

EXERCISE BEHAVIOUR IN ANKYLOSING SPONDYLITIS

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ABSTRACT

Background

Ankylosing spondylitis (AS) is an incurable, fluctuating, long-term condition for which prescribed exercise is central to management. However, many people with AS do not undertake prescribed exercises, the reasons for which are poorly-understood.

Aims

The project sought to develop a grounded understanding of the exercise beliefs of people with AS, the exercise behaviours they adopt, and the decision making processes they undergo when choosing exercise behaviours.

Design

Adopting a constructivist approach, 23 semi-structured interviews and 7 focus groups were undertaken with people with AS in the North West of England. In-depth data were analysed using open, axial and selective coding to inform the development of a conceptual model of exercise behaviour in AS. Ethical approval and informed consent were obtained.

Key findings

48 people participated in interviews and focus groups, with a disease duration ranging from 6 months to 29 years, and age range 19-62 (mean age 44.8 years) there were 37 men and 11 women. Participants described the need to predict and respond to a changing disease trajectory and utilised a number of informed strategies for long- and short-term exercise management. Participants described a process of ongoing appraisal of their AS status and used approaches similar to cost-benefit analyses to make decisions about exercise behaviour. In the context of the patient journey, four discrete exercise behaviours (no prescribed exercise, other exercise, two tier behaviour, prescribed exercise), and four responses to changing disease status (no behaviour change, transient change, goal oriented change, non exercise change) were identified. Some key determinants of exercise behaviour were also revealed.

Conclusion

This study has led to the grounding of participant perspectives on exercise in AS, rendering the proposed model both relevant and understandable to people with AS, and may have use in helping people understand and plan their future exercise behaviour in AS and forms a baseline for future study.

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ABBREVIATIONS

AS	Ankylosing spondylitis
ASAS	Assessment of spondyloarthritis international society
BASDAI	Bath ankylosing spondylitis disease activity index
BASFI	Bath ankylosing spondylitis functional index
BAS-G	Bath ankylosing spondylitis global score
BASMI	Bath ankylosing spondylitis metrology index
CT	Computerised tomogram
CRP	C-reactive protein (blood test)
DoH	Department of Health
DMARD	Disease modifying anti rheumatic drug
EPP	Expert patient programme
ESR	Erythrocyte sedimentation rate
CGT	Constructivist Grounded Theory
GT	Grounded Theory
HBM	Health Belief model
HIV	Human immunodeficiency virus
HLA B27	Human Leucocyte Antigen B27
HLC	Health locus of control
MRI	Magnetic resonance image scanning
NASS	National Ankylosing Spondylitis Society
NSAID	Non steroidal anti inflammatory drug
NHS	National Health Service
OMERACT	Outcome Measures in Rheumatology
OA	Osteoarthritis
RCT	Randomised controlled trial
ReA	Reactive arthritis
SPA	Spondyloarthritis
TENS	Transcutaneous electrical nerve stimulation
TNF	Tumour Necrosis Factor
TPB	Theory of planned behaviour
TRA	Theory of reasoned action
SCM	Stages of change model
US	Ultrasound

Actual names of participants and Hospitals involved in the study have been changed to protect their anonymity.

CHAPTER 1

Work leading to the project

Prior to undertaking this study I worked as a Chartered Physiotherapist specialising in rheumatology between 1987 and 1997 and was involved with a weekly ankylosing spondylitis (AS) exercise group. Although it has long been held, within the clinical management of AS, that daily exercise is a key element of self-management, of the 350 people with AS entered on the hospital 1 database, many chose not to attend the weekly exercise group that was offered to them. I had always believed that the people who did not attend the group were those who did not cope successfully with their own self-management.

Within the rheumatology clinic, physiotherapists attended an annual client–rheumatologist–therapist consultation where many of these non-attendees came into contact with physiotherapists, providing the opportunity to discuss their exercise behaviour over the previous year. Contrary to my belief (that people who did not attend were not coping well), it was clear that many people were coping very well and had systems in place which meant that they did not feel the need to come to a weekly group. This suggested that there existed a proportion of people with AS whose behaviour did not conform to the prevailing ethos of health practitioners. Time limitations within the clinic meant that no in-depth information could be obtained on their reasons for their exercise behaviour. In this way a personal area of interest was developed which was grounded in the comments of people with AS. In 1998 when I left clinical practice to work in academia this observation led to my choice of research topic.

The first step in my research journey was to build upon this anecdotal evidence by undertaking a randomised case note audit of people with AS attending Hospital.1. Data were obtained from the Hospital 1. Physiotherapy Department AS database. One hundred physiotherapy records were audited (18 female, 82 male, mean age 46.1 years, SD 11.89, mean time elapsed since diagnosis 9.5 years). The

objectives of this preliminary audit were to obtain demographic data on the Hospital 1 AS population and to establish frequencies of attendance at the weekly group.

Results showed that 33 (33%) of people sampled did not attend the group during a twelve-month period and that non-attendance could not be explained by geography alone since 52% of the non-attendees lived within 10 miles and 29% lived within 5 miles of Hospital 1. The data also suggested that gender and age did not appear to be factors in the behavioural differences. Three categories of attendance were postulated based upon these data.

1. No attendance in the period of one year
2. One to five times per annum
3. More than five times per annum (illustrated in Appendix 1).

The results of this audit informed the aim of this study, which was to gain a greater understanding of the factors which influence exercise behaviour in people with AS.

The literature review was ongoing from the outset of the project, with electronic updates set up in rheumatological, qualitative research methods, and health psychology literature databases. The following databases were employed: Medline, Cinahl, and Pedro, using the terms *ankylosing spondylitis*, *AS*, *exercise compliance*, *behaviour*, *health behaviour*, and *health psychology in chronic disease*, and an electronic update subscription to the *Journal of Rheumatology* was taken out.

1.1. Chronic Disease Management in the Twenty-First Century

In the United Kingdom, 17.5 million adults may be living with a chronic disease (Department of Health [DoH] 2001) and the DoH estimates that by 2030 the incidence of chronic disease in people aged over 65 will more than double (DoH 2001). There has been a growing interest in user involvement in chronic disease self-management as exemplified by national initiatives such as Working for Patients (DoH 1989a), Caring for People (DoH 1989b), the Patient's Charter (1991), and the Health of the Nation (DoH 1992). However, despite these initiatives there is a paucity of evaluation of the impact of such participatory initiatives on chronic disease self-management (Carr 2004).

In the early 1980s there was an emphasis on understanding the most effective methods of communicating information about self-management in the belief that if information was communicated effectively to people by healthcare professionals they would undertake the required behaviour change (Joos and Hickam 1990). Clinicians typically relied on "informational power" illustrated by the production of health information and "expert power" illustrated by use of their professional status to convince people to change their behaviour (Joos and Hickam 1990). As our understanding of health behaviour has increased, it has become apparent that being informed by a person of professional standing is in itself not enough to facilitate behaviour change.

Attention has therefore started to focus on to how to incorporate psychological approaches to behaviour change within self-management programmes (Lorig 2001). Health-behaviour theories and models (discussed later) provide more effective methods for understanding adherence and other behaviour change related to treatment regimens (Connor and Norman 1995). As such they enable professionals to optimise the effectiveness and efficiency of their interactions with people (Protheroe et al. 2008). The work of Kate Lorig and colleagues in the 1980s (Lorig 1982; Lorig et al. 1984) was instrumental in informing the evidence base for the efficacy of self-management interventions in long-term conditions,

informing not only the Challenging Arthritis Programme but also the Expert Patient Programme (EPP), both of which are discussed later.

The development of self-management skills is now central to the management of musculoskeletal impairments (DoH 2005), and the DoH promotes this as a key government objective (DoH 2001). The national target areas outlined in “National Standards, Local Action” (July 2004) have a strong emphasis on managing long-term conditions and improving the patient experience, and are further supported by the new standards framework “Supporting People with Long Term Conditions” (DoH 2005). The NHS and Social Care Long Term Conditions Model (DoH 2005; Figure 1.1) aims to promote a systematic approach toward the care of people with chronic illness within health and social care communities and has stratified the management of long-term conditions into three approaches which aim to match the most appropriate levels of care to differing levels of need.

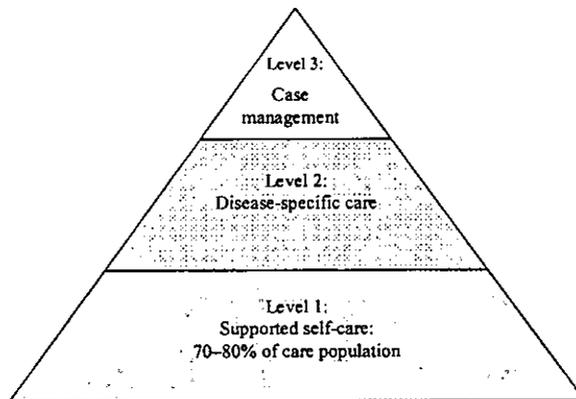


Figure 1.1. The three levels of care for people with long-term conditions requiring self-management and professional care (DoH 2005).

Level 3: Case management requires the identification of the very high intensity users of unplanned admissions to secondary care. Care of these people is to be managed by the community matron or another professional using a case management approach to anticipate, co-ordinate, and join up health and social care.

Level 2: Disease-specific care management involves providing people who have a complex single need or multiple conditions with responsive, specialist services using multi-disciplinary teams and disease-specific protocols and pathways such as the National Service Frameworks and Quality and Outcomes Framework.

Level 1: Supported self-care involves collaboratively helping individuals and their carers to develop the knowledge, skills, and confidence to care for themselves and their condition effectively. Within each level there is a strong emphasis on working with people to develop their skills in self-management to enable them to play active roles in the management of their impairments.

Two specific self-management initiatives have an impact on and relevance to long-term self-management in rheumatic conditions, namely the EPP and the Challenging Arthritis Programme, both of which are aimed at encouraging people to self-manage and have been informed by the use of psychological approaches to promoting behaviour change. .

1.1.1. The role of self-efficacy in lay-led management programmes

Kate Lorig and colleagues at Stanford have undertaken considerable work in chronic disease management, drawing on Bandura's previous work on self-efficacy (Bandura, 1977a; Bandura, 1977b; Bandura; 1982; Bandura, 1986), which stated that the strength of belief in one's capability to undertake a behaviour is a good predictor of future motivation and behaviours. Bandura claimed that self-efficacy beliefs can be enhanced through performance mastery, modelling, reinterpretation of physiological symptoms, and social persuasion. Bandura's view of self-efficacy is that a strong sense of efficacy enhances human accomplishment and personal wellbeing in many ways. People with high assurance in their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided. Such an efficacious outlook fosters intrinsic interest and deep engrossment in activities. Such people set themselves challenging goals and maintain strong commitment to them and heighten and sustain their efforts in the face of failure quickly recovering their sense of efficacy after failures or setbacks (Bandura 1977). Ultimately, enhanced self-efficacy leads to improved behaviour, motivation, thinking patterns, and emotional wellbeing (Bandura 1977a).

Lorig et al. (1989) concluded that enhanced self-efficacy is responsible for the improvements in health status demonstrated by those attending self-management programmes. Self-efficacy is seen, within the context of these programmes, as an early step in causal pathways of behaviour change in self-management; increasing self-efficacy (confidence) is a prerequisite for behaviour change (Lorig et al. 1989).

1.1.2. The Expert Patient Programme (EPP)

Launched in September 2001, the EPP proposed a new approach to chronic disease management in England. The chief medical officer describes expert patients as "people who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases" (DoH 2001). The EPP is a course designed to help people with long-term conditions develop skills to effectively manage their impairments. People who have chronic conditions act as role models and deliver the training. Over a period of six weeks they lead attendees through a structured programme focussing on issues including diet, exercise, fatigue, breaking the symptom cycle, managing pain and medication, and communication with healthcare professionals. The programme aims to develop the confidence, control, and motivation of the participants to enable them to use their own skills, available information, and professional services to manage their impairments. The key psychological concept on which the EPP draws is self-efficacy (Newbould, et al. 2006).

In a paper delivered to an international conference on chronic disease self-management, Holman and Lorig discussed the necessary skills for effective self-management which (in their view) included competencies in problem solving, decision making, resource utilisation, forming a patient–healthcare-provider relationship, and taking action (Holman and Lorig 2000). Whilst the EPP is a generic programme attended by people with a wide range of long-term conditions, there is now demand by key stakeholders for condition-specific courses (Kennedy et al. 2004).

1.1.3. The Challenging Arthritis Programme

This Challenging Arthritis Programme is one of the disease-specific programmes currently in existence in the UK. Like the EPP it is led by people with the chronic condition. This programme has been adopted by Arthritis Care (UK) and aims to empower and enable participants to take control of their

arthritis. The course runs for two-and-a-half hours each week for a period of six weeks. A range of self-management techniques are covered, including pain and fatigue management principles, problem solving and goal setting, healthy lifestyle, energy conservation, treatments and medication, coping with depression, working with healthcare professionals, and how to access community resources.

Evidence that self-management makes a difference in terms of changes in behaviour, health status, and healthcare utilisation has been demonstrated by Lorig et al. (1993, 1999) in both the Arthritis Self-management Programme (ASMP) and the Back Pain Self-Management Program in longitudinal studies of one to four years. These programmes resulted in increases in the number of minutes per week of exercise as well as improvements in symptom management techniques such as relaxation. Participants also reported improved communication with healthcare professionals and less fatigue and worry about their conditions. Whilst current evidence suggests that these programmes have a positive impact, the underlying mechanism of attainment of self-management effects remains unclear according to Lorig, who adds that:

Traditional health promotion and patient education programs have operated under the assumption that people should change behaviours in order to improve health status. This assumption has come from epidemiological studies, which link such behaviours as poor diet, lack of exercise, and smoking to future health problems. While there is little question that changing these behaviours will probably impact future health, this same assumption may not hold for people already living with chronic conditions.

(Lorig 1999, p. 229)

Many health services around the world have adopted this lay-led model in the hope that it will deliver cost-effective health gains. Recently, a review commissioned by the National Institute for Health and Clinical Excellence gave a cautious welcome to lay-led self-management interventions but pointed out that most evaluations were short term and set in the USA and some of the data were uncontrolled (Bury et al. 2005). Of the four UK studies, two evaluated the arthritis self-management programme (Barlow et

al. 2000 ; Buszewicz et al. 2006) and two the chronic disease self-management programme, including the national evaluation of the EPP carried out by the National Primary Care Research Centre in Manchester (Griffiths et al. 2005; Kennedy et al. 2007). Their findings are summarised in Table 1.1 below, reproduced from Griffiths et al. (2007) with permission. The CDSMP tends to be the model adopted in the management of long-term conditions, in Australia, China, South Africa, Canada and many European countries, where it is frequently referred to under the umbrella term of the EPP (DOH 2001).

Study	Intervention	Condition	Number of patients	Outcome			
				Self-efficacy	Psychological health	Generic health related quality of life	Use of healthcare
Barlow et al. 2000	ASMP	Arthritis	544	Improved	Improved	Unchanged	Unchanged
Griffiths et al. 2005	CDSMP	Various	439	Improved	Unchanged	Unchanged	Unchanged
Buszewicz et al. 2006	ASMP	Arthritis	812	Improved	Unchanged	Unchanged	Unchanged
Kennedy et al. 2007	CDSMP	Various	521	Improved	Improved	Improved	Unchanged

Table 1.1. Randomised trials of lay-led self-management programmes in the UK
Key: ASMP = Arthritis Self-Management Programme; CDSMP = Chronic Disease Self-Management Programme

Griffiths et al. (2005) found that a lay-led management programme improved self-efficacy in Bangladeshi patients, suggesting that it may be useful for ethnic minorities. However, the changes that they report in self-efficacy are generally modest and it is unclear how much people value improvements in self-efficacy compared with a reduction in symptoms or a gain in health-related quality of life. They found that Bangladeshi people with chronic disease benefited from a six-week chronic disease self-management programme delivered by trained and accredited lay Bangladeshi tutors who themselves had chronic disease. The programme improved participants' self-efficacy to control chronic disease and "probably" (p. 832) increased their use of self-management skills.

Qualitative interviews with attendees and non-attendees undertaken by Griffiths et al. (2005) suggest that there may be specific social and spiritual barriers to attendance in the Muslim population, however. These include responsibilities relating to social roles and health (care for family and guests, attendance at other healthcare appointments) and views that beliefs concerning predetermination of the Islamic life-course make attendance futile.

It is not, as yet, clear who will benefit most from EPP programmes, and recently Reeves et al. (2008) attempted to answer this by recruiting 629 participants with self-defined long-term conditions from community settings in all 28 Strategic Health Authorities in England. They used a post-hoc subgroup analysis of data from a randomised controlled trial (RCT) to explore predictors of three trial outcomes: self-efficacy, energy, and health-related quality of life. They conclude that participants with lower self-efficacy and low confidence and health-related quality of life at baseline demonstrated more positive health outcomes.

1.1.4. Self-management in ankylosing spondylitis

Exercise, which is a fundamental aspect of AS self-management, is typically taught upon diagnosis using a standard approach with a sheet of exercises being given to the person as a reminder (O'Hea 2008). However in the continuing management of AS, therapists in the UK adopt varied approaches to promoting the use of exercise and self-management. There is as yet no formalised programme of self-management comparable to the EPP or Challenging Arthritis. Some people are managed on a one-to-one basis, some units run weekly therapist-led group sessions where people are able to take part in exercise sessions in a group setting, and some people attend sessions run by members of the National Ankylosing Spondylitis Society (NASS) where physiotherapists may or may not attend. Some units have access to hydrotherapy facilities and others do not.

A key aspect of the management of AS is the regular use of clinical assessment to monitor disease progression and range of movement. However the regularity of clinical assessment varies from three to six or twelve monthly intervals and may change in the future with the increasing usage of anti-TNF α drug therapies which require more frequent monitoring. Clinical assessment is closely linked with the

use of exercise as, if measurements suggest that movement is being lost, people will be encouraged to engage in more exercise.

1.1.5. Summary

This section has outlined the context from which the project has developed and the main drivers for and approaches to self-management by people with long-term conditions. Currently no EPP programmes specific to the management of AS exist, and if disease-specific management programmes for AS are to be created in the future a much deeper understanding of the processes of decision-making in relation to the use of exercise to manage AS is needed.

1.2. Ankylosing Spondylitis

1.2.1. Introduction

Ankylosing spondylitis (AS) affects between 0.5 and 1.5% of the population of the United Kingdom. The term derives from the Greek words *angkylos* meaning “bent” and *spondylos* meaning “spine”. It is part of a group of conditions known as spondyloarthropathies (SpA) that are characterised by shared symptoms and genetic predisposition. The first account of the effects of AS on the skeleton was given in 1691 by Bernard Connor, who described the changes that he saw in the fused skeleton of a person with AS:

All of these Bones were so straightly and intimately joyned, their ligaments perfectly bony and their articulations so effaced, that they really made but one continuous bone, the figure of this trunk was crooked, making part of a circle.(Connor 1691)

Table 1.2 shows the joints commonly affected by AS

Region	Comments and reference
Cervical spine	Discovertebral and apophyseal joints and atlantoaxial articulations may all be affected. Occasional cases of atlantoaxial subluxation are reported (Lee 2001).
Pubic symphysis and sacroiliac joints	Osteitis pubis and sacroiliitis are common, but the most commonly affected peripheral joint is the hip, particularly in young age onset AS (Calin 1988).
Knee	AS may present as a monoarthritis (Gran 1985).
Glenohumeral Joint (shoulder)	Inflammatory arthropathy of the sternoclavicular and acromioclavicular joints has been reported (Emery 1991).
Foot	Areas most frequently involved are the calcaneal attachment of the plantar fascia and Achilles tendon (Burgos-Vargas 2002).

1.2.2. Clinical features, diagnosis, and prognosis

AS affects the spinal, sacroiliac, and peripheral joints as well as non-articular tissues. It typically affects young adults with a male to female ratio of 3:1 (Will et al. 1990). The characteristic pathological feature of AS is enthesitis, which is inflammation at the site of the attachment of ligaments or tendons to bone. The exact inflammatory, microbiologic, and immunologic events occurring at the sites of entheses have not yet been fully defined (McGonagle 1999). Figure 1.2A shows the normal radiographic anatomy of the lumbar spine, in AS bony bridges known as syndesmophytes at the margins of the vertebrae of the spine are a typical finding in AS (Hammoudeh et al. 1995; Figure 1.2B.) These may fuse (ankylose) and this is described clinically as a “bamboo spine” (Figure. 1.2C). The vertebrae in AS also typically take on a squared appearance (Ralston et al. 1992). These features may lead to postural deformities (Figure 1.3), in extreme cases resulting in a “question mark deformity”, so called because of the shape of the

flexed spinal column. In addition to spinal involvement, local tender areas are common at other entheses, for example at the distal attachment of the medial collateral ligament of the knee, the costochondral joints of the thorax, the iliac crest of the pelvis, and the plantar fascia. Additional anatomical sites of pathology are shown in Table 1.2.

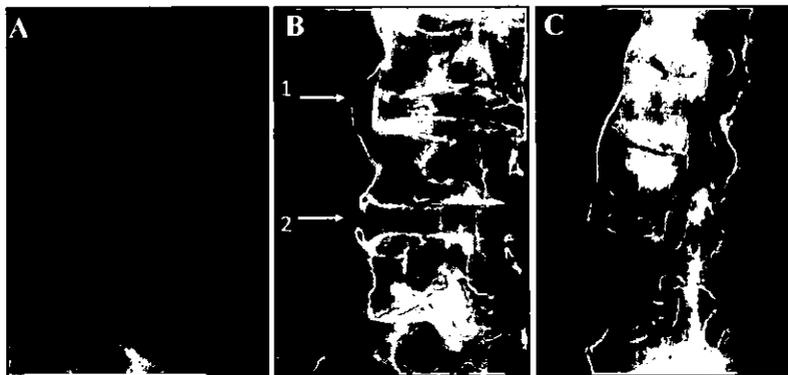


Figure 1.2. Images of normal and AS spines. A: Normal lumbar spine. B: Syndesmophyte formations in AS; between two vertebrae at arrow 1 there is complete ankylosis not evident at arrow 2 (by kind permission C Hurt, MD University of Washington department of radiology USA). C: Bamboo spine with fusion of syndesmophytes.

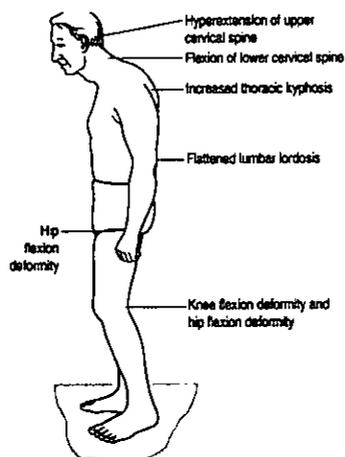


Figure 1.3. The typical postural deformities of advanced ankylosing spondylitis (reproduced from Tidys Physiotherapy 14th Edition Copyright Elsevier with permission).

AS also involves extra articular manifestations including low-grade fever, weight loss, anaemia, and axial osteoporosis (Bolzner et al. 2003). Two thirds of people with undifferentiated SpA show signs of gut inflammation, and some develop Crohn's disease (De Keyser et al. 2002). One third of people with AS also experience acute anterior uveitis, which may lead to visual impairment (Martin et al. 2002). Lung abnormalities including apical fibrosis, interstitial lung disease, emphysema, bronchiectasis, and pleural thickening are common in ankylosing spondylitis, even in people with early disease (Quismorio 2006). Cardiac manifestations including aortitis, aortic insufficiency, conduction disturbances, and left ventricular dysfunction have also been documented (Lautermann 2002).

Pain is a feature of AS and is typically described as lumbar or buttock and/or hip pain lasting longer than three months improving with activity, worsening with rest, and morning stiffness lasting longer than 30 minutes, and relieved with non-steroidal anti-inflammatory drugs (NSAIDs) (Harper and Reveille 2009). In AS, pain is a major determinant of depression for women but is of lesser importance for men. Barlow (1993), and Jones et al. (1996) found that pain was a major determinant of overall wellbeing whilst formulating the Bath Ankylosing Spondylitis Global Score (BAS-G) index (shown in Table 1.3 below).

The associated increase in pain on exercise in AS may result in confusion in patients when they come into contact with physiotherapists who advocate exercising through the pain barrier, as O'Hea notes:

It is important to point out that from a lay perspective, pain is the body's way of signalling that there is something wrong and this usually means that the individual has to rest (O'Hea 2008, p. 520.)

Fatigue is well recognised and correlates with disease activity, functional ability, global wellbeing, and mental health status (van Tubergen et al. 2002). In addition, Lacaille et al. (2007) have identified fatigue as a key worry amongst people with AS in relation to the person's ability to remain in employment.

No single blood test is diagnostic of AS. Spoorenberg et al. (2002) concluded that neither plasma C reactive protein concentration nor erythrocyte sedimentation rate (ESR) was superior in assessing disease activity in AS, and whilst various imaging tools are now used, no single tool is universally effective in the diagnosis of AS. X-rays are still used to identify bony changes such as syndesmophytes – the bony projections that grow between adjacent vertebrae causing the joints to stiffen or eventually fuse – and fractures (Hitchon et al. 2002), although the diagnostic sensitivity of X-rays is controversial (Mau et al. 1988). Enthesopathy lesions or sites of soft tissue inflammation can be identified by magnetic resonance imaging (MRI) (Braun & Golder 2002), and MRI scanning has also been shown to be a useful tool in the diagnosis of non-articular sequelae such as interstitial lung disease (Braun et al. 2003; Kiris et al. 2003). The New York criteria originally proposed by Moll and Wright in 1973 and later modified by van der Linden et al. in 1984 are therefore the accepted diagnostic criteria relying on a combination of anthropometric, radiological, and symptomatic disease behaviours.

The modified New York Criteria comprise:

- low back pain for more than three months, improved by exercise, not relieved by rest
- limitation of lumbar spine motion in both the sagittal and the frontal planes
- limitation of chest expansion relative to normal values for age and sex
- sacroiliitis. (Moll & Wright 1973)

Definite AS is diagnosed if the radiological criterion is present plus at least one clinical criterion. Probable AS is diagnosed if three clinical criteria are present *or* if the radiological criterion is present but no clinical criteria are present (van der Linden et al. 1984).

AS follows an unpredictable course of exacerbations and remissions, with no consensus in the literature regarding its natural course. Gran (1997) proposed that most functional deterioration occurs during the first 10 years of the disease, yet using radiological outcome measures alone, Brophy et al. (2002) claimed that function continues to deteriorate steadily over time, and whilst the term “burnout” is used by people with AS, the phenomenon is not supported by the literature, since less than 1% of people who present to a rheumatologist enter long-term remission (Kennedy et al. 1993). AS tends to progress from the lumbar to cervical regions of the spine (Calin & Elswood 1988) but it may follow an atypical course. Mader (1999) described four subgroups that develop AS:

1. Classic AS with characteristic clinical and radiographic manifestations
2. Asymptomatic AS with characteristic radiographic findings
3. AS with extra-articular features as presenting manifestations
4. Symptomatic AS without radiographic supporting evidence.

1.2.3. Demography and assessment

AS affects 0.6–1.9% of Caucasian populations (Brandt et al. 2003), and the prevalence closely parallels the frequency of HLA-B27-associated subtypes (Olivieri et al. 2002) The prevalence of the HLA-B27 gene in the general population shows considerable geographic variation: it occurs in 50% of Haida Indians of Northern Canada but is virtually absent among black Africans and Guatemalan Indians (Khan 1998). However, the mechanisms whereby B27 confers susceptibility to AS remain unknown.

Since the main clinical feature of AS is compromised active spinal movement, the main focus of physiotherapy assessment and monitoring is on measurement of the spinal joints. AS assessment by physiotherapists is dominated by an array of anthropometric measurements, traditionally involving an ongoing programme of measurement of the tissues stiffened by the disease. Informed by these assessments, therapists then advise people on which parts of the spine or peripheral joints are compromised in movement and need to become the focus of exercise to regain or maintain movement. This approach assumes that once informed about deterioration, people will increase their exercise.

Initial clinical measurements used in AS were not standardised, reliable, valid, or responsive to change (Bellamy et al. 1998; 1999). Therefore, accurate assessment of improvement or deterioration was not possible. Those measurements used also tended to focus on the clinical status of the AS and did not assess the impact of impairments on the broader aspects of a person's life. In the 1990s a number of disease-specific and generic outcome measures for AS were developed.

With much of the work coming from Bath, UK, disease-specific measures of the following parameters were developed: spinal measurement (Bath Ankylosing Spondylitis Metrology Index [BASMI], Jenkinson et al. 1994); quality of life (Bath Ankylosing Spondylitis Global Score [BAS-G]); disease activity including fatigue (Bath Ankylosing Spondylitis Disease Activity Index [BASDAI], Garrett et al. 1994); and function (Bath Ankylosing Spondylitis Functional Index [BASFI], Calin et al. 1994).

In 1995, the Assessments in Ankylosing Spondylitis (ASAS) working group, using the criteria of reliability, sensitivity, and ease of use, identified acceptable instruments that could be used to determine changes over time in research and clinical practice. The domains chosen by the group included pain, spinal mobility, and functional disability. Whilst they are an attempt to standardise and simplify assessment in AS, they have been criticised for their failure to include important domains such as

quality of life and psychological status (Haywood 2000). Outcome measures currently used in AS are shown in Table 1.3

Subject	Measure	Original reference	Comments
Spinal mobility	Bath Ankylosing Spondylitis Metrology Index (BASMI)	O'Driscoll et al 1978 Macrae & Wright 1969 Jenkinson et al 1994	BASMI involves five clinical measurements which provide a composite index (BASMI) and define disease status in AS. The BASMI is quick (7 min), reproducible, and sensitive to change across the disease spectrum (Jenkinson 1994), but is one-dimensional and does not reflect functional or psychological status, and metrology does not play a role in "well being" (Jones et al 1996).
Quality of life	Bath Ankylosing Spondylitis Global Score (BAS-G)	Jones et al 1996 Guillemin et al 1997	The scale involves the person answering two questions on a VAS scale about the impact of their AS on wellbeing over the last week and secondly over the last six months.
Function	Bath Ankylosing Spondylitis Functional Index (BASFI),	Calin et al 1994	The BASFI comprises 10 questions. The first 8 questions evaluate activities related to functional anatomical limitations. The final 2 questions evaluate the patients' ability to cope with everyday life.
Disease activity (inc fatigue)	Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)	Garrett et al 1994	The BASDAI consists of a 1 to 10 scale (1 indicates no problem and 10 indicates the worst problem) which is used to answer six questions pertaining to the major symptoms of AS: fatigue, spinal pain, joint pain/swelling, areas of enthesitis, morning stiffness duration, and morning stiffness severity, and takes between 30 s and 2 min to complete. BASDAI demonstrated statistically significant ($p < 0.001$) reliability. BASDAI demonstrates a sensitivity to change within a short period of time. Following a three-week physiotherapy course, patients showed a significant ($p = 0.009$) 16.4% score improvement on the BASDAI scale"

Table 1.3. Outcome measures in AS.

1.2.4. Impact on quality of life and employment

It is difficult to map an accurate picture of the socioeconomic impact of AS, since researchers have used different methodologies and benchmarks (Boonen 2006). AS tends to affect young men and has a considerable social and occupational impact (Sundstrom et al. 2002). AS will affect the person's life as a whole, not merely their ability to move their spine and peripheral joints, and socio-demographic factors, for example living conditions and marital status, are equally important variables in affecting a person's ability to function normally in their everyday life (Koukouli et al. 2002). In chronic disease in particular, social support in terms of marital status, living arrangements, and size of household correlates positively with quality of life (Nunes et al. 1995).

As AS predominantly affects young males who are still in employment, their self-management may be constrained by factors such as time available to complete exercise regimes. With modifications to the workplace, and despite long-term morbidity with gradual loss of functional capacity, 85% of people with AS are still able to work after more than 20 years of illness (Ringsdal & Helin 1991). It is unclear from the literature whether this is a consequence of improved coping strategies, improved drug management, change in occupation because of diagnosis, or other factors associated with accumulating experience of the disease journey, rather than intrinsic change in the disease.

However, high levels of disease activity, increased age, and insufficient support from colleagues or management have all been associated with withdrawal from the labour force. (Boonen et al. 2001). Ward & Kuzis (2001) suggest that those with physically demanding jobs are more likely to change their occupation as a direct result of their AS. Evers et al. (1998) found that a decrease in functional status after one year was predicted by more frequent use of passive pain-coping strategies such as worrying and resting, and that a decrease in mobility could be predicted by the presence of a small social network.

Using the International Classification of Functioning Disability and Health (ICF), van Echteld et al. (2006) found that among 111 people with AS, at least mild impairment or restriction were shown in 119 from a total of 165 categories of the extended ICF checklist. Within each of the components of the ICF (body functions, body structures, activities and participation, and environmental factors) at least one third of the categories were impaired or restricted for more than 50% of people. In the activities and participation component, 55 of the 78 categories or subcategories were reported as mildly restricted by at least 5% of the 111-patient sample. Specific activities that could relate to the broader ICF category of recreation and leisure, such as walking more than 1 km, swimming, and cycling, were identified by

patients as being restricted. The authors did not differentiate between activity and participation, as these are combined as one component in the ICF framework; A review of the results identified the following categories and subcategories as representing aspects of participation which the 111 patients indicated were at least mildly restricted: recreation and leisure (74%), community life (53%), basic interpersonal interactions (6%), remunerative employment (52%), intimate relationships (12%), informal social relationships (6%), family relationships (6%), and higher education (6%).

1.2.5. The management of ankylosing spondylitis

The management of AS falls into two broad categories: medical and exercise self-management.

1.2.5.1. Medical management

The main objectives of medical therapy in AS are to relieve pain, stiffness, and fatigue. NSAIDs are a first-line treatment and they are effective in controlling symptoms such as pain and stiffness (Elyan and Khan 2006); however potential gastrointestinal and cardiovascular side effects of these medications can occur (Akkoc et al. 2006).

Disease-modifying anti-rheumatic drugs (DMARDs) are used, as are steroid injections (Olivieri et al. 2002). With increased understanding of the pathological processes involved, new biological therapies such as adalimumab (Humira), a human monoclonal tumour necrosis factor (TNF) alpha antibody, are being used. Several studies have also confirmed the efficacy of infliximab in people with AS (Braun et al. 2003; Temekonidis et al. 2003; van der Heijde et al. 2008). Developments in anti-TNF α medications may be relevant to exercise behaviour since the dramatic effect of these drugs on the symptoms of AS may affect the perceived need to undertake exercise, although there is as yet no evidence for this.

Elective orthopaedic surgery in the form of total hip arthroplasty is commonly performed for severe hip involvement (Kubiak et al. 2005) and local therapies such as ultrasound, cryotherapy, massage, or transcutaneous electrical nerve stimulation (TENS) may ease the pain of enthesitis, although evidence supporting their use in AS does not exist.

1.2.5.2. Exercise management

The pain and stiffness of AS is usually relieved by active exercise (Gran 1985). For many years therefore, exercise has been widely accepted as a core physiotherapy intervention and central to the management of AS. Evidence for its effectiveness in the long term however is largely empirical. Early proponents of exercise advocated a lifelong, carefully devised, and well-instructed exercise programme (Corrigan & Kannangra 1978; Smythe 1979), although they failed to qualify what they meant by these phrases. This approach was reflected in physiotherapy textbooks advocating Spartan-like adherence to an active exercise programme (Thompson et al. 1991), and these views persist, with AS being referred to as “the enemy” in education leaflets, and with support groups advocating exercise sessions up to two times per day (<http://www.nass.co.uk/>). Little or no comment is made however in educational leaflets on (a) what definitive effects these exercises will have on the person’s symptoms and life in the long term and (b) the problems associated with adhering to a time-consuming exercise regime every day for the rest of one’s life.

Physiotherapy in AS is built around the use of free active exercise (i.e. exercise without the use of equipment), and paradoxically whilst physiotherapists seek to encourage people to undertake the tailored management of their own condition, many centres provide standard exercise sheets or offer

weekly classes which go through the same set of exercises each week, doing little to encourage tailoring of exercises or self-management away from a hospital setting (O’Hea 2003).

In times of disease flare-up, the patient may require admission to hospital to undergo intensive inpatient rehabilitation regimes consisting of exercise and hydrotherapy (Viitanen et al. 1995). A person with AS is encouraged to make the most of the relatively pain-free periods by exercising as vigorously as possible to maintain movement and a good general level of fitness (O’Hea 2008). This strategy differs somewhat from that advocated for other types of arthritis (e.g. Rheumatoid Arthritis) where people are advised to pace themselves so as not to aggravate their symptoms during times of low disease activity.

There is no consensus amongst clinicians as to what the specific aims of exercise are in AS, and this may have had an impact on the failure to develop a clear consensus in the evidence about the benefits of exercise. Anecdotal evidence suggests that some therapists believe that exercise will prevent ankylosis or at least encourage ankylosis in a functional position; others believe that the cardiovascular benefits outweigh the postural benefits.

1.2.6. Randomised controlled trials of exercise in ankylosing spondylitis

There have been a number of RCTs looking at the benefits of exercise in AS, such as Kraag et al. (1990, 1994), Helliwell et al. (1996), Van Tunbergen et al. (2002), Analay (2003), Sweeney (2002), and Ince et al. (2006).

Kraag et al. (1990) studied 53 people who all fulfilled New York diagnostic criteria, stratified into two age bands (18–35 years and 36 years and above). The intervention group consisted of a four-month course at home utilising change in spinal mobility measured at four months by fingertip-to-floor distance as the primary outcome measure. The control group undertook no intervention (details of how

this was monitored are absent) and the findings were that no significant pain reduction occurred between the two groups, although finger-to-floor distance was significantly improved in the intervention group ($P < 0.004$).

In 1994, Kraag completed a follow-up study reporting on the 22 controls who received the previously withheld treatment and found similar improvements in finger-to-floor distance (Kraag et al. 1994). In this study, fingertip-to-floor distance did not change in experimental patients between 4 and 8 months ($P = 0.143$); however, the initial improvement achieved was maintained. The experimental group at four months was better than the control group at eight months ($P = 0.038$), whilst following treatment, fingertip-to-floor distance did not change in control patients ($P = 0.145$). Interestingly, Schober's test (a measure of pure lumbar spine movement) showed no significant differences, suggesting that the improvements in finger-to-floor distance were a result of an increased range of movement at the hip joint. They suggested that these improvements may be easily maintained but stopped short of discussing the fact that failure of the programme to effectively decrease pain may be an overriding factor in exercise cessation, that is, improvement in one anthropometric measure may in itself be insufficient reason to maintain exercise in the long term outside the controlled research environment.

