regularity* which they performed it. At one extreme, some patients did no exercise, describing either a painful reaction to the exercises they had tried, or an absence of symptoms which made exercises seem irrelevant and unimportant. At the other extreme, there were patients who carried out regular, prescribed exercises at least twice a day, often doing other activities as well. These patients were more driven by necessity than any long term view of their health, illustrated in Excerpt 4:

³⁹ The Bath Ankylosing Spondylitis Metrology Index (BASMI) is commonly used to assess restriction of movement in AS. It is a standard set of measurements which can be repeated serially to assess disease progression and the effects of exercise and other treatments. [Jenkinson, T., Mallorie, P., Whitelock, H., Kennedy, L., Garrett, S. and Calin, A. (1994) 'Defining spinal mobility in Ankylosing Spondylitis (AS). The Bath AS Metrology Index ', *Journal of Rheumatology*, 21, (9), pp. 1694-1698.

Excerpt 4: Anew1.3

- 189 C Well that's [exercise and stretching] a big part of your life. When you have got it like you have to stretch yourself out. If it is bad you have to do it.
- 190 I Yeah.
- 191 C There are no two ways about it.
- 192 I Yeah, because if you don't then you?
- 193 C Do a good hour and a half/two hours of it a day.
- 194 I Is that what you are doing at the moment?
- 195 C I have to.

This group of patients⁴⁰ found that omitting exercise resulted in a deterioration of their symptoms which rapidly persuaded them to restart their routine, making time in their day to carry out what was often painful, and certainly repetitive stretches. In each case they performed their *own routine* of stretches which they had personalised and adapted from different sources, often picking up new stretches from physiotherapists or suggestions from internet sites. V (Crev4) was the only participant who carried out a similar daily exercise routine despite not experiencing the same immediate impact on their symptoms. V explained his routine with pride, recalling that he had begun his exercises around 25 years ago after he read a national newspaper article about AS titled 'Don't Go Bent'. This seemed to be the motivation behind his dedication; V had feared a dramatic change in his appearance and spinal mobility, and had been able to exercise in response, supported by his weekly NASS group.

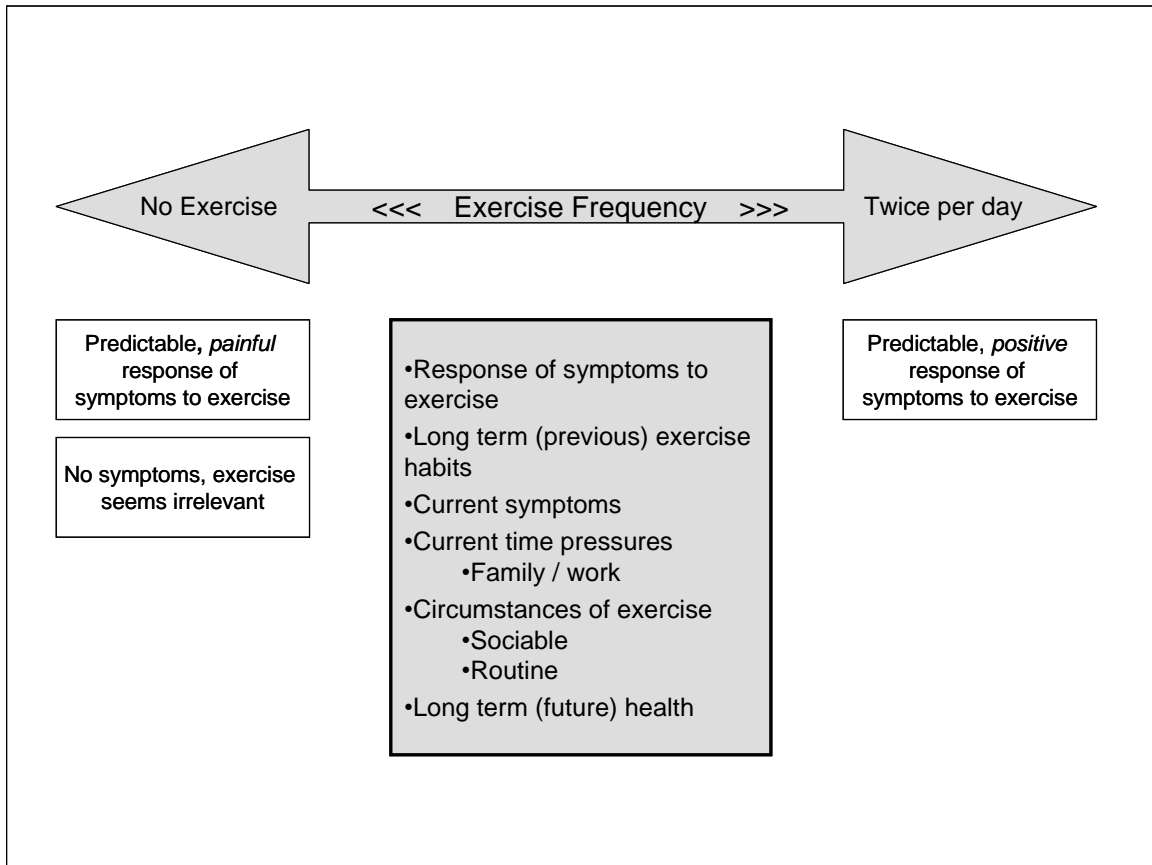
Between these two extremes of exercise are people who are equally aware of the advice to exercise, and do not describe a different process of learning about exercise. However, because of a combination of factors, they either carry out different exercises, or do not perform the prescribed stretches as often as suggested. For example, B (Bnew2) tried the prescribed stretches, found little difference to his symptoms, and therefore continued his regular swimming and gym attendance. He was initially limited by his shift pattern at work, and later by time commitments due to a new baby and his wife's illness. Q (Brev2) had previously found the prescribed exercises painful but persisted with them because they had

⁴⁰ In this cohort of new and review patients W (Anew3), P (Anew4), J (Bnew1), G (Arev4) also described a similar scenario.

some effect on his mobility and symptoms over the rest of the day. Since starting anti-TNF therapy, his mobility had improved and his pain and stiffness had nearly resolved. The stretching exercises remained painful to perform and there was no longer the benefit of any improvement in his symptoms. He therefore remained active by playing golf and walking, but had stopped the prescribed stretches.

Figure 19 illustrates the factors which the interviewees described as having an impact on the frequency of their exercise. The effect of the exercises they attempted on their symptoms was the most influential factor determining whether people with AS continued to exercise, followed by previous exercise habits. When *diagnosed*, there was a belief amongst some patients that they would exercise regularly in an attempt to maintain their flexibility, but this evaporated relatively rapidly without the feedback from improved symptoms, as exercise competed for time with the tasks of daily life. Instead, exercise behaviour reached an equilibrium determined by the factors listed.

Figure 19: Factors Influencing Exercise Frequency, As Described by Interview Participants



Within this project, therefore, the factors determining exercise behaviour and frequency do not appear modifiable through education. Instead, education soon after diagnosis is essential to *allow* people with AS to exercise effectively - to inform patients that exercise can improve the short and long term symptoms of AS, and to help them to develop a programme which is consistent with their. Initially, patients need 1:1 assessment and education with a physiotherapist who can teach appropriate exercises, address possible misconceptions about exercise and AS, and answer questions about whether they should modify any of their other activities. Equally, those people who do not exercise because they have found it painful may be doing exercises incorrectly or exercises which are inappropriate for them, and should be reassessed by a physiotherapist. For some patients, the ongoing support from a physiotherapist and the social contact with other patients provided by the NASS group encourage long term participation in exercise, but these may only be attractive to a limited number of patients, as discussed in section 7.2.3.

In summary, while education is viewed by health professionals as a method of increasing exercise by people with AS, its impact on established patients is likely to be limited. Initially, diagnosed patients need education because they are concerned that exercise may damage their now fragile backs, and want advice about the appropriate form and regularity of exercise *for them*. This is particularly important for those with severe disease, because these patients found the exercises illustrated in the standard resources impossible to perform due to joint restriction. They need help to integrate appropriate exercise into their lifestyle, given their current health and social circumstances, and to develop a programme which offers short term gains as oppose to solely the promise of long-term benefit.

However, while it was apparent that the motivation of preventing long-term restriction of spinal mobility helped patients to *initiate* an exercise programme, it was insufficient to *sustain* it. Instead, it is the factors referred to in Figure 19, particularly the response of symptoms to exercise, and pre-existing exercise habits, that better reflect the factors influencing their ongoing level of exercise. People continue to exercise if it makes them feel better, allows them to carry out daily tasks which they otherwise couldn't, or as part of a social routine with other people. One fundamental question that arises from this analysis of exercise behaviour is whether there is a subset of patients with AS who will consistently experience a deterioration in their symptoms when they exercise or stretch, or alternatively,

whether they are performing the ‘wrong’ exercise and therefore would benefit from education to improve their technique.

Until this point, I have considered how patients have used and interacted with the educational resources available to them. The next section on Vulnerable Patients continues this theme, but looks specifically at those patients who struggle to use those same resources, and often make choices about their health which are not expected by health professionals.

7.3 Vulnerable Patients

This section arose from the analysis of my interviews with patients whose pathway from *diagnosed* to *established* was not straightforward. These were people who struggled to find answers to their own questions about the condition and how to live with it. Furthermore, they did not engage with the medical or information sources which were available to them in a manner which health professionals and the organisation of healthcare might expect them to. Here, I will outline the characteristics of these patients, exploring the aspects which make them ‘vulnerable’ and considering the consequences for their health and healthcare. I will then suggest methods that health professionals could employ to recognise these patients, and modifications to practice which may improve their access to and use of resources.

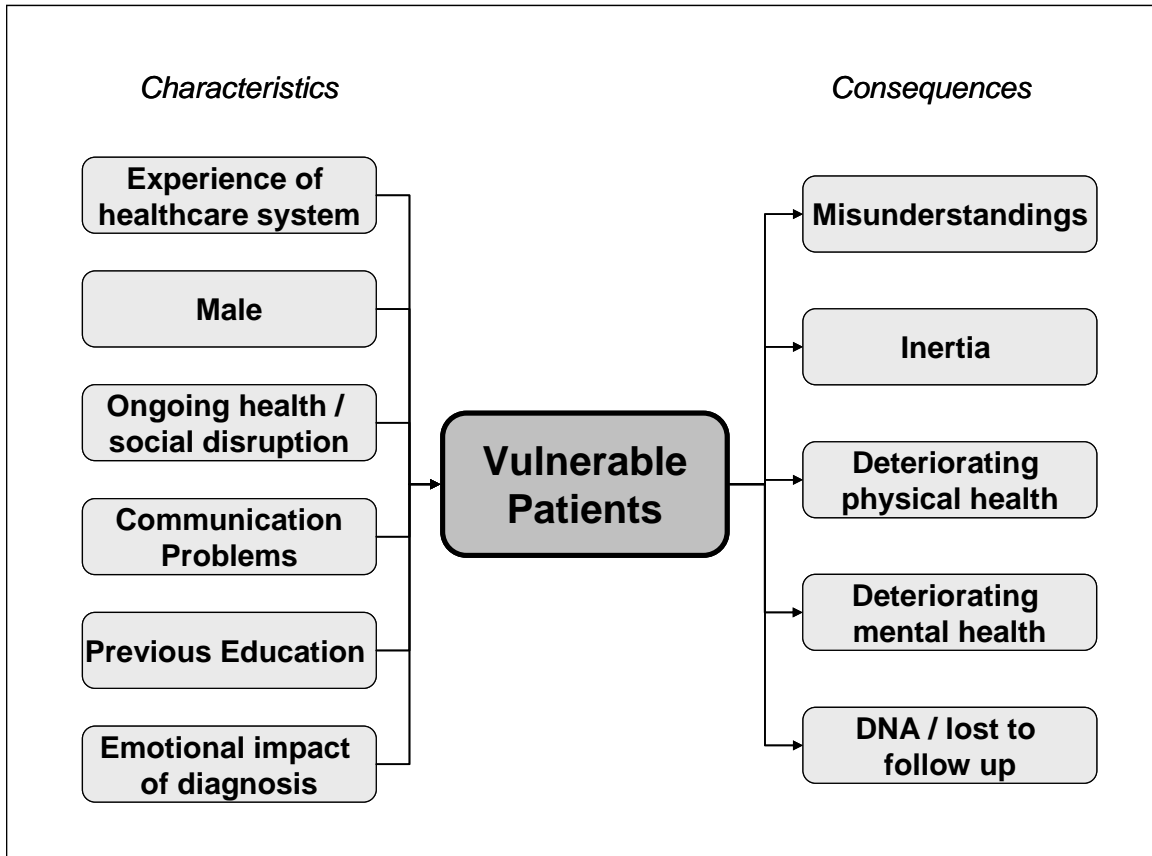
This topic first emerged following my interviews with K (Anew5), and developed through comparison with other patients, some of whom I also described as vulnerable. It proved difficult to meet with K, despite his willingness to arrange an interview when I spoke to him by telephone. On occasions he wasn’t in when I attended; on others he cancelled shortly before I was due to meet him. I made efforts to encourage him to re-engage with medical services when it was clear he would be discharged by his rheumatology team because he repeatedly failed to attend appointments. These efforts were unsuccessful, and I was unable to arrange a third interview when his phone number ceased to exist, and he didn’t respond to postal correspondence; I later found out he had moved house.

I found the interviews themselves difficult, in part because they accentuated the conflict I felt between my role as interviewer and clinician more than any of the others (see also section 4.2.2.4). Until my first interview with K I had tried to separate these roles as far as possible, answering questions about AS which arose only at the end of each interview. While I had already become uncomfortable about allowing misunderstandings to pass unchallenged, postponing explanations and leaving questions at least partially unanswered, when speaking to K I judged that this approach had become untenable. During the first interview misunderstandings emerged: he surmised from comments by clinicians that there was no effective treatment for AS, because he had been told that surgery was not an option and because his neck problems had been described as ‘degenerative’. Similarly, he considered that he was now at significant risk of ‘breaking his back’ (Anew5.1: 50) after

only innocuous injuries and that this could leave him paralysed for the rest of his life. These initial misunderstandings were to some extent consistent with other newly-diagnosed patients. However, it was their persistence and expansion at K's second interview 8 months later which was more remarkable, along with their impact on his health, healthcare and social life. During K's second interview, it was apparent that now he believed he was unable to consult his GP about his pain, because he had been referred to a Rheumatologist. Equally, he hadn't attended any appointments with his Rheumatologist, ostensibly because he still felt treatment was futile. He had also bought an exercise rower at considerable expense, but had unsurprisingly found this too painful to use, and had tried using alcohol as an analgesic.

The apparently simple solution to this situation would be to offer education to 'correct' these misunderstandings, but as I discussed in Chapter 5, K stopped searching for information about AS because he did not feel it would reduce the disruption due to AS. Similarly, my own efforts to explain more about AS and suggest methods to improve his health and social situation did not seem to influence his actions, despite both he and his partner being appreciative of my attempts to help them. This encouraged me to try to understand more about the factors influencing K's understanding of AS and his behaviour regarding his health. I did this through the analysis of my interviews with K, a comparison with other new patients, and through my recruitment and subsequent analysis of follow-up patients. My findings are summarised in Figure 20.

Figure 20: Characteristics of Vulnerable Patients, and Consequences for their Health and Healthcare



Like the model of the aims and functions of patient education from the perspective of health professionals illustrated in Chapter 6, Figure 20 remains a hypothesis rather than a substantive theory. There may be other factors, both characteristics and consequences for vulnerable patients, which I have not considered here; further interviews may allow me to refine these categories. In addition, the limitation of space within this thesis has reduced my capacity to expand on each of these categories fully. The following paragraphs describe some of the interview data which led to this model.

In Chapter 5, I explained how AS is universally *unknown* for newly diagnosed patients, a condition which most had not heard of before, and the remainder had never considered in a manner which applied to them. For C (Anew1) in particular, this lack of knowledge was heightened by the lack of any personal, practical experience of navigating the healthcare system, and additionally, the absence of social contacts with people with those skills. Practical problems resulted from this. He too was uncertain regarding whether he could still consult his GP, specifically about appropriate analgesia, and interpreted his Rheumatologist's statements with an unhelpful, unquestioning certainty. Equally, he did

not address his problems at work in a constructive manner, taking sick leave and expecting redundancy without either attempting to explain his health problems or seeking advice about his options. There was paralysis of action which, like K, seemed rooted in both a misplaced sense of futility and uncertainty about how he should behave in these circumstances.

The symptoms of AS had an impact on patients' sense of self (see section 2.2.2.2.1) which contributed to their vulnerability. In the examples I encountered it was the impact on male patients which seemed particularly important. K reported that AS made him feel 'completely useless as a bloke' (Anew5.2: 24), ranging from embarrassment that his female partner now earned more than him to his reliance on her help with physical tasks such as changing a wheel on his taxi. Other participants spent considerable time during interviews describing their personality and activities prior to being affected by AS, for example a love of ice-hockey, DIY and work (W, Anew3, *not shown*) in a manner which served to emphasise a masculinity which they had now lost. In turn, vulnerable patients retained their *self-reliance* even when it was detrimental to their health, refusing help from others in an attempt to preserve aspects of their masculinity when it was under threat elsewhere.

A (Arev3) had been diagnosed with AS 3 years ago, although he stated he had first encountered the term when he received a copy of a clinic letter 3 months before my interview. His first language was Bangladeshi Bengali; I had offered to arrange an interpreter for the interview, but he had declined because he felt this would be unnecessary. Like the people I described above, he had deteriorating physical health and was experiencing serious social consequences due to his AS, having lost his job as a chef and built up significant debt. Similarly, misunderstandings about his health were evident, and had adversely influenced his navigation of the health and social care systems. In my judgement, these misunderstandings stemmed from language difficulties, and this also seemed to limit the scope of the interview. Yet he felt that educational materials in his first language would not be useful, nor would better access to interpreters. Like other vulnerable patients, solutions to A's problems would not be by simply providing more education in its current form, but require greater investigation of A's interpretation of his problems, in circumstances where engaging with him was not straightforward. .

Based on the experiences of the patients I interviewed, I would suggest employing the following strategies with patients who have the characteristics described in Figure 20. The initial assessment is likely to take more time, and while this should ultimately involve multiple professionals, it is also vital that a single professional – likely to be the consultant or a specialist nurse – co-ordinates this and begins to build a relationship with the patient. It is unlikely that group education would be accepted, and therefore education should be one-to-one with professionals, forming part of the assessment process, and aiming to acknowledge and understanding patients’ current perception of AS and their wider problems. Where involved, occupational therapy proved particularly important at addressing the practical problems which were important to patients. Equally, for those with employment and financial problems, Citizens’ Advice and disability organisations were useful. In each of these examples it is also important that the referring Rheumatologist explains to patients the role of these professionals and the rationale behind the referral, checking their understanding in each instance.

Secondly, for those with little experience of the healthcare system, there are unwritten rules regarding its navigation which health professionals assume patients understand, but which are evidently not always acted upon. Most importantly, it seems essential to emphasise the action patients should take if they deteriorate, rather than presuming that patients will re-present or ask for help appropriately if symptoms worsen.

Vulnerable patients had particular problems explaining AS and its implications to their friends, family or employers, and therefore it may be possible to devise strategies which would help patients do this more effectively. Suggesting patients use an information booklet as a starting point would seem appropriate.

Finally, when talking about AS, it is important to not only address individuals’ particular fears about the condition and specifically their future, but also to offer hope in the form of management options. As I mentioned in section 7.2.4, health professionals are vital in setting the *tone* of the management of AS, and these patients seem to hear the negative aspects more clearly than the positive, leaving consultations with negative misunderstandings typified by K’s belief that there is no treatment for AS.

In this section I have briefly described the characteristics of a group of patients who do not navigate the health care system in ways which health professionals would expect. They have the capacity to misunderstand information about the condition itself and the best methods to manage it, making choices which are likely to be detrimental to their health. Within this research project, the characteristics of this group are summarised in Figure 20: male patients, those with little experience of the health care system, low previous educational attainment, an emotional reaction to the diagnosis, and ongoing disruption were most at risk. These characteristics do not inevitably lead to the consequences also listed in this figure. Indeed, people with very similar backgrounds can progress very differently; while S (Anew2) was as disabled as K (Anew5) and more socially isolated, he accepted help from different professions and both his health and social circumstances improved. Similarly, vulnerable patients can change; the transformation of C (Anew1) between his first interview around the time he was diagnosed with AS and his subsequent interview a year later⁴¹ was dramatic. By then, despite still having intrusive symptoms due to his AS, he understood his role in navigating and engaging with the health service, had adopted an exercise programme, and had explained his condition to his family and friends.

⁴¹ When I tried to arrange C's 6 month interview he told me, through his mother, that he would prefer not to continue in the study. He later agreed (through his consultant) to participate in a further interview a year after diagnosis.

7.4 Conclusions

This chapter has described patients' experiences of widely available educational resources for patients with AS. Focusing on the practicalities of individuals' use of resources such as information booklets and education groups, it begins to explain when, why and how patients choose to use them, and the strengths and limitations of each method. While patients use and evaluate these resources in a variety of ways, the patterns which have emerged in the analysis and which I have considered in this chapter could help the development of resources in the future.

It has been useful to apply the Established Patient Model to each resource, considering when in the disease course most patients choose to use it, or find it most useful. For example, the leaflets are used when diagnosed, but seem to offer little to those patients who are established or facing new problems. Thus, in their current form they function as an introduction to the condition, rather than providing ongoing education. Equally, the model helps to elucidate some of the reasons why opportunities to share experiences with other patients, and in particular group education, are not taken up to the extent health professionals envisage. When considered hypothetically, patients view group education extremely positively, but there are relatively few who choose to transform this interest into attendance at such sessions. There is a strong, partly moral, obligation to volunteer, but newly-diagnosed patients are unsure how to present themselves to other patients they have not met before, and find it difficult to put others' experiences into the context of their own illness. Later in the disease course offers of group education are also unlikely to be accepted unless there are significant practical benefits offered which address the problems of the established patient, because patients lack the immediate need (and therefore motivation) to attend.

The information content of each resource proved difficult to appraise, and therefore it was not possible to reach definitive conclusions about its adequacy and appropriateness. Any criticism by patients of the leaflets, for instance, was unsurprisingly related to their own circumstances. Thus, those with severe disease who had presented later than their third decade felt that their perspective of AS was not sufficiently represented. Similarly, others felt there should be more information about the specific treatment that they had been offered. While the information available via the internet is limitless, this does not mean that

patients will necessarily find what they are looking for. Equally, it is not treated as definitive, and usually requires clarification or verification that it is applicable to patients' own particular circumstances from a health professional. Therefore, with regards to the content of education, it seems futile to recommend any sort of curriculum for patients with AS. When diagnosed, patients need answers to their fundamental questions of 'why have I got AS?', 'what is going to happen to me?', and 'what can I do about it?' (See section 5.2.3). In each case the answer is different depending on the individual patients' circumstances. Subsequently, the content required by patients from the resources available depends on and is determined by their circumstances. It is only by enabling them to search for answers to their questions, encouraging HPs to answer the queries that result from these searches, and to discuss issues in a manner which enables them to ask questions that this content can be met.

Overall, the chapter has emphasised the indispensable role of health professionals in education for people with AS. In Section 5.2.2 I discussed patients' dependence on health professionals to initially diagnose AS, and allow them to access the information about their condition which was inaccessible until then. However, despite considerable availability of information, this dependence continues, manifest as a reliance on HPs to provide, suggest and interpret available resources, and then usually to facilitate the benefits – such as alternative treatments - they may have learnt about.

Finally, the topic of vulnerable patients, and specifically the optimum methods providers of education should employ to aid their education, will continue to prove difficult to study. Patients who do not engage with medical services for any reason are unlikely to volunteer to participate in research projects. In this project I purposefully recruited patients who might fit these characteristics in the review patient stage, but even with the small numbers involved in this study, it required considerable time and persistence to meet and interview such patients. Nevertheless, it is clear that the existing norm of providing written information with little additional discussion, and offering group education and referral to other professionals, again with little explanation, is not sufficient for these patients. I hope the section offers at least a starting point for the recognition of these patients, and practical changes to this norm which could be employed.

The next chapter moves away from the interviews with patients with AS, bringing together the first three results chapters and discussing feedback received from patient and professionals.

Chapter 8 – Filling the Gaps and Feeding Back

8.1 Introduction

This short chapter represents an opportunity to reflect on the results of the project, beginning to summarise the principal findings and considering their impact for patients with AS and the professionals who work with them. It will also investigate important topics which so far have been overlooked, reporting the results of the telephone interviews I carried out with Consultant Ophthalmologists and Gastroenterologists, the second focus group with NASS members, and the final online survey with patients and professionals. The rationale behind each of these studies and a description of the methods I used is outlined in Chapter 4, Methodology.

8.2 Telephone Interviews

These interviews aimed to verify that the information which Rheumatology professionals offer patients is consistent with the views and practice of the relevant medical specialists. Some complications of AS are primarily managed outside Rheumatology departments, notably those relating to eyes and bowels which are managed by Ophthalmologists and Gastroenterologists respectively. These topic areas were highlighted during new patient interviews as being inadequately covered by existing sources of information, leaving them uncertain and worried regarding the risk of these complications, which symptoms they should look out for, and the action they should take if these occurred.

During the project we therefore decided to conduct brief, structured telephone interviews with three Consultant Ophthalmologists and three Consultant Gastroenterologists, asking them about the complication itself, and the information which newly diagnosed patients with AS should be offered (see Telephone Interview Schedule, Appendix VIII). The outcome of this aspect of the project are recommendations about the content of information for newly diagnosed patients, which have been implemented as changes to the Arthritis Research UK patient information booklet (See Table 9 and Table 10).

8.2.1 Ophthalmology Consultants

Three Consultant Ophthalmologists were recruited and interviewed as described in Chapter 4. One had a particular clinical interest in acute anterior uveitis, the principal eye complication affecting people with AS.

All three participants acknowledged the importance of people with AS being aware of the potential for eye problems, because of the high probability of them experiencing the condition⁴², and the need for prompt treatment with steroid eye drops to avoid long term complications – potentially blindness. Eye symptoms which patients should look out for were stated as redness, pain, photophobia, and sometimes watering, usually unilaterally. Clouding of the vision may occur after 24 hours, but loss of visual acuity does not occur asymptotically, that is without the other preceding problems.

⁴² Lifetime incidence for people with AS 25-30%, quoted by participant 1 during the telephone interview. Rheumatology texts suggest up to 40% [Watts, R., Clunie, G., Hall, F. and Marshall, T. (2009) *Oxford Desk Reference: Rheumatology*. Oxford: Oxford University Press.]

The participants had particular concern about the urgency with which patients presented to specialist eye care, and the route by which they presented. In the ophthalmologists' experience some patients were not aware of the need to seek medical attention promptly, and they felt this needed stressing in any literature. Ideally, people with AS who develop the eye symptoms described should attend their local Eye Casualty within 24 hours of the onset. However, the opening time and location of Eye Casualties varies from region to region. In Newcastle for instance, the Eye Casualty is not at the same hospital as the general Accident and Emergency department, and is open during office hours Monday to Friday, and only during mornings at weekends. Opticians may be able to diagnose anterior uveitis (which requires a skilled, slit-lamp examination of the eye), but the participants did not consider that patients should present there because they cannot offer treatment and may not have sufficient training or experience to confirm or adequately exclude the condition. Similarly, GPs could advise where the appropriate Eye Casualty was located, but could not diagnose or treat the condition. Accurate diagnosis is particularly important because eye infections have similar signs and symptoms, and the treatment for acute anterior uveitis (steroid eye drops) causes such infections to deteriorate.

Patients who experience multiple episodes of uveitis tend to learn quickly the typical first signs of an attack. These patients may have their own supply of steroid drops, or be able to obtain them from their GP without having to attend eye casualty.

Table 9: Recommended Content Regarding Acute Anterior Uveitis For People with Newly-Diagnosed AS

People with AS can also get an eye problem called ‘anterior uveitis’ which is also called ‘iritis’.
The first signs are usually a painful and sometimes watery eye. The white part of your eye becomes red or ‘bloodshot’. It might be uncomfortable to look at bright lights. Later, if untreated, your vision might become blurred.
If this happens to you, it’s important to get medical help quickly – within 24 – 48 hours. The best place to go is Eye Casualty – there will be one in your region, but it might not be at your local hospital. Your GP surgery, local A+E, or even your optician will know where the Eye Casualty is.
Treatment is usually with eye drops, which are generally very effective. Some people get recurrent attacks, but it is extremely unlikely to cause permanent damage to your eyesight if attacks are treated quickly.

8.2.2 Gastroenterology Consultants

The three Gastroenterologists recruited each had a clinical interest in inflammatory bowel disease (IBD). They were less concerned regarding people with AS compared to the ophthalmologists, suggesting that both patients and their health professionals were aware of the link between AS and IBD, and were therefore more likely to report their bowel symptoms to their doctor than people without AS. In turn they were more likely to be referred for investigation and subsequent treatment. Similarly the consultants indicated that there is not the same need to encourage rapid presentation for treatment as for eye symptoms.

The participants discussed two types of inflammatory bowel disease - Crohn’s disease and ulcerative colitis, which are more common in people with AS. In addition, colitis associated with NSAID use was also discussed and the difficulties in managing patients with bowel problems who are reliant on NSAIDs for treatment of their joint disease.

Overall, the gastroenterologists interviewed did not feel that there was a need to routinely offer patients with newly-diagnosed AS detailed information about inflammatory bowel disease. If they developed symptoms they need appropriate investigation and management; if the diagnosis was confirmed then there were many potential information sources about IBD which could be recommended.

Table 10: Recommended Content Regarding IBD for People with Newly-Diagnosed AS

People who already have AS can also get bowel problems known as ‘inflammatory bowel disease’ or ‘colitis’. With these conditions there is inflammation in the bowel wall, similar to the inflammation affecting the back with AS.

It is worthwhile talking to your doctor if you start with diarrhoea (loose, watery stools) which lasts longer than 2-4 weeks, or if you notice blood in your stool. You may be referred to a specialist in bowel problems (a gastroenterologist).