Helliwell's approach (1996) was to use three groups, randomising 44 people (89% of whom were male) to receive either intensive inpatient physiotherapy (a three-week admission which involved daily intensive exercise, stretching, aerobics, and hydrotherapy), outpatient hydrotherapy and home exercises (a six-week period of twice-weekly outpatient hydrotherapy), or home exercise alone (people were instructed in the home exercise regime and given diary cards to complete, with a review six weeks later). Measurements of cervical rotation, chest expansion, lumbar movement, and a visual analogue scale for combined pain and stiffness were taken immediately before the start of the treatment, after the completion of treatment, and two, four, and six months afterwards. It was found at six months that

there were no differences in outcomes between the groups. This study experienced poor recruitment rates, with many refusing to enter the study: those in employment were not willing to commit to inpatient treatment, and those who were unemployed preferred to undergo inpatient treatment. There was also a high drop-out rate: at six months it was 87%, 60%, and 57% respectively in each group that attended for assessment. Some who had been randomised to groups other than those they preferred defaulted. Measurements were not blinded, the author citing insufficient funding as the reason. Measurements were also imprecise; for example, in the pilot study the repeatability of measurements was studied over three days. For cervical rotation, the mean difference between measurements was 1°, yet the standard deviation was high at 8.5°. At six-month follow-up there was no statistically significant difference in anthropometric measurements between the three groups.

Van Tubergen et al. (2001) recruited 120 people in the Netherlands, Austria, and Germany, again using the New York diagnostic criteria as inclusion criteria. Groups 1 and 2 undertook spa therapy in Austria and the Netherlands respectively (although this also included sports and walking). Group 1 (mean age 48 +/- 10 years; male: female ratio 25:15) was treated in a spa resort in Bad Hofgastein, Austria; group 2 (mean age 49 +/- 9 years; male: female ratio 28:12) Participants in the third (control) group (mean age 48 +/- 10 years; male: female ratio 34:6) undertook their normal exercise routines without spa treatment. Using BASFI, pain levels, and duration of stiffness in the morning, the authors concluded that combined spa-exercise therapy versus standard treatment with drugs and weekly group physical therapy was more effective and showed favourable cost-effectiveness and cost-utility ratios compared with standard treatment alone. Whilst the results suggest that improvements can be maintained in the long term, a problem with this study was the failure to operationalise exercise, and the mean ages of participants in groups 1–3 were 48, 48, and 49 respectively, and thus did not include the key younger adult AS demographic. After spa-exercise therapy, all participants followed weekly group physical therapy for another 37 weeks. Outcomes were functional ability, global wellbeing, pain, and duration of

morning stiffness, aggregated in a pooled index of change (PIC). Analysis of variance showed a statistically significant time-effect ($p < 0.001$) and time-by-treatment interaction ($P = 0.004$), indicating that the three groups differed over time with respect to the course of the PIC. Four weeks after the start of spa-exercise therapy, the mean difference in PIC between group 1 and the control group was 0.49 ($P = 0.004$) and between group 2 and controls was 0.46 ($P = 0.005$). At 16 weeks, the difference between group 1 and controls was 0.63 ($P = 0.002$) and between group 2 and controls was 0.34 ($P = 0.086$). At 28 and 40 weeks, more improvement was found for group 1 compared with controls ($P = 0.012$ and $P = 0.062$, respectively) but not for group 2 compared with controls.

Analay et al. (2003) investigated the younger demographic (45 people with a mean age of 36 years) using two groups, one of whom underwent an intensive exercise regime, which was supervised by a physiotherapist and included multiple therapies, namely mobilisation and strengthening exercises, aerobic exercises, and respiratory exercises (not defined), for six weeks at three days per week. The control group participants were encouraged to practise a home exercise programme and monitored by telephone. Their selected outcome measures were pain (VAS), duration of early morning stiffness, and a range of anthropometric assessment measures undertaken before, after (no indication of how soon after completion of the exercise course), and at three months. The results were mixed: a significant increase was found in Schober's measurement (a measure of lumbar spine flexion), with an average increase of 6% ($P = 0.01$), and decreased morning stiffness compared to the control group, but interestingly no improvements were reported in finger-to-floor distance, in disagreement with the findings of Kraag in 1990 discussed above.

Sweeney et al. (2002) compared a six-month home-based exercise package including educational literature, a video, and exercise reminder stickers with a control group who had no intervention. The total sample of 200 people had a wide age range of 16–65 years, with a mean of 43.2 years, and

inclusion and exclusion criteria were not described. Outcome measures were the BASFI, BADAI, BAS-G, Arthritis Self-Efficacy Scale (ASES) (Lorig et al. 1989), and quantity of AS mobility/aerobic exercise assessed at baseline and six months. Of the 200 subjects, 155 completed the study, reflecting the high drop-out rates common to many AS studies, and whilst the exercise programme to promote self-management in AS was found to have significantly improved self-efficacy for exercise, self-reported levels of exercise, and functional improvements (BASFI) at three weeks, the improvements were not sustained at six-month follow-up. It is questionable whether a three-week improvement will have a significant lasting impact or result in a change in the life of a person who has pain and stiffness every day.

Ince et al. (2006) undertook the most recent RCT investigating the effects of a 12-week, multimodal exercise programme using a convenience sample of 30 people (18 male, 12 female) with a mean age of 34.9 years (SD = 6.28), all of whom met the New York diagnostic criteria. Subjects were assigned either to a group that received an exercise programme or to a control group. The exercise programme consisted of 50 minutes of multimodal exercise, including aerobic, stretching, and pulmonary exercises, three times a week for three months. Subjects in both groups received medical treatment for AS, but the exercise group received the exercise programme in addition. Clinical measurements undertaken were chin-to-chest distance, Modified Schober Flexion Test, occiput-to-wall distance, finger-to-floor distance, chest expansion, inclinometer measurements of gross hip flexion, gross lumbar flexion, and gross thoracic flexion. In addition, vital capacity was measured by a physiologist. Their results showed that the measurements of the exercise group were significantly better than those of the control group in the following criteria: chest expansion, ($P = 0.04$) chin-to-chest distance ($P = 0.03$), and occiput-to-wall distance ($P = 0.02$) after the three-month exercise period. The spinal movements of the control group showed no significant change (no P value provided for the study). In addition, the results showed that the post-training value of gross thoracic flexion of the exercise group was significantly higher than that

of the control group ($P = 0.01$). They did not follow up this beyond the three-month period, however, so there are no data on how sustainable these improvements were.

1.2.7. Other studies

In a retrospective study of 141 people, Viitanen et al. (1992) demonstrated that following intensive inpatient treatment for three to four weeks, the majority of people experienced an improvement in range of motion of between 2% and 8%. This is substantiated by additional studies (Analay et al. 2003). Analay randomly allocated 51 people to either a home programme or a supervised exercise programme. The average (SD) age of group I was 37.6 ± 11.3 while that of the control group was 34.3 ± 7.9 (years). Of the people in group I, 3 were female and 20 male. Of the people in group II, 4 were female and 18 male. In both groups before treatment, after treatment and three months after treatment, mean resting pain and pain during activity, (VAS), duration of morning stiffness (minutes), chest expansion (cm), tragus-wall distance (cm), modified lumbar Schober and fingertip-to-floor distance (cm), intermalleolar distance (cm), were assessed. Whilst they demonstrated a statistically significant increase in chest expansion, duration of morning stiffness, finger-to-floor distance intermalleolar distance, and Schober's measurement (all $P < 0.05$), pain levels were unchanged between the two groups and the wellbeing scores were insignificant at three-month follow-up.

Intensive physiotherapy regimens (Tomlinson et al. 1986; Viitanen et al. 1995) in a group situation (Hidding et al. 1994) and during inpatient programmes (Band et al. 1997) have been shown to be the most successful in improving range of movement in the cervical and lumbar spine. However, it has been found that unless the exercise is supervised, intensive, and sustained, progressive loss of movement occurs (Lubrano et al. 2007). These authors looked at 52 active AS patients admitted consecutively to a rehabilitation inpatient clinic. Participants underwent a three-week intensive rehabilitation programme and were then discharged with home exercises. The primary outcome measure

was the proportion of patients achieving a response based on ASAS 20 at discharge and at 6 and 12 weeks afterwards. (ASAS 20 is defined as an improvement of at least 20% and absolute improvement of at least 10 units on a 0-100mm scale in at least 3 of the following domains: 1. Patient global assessment measured on a VAS scale 2. Pain assessment measured on a VAS scale 3. Function represented by BASFI. Secondary outcome measures included an improvement in the Revised Leeds Disability Questionnaire (RLDQ) and function expressed as anthropometric measures. The ASAS 20 was achieved in 46 patients (88.5%) at the end of the rehabilitation, and in 31 (59.6%) and 17 (32.7%) patients at 6 and 12 weeks follow-up, respectively. The percentage of ASAS 20 responders declined statistically over time measured from the end of rehabilitation compared with 6 ($P < 0.001$) and 12 weeks follow-up ($P < 0.001$).

The literature therefore tentatively suggests a wide variety of benefits to active exercise in AS: those proposed include improvement in vital capacity in 33 people with AS (Fisher 1990), although Fisher did not employ a control group and did not take account of lack of familiarity with the equipment (bicycle ergometer) and increase in spinal extension (Russell et al. 1993). Whilst Russell et al. made efforts to standardise spinal baseline measurements and undertake long-term (one year) follow-up, they allocated people non-randomly to the two intervention groups and the control group, and the average ages of the intervention groups differed from the average age in the control by more than ten years (mean age 52 years), thus invalidating the reliability of their control group.

Improvements in self-efficacy for exercise, self-reported levels of exercise, and a trend towards improvement in function using the BASFI have also been claimed (Sweeney et al. 2002). However in Sweeney et al's 2002 study, as with many of the RCTs above, the "exercise" intervention consisted of not only exercise but also an exercise/information video, exercise progress chart, education booklet, and AS exercise reminder stickers. Fernandez-de-Las-Penas et al. (2006) have more recently suggested that

an exercise regime based on global postural re-education focusing on specific strengthening and flexibility exercises of shortened kinetic chains offers promising short- and long-term results, although they fail to define “short” and “long” term in this context.

The current evidence base for the anthropological benefits of active exercises in AS is growing but is confounded by methodological limitations. Overall a small number of RCTs suggests that active exercise in AS is valuable in the short term, but trials cannot be compared owing to the different interpretations of exercise and multiple interventions used within the studies. Many of the studies rely on self-report measures which can result in measurement errors (Barlow 1998; Sallis 1998; Braziuniene et al. 2007; Mackay et al. 2007). For example, participants may unintentionally misreport retrospective information such as number of years of exercise, exercise frequency, duration, and intensity of reported exercise. The interventions are varied and comprise a range of modalities, not just exercise, and many of the studies undertaken either provided no long-term follow-up or found that long-term anthropometric improvements were not sustained. One of the most significant limitations is that the studies tend to have recruited from populations of self-help group attendees and no research has been undertaken with those who chose not to attend such groups.

1.2.8. Research into group exercise

Whilst the above studies have evaluated the efficacy of exercise in the management of AS, another focus of attention has been on the role of participating in group, rather than individual exercise. Recognition of the difficulty in sustaining exercise across a lifetime led to the development of local NASS groups to provide ongoing social and educational support. It has been suggested that such groups lead to decreased levels of depression and improved self-efficacy that commence early in a group setting and are still continuing to improve six months later (Barlow & Barefoot 1996).

Only one RCT (Hidding et al. 1994) has been undertaken to investigate the effects of participating in weekly supervised group exercise. This study randomly allocated 68 people to a group having home and group exercise and a control group consisting of 76 people who undertook only daily home exercise. Outcome measures were spinal mobility (thoracic and lumbar flexion and extension, chest expansion, cervical rotation), fitness (maximum work capacity by ergometry), functioning (Sickness Impact Profile [SIP] and the Functional Index [FI]), and global patient assessment of change on a visual analogue scale. After six weeks, patients had improved in all measures but only significantly in rotation (8°, 10%), fitness (6 watt, 4%), and SIP (0.6, 14%; t-test, $p < 0.05$). Global patient assessment improved by 22%. It was concluded that irrespective of disease duration, short-term supervised group therapy is effective in AS, slightly improving mobility, fitness, functioning, and global health (Hidding et al. 1994).

Studies seeking to identify psychological traits associated with group membership have suggested that group members may show a more internalised locus of control than non-group members and that the psychosocial impacts of AS may be minimised by being part of a group (Barlow et al. 1992; Ward & Kuzis 2001). Furthermore, self-help group members have shown more compliance and engagement in their treatment than a non-self-help group (Volle et al. 1990), although the sample of 138 people used mixed pathologies, including people with Rheumatoid Arthritis and Osteoarthritis in addition to AS.

Group exercise has been shown to be cost-effective (Bakker et al. 1994; Analay et al. 2003), but only in terms of short-term anthropometric improvement (typically less than six months). No study has yet established that attendance at an AS group signifies effective coping or a lack of it, furthermore group education is not a panacea for all people (Mason 2008). Studies of exercise among NASS members reflect the high attrition associated with group membership, reporting a 25% drop-out rate (Sweeney et

al. 2002), and certain aspects of managing AS such as learning how to incorporate exercise into the personal context of one's life may be best dealt with on a one-to-one basis (Barlow 1998).

1.2.9. Issues around the prescription of exercise in ankylosing spondylitis

The lack of consensus on the aims of exercise in AS may result in confusion and account for poor compliance and high drop-out rates from clinical trials, as it may appear to the person with AS that healthcare professionals offer inconsistent advice and have little to offer (Barlow, 1992). Indeed Barlow (1998) studied people's views on exercise using self-administered questionnaires administered six months apart to people making enquires to NASS. Reporting on data derived from 169 people, she found that participants did value exercise but often failed to translate these beliefs into action. Three focus groups were also used in the study to elicit participants' views on exercise. Data from the groups revealed that barriers to exercise were varied and included perceived danger of completing the exercises, lack of space and time, and the stigma of taking part in a group exercise session. As with previous studies, a convenience sample derived from those contacting a self-help group was used, which may have been subject to selection bias, and the study also relied on self-report measures- known to be notoriously inaccurate (Mackay et al. 2007; Braziuniene et al.2007).

Long-term use of exercise regimes in AS, the person's decisions behind these behaviours and the impact of home-based exercises on long-term prognosis are as yet unexplored. Furthermore, reflecting their clinical emphasis, the studies have focussed solely on exercises prescribed by healthcare professionals and have not taken into account other forms of exercise that participants may undertake. Not all people with AS do exercises every day, and some of the barriers to regular exercise have been identified – in one study in 189 people with AS in Sweden, these factors being namely lack of time and fatigue (Sundstrom et al. 2002). However researchers' and therapists' definitions of exercise may not

reflect the potentially broader spectrum of exercise which people may adopt, and whilst it has been demonstrated that a significant proportion of people with AS do not undertake prescribed exercise, it cannot be concluded that they do not do any exercise.

1.2.10. Compliance with exercise in ankylosing spondylitis management

A limitation of many of the studies reported above is that they have focussed on exploring the impact of prescribed exercise on disease status, the degree to which participants engage in these exercises and their anthropometric effects. In focusing on these issues, the current ethos surrounding promoting exercise in AS is informed by an emphasis on increasing people's compliance with healthcare professionals' prescriptions rather than a grounded investigation of peoples exercise behaviours in a natural setting and the reasons behind these behaviours. The predominant approach used by physiotherapists within the context of managing AS can be summarised as being to diagnose and prescribe interventions while the role of the person with AS is seen predominantly as one of compliance with these interventions.

Compliance has been defined as "the extent to which the patient's behaviour coincides with medical or health advice (Haynes 1979, p. 313) and adherence as "conformity in fulfilling or following official, recognised, or institutional requirements, guidelines, recommendations, protocols, pathways, or other standards" (Leventhal 1980, p. 61). Both of these definitions have paternalistic overtones that are reflected within AS physiotherapy management approaches; for example it has long been held that people with AS *must* exercise for 15 minutes every day, irrespective of their pain levels (O'Hea 2008).

This belief persists in clinical practice despite our current lack of knowledge of the behavioural choices that people with AS make.

Whilst all the previous studies have provided physiotherapists with valuable insights into the effects of exercise, we still have no knowledge concerning the beliefs of the people themselves who have AS concerning the specific exercise behaviours they adopt, why they adopt them, and the decision making processes they undergo when managing this inherently changing disease with exercise. It is therefore important that we supplement the previous research with a more grounded approach that adopts a more patient centred perspective.

With the focus of the clinical management of AS and other long-term conditions being on facilitating a person's behaviour change and an increasing awareness of the challenges and barriers that have to be overcome, growing attention has been paid to understanding the factors which influence people's behaviour changes and their decision making processes. The emphasis is moving away from describing people as either compliant or non-compliant and moving towards developing programmes of interventions which are designed and delivered optimally to promote behaviour change. The role of health psychology in helping to understand and promote behaviour change is therefore important. The next section outlines relevant concepts that are pivotal in the behaviours of people with chronic disease such as AS and are therefore key to understanding and promoting behaviour change.

1.3. Significant Psychological Concepts in Chronic Disease Self-Management

This section addresses concepts that are pivotal to the behaviour of people with chronic disease. Whilst there is currently no evidence concerning people's decision making in AS, psychologists have used various concepts, theories, and models in an attempt to better explain people's behaviour when faced with complex self-management decisions.

1.3.1. Self-efficacy

A concept which has been given a great deal of attention in the development of self-management programmes is that of self-efficacy, which is defined as "the expectancy that an individual is able to successfully undertake a desired behaviour" (Ogden 2007, p. 29). As discussed previously Bandura is credited with creating self-efficacy as a construct (DiClemente 1981; Maibach and Murphy 1995). It reflects the belief in being able to master challenging demands by means of adaptive action (Schwarzer 1992). Self-efficacy may be thought of most simply as a "can do" cognition (Schwarzer and Fuchs 1995). Within the construct of perceived self-efficacy, the predictor of behaviour is one's belief in the capability to perform an act (Bandura 1997). A person's self-efficacy develops as a result of his or her history of achievement in a particular area, from observations of others' successes and failures, from the persuasion of others, and from his or her own emotional state while performing behaviour (Bandura 1977).

Perceived self-efficacy is a major instigating force in forming intentions to undertake exercise and in maintaining the exercise for an extended time (Dzewaltowski et al. 1990; Feltz and Riessinger 1990; Johnson et al. 2000; McAuley and Blissmer 2000). Self-efficacy has been examined in chronic arthritis, for example by enhancing the perceived efficacy of people with rheumatoid arthritis in a self-management programme (Brekke et al 2001)

The EPP is grounded within the theoretical framework of self-efficacy aiming to increase self-efficacy and reduce learned helplessness through skill mastery, role modelling, persuasion techniques, re-interpretation of symptoms, problem solving, decision making, and action-planning (Turner and Barlow 2007).

Pivotal to the physiotherapy management of AS are the efforts made by physiotherapists to encourage people to undertake exercise on a daily basis (O'Hea 2008), but although physiotherapists strive to encourage people to exercise, we still have no evidence concerning people's actual day-to-day exercise behaviours and the factors which affect these behaviours let alone the belief systems that they possess about their ability to exercise or the value or effects of exercise. Before researchers can understand the reasons why people with AS may choose not to undertake a behaviour that has been recommended to them, we need to define and understand the actual behaviours that people undertake. Whilst self-efficacy explores a person's confidence in undertaking exercise behaviour it is also suggested that a person's beliefs about their condition, their illness cognitions, will also influence their behaviour.

1.3.2. Illness cognitions

The term "illness cognition" has been defined as "a patient's own implicit common sense beliefs about their illness" (Leventhal and Neremz 1985, p. 517). When people experience symptoms, they embark upon a cognitive search which enables them to interpret and make sense of the symptoms they are experiencing. Several authors have described the categories of beliefs people hold about illness (Meyer et al. 1985; Turk et al. 1986; Lau et al. 1989; Hampson et al. 1990). Typically this literature presents five categories that have commonly emerged:

1. *Identity*, which includes the description of symptoms experienced (e.g. pain, fatigue).
2. *Belief about causes* (e.g. accident, genetics or stress). It can be argued that people like to have a label for their symptoms for legitimisation although, conversely, once given, people are likely to interpret diverse symptoms as evidence of the label.
3. *Timeline* (beliefs about duration and time for recovery), namely is it acute or chronic? These beliefs will be re-evaluated as time progresses.
4. *Consequences* (e.g. loss of lifestyle, goals in life). These representations may only develop into more realistic beliefs over time.
5. *Beliefs about controllability*.

(Furnham, 1989; Landrine and Klonoff 1992, 1994)

These categories are pivotal to understanding how people make decisions with respect to managing a changeable chronic disease such as AS, unfortunately we currently have no patient-centred information about these five categories in AS.

1.3.3. Locus of control

In addition to illness cognitions, individuals maintain belief systems around control over their health. The concept of Health Locus of Control (HLC) states that through a learning process, individuals will develop the belief that certain outcomes concerning their health are either a result of their own action (internals) or a result of other independent forces (externals) or chance. (Levenson 1973). Consequently many health education programmes such as the EPP emphasise responsibility and reinforcement of internal beliefs.

Research into control in AS is limited to that of Barlow et al. (1993), who administered locus of control questionnaires to AS self-help group members analysing health locus of control beliefs along 3 dimensions: internality, powerful others and chance, and suggested that they could be distinguished

with a sensitivity of 71.9% from non-group members by their low reliance on powerful others, a greater satisfaction with available support, and increased frequency of exercise. However, this increased frequency of exercise referred to the quantity of “prescribed” exercise undertaken. People who do not attend such groups may adopt alternative methods of exercise which would not have been assessed in this study.

1.3.4. The Common Sense Model (CSM)

The key construct of the Common Sense Model (CSM) concerns the idea of illness representations or “lay” beliefs about illness. Within this model it is suggested that these beliefs integrate with existing beliefs that people hold, enabling them to make sense of their symptoms and guide any coping action. The central tenet of the CSM is that people actively test out common-sense hypotheses by their use of emotion and problem-focused coping efforts (Whitmarsh et al. 2003). People with a chronic illness obtain new information about their condition and evaluate their attempts to cope with it, and new representations develop as a result of their increased experience. Illness representations are therefore cumulative, with information being adopted, discarded, or adapted as the person deems appropriate.

Illness representations operate at abstract and experiential level, and Leventhal et al. (2003) have suggested that lay people are likely to weigh them with significances that differ from those of health professionals. The CSM is particularly relevant to those working in chronic disease because it conceptualises people as problem solvers who take an active role in the management of their own health. It implies that people achieve better outcomes when they have a more adaptive understanding of their condition and can evaluate the effects of acting on this understanding.

Whitmarsh et al. (2003) suggest that illness representations form cognitions that are then potentially alterable. This is the premise upon which self-management groups such as the Arthritis Self

Management Programme (SMP) and the Chronic Disease Self Management Course (CDSMC) are built (Barlow et al. 2000). Hence, disease outcomes might be positively influenced by cognitive-behavioural interventions.

Hale et al. (2007) have recently commented that people may not be consciously aware of how good they are at testing their illness hypotheses, and that with careful explanation and guidance they can be facilitated in constructing useful representations that assist in positive outcomes in chronic disease self-management.

Regarding the common sense model, Stafford stated: "It's all just common sense, but dressed up with big words to confuse people" (2007, pp. 94–95). Indeed the core of the CSM is that people with an illness use common sense in constructing their representations based on their accumulated knowledge and experiences.

1.3.5. Social cognition models

Along with descriptions of Locus of control (LOC) there has been a large body of literature investigating the role of social cognition models and their roles in the regulation of a person's behaviour in a given situation. There now follows an overview of the key models in terms of their usefulness in predicting exercise behaviour. Since the 1950s, health behaviour theories have focused on common parameters, namely intentions to behave, environmental constraints impeding the behaviour, skills, outcome expectancies, norms for the behaviour, affect, and self-efficacy with respect to the behaviour (Connor and Norman 1995). Attempts to change the behaviour of a person with a chronic disease must consider these factors and tailor programmes to the individual and his or her health problem. Various models have been described which attempt to outline an individual's thought processes when he or she decides whether or not to undertake a particular healthy or unhealthy behaviour. These are presented

below concluding with the stages of change model which, in the discussion chapter will be tentatively mapped against the model that this project generated.

1.3.5.1. The Health Belief Model (HBM)

This model is arguably regarded as being at the forefront of systematic, theory-based research into health behaviour (Conner and Norman 1995). The Health Belief Model (HBM) was developed by social psychologists in the USA and later formalised by Rosenstock (1974). The HBM suggests that behaviour is governed by;

- perceived susceptibility to a health threat
- perceived severity of a health threat
- perceived benefit to taking on board health behaviour
- perceived barriers such as side effects or inconvenience

(Prentice-Dunn and Rogers 1986).

The HBM is used occasionally as a template for understanding exercise behaviour. Examples include Wallace (2002), who used an expanded version of the HBM (with an added self-efficacy component) and found that self-efficacy and barriers to exercise were the best predictors of overall exercise behaviours in women with postmenopausal osteoporosis.

1.3.5.2. The Theory of Reasoned Action (TRA)

In developing the Theory of Reasoned Action (TRA), Ajzen and Fishbein (1975) explored ways to predict behaviours and outcomes. Their theory assumes that people are usually rational and make systematic use of available information to inform their behaviour. Unlike the HBM, the TRA therefore looks at intent rather than attitudes as the main predictors of behaviour.

In the TRA, behavioural intention is viewed as a function of the person's evaluation of engaging in behaviour, his or her perception of the beliefs of significant others, and his or her perception of how much control he or she has over the behaviour. In this respect it may be a more sensitive behavioural indicator than the HBM since it acknowledges the impact of social variables such as employment and marital status on behaviour.

The TRA has been used to predict behaviour in a variety of health-related situations including breastfeeding (Humphreys et al. 1998), testicular and breast self-examination (Moore et al. 1998), and condom use (Sutton et al. 1999). It was also used in rheumatology to explain adherence to medication by Lorish in 1990. Using the TRA to guide the development of questions, 140 people with rheumatoid arthritis were interviewed about their medication-taking behaviour and beliefs. Key findings included: (a) some ignorance about their drug regimen, (b) a tendency to rely just on their memories rather than environmental cues to remember doses, (c) variation in responses to a missed dose, and (d) the use of an inferential process for judging a medication's efficacy (Lorish 1990). These findings suggest that people are not blank sheets awaiting instructions but possess their own beliefs and theories about their illnesses and management.

1.3.5.3. The Theory of Planned Behaviour (TPB)

This theory maintains that human action is guided by three considerations:

1. Beliefs about the likely outcomes of the behaviour and the evaluations of these outcomes.
2. Beliefs about the expectations of others and motivation to comply with these expectations (normative beliefs).
3. Beliefs about the presence of factors that may facilitate or impede performance of the behaviour and the perceived power of these factors (control beliefs) (Ajzen 1985).

Therefore the Theory of Planned Behaviour (TPB) is an extension of the TRA (Conner and Norman 1995). Ajzen (1985) suggested that the TRA was lacking when the voluntary elements of behaviour were not complete, and it is the addition of a perceived behavioural control element which separates the TRA from the TPB.

Smith and Biddle (1999) suggest that the TPB is suited to the study of exercise behaviour, as many of the potential barriers to exercise, such as available time and work commitments, may not be under the full control of the individual. Larger population studies investigating the TPB as a predictor of exercise behaviour in older women suggested that approximately one third of the variance in intention to exercise could be explained by the three variables of the TPB (Conn et al. 2003), namely perceived control beliefs, behavioural beliefs, and normative beliefs. Specific beliefs related to non-exercise behaviours concerned tiredness as well as the lack of commitment and time. The TPB has now been used in a variety of settings, including exercise and physical activity, and is useful in predicting not only behavioural intention but also whether or not the behaviours are eventually adopted (Sutton 1998; Armitage and Connor 2001; French et al. 2005).

1.3.5.4. The Stages of Change Model (SCM)

The key differentiating concept behind the Stages of Change Model (SCM) compared to previously discussed models is the suggestion that behaviour change does not happen in a single step; rather, people progress backwards and forwards through different stages at their own rates on their way to successful change. Each person must decide for himself or herself when a stage is completed and when it is time to move on to the next stage. Stable, long-term change cannot be externally imposed (Prochaska and DiClemente 1982). (The SCM is also referred to as the transtheoretical model).

The SCM (Prochaska and DiClemente 1982) proposes five stages of change, with individuals moving through these stages with periods of progression and relapse:

1. Precontemplation: not thinking about changing behaviour.
2. Contemplation: thinking about changing in the near future.
3. Decision: making a plan to change behaviour.
4. Action: implementing the plan to change behaviour.
5. Maintenance: continuation of behaviour change.

Elder et al. (1999) mapped these stages onto clinical practice to assist professionals concerned with initiating behaviour change in chronic disease, adding that it is important to assess the person's stage of change to enable interventions to be tailored accordingly.

They suggest that people in the precontemplation stage should be made aware of the consequences of not engaging in health behaviour change and provided with the opportunity to share their feelings about their condition and to discuss how this behaviour affects them. In addition they suggest that people who are contemplators should be taught to closely monitor their motivations for engaging in the health behaviour change and to explore their ambivalence and reasons why they think change might be

beneficial. Individuals in the preparation stage should be asked to verbalise a commitment to change both to themselves and to their families. Action-stage individuals and those in the maintenance stage should work with the clinician to set up rewards for appropriate behaviour (Elder et al. 1999). Various studies have examined the stages of change for the acquisition and adherence to exercise behaviour. Nigg and Courneya (1998) used self-administered questionnaires in adolescents and found small percentages were situated in the precontemplation and contemplation stages. The distribution of the sample across the stages was: precontemplation, n = 17 (2.1%); contemplation, n = 34 (4.2%); preparation, n = 235 (28.7%); action, n = 129 (15.7%); and maintenance, n = 404 (49.3%).

Prochaska and Velicer (1997a) propose a sixth stage, termination, which is defined as when the maintenance of a behaviour continues for more than five years with 0% temptation to engage in the undesired behaviour and 100% self-efficacy to engage in the desired behaviour. Maintenance over such a prolonged period, especially when the exercise may itself be painful as in the case of AS, may well be unlikely. Furthermore, a person with an incurable disease which requires lifelong exercise can arguably never reach the end of the termination stage. Research investigating the validity of this termination stage for exercise in chronic disease is therefore limited (Cardinal 1997; Cardinal and Levy 2000; Courneya and Bobick 2000). Courneya and Bobick went so far as to add that because exercisers with chronic disease are likely to dwell in a constant state of maintenance, this may nullify the utility of the theory in the context of long-term exercise behaviour in chronic disease.

The literature surrounding the value of the SCM is fascinating yet contradictory. Part of the original appeal of *Stages of Change* was its simplicity, elegance and accessibility (Orford 1992), however for every advocate of this simplicity there are those who criticise the model on grounds of this very oversimplification (Bunton & Baldwin 1991). Research examining the SCM in exercise has been criticised

because researchers have not investigated all five of the SCM constructs simultaneously or have failed to define the constructs adequately (Culos-Reed et al. 2001). Bandura is a critic of the SCM and has commented that rather than being transtheoretical, the model appears to be *atheoretical*, and that human functioning is too multi-determined to be categorised into a few discrete stages (Bandura 1997c).

Others suggest that the model is not a genuine theory of change, since it places factors that vary on a continuum into discrete categories using arbitrary subdivisions (Budd and Rollnick 1996). Bandura for example raises an interesting anomaly with the model in that according to *the SCM* 'exercising regularly within the last six months' falls within the *action* stage, whereas 'exercising regularly' after this point falls in the *maintenance* stage. Yet these are clearly the same behaviours (Bandura 1977c).

It is also not clear how the SCM may be used for behaviours that do not go through its postulated stages, for example Sutton (1996) noted that when smokers abruptly cease smoking, there is no progression through stages since they bypass all intermediate stages of the SCM. Studies examining the predictive capacity of SCM also identified the same difficulty (Farkas et al. 1996; Belding et al. 1997). SCM similarly does not account for controlled behaviours such as intentionally rationed amounts of smoking (Rogers and Baldwin 1999). Similarly in the case of AS, it is unclear how deliberately controlled levels of exercise would fit into the model. Ultimately the predictive value of the SCM depends on accurate stage recognition and definition, and for the SCM there has been little critical examination of this, studies have instead concentrated on attempts to confirm the model, rather than to test the validity of its stages. (Budd and Rollnick 1996; Nigg and Courneya 1998; Elder et al. 1999).

The methodological problems and debates concerning the SCM appear to stem from the fact that stages are being used to justify the existence of processes, rather than explaining them. The model would therefore *predict* that contemplators are ready to change because they have been identified as being ready to change, whereas there is no hard evidence to support this, since identification is based on description of the person's disposition, not an understanding of the reasons behind their readiness to change.

Prochaska however defends the SCM using the argument that it allows a reduction of the complexity of human processes. This may account for its recent popular uptake in health promotion projects (Berry et al. 1997). Prochaska and Velicer (1997b) do however concede that future research should focus on aspects of the model that thus far have received inadequate attention, in particular decisional balance where people rank a behaviour against pros and cons.

The final difficulty with SCM is the focus on individual cognitive processes. Where such processes are considered in isolation however, social contexts such as family support can be overlooked (Bunton et al. 1991). The SCM may ignore socio-cultural factors and it may be accurate to consider that once behavioural change is contextualised, as in the case of supervised and monitored exercise in AS, behavioural processes become more complex, possibly less predictable, and less likely to conform to a simple model.

1.3.5.5. Health behaviour theory: Summary

Several theories of health behaviour have been explored, however. Glanz and Maddock (2000) argue that there is now such fragmentation within the health behaviour theory literature that there is the potential for inhibiting understanding of health behaviour. Whilst the answer to this would seem to be a single integrated theory, this would first require theorists to agree on common conceptualisations and names for similar constructs. For example, Noar and Zimmerman (2004) highlight that there is little

difference between the terms “benefits and barriers; attitudes; positive and negative expectancies; and pros and cons”, all of which appear in various guises in the health behaviour theories previously noted. Kegler et al. (2002) add that health behaviour theory development is a dynamic process, and as theories become less useful, they should be modified or discarded.

Whilst the term “model” is used frequently, arguably little specific attention is paid to the nature of a model and the expectations associated with it (Earp and Ennett 1991; Rawson et al. 1992; Haig 2000; 2007). There are varied views on the extent to which models should define the scope of the phenomenon they claim to define (Earp and Ennett 1991; Rawson et al. 1992). Whilst it is generally agreed that models are visual representations or metaphors that seek to simplify complexity, critical appraisal of the literature reveals that there are different views on the extent to which it is appropriate and necessary to abridge this complexity (Whitelaw et al. 2000; Haig 2005a; Haig 2007). For some, models offer a way to portray our understanding of behaviour, highlighting areas in which action can pragmatically be taken (Eccles et al. 2005). For others, there is less desire to restrict this vision, with attempts made to retain and acknowledge the individuality of human behaviour and its complexity (Oxman et al. 2005).

1.4. Summary

AS is an incurable, fluctuating, long-term condition for which a key component of self-management is exercise. Physiotherapists spend considerable time and effort teaching exercises to people with AS, and current national drivers promote chronic disease self-management, emphasising the role of the person as expert. Anecdotal evidence suggests that many people with AS choose not to do the exercises they are taught, but there is no evidence concerning why people with AS make these choices. Theories exist concerning the psychology of people’s behaviour and decision making, although there is no single

unified theory that will explain or predict health behaviour in chronic disease. So it was in the context of this mismatch between what health professionals tell people with AS that they *should* do and what they actually *do* that this project developed. The first step was to gain an understanding of the complex topic of exercise behaviour from the perspective of the person with AS. At this point, there is no evidence concerning:

- a) People's beliefs about why they should exercise
- b) The exercise behaviours that people engage in and factors influencing them
- c) How exercise behaviours change over the course of a person's illness.

1.5. Aims and specific objectives

The overall aim of the study was to increase understanding of the exercise behaviours of people with AS. The specific objectives were:

- a) To obtain in-depth understanding of people's beliefs about exercise
- b) To understand the exercise behaviours that people engage in and factors influencing them
- c) To explore how exercise behaviours change as a person's AS changes.

CHAPTER 2: METHODS

Following definitions and explanations of the terms that will be used throughout the chapter, the first section outlines methodological issues including the methodological stance adopted and the underlying rationale, the second section covers operational aspects of study design, whilst the third section covers data analysis as it was employed in the project.

2.1. Definition of terms

2.1.1. *Ontology*

Ontology is the study of the nature of being; basic categories of being and their relations. As a branch of metaphysics, ontology deals with questions concerning what entities exist, and how such entities can be grouped or subdivided according to their similarities and differences (Lincoln and Guba 1985). Different ontological stances are located within paradigms.

2.1.2. *Paradigm*

A paradigm is a collection of concepts, values, perceptions and practices shared by a community, which forms a particular vision of reality that is the basis of the way a community organises itself (Capra 1997). Paradigms are broadly divided into positivist and naturalist paradigms, outlined below.

2.1.3. *The positivist paradigm*

Positivism holds that one objective truth can be obtained and that reality is single and tangible; the researcher and subjects are independent; time and context-free generalisations are possible and reality exists independently of the individuals who create or observe it (Donovan-Hall and Dibb 2008). Quantitative research is located within this paradigm.

2.1.4. *The naturalist paradigm*

This proposes that social realities are constructed by the people who participate in them (Gall et al. 1996; Willis 2007) and there are different truths relating to the individual's subjective and cultural

experiences (Murray and Chamberlain 1999). Qualitative research sits within this paradigm, and as noted by Finlay, at the heart of qualitative research is the desire to:

Investigate and understand the social world rather than predict, explain and control behaviour. (Finlay & Balinger 2006; p 7).

2.1.5. Epistemology

Epistemology is the branch of philosophy concerned with the nature of knowledge and specifically addresses the following questions: What is knowledge? How is knowledge acquired? (Lincoln and Guba 1985). Epistemology will inform the specific methodological approach and methods of data collection used within a study.

Fig. 2.1 illustrates the key differences between positivist and naturalistic research approaches and their relationships to paradigm, ontology and epistemology.

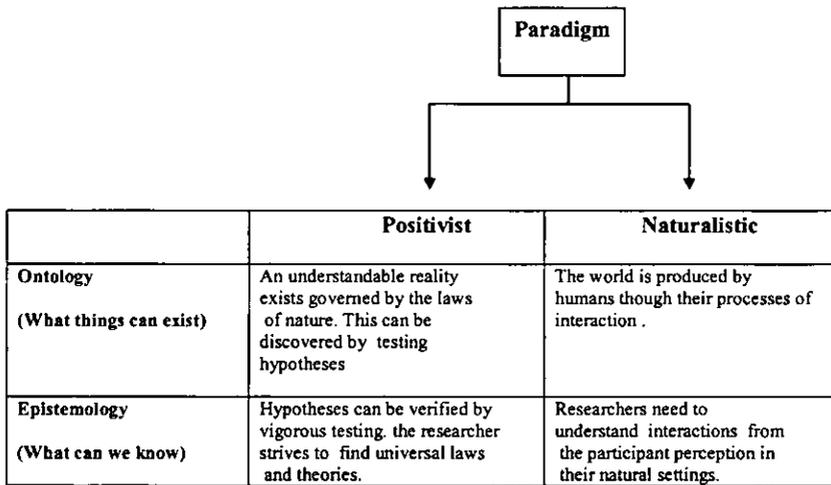


Figure 2.1. The relationship between paradigm, epistemology and ontology in positivist and naturalist research.

2.2. Methodological Issues

2.2.1. Methodological stance

Located within a naturalistic paradigm this project adopts a constructivist stance, the reasons for which will now be discussed focusing on the specific methodological stance and rationale adopted in this project.

The naturalistic paradigm uses inductive processes, which allows ideas to arise from the data rather than using a pre-existing framework. The aim is to understand a research situation and to discover the theory implicit in the data (Dick 1999). This project sought to understand how people use exercise to manage a chronic health condition in an area where there was no clear pre-existing hypothesis; in this case how people with AS use and view exercise in their lives. It therefore required an academically robust approach that could probe the areas of interest grounded in the experience of people living with AS, and was responsive to insights provided by the participants as the project unfolded. The approach needed to encompass the following axioms:

1. Inquiry would raise further questions as the project progressed, leading to an increased understanding of exercise in AS grounded in participants' experiences.
2. The relationship of the researcher and the participant are inseparable - the researcher would be physically entering the world of the participants, albeit in a limited way, and the data would be generated through interaction between the researcher and participants.
3. The ability to make generalisations about data would be inseparable from study time and context (Lincoln and Guba 1985).

It was important to adopt an approach in which people felt able to freely describe their experiences and approaches to managing their condition especially if these were at odds with recommendations of health care professionals. This project therefore needed to adopt methods that would effectively "Hear the voices of those that would otherwise be silent." (Grills 1998 p16).

By locating the study within the context of participants' experience, this project had the potential to describe the structure of a multi-layered phenomenon (Cupchick 2001), and acknowledge its complexity by acknowledging that *the truth* that participants generate is the result of perspective, is pluralistic, and that *meaning* is constructed by the individual, and by the interaction between the individual and the researcher (Lincoln and Guba 1985).

This project has also adopted the stance that the researcher cannot be separated from the participants when constructing the data. Consequently a constructivist stance is taken in acknowledgement that reality is generated jointly by both the participants and the researcher. Having identified this constructivist stance, its ontological and epistemological assumptions will now be outlined and examples given of why this was felt to be the most appropriate stance for the project.

2.2.2. Constructivism

Crotty (1998) defined constructivism as:

The view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context (p. 42).

Constructivism can be traced back to the work of the philosopher Giambattista Vico (1668–1744), who maintained that humans understand only what they have themselves constructed. Meaning or truth cannot be described as objective; that is, knowledge does not exist independently from the holder (Lowenthal and Muth 2008), and is socially and historically constructed.

Formalisation of constructivist theory is generally attributed to Jean Piaget (1896 –1980), who suggested that through processes of accommodation and assimilation, individuals construct new

knowledge from their experiences. Lowenthal and Muth consider constructivism to be the product of a synthesis of ideas from philosophy, sociology, psychology, and education (Lowenthal and Muth 2008). The constructivist notion of multiple constructions of reality may facilitate understanding of complex social phenomenon such as chronic disease self management (Johnson et al 2000) where people may simultaneously hold opposing views.

The open-ended perspective of constructivism allows participants to assist the researcher in the direction of the research question as well as with the data collection (Johnson et al. 2000). This principle of participants and researcher jointly constructing and testing theory was employed and encouraged in this study.

2.2.2.1. Assumptions of constructivism

Constructivism is based on certain assumptions about reality, knowledge, and learning. To further understand why this project has adopted a constructivist stance, it is important to engage with the premises that underlie constructivism, relating these to this project:

Reality: People do not perceive reality directly but always through the lenses of their interpretation. (Kukla 2000). For the constructivist, reality does not exist prior to its social invention. People with AS perceive the need to exercise in the context of their own circumstances, a reality that may not conform to that of others with AS or professionals.

Knowledge: knowledge is personally constructed but socially mediated (Tobin and Tippins 1993; Prawat and Floden 1994; Gredler 1997). This means that people will have personal beliefs about AS self-management which will change with the passage of time, accumulated experience of disease

behaviour, its response to exercise, and exposure to others with AS and with people in the therapeutic, medical, home, social, and work environments.

Learning: Constructivists view learning as a social process that does not take place only within an individual (McMahon 1997). The external forces that a person with AS are exposed to include other people with AS and their therapists and other health care providers. Meaningful learning occurs when individuals are engaged in social activities such as the AS group. Guba and Lincoln (1994) have summarised constructivist assumptions on ontology and epistemology and these are shown below.

Table 2.1 below illustrates key constructivist perspectives on ontology and epistemology

<p>Constructivist assumptions on ontology and epistemology</p> <p>Ontology: reality is constructed by individuals or groups "in the form of multiple, intangible mental constructions, socially and experientially based, local and specific in nature."</p> <p>Epistemology: the researcher and research participants interact "so that the 'findings' are literally created as the investigation proceeds." (Guba and Lincoln 1994, p110)</p>
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Table 2.1. Constructivist ontology and epistemology.

The section concludes with examples of why a constructivist stance was specifically adopted to explore the exercise behaviour of people with AS, (Table 2.2)

Four key constructivist assumptions. [Gredler, 1997; Prawat & Floden, 1994].	Applicability to AS self management
1. Reality is complex and subjective multiple truths co exist	People with AS may acknowledge the importance of exercise in AS but hold themselves to be different and decide not to undertake, or to modify exercise.
2. There is no meaning in the world until people construct it.	People with AS live in a world where they are encouraged to see exercise as a meaningful part of their lives. They must construct their own meaning for exercise, and gain experience about how to use or reject exercise in managing their own AS.
3. Human cognitive development is mediated by prior constructed realities and is associated with a process of assimilation accommodation and correction	AS symptoms fluctuate, people with AS construct a role for exercise and rules for its use, but these rules need to be able to respond to disease changes.
4. Individuals construct new knowledge from their experiences	People with AS will evaluate their exercise experiences and this will either reinforce or refute the success of an exercise behaviour in AS.

Table 2.2. Assumptions of constructivism and their applicability to AS self management

Having provided the rationale for locating this study within a naturalistic, constructivist paradigm, the specific methodological approach adopted within this study, grounded theory, will now be explored.

2.2.3. Grounded Theory

This section starts with an historical overview of Grounded Theory (GT), and then highlights the ongoing debate as to what GT is. Examples of modifications to GT will be provided, and it will be argued that whilst a modified GT technique was utilised in this project, the modified approach retained the academic rigour and acceptability of GT.

GT was first described by Glaser and Strauss in “The Discovery of Grounded Theory” in 1967 (Glaser and Strauss 1967) proposing for the first time that theory could be derived from a body of data rather than data being generated to test an hypothesis. The tenets of GT are: theoretical sensitivity, theoretical sampling, constant comparison, and finally a systematic approach to data analysis comprising open, axial, and selective coding (Glaser 1967) each of which will now be discussed.

2.2.3.1. Theoretical sensitivity

Theoretical sensitivity was described by Glaser (1967) as the process of developing the insight with which a researcher comes to the research situation, whereby they are able to recognise important data and formulate a rich theory through understanding the meaning and subtlety of data. One enters research situations with varying degrees of sensitivity depending upon previous reading and to a greater or lesser extent experience in an area. Theoretical sensitivity in this project was gained from both past clinical rheumatology and more recent academic experience. Theoretical sensitivity is a reflective process of continually increasing ones sensitivity to concepts, and their meanings. It was therefore important to periodically reflect on what was going on with the data, and to ask what I thought fitted the reality of the data? (Strauss and Corbin 1990) facilitating the development theory that was grounded, conceptually dense, and well integrated (Strauss and Corbin 1990).

2.2.3.2. Theoretical sampling

As a result of simultaneously collecting, coding and analysing data throughout the fieldwork, decisions about sampling are made on a continuous basis with the researcher making informed decisions about which data to collect next and where to find these data, in order to develop an emerging theory (Glaser 1967). Theoretical sampling is also used to test, elaborate, and refine categories or to test their validity (Glaser 1967). Thus, particular participants may be selected because of their characteristics (Coyne & Cowley 2006). The critical question in theoretical sampling is: to what group does one next turn for furthering the development of emerging categories? However it has been suggested that this approach to sampling may result in a 'smash and grab' attitude towards data collection which dispenses with the rapport so important in grounded research (Dey 1999).

2.2.3.3. Constant comparison

Strauss and Corbin (1998) describe constant comparison as the means by which the researcher is able to weave a loose array of concepts and categories generated in open coding back together into a pattern. There is wide discussion of constant comparison as an analytical method, and yet the process for carrying out the analysis remains vague (Boeije 2002). While this ambiguity allows for creativity in the art of GT research (Strauss and Corbin 1998), it creates problems for the researcher who is striving to illustrate and argue their methods clearly. The results chapter will provide examples of how constant comparison was employed throughout the project, beginning with fragmentation of the data and then rebuilding it into larger concepts of increasing abstraction, finally resulting in a conceptual model.

2.2.3.4. Coding

The coding in this study followed GT principles of open, axial, and selective coding, and these are expanded upon in chapter 3. Open coding is the part of data analysis concerned with identifying, naming, categorizing and describing phenomena found in the text. Essentially, each line, sentence, paragraph etc. is read in search of the answer to the repeated question "what is this about? Axial coding is the process of relating codes to each other. Selective coding is the process of choosing one category to be the core category, and relating all other categories to that category. The essential idea is to develop a single storyline around which all everything else is structured.

The results chapter includes a list of open codes and examples of how there were built up into progressively more abstract levels of concepts to form the building blocks of a theory of exercise behaviour in AS.

2.2.4. Evolution of Grounded Theory

Glaser and Strauss began to work separately after their initial work, each with different views on GT. The arguments between Glaser and Strauss termed "rhetorical wrestle" by Glaser (1992) resulted in

some of the most vitriolic attacks in academic history (Gurd 2008) and led to the evolution of a range of approaches, referred to as an extended GT family (Warburton 2005). It is therefore important to engage with GT as an evolving methodology, appendix VII illustrates the evolution of grounded theory. Whilst many qualitative studies describe using a GT approach, GT is more frequently honoured via breach than in its observance (Bryman and Burgess, 1994), and inconsistencies amongst studies claiming the use of GT are common (Stern 1994).

Thorne et al. (2002) suggest that the key reason for the modification of GT lies in the practical difficulties of implementing it in its original form, which has resulted in debate about what adaptations to the methodology are, or are not, acceptable whilst still entitling a study to be called GT.

Some believe that the term *Grounded Theory* is used as "an approving bumper sticker" invoked to confer academic respectability (Bryman and Burgess 1994). Parker and Roffey (1997) suggest that whilst researchers might debate the differences between the methods advocated by Glaser, Strauss and Corbin, the methodology will continue to diversify and expand as a useful qualitative research tool. Dey (1999) believes that GT raises more questions than it answers, however, he suggests that this obliges us to face up to basic questions about the very nature of research which requires reflection on what we are doing and how we do it.

Glaser adopted a purist approach relying on an open attitude to research, where the researcher took on the role of a detached observer so as not to compromise the emerging theory.

In contrast, the approach developed by Strauss and Corbin, could be described as more pragmatic with a structured approach to theory building in which the researcher was encouraged to "mix GT with other methodologies" and to "apply existing insights and experience to the subject matter where appropriate" (Strauss & Corbin 1998 p.33). Charmaz (2000) maintains that Strauss and Corbin have moved towards post positivism, in that they propose giving voice to their respondents, acknowledging

how respondents' views of reality conflict with their own, and "recognizing art as well as science in the analytic process" (Charmaz 2000; p. 510). Skodol-Wilson and Ambler-Hutchinson (1996) also hold that the importation of rigid rules is counterproductive to the spirit of creativity needed to generate a GT.

Charmaz (2000) has argued that GT methods are evolving in different ways depending on the perspectives of the researcher and Mills et al. (2006) concur, suggesting that GT is a methodological spiral that begins with Glaser and Strauss' original text and continues today. Punch (1998) concurs with the need for adaptability in GT methods adding that "GT is essentially an inductive technique, but it uses deduction as well" (Punch 1998; p. 166). Coyne and Cowley (2006) similarly state:

Each researcher who uses GT will develop their own style depending on their interpretations of the method.

In this way, the logic-of-justification of the method (Piantanida et al. 2004) becomes particularly important in GT.

Strauss and Corbin (1984) reinforce the importance of interplay between the researcher and the participants and the incorporation of multiple perspectives in writing the emerging theory. This has led Mills et al. to remark that 'Strauss and Corbin's evolved GT has some constructivist intent' (Mills et al. 2006; p.9) stressing the need for reciprocity between the researcher and participants to aid the co-construction of meaning, leading to the use of participants' stories framed within a theory. Using the analogy of creating a plausible story. Charmaz has created the term constructivist GT (Charmaz 2006) suggesting that GT is best thought of as "systematic inductive guidelines for collecting and analysing data to build middle-range theoretical frameworks that explain the collected data" (Charmaz 2006, p. 509).

2.2.5. Advantages of Grounded Theory

The key advantages of GT are:

Faced with the task of managing unstructured qualitative data, where there is an area of interest but no specific research question, GT provides a framework for the analyst to deal with the unstructured complexity of social reality and to render it manageable (Henwood and Pidgeon 1995).

The emergent theory generated within GT maintains a close link with the data and thus reflects the social realities of the group being studied and could, if necessary, be understood and used by them (Turner 1981; Bryman 1988). This has obvious advantages when, as in this project, the project is informed by and hopes, in turn, to inform clinical practice.

2.2.6. Limitations of Grounded Theory

In the same way that no researcher can hope to possess all of the answers, no single research method is infallible (Robson 1993). GT in particular has been subjected to a considerable amount of criticism and debate, principally on the grounds that the approach signals a return to inductivism (Haig 2005a), and that there is a lack of consensus in its epistemological assumptions (Charmaz 2000). Perhaps the most common criticism of Strauss and Corbin's work (1990, 1998) is that they make grounded theory too formulaic (Clarke 2005).

Glaserian GT stressed the need to enter a project with general wonderment and an empty mind (Glaser 1967). Whilst this may sound appealing, it is unlikely that this approach would result in success at ethics committees, where a substantial literature review and therefore knowledge of the research situation is conventionally required. GT has also been criticised in terms of threats to theoretical

sensitivity caused by over familiarity with the situation being investigated (Skodol Wilson and Ambler Hutchinson 1996; Backman and Kynga 1999).

It is also not certain how one can retain the position of distant expert, since for example in a project of this nature which required interaction, one cannot separate the observer from the subject (Charmaz 2000). Melia (1997) also adopts a position of mutuality between researcher and participant, which necessitates a rethinking of the grounded theorist's traditional role of objective observer (Gurd 2008).

This thesis embraces the flexibility advocated by many in GT as a research technique, and ultimately stands on its own as grounded and relevant to the data (Skodol-Wilson and Ambler-Hutchinson 1996; p.123). In chapter 4 I will return to the success or otherwise of this project as measured against accepted "good" grounded theory criteria (Strauss & Corbin 1998).

This projects' deviation from classical GT is to be found in its initial purposive sampling and consequently is classified as a modified GT (Kitko et al. 2008; Cutcliffe 2005). It is argued that this in no way negates the study being a GT study, since three key tenets of classical GT remain controversial, and the extended GT family (Irurita, 1996) continues to grow and evolve. For example Dey (1999), claimed that theoretical sampling is too "anywhere" since concepts drive it to "wherever" in the search for more data.

This methodological change of direction is commonly encountered by novice GT researchers, who often find they only truly adopt GT approaches part way through a study (Gynnild 2006). Glaser (2006) describes this change as a *mind shift* that takes the researcher from description to conceptualisation.

This is something that this project embraced rather than fought as part of the flexibility constructivist GT offers (Charmaz 2006).

Ultimately while methodological issues are unarguably essential in this and any other study, what matters equally is how the researcher integrates their methodology with the overall process (McCallin 2006). This project, as will be discussed in the next section combined methods to form a thick description of exercise behaviour in AS with the GT analysis providing conceptualisation of the data into a clinically useable format. The project attempted to search for what Charmaz (2000) described as the “the mutual creation of knowledge by the viewer and the viewed” (p.510). This constructivist approach to GT is championed by a range researchers who advocate that GT is underpinned by a constructivist paradigm (Stratton 1997, Norton 1999, Nelson and Poulin 1997, McCann and Clark 2003a). Charmaz coined the term Constructivist Grounded Theory (CGT) suggesting that people create and maintain meaningful worlds through a process of sense making (Charmaz, 2000). This study has also maintained as a guiding principle the axiom that “simple language and straightforward ideas make theory readable” (Charmaz 2000; p.527); not least because it is hoped that the model derived from the study has a clinical application.

It is argued by Charmaz (2000) that CGT improves on classical GT in that it can help the researcher further their knowledge of subjective experiences of people - this was a key deciding factor for the adoption of CGT in this study which views GT as a “set of principles and practices not as prescriptions” (Charmaz 2006; p.9).

2.3. Study Design

This study comprised two stages, each with specific aims building logically upon each other. Appendix VIII shows an overview of the project stages. Stage 1 consisted of semi-structured interviews and one focus group with participants from Hospital 1 which sought to:

- Gain an understanding of the effect of AS on daily activities.
- Explore the role of exercise within the context of a person's life.
- Explore exercise self-management behaviour and the reasons behind these and motivations to attend or not to attend the exercise group.

Stage 2 consisted of a series of focus groups conducted with participants with AS from two NHS Trusts in Liverpool and Manchester. This stage of the study sought to:

- develop further the insights that had emerged during the first stage of the study by clarifying and developing areas of interest
- explore and exploit areas of interest or confusion that had arisen in the first stage of the project.
- check the trustworthiness of the interpretation of the interview data with a larger and more diverse cohort in a group setting

The use of multiple methods, interviews and focus groups, enabled the interpretation of data derived from the interviews to be explored within the context of a focus group to explore the credibility of data interpretation.

Having summarised the design of the study, the rationale for the use of specific methods of data collection will now be provided along with an explanation of how they were utilised.

2.3.1. Interviews

An interview is a “conversation with a purpose” (Denzin and Lincoln 1998; p.69) used to gain rich insights into peoples’ biographies, experiences, opinions values and feelings Mays & Pope (1995). Within interviews complex questions can be posed and responses explored and clarified face to face (Strauss and Corbin 1998) providing a means of obtaining the maximum amount of useful information in an uncertain area (Powney and Watts 1987). The epistemological basis for using interviews in this study was the belief that they would provide access to the personal world of the research participants (Holloway 1997) by permitting people with AS with the opportunity to express their own thoughts and feelings about exercise, and the factors that determined these.

2.3.1.1. Structured

Structured interviews involve the use of a highly-structured schedule containing pre-defined often closed-ended questions that are read out in an identical manner to each participant. Fixed responses may be provided with an allocated numerical code and therefore analysis usually leads to the production of quantitative data. Although structured interviews with set answers are essentially the same as a spoken questionnaire, delivery in an interview format provides the researcher with the opportunity to clarify any questions that the participant may not understand and ensure that all of the questions are answered (Drummond 1996). This type of interview normally obtains short factual answers (Seale & Barnard 1998). As this method does not provide the participant with the opportunity to discuss their experiences and views in-depth, it was inappropriate to a study that aimed to develop an in depth understanding of participants’ experiences.

2.3.1.2. Unstructured

Unstructured interviews do not involve following a pre-determined set of topics or questions. The aim is to cover one or two main areas in greater detail and this therefore allows participants to discuss the issues that are important to them and not merely answer the researcher's questions (Seale, & Barnard 1998). Each interview carried out can be different in content. Whilst this can make analysis difficult (Seale & Barnard 1998), the approach is used frequently within biographical or narrative research and less frequently in studies where a researcher is seeking a level of control over the issues discussed and the focus of the interview. For these reasons, this approach was not chosen for this project.

2.3.1.3. Semi-structured

Semi-structured interviews involve the use of a series of broad open-ended questions used to guide the discussion which the interviewer retains some freedom to modify. Whilst the interviews are guided by a schedule there is freedom in the sequencing, wording, and the relative proportions of time allocated to different parts of the interview (Robson 1993). Modifications may involve changing the wording and order of the questions, including additional prompts to further explore the participant's response, omitting later questions if they have already been answered or seem inappropriate based on the participant's responses to earlier questions, and the inclusion of new questions informed by insights from previous respondents (Donovan-Hall and Dibb 2008).

In order to obtain the participant's beliefs and perceptions about the subject matter, questions need to be carefully worded in an open and non-directive manner. These types of interviews are particularly useful for exploring complex issues and can provide a detailed picture of the participant's experiences. Those being interviewed are also able to ask questions of the interviewer, and in this way stimulate the researcher to rethink the schedule accordingly in terms of content, structure and emphasis, and explore avenues of interest as they arose. For these reasons, this approach was chosen for this study.

2.3.1.4. Preparations for and conduct of the interviews

The next section outlines the preparation that was undertaken for the interviews and how they were conducted. The interviews were developed using the following process shown in figure 2.2:

Stage 1	Clearly define research aims
Stage 2	Identify broad topics that explore this
Stage 3	Use these topics to construct open-ended questions
Stage 4	Put the questions in a logical order, starting with least invasive questions and leaving the more sensitive topics to the end
Stage 5	Add introductory comments: Introduce the participant to the topic area
Stage 6	Add closing comments.
Stage 7	Pilot the interview schedule to provide the opportunity to a. check the structure of questions b. practice interview skills.
Stage 8	Tape record and transcribe pilot interviews Make final changes to the interview schedule.

Figure 2.2. Steps in development of interview questions.

2.3.1.5. Sequencing of interview questions

Once the questions had been constructed it was necessary to think about the order in which they would be asked. Ice-breaker questions on timescales since diagnosis and treatment were used as a mechanism for leading into more probing areas of interest. The ice-breaker questions were followed by questions about the impact of AS upon the person's life and then on to more personal issues of coping. The final questions concerned the complex topic of awareness of the state of the person's AS, and culminated with an in-depth discussion of beliefs about physiotherapy and the effects of exercise in AS, thus leaving the most complex and sensitive questions to the end of the session. Figure 2.3 shows the order of key questions.

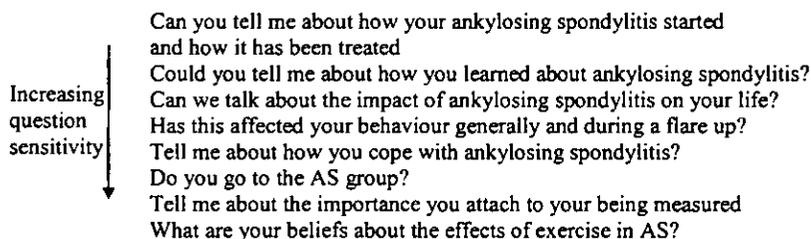


Figure 2.3. A summary of the order of the key questions used in the semi-structured interviews.

The first two pilot interviews were undertaken with regular AS group attendees, however this introduced a potential selection bias towards people who exercise on a regular basis in a group. This meant that the direction in which the schedule was developing would not have resulted in appropriate questions for non-group attendees. Flexibility was therefore taken advantage of at the pilot stages of the interviews, where it became necessary to modify the pilot interviews in such a way as to ensure maximum results for the actual interviews. This was achieved by undertaking the final pilot interview with a non-attendee to permit modification of the interview schedule. This corresponds to stage 8 proposed above (Donovan-Hall and Dibb 2008).

Information obtained from semi-structured interviews has the potential to provide not just answers, but insights into some of the underlying reasons behind the answers (Honey 1987). One of the mechanisms by which this was achieved was via the use of hypothetical contexts; for example one of the questions “What would you do if you were told that your measurements had become worse?” put the person in a hypothetical situation requiring them to think about a proposed course of action. This approach also permitted the researcher to remain receptive to whatever emerged (Patton 1990), leading to the generation of rich data grounded in description.

During the interviews it was important that participants felt free to express their beliefs and attitudes about exercise. This may have been more difficult to achieve within a therapy environment with

exposure to physiotherapists and other people with AS whose behaviour differed from their own. In the real-world environment of a participant's home (Robson 1993), the researcher was more likely to develop a rapport with the participant, as participants feel more comfortable, and are removed from fear of the consequences of divulging information that they may see as contradictory to what they had been advised to do in terms of exercise. Consequently the decision was made to undertake interviews in participants' homes.

The choice of interviews conducted within the home allowed the researcher to gain insight into what it meant to live with AS in dimensions that went beyond the spoken word. Examples included face-to-face contact with a person with an obvious spinal deformity who is unable to sit still for long periods, observations of non-verbal communication when the person was describing their pain and insights into participant's home environments providing a means to interpret the person's actions in the social world (Lincoln and Guba 1985).

To maintain the GT nature of the study, it was important that data analysis was ongoing with data collection which enabled the researcher to modify and explore areas of interest that arose from the data (Honey 1987). Figure 2.4. shows three examples of how interview questions were modified as a result of the emerging comments from participants which reinforced the grounded nature of the developing project (Charmaz 2000).

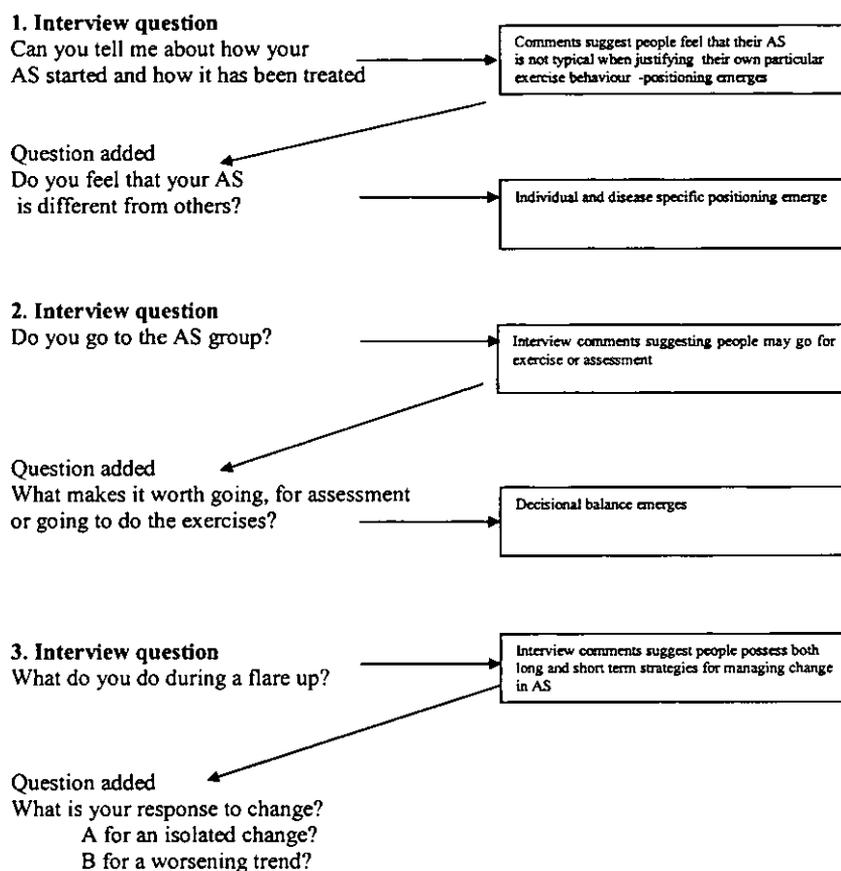


Figure 2.4. Three examples of modification of interview questions as a result of the emerging comments.

Interviews in this study gave the researcher the opportunity to hear participants talk about the place of exercise in their lives. The interviews also facilitated discussion about past exercise behaviours, possible projected future exercise behaviours, how these had been effective, or not, and how the person's appraisals about the usefulness of exercise had evolved during their disease journey.

2.3.2. Focus groups

Focus groups are defined as small structured group discussions with selected participants normally led by a moderator (Litosseliti 2003). In this project they served two methodologically distinct purposes: Firstly a focus group (Wrightington) was undertaken in stage I with seven purposively-selected interview participants to explore the results of data analysis from the interviews and the relevance of a primitive conceptual model of exercise behaviour. In the second stage of the study, focus groups were used to explore the generalisability of the findings from the first phase of the study using different populations of people with AS, and to build and develop insights from the in-depth interviews.

A key asset of focus groups is their ability to generate a group dynamic arising from discussion amongst participants (Litosseliti 1993). The interaction between participants and the interplay and modification of opinion resulted in insights and ideas about the use of exercise in AS self-management that had not been uncovered in individual interviews. For example it was insightful to hear people defend their views about their use of exercise against opposing opinions; a useful consequence of the purposive sampling employed. In this way, focus groups were a useful tool to explore different perspectives on a complex issue (Litosseliti 2003; Morgan and Krueger 1993). Their use enabled the researcher to identify both common experiences and individual differences, and to further explore, probe, and clarify within the groups the categories that emerged from the interview data. In this way, conversation among participants resulted in data that paint a portrait of combined perspectives (Duncan and Marotz-Baden 1999).

The focus groups obtained both the natural features of conversation as well as focused discussions about exercise behaviour (Morgan and Krueger 1993). This was achieved by using a guide designed to assist group members to relax, think about, and verbalise their thoughts.

2.3.2.1. Format

Although there was some flexibility in the direction of each of the stage 2 focus groups, it was important that they addressed the four core categories identified in stage 1, hence guides were used. As with the semi-structured interviews, the researcher had a set of pre-determined topics and questions that were presented to the group. However, unlike in the interviews, instead of asking the questions on an individual level, the researcher acted as a moderator; presented the topics to the group and allowed discussion to take place.

As the aim of the focus group was to create naturalistic conversation, the discussion therefore involved the participants sharing their ideas and experiences or taking part in some debate and possible disagreement. Focus groups also provided the opportunity to observe the group dynamics and witness how the discussions initiated and developed (Wilkinson et al. 2004).

2.3.2.2. Number of groups

It was felt that running three focus groups consisting of 6-8 purposively recruited participants in each of the two clinical centres would be sufficient to obtain data saturation (Robson 1993). Therefore a series of six focus groups was planned. Further focus groups were to be planned should saturation not occur upon completion of the six groups as premature closure is a recognised error of GT-related studies, where researchers commit themselves to ideas, categories, and theories that have not been saturated in the data and, as a result, lead to theory which is descriptive, lacking conceptual depth (Becker & Rosenstock 1987; Hutchinson 1986).

2.3.2.3. Number of participants

Most focus groups generally involve six to eight participants (Litosellitti 2003), but may work with as little as four or as many as ten participants (Donovan-Hall and Dibb 2008). Larger focus groups risk participants breaking into smaller discussion groups impacting on group dynamics and making the discussion impossible to record and transcribe. Larger numbers also enable some participants to take a less active role in the discussion. Similarly too few participants stifle rich discussion and may inhibit expression (Litosellitti 2003). For these reasons each of the groups was planned to run with six to eight participants, however, unforeseen circumstances including snowy conditions in Manchester meant that numbers were smaller on some occasions (see tables 2a and 2b in chapter 3).

2.3.2.4. Location of groups

People who volunteered to participate in the focus groups lived across a wide geographical area, it was therefore necessary to use the most central and accessible location which was thought to be their local hospitals. The Hospital 1 group was conducted in the Occupational Therapy consulting room and the Manchester groups were conducted in the therapy kitchen area. The Liverpool groups were conducted in the clinical sciences building which is a research building. These locations are arguably not totally neutral. Since they were within a hospital setting where people may have felt reluctant to express themselves freely when in a health care professional- rich environment

2.3.2.5. Moderator

The researcher acted as the group moderator for the focus group introducing the topics and questions and encouraging on-going discussion by prompts and appropriate follow-up questions (Wilkinson et al. 2004). The moderator also needed to ensure that the discussion remained focussed on the topic of interest. This involved making decisions on whether certain issues raised by the participants should be explored further, avoided, or modified. It was also important that everyone within the focus group was

encouraged by the moderator to be involved in the discussion so that the discussion was not dominated by one or two individuals (Litosseliti 2003).

2.3.2.6. Observer

A second person (the observer) was involved in the groups. In addition to observing the focus groups and writing notes, the observer assisted with greeting participants on arrival. The observer also ensured that all participants completed a consent form, managed refreshments for the participants, and checked that the recording equipment worked correctly. The observer was also able to interject to clarify points of confusion that arose.

2.3.2.7. Running the focus groups

It was important to start the focus group by relaxing the participants and setting the scene for the discussion that was about to follow (Wilkinson et al. 2004). The first part of the introduction started with welcoming and thanking participants for taking part, providing an explanation of the study (participants had already received a Participant Information Sheet reminder), and answering any questions they had. At this point a note of the seating plan was made.

Before beginning the discussion, ground rules were stated. This involved reminding participants that everything that was to be said within the group would be kept completely confidential and asking them not to talk over each other and respect everyone's opinions (Litosseliti 2003). It was also important to reassure participants that their answers would not be judged as either right or wrong, and that any statements made would in no way affect their current therapy. All focus groups were tape recorded and transcribed verbatim.

During the focus groups it was important to maintain an atmosphere that was as relaxed as possible, to maintain free flowing discussions (Wilkinson et al. 2004). To this end it was important to start with simple and unthreatening questions, leaving the complex or slightly sensitive questions towards the end (Litosseliti 2003). Ending the session normally involved asking the participants if they had any further points to add, restating the confidential nature of the groups, and thanking the participants both on the day and also by a follow up letter.

2.3.2.8. Composition of focus groups

It is difficult within a group discussion to distinguish between individual and group views. Consequently they may not be reliable in determining an individual's authentic point of view as social norms may inhibit speech in a group situation (Creswell 1998). This methodological concern was raised in this project when it was initially felt by the researcher that bringing non-exercisers together with people who exercised regularly may impede the freedom of expression of non-exercisers. Some literature supports this; Krueger and Casey (2000) advocate homogeneity in selection, believing that composing a group of different characteristics will decrease the quality of the data since people tend to censor their ideas in the presence of people who differ greatly from them in power, status, job, income, education, or personal characteristics.

It was decided that a homogenous group (in terms of their exercise behaviours) would not stimulate the deep discussions that are such a valuable component of focus groups, hence mixed groups were used. Seale & Barnard (1999) state that the researcher's role could best be viewed as an attempt to facilitate the expression of the accounts of a number of people rather than to create an artificial consensus. Therefore in the groups held in stage 2 of the project participants were purposively sampled across exercise behaviours.

2.3.2.9. Stage 1 focus group - Wrightington

The format of the single focus group held with participants involved in the interviews is shown below in Figure 2.5.

<p>Focus Group Format Coffee and welcome Introduce self and facilitator, cover session ground rules and aims of the focus group. Stress the need for confidentiality, anonymising of data upon transcription, and stress the need for free speech and uninhibited contributions by all group members. Collect consent forms.</p> <p>Task one Introduction of the aims of the focus group and presentation of key findings from interviews</p> <p>Task two discussion using the prompts below</p> <p>How people manage their AS. Their beliefs about the role of exercise. Is their management reactive or proactive? The value of measurement and its relationship to exercise behaviour. Presentation of the four scenarios found as response to deteriorating/changing disease. Ranking of the importance of exercise. Guilt about behaviour.</p> <p>Task three Presentation of model of exercise behaviour and a discussion about its strengths-weaknesses and relevance to patient experiences. Conclude session; any questions, reminder about confidentiality.</p>
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Figure 2.5. Hospital 1 Focus Group format.

2.3.2.10. Liverpool and Manchester format

The format of the six focus groups held in stage 2 of the project is shown below

in Figure 2.6. can you standardise this table - it has bits of exact question dialogue and summaries -- ue the same format as in previous table.

<p>Focus Group Format Coffee and welcome Introduce self and facilitator, cover session ground rules and aims of the focus group. Stress the need for confidentiality, anonymising of data upon transcription, and stress the need for free speech and uninhibited contributions by all group members. Collect consent forms.</p> <p>Task one Discussion of what people perceive to be their Exercise behaviour (participants given a piece of paper containing the words "exercise is..." as an ice breaker). prompts a. has your approach to exercise changed? b. How has it changed?</p> <p>Task two Behavioural determinants and daily exercise behaviour To discover the kinds of things that affect exercise; how much, the type, etc prompts cost benefit. Past experience; importance of exercise; effects of exercise; disease sensitivity; lifestyle factors; reactions to being measured.</p> <p>Task three To identify strategies for response to change I. Isolated change II. Worsening trend</p> <p>Task four To assess the cycle of behaviour and the overall model Present the model as laminated A4 colour copies Conclude session; any questions, reminder about confidentiality.</p>
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Figure 2.6. Liverpool and Manchester Focus Group format.

2.3.3. Recruitment and sampling

This project employed purposive sampling in which participants are chosen with some particular focus in mind (Irurita 1996; Punch 1998). Advocates of classical GT however propose the use of theoretical sampling (Glaser and Strauss 1967). Before explaining the sampling process a justification for the use of this approach is therefore provided.

This project had to satisfy ethics committees at health authority and university levels, in addition to gaining the approval of clinical managers, physiotherapists and consultants. This required documenting (in advance) explicit sampling procedures incorporating; 1: a sound literature review of the area of study; 2: a clear research question ahead of the commencement of the project; 3: an explicit identification of which participants would be recruited and the criteria therein. It would not have been possible to successfully complete these processes with the following classical GT recommendations (Glaser and Strauss 1967):

1. General wonderment / no preconceived ideas.
2. The conscious decision not to undertake a prior literature review.
3. Theoretical sampling based solely upon the emerging data rather than specific participant selection.

Purposive sampling enabled the researcher to recruit people with AS who encompassed a range of exercise behaviours, and rather than entering the field with general wonderment, the initial case note survey served as a sensitising process that identified potential areas of discussion.

Purposive sampling also provided the advantage that the novice researcher could quickly identify differences between individuals. This in turn increased the researcher's theoretical sensitivity, and had the associated advantage of enabling rapid development of the emerging theory.

Precedents do exist in health research where modified GT studies have adopted purposive sampling to good effect (Kitko & Hupcey 2008, Hysong et al. 2005, Coyne and Cowley 2006). Hysong et al. (2005) collected information on mental models of clinical practice guidelines, implementation strategies and barriers to behaviours in Mental Health Administration facilities throughout the United States. Participants were purposively selected from different levels throughout each service setting. Kitko & Hupcey 2008, in a study to generate explanatory models of behaviour used purposive sampling to elicit

descriptions of patient decision-making processes. Coyne and Cowley's (2006) rationale for purposive sampling was the need to purposefully select participants from an area where a particular phenomenon was found to exist; in this case children, parents and nurses who represented information-rich cases. Purposive sampling was therefore chosen for this project was, methodologically logical and reflected the project aims.