Inflammatory bowel disease is variable, but it can usually be treated successfully with medication. Sometimes treatments like NSAIDS can make bowel problems worse, and you might be advised to try and stop them.

8.3 Feeding Back to NASS

Members of the Tyne and Wear NASS Group took part in a focus group at the outset of the project which aided the development of the interview schedule for the patient interviews, and which also offered insights into the differences between patients' and health professionals' perception of patient education. This second focus group, at the close of the fieldwork, aimed to offer feedback regarding the results of our research to NASS members; the session was also designed to provide further verification for our results, through the discussion and comments generated by the presentation (see Chapter 4).

Seven NASS members (5 male, 2 female) participated in the focus group, which took place after the normal weekly meeting. Four of the participants had taken part in the first focus group. In addition the physiotherapist who facilitated and supervised the NASS group participated in the discussion, in contrast to the first focus group which was not attended by other health professionals. Written consent was obtained, and no members declined to take part - although the group had been planned and publicised at earlier meetings, allowing those who potentially did not want to take part to choose not to attend.

My presentation focused on the Established Patient Model and sought to encourage participants to share their own experiences and opinions which could be either consistent with or contradictory to our findings, and to discuss the results amongst themselves. It was therefore regularly interspersed with questions for the participants, and questions for clarification or comments were encouraged. Topics raised by the participants themselves were pursued as per standard focus group procedure, with any relevant additional results from the project put to the participants during this phase of the discussion. While I had originally planned to discuss other topics from the project, such as vulnerable patients (Chapter 7) my opportunities to do so were curtailed by time.

The explanation and examples I used to illustrate the stages of learning described in the Established Patient Model were recognised as valid and representative of participants' own experiences. In particular, the search for an explanation, for information and for legitimacy which occurs *prediagnosis* was acknowledged and paraphrased as the process of 'fighting to get a diagnosis'. Similarly one participant's recent experience was seen as an example of an *established patient* returning to educational sources he had used previously when he

encountered a deterioration of his symptoms – his *new problem*. He had returned to the NASS group after a period away when his ankylosing spondylitis was less disruptive.

All the participants had been diagnosed with AS more than 10 years ago, and the group spent time discussing the extent to which the *rush for information* during the diagnosed phase had changed since they were told they had AS. This ranged from the explanation patients were now offered by health professionals at diagnosis to the accessibility and range of information now available on the internet. They felt that in the past, patients were more reliant on information obtained by talking to other patients about their experiences face-to-face, particularly through NASS. They felt that Rheumatologists had become better informed about the condition and were now able to offer better advice, reducing the need for patients to join organisations and meet other patients. With respect to the internet, they highlighted the magnitude and complexity of the information available and the prevalence of illness narratives on the internet, most of which emphasised the pain and suffering caused by AS as opposed to positive representations of the condition:

Excerpt 1: 2nd NASS Focus Group

196 L People don't write about the normal cases they tell you about the worse cases.

.....

393 T If [your pain] is one out of ten you are not going to be shouting from the roof tops about it but if you are interpreting your pain as nine out of ten you are going to tell everyone who will listen.

Excerpt 1 illustrates the participants' interpretation of the dangers of the internet, particularly for newly-diagnosed patients who would have difficulty interpreting these narratives and deciding whether their own illness trajectory would one day incorporate these examples of pain and disability. These internet accounts represent 'atrocious stories' (Dingwall, 1977), examples of events and emotions which can be effectively told as stories. In contrast, the NASS group had been able to offer a 'wide range, from the mild to the severe, and all bits in between' (255: not shown) which had been an advantage to those people who had just found out they had AS, especially as the group had encouraged people to share their experiences and advice.

While the majority of the discussion was consistent with my description of the experiences of people with AS, Richard (R, below in Excerpt 2) questioned one of the underlying principles of the project – that better information and education for people with AS should be a priority for health professionals and Arthritis Research UK. This exchange is illustrated in Excerpt 2:

Excerpt 2: 2nd NASS Focus Group

- 462 R You think they have been going to their doctors for ages and you think ‘why haven’t their doctors been telling them this? [advice about treatments for back pain]’, so I’m thinking instead of writing this booklet for this why aren’t more doctors aware of it. Why aren’t more GP’s genned up on it and that’s what I would say, you are talking to the wrong people.
- 463 I Yeah.
- 464 R There is all sorts of information for patients, whereas what are the doctors doing about it?
- 465 N It is hard for the doctors.
- 466 R No it is not, he is getting paid a fortune.
- 467 I I think,
- 468 N He said ... I mean the doctor you tell him the symptoms and everything and he sends you to see a specialist right away. He cannot deal with every ailment.
- 469 R They don’t.
- 470 N Well they should do.
- 471 R GPs generally don’t send you to see a specialist.
- 472 N The specialist generally doesn’t know either like but.
- 473 R The number of people I see at work, this is customers who have been on benefit for years and that they are being told ‘oh they have got to get back to work because they can walk and talk, they are fit enough for work’. It is shocking how little help they have had from their doctors.
- 474 N Aye.
- 475 I Yeah.
- 476 R You know they are still just getting Paracetamol, Diclofenac and that’s all they are getting.
- 477 I Yeah, I agree entirely. It is a separate problem though in terms of GPs knowing more about musculoskeletal back problems and ank spond and all those problems. I think GPs just feel a bit overwhelmed by what they could know. They could know everything but yeah and I think there is a lot of variation between fantastic GPs and GPs that don’t, don’t help. But you

know it is another thing that the arc [Arthritis Research UK] are involved in quite a lot is in trying to get the message out, the messages out to GPs.

In this excerpt, Richard, a Disability Employment Advisor who has AS, displays his frustration with GPs whom he feels do not offer people with back pain appropriate support or treatment. His comments are initially contested by another NASS member (N - 465, 468) but he continues his criticism, questioning whether I should have tried to increase GPs' knowledge about AS rather than people with AS themselves - 'you are talking to the wrong people' (462). In turn, I responded by indicating that it was a valid problem which would not be straightforward to resolve, but which was being addressed separately (477).

This passage reflects a theme which arose frequently during the interviews with new and review patients - the judgement of health professionals by patients. In Chapter 6, I explained that health professionals made moral judgements about their patients, regarding both their reasons for attending educational groups and the likelihood of them benefiting from attendance. Here we see the reverse occurring; this was commonly seen elsewhere in the fieldwork, particularly with respect to professionals' personal and communication skills, but also their knowledge about AS, and occasionally their commitment to their patients. Disagreement regarding the practice and judgements of health professionals is not unusual (Dixon-Woods et al., 2001). However, Richard is also raising another important point. He is highlighting the limitations of education as a tool for patients to improve their own lives, reminding us of their continued reliance upon health professionals for accurate assessment and diagnosis, practical help such as employment advice and access to effective drug treatment. Health professionals co-ordinate and legitimate access to symbolic and material resources, which cannot be achieved by patients themselves, and Richard argues that these educational topics, specifically in the case of GPs, should have greater priority. While he also states that 'there is all sorts of information for patients' (464), implying that there is sufficient educational resources for patients, I feel this reflects his status as an established patient, with a mature *network of solutions*, and an understanding of AS which allows him to get on with his life.

In conclusion, this focus group with NASS members provided a useful opportunity to feedback some of the results of the project to an interested group who had participated in the project at its outset. It also offered further confirmation of the validity of the

Established Patient Model in this context, as the participants discussed their own experiences and opinions in relation to the stages of learning I described. The participants were very accustomed to talking about AS, and were able to discuss my findings at length between themselves, contributing both confirmatory and occasional contradictory evidence. This produced an extremely interesting discussion. However, they also represented a relatively small subset of the whole population of people with AS - patients who had chosen to attend a specific AS group, and in fact had done so over a long period of time. Thus the focus group did not necessarily reflect the opinions of all AS patients, and confirms the need for the sort of recruitment and sampling, and indeed the individual interviewing carried out in earlier phases of the research.

8.4 Feedback from Health Professionals and Patients – A Web-Based Survey

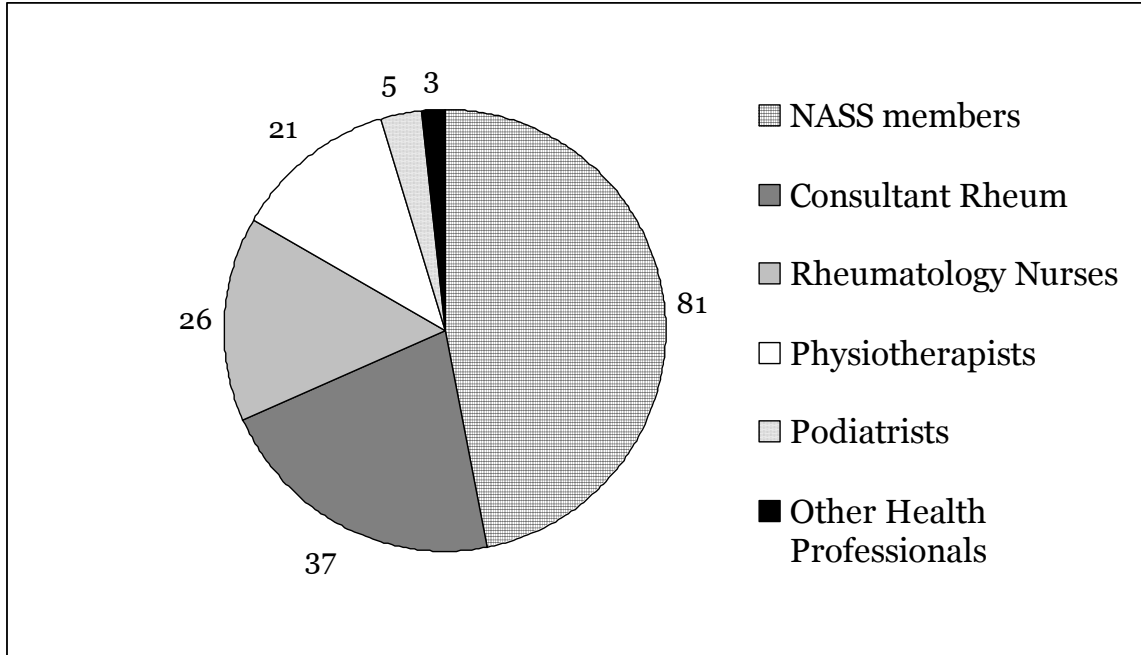
This exercise provided the opportunity to summarise the findings of our research project whilst also offering stakeholders the chance to comment on and influence our results. Initially, the research team wrote and agreed upon 30 statements which best summarised our results (see Table 11 for these statements). 100 NASS members and 100 health professionals were invited to take part in a process which selected 10 of the 30 statements as the most important research finding by these participants (see Table 12). The process took place over two rounds via an anonymous web-based survey. It also allowed participants to review some of our results which were presented as part of the introduction to the survey, and offer free-text comments regarding the research. The methodology is discussed in more detail in Chapter 4.

8.4.1 Participants

In Round 1, 38 of the 100 NASS members approached completed the survey, and 43 of the 100 health professionals. In Round 2, the response rates were 43/100 (NASS), and 49/100 (health professionals). The same 100 patients and 100 health professionals were approached for Rounds 1 and 2. Participants were able to complete the survey for Round 2 even if they had not completed Round 1.

The characteristics of responders are shown in Figure 21. The ‘other’ health professionals were 2 dieticians and a psychologist. Additional demographic information was collected from patients: the majority of NASS members responding were male (64%); the median age of these respondents was 51 (range 26-73 years). Health professionals were all based within the UK, with the majority from England (80/92, 87%); the most represented region was the South-West (14/92, 15%).

Figure 21: Survey Respondents– Totals Combined from Rounds 1 and 2



8.4.2 Propositions – Selecting the Most Important Statements

The results of Round 1 are shown in Table 11, and those of Round 2 in Table 12. Within Table 11 the propositions are grouped by topic area, as presented to the participants; in Table 12, they are ranked with respect to the number of times each was selected. Thus, the final ten statements selected as the most important findings of the research are those shaded in Table 12.

There were some differences between patients’ and health professionals’ responses. For instance, in Round 1 statement number 4 (‘Patients reach a stage when they feel / behave as though they have sufficient knowledge about ankylosing spondylitis to be able to get on with their lives’) is rejected by a high proportion of health professionals (27/43), but relatively few patients (13/38). This suggests that while patients recognise the characteristics of Established Patients, the concept that patients do not continually seek information and education is not necessarily accepted by health professionals. Equally, a high proportion of patients (20/38) rejected statement 29 (‘The topic of sex and relationships is difficult for both patients and health professionals to address’) compared to health professionals (7/43), indicating that within this population of patients, these topics were not necessarily as problematic as I had found during the research.

In Round 2 there were similar differences, with more patients than HPs selecting statements concerning the benefits of sharing experiences with other patients, and the need for improved education regarding practical solutions to day-to-day problems. However, overall there was good consistency between the two groups' responses; if the results are analysed separately there are only 2 of the final 10 statements selected by patients which would not be included in the professionals' final 10. Similarly, there are no changes to the final 10 statements if NASS members' scores are weighted to compensate for their slightly lower response rate.

Table 11: Round 1- 30 Statements and the Numbers who Rejected Them. The shaded statements were rejected.

		NASS	HPs	Total
Timing of education	1. The first step is getting a diagnosis, and for many patients this is difficult.	2	6	8
	2. The important questions which newly-diagnosed patients try to find the answers to are: 'why me?', 'what's going to happen to me and my family?', and 'what can I do about it?'	12	8	20
	3. When newly-diagnosed, patients are seeking straightforward, definitive and optimistic answers to questions, and they can struggle to find these.	10	22	32
	4. Patients reach a stage when they feel / behave as though they have sufficient knowledge about ankylosing spondylitis to be able to get on with their lives.	13	27	40
	5. When established, patients want practical solutions to day-to-day and newly-encountered problems, and they can struggle to find these.	10	11	21
Health Profs and healthcare	6. Newly diagnosed patients rely on their rheumatology consultant to supply and recommend educational resources.	15	27	42
	7. Rheumatology health professionals can help relate generic information about AS to patients' individual circumstances and specific questions.	11	8	19
	8. Health professionals view education as a means to improve relationships and trust between patients and rheumatology departments.	24	20	44
	9. The information and care available to patients is shaped by the enthusiasm and expertise of the health professionals they see.	10	9	19
	10. Patients who have difficulty navigating the healthcare system are vulnerable in terms of getting support, information and care.	11	8	19
Use of info and education	11. There is lack of consensus about the aims of education for people with AS.	23	24	47
	12. Patients use information to inform questions to health professionals and discussions within consultations, rather than to demand different treatments.	13	19	42
	13. Patients use information to inform them about the range of options to improve physical, social and financial health e.g. potential treatments, their working and home environment, benefits, and insurance.	6	5	11
	14. Over time, education can build a network of potential solutions to problems for patients.	10	13	23
	15. When explaining their diagnosis to others, patients are concerned not to be labelled as having 'just' back pain, and use information resources to make this possible.	9	20	29
Sharing experiences / groups	16. Through sharing experiences, patients gain new ideas about how to manage their condition and, at times, hope for their future.	7	9	16
	17. Patients' experiences can be shared in many ways - for example through the internet, through group education, or during other activities involving other patients. These have different 'costs' for patients - in terms of the time and emotional involvement required to take part.	10	16	26
	18. The appropriate timing of group education is problematic - some patients don't feel qualified to take part soon after diagnosis, while later they may feel they do not need it.	22	26	48
	19. Patients give the following reasons for not attending group education: privacy in relation to their health, low self-confidence, competing priorities for time, emotional cost of sharing experience face-to-face, and fear of contact with people with severe disease.	16	12	28
	20. Access to group education for people with AS varies across the UK, and is reliant on both voluntary groups and key individuals within rheumatology and physiotherapy departments.	5	7	12
Patient info booklets + the web	21. Information booklets are generally used by newly-diagnosed patients as an introduction to the disease.	7	12	19
	22. Information booklets could be improved by including a summary page for newly-diagnosed patients, which would cover basic information in as widely understandable format as possible.	8	18	26
	23. Information booklets could be improved by listing and discussing questions patients may want to ask health professionals.	10	14	24
	24. Written information is not enough to support prescribed exercises - they need to be demonstrated and followed up by physiotherapists.	5	4	9
	25. When patients with AS seek information on the internet, there is often no guidance about where to look, and no boundaries to what they can find.	17	25	42
Unmet need	26. Common problems which established patients would appreciate more education about include flares of their AS symptoms, the development of new symptoms, and dealing with routine problems at work and at home.	3	10	13
	27. Patients with late diagnoses may find the information available is not relevant and does not meet their needs.	21	28	49
	28. Patients struggle to find useful information and advice when deciding whether to continue working and when making career choices.	19	8	27
	29. The topic of sex and relationships is difficult for both patients and health professionals to address.	20	7	27
	30. Arthritis organisations (eg NASS, arc), Citizens' Advice Bureau and disability advisors can provide useful sources of information around topics which are important to patients.	6	3	9

Table 12: Round 2 – Selecting the Most Important 10 Statements. The numbers of NASS members and HPs who nominated each statement are tabulated.

	NASS	HPs	Total
Written information is not enough to support prescribed exercises – they need to be demonstrated and followed up by physiotherapists.	32	40	72
The first step is getting a diagnosis, and for many patients this is difficult.	36	32	68
Access to group education for people with AS varies across the UK, and is reliant on both voluntary groups and key individuals within rheumatology and physiotherapy departments.	30	33	63
Common problems which established patients would appreciate more education about include flares of their AS symptoms, the development of new symptoms, and dealing with routine problems at work and at home.	34	29	63
The information and care available to patients is shaped by the enthusiasm and expertise of the health professionals they see.	31	30	61
Arthritis organisations (eg NASS, arc), Citizens' Advice Bureau and disability advisors can provide useful sources of information around topics which are important to patients.	29	30	59
Information booklets are generally used by newly-diagnosed patients as an introduction to the disease.	24	29	53
Patients use information to inform them about the range of options to improve physical, social and financial health e.g. potential treatments, their working and home environment, benefits, and insurance.	20	32	52
Rheumatology health professionals can help relate generic information about AS to patients' individual circumstances and specific questions.	21	30	51
The important questions which newly-diagnosed patients try to find the answers to are: 'why me?', 'what's going to happen to me and my family?', and 'what can I do about it?'	22	27	49
Through sharing experiences, patients gain new ideas about how to manage their condition and, at times, hope for their future.	28	20	48
When established, patients want practical solutions to day-to-day and newly-encountered problems, and they can struggle to find these.	24	20	44
Patients' experiences can be shared in many ways - for example through the internet, through group education, or during other activities involving other patients. These have different 'costs' for patients – in terms of the time and emotional involvement required to take part.	22	21	43
Patients who have difficulty navigating the healthcare system are vulnerable in terms of getting support, information and care.	17	24	41
Patients struggle to find useful information and advice when deciding whether to continue working and when making career choices.	11	21	32
Patients give the following reasons for not attending group education: privacy in relation to their health, low self-confidence, competing priorities for time, emotional cost of sharing experience face-to-face, and fear of contact with people with severe disease.	12	17	29
Over time, education can build a network of potential solutions to problems for patients.	11	17	28
The topic of sex and relationships is difficult for both patients and health professionals to address.	10	18	28
Information booklets could be improved by including a summary page for newly-diagnosed patients, which would cover basic information in as widely understandable format as possible.	16	9	25
Information booklets could be improved by listing and discussing questions patients may want to ask health professionals.	10	13	23

8.4.3 Free-text Comments

Participants were invited to make comments about the survey; 60 of the total 173 responses were accompanied by such comments, of which 25 were from health professionals and 35 from NASS members. Most offered encouragement and expressed interest in the research. Many of the health professionals' comments (14 of 25) described their difficulty in choosing the most important statements, explaining that 'they are all pertinent' and that their choices were 'not clear-cut'. Patients often described their current health and the circumstances of their diagnosis, and these comments also emphasised a lack of awareness regarding AS, particularly amongst non-Rheumatology health professionals. Excerpt 3 offers some examples:

Excerpt 3

Severe sciatica, joint pain and neck pain started in mid teens and got worse into my mid twenties. Hospital consultant in area I lived at the time just said I had curvature of the spine and that they could not do anything to reverse this! (Female, age 42. Diagnosed age 30)

In my opinion the problem with AS sufferers and the medical world is that there is little understanding about AS other than Rheumatologists. For example it took me from the age of 23 to 40 to be diagnosed and in that period I had seen endless GPs, orthopaedic surgeons of note, physiotherapists and the only person that recognised something was my osteopath that then ordered an X ray and was seen by a friend who happened to be a Rheumatologist! (Male, age 49. Diagnosed age 40)

Three NASS members' comments were more critical, describing the thirty statements as 'vague', 'pretty odd' or 'wordy'. Each of these participants expressed their difficulty choosing which statements to either reject or select, and were concerned that the results 'wouldn't be consistent' between responders.

8.4.4 Discussion

The survey proved to be an interesting tool with which to consider the potential impact and future implementation of our results. Firstly, it provided the impetus for the research team to condense our findings into short statements, and this exercise itself was useful. The significance of the result, specifically the importance which should be attached to the 'final' ten statements at the expense of the remainder is less clear. As described in section 8.4.3 above, the participants struggled to choose which statements to reject in Round 1, and to a lesser extent, which to select in Round 2. We did envisage that the survey would be difficult to complete, and deliberately did not offer specific guidance on how participants should decide whether a statement was important or not. We did not suggest, for instance, that importance should necessarily equate to the *novelty* of the statement, to the *degree of*

certainty that it reflects reality, or the likelihood that each statement will improve the lives of people with AS. We did indicate that participants should make their own judgement about importance, but allowed participants to use their own criteria.

The result of this strategy has been, on the whole, the selection of statements which reflect current norms of patient education – those which are already widely accepted and not those which I (and the rest of the research team) found most striking and interesting from this project. For example, I would consider one of the most important findings of this project to be the description of patients ceasing their search for information when they become established, and the related problems regarding the appropriate timing of group education. Yet the statements related to these issues (numbers 4 and 18 in Table 11 above) were rejected in Round 1, reflecting their status as novel findings which were perhaps not necessarily recognised as valid. Similarly, the statements which were selected by most participants, such as the need for ongoing input for people with AS from physiotherapists (number 24, Table 11), were those which, although certainly valid, could be considered to be *less important* findings because they are already widely accepted.

Therefore this exercise has not necessarily prioritised our results in such a way that would determine which areas we should address first when implementing our results and which would make the greatest impact on patients' lives. However, it has provided information about the extent to which our findings are outwith current norms in patient education. Thus those statements which were rejected in Round 1 are not necessarily less valid than those selected in Round 2, but the implementation of education strategies based on those findings would need to be informed by these results, taking into account that they would not immediately be accepted by stakeholders⁴³. Importantly, it has also allowed us to receive more general feedback regarding the research, and this was virtually all positive and accompanied by recognition of its value and validity.

⁴³ These ideas have less 'coherence' with current values and work would have to orientate to their legitimacy in order for them to become embedded in normal practice [May, C. and Finch, T. (2009) 'Implementation, embedding, and integration: an outline of Normalization Process Theory', *Sociology*, 43, (3), pp. 535-554.]

8.5 Conclusions

This chapter has provided further evidence for the validity of the Established Patient Model. Initially proposed during the analysis of the interviews with newly diagnosed patients and developed further through the interviews with review patients, we have now presented the model to health professionals and NASS members and received both confirmation and feedback regarding our findings. The model was viewed as an accurate reflection of the experiences of the NASS members in the focus group (Section 8.3), while the online survey results demonstrated which of our findings stakeholders felt were most important, at the same time suggesting those which were most novel.

The brief telephone interviews will enable rheumatology teams to provide information about potential complications of AS which is consistent with the views and practice of ophthalmologists and gastroenterologists. This was a topic area which newly diagnosed patients felt had been presented to them in an unclear and worrying way, both on the internet and in booklets. In addition, conflicting messages from different professional groups can undermine patients' confidence in their care. Therefore addressing these topics in this way not only meets patients' information needs, but could also make it less likely that patients will be told one thing by a rheumatology source and contradictory advice by another specialist.

In Chapter 6 I considered the differences between health professionals' and patients' perspectives of patient education, particularly regarding its aims and functions. In this chapter I have returned to this theme, noting differences between the statements selected in the online survey (see section 8.4.2). While some differences between their priorities and perspectives may be expected, their nature has not previously been described or considered. An understanding of these disparities will help people design and provide patient education, allowing professionals greater insight into the views of patients, and similarly allowing patients who provide education for others to understand the topics which are not well covered by professionals.

Equally, while it is important to understand the differences between patients and professionals when considering education, it is also important to understand the differences *amongst* patients. Within the literature review (Chapter 3) I criticised studies of educational

interventions for failing to reflect patients' choices about the resources they wanted to use, or the resources that would be most useful for them at that time. I argued that it is inaccurate and unhelpful to view patients as a homogeneous group in this way. This chapter returns to this theme, particularly considering the responses of the NASS members to the online survey, alongside some of the comments from the focus group. In Excerpt 2, Richard states that attempting to improve patient education should be a lower priority than targeting GPs with education regarding the management of back pain. I have already described how, irrespective of the level of knowledge about their condition, patients remain reliant on health professionals for both diagnosis and later with the practicalities of managing their condition. Therefore I have sympathy with his argument, and understand his frustration with health professionals who do not seem to offer the support patients would benefit from. However, his argument that the available resources for patients were already sufficient was not supported by my interviews, particularly with newly diagnosed patients. As an experienced and established patient, Richard has built a network of solutions to the potential problems he faces everyday as a result of his AS. He is aware of where he can access help, and is likely to be highly skilled in accessing medical and social care. His viewpoint is influenced by this status, and therefore contrasts sharply with those of patients who have yet to build the same network, develop the same skills and normalize the disruption caused by AS.

The survey results showed only small differences between the statements selected by patients and those by professionals, as discussed above (Section 8.4.2). However, the results of the earlier phases of the research suggested that greater differences existed between the reality of patients' learning described in Chapters 5 and 7, and professionals' views in Chapter 6. There are a number of possible explanations for this: firstly, that the statements chosen for the survey were either not related to those topic areas where differences exist, or were too bland to demonstrate differences; secondly, that moral factors influenced the choices of both patients and professionals, such that both groups were more likely to choose statements that they felt reflected 'good' patients and were not critical of their behaviour; finally, I would suggest that there is a convergence of views between patients and professionals as patients become more experienced, and their understanding of the condition and the health service increases. Thus, the perspectives of people with AS who have had the condition for a long time, and perhaps engaged with organisations like

NASS, may be more akin to professionals than the newly diagnosed patients interviewed in other parts of the study. As described in Chapter 6, one of the functions of education is the alignment of patients' understanding of AS with that of health professionals, and this may be one of the consequences. This opinion doesn't undermine or devalue the opinions of those experienced, established patients, who clearly have much to contribute to this discussion. However, it emphasises the need to seek the views of disparate patients, and once again, ensure that patients are not viewed as a homogenous group, with homogenous opinions and needs.

This final results chapter has brought together some of the themes which arose in previous chapters, and considered how the work contributes to the understanding of patient education for people with AS. Like every research study, the methodology and the participants chosen for this aspect of the thesis have influenced the claims that can be made regarding the results. The final web-based survey offered stakeholders the opportunity to review some of our results, and to choose aspects they felt were important. In the following chapter, I will reflect on the study as a whole, continuing to consider which of the findings are novel, and how it should influence the education offered to people with AS.

Chapter 9 – Conclusions

9.1 Introduction

This chapter is the culmination of the thesis - an opportunity to bring together the four phases of this research and to consider their implications within four broad topic areas. It also represents a return to *my* interpretation of the research, regarding the web-based survey which encouraged feedback from patients with AS and health professionals not as a definitive ‘consensus’, but as another data source from which to draw conclusions.

The first section of this chapter (9.2) concerns the implications for education for people with AS, describing how understanding of this topic has developed as a result of the research, and the practical changes to the provision and organisation of education which could be implemented. Section 9.3 considers how the wider topic of patient education within healthcare has changed, acknowledging the comments I made about the generalisability of this research in Chapter 4. Section 9.4 describes a research agenda which would extend and complement this thesis, while section 9.5 considers the practical steps required to begin to implement the changes described.

9.2 Implications for Education for People with AS

In Chapters 2 and 3 I reviewed the available literature with a view to answering two specific questions – ‘What are the consequences of a diagnosis of AS and how do people respond?’, and subsequently ‘Which educational interventions are effective for people with AS?’. These chapters not only provide an historical and an academic perspective to the thesis, but also highlight areas where knowledge was incomplete or inconsistent. This section documents the contribution this thesis makes to these themes.

9.2.1 Timing of education

Timing is recognised as a difficult subject for researchers and practitioners of patient education, with the question frequently posed being ‘What education should be offered to patients, at what time?’ Arthritis Research UK has recently funded projects examining this question for patients with other rheumatological conditions - vasculitis and systemic lupus erythematosus (SLE) (Waldron et al., 2010). However, the range of physical, social, psychological and emotional problems faced by such patients, along with considerable differences in patients’ characteristics and disease trajectory, have made comprehensive and effective answers to this question impossible. Until now, issues relating to timing have been considered in relation to factors such as patients’ ‘readiness to learn’ (Bastable, 2006) or their ‘stages of change’ (Prochaska and Diclemente, 1998), the limitations of which I outlined in section 5.3. Both these concepts view education as unquestionably beneficial for patients, and view the judgements that patients make not to engage with education as inherently flawed and invalid.

In Chapter 5 I outlined the Established Patient Model (see Figure 8 for an overview). The model emerged from my analysis of serial interviews with newly-diagnosed patients with AS, and was subsequently validated by further interviews with review patients, and through feedback to NASS members in the second focus group. Aspects of the model were also selected as important findings by participants in the web-based survey (see section 8.4). It provides a new perspective for those considering the timing of education for people with AS, relating their aims for education and the practical steps they take to learn about AS to one of four stages in the model – *pre-diagnosis*, *diagnosed*, *established* and *facing new problems*. A person’s stage is determined by routine information such as whether they have received a diagnosis of AS, changes in health, healthcare and social life, and their

perception of whether their knowledge of AS is adequate. Hence there is no need for patients to undergo extensive testing in order to employ the model. It reflects, extends and corroborates the work of others who have studied chronic illnesses, notably Bury (1982) and Strauss and colleagues (1984) (see section 5.3), providing details of patients' practical responses to chronic illness, and offering the potential to counteract its negative effects. It also recognises that people with AS do not constantly search for information about their condition, and that this inactivity can be appropriate and represents times when other aspects of their life take priority, when they are unlikely to take up opportunities for further education.