2.3.3.1. Recruitment and Sampling for Stage 1

The Hospital 1 AS database began in 1985 and at the time of the study contained details of 350 people with Consultant rheumatologist diagnosed AS, all of whom have been seen by a Chartered physiotherapist at some point and invited for assessment and to attend the weekly exercise class. Participants from the database were chosen using purposive sampling by letter inviting them for interview (see appendix). Participants were chosen from the three categories of attendance frequency evident in the case note audit that informed the development of this project. Thirty letters were sent out to potential participants in each of the three categories, numbers and percentages of replies are shown in table 2.3 below:

Hospital 1	
Letters sent	90
Total replies received	44
Replies by category	Category 1 No attendance at exercise group in the last 12 months 14 (32%)
	Category 2 1-2 attendances at exercise group in the last 12 months 18 (41%)
	Category 3 >2 attendances at exercise group in the last 12 months 12 (27%)

Table 2.3. Hospital 1 letters sent and replied received including categories of exercise behaviour.

2.3.4. Inclusion and exclusion criteria

Inclusion and exclusion criteria were established prior to sampling procedures and were maintained for both the interview and focus groups stages of the project.

Stage 1

Inclusion criteria

Any person held on the Hospital IAS database with consultant rheumatologist diagnosed AS over the age of 18 was eligible.

Exclusion Criteria

Patients with an uncertain diagnosis and patients who had been transferred out of the area for group therapy.

Those who had undergone surgical procedures such as arthroplasty which would entail an enforced change in exercise behaviour.

No children were included in the study.

None of the participants were undergoing, or being considered for, biologic therapy or had been so in the past.

Potential participants were sent an information sheet and reply slip (see appendix IV & V). A stamped addressed envelope was provided and people willing to take part were asked to return a reply slip and were subsequently contacted by telephone. The information sheet explained the study, what was being

asked of the participants, and provided a contact number for people requiring further information. From the 90 letters sent out, 44 replies were obtained.

Twenty-three people made up the sample (including 3 for pilot interviews) The 23 were selected from a potential sample of 44 based upon the need to obtain a purposive sample of non-attenders, intermediate attenders and regular attenders. Following completion of the interviews everyone participating in the original interviews was contacted by letter inviting them to participate in the focus groups (see appendix number). From the 10 respondents, 7 people were chosen based upon the need to obtain a range of exercise behaviours. It was felt that 10 participants would have been difficult to control and the risk of group fragmentation noted above was too great.

2.3.5. Stage 2 recruitment and selection

The next section details recruitment and sampling for the Liverpool and Manchester focus groups. Potential participants were identified from the AS databases within the Physiotherapy departments at Manchester (Hospital 2) and Liverpool (Hospital 3) Hospitals, each Hospital has detailed attendance records to facilitate this sampling procedure. Participants from the database were chosen using purposive sampling from the three categories of attendance frequency that were identified in a case note audit. Definitions of attendance frequency were the same as informed the original survey in stage 1 of the project, i.e.

- Category 1 No attendance at exercise group in the last 12 months
- Category 2 1-2 attendances at exercise group in the last 12 months
- Category 3 >2 attendances at exercise group in the last 12 months

A sampling frame was developed to inform recruitment, and is shown below (Table 2.4). The criterion informing sampling being the number of times patients attended exercise groups held in the Hospital 2 and Hospital 3 physiotherapy departments.

Hospital	Category 1	Category 2	Category 3	Total participant recruitment
Liverpool	6-8	6-8	6-8	18-24
Manchester	6-8	6-8	6-8	18-24

Table 2.4. Sample Frame.

A total of 60 invitation letters from the Liverpool Hospital's AS database were sent out and 55 from Manchester Hospital's AS database. A stamped addressed envelope was provided and people willing to take part were asked to return a reply slip. They were subsequently contacted by phone. The letter asked people to indicate in their response how often they exercised; never, sometimes or always.

From the 60 Liverpool letters sent out, 51 replies were returned (85%) and from the 55 Manchester letters 39 were returned (71%). The breakdown of these in terms of their exercise behaviours is shown in table 2.5.

Hospital	Liverpool Hospital	Manchester Hospital
Total replies received	51 replies (85%)	39 replies (71%)
Replies by category	Category 1 13 (26%)	Category 1 9 (24%)
	Category 2 20 (39%)	Category 2 15 (38%)
	Category 3 18 (35%)	Category 3 15 (38%)

Table 2.5. Focus group replies and categories of exercise obtained.

Following collation of the replies, each focus group was constructed from equal numbers (minimum 2 participants from each category in an attempt to stimulate deep discussion and exchange of ideas and beliefs necessary in focus groups (Litosellitti 2003).

For both stages 1 and 2 of the project more people volunteered to take part than were required. Everyone who responded to the request to attend for interview or focus group were telephoned and thanked for their reply. For those who were not chosen for the study an explanation was given that more people than were needed had come forward and they were asked if they may be contacted at a later date should any participants drop out of the study or should more participants be needed. This was important to ensure that participants did not feel neglected or have reservations about their involvement in future studies.

2.4. Data Analysis

This section outlines how the analysis moved through stages of open, axial then selective coding, beginning with textual data and ending with the conceptual model of exercise behaviour in AS. The interviews and focus groups were tape recorded, read then transcribed verbatim, to permit the researcher to totally familiarise himself with the data (Litosselitti 2003). The next stage in the process was the coding stage. Each line of text was numbered and wide margins were put in place to allow memos, codes and other comments to be written alongside the relevant text. No electronic analysis packages were employed in the study. Whilst the manual coding and analysis undertaken was time consuming it was justified in that it allowed the researcher to become closely involved in the emerging data, increasing the researcher's theoretical sensitivity. This enabled the researcher to fully understand what the participants were saying about their experiences. Data analysis was concurrent with data collection.

2.4.1. Definition of terms

Open, axial and selective coding are the key stages of managing data and subsequent theory generation in GT analysis, (Strauss & Corbin 1998: Charmaz 2006) it is therefore important to define them.

The same process of analysis was employed for each stage of the project.

2.4.2. Open axial and selective coding

2.4.2.1. Open coding

Open coding is the process of breaking down, examining, comparing, conceptualising and categorizing data (Strauss and Corbin 1998). This was the first coding process where the data was explored without making any assumptions about what one might discover. Data was constantly compared and contrasted within an individual's data, between individuals, between and within codes, going through the data repeatedly and highlighting sections of text. Text was often categorised in more than one code and re-reading and memoing of each code allowed further refinement and ongoing comparison. Discrete

events and instances in data were ascribed to codes, shown in table 2.6 and to ease organisation the open codes were initially grouped into four broad areas as shown below. The initial approach was to "categorise richly and to code liberally" (Richards and Richards 1995).

Psychological issues	The disease
<p>Code1 Guilt Code2 Control Code3 Proactivity Code4 Reactivity Code5 Self efficacy Code6 disease positioning Code7 Denial Code8 Depression Code9 Self regulation</p>	<p>Code10 Pre diagnosis behaviour Code11 Feelings on diagnosis Code12 Early inappropriate management/misdiagnosis Code13 Fear about prognosis Code14 Strategy for tiredness Code15 In patient impact Code16 AS impact on occupation Code17 AS impact on social life Code18 Long term planning & projection as coping Code19 Alert assistants Code20 Pain impact Code21 Self reported knowledge of AS Code22 Insight into current AS disease state Code23 Sources of information Code24 Seeking out appropriate professionals Code25 Awareness of AS status Code26 Exacerbating /improving factors Code27 Belief about progression (burn out) Code28 Alternative therapy Code29 Cost/ benefit for a. Pain b. Exercise. c. Drugs d. ADL e. Body image</p>
Exercise and measurement	AS Group issues
<p>Code30 Childhood exposure to sport Code31 ADL as exercise Code32 Hobby as therapy Code33 Work as therapy Code34 Measurement as a barometer Code35 Exercise as a penance Code36 Specific exercise as therapy Code37 Beliefs about effects of exercise Code38 Reaction to change Code39 Measurement as reinforcement to behaviour</p>	<p>Code40 NASS (national AS society) Code41 Introduction to the group Code42 Attitude towards group Code43 AS group as a social event Code44 AS group attendance patterns and variations Code45 Peer support Code46 Group as positive reinforcement Code47 Bars a. time b.distance Code48 AS group as a motivator/demotivator</p>

Table 2.6. Open codes generated from the interviews.

2.4.2.2. Axial coding

Here the aim was to put data together in new ways making connections between codes (Strauss and Corbin 1990). The aim of this second step in data management was to broadly categorise the 48 open codes although it became clear from constant comparison at an early stage that there was cross-over between codes. Axial coding involved regrouping and linking categories with each other. Axial coding seeks to group codes and identify causal relationships between categories. The aim is to make explicit connections between categories and sub-categories. Axial coding involves explaining and understanding relationships between categories in order to understand the phenomenon to which they relate.

2.4.2.3. Selective coding

Selective coding studied the relationship between a core category and related categories which became the building blocks of a theory (Goulding 1998). These building blocks were then combined to form a tentative model of exercise behaviour, which in turn was deconstructed to form questions to be posed in the multi-centre focus groups.

Selective coding involves selecting and identifying the core category and systematically relating it to other categories. It involves validating those relationships, filling in, and refining and developing those categories. The process involves generation of the story line then relating subsidiary categories to a core

category. In this project, four core categories resulted, these categories are integrated together and a Grounded Theory is arrived at.

It is also important to understand the range of values that categories may have. For example, in this project the category "exercise" consisted of data that ranged from regular exerciser to non exercisers.

Table 2.7 (p100) illustrates this process for the generation of one core category and how a coding matrix was employed to assist in the generation of the core category of a behavioural cycle in AS.

Once a core category had been established, it was important that the researcher reflect on important issues such as were the categories accurate/exhaustive/mutually exclusive? Was there data still unclassified? If so what other categories might be constructed to adequately account for the unclassified data? Finally, was each category adequately supported by data (Strauss and Corbin 1998)? The key components of these were that they should be meaningful in relation to the data and also in relation to other categories (Dey 1993). In this stage the key was in understanding how various categories related to each other in relation to time, space, and context.

It was found useful to represent these core categories as conceptual maps; diagrams showing inter-relationships among concepts (Novak 1995). Examples of these are presented in the results section. These provided a spatial representation of a body of knowledge. Creating concept maps facilitated the

researchers' ability to deepen understanding of the emerging categories and the interrelations among them towards building a model (O'Donnell 2002) that would also be understood by the participants (Charmaz 2006). It was important to periodically step away from this data and ask "What over-riding story is the data saying about AS and exercise? Does this story present the complete picture of exercise behaviour in AS?"

The ultimate aim of the analysis was to "generate theoretical constructs that formed a middle range theory that encompassed as much behavioural variation as possible" (Hutchinson 1986; p. 122).

Actual data from the present study will be used below to illustrate the progression from open to axial to selective coding. The following section sets out the progress of analysis, i.e. the order in which data were analysed. Core categories were:

1. **Determinants of Exercise Behaviour**, this included the various beliefs and factors that subsequently determined the exercise people with AS undertook

2. **Managing change**, this section concerned the strategies (or lack thereof) when people were faced with a change in either pain, stiffness, anthropometric measurement by their therapist or change in social circumstances

3. **Exercise Behaviours** this section identified the actual day to day behaviours that people with AS undertook

4. **The AS Journey** this section incorporated and combined components from much of the previously generated data and investigated the overall philosophy that people had about their life with AS and how this could be interpreted and then presented as a cycle or journey

5. **Generating a Model of Exercise Behaviour**. This is the point where the above core categories were combined into a plausible story to present exercise behaviour in AS

2.4.3. Example of coding matrix

Below one example of the mechanics of generation of a core category (“Behavioural cycle” core category) from raw data is shown, reading the table from left to right one notes that fragmented data becomes more conceptually dense and ends in a more abstract concept- the example below shows how the basic structures of a model was generated from data surrounding the overall journey taken by people with AS Table 2.7 below shows a coding matrix as a means to visually illustrate data management. In the case of the generation of a cycle:

Table 2.7. Coding matrix for generation of a behavioural cycle in AS.

Open coding fragmentation of data (Strauss and Corbin 1990)	Axial coding (formation of sub categories) Data regrouped in new ways making connections between categories (Strauss & Corbin 1990)	Selective coding (formation of Core category) Satisfy 2 criteria. 1. What is going on here? (Strauss and Corbin 1990) 2. Will it constitute building blocks of theory (Charmaz 2000)
<p>CODE 10 <i>Pre diagnosis behaviour</i> CODE 11 <i>Feelings on diagnosis</i> CODE 12 <i>Early inappropriate management</i> CODE 13 <i>Fear about prognosis</i> CODE 4 <i>Reactivity</i> CODE 23 <i>Sources of information</i> CODE 29 <i>Cost/ benefit appraisal for</i> a <i>Pain</i> b <i>Exercise</i> c <i>Drugs</i> d <i>ADL</i> e <i>Body image</i></p>	<p>Sub category <i>Micro and macro Behaviours</i></p>	<p>Behavioural cycle in AS</p>
<p>CODE 3 <i>Proactivity</i> CODE 6 <i>Positioning "plenty worse than me"</i> CODE 9 <i>Self regulation</i> CODE 18 <i>Long term planning as coping</i> CODE 22 <i>Insight into AS status</i> CODE 23 <i>Sources of information</i> CODE 9 <i>Self regulation</i> CODE 22 <i>Insight into AS status</i> CODE 23 <i>Sources of information</i> CODE 28 <i>Belief about progression (burn out)</i> CODE 18 <i>Long term planning as coping</i> CODE 6 <i>positioning "plenty worse than me"</i> CODE 3 <i>Proactivity</i> CODE 21 <i>Self reported knowledge of AS</i></p>	<p>Sub category <i>Positioning</i></p>	
	<p>Sub category <i>Decisional balance</i></p>	

2.4.4. Establishing rigour in the project

Qualitative research methods have previously been criticised for a lack of rigour (Seale and Silverman 1997; Popay & Williams 1998; Strauss and Corbin 1998). Lincoln and Guba comment that qualitative researchers become accustomed to hearing charges that their methods are seen as “undisciplined, sloppy and merely subjective.” (Lincoln and Guba 1985; p. 234). In response to these allegations there is now a substantial body of methodological papers written outlining the standards to which qualitative research should aspire (Cope 2004; de Wet and Erasmus 2005). The next section outlines the steps taken from the outset of this project to ensure that rigour was maintained.

Lincoln and Guba (1985) proposed that the terms credibility, trustworthiness, transferability, and confirmability should be used in qualitative research. Whilst these terms are not without critics, Morse et al. (2002) for example claiming that these terms refer to the impact of a completed qualitative project rather than the rigour imposed during the research process, they are a useful template and will be used during the remainder of this thesis and are defined below (table 2.8).

Definition of terms	
Credibility	The extent to which the research is “worth paying attention to”.
Trustworthiness	Confidence in the 'truth' of the findings.
Transferability	Showing that the findings have applicability in other contexts.
Confirmability	The degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest.
Dependability	Showing that the findings are consistent and could be repeated

(Lincoln and Guba 1985)

Table 2.8. Definitions of terms of rigour in qualitative research.

2.4.4.1. Credibility

The next section engages with the concept of credibility within the project and how this was maintained, the topics covered are prolonged engagement, persistent observation, triangulation, peer debriefing and member checking.

Prolonged engagement

Whilst the contact with the participants in this study was not prolonged, the researcher had 15 years expertise in the physiotherapy management of AS, permitting rapid orientation to the situation and appreciation and understanding of the management of AS (admittedly from the therapist’s perspective). Yet also possessing several years away from clinical practice permitting “a professionally naïve” observer (Strauss & Corbin 1998). The researcher was able to acknowledge distortions that might occur in the data, e.g. researcher as therapist issues, whilst acknowledging the “messy reality” of social research (Gummesson 2006; p167). This facilitated understanding and co-construction of meaning between researcher and participant in line with the constructivist approach adopted (Charmaz 2006).

Persistent observation

As above, although the contact during the project with each participant was relatively brief and could in no way be termed persistent; there was an exception in that seven of the interviewees were brought together for one focus group at a later date in the project allowing analysis of whether their views or beliefs had changed. The purpose of persistent observation is to identify the characteristics of the research situation that are thought most relevant to the issue being pursued and to focus on them in great detail.

Triangulation

Triangulation involves using multiple data sources to produce a more complete understanding of a phenomenon (Robson 1993). Multiple data sources in this project took the form of the three different clinical centres (Wrightington, Liverpool and Manchester). The methodological value behind triangulation as a means of corroborating or increasing the completeness of qualitative findings is however complex. Jick (1983) believes that completeness cannot be achieved without the existence of a fixed social reality.

Some adopt a separatist position concerning the use of multiple methods (Lincoln and Guba 1985) their view being that at best, two methods are complementary theories of a larger complex phenomenon. Others reject separatism, holding that widely different methods can be productively combined in social science research into a unified study of a phenomenon (Risjord et al. 2001). Glaserian grounded theory holds that "all is data, and many methods may be combined into a study to add depth to the description (Glaser 1992).

Therefore in line with the epistemological assumptions of this project, rather than seeing triangulation as a method for validation, the technique of using three different clinical centres was employed to ensure that the interpretation of the interview accounts was rich, robust, and comprehensive for the phenomena it represented, in line with constructivism they provided additional facets to a multi-layered

phenomenon (Cupchik 2001). Similarly interviews and focus groups were employed to produce additional facets.

Peer debriefing

Peer debriefing refers to the process of exposing oneself to a peer for the purpose of exploring aspects of the inquiry "that might otherwise remain only implicit within the inquirer's mind" (Lincoln and Guba 1985; p. 308). In this project this was achieved by ongoing discussion with the supervisory team and presentation to clinical and academic persons throughout the course of the project. For example: invited keynote presentation to the AS clinical interest group; AStretch National presentation at the Chartered Society of Physiotherapy; British Society of Rheumatology poster presentations, in Birmingham (UK); an abstract/poster submission to the America College of Rheumatology Florida USA and presentations at the Universities of Salford and Central Lancashire. Membership of the Grounded Theory Institute also provided a useful forum for discussion of theory generation and methods adopted. Peer exposure also occurred during the process of obtaining ethical approval.

Member checking

This describes the process whereby data are tested with members of those participants from whom the data were originally obtained (Robson 1993). In this project, member checking was employed as a technique for establishing the credibility of the interview analysis. Specifically, member checking was achieved by presentation of the core categories (model components) developed from the interview analysis to a group of interview participants within the context of a focus group. This data was presented in two ways; firstly as individual components of the model, and then finally a completed version of the tentative model was shown to the participants for comment on its relevance accuracy and clinical utility. This also provided participants with the opportunity to correct or challenge the

researcher's misinterpretations. The Hospital 1 focus group also provided the opportunity for participants to volunteer additional information on their exercise behaviour and to further give dimensions to the core categories that were emerging.

2.4.4.2. Trustworthiness

The aim of trustworthiness in a qualitative inquiry is to support the argument that the inquiry's findings are "worth paying attention to" (Lincoln and Guba 1985; p.290). Trustworthiness is roughly equivalent to the concept of validity in traditional quantitative research. Constructivist researchers think of trustworthiness as a system of checks and balances that take form in criteria that reframe traditional, positivist elements of validity. Trustworthiness in this project was achieved by the generation of thick description of the phenomenon using various clinical centres and multiple methods, this thick description also aided in addressing transferability of the findings which is discussed below. Trustworthiness was also maintained by the processes and systems inherent in any PhD programme of study, i.e. regular meetings with the supervisors and team as a whole, monitoring of the progress of the study in annual appraisals for both UCLan and the University of Salford, presentations at academic meetings ethical committee presentations and the retention of all transcripts and tapes for scrutiny by external parties

2.4.4.3. Transferability

Thick description

This was described by Lincoln and Guba (1985) as the means by which transferability is attained. By describing a phenomenon, a participant or a whole study in sufficient depth, the inference is that one can evaluate the extent to which the conclusions drawn are transferable to other times, settings, situations, and people; in this case other clinical centres managing people with AS. Thick description in this project explained not just the exercise behaviour, but its context as well, such that the behaviour

becomes meaningful to an outsider, for example many of the interview and focus group questions discussed social, occupational and therapeutic parameters to peoples exercise behaviours and the wider context of exercise in their lives. The descriptions of exercise also included temporal components of exercise behaviour i.e. they enquired about changes to individual exercise behaviour that occurred over time, again putting the developing AS journey into context. Finally, field notes on the interviewees made on the day of each of the interviews added to the thick description and can be seen in appendix VI.

Whilst the description of the core components of the AS model is described here, post-doctoral study will be needed to address more fully the transferability of the model. To address future transferability, the complete set of data analysis documents including tapes, transcripts and rough diagrams and notes are saved. At this point however it would be naïve to make claims on the transferability of the model without the benefit of further studies using the model.

2.4.4.4. Confirmability

Reflexivity

Reflexivity is defined by Russell and Bohan (1999) as the process of honouring oneself and others in our work through an awareness of the relational nature of the task. The very core of constructivist GT as exemplified in this project is the belief that the researcher should not stand apart from their own humanity and that research does not result in an objective rendering of reality but a form of participation in the phenomenon being studied (Russell and Bohan 1999). Similarly, Malterud adds:

A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions (Malterud 2001).

The researcher in this study therefore acknowledges that any rendering of the reality of exercise behaviour in AS has been generated through the lens of my own interpretation, in line with

constructivist assumptions. This is in fact a criticism of classical GT in that the researcher is expected to be both subjective and objective at the same time- a dilemma remains unresolved, this resulted in the researcher aligning himself more closely with Charmaz' (2006) more pragmatic view of GT. Maintenance of an audit trail for the project, field notes, memos and other electronic and hard copies of data also established both reflexivity and confirmability. Appendix VI contains a project timeline that sets out the key stages and events for the project.

2.4.4.5 Dependability

This was achieved in this study by the use of established GT coding procedures, and engagement with the GT community via the grounded theory institute, and independent coding by the principal supervisor. In addition personal communication with some of the key players in the field was a useful "sounding board", including Kathy Charmaz,(constructivist GT) Kate Lorig (the expert patient) Brian Haig (model and theory generation) and Juliette O'Hea (physiotherapy advisor to NASS) the logical methodological structure of the project as a whole speaks to the dependability of the data generated (appendix IX) and finally dependability of the project was maintained through ethical approval for a multi centre study and related presentation to ethics committees, national and international presentations to the British Society of Rheumatology, AStretch (the clinical interest group for Physiotherapists with an interest in managing AS). 2.4.5. Ethical considerations

While constructivism does not have core assumptions about what is substantively good or ethical, it does provide underlying notions of what makes a good process. Constructivists aim to show that moral properties depend on what we have agreed or would agree them to be, and are consequently reason-giving. Harman (1999) argues that moral judgments make sense only *relative* to an implicit agreement or tacit understanding within a group. It is not within the remit of this study to go into depth in this area however, throughout this project, in line with the constructivist approach adopted it was understood that there are *facts* about what it is morally right or wrong to do, but because they depend on implicit agreement, they can be different in different cultures or subcultures.

The personal and conversational nature of interviews and focus groups situations often highlight ethical issues or confidentiality and anonymity (Robson 1993). It was therefore important to honestly assess issues including who had access to the data and who "owned" it, and to reassure all participants of confidentiality - to this end respondents signed a permission and information form agreeing to participate, after being informed of the protection and anonymising of their comments.

During the process of taking informed consent, care was taken to emphasise and check that all participants understood that participation was voluntary, there were no right or wrong answers and that any comments that they made during the course of the project would be anonymised and would not affect any treatment that they were receiving. It was also important to stress that the project had the approval of the local ethics committees and the therapy managers and therapists and consultants of the three clinical centres involved.

A key ethical issue centred on asking people to divulge a behaviour that they may have perceived as being unacceptable to health care professionals, i.e. physiotherapists. It was therefore important to explain that the aim of the interviews and focus groups was to obtain free-flowing discussion that is patient-centred, that there are no right or wrong answers, and that any information that they divulge would not be viewed by their physiotherapists, and that they would not be personally identified from this research.

Ethical approval was obtained for all stages of the project from relevant NHS Trusts and from the Faculty of Health Ethical Committee at the University of Central Lancashire.

Transcripts and tapes were stored under lock and key in the office of the principal researcher, and on a

password-protected PC at the University of Salford. No identification of patients or Health Care Professionals by name was made. Age, gender and other demographic data was collected and patients coded to preserve anonymity. Participants and ethics committees were assured that transcripts and tapes are to be destroyed upon completion of the project.

2.4.6. The researcher's influence on data collection

Data derived from interviews and focus groups is by its nature derived from the interaction between two or more people (Finlay and Ballinger 2006), therefore the researcher and the subject cannot be viewed separately (Strauss and Corbin 1990). Qualitative research acknowledges that the researchers brings with them their own professional or personal experiences and views and whilst this may be viewed as a potential pitfall, Strauss and Corbin suggest:

The touchstone of your own personal experience may be a valuable indicator of a potentially successful research endeavour. (Strauss and Corbin 1990; p. 231).

They also add that it is often the professional expertise of the researcher in the field that adds to their theoretical sensitivity, which is an important element of naturalistic methods. Constructivism similarly embraces this philosophy of mutually generated theory (Mills et al. 2006).

2.4.7. Disclosure of Reseachers status as a therapist

"Therapist/researcher self-disclosure" (Kottler 1991; p. 167) is a particularly difficult skill to use appropriately and judiciously. The methodological decision not to present oneself as a chartered physiotherapist was taken at the outset of this project since it was felt to be important that the participants felt free to articulate their views about exercise without feeling pressure to comply with a person that they perceived to be a physiotherapist.

The approach employed was to call oneself a researcher with an interest in exercise whilst acknowledging that should the question arise, it would be answered honestly. This was the case in one interview, however this occurred upon completion of the interview so did not impact upon the preceding conversation. It was therefore felt that to disclose oneself as a physiotherapist was appropriate.

This decision allowed the researcher to enter the world of the participant and facilitate deep discussion without putting the participant under duress to answer in a way that would reflect positively on physiotherapists and physiotherapy management. Therefore not introducing oneself as a chartered physiotherapist was methodologically advantageous, for example allowing participants to freely disclose how on occasion they did not place significance on their anthropometric measurements, or similarly how they did not on occasion disclose their true exercise behaviour to their therapists.

2.4.7.1. The therapist as researcher

Within qualitative research it is accepted that 'the researcher is a central figure who influences, and perhaps actively constructs, the collection, selection and interpretation of data' (Finlay & Balinger 2006; p. 6). In the case of the therapist-as-qualitative-researcher, therapists have inevitably made some sort of sense of the research area by virtue of their previous experiences and exposure to the population in question (Shields and Dervin 1993).

It was important in this project to acknowledge and embrace this and to face any previous constructions I may have possessed concerning exercise in AS, employ methods which challenged these constructions, (Dervin 1992; Duffy 1995).

For example, I had assumed that non-attendees of the exercise group would be reluctant to communicate with a researcher about their behaviours, therefore selecting regular exercisers early on to

inform my interview schedule. This was because of my preconception of them as non-compliers, who had always been discussed in physiotherapy circles in somewhat derogatory terms. However as it became clear that the whole spectrum of exercisers needed to inform the schedule it was modified to elicit data from all participants, for example questions about group attendance were reduced and supplemented with questions about what people understood by the term “exercise”.

2.4.8. Summary

Decisions about methods and methodology are rhetorical if ultimately the research that they produce is not plausible. Melia (1997) in developing an approach to GT advocated pragmatic approaches and again refers to the *plausible story* rather than over reliance on epistemology and description of methods concluding that the overall goal is:

Translating that data from the field into an explanation of the topic in hand which can be conveyed to others, and understood by others... If we can collect data with which to tell a plausible story, perhaps we should settle for that (Melia 1997; p. 35).

The aims of this chapter were therefore to present the operational details of how the project was designed and undertaken, the academic rigour and principles abided by in order to allow a plausible story to be generated, and to rationalise the methodological decisions underpinning the approach taken. In this case a constructivist stance using modified GT analysis of that data is supported.

CHAPTER 3: RESULTS

3.1. Re-statement of aims and objectives

Focussing on the experiences of people with Ankylosing spondylitis, this project aimed to provide an understanding of their beliefs about exercise: the decision making processes they underwent when deciding upon exercise behaviour, and the exercise behaviours they adopted. Semi-structured interviews and focus groups were used to obtain grounded accounts of peoples' experiences, and provided in-depth descriptions of the role of exercise in AS self management. Located within a constructivist paradigm a grounded theory approach to data analysis was utilised (Charmaz 2006). Before results are presented, the demographics of the participants will be provided to contextualise the findings and contribute to an understanding of the generalisability of these findings to other people with AS.

3.2. Participant demographics

3.2.1. Stage 1: Semi- structured interviews and Hospital 1 focus group

3.2.1.1. Semi-Structured interviews

The first stage of data collection comprised of semi-structured interviews with 20 participants of whom 5 were female and 15 male. Their ages ranged from 28 - 62 years and their disease duration ranged from 3 - 22 years. There was one father and son combination. Of these 20 participants, 11 never attended the Hospital 1 AS exercise group, 5 attended occasionally (between 2 and 5 times per year) and 4 attended the exercise group every week. The demographics of the participants are shown in Table 3.1.

Code	Age	Gender	Employment	Exercise behaviour (obtained from invitation to attend to interview letter and/or interview data)
A	34	Female	Teacher	Prescribed exercise at group; minimum prescribed exercise at home
B*	50	Male married 2 children	Manager	Modified ADL exercise only Exercises only if ROM worse
C*	58	Female	Retired	Modified ADL only
D	46	Male married 3 children	Manager	No prescribed exercise, occasionally does modified ADL or seeks out private physiotherapy in times of flare up
E	46	Male married 3 children	Insurance claims advisor	No prescribed exercise. Ankylosed, feels it is "too late" but wants his son to adopt prescribed exercise
F*	46	Male divorced 2 children	Factory worker	Very regular prescribed exercise (daily) but not at AS group
G	52	Male married 2 children	Construction worker	Modified ADL only
H	39	Male married	Businessman	Initially undertook prescribed exercise at group which developed into modified ADL, now changing employment to a less physical occupation, and may revert
I	19	Male	Student	Minimal prescribed exercise at present, recently diagnosed and introduced to AS group
J*	39	Female lives alone	Office worker	Modified ADL, prescribed exercise only in times of flare up
K	31	Female 3 children	Housewife	Modified ADL only
L	55	Male divorced	Self-employed odd jobs	Modified ADL but feels that since disease is becoming more of a problem to him, he may now change his behaviour to include increased prescribed exercise and swimming
M	63	Female married	Retired	Modified ADL for neck and general AS; prescribed exercise for hips
N*	49	Male 2 children	Deputy head	Regular prescribed exercise both at home and weekly at class
O	28	Male	Shop worker	Modified ADL
P*	62	Male	Retired	Modified ADL
Q	40	Male divorced 2 children	Electrician	Prescribed exercise undertaken at the group in view of motivation needed to adhere and social aspects of the class
R	35	Male	Office worker	No exercise – heavily reliant on drug management of his AS
S*	54	Male	Retired builder	No exercise
T	41	Male	Warehouse worker	Modified ADL and occasional sporadic prescribed exercise

Table 3.1. Interview participant information. The interview code that is used in quotes for each participant in the results is shown in the first column. Their age, gender, employment status and their exercise behaviour at the time of interview is also presented. An asterisk indicates participants who also took part in the later Hospital 1 focus group.

3.2.1.2. Hospital 1 focus group (W1)

The Hospital 1 focus group consisted of seven participants who were selected purposively from the original interviewees, 1 was a non-exerciser, 4 exercised intermittently and 2 were regular exercisers.

3.2.2. Stage 2 Liverpool (F1-3) and Manchester (H1-3) Focus Groups

Six focus groups were undertaken in Liverpool and Manchester. 28 people took part who had a wide range of employment backgrounds. There were 22 men with a mean age of 44.3 years, and 6 women with a mean age of 48 years. These ranges reflected the typical demographics of age and gender of AS. All focus groups were constructed to reflect a wide range of exercise behaviours. A more detailed breakdown of their composition and demographics are shown in tables 3.2 and 3.3 below.

Table 3.2. Liverpool focus group participants' details

Hospital 2 Clinical Sciences Building 14th October 2005			
Name	Age	Gender	Occupation and exercise category
Eddie	55 y	Male	Retired regular exercise
Kath	33 y	Female	Office work occasional exercise
Chris	32 y	Male	Office work non exercise
Robert and Pat (wife) in attendance	61 y	Male	Retired occasional exercise
Tim	40 y	Male	Office work regular exercise
Richard	43 y	Male	Accounts non exercise
Hospital 2 Clinical Sciences Building 24th October 2005			
Nan	61 y	Female	Retired non exercise
Alan B	43 y	Male	Driver occasional exercise
Alan C	56 y	Male	Accountant occasional exercise
Mike	30 y	Male	Technical officer occasional exercise
Ronnie	60 y	Male	Retired regular exercise
Hospital 2 Clinical Sciences Building 14th Dec 2005			
Bill	55 y	Male	Retired occasional exercise
Jo	30 y	Male	Fireman non exercise
Gareth	19 y	Male	Student occasional exercise

Focus group 1 17th Nov 2005 Hospital 3 Physiotherapy department			
Name	Age	Gender	Occupation and exercise category
Kenny	31 y	Male	Unemployed regular exercise
Tom	52 y	Male	Technician occasional exercise
Ian	50 y	Male	Self-employed occasional exercise
John	47 y	Male	Unemployed non exercise
Focus group 2 24th Nov 2005 Hospital 3 Physiotherapy department			
Bob	52 y	Male	Retired non exercise
Anna	61 y	Female	Retired regular exercise
Norman	58 y	Male	Family business occasional exercise
Jenny	53 y	Female	Warehouse work occasional exercise
Focus group 3 1st Dec 2005 Hospital 3 Physiotherapy department			
Dorothy	33 y	Female	Housewife occasional exercise
Colin	48 y	Male	Teaching regular exercise
Joan	50 y	Female	Cleaning work non exercise
James	44 y	Male	Driver occasional exercise
Rod	40 y	Male	Unemployed non exercise
Keith	29 y	Male	Student occasional exercise

Table 3.3. Manchester focus group participants' details.

3.3. AS Physiotherapy provision

The three clinical centres from which participants were recruited for this study had variations in their physiotherapy services to people with AS. These differences did affect the exercise opportunities open to participants via the NHS and therefore are explained; for example the Liverpool Hospital patients were experiencing difficulties in accessing hydrotherapy which was not an issue at the Hospital 1 group.

3.3.1. Hospital 1

Hospital 1 had a weekly AS group comprising group exercises and hydrotherapy led by a physiotherapist; in addition to this a rolling programme of assessment was in operation comprising an annual assessment of all patients, along with an open door policy of self-referral to the physiotherapist for treatment in times of flare up.

3.3.2. Liverpool Hospitals (Hospital 2)

At the time of the focus groups, a rolling programme of yearly physiotherapy assessment was in operation but hydrotherapy was restricted (a source of frustration to the participants). At the time of the focus groups there was no weekly group in operation although there had been in the past.

3.3.3. Manchester Hospitals (Hospital 3)

Weekly group sessions and hydrotherapy led by a physiotherapist were available along with a rolling programme of assessment.

3.4. Presentation of results

Strauss and Corbin (1998) advocate that the researcher should use their “*gut sense*” (p. 150) about the subject matter of the research when presenting the results of a study. Charmaz (2006) adds that the presentation of results should be adapted to fit the story being told rather than “*being poured on to conventional categories*” allowing the researcher to “*present data in a way that works for ones ideas rather than compromising the analysis*” (p.154). Furthermore Charmaz (2006) advocates a writing style which evokes the experiences of the participants.

Analysis within this project led to the generation of four core categories which will therefore serve as the guiding principles for the results chapter. The results are presented using these categories as the organising headings of the chapter.

The core categories were:

1. Exercise behaviours,
2. Determinants of Exercise Behaviour,
3. Managing change,
4. The AS journey.

The definition of a core category is still debated, in Glaser’s opinion there will ultimately only be one core category, (Glaser 1992) whereas Charmaz contends that it is not necessary to have a single core category (Charmaz 2006), this is in turn vehemently objected to by grounded theory purists who believe that this is a step “on the slippery slope to description rather than conceptualisation” (Personal communication with editor of the Grounded Theory review 2009).

In line with the need to facilitate understanding of the data Strauss and Corbin's (1998) criteria were adopted in presentation of the results, they advise that a core category should:

- I. Appear frequently in the data.
- II. Be central i.e. all other major categories can be related to it.
- III. Logically relate to other categories.
- IV. Be abstract, in that it can lead to the development of general theory.
- V. Be able to explain variation.

(Strauss and Corbin 1998)

These were the criteria that all four core categories in the study fulfilled.

The chapter concludes with an insight into how these categories were constructed into a model. This is included within the results chapter since the approach adopted incorporated ongoing interplay and constant comparisons between the data and its interpretation, between, codes, memos and sensitising concepts. In this respect the model was built up by constant comparison as the results were analysed and refined for increasing levels of depth and abstraction (Strauss and Corbin 1990).

It is important within this chapter to illustrate how the researcher made sense of the messy reality that is so often inherent in the world of qualitative data analysis. Therefore examples of conceptual diagrams that were used at various points in the analysis, both to organise principles and guide the researcher through the large volume of data that had been generated, are provided. The results chapter also includes examples of how memos and a coding matrix were used to develop core categories. The section entitled core category 1 is used to illustrate how conceptual diagrams were used in analysis and the section entitled core category 2 to illustrate how sensitising concepts and memos were employed in the study.

The abbreviations that feature at the start of each section of text are as follows: A, B, C etc represent the interview designations for the individuals. W represents the Hospital 1 focus group. H1, H2 and H3 represent Manchester (Hospital 3) focus groups 1, 2 and 3 respectively; and F1, F2 and F3 represent Liverpool (Hospital 3) focus groups 1, 2, and 3 respectively. Questions from the researcher are presented in plain type, quotations from participants in italics.

3.5. Core category 1: Exercise behaviours

This project identified four distinct categories of exercise behaviour that people employed on their disease journey. These categories refer to a person's normal (i.e. day to day) approach to exercise, these are:

No exercise.

Regular prescribed exercise.

Other forms of exercise.

Two-tier behaviour.

Each of these will be described in detail.

3.5.1. No exercise

This group did not undertake exercise for their AS, instead they relied either on medication, no action, or other physiotherapy modalities.