Ultimately, the impact of this model will be determined by its use by practitioners and researchers in the future, and whether it is also valid in other patient groups. In its current form it is primarily a tool to be assessed by further research (see Section 9.4). However, it could be used to improve the quality of the production and evaluation of educational resources and programmes, or to assess whether they were appropriate for and met the needs of people at different stages. It also highlights the moments when people are most likely to accept and volunteer for education, potentially allowing resources to be allocated more efficiently. Similarly, it has implications for the content of education for people with AS (Section 9.2.4), and for understanding their experiences.

9.2.2 Understanding the experiences of people with AS

In Chapter 2 I described the contribution of qualitative and quantitative study to our understanding of the experiences and characteristics of people with AS. However, in Chapter 3 I was unable to determine which educational interventions were effective for people with AS in part because of an incomplete understanding of the similarities and differences between people with AS and those with other chronic diseases that had been studied in more depth.

The thesis has offered substantial insights into the practicalities of the search for information for people with AS and the process of learning about their condition. While researchers have investigated how people with chronic illnesses use specific educational resources such as the internet (Nettleton et al., 2005), patient information leaflets (Barlow et al., 1995) and health professionals (Kinnersley et al., 2008) to learn about their

condition, an overview which highlights the choices patients make and when and how resources are used has not, to my current knowledge, been produced before for any chronic illness. Accounts of illness make passing reference to education as a potential solution to the disruption and hardship caused by chronic illness (see section 2.2.2), and this thesis has explored how they do this. Mengshoel (2008) in her qualitative study of twenty people with AS in Norway, suggested that people learnt how to manage their AS by ‘trial and error on their own’ (ibid: 1443), but this is not substantiated by the interviews I carried out. Instead it was often a collaborative effort with family members, with significant involvement of health professionals and reliance on them for advice and help.

Greater understanding of the practicalities of education for this group, like the Established Patient Model described above, and the descriptions of patients’ use of resources in Chapter 8, offer insights into the experiences of people with AS. In turn these allow those involved in the care of people with AS to consider their practice in the light of this information, and ensure that new and existing health and educational resources are consistent.

Separate from the process of education, topics such as participants’ experiences of exercise were also examined, and I was able to make suggestions about the determinants of regular exercise in this cohort (see Figure 19). Equally I added description and depth to characteristics like those of work disability and depression which have previously been identified with people with AS. While there were patients who were self-reliant (for example J (Bnew2)) the ‘AS personality’ described to Williams by a Rheumatologist during his fieldwork (1984: 141) was not an over-riding characteristic, and cannot be assumed to be widely relevant today.

9.2.3 Understanding the needs of vulnerable patients

Vulnerable patients struggle to answer their own questions about AS, find it difficult to navigate the healthcare system, and make choices which are likely to be detrimental to their health. Their characteristics and the consequences of this vulnerability are described in section 7.3, and summarised in Figure 20. Potential methods to identify and address their needs are also included in the same section.

Vulnerable patients are a difficult group to study because of problems recognising and subsequently recruiting them to research studies; there are similarities between the characteristics of vulnerable patients and the use of the term ‘hard-to reach’ in some research literature, although there is no single accepted definition of this latter term. Within diabetes education, ‘black and ethnic minority peoples’ (Parken and Sturt, 2009) and those of ‘particularly high social deprivation’ (Smythe, 2009) have been identified as hard-to-reach, and efforts made to determine their needs or to improve their health outcomes. Similarly, some commentators would include men in these groups, recognising that not consulting health professionals and ignoring health problems are key ‘practices of masculinity’ (O’Brien et al., 2005: 515), and that ‘health information and services are not male friendly’ (Banks, 2001: 1058).

In this thesis I have therefore highlighted the existence of vulnerable patients, and that their voices are unlikely to be heard through less rigorous attempts to address educational need. I described some of the difficulties they have utilising the resources which other patients benefit from, emphasising the need for a different approach to education for this group. Their significant needs would not be met by a health care system which relies on patients to understand what would be the best care for them, and to actively seek it out. Thus policies which promote self-care at the expense of care from health professionals threaten to leave them behind, and increase health inequalities.

9.2.4 Considering the content of education for people with AS

One of the outcomes I envisaged at the beginning of this project was the development of a ‘core content’ of education for people with AS – a list of information and skills which would be useful for people with AS, and which should be included in educational programmes and resources in the future. I haven’t done this, at least in the manner I had envisaged, because it would be difficult to defend the validity of any such curriculum, and it wouldn’t be the ‘evidence-based’ curriculum expected. In the conclusion to Chapter 7 I explained the barriers to producing such a curriculum, focusing on patients’ appraisal of educational resources and educational need, which is based on their own experiences and disease trajectory. In turn, these variables are different for every individual, and thus any curriculum would be inadequate for every individual and of limited utility to patients and health professionals.

Instead, I have related content to the stages of the Established Patient Model, emphasised the need to enable patients to search for information independently, relate it to their own circumstances, and allow them to discuss their findings with health professionals. Thus when *diagnosed*, for instance, educational content should be directed at answering their fundamental questions – ‘Why have I got AS?’, ‘What is going to happen to me (and my family)?’, and ‘What can I do about it?’. When *established*, content should be directed towards keeping up to date, and when *facing new problems*, it is directed towards solving or normalizing those specific health, healthcare, social or emotional problems.

Despite these difficulties producing a curriculum, it is possible to identify educational topics as areas of unmet need which could be addressed more effectively by existing educational resources:

- The provision of brief, straightforward, definitive information about AS to newly-diagnosed patients who initially find the longer leaflets difficult to understand.
- Including questions which newly-diagnosed patients and people facing new problems may wish to ask and discuss with their health professionals.
- Communicating uncertainties where medical knowledge provides only incomplete understanding. Statements like ‘we do not know why some people develop AS and other people don’t’ could be used.
- Information about and suggestions for coping with routine problems at work and at home including flares of their AS and the development of new symptoms.
- Information about basic employment rights and sources of help when addressing employment or benefit problems.
- Information for groups of patient who may need different or additional advice compared to the majority of people with AS, such as women, those diagnosed later in life, and parents.
- Topics such as insurance, driving, and sex and relationships, which may not be dealt with effectively during routine consultations with Rheumatology health professionals.

- Topics which appear to have the potential to do harm to patients could be emphasised. For example, the internet atrocity stories they may encounter when newly-diagnosed, before patients learn to put information like this into context, and the lack of evidence for the benefit of starch-free diets.
- Topics which are routinely managed by professionals outside of rheumatology departments, such as eye or bowel complications.

9.2.5 The limitations of patient education

When I reviewed the literature related to the efficacy of educational interventions for Chapter 3, I felt that some authors overemphasised the positive effects of education, especially its potential for large therapeutic effects on physical and psychological outcomes (Lorig, 1995). Health professionals viewed these positive outcomes as a possibility, part of ‘making patients feel better’ (See Figure 10). However, patients’ initial hopes that their problems could be solved by understanding *everything* about AS dissipated soon after diagnosis. This is analogous to Bury’s description of patients realising that medical knowledge is incomplete and instead relying on their own knowledge and biographies (Bury, 1982).

This study has therefore elucidated some the limitations of patient education. Firstly, for many patients, education is not a priority. In some cases health professionals may share patients’ assessment of their lack of need for education, and in others they may not. Patients would certainly prefer to be *cured* of their condition, or to be symptom free, than to *understand* it. Equally, when possible people will keep ankylosing spondylitis at the periphery of their lives and attempt to normalize its consequences. A persistent search for education is not consistent with this aim.

Secondly, patient education does not enable people to manage their condition independently, and in fact the majority of the potential benefits are achievable only through the utilisation of other resources, as described in section 5.2.5 (Facing New Problems), and indeed by Talcott Parsons in 1951 (see section 2.2.1). While there are exceptions⁴⁴, the

⁴⁴ Examples arising in this study would include advice about routine matters such as getting comfort while sleeping, or sneezing in ways which are less painful when one has severe back pain.

process of education remains reliant on health professionals to provide practical care and advice, or friends, families and others to provide additional resources.

Finally, the effect of education on behaviour was less apparent in this study than could be envisaged after reading self-management studies such as those in Chapter 3. For example, levels of exercise were primarily determined by pre-diagnosis exercise behaviour and the effect of exercise on symptoms of pain and stiffness, rather than any response to education (Figure 19). In this cohort patients behaved as practical beings, attempting techniques to improve their health which were suggested by education, but only persisting with them if they were effective for them and consistent with their other priorities.

In summary, while information and education were appreciated by patients, and do have the capacity to improve peoples' lives, their potential effects are not unlimited and should not be overstated.

9.2.6 The importance of building a network of solutions

In Chapter 5 I described how people with AS began to build a *network of solutions* when diagnosed, based upon the sources of information and help they could access (see section 5.2.4.4). The participants continued to develop this network after they became established as they returned to old sources and discovered new ones, building a range of interconnected potential solutions to problems. This concept has analogies to health professionals' view of education as a method of *building relationships* between the hospital department and patients, and amongst patients themselves (see Figure 10). Thus education is not only about knowing more about AS and how to live with it; it is also about developing the relationships and knowledge about relevant sources of information which can be accessed again in the future. This suggests that there is a need for education to be provided locally, and preferably by methods that enable patients to meet the health professionals who could be contacted for further advice and help.

9.2.7 Solutions to education need to be found from limited resources

The availability of resources – financial, time, expertise and space – were the primary explanation for rheumatology departments not offering more educational resources to people with AS (see Table 6). The funding situation is unlikely to improve in the near

future, therefore additional resources for patient education will be difficult to obtain. Financial constraints and attempts to persuade purchasers of healthcare to provide education were also the primary factor behind research regarding the long-term cost-effectiveness of patient education (Lorig et al., 1999). In addition, much of the expense of providing educational resources in the UK is currently provided by charities such as Arthritis Research UK and NASS, and not by the National Health Service. Therefore, solutions to providing education for people with AS must be realistic, and conscious of the resources required to implement them. While the effect of 1:1 education programmes run by health professionals for all patients with AS may be interesting to investigate, it is difficult to envisage such a resource being implemented. More realistic would be the careful targeting of such programmes, potentially for vulnerable patients, with a simultaneous development of other, less costly resources for other people with AS.

9.2.8 Making education more acceptable to people with AS

In Chapter 3 I suggested that patients' *choices* regarding their use of particular educational resources had been overlooked in attempts by researchers to determine whether they were effective or not. In Chapter 7 I considered the *image* of group education, reporting that some interviewees had envisaged groups to be like 'Alcoholics Anonymous' and others had similarly linked them to ill-health and dependence (see section 7.2.3). In contrast, patients want education that provides tangible, practical benefits, and it is these factors which should be emphasised in order to make them more attractive. For example, education could be the opportunity to discuss exercise with a physiotherapist or the opportunity to learn about a new treatment. Thus the opportunity to 'share experience' with other people with AS is not, on its own, sufficient motivation to attend a group. This may be linked to masculine patterns of healthcare utilisation (O'Brien et al., 2005) and does not necessarily mean they would not find this useful if they did attend. Similarly, introducing opportunities to share experiences with other patients into routine care may also be useful, such as when attending for appointments or treatments, or when discussing new medications. The role of health professionals in endorsing resources, as well as explaining their purpose and what they entail, is also important.

Increasingly, the internet is becoming part of peoples' lives, and crucial to how we routinely communicate with one another (Hoffman et al., 2004). Its capacity to enable

people with AS to share experiences and search for information which is relevant to their own health is significant. Attractive information for many people will therefore be through the accessible, flexible medium which they use everyday – the internet.

9.2.9 Organisation within Rheumatology departments

In Chapter 7 (7.2.4) I described the vital role health professionals play in the education of people with AS, fulfilling a number of roles, including relating ‘generic’ information about AS to their specific clinical and personal circumstances, signposting resources and other professionals, setting the tone for the management of their condition, and by being part of the solution to many of the problems they encounter. In most instances, the health professionals seen by people with AS will work within a rheumatology department within a hospital; this thesis has raised issues about how these are organised.

Of the departments which responded to our postal survey just over half recognised someone who co-ordinated education for people with AS; this was usually a physiotherapist. The survey did not ask about their precise role, but an effective coordinator could oversee the provision of education within their department, ensuring the needs of different patients are met, offering limited 1:1 support and education to vulnerable patients, and cascade knowledge about best practice and new resources to other members of the team. This would need to be an interested and motivated person – the exact professional role of the individual is probably less important.

9.3 Implications for the Wider Topic of Patient Education

In this section I have considered the findings from my research with people with AS in reference to my knowledge and experience of the wider topic of patient education, focusing on the areas in which my observations have made a contribution to the topic. Reflecting on the implications of my thesis with respect to patient education for other conditions raises issues of generalisability which I discussed in Chapter 4 (section 4.2.3.3).

9.3.1 Definitions of patient education do not correspond with the reality of people learning about their condition

Within the Introduction (Chapter 1), I reviewed the definition and aims of patient education, revisiting the topic in Chapter 3 with reference to outcome measures used in trials of educational interventions. Lorig's definition of patient education (1996), widely used in rheumatological and other literature, indicates it is restricted to 'planned activities' while Burkhardt (1994) suggests it must be 'separate from clinical patient care'. I have demonstrated that within this cohort of people with AS this definition does not reflect the reality of learning about AS. Their learning has been largely *unplanned*, and often *within* the realms of clinical care – through routine consultation with health professionals, and the resources they have recommended and offered. I have also offered evidence that this approach may be *more effective*, and certainly *more attractive* than the planned, detached education described by Lorig and Burkhardt, allowing patients to build networks of solutions, solve problems as they occur, and minimise the impact of their condition on other priorities in their lives. Equally, there has been little to suggest their experiences would be significantly different from those with other chronic conditions, at least within this theme.

These existing definitions of patient education reflect interventions which can be evaluated using standard methods such as controlled trials. Thus it is only by *planning* and *separating* these interventions that their effect can be measured without the 'contamination' of other influences, and therefore 'proof' of efficacy can be achieved. Yet this approach may be leading the research community to appraise only those interventions which overlook many of the features of education which make it useful and effective for both patients and health professionals, simultaneously minimising the potential benefits which patient education could offer.

9.3.2 Patient education has broad aims and functions, reflecting different perspectives

In addition to not representing the reality of learning about a chronic condition, the definitions discussed above, along with the outcome measures used in research trials, do not reflect the broader aims and functions of education. These include additional aims for patients, such as building a network of solutions, but also functions for health professionals, proposed in Figure 10. Existing trials have focused on *individual* and *societal* aims for patient education without acknowledging that these may sometimes contradict (see section 3.4). Evaluation in the future may better reflect the complexity of patient education if these additional functions could be evaluated.

9.3.3 Differences between patient education and professional education

This is an important topic which would reward greater study than I have afforded here. Fundamentally, I would consider the education of patients to be different from that of professionals. However, there were instances during the thesis when it emerged that the division may be less clear for some observers, and characteristics which I would attribute to professional education were also influencing the education of patients.

Throughout an individuals' schooling there is an obligation to learn and better oneself, from childhood to obtaining professional qualifications. This may be felt to different extents by different individuals, dependent on factors such as parenting and peer groups. One of the questions posed by this thesis is 'To what extent does this obligation apply to patients learning about their own health, and how to manage their ill-health?' In Chapter 2 I discussed Parson's sick role (1951) which states that when unwell, people are subject to two 'rights' and two 'responsibilities' (see Figure 1). Evidence emerged during the research of an additional, third responsibility – 'to learn about your illness and how to manage it yourself', which could be subject to the same repercussions as the original four. This increasing responsibility for patients has been discussed previously as a 'duty to be well' (Greco, 1993). Firstly, during the interviews, focus groups, and indeed the surveys, there was a sense that a 'good' patient was one who was prepared to learn about their condition, and patients tended to emphasise these elements during interviews as part of their illness

narrative⁴⁵. Secondly, the promotion of self-care as the basis of the organisation of healthcare in the UK, and the increasing orientation of services around this strategy, risks leaving behind those people who are unwilling or unable to effectively self-manage (Kendall and Rogers, 2007).

Practical differences emerged between patient and professional education. As mentioned previously, patients orientated towards minimising the effect of their condition on the rest of their lives, therefore education was predominantly a means to achieve this. For some this entailed a greater understanding of more academic, medical knowledge such as the pathophysiology of AS; for others it was focused on the practical benefits which could make their lives more bearable. For this latter group, an academic or professional understanding of AS was not important, and therefore obligations to learn more about this are unhelpful. Equally, the term ‘education’ may itself be off-putting for this group, perhaps forcing them to return to images of school and professional education which may be negative and unattractive.

9.3.4 There is no single ‘patient’s perspective’

The need to include patients or ‘lay people’ in the design and evaluation of both health services themselves and the research which influences them is well-recognised, such that it is increasingly routine practice. However, the optimal methods of involving lay people and the practical benefits which result are still not clear (Entwistle et al., 2008), even to early proponents (Entwistle et al., 1998). This thesis raises issues which could influence how patients’ perspectives are sought and interpreted.

When seeking lay or patient perspectives to evaluate interventions, there is no single patient perspective which is representative. They are subject to the same influences as any other source of opinion, and should be interpreted with this in mind. This may be particularly important when considering educational interventions; naturally patients will evaluate interventions according to their own experiences, and we have seen this with respect to educational content. Similarly, experienced, established patients may be more likely to volunteer for these advisory roles, and therefore the views of diagnosed and vulnerable patients will not be heard. Asking established patients to propose what

⁴⁵ The manner by which they did this is displayed in Appendix V, ‘Diagram of expertise’ – the image of expertise, one of my early analytical diagrams.

education should be available for newly diagnosed patients is equally problematic, as their opinions will be influenced by their own disease trajectory, and may have grown closer to the views of health professionals. This could be compared to asking University Professors what should be taught in primary and secondary schools – their opinions would be swayed by their life course and where their education had taken them, and what had worked for them. I'm not arguing that these patients' opinions should be ignored, but that their opinions should be subject to the same critical analysis as others', (like that offered by Prior (2003)) and efforts should be made to sample other groups of patients.

9.3.5 Educational needs-assessments should go further than assessing what patients want

In section 3.3.6 I addressed the concept of needs assessment, and studied examples in the literature which considered patients' educational needs. The results of this thesis suggest that quantitative approaches such as Pickles' (2006) may offer some useful information to providers of education but are unlikely to reflect patients' educational needs comprehensively. These approaches will be significantly affected by the design of the questionnaire itself and the circumstances in which it is completed. Equally, we have seen that patients want answers to questions which health professionals would not always envisage – they may not volunteer these, and are only encountered when you build a relationship with that person. These techniques may also be influenced more by attempts to portray oneself as a good patient as described above – one who is motivated to learn about their condition. Similarly, I have demonstrated that there are differences between what patients say they want and what they are prepared to go out and get against a backdrop of competing social priorities.

9.4 Implications for Future Research

In this section I will reflect upon the research methods I used in the context of my results, focusing in particular on the topics which I consider should form part of a future research agenda.

9.4.1 Useful research methods

This research project has provided an extensive overview of the topic of education for people with AS. By examining the perspectives of different stakeholders and by producing a detailed description of the practicalities of searching for information for both newly-diagnosed and existing patients, I have been able to offer insights which I hope will be relevant to patients, health professionals and other interested parties. The serial interviews revealed information about how this search developed over time, and the methodology may have reduced patients' obligations to portray themselves as the 'good' patients described here. Recruiting review patients after the analysis of these new patients allowed these findings to be rigorously tested and refined. Feeding back to stakeholders offered an opportunity to further validate my findings, and gain insights into how the findings may be implemented.

Overall, I feel the methods chosen have been effective in enabling me to achieve the research objectives, and indeed to achieve more than these initial aims. Where I have modified my proposal, this has been in response to my developing understanding of the research methods used, and the strengths of the data I was collecting. These methods could be employed to examine patient education and learning in the context of other chronic conditions.

I have not sought the views and experiences of GPs during this project, despite their involvement in the care of people with AS. I considered reviewing my findings with a group of GPs as an additional aspect of Phase IV, but was restricted more by time than anything else. Equally, they were not identified as a crucial source of information by patients or by other health professionals, beyond their important role in recognising a *potential* diagnosis of AS, and potentially dealing with problems of pain-relief. Recruiting GPs who would be willing to discuss education during such a focus group may also have been challenging, as they themselves may not perceive the topic as crucial to their practice.

The GPs who were willing to attend may not have been representative of this professional group.

9.4.2 Geographical differences

The patients interviewed in this project were all living in the North-East of England, and while there was variation in terms of the hospital they attended, and whether they lived in a rural or urban setting, the suggestion that some or all of my findings may be a regional phenomenon cannot be immediately discounted. As discussed in section 4.2.3.3, some concerns regarding generalisability may be allayed by the recruitment of patients and professionals from outside the North-East to take part in Phase IV. Interviewing people with AS from other regions of the UK may offer an additional perspective, particularly around cultural or ethnicity issues which were not a focus of this study.

9.4.3 Other chronic illnesses

In Chapter 3, I concluded that there were difficulties determining whether educational interventions were effective for people with AS when they had only been evaluated in people with other chronic illnesses, other types of arthritis, or even people with AS who were not representative of the wider AS population. There is a tradition of emphasising the similarities between people with a range of chronic illnesses and being more inclined to overlook the differences, typified by the topic of the ‘Sociology of *Chronic Illness*’. If this tradition were followed, then there would be an argument for applying the findings described in this thesis to people with other chronic illnesses. However, I suggest this should be resisted because of the differences we know between people with AS and those with other chronic illnesses as described in Chapter 1. Therefore, studies examining the validity of the Established Patient Model with people with other chronic illnesses would also be useful.

9.4.4 Recognising vulnerable patients

In section 7.3 I described how the concept of vulnerable patients emerged, summarised in Figure 20. This figure was described as a ‘hypothesis’ rather than a substantive theory because there is a need for further study to elucidate this concept more fully, discovering and refining characteristics or consequences. In turn, it may also be useful to develop tools (such as a simple quantitative questionnaire) to help health professionals recognise

vulnerable patients, and indeed, evaluate whether specific resources can meet their needs and improve outcomes.

9.4.5 *The role of people around patients – carers and significant others*

During this project I recognised the key role that the people around the patients played in helping them learn about their condition, and moderating how their lives were affected. I also observed that they too sought to learn about AS, and made adaptations to how they lived their lives. My approach to studying this was opportunistic rather than systematic, interviewing family members along with the patient when circumstances allowed it. A more rigorous approach to describing the experiences and educational needs of these people is required.

9.4.6 *Developing resources based on the Established Patient Model*

The findings from this project have already influenced the educational resources available to people with AS. In my role as Clinical Advisor to Arthritis Research UK and member of the Patient and Public Publications Advisory Group (PPPAG) I have re-written the Ankylosing Spondylitis information leaflet in the light of this research, and continue to edit other patient information booklets. The newly-designed booklets are also much more visual than previous versions and include an ‘At a Glance’ section at the beginning of each booklet, designed to offer patients an easily comprehensible summary as suggested in section 9.2.4. Similarly, the NASS website was recently redesigned and is now consistent with the Established Patient Model; visitors to the site are offered information according to whether they are ‘Getting my diagnosis’ (analogous to *prediagnosis*), ‘Just diagnosed’ (*diagnosed*), or ‘Managing my AS’ (*established / facing new problems*) (NASS, 2011). These changes represent a change in how information is organised and delivered, hopefully making it more accessible to those who need it and more attractive. Evaluation of these changes is ongoing, and should involve consulting a range of patients, and in the case of the website changes, potentially observing how patients navigate the site in practice and find the information they are looking for.

9.5 Implementing These Findings

At this stage of the research project there is not a specific educational intervention which I have demonstrated or even suggested is more effective than others. In this sense by *implementation* I am advocating an uptake of the ideas of the project by those who provide or research patient education, with further testing and refining where necessary. This process has started already as I described in the previous section (9.4.6), with changes to the widely available and widely used resources provided by Arthritis Research UK and NASS. Beyond these initial changes, influencing the practice of patient education will be challenging, both for people with ankylosing spondylitis and potentially people with other chronic illnesses. Many of the reasons for this have already been raised, notably:

- The involvement and interest of multiple professional groups and perspectives, each of which have developed their own areas of expertise and represent a range of entrenched practices.
- Lack of clarity regarding what constitutes an educational intervention, and its interaction with normal, routine care.
- Difficulties defining and measuring the efficacy of educational interventions
- The limitation of resources required to implement changes

Aware of these challenges, implementation has continued by engaging with relevant stakeholders, through the presentation and discussion of my results at conferences and to interested groups, and subsequently via the publication of papers in peer-reviewed journals. Phase IV of the research began this process through the web-based feedback survey, which may have increased interest in the study.

9.6 Conclusions

This project has created an overview of patient education for people with AS, encompassing different perspectives and using multiple sources, but focusing on the practical search for information on which patients embark. It has not sought to answer all the questions which still surround this complex topic, but instead I hope the theories and observations I have outlined will form a building block for further research and changes to practice. In particular, I hope this thesis can improve the process of needs-assessment for people with AS, performed formally or informally, and for either individuals or across larger populations. In turn, I hope this will improve the educational resources that are available to them, and the standard of care they receive. I believe it offers all professionals who work with people with AS an insight into their experiences and perspective. Similarly, it offers people with AS the opportunity to compare their experiences with those of other patients.

Patient education remains a challenging topic to study, but academics in particular may find my description of its broader aims and functions useful when considering the evaluation of its effects. It is not the elixir of eternal life which some of its proponents seem to suggest, nor is it a behavioural silver bullet. It is also inevitable – patients will learn about their condition and how to self-manage whether health professionals intervene or not. The question is therefore how best to support this existing process, in the context of the rest of their lives. Fundamentally, education is about helping patients solve their problems, and to answer their own questions. These problems and questions can be predicted to some extent according to their circumstances, but never fully. Judgements about the education which would be useful for patients should be made according to what individuals want to know, but also according to experienced professionals who understand the trajectory of AS, and equally understand concepts described here including the Established Patient Model.

Personally, the research has been incredibly valuable. My introduction to qualitative research has been enlightening, both practically and philosophically. Not only has it been a privilege to interview and get to know people, and for them to describe their experiences to me so generously, but it has certainly changed my clinical practice. Such close analysis of events and lives outside the clinic room and hospital ward has interrupted the otherwise

relentless evolution from medical student to consultant, and has influenced my interactions with patients and broadened my horizons as a doctor.

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Appendix I – NASS Focus Group Topic Guide

What do Patients with Ankylosing Spondylitis Need and Want to Know About Their Condition?

NASS Focus Group –Topic Guide

Plan of interview

- ❖ Introduction
- ❖ Introductory question
- ❖ Sources of information for patients with AS
- ❖ Content of information for patients with AS
- ❖ Why is patient education important?
- ❖ Feedback – further questions I should ask

Setting

- ❖ NASS group, XXXXX Hospital. Meeting / exercise room.
- ❖ 21st February 2007 7:15pm onwards.
- ❖ Circle of chairs, table in middle with microphones
- ❖ Refreshments on table.
- ❖ (physios won't be present). Observer – Nicky M

Introduction

- ❖ Explain purpose of project and 'small group discussion'
 - Development of themes for future survey questions and interviews with patients.
 - Need their views and experiences in order to carry out this project
- ❖ Expected duration / no right or wrong answers, expect there to be disagreement and discussion / need to contribute and get opinions / light hearted, interesting and enjoyable / here because we consider them to be experts – value their opinions very highly / don't need to say anything you don't want to / one person speaking at any time.
- ❖ Consent – written, in conjunction with information sheet.
- ❖ Characteristics of group – questionnaire with consent form (voluntary)
 - Name Age Ethnicity
 - Occupation (or previous job if not working)
 - Hospital attend for care of AS
 - Disease duration
 - Email / tel contact details if prepared to be contacted
- ❖ Explain focus group recorded but details will be confidential – not fed back to consultants / physios, names not reproduced in any writing we do.
- ❖ Won't affect the care you receive.

Topic

- ❖ Question
 - Potential prompt

Introductory question

- ❖ Can we start by everyone introducing themselves? Tell us your name and say, in one or two sentences, when you joined NASS, and why? (go round the group)

Sources of Information for Patients with AS

- ❖ We're going to start with a task so that I can get to know some of the areas you think are important, and hopefully don't end up firing questions at you all evening.
 - I've got a few different ways you might get information about Ankylosing Spondylitis written on cards
 - What I want you to do is, as a group, discuss the 'information sources' described on the cards, and put them in order of how useful they are to patients with AS – so most useful at the top, least useful at the bottom.
 - There are no right or wrong answers, but I'd like you to talk about why you've found them useful, or whether they'd be useful for other people.
 - I want you to come to your own conclusions – I'm going to take a back-seat, but might ask a question if there's something I don't understand.
 - Cards
 - Patient information leaflets
 - AS Support groups
 - Nursing staff at hospital
 - Hospital specialist - Rheumatologist
 - GP
 - Physiotherapist at hospital
 - Pharmacist (community or hospital)
 - Other patients with AS
 - Family members and Friends
 - DVDs/videos about AS
 - Internet sites about AS
 - Blank cards for them to fill with sources not included above
 - Why are they useful – is it what they tell you or how they get the information across.
 - Who would use them and why?
 - When would people with AS use them?
 - Are there questions patients ask other health professionals eg nurses and physios that they wouldn't ask Drs?
 - What sorts of questions do you use the internet to answer – are these questions you wouldn't ask health professionals?
- ❖ What do you think of the NASS and arc information leaflets for patients with AS?
 - Do they include all the information you want?
 - Will they work for everyone?
 - Advantages / disadvantages – alternative sources
- ❖ Why do some patients join groups like NASS and others don't?