This participant stated that he never thought about exercise unless there were extenuating circumstances:

I tend not to think about that (exercise) unless I've just driven 200 miles down the M6. I get out the other end, then I'm really stiff then I'll just (demonstrates cervical rotation) but I think everyone does that don't they. [Int E]

Participant S was also a non-exerciser who had his own rationale for not exercising which incorporated the concept of being caught in a catch 22:

When I'm feeling that bad that everything hurts, exercise is the last thing on my mind. I just reach for the painkillers. When it's better I think well I don't need to do the exercise now 'cos I'm ok. [Int S]

Participant D on the other hand would choose private physiotherapy over exercise, being particularly opposed to the ethos of his local AS group (see field notes in appendix VII):

So for you it's better to go to a private physio than to do exercises?
It's stupid really because I'm paying, it's like I'm going to have something done as a last measure because I've let myself get to a situation where I've seized up. [Int D]

He went on to explain how he had made suggestions for change over the systems in place at his local unit:

*I must admit I made a comment to this girl...(physiotherapist) it would be really nice if the treatment plan could include the person could drop in and the physio would see them.
Do you not feel that you can do that?
Absolutely no way, I mean I mentioned to the physio and didn't get an answer to the question. [Int D]*

The person in the next excerpt was the father of the father and son combination interviewed on the same day. He felt that it was too late for him to start exercise, because there was insufficient evidence that exercises would make an impact upon his life if he were to start doing them now. This gentleman was extremely kyphotic, and had the outward appearance of being completely ankylosed, although his view of reality changed when talking about his son who had recently been diagnosed:

Well I've never been told they do any good, and by the time I found out about them the condition had burned out, and that it wasn't going to get any worse, they never said that doing exercises would make it any better. I get no pain, I get no spasms, so I was told it could burn itself out...but nobody ever said well if you exercise you'll start to straighten up even by degrees. [Int E]

Although this man initially appeared to rigidly adhere to non-exercise, on deeper questioning he too acknowledged that he possessed another level of belief, which incorporated fluidity in his future behaviour. His behaviour was adaptable enough that he would change it if he were given convincing evidence, going on to add:

If somebody came up to you and said if you do these exercises it would improve you x degrees then what?

Well, I'd do it, yeah, if it took 6 months or a year I'd give it a go, especially now as my son's been diagnosed. [Int. E]

3.5.2. Regular prescribed exercise

This group regularly undertook prescribed exercise; either allotting set times at regular intervals during the week to undertake exercise or regularly attending weekly AS groups. This group had a more favourable view of the effects and objective benefits of prescribed exercise in AS and they ascribed a high importance to prescribed exercise when compared against other life events:

It must be hard to set aside time every week to go through a sheet of exercises regularly for the past four years, busy man, family, what I'm trying to get at is why?

Because it helps me.

Can you quantify how much it helps you compared to the painkillers?

Oh, being realistic as opposed to ridiculous, painkillers stops it hurting for a while, but that's all. I'd rather take no painkillers. I'd rather take no painkillers and do things every day if I could, rather than take painkillers and do nothing. [Int N]

This man believed that exercise would immediately quell a flare up although his definition of what constituted a flare up seemed to relate to an increase in pain during the day rather than a more prolonged increase in disease activity/ESR that would typically be classed as a flare up:

When you're having a real bad flare – would you exercise or not?

I'd exercise.

Even if it was a terrible flare up?

I'd still exercise.

If the flare up was bad and you exercise, would it make it better, would it make it worse?

Most times it's helped, there's times like I say within half an hour you've exercised, your flare up could be coming back.

Has the pain ever been so bad that you just couldn't exercise?

Probably, yeah, but I've done it.

But you've done it anyway?

I've done it anyway, aye. [Int F]

In the only example from the individual interviews, participant F was adamant that no matter what his pain, social pressure or other situation, he would undertake the exercises exactly in the form in which

they had been taught to him by the physiotherapist many years earlier. This participant managed his fatigue by exercising; in this respect he was unique.

It remains to be seen therefore, whether this is a truly distinct category of behaviour or an extreme case, an artefact of premature closure from the grounded theory approach taken (see study limitations). Similar extreme comments from a Manchester focus group suggest the former although the focus group excerpt may have been an example of bravado in a group of males:

Joan: you try and push your body.

*Keith: you've got to go though the pain barrier.
how hard have you got to push it?*

Keith: if you're really bad, you've got to really push it. [H3 focus group]

3.5.3. Other forms of exercise

These people had been taught prescribed exercises but no longer did them in their original format. Instead they constructed new exercises by adapting and dovetailing the original exercises to best fit their own particular AS journey. For example they may incorporate a modified exercise into a movement such as the engineer (designation G) who intentionally extended his shoulder joint fully when reaching under large machines as part of his job or the retired lady (designation C) who deliberately flexed her lumbar spine when tying her shoelaces or putting on her tights each day, consciously rejected aids and adaptations that would have helped considerably in favour of her own modifications.

This group believed that they were “doing their exercises” but not necessarily those that they were taught. The following quote illustrates how this lady modified her activities of daily living, not merely to make her life easier, but also as a conscious strategy to incorporate her originally prescribed exercises into her daily life:

When you have something like this, you adapt the way that you do everything, to make things easier for yourself. Day-to-day jobs that you do or your day-to-day living. A GP asked me years ago how I put my socks and my tights on, I just didn't know and it wasn't until I got home and did it, I'd adapted way of doing it because that was the only way of doing it, but I can't sort of bend down and tie shoe laces, I'll put my foot on a chair but while you're doing that, that's one of the positions that you're in, so you can just sort of stretch your back leg.

And you can incorporate those into the position that you get yourself into everyday? Exactly, without having twenty minutes or half an hour to one side. When I'm gardening, I think about the way that I'm doing things because you can hurt yourself, it's so simple that the tiniest movement can cause a terrible spasm and can harm you for days so I'm always conscious of the way that I move or that I do things, so you might as well do them in a beneficial way ... to stretch things you know.[Int C]

Another participant believed that prescribed exercise was unproductive and as a result unacceptable in his overall construction of what successful self-management entailed:

So you feel your work was an exercise?

Cor, definitely, used to do a lot of lifting and replenishing of products on to shelves which is up and down stairs. We were very shop floor based rather than sat in an office I tended to drop exercises for things that I found more acceptable, like sport, gardening. I'm not a great one for doing sort of non-productive exercise I prefer to do something that's got some end product, so if I can get the same amount of exercise digging the garden, bending down pulling weeds out, or climbing up a ladder.[Int H]

And this excerpt came from a middle aged man who had a manual job, worked long hours and had taken the view that exercise was best incorporated into his daily activities:

Well my job takes care of a lot, the extension, sort of you know movement of me legs, me legs and me arms probably all me body because of the job I'm doing.[Int G]

3.5.4. Two tier behaviour

This group represented the ability of participants to act as expert problem solvers operating on multiple levels. Participant C for example had one flare up behaviour and one behaviour for quiescent periods:

In a flare up I will try and do a few exercises.

And what effects do they have when you're flared up?

It's, it's painful to do them when I have a flare up and I can't do them as well. I wouldn't get down on the floor or do anything like that, I'll do whatever I can, and do the exercises that I can without having to get into a position where I wouldn't be able to get up.

What would you do when the flare up ended with regards to exercise?

Carry on doing them for a few days after, I need to get moving, get out and about, then it just gradually stops and I don't do them then. [Int K]

These comments came from the same participant in the Hospital 1 focus group:

I do a mixture, depending how I feel. I wouldn't do everyday sort of exercises but I will do the exercises that the physios have taught me if something in particular is hurting but I also incorporate exercises in the day-to-day things that I do, you adjust to doing things in a certain way that you think well if you have your foot on a stool to fasten your lace, well if you straighten your other leg out and stretch it well you're doing one of the exercises and it's a little bit more fun that way than being a strict regime of right I'll have to do half an hours exercise because I never find the time to do that, you think I'll do it later and you don't do it, so you're conscious of it all the time, so I've got a couple of different behaviours. [W1 focus group]

Participant N had also built up a two tier behaviour based upon how easily an exercise could be hidden within his daily life, and also by disease status:

Do you set aside time to do exercise, or do you try and incorporate it into your life?

Bit of both, I can do my neck ones anywhere, I'm sat here like a prat doing my neck ones, quite often when I sit down and people come to our house I'm like a lunatic 'cos I have the advertisement walk around the kitchen so I don't get too stiff, my neck's like on a swivel so I can incorporate that quite happily, some of the other ones are harder to incorporate into everyday life, you just find it difficult to do for one reason or another, time, space, whatever.

Tom: I'm constantly on the move all the time so I don't feel the need to exercise but if I do find that my neck is stiffening up, there is a problem, then I will take time out if I'm told by a physio to move it about and get things working.[participant N, W1 focus group]

A further example of multi-level self-management is shown below. This comes from the first Manchester focus group:

(facilitator) so for you Ian you have a dedicated two hours a week that's pure sort of physio and for the rest of the time it's your lifestyle that gives you your exercise?

Ian: Yes plus I do some exercises if I've gone a period of time, if for example I've gone a period of 2 or 3 days nothing to do, if business is quiet, then I'll do the exercises but I know and it's just a case of managing your own lifestyle. [H1 focus group]

Figure 3.1 below is the first Conceptual Diagram; a portion of data analysis that assisted in the construction of daily exercise behaviours as a core category.

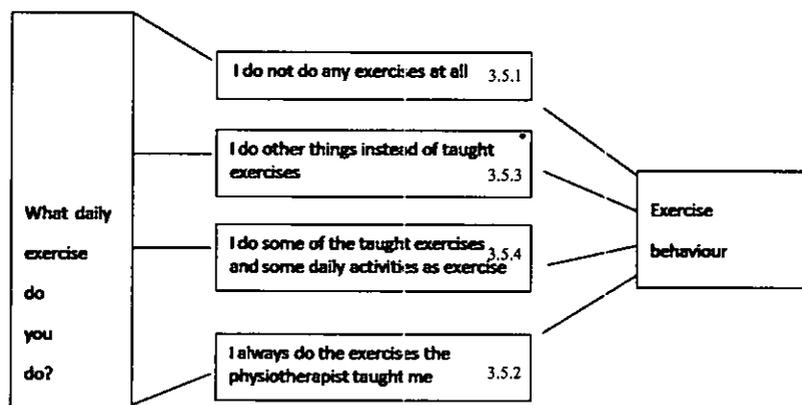


Figure 3.1. First Conceptual Diagram: The generation of exercise behaviours into a core category

Memos are widely used in grounded theory analysis (Strauss 1987; Strauss & Corbin 1990; Goulding 1998; Toscano 2007). The following principles (taken from the Grounded Theory Institute) guided the construction of memo writing during this study:

- Ideas for memos are fragile thus written down at the earliest possible time.
- Memos take the form of post it notes using imagery, humour and diagrams.

The example below shows how key memos (blue boxes) served as sensitising concepts guiding the researcher towards the emerging categories (yellow lines), relating to exercise behaviours. Strauss and Corbin (1998) suggest that once created the researcher should then ask questions about the conditions revealed, their interactions, and their consequences.

On the following page, Figure 3.2 (second conceptual diagram) shows a simplified diagram to illustrate the pinning of memos to axial coding related to the generation of exercise behaviours. Memos that

served as important sensitising concepts are shown in blue boxes, the four axial codes concerning exercise behaviour are shown being generated in yellow.

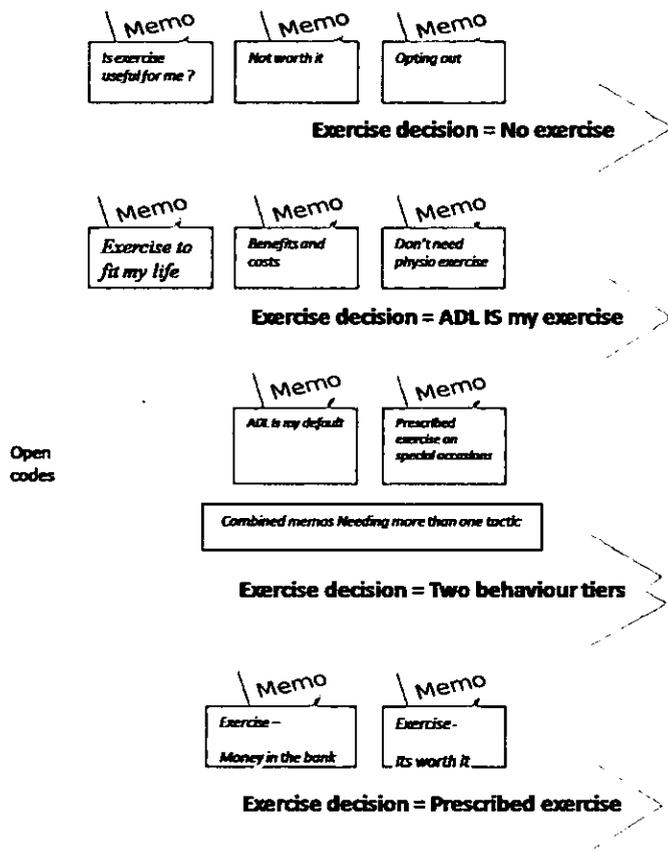


Figure 3.2. Second Conceptual Diagram: an example of the use of memos

3.6. Core Category 2: Determinants of Exercise Behaviour

This section details the factors that were identified as directly determining a person's exercise behaviour, these were: pain, fatigue, beliefs about exercise, accumulated experience and lifestyle factors.

3.6.1. Pain

Participants described coping with a pattern of unpredictable exacerbations and remissions superimposed on top of daily pain. Whilst pain in AS usually eases on active movement, it also restricts a person's movement and, by association, their daily living activities. Analysis revealed three responses to pain which are described as die hards, enjoyers and protectors.

3.6.1.1. Die Hards

This referred to the belief that an increase in pain is something that must be fought; often the comments here referred to pain as an enemy, or in terms of a battle that must be fought and won. People often commented that they were afraid that their AS would progress, and that they needed to maintain the status quo in terms of their function or posture. People's decisions to increase their exercise levels often led to immediate and prolonged soreness that many nonetheless still believed to be worthwhile:

Anna: If you're just sitting, it makes it worse, you've got to get up and move, on those bad days.

Is that the time to exercise, or is that the time to drop down a gear?

Anna: I still make myself do my exercise. It will take me longer to do them but I still make myself do the same exercises. [H2 focus group]

This second example further illustrates the concept of fighting the pain described as an enemy- and perhaps ascribing AS a human quality by referring to it as "he":

Jo: I don't know if it's psychological, but you feel as though you're having a go back at it. I feel better, I go and do a workout and I think - all right it was hard, he killed me today. [F3 focus group]

Participant P provided an eloquent account detailing his views about the long term fight against his AS:

The battle is to maintain the normal range of movement, so I can carry on a sort of normal life...It seems to be almost a battle to the grave, and the only way it burns itself out if you let it progress to the point where you become as stiff as a board, you don't have any pain, but that's not the name of the game as far as I'm concerned, the name of the game is to keep on top of as long as I can, Hope that it doesn't get the better of me until I'm well into old age. [int P]

This illustrated several interesting points; firstly that this person knew that he could expect much less pain when, or if, his spine ankylosed and that he was possibly delaying this by continuing his exercises; secondly that at his current age this course of action was not yet an option, he was 62 years old and had been retired for several years. The fight that people described occurred in both the short and the long term:

Are you fighting it day to day or are you fighting it long term?
Gareth: Both, I just hate the idea of losing ground. [F3 focus group]

The decision as to whether or how much to fight the pain was a complex construct that incorporated cost versus benefit for a particular exercise, how bad the AS was perceived to be at any given time and finally any likely benefits of increasing exercise as a useful self-management tool in light of their past experiences. This cost benefit is presented later.

The fight against the pain was not, however, limitless: most people pragmatically acknowledged that they had a cut off point at which exercise was considered no longer practical; i.e. the costs in terms of pain outweighed the benefits of exercise. There were, however, exceptions to this: two people described a positive correlation between pain level and the need to exercise:

If you've lost mobility do you try and do more?
Joan: (nodding) You try and push your body

*Keith: You've got to go through the pain barrier
How hard have you got to push it?
Keith: If you're really bad, you've got to really push it. [H3 focus group]*

There was an acceptance within this group of participants of the need to keep exercising no matter what their pain level:

*Stuart: How much does your body tell you what to do? I hurt my neck last Christmas, my body was saying don't move, - it was horrible, that's what its like for you all the time, how on earth do you fight against that?
Colin: Well what's the alternative?
Keith: Long term- you'll end up (gestures flexed posture with his hand). [H3 focus group]*

3.6.1.2. Enjoyers

People within this group expressed the belief that a period of low pain was the time to reject exercise, and live a normal life, by taking advantage of their pain-free periods. They recounted a Catch 22 scenario whereby they *did* not feel the need to exercise when their pain levels were low yet *could* not exercise when their pain was high. This exercise behaviour, or lack of it, was often associated with guilt but also reflected an underlying strongly held belief in their ability to manage themselves successfully without exercising:

*So when the inflammation was switched off, did you change your approach to exercise?
Tom: Yes, - stopped exercising, and then I was leading what was the best part of a normal life. [H1 focus group]*

A further example of a person's tendency to avoid exercise at certain times is shown below; this man made this decision relying on his experiences of his AS:

I never raise the subject because I'm always embarrassed to say, whether it be the nurse or the doctor, they say are you doing your exercise? I'll say well, yes when I need to, they'll say- well you should do your exercises... that doesn't bother me. I know they're doing their job and I know they believe that, and for 99% of people with this condition it probably is the right thing. [Int B]

His answer also suggested a belief that he was different from his peers, this thread would recur throughout my interactions with the participants and will be discussed later under the sub heading of positioning.

Another example of such a Catch 22 philosophy is shown below, this participant exemplified the belief in the need to exercise when the disease was quiescent, but this need was outweighed by the relief from symptoms that such quiescent periods gave him, and the associated desire to continue with as normal a life as possible:

Norman; The problem is when it switches off and starts going through the healing process - that's when you should be exercising, and then it switches off (clicks fingers) you think- oh bloody hell! You try and have a normal life. So at a time when you should be exercising you're not, because you think- all right - I've got a bit of relief. [H2 focus group]

People with AS are bombarded with regular requests to exercise by their physiotherapists, and the people in this project described how they often appeased their therapists by telling them what they wished to hear. For example whilst this person was temporarily convinced by therapists of the virtues of exercise, he later reverted to using activities of daily living as a form of exercise, describing how his own lived experiences carried more significance than expert physiotherapist opinion. Whilst this man consciously did not exercise, he could not bring himself to disclose this to his physiotherapists, nurses or his consultant. When asked about this he went on to explain:

Countless people, all sorts of people, consultants, nurses have said 'you must do your exercises'. I say 'yes, yes, course I will, and I do mean it at the time. Then I'm going away thinking - well I feel ok I don't need to do it. The next time I can't move I think, well, when this goes off I'll start the exercises again. Of course when I feel better I think - well it's all right now, I don't need to do the exercises.[Int B]

3.6.1.3. Protectors

This group employed exercise, but much more cautiously than the die hards, in that high pain levels were viewed as an indicator that more exercise would exacerbate an already painful situation.

Participant Q for example was judicious about his use of exercise, even when not experiencing a flare up. He based this caution upon his previous experience of what exercise could do to exacerbate AS, or even in his opinion, cause a flare up. This excerpt illustrates how the protector strategy was formulated informed by experiences of how exercise could increase pain:

*Once you start doing exercise –that's when it starts to flare up
Have you tried that in the past, when you've been fine?
Yeah I've been fine, no problems whatsoever and I've sat and started some exercises and
the following day I've not been able to move – in a lot of pain, and I always say to myself
– Why did I do that? I shouldn't have done that - I shouldn't have done that yesterday.
I've spoiled it. [Int Q]*

The focus groups provided the opportunity to explore how people generated this cautious approach to exercise; from these discussions it was clear that this approach was adopted in the light of peoples' wariness of the effects of exercise. In the first Manchester focus group I asked what determined how much exercise people did, one discussion is shown below:

*Kenny: PAIN, that's the be all and end all
Ian: Well its experience, if you put your finger in the fire and it burns then you don't do
it again, and so you keep it a little bit further away from the fire..... I would have
lapsed because the pain would still have been there regardless of what I'd done. Pain
was constant and it gets to a stage where you're saying - I've had enough.
Tom: Then as soon as you actually feel better you're then on catch up if you know what I
mean. You then go off like a greyhound out of a trap (in terms of exercise) - feel great
now - and you're on a high, and all of a sudden then – BANG! And it's just given you
another kick in the teeth.
[H]focus group]*

The group interaction below illustrated the important issue that failure to exercise did not equate to absence of desire to effectively manage their AS:

What would affect how much you do (exercise)?

Anna: How much pain you're in.

Jenny: (nodding) How much pain how much movement you can actually achieve without crying.

Bob: Yes, you might want to exercise, but you're in that much pain you couldn't do it. [H2 focus group]

Participants explained how their decision to curb exercise levels was made after careful consideration, and how this often conflicted with what they were being told to do by their physiotherapists. This again clarified an underlying robust belief system that people with AS had built up as a result of the experiences of their AS journey.

The excerpts below illustrate how some believed that their physiotherapist's advice was naïve when they advocated exercise against the pain. The first example comes from a semi-structured interview and the second example from a focus group:

Do you find that people encourage you to fight through it?

Yes they do, still tell you, do your exercise - but I don't think it works.

So what do you tend to say to the people that say fight it?

Well you do fight it, you fight it every day.

If someone says you must exercise through it, what do you tell them?

You can't!

And how do they handle that when you tell them that?

They say you can! (Laughs). [Int Q]

And:

Tom: And so you moved on, junior doctor to junior doctor. I may not be over intelligent, but I'm alert enough to tell me that what I'm doing hurts.... and if I tried to force my head round, either up down left right, it hurt and my brain said - don't do that please it hurts! And the response is from the hospital - well you've gotta do it.

Ian: You nod, you nod, (they say) are you exercising? You say yes, and if I said no - the response would be "well you should do", if you was really honest, and I've been honest and said - my brain's telling me it hurts and the more I do it hurts more. So I'm listening to what you're saying, but I'm finding exercise really hard. [H1 focus group]

The third conceptual diagram, Figure 3.3 below is an excerpt from the analysis that illustrates how the axial and selective coding (following left to right on Figure 3.3) was employed with increasing degrees of abstraction to build up to a larger category - the building block of theory (Charmaz 2006).

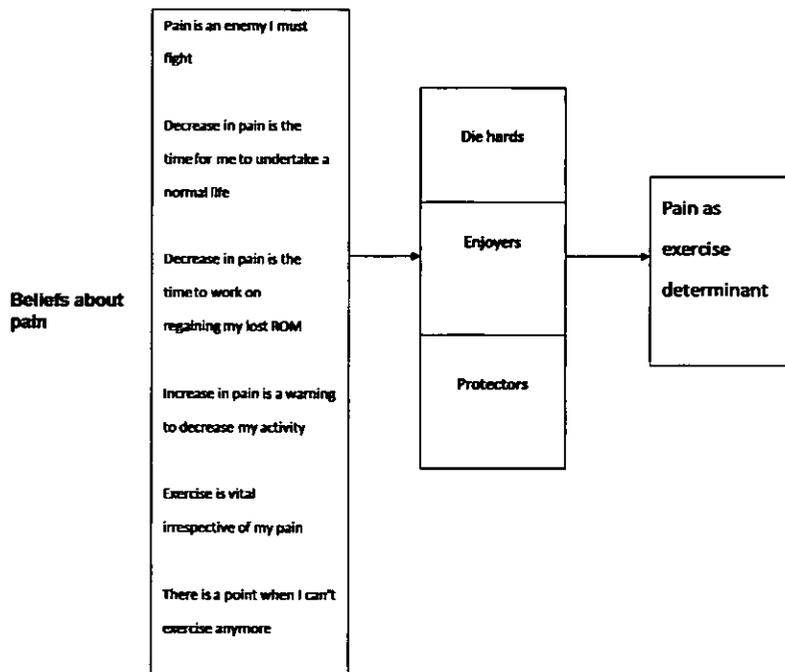


Figure 3.3. Third Conceptual Diagram: Pain as an exercise determinant

3.6.1.4. Summary

Participants held strong beliefs about the relationship between their pain and exercise, and how this relationship should be handled. These beliefs were informed by past experiences of the AS journey which will be discussed later. For some, the trigger to change exercise behaviour was an increase in pain, while for others it was a decrease. Nonetheless, pain was identified as a major determinant of exercise behaviour. People often favoured their own beliefs about pain and exercise in preference to

advice from professionals, even when this professional advice was at odds with their internal beliefs. In this study, for the first time; three classifications of response to pain have been identified.

3.6.2. Fatigue

People referred to fatigue as both physical tiredness and mental weariness and reference to it arose throughout the interviews and focus groups indicating how it had a significant impact upon exercise behaviour. Peoples' answers were pragmatic, recognising fatigue as inevitable, and something that should not, or through their own experience, could not be fought. When probing the reasons behind this, participant A for example explained that trying to constantly fight the fatigue was in itself a cause of major stress, and that to succumb to the tiredness was the best option. I had asked how he dealt with the tiredness:

I give in to it, because I fought it for so long, and I've realised it's the wrong thing to do, because I get upset. I get emotional, it upsets everybody around me and everybody now just accepts that if I can't do something because I've had to go to bed nobody gets upset with it anymore..... it has knock-on effects because if I get wound up, better to just give in, sleep. [Int A]

An example of the emotional tiredness of fighting AS and its impact is illustrated in the following excerpt from a lady who was 39 years old with a three year old child:

*What do you think makes you tired?
(Pause) don't know, I suppose the constant fighting against it.
What do you do when you do get tired, how do you handle it?
I do get snappy. If I can I'll just nod off but most of the time
I can't do that because (child's name) is running about. [Int J]*

People described how the fatigue of AS appeared without warning, which forced an instantaneous behaviour change that had an immediate impact upon, other life events, overtaking them. For example whilst driving or when at work:

What do you do to handle the tiredness?

Well it depends, if I'm in the office I just have to work through it, do something else and within half an hour I've forgotten I was tired. If I'm in the car will pull over and go to sleep, literally, for 10 minutes. [Int B]

People also disclosed how tiredness limited their activities and directly affected the exercise that the person believed he or she ought to be doing. This made them feel conflicted, continually appraising their self-management options. As was the case with exercise and pain, feelings of guilt were often superceded by the need to acquiesce to the tiredness:

You just have to lie down and think, bloody hell, pack it in for a bit, it's contrary to what I want to do, I am generally active. I believe in activity as the way forward. [Int I]

Many participants found it difficult to distinguish between the tiredness of the disease and the tiredness that everyone experiences. Downplaying their tiredness may have been an attempt to minimise the effects of the disease, and to situate themselves within the norm:

What do you do about the tiredness?

Lie down basically, It's not clear whether it's ankylosing spondylitis or whether it's old age, but I do get very much more tired, particularly in the late afternoon. [Int N]

Whilst for the majority of people, exercise was not used to fend off the tiredness, there was one case of someone exercising through the tiredness. This gentleman was an avid advocate of prescribed spinal exercises:

Have you tried different ways of dealing with the tiredness?

Well I've always tried to do my exercises because I've wanted to keep looking right, Does the tiredness stop you from doing things or wanting to do things? No not really because I think I've got a strong willpower and I think you have to have to cope with it really. I think you have to be a very strong personality. [Int F]

Summary

Fatigue was described as a common feature of AS in this study, the participants recognised it and acted as to minimise it, or using their experience of the cycle of AS simply allowed it to pass. Fatigue is

commonly associated with a decrease in exercise and is by definition an exercise behavioural determinant.

3.6.3. Beliefs about exercise

This section describes how people's beliefs about the effects of exercise affected their exercise behaviour. I had naïvely assumed that people would possess one or two beliefs about the effects of exercise, questioning of people, however, revealed a range of beliefs. Beliefs were grouped into the following 3 categories: Objective benefits of exercise, less well-defined benefits of exercise and finally negative views or uncertain about the effects of exercise, data to support these are presented below.

3.6.3.1. Objective (positive) benefits of exercise

This group held the belief that exercise would result in a positive benefit or change in their AS status, discussion tended to revolve around the issue of relief of stiffness, pain relief *per se* was not cited within this group as a reason to exercise although this group acknowledged that maintenance or range of movement would by association result in decreased pain levels, for example participants N, H and G below.

ok what do you think exercise does for ankylosing spondylitis?...what I'm trying to get at is why do you do these exercises, you said you go 46 weeks out of the year?
yes I do the exercises because I'm better doing them than not doing them, simple as that and how do you define better?
I'm better doing them 'cos I'm not as stiff, and I'm not as sore as if I didn't do any exercise at all, so I'm not as sore in the sense 'cos I've been more mobile or whatever, then the stiffness that you wake up with occasionally will go as quickly or far more quickly I wouldn't describe myself as loose and fit. I'm not, but its probably not as hard for me to do things as if I did not exercise [Int N]

What do you think exercise does in ankylosing spondylitis?

I think It keeps your joints, em mobile it keeps that the way I've read it well (physio name) talked about it the spine sieze up in that position, the exercise obviously stops it from siezing [Int H]

Right ok just to move on to how much you know about the condition, have you been given any information about the condition?

well, I got a booklet on ankylosing spondylitis how it starts and obviously how it starts, what it does and what happens to your vertebraes, you know. Apparently if you just let it, don't do any exercise, the cartilage between the joints will just turn to bone, that's as far as I know really, and once they turn to bone they fuse together and that's it – that joints had it

So you are keen on sport but you don't do sport. What about exercise in spondylitis, what does exercise do for spondylitis?

I don't know

what do you think it does?

oh from what I can gather I think it keeps the joints moving whether its spinal joints, elbow joints, knee joints I would imagine if you became immobile, say you had to have an operation – go in Hospital might be laid up for 5 or 6 weeks I would imagine that when you came out after 6 weeks you'd be as stiff as a board I think [Int G]

Although this person believed that prescribed exercises relieved stiffness, he did not do them regularly, citing his busy life as the main reason, however he readdressed his decisional balance if stiffness became a problem for him.

do they make you feel better? (The exercises he had been taught)

em, yeah, I suppose , yeah, I suppose they do, especially my neck one 'cos that gets quite stiff

if it makes you feel better, how come you don't do them everyday?

I don't know, I don't know, I don't know. I think I just forget and you get stuck into doing, you know you get stuck in your own routine and I don't know really, I honestly don't know

I don't exercise everyday, I'm not blaming anybody, do you think if your life was less busy do you than you'd do more exercise or less exercise?

I think I probably would try and do more because I might stiffen up and need to do it really

So is it fair to say that because you're doing so much with your children, house, day to day stuff, that makes up for the fact that you don't do the exercises on the sheet?

yes, I would say so

Is there any reason when you would do the exercises on the sheet rather than day to day stuff?

(pause) em if I'm extremely stiff it'll trigger so I will do it [Int R]

Participant N was a deputy head master who attended the AS group regularly and also undertook prescribed exercises twice a week to supplement his group exercise. He was able to give objective benefits (an increase in anthropometric measurement that he kept a record of himself) as validation for his behaviour.

do you think you're more mobile now generally because of the way you've behaved over the past 3 of 4 years?

yes, definitely, that's not just 'cos the numbers say so

what do the numbers say?

the numbers say that my hips are quite stiff but I can reach nearer to the floor than I could at one stage, there's more flexibility in my hips generally

so you've actually improved?

yeah they're not good by any stretch of the imagination, but they've improved a few centimetres and stayed at that

and do you think it will stay at that?

I'd like it to, I Hope so

do you think it will?

em, twenty years time, no [Int N]

3.6.3.2. Less well-defined benefits of exercise

This group of answers related to the belief in less tangible benefits of exercise in maintenance of body image, control of disease activity, causing disease burn out or maintenance of quality of life. This group of people believed that prescribed exercise had positive effects that were less quantifiable than the objective benefits described above. For example people in this group held beliefs that exercise would improve their overall quality of life, overall health, control future disease activity, or improve body image and posture.

Participant F's belief was that exercise would improve overall quality of life, of all of the participants in this study, this gentleman was the most avid (prescribed) exerciser, blocking off time slots every day to undertake the exercises in exactly the format that they had been initially prescribed to him.

I know by doing some of the things I've been told, eh, that's how I've managed to keep working as long as I have I think- keeps my life ok you know [Int F]

He went on to elaborate on his beliefs about the importance of prescribed exercises in maintaining body image and posture.

What would the ideal situation be, if a drug came out that meant you didn't have to exercise, would you stop exercising?

no, no I like my appearance an' all I think, so that helps me I think

so are we talking about muscle bulk or your spine posture?

yeah posture really, not bending over and things like that

you certainly don't look bent over, you look fit and healthy

yeah, and I think that's how I've done it, I like keep exercising and doing all the stretching exercises 'cos sometimes when I'm doing my stretching, my back you can feel it like even now really tight

what do you think the exercise does to your joints or muscles, what's your opinion that its doing?

I think its strengthening the muscle round the joint, your ligaments and all that

and what does that do?

I think I helps keep me straight by exercising your muscles, helps keep you straight I think [Int F]

Interviewee L had a similar belief about exercise

it's a case of picking an exercise that will give me sort of good all round benefit that'll help my life I think. [Int L]

Participants B and C believed that exercise controlled future disease activity, this would resonate with the comments of participant Q who had a macro behaviour approach the prolonged exercise viewing exercise as “*money in the bank*” (p184)

So I know a little about how it operates and how the disease affects people, how it can develop and cause further problems say in the spine , fusing joints whatever, so every year that goes by that I haven't ceased up completely I think yes! (punches the air) [Int B]

And

when you are in a flare up, do you think that doing the exercises alters the course of the flare up?

(Nodding)I just feel as though If there is some inflammation there, if I keep the joints moving that maybe they wont knit together as much as if I didn't do them. I might be totally wrong [Int C]

3.6.3.3. Negative views or uncertain about the effects of exercise

Discussions also revealed that the belief existed that exercise made pain worse, caused flare ups, or had no effect. Furthermore some admitted that they did not know what the effects of exercise were.

Participant Q believed that prescribed exercise would cause a flare up, and this man was instead a strong advocate of his work as exercise –see appendix VII field notes

would you feel guilty about not doing anything?
No, I'd be quite happy with not doing nothing 'cos once you start doing it (exercise) is when it starts to flare up [Int Q]

Participant S admitted that he knew that exercises *supposedly* (his words) mobilised joints but the immediate pain that they caused meant that in his view the overall effect of exercise was negative, therefore another example of strong internally reinforcing belief systems

I just want to ask you about exercise again, you said the exercises are painful and they can make it worse, why do you think they make you worse?
what they actually do supposedly is free the joints or keep them moving to me when I 'm actually doing them you feel worse at the time cos you 're actually stretching things which are still sore.
still sore?
yeah, they say if you have a very stiff neck and you try and move it you know yourself its gonna hurt - and it does. It may help in an hour or two's time but at the time you think- I know its gonna hurt now so I'll not do it [Int S]

In addition to the belief that exercise had negative effects on AS, there were participants who did not know what the effects of exercise were, for example interviewees G and K below

so you are keen on sport but you don't do sport. What about exercise in spondylitis, what does exercise do for spondylitis?
I don't know [Int G]

and

ok what do you think exercise does do for AS?
I don't know really if I'm honest
ok, no idea what it does?
(Shrugs shoulders) I don't know [Int K]

Finally under this concept, participant R stated that he had no interest in the effects of exercise and furthermore believed that his condition had not suffered due to his non exercise, his stoicism was also noted in appendix VI 1 field notes.

ok so you don't pay much attention to what your measurements are
no
do you think you ever would or is it just not something...
its not something I'm interested in

ok fair enough, do you think that if you'd exercised for the past 20 years you'd have been better than you are now, or the same, or worse?
I'd say the same [Int R]

The findings are summarised in Figure 3.4, the fourth conceptual diagram below, which illustrates how a wide range of beliefs about the effects of exercise in AS were axially coded into three broader groups before being amalgamated into an over-arching concept titled beliefs about exercise. This is presented as a means of illustrating the wide variations in belief about the effects of exercise in AS, and how the researcher interpreted this data using participant comments.

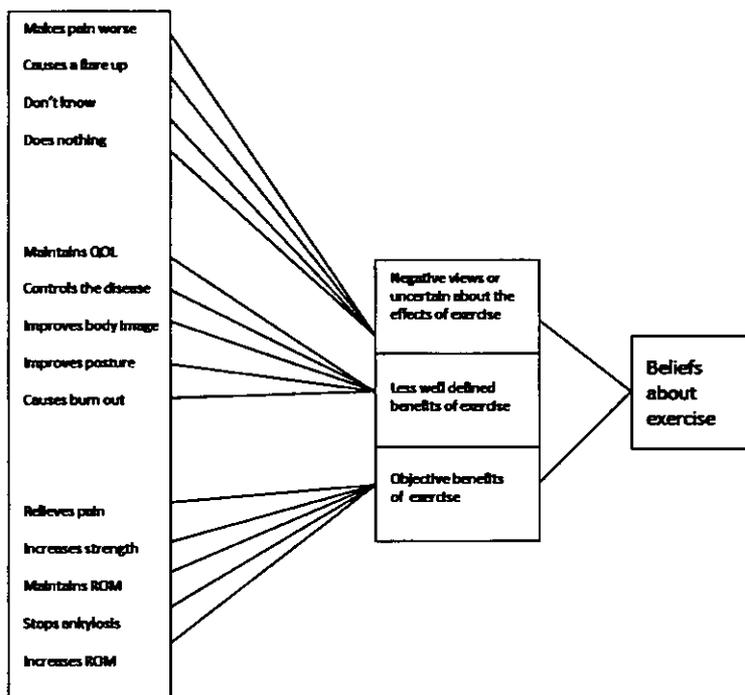


Figure 3.4. The fourth conceptual diagram: The construction of beliefs about the effects of exercise in AS.

Summary

Although the data in this project concerning beliefs about exercise was managed by grouping into three broad categories, there were many discrete views from the patient perspective about why they should be exercising to manage their AS. Irrespective of what these beliefs were, and whether or not they conformed to what they had been taught by professionals, peoples' beliefs about the effects, benefits or otherwise are a key determinant of their exercise behaviour.

3.6.4. Accumulated experience

People with AS live with their disease every day, they therefore accumulate a great deal of experience concerning how the disease progresses and reacts to various external or internal events such as exercise or change in disease status. People in this study described how they were able to use this accumulated experience to more effectively plan their AS journey. In this first example participant A illustrated how he had become the expert over time:

I've learned what I know from the various Hospital departments who provided me with the booklets, so I read the booklets and I know about all the things I should be doing in terms of exercise to control it, em, but now I take varying degrees of notice of that. [Int A]

His last comment about *varying degrees* reflected the need for flexibility to respond appropriately to his changing AS.

This participant explained how the knowledge that he had gleaned since his time of diagnosis enabled him to cope:

I do better on the whole now because I understand it. I know what's going to happen, whereas when you first start you didn't know what gonna happen. Once you can put your mind to rest that was the thing about what (consultant rheumatologist) said to me – you've got spondylitis, this is what it does, you'll end up with a curved spine if you don't do this and the other, once somebody explains to you what you've actually got, you know you can, start to live with it. It's when you don't know what you've got. [Int G]

Summary

People in this study illustrated how their accumulated experience enabled them to become problem solvers who possessed logical decisional algorithms that they were able to follow in what is an inherently unpredictable disease. The examples above all illustrate various aspects of this phenomenon.

3.6.5. Lifestyle factors

People live with the pain of AS for much of their adult lives, and this pain impacts upon all aspects of the lives of sufferers. It was common for people both in interviews and focus groups to describe their ability to maintain lifestyle activities but at a reduced pace or in a modified way, for example:

There are some things that take a little longer than they used to but you can do them if you take a bit longer, there's nothing I DON'T do. [Int B]

And:

*Like really bending down when it's flared up, is very difficult,
I need either my husband or my children when it's at its worst.
And what about when it's at its best?
I can do more or less plenty things, it just, how can I put it,
I find it harder I suppose than somebody without (AS) but I can do it.
[Int K]*

People described how living with AS often resulted in an enforced reduction in pace that meant that activities with other family members or partners had become impractical, for example this person noted a divergence in their family leisure activities:

*I don't sort of participate in the majority of my husband's hobbies because he likes walking a lot and I just can't walk at the speed that he needs to walk, I can only walk short distances and slowly.
Most of his interests are outdoors and he likes canoeing and I just can't do those things so our interests have sort of gone two separate ways. [Int C]*

Furthermore, there was a great deal of fear about the potential financial and social impacts of AS, as participant F explained:

I was scared of being out of work, I couldn't afford it. I'd gone on regular day shifts; I thought that'd suit me better. I'd be able to plan my life better, and the money was as good as I'd been getting before. I knew I had to work, I didn't want to lose my property, and that's another scaring aspect about it, you know-finance. [Int F]

*Stuart apart from the exercise, what has helped your spondylitis the most?
em,(pause) I think motivation really, I think motivation and scared of losing my job, well not actually scared of losing my job, scared of losing things I've worked for
Stuart yes*

if I'd have stopped married I wouldn't have had that problem, but you have to re-mortgage and that scares you like don't it when you've been at work all your life then you lose things you've been trying for [Int F]

Participant J described how he had gone from daily exercise to much lower levels of exercise, the trigger for this was a change in social circumstances- his becoming a father

well I started going from every week like at the exercise classes then it would be every month then every second day at home to once a week and then it got to the gradual stage where my little lad came along and I had responsibilities when I came home from work to help with himself and appease him and play with him which is quite rightly so , but it weren't affecting my lifestyle the actual physical condition Stuart so as you tailed off the exercises gradually, and you didn't get any worse? yes [Int J]

The discussions and interactions in this project revealed complex inter-relationships between symptoms and lifestyle in AS. People revealed how their symptoms impacted upon their lives. Conversely they also discussed how their lifestyle choices including career decisions may affect the symptoms that they experienced, and to what extent prescribed exercise needed to be added to or subtracted from their lifestyle to supplement their journey.

People had to modify their exercise levels in response to the signs and symptoms that they encountered, and also had to modify their lives to adapt to their symptoms. This reflexivity was a key part of daily management in AS. A change in social circumstances such as change in employment needed to be factored in by the person with AS if they were to maintain an acceptable level of function. Therefore lifestyle factors are direct determinants of exercise behaviour in AS.

3.6.6. Summary

This section has detailed and explained the data that directly determines a person's exercise behaviour, namely: pain, fatigue, beliefs about exercise, accumulated experience and lifestyle factors. For the first

time this study has identified what and how these factors directly affect the exercise behaviour of a person with AS.

3.7. Core category 3: Managing change

This section presents the data on how people described their management of an ever-changing disease –

this core category was built from five categories of responses to managing change in AS:

1. No action taken.
2. Increase in medication.
3. Localised physiotherapy.
4. Increased exercise.
5. Non-exercise related change.

Each of these strategies is presented below. In addition to this, under each title are brief excerpts from the data which were tagged as memos. These in turn served as sensitising concepts, that is to say an example that guided the researcher by offering ways of seeing, organising and understanding the phenomena under investigation.

The data below is presented as five clusters of discrete responses to change. Some of these involved an exercise response but some involved some other behaviour since exercise was not universally employed to manage change. This study uncovered for the first time the extremely complex heuristics and abstract thought processes that people were faced with when attempting to implement specific responses to change in AS.

3.7.1. No action taken

Sensitising concept - “I don’t take any notice”

One response by people was the conscious decision to make no change to their exercise behaviour during a flare up, or some other change in disease, especially when they encountered familiar signs and symptoms. The person below, for example, ignored his physiotherapy assessment measurement data and adopted a fatalistic philosophy to whatever the disease was going to do to him in the future. It was not possible to elicit from this person an answer to why he still went to be measured if he was nonetheless going to ignore the results:

How've your measurements been, do you take much notice of them?

(Shakes head) They (the physiotherapists) just do them.

Do they tell you what the results are?

Yes, but I don't take any notice!

If they said to you well this has gone a lot worse, what would go through your mind then?

I think in the back of my mind anyway I know that it's gonna get worse anyway. If my hips fail in 15 years time I know that I'm going to be in a wheelchair, so I'm just expecting this to happen anyway, I don't think there's anything I can do to prevent it happening. [Int R]

Another example is shown below. Interestingly both of these participants still attended every three or six months for physiotherapy assessment but did nothing with the results that this assessment provided:

So you don't pay much attention to what your measurements are?

No.

Do you think you ever would or is it just not something...?

(interrupting) It's not something I'm interested in.

When you are having a flare up, do you fight it, give in to it, do you seek help?

If it's something I've had before I will give it a week if you see what I mean. [Int A]

However, it is important to stress that a lack of the use of prescribed exercise during a flare up was not synonymous with an absence of activity, many people recognised the need to “keep moving” by whatever means they were able, for example:

So what would you do in a typical flare up?

I don't stay in bed, people with some illnesses would say I feel awful I must stay in bed, that's the last thing I'd do. I need to get up and move around. [Int C]

3.7.2. Increase in medication

Sensitising concept- “I tend to exist on them”

Exercise or a change in exercise behaviour was not the only option for self-management during a flare up, for example the decision to increase medication (typically NSAIDS) was adopted by many during periods of disease flare up, either with or without an associated exercise change. Participant O was a person who managed his AS entirely by pharmacological means:

So when you get a flare up do you change your behaviour?

I take more tablets basically - voltarol. I tend to exist on them, I'm a great believer in the minimum of drugs to control the condition so I've got a voltarol prescription which allows me to take three tablets a day and I take one tablet a day, but if I find you know that I'm suddenly in pain - I'm having problems with mobility, I step it up. [Int O]

Whilst participant B had stated on the response letter that he undertook some exercise when his measurements deteriorated significantly, he explained later in the interview that his first choice was pharmacological management:

*When I'm feeling that bad that **everything** hurts, exercise is the last thing on my mind – I just reach for the painkillers. When it's better I think, well I don't need to do the exercise now 'cos I'm ok.*

Right, so there is no situation you could think of where it is worth you doing the exercises?

Not for any length of time, no. [Int B]

In addition to increasing medication during a flare, prophylactic medication was sometimes used in preparation for an upcoming painful or difficult life event:

So how long would you wait before you said – right I'll take some painkillers?

If I wasn't feeling so good and the kids were coming, the grandkids to make us feel that bit, it can dull the pain, I'll take one. [Int M]

People were aware when they had returned to what they understood to be “normal” and subsequently they returned to their regular form of self-management, in the example below dropping from three tablets back down to one:

So you take one tablet a day when it's relatively good?

Yep, and I go up to three when it's showing signs of being a pain.

When would you drop back down to one?

Once it's sort of plateaued out and I've got back on top of it. [Int M]

3.7.3. Localised physiotherapy

Sensitising concept – “I must admit it’s not as good as a massage”

Physiotherapy modalities such as ultrasound or massage were employed by some in preference to exercise, particularly for local enthesopathy pain. People stated that this was a more effective and active treatment than doing exercises.

This participant went so far as to discuss the point at which he would need an injection, or how many ultrasound sessions he would need:

If it gets really bad it's an injection, I've nothing inbetween, but normally, if I do get a flare up they'll give me a little bit of ultrasound, something like that, if they can get to it quite quickly and I'm not waiting, that does seem to shift it, certainly two weeks, one, two sessions a week apart of ultrasound definitely helps me. [Int L]

Participant G had similar views, but for him the treatment of choice was firstly massage and secondly localised heat therapy:

I've got a hot electric heater –vibrating pad which goes on the back of the chair that gets hot, vibrates, but other than that nothing really, that helps it settle down a bit, I must admit it's not as good as a massage.[Int G]

Some preferred private physiotherapy during times of flare up. Participant D, for example, valued the one-to-one contact that private treatment gave him. This person objected vociferously to the group assessment and management of AS, specifically the embarrassment and distress that being assessed in public caused him. He explained:

The impression I get is they (the AS group physiotherapists) are there to take measurements but they lack knowledge of you as an individual 'cos you're not seeing one person all the time. You just come across as a bit of a number, you're in, you're out and that's it.Every time I've been it's been someone different. I think if anybody's got a condition which is currently with them, sometimes psychologically I think you do need to know that there's somebody that's aware of you as a person, has an understanding of where you're coming from. [Int D]

He went on to explain why he preferred to use private physiotherapists, rather than the NHS Services that were readily available, and geographically very close to him:

She's got a record and she knows you personally so you build up a rapport with them. You do feel as though you're getting that personal touch, ok they're making money, it's a business, but at least they seem to be able to relate you know to your previous treatment and condition.

In the past have you tried making yourself do more exercise?

That's quite interesting 'cos I've found that if I have a really bad flare up it's very difficult to maintain exercises which have been suggested by the Hospital... I've found it really difficult, I've always found like the heat treatment and massage has been the way into it. [Int D]

3.7.4. Increased exercise

Sensitising concept – “You’ve got to go through the pain barrier”

Within the discussions concerning increasing exercise at times of crisis in their AS there were two behavioural distinctions that could be made. Some people increased their exercises for a short time, almost as a penance associated with the guilt of not exercising every day, and others increased their exercise until the attainment of a specific goal, this is presented below. They were termed transient change and goal-oriented change.

3.7.4.1. Transient change

Sensitising concept- “A few frantic days”

With this sub-category, a decrease in movement or an increase in pain resulted in a self-limiting increase in prescribed exercise. This tended to be fleeting in its nature, lasting a matter of a few days, then ending:

So if (physiotherapist name) measured you and said your neck's gone a lot worse. When you went home, would you plan it out? How would you...

(Interrupts) I'd know that I'd need to do it, I'm not saying I'd do it every day, it'd probably be on an ad hoc basis but I would make an effort. Well initially I'd go to like doing it on a daily basis if I could and then try to increase the repetitive, increase the amount of repetitions.

How long would you keep doing more and more and more, what would stop you?

Like with my neck I can feel sometimes it stiffens up a bit or whatever, nothing but I'd just do it until – yes I feel in a stronger position, I wouldn't wait for 6 months or carry on for 6 months. [Int A]

Participant B gave an account of these “few frantic days” following a flare up:

If you went for physio and (physio) said your neck's gone worse what would you do?
For a few frantic days I do all the exercises until I've convinced myself that it's ok and I don't feel I need to do it.
Ok, right, do you think that it is a case of convincing yourself that it's ok or does it physically make a difference when you do these exercises?
I think in my case because I know that this comes and goes, I must be one of the lucky ones because having seen a lot of people with this – much worse than I have I think I am fairly fortunate, but I tend to take the view that, well, it'll get better anyway so if my neck's stiffened up at the moment or my chest is giving me problems, I'll do the exercises but then in three days time it could have cleared up anyway and then I don't feel as though I need to do the exercises. [Int B]

3.7.4.2. Goal-oriented change

Sensitising concepts – “Back to what I was before, till I'm ok”

This refers to the phenomenon whereby a decrease in spinal movement resulted in increased exercise, which was terminated by the person upon the attainment of a specific objective. This objective had usually been set by the person themselves, for example:

So if the physio says your neck's gone worse, would you carry on exactly the same, just be aware of it, would you do more neck exercises or try to push it further?
I'd try and push it further I think.
Right and how hard would you push it?
Oh I'd only take it as far as I could go, and keep it going like, not too far, till I'm ok. [Int G]

This second example shows how repeat anthropometric assessment by the physiotherapist could serve as an objective signalling an exercise cut off point:

I'd just put more effort into trying to correct that particular measurement.
And how long would you keep doing that for?
Well, probably until, until the next time I was assessed, or actually you can tell yourself when you're feeling better. [Int N]

And:

And what would you do, would you work on all the exercises or just the one?

Just the one I thought was the most relevant.

Would you do more of them, or push it harder or...

(interrupts) I'd probably push it harder.

And how long would you keep pushing if for?

Probably until the next time I go to (Hospital) and I'd get to know how I'm doing.

Right, now if you went to (Hospital) and they said you're a lot better, what would you do?

I'd probably go back to what I was before. [Int N]

This person who was a regular group attendee went a step further; he discussed how he would often request an additional spinal assessment from his physiotherapist as a means of checking on the success or otherwise of his exercise strategy:

So if the physio said, your neck's gone stiffer, what would you do when you came home?

That night – not necessarily anything, but what would I do over the period? I'd be absolutely certain that the exercises I could do to help that side of my neck would be done far more often.

How often, going from twice a week, what would you up it to?

Every day virtually.

And how hard would you push it when you did it?

If I'm not sore, very.

And when would you stop doing that or go back to twice a week?

Occasionally I'll cheat, I'll just get one thing measured between assessments just one thing.

So if your measurements had then gone back to what they were would you then go back to the twice a week?

Yeah, go back to that. [Int P]

People accepted that flare ups were a key factor in the changing nature of AS and that they were inevitable. Consequently, many of the discussions focussed on peoples' views about exercise in the post flare up period, with people discussing flare ups in the wider context of their lives and discussing their plans for the time after the actual flare up. Participants all had strategies in place to manage this post flare period, indicating the ability to forward plan their AS journey:

What goes through your mind when you are brewing for a flare up?

Well, I just carry on as normal, when it starts and I just know it will settle down in time. [Int C]

This person explained that a detailed understanding of a flare up and their ability to project to the post flare up period permitted them to cope with what was about to come, this was used as a coping mechanism:

Do you think – got to do something – or do you think – it'll be better in two weeks anyway?

I think I've got that used to the pattern. I think, it'll have gone, I'll be all right in a few days.

Does it affect your behaviour because you know what's going to happen?

I suppose so, I know it'll only last a few days, I know what's coming.

[Int K]

Peoples' knowledge of the pattern of their disease behaviour or journey permitted them to firstly recognise, and secondly make the most of quiescent times. This was typified by participant D's comments below:

I think what you do is just realise that it's here to stay, you just say – well I know I'm going to have some bad times but at the present time the good times outweigh the bad times – and so you just get on with things.[Int D]

Because people regarded flare ups as inevitable, many people in this study explained that the period immediately following a flare up was the time that they should increase their exercise levels in an attempt to return to their pre flare up level of function and movement; this was often a short term self-limiting measure as the excerpt below illustrates:

What would you do when the flare up ended, regards to exercise?

I'll carry on doing them for a few days after because I need to get moving, get out and about, then it just gradually stops and I don't do them then.

I just do them every now and then.[Int C]

Following this short term increase in exercise, people sensed when they had attained their normal level of function or movement. Upon having attained this level, they then returned to their more usual behaviour once they believed that the crisis has passed. This process was often described as being subconscious. The excerpt from participant L below indicates the participants' instinctive behaviour:

When would you stop doing that? (Increased exercise)

I don't make a conscious decision, I realise I don't seem to have problems ,it just fades away.

Why do you stop it when you do stop it?

I probably stop it because I don't feel the need to do it, I feel like it's, you know, it's back to normal, it sort of indicates that we're back into a stage of normality and I'm not chasing something that doesn't need treatment, seems to be ok.[Int L]

This was an example of people temporarily stepping outside the journey that they had constructed, appraising their behaviour and then re-entering their journey with any relevant modifications in place.

The concept of people having such sensitivity to their AS that they no longer needed to think about a course of action permeated many of the interactions with participants, and we will return to this again in the discussion.

3.7.5. Complementary therapies

Sensitising concept – “I think it's mumbo jumbo”

Exercise is still considered to be the most appropriate physiotherapy treatment to combat pain and stiffness in AS (O'Hea 2008). However, it would be naïve to think that exercise featured in everyone's decision making construct; there were occasions when people tried different approaches. The interviews specifically enquired about peoples' use of complementary therapy and the data concerning this is presented below.

Most people had tried and almost immediately dismissed alternative therapy; answers to these issues were dismissive and blunt:

I've tried acupuncture, em I've tried resting, sleeping, I've tried diets as well, been on like a milk-free diet... cut out oranges and citrus fruits, even done one when you cut out potatoes. I've been to physiotherapy, I've been to chiropractic... I think that just made the situation worse. [Int R]

And:

I don't think acupuncture does anything. I think it's mumbo jumbo I'm probably dead wrong.

So it's what you think really, are you fairly happy with the management that you're doing now, do you feel you're on top of it as best you can be?

Aye as best I can be, yeah. [Int Q]

Some people had concerns over the toxicity of NSAIDS, which had prompted them to seek alternative remedies and to take a minimal maintenance dose of NSAID;

I've started to worry now about how many of these anti-inflammatories I've swallowed over the years and the effect they can have on the stomach and so on, tried to cut down on those. So I only take one a day in the morning, I take 75 milligrams in a morning, used to take one at morning, one at night, cut down, got away with it. I occasionally try what is it? ...glucosamine. I'm told they help arthritis generally, but I've never really noticed any difference... I can't say that I've taken a pack of those and thought – oh they've worked. [Int B]

There was also the view that NSAIDS and conventional medicine were effectively controlling their disease. As a result, some people were reluctant to change to complementary therapy when they perceived that conventional medicine was effective or at least holding their condition at bay:

Have you ever tried alternative therapy?

No, for the simple reason that whenever the situation at any time of a flare up, conventional medicine has sorted it out. [Int H]

And:

I get loads of people bringing me books about green mussels and all sorts of things (laughs) and I always think, well if I'm on the medication from the doctor and from the specialist, how do you know what is doing you good and what isn't unless you stop taking the medication? [Int C]

Participant J went on to explain that whilst they saw no obvious benefit to complementary therapy, it may be that it was holding their symptoms at bay. In J's case the cost of taking a tablet every day was so insignificant that it remained part of their self-management despite no hard evidence of its benefit.

perceiving that the cost (both financial and in terms of effort required) meant that the potential benefits outweighed the risk of discontinuance:

Halibut I've taken for 4 years, the omega 3, I've only been taking for 6 months it was just something I read, I read these health magazines.

And do you feel better for taking it?

I've not noticed that much difference really!

So why do you take it if you've not noticed much difference?

Because I think if I stop taking them, I might go worse and there's no point going worse is there for the sake of a pound – they're only a pound.[Int J]

People however occasionally expressed an open attitude to new ideas and therapies:

I'm actually reading a book at the moment, which is on alternative therapy it's called (brand name). It's something natural that's in the body, that helps people. I'm halfway through it, and I might consider trying it. I don't know how much these things are but it says that people who've been on it have suddenly been miraculously cured, once I've read this book I might consider trying it whatever it is.[Int J]

3.7.6. Summary

Five responses to change in AS status were identified in the previous section. AS is inherently unpredictable in its course. However, people who live with AS are forced, within the constraints of this unpredictability, to manage their disease if they are to function in the world. To this end people were able to call upon an arsenal of personally effective exercise and other behaviours that they had built up. People with AS simultaneously employed long and short term behaviours for the flare up and post flare up periods using the accumulated experience of past disease behaviours to inform a response that they believed best fitted their individual self-management needs.

Figure 3.5 (conceptual diagram 5) below shows a portion of how the core category of managing change was visualised and constructed.

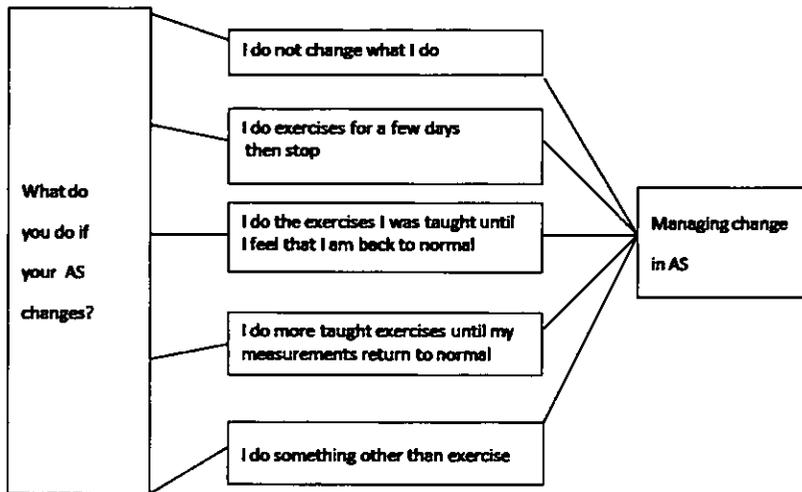


Figure 3.5. Fifth Conceptual diagram: the generation of managing change as a core category

3.8. Core category 4: The AS Journey

Living with AS is an iterative journey , a non-linear process that evolves over time, and may take different directions depending on a person's significant life events. Many of the people interviewed described experiencing difficulty exercising as children, possibly an early manifestation of AS, which may therefore have been the beginning of the generation of a learned cycle of exercise behaviour which would become more formalised following the diagnosis of AS:

*I could never bend over properly – so I found that very, very difficult. I actually **couldn't** do it. I mean I tried **really really hard**. I really tried and I'd just be discouraged at every turn, you're not doing that right – why can't you do this – why can't you do that? So I just sort of pulled back – I wasn't interested. [Int A]*

Many people described an evolving philosophy towards exercise, commencing with their introduction to prescribed exercise soon after their AS was diagnosed, which at a later date evolved into a personally engineered, more responsive exercise behaviour:

When you were first diagnosed was there a period when you exercised every day?

Yeah.

Why did you stop?

Because I actually weren't suffering at that stage, it's a combination of not suffering and trying to balance your lifestyle, I'd got to the stage where everything were great, I'd started working in Blackpool and I got promotion, doing longer hours, little lad were coming round the corner.

How long did you do the exercises for?

I would have said, it wouldn't have been every day but every second day for the first 3 years. [Int G]

The example above also illustrated how people had to make decisions about what was right for them at a given point in time. I probed more deeply into the reasons why participant G had decided to stop exercising after three years of having exercised consistently:

Just the simple fact that I think when you were told about the condition and the implications regards to exercise that I felt the only way to help the condition were to

make sure that I did the exercises and went to the exercise class so that then I could try and keep control. [Int G]

I talked to him further about the specifics of how he had changed his exercise behaviour, asking whether he had tailed them off gradually or had ceased exercising abruptly. His answer was insightful, illustrating how he continually appraised each stage of his process of change. Furthermore there were two factors influencing this behaviour change, his initial tailing off informed by a process of trial and error to assess the impact of reducing exercise, but later becoming a father was a key determinant of change:

Well I started going from every week like at the exercise classes, then it would be every month, then every second day at home to once a week. Then it got to the gradual stage where my little lad came along and I had responsibilities when I came home from work to help with himself and appease him and play with him which is quite rightly so, but it weren't affecting my lifestyle, so I tailed off exercises gradually – didn't get any worse. [Int J]

I ended by asking him how he felt about his actions:

Well It's always in the back of your mind because it's a condition that could flare up any time, I mean I wasn't naïve enough to think you know – it's gone forever, because that little bit that I've read that's it's an ongoing condition that can flare up any time so I felt that yes I'm not doing the exercises but my health's not suffering and at this stage I don't need to go back onto it, I've enough things in my life. [Int J]

His comments effectively summarised the complex choices faced with people with AS on a daily basis that carry on for the rest of their lives and informed the final core category which locates the self-management of AS within the overall life context of participants and was depicted as a journey.

The core category comprised a number of lower order codes presented below in Table 3.4 to illustrate how they were amalgamated to inform the category of a cycle or journey of exercise behaviour in AS.

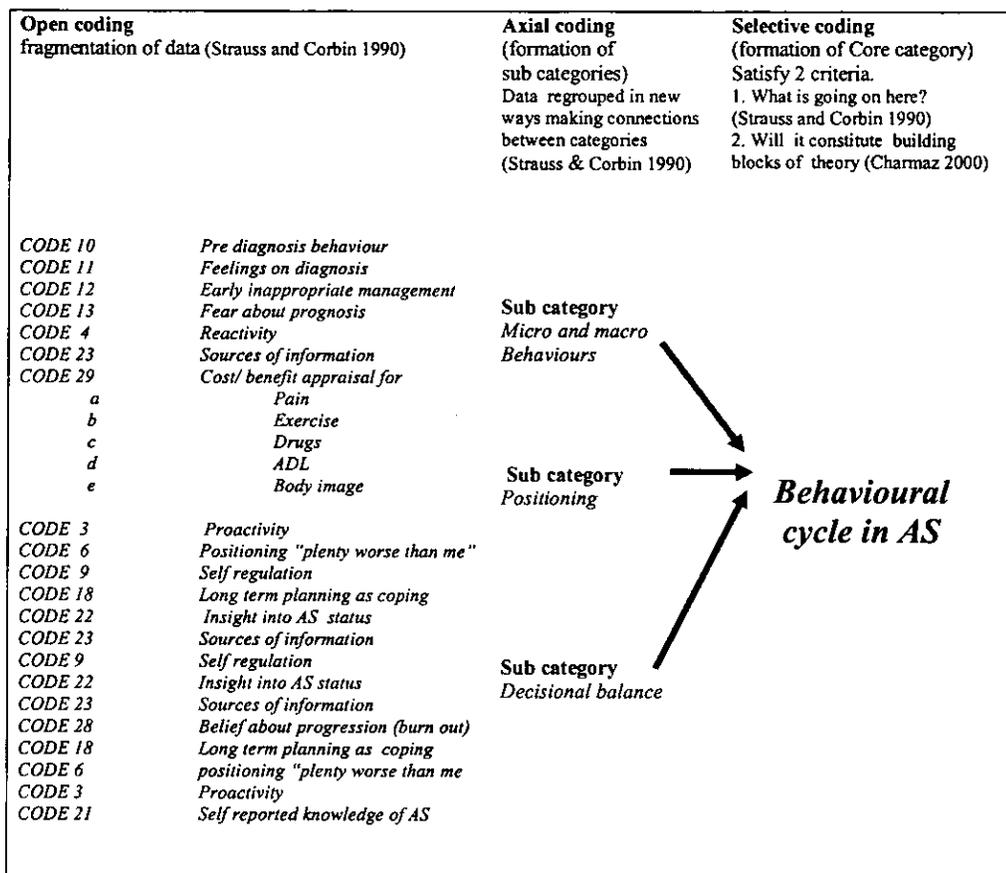


Table 3.4. Coding matrix for behavioural cycle in AS

The three overarching concepts that formed the core category of a behavioural journey are presented below, they are:

1. Positioning
2. Decisional balance
3. Micro and macro behaviours

3.8.1. Positioning

This section engages with how people viewed themselves in relation to other people with AS and other diseases or conditions. The original title allocated for this code was “plenty worse than me” since this encompassed the recurring concept of peoples’ perceptions throughout the study. The term positioning was finally chosen when further constant comparison revealed that positioning would more accurately reflect the concept that people could compare themselves either favourably or unfavourably with their peers. Later literature searching revealed that this is a well recognised phenomenon in psychology termed social comparison. This was a useful lesson of how entering the research area without an exhaustive literature review so often advocated in grounded theory studies permitted insight into the phenomenon without prior conception or bias. Individual and disease-specific positioning are presented and explained below.

Almost all of the people in this project expressed the belief that they were not typical in terms of their AS. This belief was often their rationale for not having to do prescribed exercises, or a legitimisation of their current exercise behaviour. Insights into this perception illustrated how people felt that their needs changed and evolved over their life course and that the management of their AS should be informed by an understanding of their individuality.

Those who had had AS for a long time often suggested that prescribed exercise was no longer an appropriate option for them, but held the simultaneous view that if had they been recently diagnosed then exercise would have been appropriate. This was rationalised in terms of exercise being used in the early stages of the disease to make an impact before the disease process could “get hold” of them:

Norman: I don't think they know a lot about it, (AS) it was just people like Prof X who was the leading specialist in the country at the time that knew what they were talking about, but I think it's spread a lot more now...

*Bob: ...they're diagnosed sooner and being put on a regime of exercise **before** it gets hold. [H2 Focus group]*

Bob went on to explain his initial mismanagement with some resentment:

It's took hold with us whereas if we'd exercised right from the beginning and come to these groups, I think we'd have been a lot freer. [H2 Focus group]

And these comments came from the Hospital 1 focus group:

*John: Maybe I'm luckier than most because I'm not as bad as them.
Margaret: It seems to affect people differently, I don't think there's only certain things I need to do because I'm different to everybody, but I have noticed over the years of coming here that other people seem to be affected in a different way like everybody's **different** and we'll deal with it in a different way. I think I've learned a lot of it through the years but I wouldn't say to anybody else, oh you **should** be doing this because they've got the same diagnosis as I have, it affects everybody differently... So I wouldn't you know pretend to be an expert on everybody else in this room, cos I'm sure what's right for me would be wrong for them. [W1 Focus group]*

It was interesting that in the first Liverpool focus group, participants made a distinction between themselves and those who were recently diagnosed, and referred to the newly diagnosed in detached terms as “these people”:

*Robert: But at least now we're accepting the fact that we need to do something about **these people**. It's a different form to other illnesses... now they are looking into it exercise-wise, just because a similar tablet for rheumatoid arthritis, but you know exercise is a different kettle of fish, we need looking into in more detail. [F1 Focus group]*

In the above excerpt (and given bold emphasis for clarity) although he did refer to *these people*, it is interesting to note that he used the term “we” twice on the first line, and again four lines later, hinting at a constructed collective responsibility involving both patient and provider.

Whilst it has always been claimed anecdotally by physiotherapists that a positive aspect of group exercise therapy is the feeling of belonging that it inherently generates, some in this study used their group experience to reinforce their belief that their AS was different from their peers. For example,

when talking about his first time meeting others at the AS group Kenny at the first Manchester focus group, said:

Kenny: ...and I thought, all these here are different fish from me. [H1 Focus group]

This participant ended the focus group by commenting on how much he had gained from the focus group itself in a therapeutic sense, by the very act of being exposed to others with AS in a non-physiotherapy environment.

Others, however, embraced AS management in a group. The quote below came from a regular AS group attendee:

Tom: It's a difficult set of symptoms we've got, we might have eighteen in there (the group) on a Thursday morning and we've all got different symptoms. [H1 Focus group]

The diversity seen in the group was often cited as evidence that they were all different and as a consequence needed to develop their own personal management strategy.

The incurable nature of AS was discussed by many again, the broken bone analogy was used by participants at the third Manchester focus group inasmuch as the management of AS being geared towards maintaining the status quo and preventing deterioration, rather than rehabilitation to improve or restore normal function:

Colin: My contention is that when they're (the hospital managers) looking at the money this isn't a thing where you can say – broken leg – gone to physio – got all the exercises – tick – success! All ours can do is show hasn't got much worse! [H3 Focus group]

People strongly expressed the need to communicate their individual symptoms to a therapist rather than be given a standard sheet of exercises. The next excerpt gives insight into some of these discussions and the cognitive processes behind this desire for interaction:

Robert: if this gentleman broke a leg, and the physio comes along and treats the legs exactly the same – this is how far you're gonna move this leg, this is how far you're gonna move today, this is how far you're gonna walk the next day, with ankylosing spondylitis they go – right this is the way we want you to do it, and they give him a set piece right, then the next patient comes along, they give her exactly the same set of rules, whereas if you insist – I can't do this! [F1 Focus group]

The concept was explored one week later at the second Liverpool groups:

One of the comments was exercises aren't worth the paper they are written on.
Nan: They may well be to some people, but I think people are individuals and we can't all like that exercise or that exercise, we're all different, and we all find that things are different for us. [F2 Focus group]

One interviewee who was a non-exerciser did however advocate exercise for his son who had been diagnosed with AS six months previously. His comments reflected the importance of the early introduction to exercise; however, he admitted that in his own case he had buried his head in the sand with respect to any form of exercise to manage his own AS:

All the advice I've been given up to now, and even repeated to (son's name) is that now is the time, what you do now will give you a benefit in the future when the condition either burns itself out or gets to a stage... What you do now you're putting in the bank, so if you do your exercises and your posture and your regime and you come to the club and keep an eye on it. It's not treatment as such but what you do now, I mean your posture will be that much better. So we always use – well if you wanna end up looking like me, don't do your exercises. If you do them and the condition obviously runs its course you'll end up better than you might have done. [Int E]

Barlow and Barefoot (1996) noted that people with AS value exercise but often did not translate these beliefs into action which is also illustrated by participant J:

I'm good at telling people – well you should do specific exercises for your tummy, and for this and for that, but I don't really practice what I preach. [Int J]

Whether people believed that they lay within the normal spectrum of AS or outside it, both beliefs were used to provide self reassurance and justification for their own particular exercise behaviour. The following excerpt from a Manchester focus group illustrates how participants used the former (within

the spectrum of normality) to good effect and another person used the latter (outside the spectrum of normality) strategy:

Jenny: As I'm saying I'm probably not as bad as these people here, I mean I was diagnosed in 1984 and I still keep querying have I got this spondylitis? I mean they've shown me the x-rays, "you've definitely got it" but I don't look as bad as some.

How many of you feel you're not typical?

Anna: I don't think I'm typical.

Norman: I see myself in the middle, there's an awful lot worse and an awful lot better, I see myself somewhere in the middle.

How about you Bob?

Bob: Yes somewhere in the middle.

Jenny: But it's 18 months ago I queried (Dr) about it. He said – right we'll send you for x-ray and he showed it me there and then you know, tried to convince me that is was this I've seen people bent over I've had it since 1984 and I've had none of that! [H2 Focus group]

Summary

Despite therapeutic standards in AS to standards comparable to any other disease in the 21st century. People often believed that their AS was misunderstood or inappropriately managed. The great majority in this study believed that their AS was not typical, This may be their method of making sense, constructing and rationalising their exercise behaviours. Nonetheless these beliefs of uniqueness impacted upon their exercise behaviours and were used as a rationale when explaining why they did what they did, and as such positioning is an integral determinant of a person's exercise behaviour.

3.8.2. Decisional balance

This section presents the beliefs that people expressed about the benefits of exercise weighed against its drawbacks and is termed decisional balance. The decisions ranged from exercise never being worthwhile to it being totally worthwhile, examples of each end of the spectrum are provided.

3.8.2.1. Scenario 1

Exercise was never worthwhile; the costs of doing an exercise significantly outweighed any benefits that might result:

Do you think you are any worse off because you don't exercise?
No because it just knocks us sick. I just feel lousy so there's no point.
So there's no point in doing the exercises?
No.
So there's nothing to be gained by doing exercises?
No.
Do you feel guilty about not doing them?
No.
Why?
(Laughs) 'cos I feel all right with not doing em! [Int M]

Contrast this with the case below at the opposite end of the belief spectrum.

3.8.2.2. Scenario 2

Nothing outranks exercise, i.e. the benefits of exercise outweigh any negative consequences:

I know by doing some of the things I've been told em, that's how I've managed to keep working as long as I have I think
When you're having a real bad flare up what would you do, would you exercise?
I'd exercise.
Even if it was a terrible flare-up?
I'd still exercise everyday. [Int F]

More typically, however, people situated themselves between these two extremes. Participant B, for example, believed that the large geographical distance from his home to the AS group outranked any benefit he may gain from attending the AS exercise group. Therefore he did not attend the group, yet attended for regular spinal assessments which were more important to him:

When you go to the group, have your measurements, you don't go in the pool or exercise?
I have on 2 or 3 occasions joined the exercises but only went 2 or 3 times because I was travelling... Crewe, 50-60 miles so it was a bit much, but again because I've never found exercise that much of a critical thing for me. [Int B]

The fact that exercise provided no immediate payback was the key determining factor for participant C:

What happens if you do them is it worth it to you or not?
*I suppose when you do it you feel good, but you don't always feel an immediate
payback.[Int C]*

In a similar discussion, this person noted one benefit of exercise, which was not however perceived as enough of a benefit for exercise to become part of their adopted pattern of behaviour, prescribed exercises did not make enough of an impact on AS for them to be personally worthwhile:

So what would have to change for the exercises to be worthwhile? I mean spinal exercises?
I think a lot of it is personal motivation really 'cos I think they do help but I still don't do them.
Do they help as much as swimming?
No, I don't think so.
If they helped you more, would you do them more?
Perhaps I would yeah, perhaps I would. [Int J]

The interview with participant F probed deeply into the importance of exercise, and he acknowledged that whilst exercise was boring, the boredom was less important than the ongoing need to exercise. I asked specifically if he could rank exercise in the ten most important things, where would it be? His answer was:

I think it'd definitely be in the top 5 — probably your main thing. It's always in my mind, never thought about what priority, I just know I have to do it... they're there to do me good, so I have to do em.[int F]

Participant J cited a lack of personal discipline as the key determining factor:

You're given a sheet with exercises on – what are the reasons you don't do them every day?
Well it is time and motivation... and also sometimes when you do them, it does hurt a little more than others and it puts you off doing them the next time you do them, you kind of skimp on them, you kind of go through this – right I'm gonna do them everyday so you start doing them, and – oh that hurts a bit, so you do less of that, less of that, and it gradually comes to the point where you're not doing any.[Int J]

A similar response was provided by participant G as to why prescribed exercise was not worthwhile:

So it's not worthwhile doing half an hour a day?

Well you don't feel like it, you come home after a hard day's graft and you had your tea and you sit in the chair with a cup of tea and you're watching the telly Its like a chore if you will that you don't wanna do, and you'll find you make up excuses to yourself not to do them.[Int G]

Peoples' perceptions of the importance of exercise was not static, for example prescribed exercise became more important if other activities were not in place to supplement movement, this person referred to a trigger that would initiate a change in behaviour:

So is it fair to say that because you're doing so much with your children, house, day-to-day stuff, that makes up for the fact that you don't do the exercises on the sheet?

Yes, mmm, I would say so.

Is there any reason when you would do the exercises on the sheet rather than day-to-day stuff?