- You said last time we met that NASS members were different from the majority of patients with AS. In what way and why? Are your educational needs substantially different?
- ❖ Has the way you've got information about AS changed over time?
 - Dependent on your age?
 - How bad your disease is?

Content of Education

- ❖ What do you think are the most important questions patients with AS need to know about their condition?
 - Are these questions being answered?
 - Why / why not?
- ❖ One criticism is not enough detail on 'non-medical' information – finance, employment, sexual issues, driving – is this true?
 - How should this be addressed?
 - Who or what is best placed to do this?
 - Any examples of how this can be done well?
- ❖ It's always very difficult to explain to newly diagnosed patients what might happen to them in the future. What is the best way for us to do this?

Importance of Education

- ❖ Why do you think people want to learn about AS – what's in it for them?
 - Knowing what's likely to happen in the future
 - Knowing what to do in a flare
 - Knowing about treatments etc
- ❖ How should we approach patients who don't seem as keen to learn?
 - For example – not reading the leaflets, not attending physio, not joining NASS(!)

Feedback

- ❖ Thank you
- ❖ Are we asking the right questions?
- ❖ Have these questions allowed you to talk about what is important to you?
- ❖ Is there anything else you think it would be useful for us to know?

Conclusion

- ❖ Thanks again
- ❖ More about use of information, reaffirm confidentiality
- ❖ Further group in ~ 1 year – to discuss findings of interviews.
- ❖ Feedback – using email addresses, at end of study?

Appendix II – Interview Participants’ Characteristics

Summary of Interview Participants' Characteristics

Code	Initial	Age	Sex	Household / Relationship Status	Employment Status	Educational Attainment	BASFI	Self-reported disease severity	Place of Interview
ANew1	C	19	M	Has own flat, but spends proportion of time at mothers house. Contact through her.	Employed-manual work in a furniture factory	GCSEs or equivalent	6.00	Moderate	Patient's Mother's Home
ANew2	S	55	M	Living alone at time of first interview. Split from mother of their 2 children. At time of 2 nd interview, 11 yearold son had moved in.	On disability benefit	No GCSEs or equivalent	7.75	Moderate	Patient's Home
ANew3	W	33	M	Living alone. Has a long term partner who has a child who doesn't live with him	Not working. On benefit – not sure if this is 'unemployment' or 'disability'	GCSEs or equivalent	5.57	Moderate	Patient's Home
ANew4	P	31	M	Lives with male partner	Professional (GP)	Professional qualifications	0.00	Mild	Office at the hospital
ANew5	K	48	M	Lives with female partner	Employed – taxi driver	No GCSEs or equivalent	6.30	Severe	Patient's Home
BNew1	J	35	M	Lives alone. Moved in with girlfriend by time of 3 rd interview	Receiving benefit, working casually maintaining a hotel his friend owns.	Professional qualifications	5.17	Moderate	Patient's Place of Work
BNew2	B	26	M	Lives with wife	Employed – ITU nurse	Professional qualifications	1.82	Mild	Patient's Home
BNew3	T	21	M	Lives with parents and sister	Employed – office work	GCSEs or equivalent	2.97	Mild	Patient's Home
CNew1	F	28	M	Lives with partner (and child by 2 nd interview)	Employed – office work	A-levels or equivalent	0.21	Mild	Patient's Home
CNew2	L	23	F	Lives with partner	Employed – lab technician	Degree	1.67	Mild	Patient's Home

Afup1	M	72	F	Lives with husband	Retired – bank clerk as young woman	GCSEs Or equivalent	4.69	Mild	Home
Afup2	D	32	M	Lives with wife and young son	Unemployed / childcare	Degree	5.72	Severe	Home
Afup3	A	35	M	Lived with wife and young daughter	Trying to arrange disability allowance	No GCSEs or equiv	5.65	Moderate	Home
Afup4	G	27	M	Lives with fiancée	Employed – by his father. Office work	Degree	7.74	Severe	Outpatient dept
Bfup1	H	35	F	Lives with husband – hope to adopt	Own business – swimming teacher	Degree	4.65	Moderate	Home
Bfup2	Q	49	M	Lives with wife	Own business – pump maintenance	GCSEs or equiv	0.6	Mild	Home
Bfup3	Y	60	M	Lives with wife	Seeking disability allowance – recently stopped working	GCSEs or equiv	5.2	Severe	Home
Bfup4	N	41	M	Lives with wife and teenage daughter	Office work	GCSEs or equiv	3.34	Moderate	Home
Cfup1	R	24	M	Lives alone	Chef	A-levels or equiv	2.78	Moderate	Home
Cfup2	U	32	F	With daughter	Physio	Degree	0.72	Moderate	Workplace
Cfup3	E	61	F	Lives with husband	Retired – never worked	None	6.11	Moderate	Outpatient Room
Cfup4	V	65	M	Lives with wife	Retired – engineering	GCSEs or equiv	6.82	Moderate	Home

Appendix III – New Patients’ Interview Schedule

What do Patients with Ankylosing Spondylitis Need and Want to Know About Their Condition?

New Patient Interview Schedule

Plan of interview

- Introduction
- What's the starting position?
- Circumstances of finding out about AS?
- Independent education
- Learning needs?
- Future education.
- Feedback – interview technique, further questions I should ask

Introduction

- ❖ Explain purpose of project and this interview
 - ❖ Won't affect the care you receive – separate from medical care
 - ❖ We're looking at whether patients with arthritis feel they have been told enough and the right sorts of things about their condition
 - ❖ No right or wrong answers – not a test of your knowledge
- ❖ Consent – written, because this is extra to your standard care.
- ❖ Explain interview recorded but details will be confidential
- ❖ I do look after patients with AS, if you do have any questions about your condition I could try to answer them or point you in the direction of who could help at the end of the interview rather than during it. It would be helpful if we use the interview to try to find out more about your questions, rather than spend time answering them – could we leave them till the end
- ❖ Questions or concerns?

What's the starting position?

- ❖ Start by just telling me briefly about your own problems, and how they affect you
 - ❖ Have you heard of ank spond?
 - ❖ Is that what you consider you've got?
 - ❖ How bad is it?
 - ❖ What does it stop you doing?
- ❖ Do you know anyone else with AS?
 - ❖ How did that influence finding out about it?
- ❖ Had you heard of AS before you were diagnosed? What was your image of someone with AS?

Circumstances of finding out?

- ❖ What happened when you were told you had AS?
 - By whom?
 - How useful?
 - How did you feel?

- ❖ Do you remember much about it? What specifics can you remember?
- ❖ Did you ask any questions? Did you wish you'd asked questions? Why didn't you?
- ❖ Written info – what did you do with it?
 - What did you think of it?
- ❖ Told about groups / exercise / treatments / internet sites / DVD videos
- ❖ Overall impression – positive? Outlook for the future?
- ❖ Improvements in this process?
- ❖ Have you talked to other people about AS since you found out?
 - Who? Family and friends?
 - How did you describe it?

Independent education

- ❖ Where else have you looked for information– people / internet / leaflets?
- ❖ What questions, what responses?
 - Satisfied with these?

Learning needs?

- ❖ Has AS affected
 - Relationships / work / financial situation / driving
- ❖ Happy with care from hospital?
- ❖ Know where to go for help?

Future education?

- ❖ What sorts of things make you want to find out more? Are you keen to find out more?(motivation)
- ❖ Expectations and willingness to participate – what are the issues? What would help? [In the future, how do you think you'll find out about AS?] Would you use them – why, why not
 - Information from health professionals
 - Meeting other patients
 - Going to groups
 - Exercises
 - Books /leaflets/DVDs –
- ❖ Do you think doctors / other health professionals gain from having informed patients?

Feedback

- ❖ Thank you
- ❖ Are we asking the right questions?
- ❖ Do these questions relate to your own experience?
- ❖ Do these questions allow you to talk about what is important for you?
- ❖ Is there anything else you think it would be useful for us to know?

Appendix IV – Ankylosing Spondylitis Information Diary

Ankylosing Spondylitis Information Diary

We are interested in how you find out information about ankylosing spondylitis, and ways to cope with your symptoms. We would be very grateful if you could fill in this information diary between now and our next meeting.

Each time you have a question about ankylosing spondylitis, or find out something you did not already know, we would like you to fill in a page. This will help us to know which sources of information and skills are most useful to you.

We hope this will not take very long. We'll pick up your completed diaries at the next interview.

**Dr Ben Thompson
December 2006**

Are you describing (please circle)?

- a) a question you have about ankylosing spondylitis (AS)?
Complete section 1 (ignore section 2)
- b) something you have learnt about AS?
Complete section 2 (ignore section 1)

Section 1

What is the question about ankylosing spondylitis you have thought of?

.....
.....

Have you tried to find the answer to this question? (please circle)

- Yes – succeeded in answering question
- Yes – looked for answer but haven't found it
- No – have not tried to find answer

Where have you looked or who have you asked to find the answer to this question?

.....
.....

What were the good and bad things about the information from these places/people?

.....
.....
.....
.....

Section 2

What is the information you learnt about AS on this occasion?

.....
.....

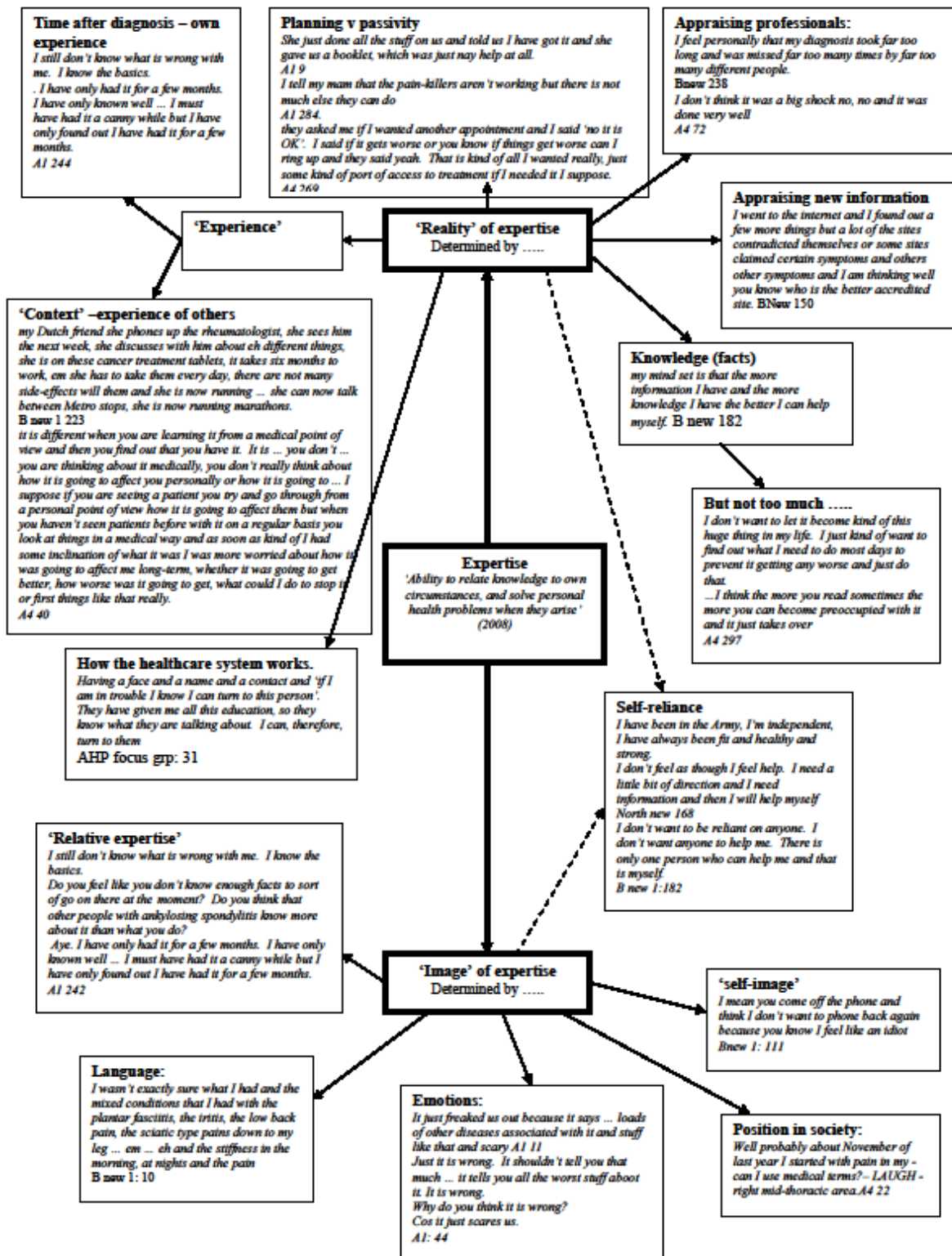
Where did you see / hear this?

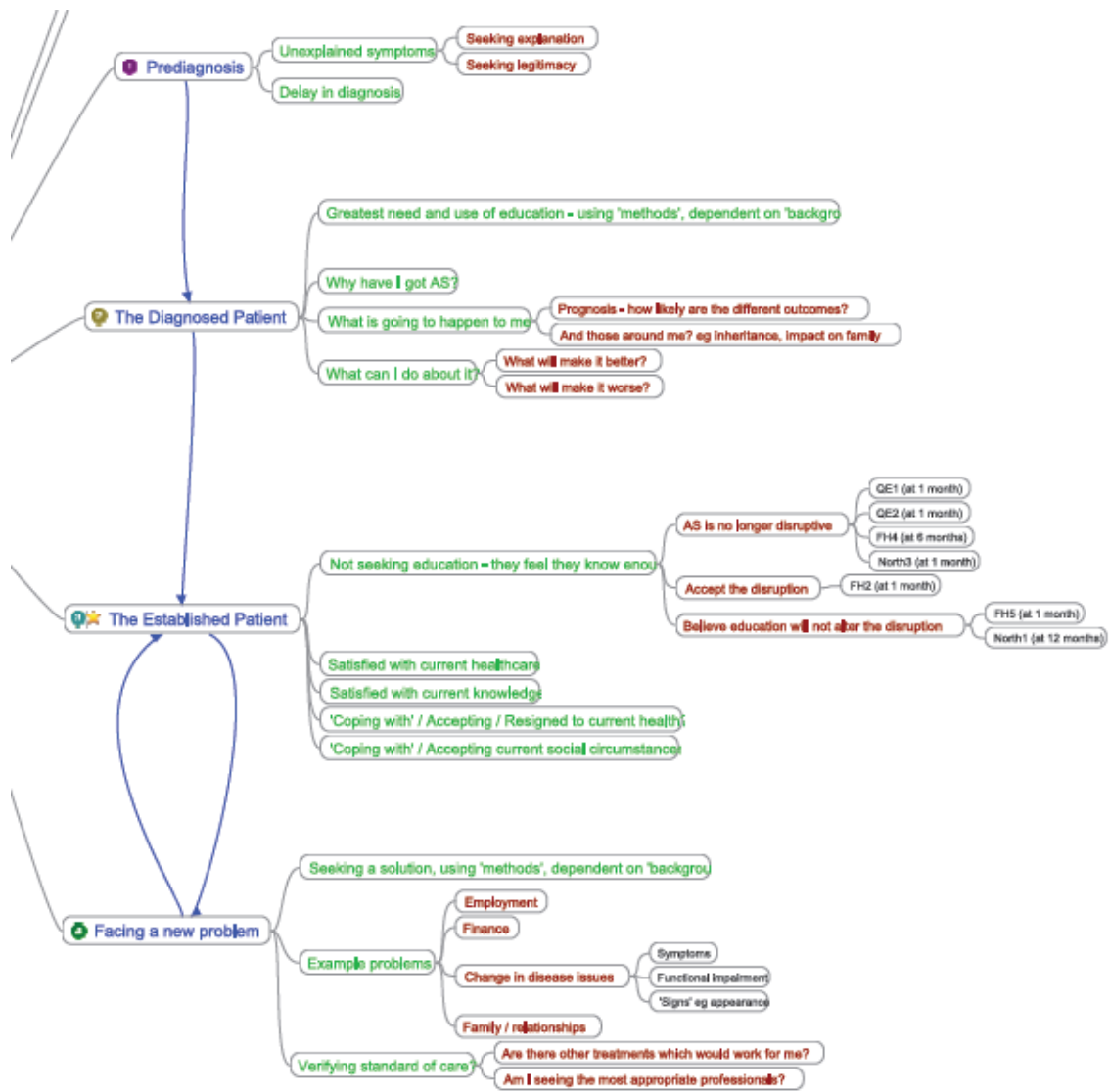
.....
.....