If I'm extremely stiff, it'll trigger, so I will do it. [Int K]

People's decisions were often complex with carefully rationalised answers given as to how they had arrived at what they considered to be their optimum exercise behaviour, and how this had changed over time with increasing experience of the disease, for example:

Well I was first diagnosed in the seventies, it was quite early seventies, and it wasn't sort of the time where you got the mine of information that you get these days, it was more or less I'm the doctor you're the patient, I'll just sort of tell you I'll give you a name for it, I'll give you some drugs and I'll give you some exercises, if you stay on top of it, you'll probably be ok. I tended to drop the exercises for things that I found more acceptable, like sport, gardening, maintained them I'm not a great one for doing sort of non-productive exercise. I prefer to do something that's got some sort of end product, so if I can get the same amount of exercise digging the garden, bending down pulling weeds out or climbing up a ladder.[Int L]

Other more enjoyable and productive things were more important than exercise:

The exercises on the sheet – you're not achieving anything – I would like to combine keeping supple, keeping fit with productivity as well. I find it difficult to motivate myself to get up, put a mat on the floor and actually do exercises in that way, its not something that I particularly feel motivated to do, I believe I can create the same effect by doing other things more pleasurable.[Int L]

When probed more on this issue, he expanded:

What is it about exercises that you will do but about the exercises on sheets that you won't do?

It's not to do with the net effect, it's to do with the motivation to actually go through the motions of doing it. If it's not sort of competitive or productive I'm not particularly well motivated. [Int L]

Participant N described how he had performed a complex decisional analysis of the optimum frequency of exercise and calculated that exercising twice a week was the right balance between rest and exercise for him in his present situation:

How have you consciously decided over years on twice a week? Have you mixed and matched?

I've done that for some time, I've tried different things.

And is twice a week the best compromise?

Yeah, for me it is, once a week's not enough, I'm too sore, and four times a week like alternate days it would never drop Tuesdays every time, and two days on the run would do me no good. [Int N]

The decisional balance was not only taken in relation to exercise, other aspects of a person's self-management were similarly appraised including: drug therapy, hydrotherapy, group attendance and surgery. These are not presented here.

Summary

People deciding upon how or if to use exercise demonstrated a complex decisional balance which was adaptable and personally effective. This was at the heart of peoples' constructions of the role of exercise management in AS.

3.8.3. Micro and macro behaviours

This section presents two concepts, micro and macro behaviours, which are used to describe the short and long term strategies that participants employed to manage their AS.

3.8.3.1. Micro behaviours

Micro behaviours, as they are presented in this project, were deliberately constructed short term strategies targeted to a particular anatomical area, or undertaken to attain a particular level of function for the day ahead. They tended to be dictated by pain. As such they were a pivotal yet pragmatic necessity. These micro behaviours were often informed by personal experience of the AS journey. Once developed, micro behaviours were viewed by many as operating on an instinctive level illustrating how such behaviours had become such an integral part of their lives:

Are you constantly aware of the status of your spondylitis, good days and bad days, how sensitive are you to that within this behaviour that you've got, are you able to say – well today is a good day so I'll do X?

Margaret: It's a natural instinct what you can do on that day, I don't plan very far ahead.

Denise: No, I don't either. [W1 Focus group]

People described needing to be flexible enough to respond to each day and the symptoms that AS presented them with:

How rigid are you about what you do?

John: You do it on a day-to-day basis, if today's a bad day I just do what it takes... there are all sorts of gadgets you can get to make it a bit easier, but exercise on a strict regime? No I don't do that, but when I feel certain parts of my body stiffening up then I concentrate on that now. [W1 Focus group]

This need to react quickly – often in real time, to their AS with some form of exercise or a deliberate abstinence from exercise was discussed by many focus group participants as a means of coping:

How many of you feel that your exercise is a response to something going worse, or is it something that you do to make it better in the future? Is it a reactive thing or is it proactive?

John: Mine's reactive.

Margaret: Mine is as well. (Mary and Margaret both nod). [W1 Focus group]

Furthermore it was evident that such responses were often directed towards a specific anatomical area affected on a particular day. I posed this question in the Hospital 1 focus group: “Would you specifically target a part of your body if it had got worse?”:

Mary: I'd start doing all the exercises then, but doing a bit more on that specific one...

Ron: We would do the lot, but we'd concentrate more on the neck.

When would you stop doing them, would you decide when to stop or wait until somebody said you're better?

Mary: I'd have to decide myself, you can feel yourself the movement you've got really.

Margaret: I will do the exercises that the physios have taught me if something in particular is hurting, but I also incorporate exercises in the day-to-day things that I do.

[W1 Focus group]

On occasion people described employing micro behaviours to facilitate their activities of daily living for the day ahead. In this respect, although the behaviour was a short term strategy it involved some planning:

John: I'll do ten minutes in a morning, and after dinner I might do a few leg stretches night time. Before I go to bed I'll have a good soak in the bath, do a couple of exercises just to make sure I'm loosened up and am not all stressed out or tightened up when I go to bed.

Bob: You know the consequences if you don't, see if I don't do my exercises first thing in the morning I don't function basically that's what it is.

Anna: It's a start to the day. [H1 Focus group]

Another example came from the second Manchester focus group involving a middle-aged female participant who described how it was necessary on the day of the focus group for her to get out of bed early to stretch and exercise in order to get to the group in time (contrast this with the previous example where the person had made the decision to exercise *before* going to bed – as an example of multiple constructions of reality). She relayed this as something that *she knew* she had to do as part of her day-to-day self-management:

Anna: I mean with all due respect I've had to set the alarm clock early because I need that time, I could not have got up at 9 o'clock this morning and been in the car for quarter to ten, I mean I have set the alarm for quarter past seven this morning to give me an hour to stretch and wake up and shift myself around, and get myself moving and do my exercises before I even try. [H2 Focus group]

3.8.3.2. Macro behaviours

Macro behaviours referred to longer term strategies which incorporated exercise to maintain a level of function for the future that would be acceptable to the person. The ethos of this was summarised well by participant Q who attended for the weekly class and I asked him why he went every week to do the same exercises:

Well I think of it as money in the bank really – keeps me on track for the future. [Int Q]

Macro behaviours were informed by the person's views about, and experiences of their disease journey, and were sometimes, but not always influenced by external factors such as trends in anthropometric measurements provided by physiotherapists. Margaret, for example, at the Hospital 1 group described how she sometimes knew that her measurements were going to be worse, but located such measurements within the overall longer term context of living with AS:

Margaret: I think also sometimes before you come you have an idea what the reasons are of you having a worse measurement, you half expect it but you also know the reasons sometimes whether it be a flare up, or because of circumstances in your life that you've been doing things differently and you can almost expect it and know what the reason are and Hopefully that will come right and you'll be better next time..... and even that you may be able to say – ok I know I'm having a bad time but I know it will get better. [W1 Focus group]

Later in the interview, this discussion went on to explore her understanding of "better". At this point it became apparent that it was the trend in successive measurements that was her determinant of future exercise behaviour, rather than an isolated single anthropometric measurement.

Ian emphasised the importance of maintaining a long term view to any new recruits to the exercise group, again hinting at the construction of a collective consciousness in the AS community:

Ian: I'm interested in what the trend is, as a whole are things going steadily worse, staying the same or improving 'cos quite often you'll say to somebody who starts coming to the class and they are measured, and they are measured in three months and you try to tell them they will go better, better in the first three or four months no matter what they've done 'cos they are aware of what they've got and they'll do something either here or outside about it. [W1 Focus group]

He went on to outline his long term view of anthropometric measurements and was joined in the discussion by John who had a similar view:

Ian: I accept that things progress over time, the actual movement and restrictions will go worse, what I want to see is that if there is any worsening that it is gradual and not suddenly downhill.

John: It comes back to what Ian said, if it's the fourth time this has happened then you'll do something about it, but if it's just the odd one I'll just do whatever exercise until it gets better, that may be a couple of days or it might be a week then its better so I don't worry about it. If it went on longer than that I personally would take more tablets, do some exercise until it's gone, then see what the measurement came up with in six months time. That's as far as it goes. [W1 Focus group]

Figure 3.6 (conceptual diagram 6) below illustrates how the concept of micro and macro behaviours was generated

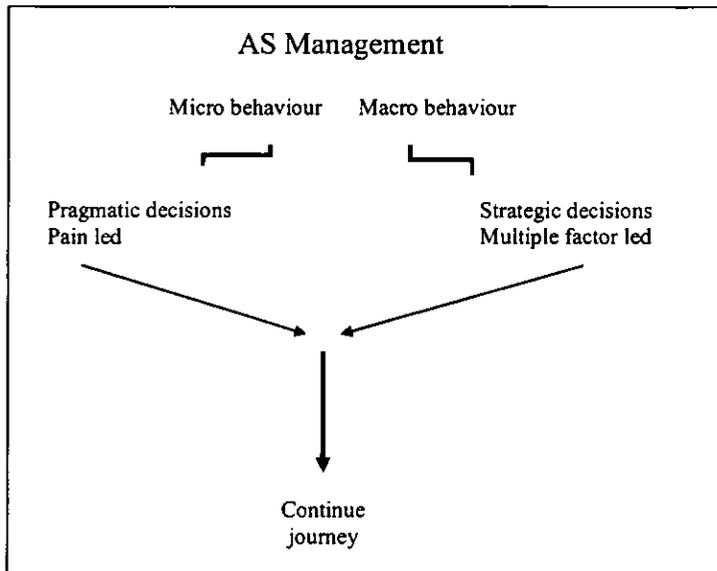


Figure 3.6. The sixth conceptual diagram: micro and macro behaviours in AS management

3.8.4. Summary

People with AS employed both microscopic and macroscopic approaches to their symptoms and AS in their lives, both of these approaches combine and compliment each other to produce an effective means of continuing on their AS journey, they are therefore integral parts of the journey.

3.9. Generating a Model of Exercise Behaviour

3.9.1. Defining model, theory and framework

A grounded theory approach to research aims to produce theory from data, the discussion will engage with this in greater depth, but this section describes the evolution of a model of exercise behaviour in AS and starts with an exploration of the location of a model within a grounded theory approach.

In seeking to locate the model within the methodological approach I begin with an excerpt from a personal communication from Brian Haig who has written extensively on the subject of theory and model generation in the social sciences (Haig 2005a; Haig 2005b; Haig 2006; Haig 2007; Haig 2008a; Haig 2008b; Haig 2008c; Haig in print a; Haig in print b):

...Whether you have produced a theory, a model, or a conceptual framework would unlikely receive a widely agreed upon answer. The terms 'theory' and 'model' are both rather ambiguous in the methodological literature, and they are also sometimes used interchangeably... A theory can include a model within it, though it need not do so. It can also be small or large in scope, with large scale theories sometimes functioning as conceptual frameworks. ... In short, I am suggesting that there is no strong consensus in the literature.

*Personal communication 2007
Brian Haig
Professor Department of Psychology
University of Canterbury Christchurch New Zealand*

Another term that may apply to the end product of this study is that of a concept map. A concept map is a diagram showing interrelationships among concepts (Novak 1995). It can make the macrostructure of information more salient, by providing a spatial representation of a body of knowledge. In many different studies concept mapping has been found to support and promote the exploration of concepts, thinking processes, problem solving, information recall, peer discussion, learning transfer, motivation and more (O'Donnell, et al. 2002). Concept mapping also aids analysis of qualitative research data, specifically within the GT method.

Central to the definition of models is the employment of representation to describe particular aspects of a phenomenon or interactions amongst phenomena. (Haig 2008a) from this point therefore the end product of the results will be classified as a model since it portrays both various aspects of exercise behaviour and their inter relationship to each other.

3.9.2. Generating a cycle of exercise behaviour

This section sets out the steps that were taken in the construction of the model of exercise behaviour in AS and illustrates how each core category described previously contributed to the model.

The model comprises four key elements, these are:

- 1 The AS journey
- 2 Exercise behavioural determinants
- 3 Managing change
- 4 Exercise behaviours

Each of these is now presented and its inter relationship to other elements is illustrated.

3.9.3. Generating the model

3.9.3.1. The AS Journey

Those who are newly diagnosed need to develop their responses to AS, having done so people living with AS use their personal experiences and appraisals of past exercise behaviours and project these onto their AS journey. This permitted rapid and tailored responses to the changing nature of AS. In addition to this they simultaneously possessed micro and macro views of the place of exercise in their lives, and viewed themselves as individuals with individual methods of managing AS with exercise.

The basic structure of the model is therefore a circular pattern of behaviour upon which the patient embarks (Figure 3.7). The reader's attention is also drawn to the appraisal portion of the model which represents the participants' appraisal of cost versus benefit for a particular behaviour; in fact this is an

ongoing iterative process that accompanies all points of the cycle. However, it was felt that the model needed to reflect this process as a distinct entity since it was such an important part of the behavioural cycle.

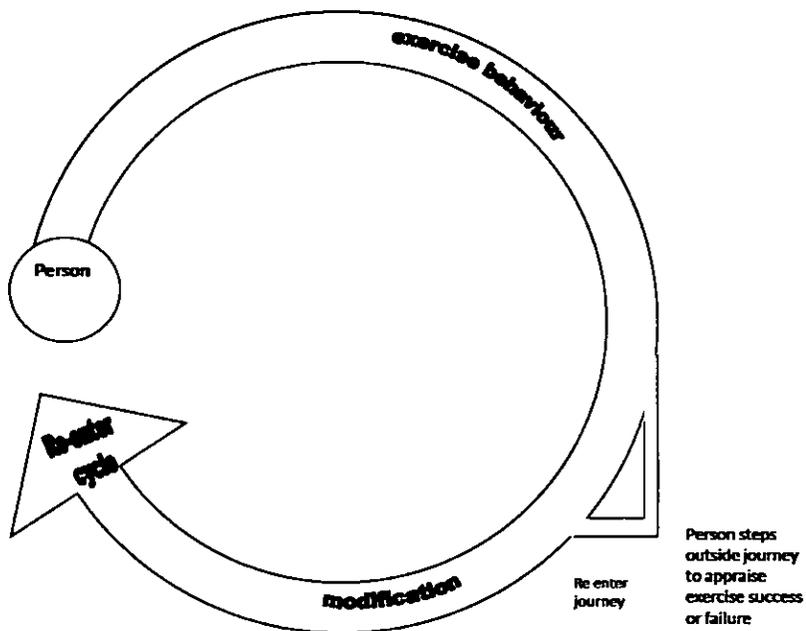


Figure 3.7. Stage 1 of the model the AS journey

3.9.3.2. Exercise behavioural determinants

Once this cycle had been constructed, it was possible to add the factors which determined the exercise behaviour in AS, shown below in fig 3.8 and illustrated sitting within the cycle of behaviour. They all impacted upon this cycle to a greater or lesser degree which is indicated by yellow arrows.

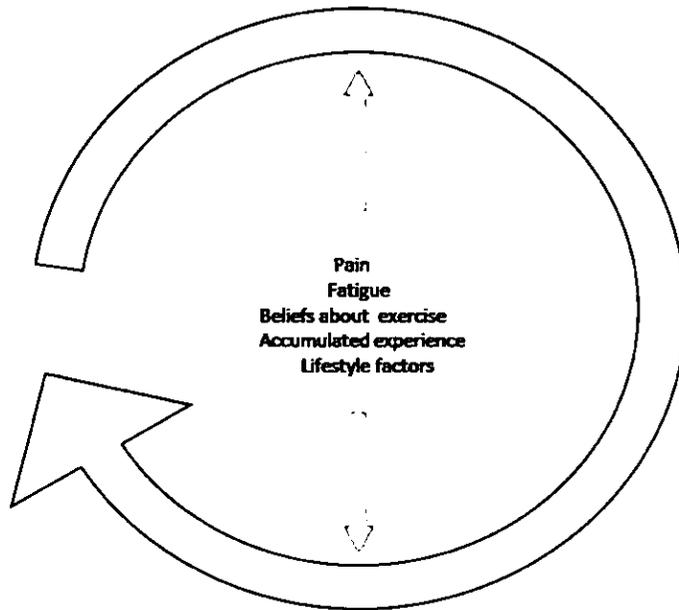


Figure 3.8. Stage 2 of the AS model incorporating the factors which determine exercise behaviour

3.9.3.3. *Exercise behaviours*

The four choices of exercise behaviour were also superimposed onto the cycle, so that the framework consisted of a cycle with four behaviours for the person to adopt, as in Figure 3.10.

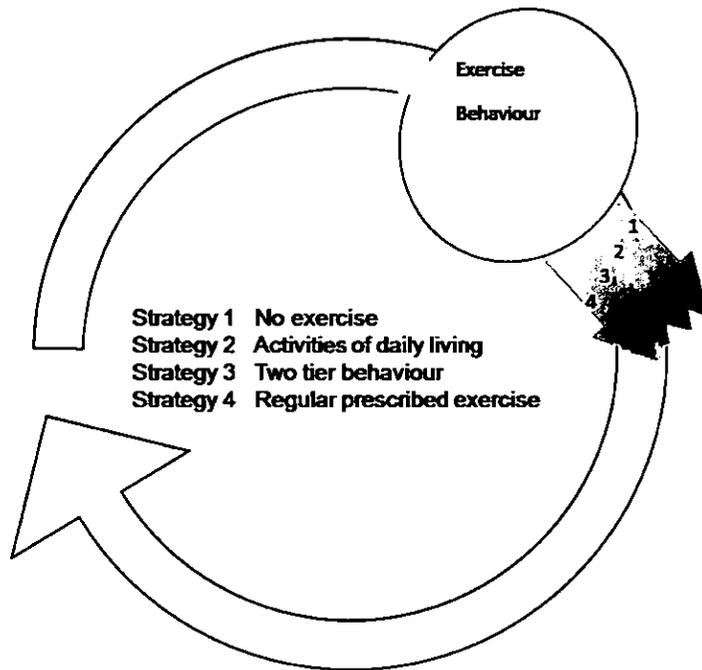


Figure 3.9. Stage 3 of the model with the addition of daily exercise behaviour

3.9.3.4. Managing change

The analysis identified four exercise-related responses to change in AS (figure 3.9). Since change is such an integral part of AS, it was important that the change responses should be incorporated directly onto the AS cycle. Since they could not be isolated from the overall AS journey these responses to change were therefore superimposed onto the cycle. This meant that the framework consisted of a cycle with four potential response options to change.

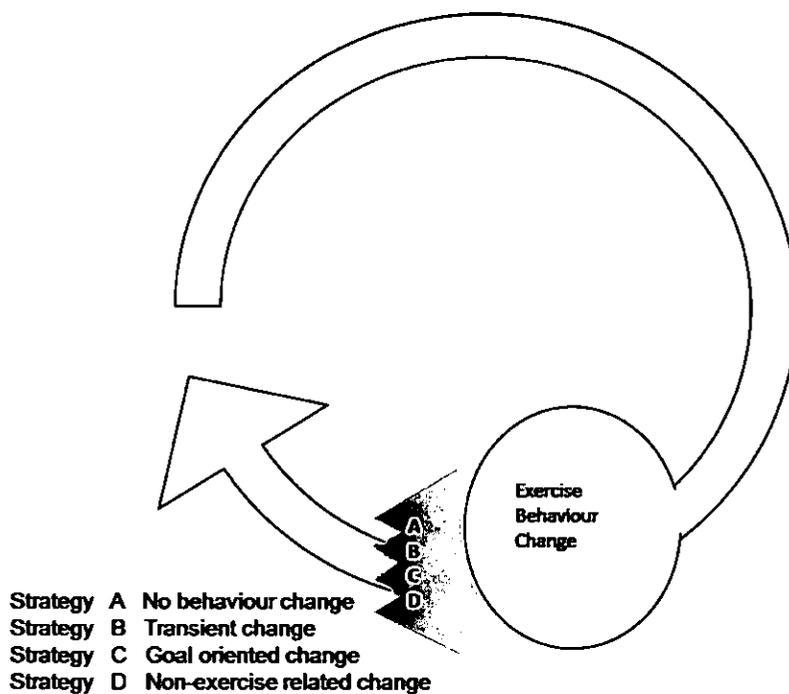


Figure 3.10. Stage 4 of the model with the addition of response to change in disease status

3.9.3.5. *Micro and macro behaviours*

These were also an important part of the cycle since they permitted the person to deal in both the long and short term with their AS, and were therefore added to the overall framework (Figure 3.11). These micro and macro behaviours were used both in times of flare and quiescence and were therefore placed on the cycle separately from the response to change options.

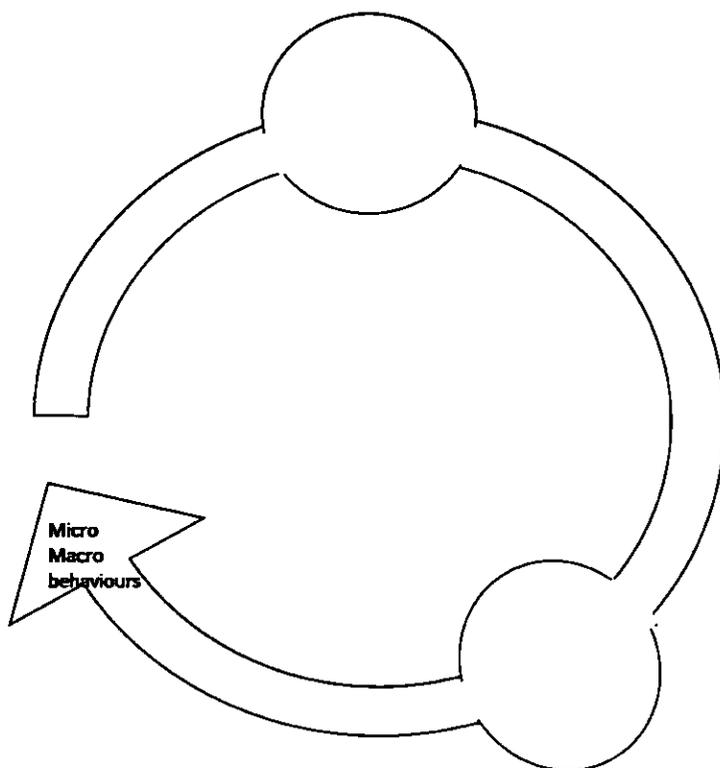
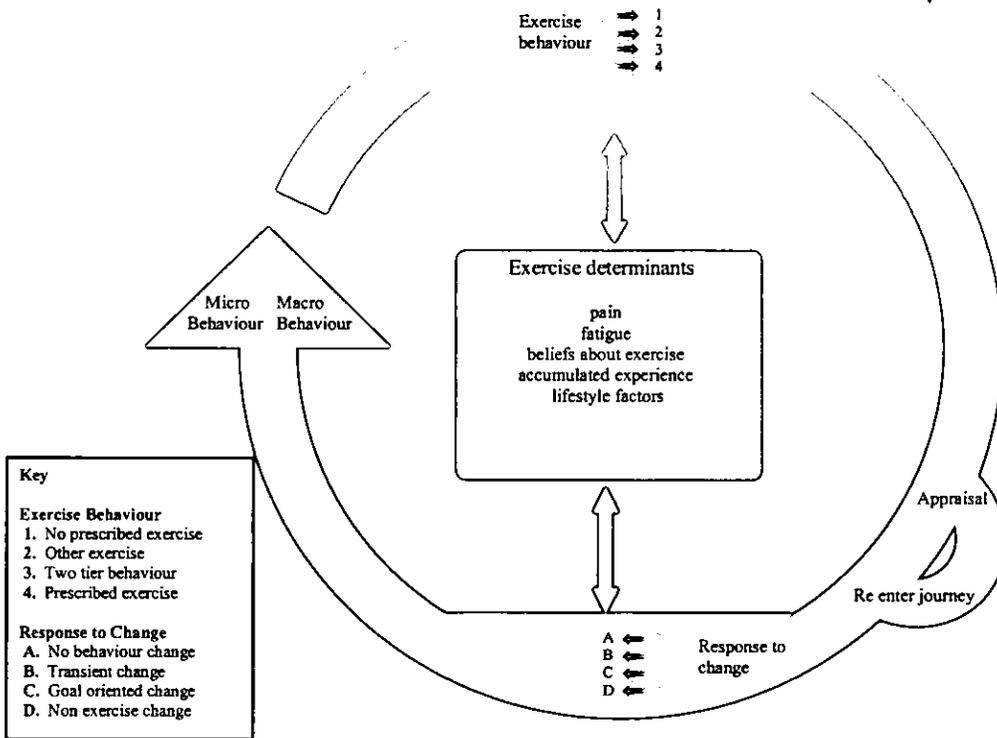


Figure 3.11. Stage 5 with the addition of micro and macro behaviours

The final model is shown on the next page

#

3.9.3.6. Exercise model in Ankylosing Spondylitis



3.10. Some participant views on the model

It is not possible to defend this chapter without incorporating comments from the participants who allowed me into their world to generate the model. I feel a moral obligation to include at least some comments about the model from the people who were in part responsible for its construction. There is also an academic obligation which is now explained below.

The discussion chapter commences with a mapping of this study against GT evaluation criteria (Strauss and Corbin 1990). Comments from the participants themselves are an integral part of this mapping, since evaluation criteria discuss amongst other criteria user understandability (Strauss and Corbin 1990; Charmaz 2006).

One criticism of the conceptual model was that it may be too broad, this was picked up firstly by the patients in the Hospital 1 group, and although the question was rhetorical it does raise an interesting point:

Ian: Is someone going to criticise that for being too broad? I don't know.

How do you mean broad?

Ian: because by incorporating everything and I'm not expert on it, don't pretend to be expert on it, is it possible that some other people would say this is too broad, I clearly think that a lot of people with AS can see where they fit, and I would be surprised if ninety odd percent that come along here can't think oh that's me or that's me (pointing to different parts of the model as he speaks) or those two bits or those two bits, but because everyone can virtually fit into that model is it too broad? [W1 Focus group]

This potential criticism of the model was immediately defended in the same discussion:

Mary: You'd have to probably say that in studies that have taken place we found that a number of patients exercise and a number of patients don't, and a number of patients do their own thing and that's how they manage their disease and you have to find that niche yourself, and it's only yourself that can find it really.
Tom: That's right. [W1 Focus group]

It would be naïve to assert that any single model is perfect or reflects the whole truth of a complex topic such as this, as noted in the earlier chapter on health behaviour theory. The terminology used within the model is something that has always been a double-edged sword, too much broadness negates its clinical utility but the same could be said of a model that was so specific or complex that it was not clinically practical or failed to incorporate the views of most people with AS. Finally a compromise has to be reached, again bearing in mind the original aim to produce a middle range theory (Charmaz 2000), it remains to be seen whether or not this becomes a problem in the future.

It is tempting to attach significance to the positive comments that followed the presentation of the model to patients but it is difficult to assess in a totally impartial way the exact utility of the model in the self-management arena and it was not the remit of this project to do so. Indeed it is hoped that this will form the post doctoral study aspect of the project. Ian at the Hospital 1 group noted the clinical potential of the conceptual model which would take us (patients and therapists):

Ian: Sort of from the theoretical to the practical. [W1 Focus group]

This participant had unwittingly articulated the ethos of the study and outlines one of the criteria for a successful GT study as outlined by Corbin & Strauss (1998).

Some at the Hospital 1 focus group described how the conceptual model would have enabled (and thus empowered) them to describe their exercise pattern to their therapists or consultants in more subtle and

complex terms than the exerciser/non-exerciser categories that people with AS have previously had to rely upon when speaking to professionals:

Mary: I think its all about understanding and the knowledge that they're given when they're diagnosed, about how lifestyles can affect you, and how exercise can affect you and everything, some people are different than other people, why do I not feel like that, you know.

John: That's right, I think in my case if I'd seen the this thirty years ago when I was diagnosed and somebody had explained it to you as you've just done, I would have worried a lot less and got a lot less depressed over years at times if I'd seen this and thought yes I'm following this pattern here so this is going to happen and if I get really bad I'm going to have to do exercise, I'm going to have to do exercises but in the meantime I could get away with[W1 Focus group]

The model may also have the ability to empower the professional who has to impart the information to the person with AS. This comment came from the first Liverpool group:

Tim: If you're sitting down with somebody (as their therapist) – this is from a person with your disease blah blah blah – it would help. [F1 Focus group]

This group ended with a discussion about how the model might allow the voices of previously unheard people to be heard, this was one of the original methodological aims and as such is a good point to conclude the results of the study, adding that physiotherapists currently may not take notice of the expertise that people have gained over their disease journey:

Robert: 'Cos it's information that they (physiotherapists) don't know about, from the horse's mouth, they would have to take note, there's no two ways about it, you know you can't have someone doing a general thing with people from different hospitals putting it all together putting together a rough draft or what ever it is, and then showing them and them saying – oh no. Because I bet they haven't met a hundred people with ankylosing spondylitis. You have, they haven't. [F1 Focus group]

3.11 Conclusion

Using four core categories to organise the data, this chapter has provided insight into the beliefs of people with AS about exercise, the processes they underwent when deciding upon exercise behaviour and the exercise strategies they finally adopt. Semi-structured interviews and focus groups in the North west of the UK enabled the construction of a conceptual model that portrays for the first time the complex and fluid dynamics of exercise behaviour in this variable chronic disease.

Participants in this study responded to a changing disease trajectory by utilising a number of strategies for long- and short-term exercise management, this incorporated ongoing appraisal of AS status with references to past, present and likely future disease behaviours, that were built up as a result of accumulated experience and used approaches similar to cost–benefit analyses to make decisions about exercise behaviour. Placed into the context of the patient journey, four discrete exercise behaviours and four exercise-related responses to changing disease status were also identified. Some of the key determinants of exercise behaviour in AS were also revealed.

CHAPTER 4: DISCUSSION

4.1. Introduction

The overall aim of the study was to increase understanding of the exercise behaviours of people with AS. The specific objectives were:

- a) To obtain in-depth understanding of people's beliefs about exercise
- b) To understand the exercise behaviours that people engage in and factors influencing them
- c) To explore how exercise behaviours change as a person's AS changes.

23 semi-structured interviews and 7 focus groups were undertaken with people with AS and an in-depth analysis of data informed the development of a conceptual model of exercise behaviour in AS.

Participants described the need to predict and respond to a changing disease trajectory and utilised a number of informed exercise strategies for long- and short-term self management. They described a process of ongoing appraisal of their AS status with references to past, present and likely future disease behaviours, and used approaches similar to cost-benefit analyses to make decisions about the most personally appropriate exercise behaviour. Four discrete exercise behaviours and four exercise-related responses to changing disease status were identified. Some key determinants of exercise behaviour were also revealed. This chapter now presents a discussion of the results.

4.1.1. Exercise behavioural determinants

A wide range of factors influence exercise behaviour, for example in cystic fibrosis factors related to exercise compliance have been found to include social support, self-esteem, enjoyment of activity, and

availability of a variety of activities (Prasad & Cerny 2001). Brekke et al. (2001), found that self efficacy in ones ability to perform exercise is associated with exercise adherence in rheumatoid arthritis and illness cognitions have been found to play a part in exercise compliance in osteoarthritis (Hampson et al. 1990). In long term conditions where people are expected to engage in exercise across the trajectory of their illness developing an understanding of such factors is fundamental to the development of effective interventions (Trost et al 2002). However the determinants of exercise behaviour in AS have not, to date been explored and within this study were identified as: pain, accumulated experience, decisional balance, beliefs about exercise, positioning, and lifestyle factors. Each of these factors is now discussed.

4.1.1.1. Pain

Pain is one of the primary symptoms of AS (Elyan and Khan 2006). Moreover due to the changing nature of AS patients experience varying levels of pain (Harper and Reveille 2009). Data from this study have provided insights into how changing levels of pain affect people's exercise behaviour highlighting 3 different responses entitled; enjoyers (people who associated low pain with a rejection of exercise, and living a normal life); protectors (people who employed exercise cautiously, high pain levels were viewed as an indicator that more excise would exacerbate an already painful situation); the die hards (people who believed that an increase in pain must be fought).

Whilst the identification of these responses is intrinsically novel, they require further exploration. Whilst there is no other literature on pain responses in AS to draw upon, there are studies concerned with how people with non-specific low back pain, in particular use fear-avoidance (Macera et al. 1989a; 1989b; Waddell et al. 1993; Crombez 1999). Many of the participants in this project relayed a similar fear of symptom exacerbation caused by exercise, and whilst caution must be taken when making generalisations about AS, (inasmuch as this study also identified a sub group who actively fought pain

increase with exercise) the conclusions of Waddell et al. (1993) and Crombez (1999) bear parallels to the findings in this project; namely that the anticipation of pain developed as a result of accumulated experience may act as a direct determinant of future exercise behaviour (Waddell et al. 1993; Crombez 1999). The participants identified as “protectors” in particular bore strong parallels to the work of Waddell (1993) in that the anticipation of increased pain was an over riding determinant of their exercise behaviour.

Physiotherapy management of AS is a rare example of where people are advised to exercise though pain barriers (OHea 2008). Whilst one group of participants did indeed behave in this way (diehards), insights from others (the enjoyers and the protectors) suggest that therapist’s advice to exercise at all times may not be heeded by some people. Advice to exercise through pain may only serve to reinforce beliefs that physiotherapy is not in touch with their personal situation and may explain the findings in a previous study that some with AS believe that physiotherapy has nothing to offer them (Barlow & Barefoot 1996).

4.1.1.2. Accumulated experience

For people living with chronic disease, informed decision-making is made possible largely by their accumulated knowledge and experiences of their disease and as such is an important component of managing the complexity that living with chronic disease brings into their lives (Price 2007). The project’s key message concerning accumulated experience was that people used their accumulated experience of symptoms and their likely reactions to exercise to inform the exercise behaviours that they implemented. Consequently robust exercise strategies evolved which were adaptable over time as people progressed on their AS journey; these in turn could be used by the person to rationalise their future exercise behaviour.

In addition to gathering advice from physiotherapists and other sufferers, people in this study built up their exercise beliefs over time employing their accumulated experiences of the disease's behaviour, i.e. physiotherapists were not the sole architects of a person's exercise behaviour. Popay and Williams (1996) also recognised the diverse information gathering by people with chronic disease and indicated that accumulated experience is an important part of the self management process. They suggest that this should be more widely recognised when planning therapeutic interventions. This is significant as to date the importance of lay knowledge has not been acknowledged in AS self management; physiotherapists have previously perceived themselves as the expert who imparts information to a person who is expected to undertake exercise irrespective of disease state (Mihai et al 2005). Data from this study suggests that self generated knowledge may be equally important in determining how each person makes sense of exercise. This requires further study however, as earlier sections of this thesis highlighted that some self generated knowledge may be inaccurate. Ultimately the role of the therapist may be to encourage the person to openly discuss their own experiences and how they can use their own knowledge of symptoms knowledge and provide the person with AS with explanations for what they are experiencing.

Whilst it is important that therapists listen to patients, it is also acknowledged that they need to adopt a variety of strategies to encourage honesty from people concerning their long term compliance in chronic illness to obtain accurate patient accounts. For example Helme & Harrington (2003), investigating people with diabetes, suggest that physicians need to be prepared to hear concessions and excuses when they question patient compliance. Helme & Harrington (2003) suggest that therapists working in chronic disease should consider expanding their repertoire to include positive, neutral, and negative-regard strategies. As a result of this study, we may also need to consider acknowledging

patient comments on their accumulated disease experience if we are to more fully understand patient choices and behaviours.

This study's findings suggest that it may be useful to add patient comments on how they have built up a body of experience to future educational literature, leaflets, DVDs to encourage other people with AS to embrace the importance of, their own self generated knowledge which should supplement the equally important advice provided by their therapists. The acknowledgement of using patients as role models maps directly onto the approach adopted within the EPP, a key aim of which is to encourage the use of role models to facilitate self efficacy for newly diagnosed people and encourage subsequent uptake and adherence to long term self management (DOH 2001; Kenndey et al 2005; Kennedy et al 2006; Lee et al 2006). Furthermore, embracing insights from patients about the challenges of managing AS and representing these comments to the newly diagnosed may also mean that people are more likely to give honest answers about their behaviours in the future (DeVita 2001). Such " Negotiated empowerment" as termed by Haidet et al (2006 p326) has been found to be an effective strategy in facilitating patient empowerment and successful long term self management in a range of chronic diseases including arthritis and diabetes (Haidet et al 2006).

Chronic diseases require people to make significant adjustments over time. The literature now provides increasingly refined conceptualisations of these adjustments, acknowledging that the experience of chronic disease necessitates adaptations in multiple domains of the person's life. This adjustment is often referred to as a trajectory (Stanton et al. 2007). This concept, introduced by Strauss in an attempt to capture and describe the experiences and behaviours occurring in response to chronic illness (Strauss & Corbin 1998), goes beyond depicting the physiologic unfolding of disease and encompasses the total organisation of work done over the course of the illness (Strauss and Corbin 1984). The finding in this

study that behavioural trajectories developed as experience accumulated, suggests that the current practice of repeating the same exercise format as a “one size fits all” for people with AS may be ineffective for people with different experiences and at varying points on this trajectory or journey. More longitudinal studies are needed before we can more fully understand the differing needs of people at different points on their disease journey and of those with different experiences of their disease so that we can begin to fine tune our management procedures accordingly.

People accumulate knowledge from sources that are most accessible to them, sometimes referred to as the principle of least effort (Harris and Dewdney 1994). In AS this included self generated knowledge and lay beliefs, possibly encouraged by the patients’ belief that physiotherapy was failing to meet their needs by not providing personally tailored exercise advice.

Initiatives such as the EPP are being carried along by a groundswell of enthusiasm amongst researchers, and service managers at a strategic level. (Kennedy et al 2004). When championed in 2001 by Sir Liam Donaldson the Government Chief Medical Officer GPs in particular expressed concerns that it was an “Anti professional initiative” (Fitzpatrick 2005 p501) which elevated subjective experience and consumer choice over medical science and professional judgement leading to the creation of unaccountable groups of self-proclaimed expert patients. (Fitzpatrick 2005).

This study similarly highlights the need for caution when equating experience with clinical accuracy. Whilst people with AS are experts in the sense that *they* alone experience *their* illness and have an accumulation of knowledge about its behaviour, as this study highlighted some of the beliefs about the disease were based upon misconception thus confusing experience with expertise. For example one participant believed that his AS had been caused by sitting on a stone step as a child, and another that it

had been caused by an accident during military service, both illustrating inaccurate beliefs about causality.

Currently no AS EEP programme exists, however there are moves toward gaining truly grounded information concerning patient experiences that can be used to educate and advise those newly diagnosed with rheumatological conditions (Swift and Dieppe 2004). The findings concerning the accumulation of experience by people with AS support the creation of such a programme, as people in this study were found to be experienced in handling their AS, having accumulated considerable insight into its daily behaviour and its likely response to exercise. People with AS are a useful and currently underused resource in the current climate who need to be more closely involved in the production of educational literature and other resources.

4.1.1.3. Decisional balance

People in this study continually balanced the pros and cons of exercise to inform their subsequent decision about whether or not to exercise. The solutions generated after this evaluation were personally effective yet responsive to changing needs. Their decisions existed on a spectrum, some believed that exercise was never worthwhile; others that it was always worthwhile and one subgroup used activities of daily living combined with exercises to specifically target anatomical regions depending on perceived varying need. Currently there is no literature on these behaviours in AS. The triggers that inform and more importantly alter this decisional balance and in particular this two tier behaviour are not currently fully understood and warrant further study since they illustrate the diverse range of beliefs and sophisticated problem solving ability and may provide greater insight into the actions of people with a changing set of symptoms.