What were the good and bad things about the information from these places/people?

.....
.....
.....
.....

Appendix V – Analytical Diagrams





Appendix VI – Professionals’ Focus Group Topic Guide

What do Patients with Ankylosing Spondylitis Need and Want to Know About Their Condition?

Consultants' Focus Group – Topic Guide

Plan of interview

- Introduction
- Introductory question
- Current provision of patient education in AS
- Aims of patient education in AS
- Improvements in patient education
- Feedback – further questions I should ask

Setting

- ❖ After department meeting – Freeman Hospital Education Centre, Sem Room 3
- ❖ 13th March 2007 5:30pm onwards.
- ❖ Circle of chairs, table in middle with microphones
- ❖ Refreshments on table.
- ❖ Observer – Tim Rapley

Introduction

- ❖ Explain purpose of project and ‘small group discussion’
 - Development of themes for future survey questions and interviews with patients.
 - Need their views and experiences in order to carry out this project
 - Focus today – what you provide and why, possible improvements.
- ❖ Expected duration / no right or wrong answers, expect there to be disagreement and discussion / need to contribute and get opinions / light hearted, interesting and enjoyable / one person speaking at any time.
- ❖ Consent – written, in conjunction with information sheet.
- ❖ Explain focus group recorded but details will be confidential, names not reproduced in any writing we do.

Topic

- ❖ Question
 - Potential prompt

Introductory question

- ❖ For the purpose of the recording, can we start by everyone introducing themselves? Tell us your name and say, in one or two sentences, whereabouts you work, and what contact, if any, you have with patients with Ankylosing Spondylitis?

Current Provision of Patient Education in AS

- ❖ Looking at some of the early work we've done in this area, most patients see you as the most important and useful source of info – why do you think this is?
 - What do you think the role of the consultant is in this area?

- ❖ I want to talk first of all about the information sources available to patients with AS in your hospital. I want to get an idea of the similarities and differences between hospitals and doctors.

- ❖ Can we imagine a hypothetical patient who's just been diagnosed with AS. In terms of telling them about AS, and giving them information, where would you start?
 - What do you tell them? What don't you tell them?
 - What literature do they receive?
 - How do you think patients will use this?
 - Do you suggest any groups they should go to?
 - All patients, or just some?
 - Which health professionals or patients run these groups? Why?
 - How do patients benefit?
 - Do you suggest exercises?
 - How do they know which ones to do?
 - What do you tell them about medical treatments?
 - What would you say about their future health?
 - Do they routinely see anyone else?
 - How much time do you spend? Is this an issue – ie if you had more time, what would you do differently?
 - How much is all this tailored to the individual patient?
 - What judgements do you make?
 - Are these accurate / do they help – in what way?

- ❖ If there is an 'educational programme' – what does this consist of?
 - How was this developed?
 - By whom? What support was needed?
 - What benefits do you / the patients / those running the course expect?
 - What's the feedback from patients?
 - Which patients attend / don't attend?
 - What factors do you think influence this?
 - How hard should we try to persuade these patients to attend?

- ❖ What do patients know already?
 - Where have they got this info from?
 - Any recurrent misunderstandings / preconceptions?

- ❖ How has your practice changed over time – ie what do you do now that you didn't do and why?

- ❖ Are there any questions patients with AS have asked that you've struggled to answer?
 - Do the types of questions they ask change with time after diagnosis / stage in life?
- ❖ What would you say if a patient with AS asked
 - About stopping work? What benefits they'd be entitled to?
 - About getting travel insurance?
 - Complementary medicines?
 - About safety to drive?
 - About pain while having sex?
 - What's going to happen to my health in the future?

Improvements in Patient Education

- ❖ If we were planning an educational programme, what should its aims be? Ranking exercise?
 - Improve measurable patient psychological outcomes
 - Anxiety, depression, self-efficacy
 - Improve measurable patient physical outcomes
 - Pain / range of movement
 - Improve patient satisfaction with care
 - Increase knowledge about their condition
 - Change patients behaviour
 - Increase exercise
 - Allow patients to make choices about treatments
 - Encourage patient's concordance with treatments
 - Reduce their 'burden' on health care
 - Allow patients to make non-medical choices
 - Employment, family, relationships
 - Improve doctor-patient relationship and consultations
 - Plus blanks for their ideas.
- ❖ What is currently not available which you feel would be useful to patients?
 - Booklets
 - Websites
 - Personnel
- ❖ Why is it not being provided already?
- ❖ Could we tailor what we provide to each patient – how?
 - Can we identify those patients who are unlikely to participate in education and approach these patients differently?
 - Any examples of education programmes which progress over time?
- ❖ Does the way we should approach this group differ from patients with other arthritic conditions like Rheumatoid arthritis?

Feedback

- ❖ Thank you
- ❖ Is there anything else you think it would be useful for us to know?

Appendix VII – AS Education Questionnaire

Ankylosing Spondylitis Education Questionnaire

Dear Consultant Rheumatologist,

Thank you for taking the time to read this letter and, we hope, to complete the attached questionnaire.

You have been approached to take part in this survey because you are a member of the **British Society for Rheumatology (BSR)**. We have sent a similar questionnaire to members of British Health Professionals in Rheumatology (BHRP).

The survey concerns the educational resources available to people with ankylosing spondylitis (AS), and forms part of a wider research project examining education for this group of patients. This research is funded by the Arthritis Research Campaign, and also consists of interviews with people with AS and focus groups with health professionals.

The questionnaire should take **no more than 10 minutes** to complete. If you have any further questions please feel free to contact us using the details below.

We feel it is worth mentioning that we will not be sending out reminders or further copies of this survey because of Data Protection Act issues - so we'd be very grateful if you'd take this opportunity to fill it in and send it back to the address below, using the stamped addressed envelope enclosed.

We appreciate your help and time,

Dr Ben Thompson
arc Educational Research Fellow
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Newcastle-upon-Tyne
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(0191) 223 1518

Dr Lesley Kay
Consultant Rheumatologist /
Honorary Clinical Senior Lecturer
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NE7 7DN

lesley.kay@ncl.ac.uk
(0191) 223 1518

NB: If you are not a Consultant Rheumatologist, please tick this box , indicate your professional role here and return the questionnaire uncompleted.

Ankylosing Spondylitis Education Questionnaire

Section 1: Professional Details

Q1.1: Which term best describes your work?

Clinical.....	<input type="checkbox"/>
Academic	<input type="checkbox"/>
Both Clinical and Academic	<input type="checkbox"/>

Q1.2: Which county do you work in?

Q1.3: How many people with ankylosing spondylitis (AS) do you see professionally in a typical week?

.....

Q1.4: As part of your current role, are you involved with the planning or delivery of education for people with ankylosing spondylitis (AS)?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

If 'Yes', please could you provide brief details of the education you are involved with?

.....
.....

Section 2: Provision of Education for People with AS

These questions refer to educational resources which are available to patients who attend your service.

Q2.1: Which of the following group education programmes are available to patients?

(tick all that apply)

Expert Patient Programme	<input type="checkbox"/>
Arthritis Care – Challenging Arthritis	<input type="checkbox"/>
National Ankylosing Spondylitis Society (NASS) – branch meeting.....	<input type="checkbox"/>
Generic arthritis education group (hospital-based)	<input type="checkbox"/>
Rheumatoid arthritis education group (hospital-based)	<input type="checkbox"/>
Ankylosing Spondylitis education group (hospital-based)	<input type="checkbox"/>
Others: (please state)	<input type="checkbox"/>

Q2.2: Is there a group education programme specifically for people who have recently been diagnosed with AS?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

If 'Yes', who is this group organised by?

Q2.3: Do you recommend group education programmes to all the patients you see with AS?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

Please explain your answer:

.....
.....

Q2.4: In your opinion, how likely is it that patients with the following characteristics will benefit from group education?

(Please place a vertical mark on the line to indicate your answer to each statement)

NOT AT ALL LIKELY	1. Severe disease	_____	VERY LIKELY
NOT AT ALL LIKELY	2. Complex treatment regime	_____	VERY LIKELY
NOT AT ALL LIKELY	3. Anxious personality	_____	VERY LIKELY
NOT AT ALL LIKELY	4. Socially isolated	_____	VERY LIKELY
NOT AT ALL LIKELY	5. Male gender	_____	VERY LIKELY
NOT AT ALL LIKELY	6. Introverted personality	_____	VERY LIKELY
NOT AT ALL LIKELY	7. Recent diagnosis of AS	_____	VERY LIKELY
NOT AT ALL LIKELY	8. Young age	_____	VERY LIKELY
NOT AT ALL LIKELY	9. Previous low educational achievements	_____	VERY LIKELY
NOT AT ALL LIKELY	10. Not concordant with treatment, including exercise	_____	VERY LIKELY

Q2.5a: Are you aware of one-to-one education programmes specifically for AS patients available to patients who attend your service?

- Yes, just one programme
- Yes, more than one.....
- No..... (go to Q2.6)

Q2.5b: Which organisation(s) are they associated with? (tick all that apply)

- National Ankylosing Spondylitis Association (NASS)
- Arthritis Care
- NHS – Community
- NHS - Hospital
- Other
- (please state)*

Q2.6: Which of the following written educational resources for patients with AS are you aware of, and which do you give to patients?

	Aware of	Give to Patients
Arthritis Research Campaign (arc) booklet on AS	<input type="checkbox"/>	<input type="checkbox"/>
National Ankylosing Spondylitis Society (NASS) booklet	<input type="checkbox"/>	<input type="checkbox"/>
Locally written information on AS	<input type="checkbox"/>	<input type="checkbox"/>
Other written resources (<i>please specify</i>)	<input type="checkbox"/>	<input type="checkbox"/>

(tick all that apply)

Q2.7: Do you advise patients to use the internet to find out about their condition?

Yes – routinely	<input type="checkbox"/>
Yes – only if the patient asks.....	<input type="checkbox"/>
No	<input type="checkbox"/>

Q2.8: Which of the following websites have you recommended to patients with AS? (*tick all that apply*)

Arthritis Research Campaign	<input type="checkbox"/>
National Ankylosing Spondylitis Society (NASS).....	<input type="checkbox"/>
Arthritis Care	<input type="checkbox"/>
KickAS (AS chat room).....	<input type="checkbox"/>
Local AS web resource	<input type="checkbox"/>
Others (<i>please specify</i>)	<input type="checkbox"/>

Q2.9: Are you aware of the availability of any other resources for people with AS who attend your service? (*tick all that apply*)

DVD / video	<input type="checkbox"/>
Telephone advice line to Specialist nurse	<input type="checkbox"/>
Self-referral to physio	<input type="checkbox"/>
Others (<i>please specify</i>)	<input type="checkbox"/>

Section 3: Aims of Education for Patients with AS

Q3.1 In your opinion, how important are the following aims for education for people with AS?

NOT AT ALL IMPORTANT	1. Increase understanding of prognosis	VERY IMPORTANT
NOT AT ALL IMPORTANT	2. Increase frequency of exercise	VERY IMPORTANT
NOT AT ALL IMPORTANT	3. Increase awareness of side effects of medication	VERY IMPORTANT
NOT AT ALL IMPORTANT	4. Meet other patients with AS	VERY IMPORTANT
NOT AT ALL IMPORTANT	5. Improve participants' self-confidence	VERY IMPORTANT
NOT AT ALL IMPORTANT	6. Increase awareness of sources of medical and social help	VERY IMPORTANT
NOT AT ALL IMPORTANT	7. Improve overall disease control	VERY IMPORTANT
NOT AT ALL IMPORTANT	8. Increase understanding of pathophysiology of AS	VERY IMPORTANT
NOT AT ALL IMPORTANT	9. Improve communication with health professionals	VERY IMPORTANT
NOT AT ALL IMPORTANT	10. Improve patients' mental health	VERY IMPORTANT

Section 4: Professional Roles in AS Education

Q4.1a: Within your service, do you feel there is someone who co-ordinates patient education for people with AS?

Yes
 No (If 'No', go to Q4.2)

Q4.1b: Which term best describes their professional role?

Physiotherapist
 Occupational Therapist.....
 Specialist Nurse.....
 Doctor (Rheumatologist)
 Other (please state)

Q4.2: Within your service, which professional group do you feel is most effective at dealing with patients' questions about the subjects in the table below? (one tick per column)

	Driving	Insurance	Sex
Occupational Therapist			
Physiotherapist			
Specialist Nurse			
Doctor (Rheumatologist)			
Other (please specify)			

Section 5: Concluding remarks

Q5.1a Are there any educational resources which you feel would be useful for patients with AS, but which are currently not available within your service?

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.....
.....

Q5.1b In your opinion, why are these resources not available?

.....
.....

Q5.2 Are there any other potential educational resources which patients have suggested?

.....
.....

Thank you very much for completing this questionnaire.

We are planning to distribute our interim findings from this research project to interested patients and professionals, in order to reach consensus recommendations.

Please include your email address here if you would be happy to be contacted in the future and invited to take part in this process. It will not be used for any other purpose:

Email address:

If you would like to make any further comments, please do so here.

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**Please place the completed questionnaire in the stamped addressed envelope provided and return to:
Dr Ben Thompson, c/o Ann-Marie Smith, Musculoskeletal Unit, Room 22, Level 2, Freeman Hospital, High Heaton, Newcastle-upon-Tyne. NE7 7DN**

Thank you once again for your time and participation.

**Appendix VIII – Interview
Schedule for Telephone
Interviews**

Interview Schedule for Consultant Ophthalmologists –

- What sort of eye problems do you see in patients with ankylosing spondylitis?
- How would you explain this diagnosis / these diagnoses to a patient?
- How would you answer questions about their prognosis?
- What should a patient with AS do if he or she develops a red, painful eye?
- How quickly do they need to see an ophthalmologist?
- Do you think there is anything else someone with AS should know about eye problems?