Decisional balance is not acknowledged in current AS programmes which currently advocate adherence to daily prescribed exercise irrespective of changing disease state. (www.nass.co.uk). There is therefore a failure to acknowledge the complex nature of fluctuating symptoms, change in disease patterns over time, and the myriad social pressures and commitments that run alongside a diagnosis of AS, and more importantly influence the choices and decisions made by people with AS. The clinical significance of this lies in the suggestion that therapists may need to devote more time to understanding and exploring a person's decisional balance when constructing a tailored exercise programme, rather than the current typical three or six month interval monitoring at which exercise behaviour is also discussed. Rau and Peterman (2008) concur with this approach, suggesting that therapists need to consider using decisional balance as part of patient management via motivational interview techniques to facilitate long term adherence, in preference to non specific exercise prescription followed by adherence monitoring, which still as OHea (2008) points out dominates AS management programmes.

There is research suggesting that people with other chronic diseases engage in a cost-benefit analysis of whether or not to make use of a therapeutic intervention, similar to the descriptions of exercise behaviour in this study. Home & Weinman (1998) for example undertook a study which evaluated beliefs held about the benefits of taking medication in asthma, renal and cardiac problems. They elicited patients' beliefs about the necessity of their prescribed drugs and assessed the relationships between these beliefs and adherence to a long-term regime. More specifically they assessed patients' beliefs about the necessity of the intervention for controlling their illness and their concerns about the potential adverse consequences of taking it. As a result of their study, Home et al suggest that people make rational responses, and that their behaviours are a product not only of the beliefs about the nature of their condition but also about the therapeutic interventions (Home et al.1997). Home's work has extended previous approaches to theories of behaviour change by introducing the requirement to not

only understand a person's belief about their illness but also their beliefs about their treatment. The next section discusses these beliefs as revealed in this study.

4.1.1.4. Beliefs about exercise

This study recognised that beliefs about exercise in AS played a part in determining a person's subsequent exercise behaviour. A large body of literature echoes this finding in other areas, for example there is a link between beliefs about positive benefits of exercise in pregnancy and amount of daily exercise undertaken (Kraans et al 2005). In eating disorders there is evidence that the belief that one is overweight positively correlates with exercise levels (Ingledeew & Sullivan 2002), and Gecht et al's (2005) study of people with arthritis found that those who were most likely to exercise believed in the positive benefits of exercise. Whilst there is no other comparable data in AS, there is evidence that a key factor in a person's motivation to comply with exercise programmes in another painful spinal condition- spinal injury is a persons beliefs about the importance of and the effects of exercise (Molton et al. 2008).

This study identified and categorised participant's beliefs about the effects of exercise in AS and importantly revealed that despite the best efforts of therapists, not everyone held positive beliefs about exercise. The beliefs identified were divided into three categories; objective benefits of exercise- this was broadly the belief that exercise would result in a positive benefit or change in their AS status; less well defined benefits of exercise- this related to the belief in less tangible benefits of exercise in for example maintenance of body image, control of disease activity, causing disease burn out or maintenance of quality of life, and finally negative or uncertain beliefs -that the belief that exercise made pain worse, caused flare ups, or had no effect.

These findings are relevant to therapists who may be under the impression that their patients will embrace exercise as a positive component of self management. More specifically the finding that there are different belief categories means that we need to reevaluate our approaches towards patients since physiotherapists currently adopt therapist led sessions with no apparent rationale for the approach taken (Leach et al 2009). If we are to adopt truly patient centred approaches then therapists need to discover the beliefs of clients to inform the appropriate educational strategy rather than assuming that everyone will see the positive benefits of exercise. These findings may increase understanding as to why people with AS change or do not change their behaviour when encouraged by therapists to do so and encourage therapists to look beyond the current expectation that feedback of anthropometric data alone will suffice as the trigger to change a person's exercise behaviour (OHea 2008).

Finally and perhaps most significantly, this project found that a person's understanding of what constitutes "exercise" is not always the same as that of their therapists. Previous AS studies have not factored in this discrepancy, and in addition have frequently used compound or non standardised interventions which they have grouped under the title of exercise. It may therefore be the case that previous studies have been asking the wrong questions of people with AS, i.e. by focussing on people's engagement with prescribed exercise their engagement with non prescribed exercise behaviours has gone unrecorded, or have been erroneously recorded as failure to adhere. This finding has the potential to inform future studies, by highlighting the need to operationalise exercise more rigorously than has been the case.

Whilst there is intrinsic value in having for the first time identified categories of belief about the effects of exercise in AS, further study will be needed to build upon our knowledge of their significance in long term compliance with exercise –still the cornerstone of AS physiotherapy management. (Viitanen et al. 1995 ;Van Tubergen et al. 2001; Analay et al. 2003).

Whilst this study suggests the need to reconsider our means of obtaining assessment information *from* people with AS, it also suggests that people with AS may not disclose their true beliefs or exercise behaviours *to* their therapists. It therefore also raises the prospect that therapists may need to re-evaluate the way in which they gather information if they are to fully understand people's behaviour, and also to reconsider the way that they provide information to their patients in an attempt to advise them on the most appropriate exercise behaviour. The next section discusses the concept of positioning

4.1.1.5. Positioning

In this study, peoples' exercise behaviour was based in part on how they compared themselves to others with AS. Clinically this may be a very important issue since the majority of study participants stated that they were not typical, and more importantly went on to use this to rationalise their exercise behaviour. It has been suggested that people intentionally compare themselves with others to reinforce their existing behaviours (Suls et al. 2002). Two types of social comparison exist: upward and downward. *Upward social comparison* occurs with others who are deemed to be better in some way, this type of social comparison occurred commonly in the interviews and focus groups. *Downward social comparison* acts in the opposite direction and is a defensive tendency to evaluate oneself with a comparison group whose troubles are more serious than one's own. For example, a breast cancer patient who has had a lumpectomy may see herself as better off than another patient who has lost a breast (Suls et al. 2002).

To date it would appear that there is only one study in rheumatology that employs social comparison theory. Hooper et al. (2004) used semi-structured interviews to explore coping and feelings of control in

RA. As was the case in this study of AS, a comparison with previous disease states and other sufferers was used by every participant to enhance their sense of control over their condition and foster a sense of well-being. A knowledge of social comparison may therefore be an important strategy in future studies of coping in AS which may investigate the use of social comparison as a therapeutic intervention encouraging people to employ upward social comparison. A large proportion of participants in this study expressed the belief that they were unique, consequently this area may be pivotal to understanding the rationale behind why people with AS do what they do.

It may also mean that therapists may need to re-evaluate their rationale for providing group sessions for management of AS. It has always been held anecdotally that contact with other sufferers with the same disease was a positive experience because of the homogeneity between members, it may actually be the case that AS groups are enabling people to reinforce the belief in their uniqueness and thus their behaviour. Whether this is a positive or negative component of group therapy in AS is as yet unresolved.

4.1.1.6. Lifestyle factors

In this study, lifestyle factors such as change in employment were described by participants as having an impact upon exercise behaviour. Although the factors themselves were often outside the person's control, all participants had developed personally effective strategies to manage their impact, whether this was by maintaining lifestyle activities at a reduced pace or via the use of a continual decisional balance (discussed previously) as a tool to appraise the best self management options in view of the person's lifestyle demands. Whilst a cross-sectional study such as this does not allow definite conclusions to be made as to which specific lifestyle factors were determinants of exercise behaviour, a key finding was the need to employ pacing as a strategy- in terms of frequency and type of exercise that was personally effective.

Nielson et al. (2001) have stressed that “pacing is a poorly understood concept for which there are no available measures” (p. 111). In the literature of the mid 20th century pacing for rheumatoid arthritis (Nichols, 1976; Melvin, 1977) stressed the importance of the “3 Ps” (planning, positioning, and pacing). However, Hagedorn (2000) believes that pacing is a higher level component of problem-solving in chronic disease, mediated by cognition and choices, not simply by physiological demands. Using this argument therefore the decisional balance demonstrated by people in this study may be thought of as an attempt at pacing, involving deliberate higher cognitive decision making processes. For example the person who was about to change employment was proactively considering a change in exercise frequency, and another participant who was a deputy head master, had through trial and error arrived at a pacing solution of attendance one per week at hydrotherapy and twice per week exercise sessions which would change depending on how busy he was throughout the academic term.

Whilst pacing is a widely accepted component of successful long term self management (Birkholtz et al. 2004; Mckracken & Samuel 2007; Gill & Brown 2009) and is taught as an integral part of many EPP programmes, it is not a current feature of AS physiotherapy management. Instead AS is described in educational literature as an enemy to be fought with the same exercises irrespective of disease state. (<http://www.nass.co.uk/>). In this study therefore rather than having been taught pacing by professionals it was a self generated strategy and was in stark contrast to guidelines that had been provided by their therapists. This also warrants further study since it may mean that the advice of therapists (of spartan adherence to prescribed exercise) is either inappropriate or impractical and is very often being ignored by some patients.

As a result of this study, determinants of exercise behaviour have been identified in people with AS. A deeper understanding of these will permit therapists to better comprehend the decisions that their patients make rather than perceiving them as non compliant or failing to cope. Further study is needed to explore the relative contributions of each of these determinants, the interrelationships between them

and the precise effects that each has upon the exercise behaviour. The next section discusses the exercise behaviours revealed by the project.

4.1.2. Exercise behaviours

Four distinct exercise behaviours were identified that people described as being personally effective. These were: no prescribed exercise, where people undertook no exercise; other forms of exercise, which included activities of daily living or recreational exercise such as swimming or walking in place of prescribed exercise; two tier behaviour where people simultaneously employed some prescribed exercise alongside activities of daily living and finally, regular prescribed exercise whereby people regularly and consistently undertook the exercises that they had been prescribed. This has implications for clinicians who prescribe standardised exercises and expect a standardised behaviour to result. The need to recognise variability in exercise behaviours is even more pressing when we consider the significant discrepancies that still exist between clinical centres as to which exercises are provided to people with AS, and how often people are monitored. (Fernandez-de-las-Penas et al 2006)

In AS prescribed exercises are provided at the time of diagnosis in the form of a leaflet and, the contents of this leaflet and therefore the exercises remain unchanged throughout the course of the person's disease (OHea 2008). The professional has the expectation that the exercises will be adhered to, unaltered by the patient in the belief that these prescribed exercises will affect the disease outcome. Regular anthropometric monitoring is undertaken by the physiotherapist and these measurements are often used as the basis for monitoring whether or not the patient has been "doing their exercises". However, definitions of exercise vary (Dishman and Sallis 1994), and the word "exercise" has such heterogeneous meanings that it is difficult to place the evidence concerning exercise within the context of prescribed exercise in AS. Furthermore this project has highlighted that "doing exercises" may not have the same meaning for therapist and patient therefore risking erroneously branding patients as non compliant.

People with AS interpret standardised exercise information in different ways to produce their own unique yet reasoned and categorisable exercise behaviour. The important message therefore is that people with AS should no longer be divided into a dichotomous split of being either compliant or non compliant. The study for the first time illustrates that people's behaviour is far more complex than was previously thought albeit anecdotally by therapists. The key to the successful future management of people with AS should be centred around identification of the particular sub group of exercise behaviour into which that person falls, and subsequently making an informed joint effort to facilitate exercise within that particular niche.

It may be useful in the future to build up a body of knowledge over time to gain data on exercise modifications as they are generated and create a resource documenting the rationales behind these adaptations in order for us to tailor our interventions based upon greater insight into the decision making processes of people with this disease. We would then be able to claim greater moves towards mutually agreed therapist-client goals which are now so important in Physiotherapy (Bassett & Petrie 1999), particularly in AS where the goal of therapy is synonymous with facilitating appropriate exercise behaviours. If we do not heed the beliefs and comments of patients, we cannot expect the therapist-client experience to improve (Arnetz 2004). Many people in this project chose their own form of exercise or activity in preference to exercise as it was originally prescribed. Whilst we still possess no information on whether or not these behaviours produce any superior improvement in range of spinal movement, we should acknowledge that people interpret and utilise exercise information in different ways and that clinical interventions should be informed by an understanding of how patients are applying and interpreting such information.

Having discussed exercise behaviours, the next section discusses the study's findings concerning people's responses when their AS changed.

4.1.3. Response to change

In clinical practice there is the expectation is that when disease activity increases people will change their exercise behaviour.

The people in this project indicated that they managed change in disease status in one of four ways: no exercise behaviour change; transient change whereby they undertook exercise for a limited period—usually a few days as a result of being told that their measurements were worse or a personal perception that their condition had changed; goal oriented change where people strove to attain a quantifiable improvement in anthropometric measurement or functional ability, and finally a non-exercise related change where people would increase their medication or seek out non exercise treatment. These strategies, even non - change were informed by a person's perception of their symptoms, assessment of the effectiveness of exercise, and willingness and ability to incorporate exercise into everyday life.

This insight suggests that therapists should work alongside patients through their disease journey to discuss with and help them to identify the most appropriate strategy to manage such change. For example if a person is identified as being goal oriented then it may be more appropriate to emphasise anthropometric targets whereas those who admit to making no behavioural change or a non exercise change are less likely to respond to such an approach. Further study is needed before we can identify the most appropriate approach to treatment mapped against a person's individually preferred change strategy. Research to date on preferred management of change and decision making by patients is cross sectional (Protheroe et al 2008), however longitudinal studies are required to investigate whether

preferences change over time and are related to treatment choice, adherence, and health outcomes. As Corder et al (2009) have recently pointed out.

*"Determinants of behaviour change...are likely to change constantly throughout life, but it is largely unknown which determinants are most important at each life stage...Better evidence on determinants of behaviour change throughout the life course would contribute greatly to understanding when and how to intervene to help create and sustain lifelong healthy behaviour patterns in those who have the most to gain from adopting them."*p213

There is currently no data concerning changes from one exercise behaviour to another in chronic disease, since the literature currently concentrates on the adoption of and adherence to new exercise behaviours (Corder et al 2009). Broadstock et al. (2000) comment that our approaches to understanding the decisions that our patients make must be flexible enough to incorporate the variety of simultaneous decisions with which they are faced in chronic disease. This is particularly true in AS where decisions are not simply about whether to exercise or not, but related to the persons' appraisal of the need to undertake change or not. They may include decisions about whether the need for change in exercise is a long term need or a "one-off", whether such change is considered to be high risk (i.e. would exacerbate pain), whether it would be likely to lead to an immediate or delayed improvement, or even any improvement at all. Whilst we currently possess no data concerning the effectiveness, or otherwise, of these different exercise behaviours this study has acknowledged their existence and provides a platform for further study.

The decisions that people in this study made about changing their exercise behaviours were taken in a particular social context specific to each person. The person considers these parameters to follow or ignore his or her therapist's advice, or to make a decision based upon their own experiences.

Essentially, in AS, decision making involves the person surveying a fixed set of alternatives, weighing the likely consequences of each, and seeking the best personal solution. In the literature, the most

common associated theory concerning patient decisions is that of the maximisation of subjective expected utility (Savage 1954); This involves the perceived value of undertaking a behaviour multiplied by the probability of it occurring. This can be directly mapped onto the findings of cost benefit analysis that was such an important concept in this project. Decision models have often been advocated as a tool to understand and explain patient decision making (Bohanec et al 2000; von Winterfeldt and Edwards 1986; Pauker and Kassirer 1987). These assume that people's decisions are based on well-defined, consistent and quantifiable preferences (Fischhoff et al. 1980). However, AS is unpredictable, and consistent decisions about exercise may not be possible when people are expected to rely upon standardised exercises in a changing disease with unpredictable flare-ups and remissions.

In addition to the consciously planned decisions made about changing exercise behaviour, some participants also described an automatic decision making processes, and there is some evidence in the literature to support this; including the use of short-cuts, rules of thumb, gut feelings and intuition (Fiske and Neuberg 1990; Louis and Sutton 1991; Klein 1989. Maheswaran and Chaiken 1991). Automatic decision making was evident in the interviews and examples focus on decisions about when to start or tail off exercise following a relapse. This subconscious decision making may be an important aspect of self management since it has been suggested that people lose confidence in their intuitions when asked to think analytically about them (Wilson and Schooler 1991; Ubel and Loewenstein 1997).

The lack of literature concerning how people manage change in chronic disease remains problematic for those investigating long term compliance since patient participation in decision making is regarded as being a desirable or even essential component in effective self management (Sutherland et al. 1989).It is important that therapists and researchers begin to identify the parameters that contribute to the persons ultimate exercise behaviour, rather than assuming that reliance upon and feedback of anthropometric data alone will instigate behaviour change. This study also illustrates the need to

conduct more qualitative research nested within RCTs where there is the suggestion that non-compliance might be occurring if we are to truly understand why this is the case. For example by investigating the narratives of people with arthritis and diabetes Haidet et al (2006) found that their patients' illness-management strategies were explained by four thematic story elements in dynamic interplay with unique variations for each individual revealing a level of complexity to patients' healthcare participation that had not been previously described.

This project has for the first time provided insights into the decision making processes that people with AS undergo when deciding if, when and how to exercise when their disease changes. It suggests that people managed change in four ways using complex decision making processes that may be consciously planned or at sub conscious levels. Lack of knowledge about patients' decision making processes in a changeable disease has been identified as the missing ingredient in research into long-term therapeutic regime adherence (Donovan 1995), and we must continue to make attempts to fill this gap if we are to include patients as partners decisions about their therapy. Without such information, the belief systems behind peoples non-compliance will continue to go unacknowledged and misunderstood.

Ultimately the findings of this study were used to inform the production of a conceptual model, the next section explores the key attributes of what constitutes a model in the literature.

4.1.4. The model

Of each particular thing, ask what is it in itself, in its own construction?

Marcus Aurelius 121-180 AD

The model and thick description provided portray for the first time a “plausible story” of exercise behaviour in AS. The model will also evolve in the future as further theoretical sampling is employed; and as other parties attempt to use, replicate, refute, or refine it. Further refinement could inform the development of a more tailored approach to exercise in AS and produce a planning tool that would be useful for facilitating decision making in those with established AS by giving them encouragement and insight by using comments of people who have had experience of living with the same disease. Following further work, the model may have applicability to people more recently diagnosed with AS.

There is no consensus in the literature on what constitutes a model, a theory, or a conceptual framework (Dubin 1978; Whetten 1989; Haig 2005a; 2005b) and the terms chosen are often dependent upon the researcher (Gioia and Pitre 1990). Dubin and Whetton (1989) believed that the researcher who generates a model should initially err in favour of including too many factors, in the knowledge that over time ideas will inevitably be refined, whilst maintaining the delicate balance between parsimony and comprehensiveness. It is important to acknowledge that the model generated by this study is still developing and will continue to be refined as further work is undertaken.

Dubin and Whetton (1989) suggest that it is important to ask why a model should be given credence by researchers, clinicians and patients. In this study, the methodological approach taken -constructivist GT inherently addressed issues of clinical, academic and service user credibility (Charmaz 2000; Coyne &

Cowley 2006). It was also important however that the researcher should acknowledge findings of commonality with existing health behaviour theory. The categories and model in this study were generated using grounded theory principles which by definition permit freedom from existing hypotheses or frameworks, it would however be academically naïve to ignore the existing body of health behaviour work. This is not a straightforward task, chapter 1 suggested that whilst many social cognition models exist, they have not been rigorously and systematically compared against one another to determine whether one offers a superior explanation of behaviour. Furthermore their constructs are often non specific and therefore not testable and the conclusions resulting from their application are often true by definition rather than by observation (Ogden 2003). Ultimately a single study or theory can provide only a limited representation of a complex phenomenon, and it is with this caveat that the model and results generated by this study should be viewed.

For example, it could be argued that participants comments bear parallels to some elements of The Theory of Reasoned Action (TRA) (Ajzen and Fishbein 1975) in that their behaviours are rational and make systematic use of information to inform their exercise behaviour, as exemplified by the specific responses that resulted as a consequence of being aware of their own pain levels.

Using the example of this study's findings concerning pain once more, elements of the Theory of Planned Behaviour (Ajzen 1985) could equally be said to be present. Participants in this study held beliefs about the likely impact upon pain of a given exercise behaviour and, participants used these likely impacts to inform their future exercise behaviour, going on to develop three categories of belief about how to respond to changes in pain levels. A further component of the theory of planned behaviour was also found in this study where participants also possessed beliefs about the presence of factors that

would facilitate or impede performance of the behaviour (in this case exercise) and the perceived power of these factors . The Theory of Planned Behaviour would term these control beliefs. In this study, however they were referred to as behavioural determinants. This also highlights a pitfall of social cognition models in that different terminologies may be used to represent similar phenomena, (Noar and Zimmerman 2004) making meaningful comparison difficult as outlined in chapter 1.

At this stage of the models development and due to the cross sectional nature of the work, whilst possessing some characteristics of other models, it does not align closely to any specific one (with the possible exception of the Stages of Change Model which is discussed below) and further work needs to be conducted.

More than any other of the social cognition models, the model generated in this study bears most parallels to the SCM discussed in chapter 1. Whilst the numbers of participants in this study was small it is possible to see where some of the concepts championed by the SCM may be tentatively mapped against the model generated in this study. It is important to engage with the rationale for this mapping primarily this being that there is now evidence that transitions between most stages of change may be reliably predicted thereby providing potential targets for management interventions, (Arden & Armitage 2008). Horowitz (2003) similarly identified 32 applications of the transtheoretical model to pregnancy and sexually transmitted disease prevention, and concluded that the stages of change held much promise for the development of self management interventions.

The basic foundation of the SCM is that people move through successive stages during the process of a behaviour change. The SCM has staunch proponents and also unshakable antagonists. On one hand, the model has a substantial following amongst investigators and clinicians buttressed by prolific literature

while on the other hand there is serious discontentment amongst many scholars regarding the precision and application of the model. Specifically, limitations of the SCM have been suggested in terms of its oversimplification, arbitrary sub division of stages and its use of fixed time-frames to distinguish between stages neglecting to appreciate any gradual change in behaviour. (Bandura 1977a; Budd and Rollnick 1996).

The literature concerning the exact determinants of progression between stages of the SCM is not consistent. Whilst cross-sectional analyses have generally found that self-efficacy and decisional balance show linear differences across the stages of change (e.g. DiClemente et al., 1991; Herzog, et al 1999; Prochaska et al., 1994) ,longitudinal analyses designed to predict stage transitions have produced more mixed findings (e.g. de Vries & Mudde,1998; DiClementa, et al 1985; Velicer, et al 1999). For example, in the domain of smoking, Dijkstra, Tromp & Conijn (2003) found stage-specific SCM determinants for stage changes except those from contemplation, while Herzog et al. (1999) could not predict stage progression in smokers from 10 SCM variables.

The SCM implies that a central goal for health education and promotion should be to promote forward transitions through the stages to attain lasting behaviour change (De Vet 2005). Insight into stage transition determinants is therefore necessary if we are to develop and evaluate stage tailored health-promoting interventions in conditions such as AS. It is important to engage with why the SCM bears particular parallels to this study. Firstly as was found to be the case in this study, non linear behaviour patterns incorporating temporal dimensions existed, similarly a key component of the Stages of Change Model is its incorporation of cyclical rather than linear patterns of behaviour implying that phenomena occur in various directions over time.

Secondly, the stages of change model construes the process as progression through a series of stages which are now discussed in the light of the findings of this project to further illustrate the parallels with

the findings of this study. Fig 4.2 below commences this with the superimposition of the stages of the SCM onto the conceptual AS model.

3.9.3.6. Exercise model in Ankylosing Spondylitis

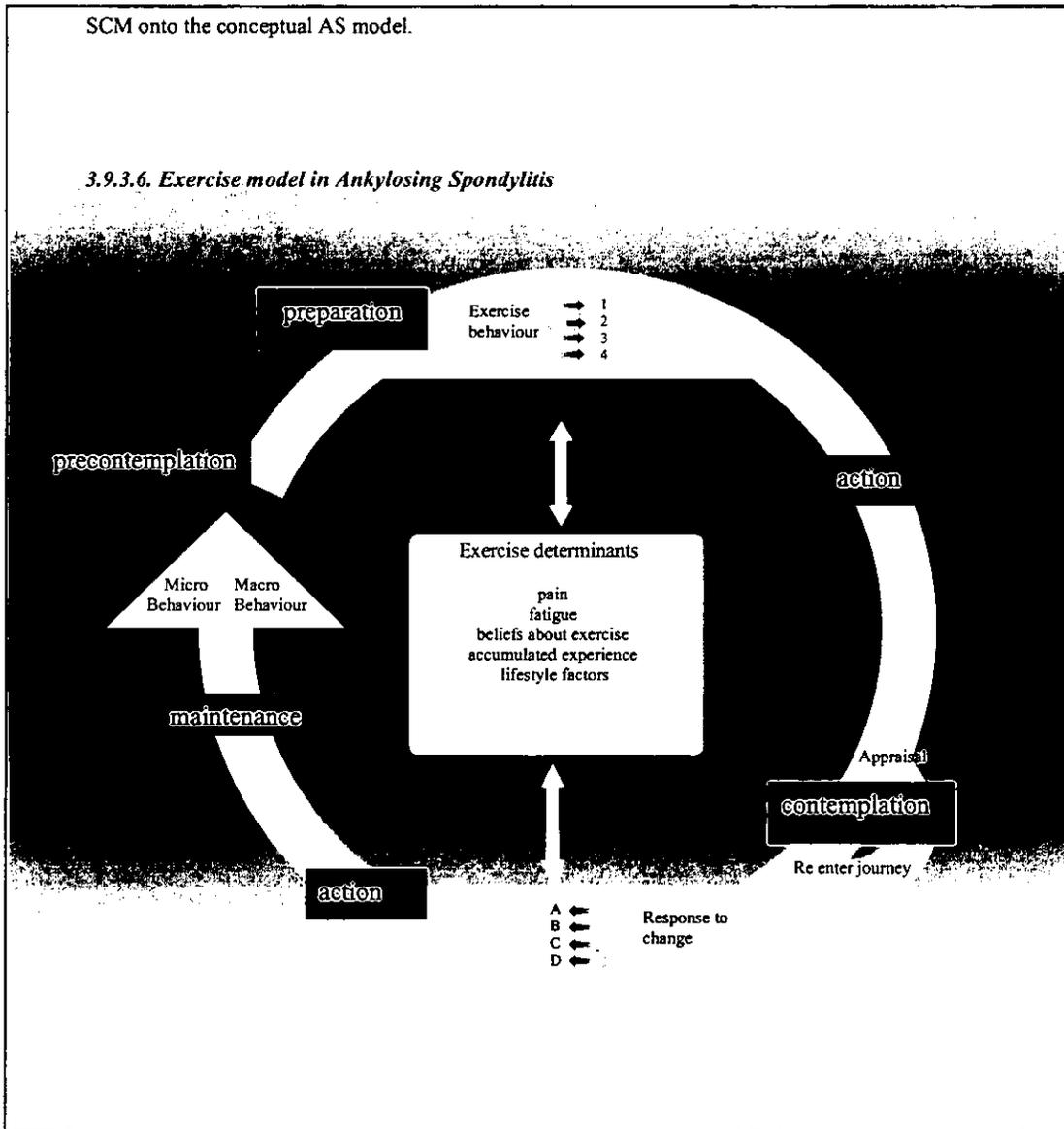


Figure 4.2. Mapping of stages of the Stages of Change Model against this projects model.

The following section presents the reader with examples of both resonance and discordance with each of the stages of the SCM and uses these to propose some interesting questions about strengths and limitations in current AS physiotherapy practice.

Precontemplation- the stage in which people are not intending to take action in the foreseeable future. In De Vet et al's (2005) Delphi study, respondents strongly agreed that the transition from precontemplation to contemplation was determined by awareness-related factors such as awareness of the personal relevance of changing an unhealthy behaviour; this is possibly explained by the positioning described by participants in this thesis. The continual re-evaluation process of change also found to be important by De Vet et al (2005) – is also an element found in participants in this AS study, reinforcing the view that as a consequence of the changing nature of AS, people are required to exist in some degree of precontemplation.

The precontemplation stage of the SCM has particular parallels with the sub group of people in this AS study who described no need to change their behaviour (i.e. no action) following assessment by their therapist irrespective of measurement results or therapist comments. In addition to times of disease flare as previously noted, this precontemplation may also be important in AS during its quiescent periods which requires (from the perspective of some people) no exercise or change in exercise behaviour. Current AS exercise programmes however are not designed to acknowledge individuals in this precontemplation stage and are therefore not matched to their needs; that is, they imply that people should *always* undertake prescribed exercise, irrespective of the state of their disease or perhaps more importantly their state of mind.

Contemplation - the stage in which people are intending to change in the next six months. Some people in this study did indeed indicate such long term intentions to change their self management which

would incorporate this six month figure; for example the participant who had just changed occupation and as a result was contemplating the need to change his future exercise behaviour , however people also described short term micro behaviours –whereby contemplation could be seen to be occurring on a significantly shorter timescale, for example a person undertaking exercise several minutes immediately after a long car journey. This is further evidence of the limitation of the arbitrary figure of six months commonly employed by the SCM.

According to Glanz et al. (1997), people in the contemplation stage are not ready for traditional exercise programmes, Velicier et al (1999) found that raising the cons (of smoking) resulted in movement from precontemplation to contemplation, therefore it is logical to assume that raising the cons (of not exercising) may similarly be an effective strategy in AS education sessions.

De Vet et al (2005) found that perceived control was predictive of progression from the contemplation stage, meaning that interventions should be targeted at people in this stage who are low in perceived control. This suggests that the concept of control should be investigated in future studies of AS exercise behaviour.

Whilst it could be argued that people in this study managed an inherently changeable condition with constant and ongoing contemplation, this is not acknowledged in current AS self-management approaches, which advocate that people with AS should undertake prescribed exercise at all times (O’Hea 2008). The current approach by physiotherapists is to prescribe exercises at the initial appointment, and expect unchanging adherence from the outset.

Preparation - the stage in which people are intending to take action in the immediate future. Individuals in this study employed simultaneous long and short term approaches to self management ranging from intended behaviours within the next several hours to many months into the future, so it is not clear how “Immediate future” would fit into the SCM. However, according to the SCM, these individuals have a plan of action, and according to Prochaska (1997a) they are the people who should be recruited for action-oriented exercise programmes. In the case of AS it may be that the exercise determinants revealed by this study are the key to entry into this preparation stage. For example a person who was contemplating a change in employment may now be able to use the model to identify this as a trigger that may require them to prepare for a change in exercise behaviour and to put an action plan in place rather than waiting for a retrospective enforced exercise change that a change in employment necessitated.

Action - the stage in which people have made specific modifications in their lifestyles within the past six months. In the action stage, the pros outweigh the cons. (Prochaska et al. 1985; Prochaska et al. 1991). In the same way that it has been argued above that people with AS are continually contemplating, It could be similarly argued that people with AS are continually in the action stage since they continually have to battle (take action against) their AS, and the modifications to their lifestyle are part of an ongoing process rather than a stage per se. The action stage is also the stage where vigilance against relapse is critical (Velicer et al. 1998; Callaghan 2007). In the case of AS the ongoing vigilance permeating many of the discussions in this study may be as important as blind adherence to exercise programmes. Velicer et al (1999) found that shifts towards the pros of a particular behaviour become very important during the transition from preparation to action stages of the SCM. It may therefore be very important at this stage transition that expert patients with AS are recruited to discuss these pros and act as act as positive role models in AS management.

Implementation intentions represent a means by which preparation might be translated into action. Implementation intentions are *if-then* plans, which specify both a critical situation (“if”) and appropriate behavioural response (“then”) that become linked in the person’s memory (Gollwitzer, 1999). Consistent with this and with direct parallels to the finding of this thesis, studies show that these intentions can operate beyond conscious awareness i.e. when the critical situation is encountered, the appropriate behavioural response is initiated automatically (see Gollwitzer & Sheeran, 2006).

Maintenance - The stage in which people are working to prevent relapse and are increasingly more confident that they can maintain their behaviour. Adherence with exercise is known to be poor in the long term (Dishman and Buckworth 1996; Raglin 2001; Ashe et al. 2007), and even in AS which has improvement with exercise as one of its diagnostic markers, only two of the people interviewed in the project unswervingly maintained prescribed exercise. There is no evidence that maintaining exercise in AS decreases the number or intensity of flare ups. The definition or even existence of a maintenance stage of the SCM is therefore uncertain in AS, yet maintenance is at the very heart of the efforts of therapists in AS self management. The Delphi study undertaken by De Vet (2005) stressed that the action–maintenance transition was perceived to be determined by feedback-related issues like feedback about success, and feedback from respected others. If this is also found to be the case in AS, it would reinforce calls for the continual monitoring and praise of people with AS by both therapist, experts and peers in relapse prevention. Conversely it may be the case that relapse prevention (as defined by the SCM) is perhaps not an appropriate construct and it may be the case that there is no such thing as a maintenance stage in AS. Whilst there is currently no other research specific to AS in this area, data on people’s self-management in type 2 diabetes, HIV/AIDS, and MS concur strongly with the findings of people with AS in this study; that is, people with a chronic disease who have to maintain long term

behaviour undergo logical decision making processes whereby they first learn, then fine tune, and finally evaluate their own self-management. This evaluation (as was the case in this study) is a complex product of professional and personal opinions and behaviours that they have themselves created over the course of their experience with the disease (Thorne et al. 2002). Thorne added that this appraisal cycle always occurs within the context of the person's particular disease trajectory, hinting therefore that whilst there are set parameters and processes that a person with chronic disease undergoes, we must be aware that the individual nature of that disease will impact upon the choice of self-management behaviour. This makes the study concerning AS all the more relevant since there is currently no other information about long term exercise maintenance from the patient's perspective.

In summary, the AS model can be mapped against the SCM. However, discrepancies exist and a great deal of further work needs to be undertaken in this area before any unequivocal conclusions can be made about the place of the AS model in the wider context of social cognition models and health behaviour theory. Nonetheless we now possess tentative evidence suggesting that people with AS may reside in different stages of the SCM and therefore they require different physiotherapy management strategies. Furthermore this superimposition of established theory (SCM) and newly evolved (AS) model may add to the credibility and clinical usefulness of both models. It may bridge the gap noted by Brug et al (2005); in that whilst many social cognition theories explain behavioural intentions or motivation well, they are less well-suited to predicting actual behaviour or behaviour change.

4.2. The project in the context of Grounded theory

The adoption of grounded theory analysis and the use of diagrams in the analytical process informed the production of a model portraying exercise in the management of AS. Ultimately this model must be judged against a benchmark for Grounded Theory. Strauss and Corbin (1990) proposed four criteria for what constitutes a “good” Grounded Theory which are outlined and discussed below:

1. Fit – the theory should fit the phenomenon, and be faithful to the everyday reality of the area.
2. Understandability – the theory should provide understanding, and be comprehensible to both the persons studied and others involved in the area.
3. Generalisibility – the theory should provide generality, include variation and be abstract enough to be applicable to a wide variety of contexts in the area.
4. Control – the theory should provide control, in the sense of stating the conditions under which the theory applies and providing a basis for action in the area.

4.2.1. Fit

This study was undertaken exclusively with people who have AS. Although on a small scale, presentation of the constructed model both as a whole and as fragmented core categories to its original architects confirmed that the model is one that faithfully illustrates their “story” of exercise in AS and fits the comments of the participants in the study.

4.2.2. Understandability

There is limited indication that people with AS understand the model (see section 3.9.3 participant comments). The evolving model was also shown at the AStretch /NASS national meeting to chartered physiotherapists with extensive clinical expertise in managing AS, and was received positively. The

model has also been received positively by student physiotherapists. Further work, however, is needed to assess its understandability and therefore clinical utility to wider ethnic groups, those in different geographical locations and those newly diagnosed with AS.

4.2.3. Generalisability

Whilst this model reflects a middle range theory, it also incorporates the flexibility in exercise behaviour shown by people with AS. The model evolved from work with a wide range of people with AS although claims about its generalisability to wider ethnic populations or to those newly diagnosed cannot yet be made. Further work will assess whether or not the model will be generalisable to people with newly diagnosed as well as established AS.

4.2.4. Control

The unknown aspect of the study currently lies in its predictive capability. Participants who were shown the model commented that it would give newly-diagnosed people a degree of control over their exercise journey by providing a grounded summary that they could map their behaviour onto, using the experiences of those with established AS. Since no newly diagnosed people were included in the study, this is an area needing future exploration. In terms of forming a basis for future action, the model will be used as a platform for further study recognising the need to adapt and modify it as future research findings emerge.

4.3. Clinical relevance of the work

This study has provided insights into the role of exercise in AS from the patients' perspective, and provides the academic and clinical communities with a base from which to build our understanding of this important component of clinical management. Specifically this research has recognised, categorised and visually portrayed the discrete yet adaptable behavioural pathways adopted by people with established AS.

Clinicians now have evidence that suggests that in AS, peoples' responses to the need to exercise do not simply fall into categories of compliance or non-compliance; rather their exercise behaviours have temporal and fluid components, and are informed by beliefs about exercise, current disease status, past experience, projected future management of their own condition, and current lifestyle demands. It is also important however that those clinicians are able to see from the model that AS exercise behaviours can be categorised and follow logical processes with set parameters and determinants.

The work recognised and engaged with peoples difficulties in adhering to inflexible, prescriptive exercise regimes in AS. Participant comments reinforced the view that long-term exercise needs to be realistic, tailored to the person and consequently practical. Consequently our definitions of what the therapist understands by exercise and our views on compliance may need to change.

The three key findings of the study, the determinants of exercise, exercise behaviours and responses to change in AS all have the ability to inform future clinical practice in three ways:

1. By highlighting the need for comprehensive assessment that encompasses all aspects of a person's life not just their clinical status – working within a biopsychosocial model of

assessment with the need to acknowledge that a wide range of factors will impinge upon behaviour and should be recognised and addressed in future clinical management

2. By contributing to the understanding that exercise behaviour is far more complex than compliance or non-compliance – that people make sense of information in unique ways, applying it to their own contexts and adapting it as their lives change.

3. By highlighting the need to develop our understanding of how people respond to change and how needs may also change across the trajectory of an illness. This is true of any chronic illness but in particular in AS, which is a fluctuating variable impairment that brings its own challenges to a person trying to make sense of self management and how they can use exercise in the most effective way.

The model generated from this study may, with further refinement, provide a useful teaching tool for students and newly-qualified physiotherapists as an accessible template for planning interventions, for those who may not have previously encountered AS as a clinical entity for those who are setting up new AS services, or as an example of GT in physiotherapy research. For the first time clinicians may now be able to sit down with their patients and use the model as a focal point for discussions or a starting point to jointly construct treatment plans for people with AS.

An anticipated future clinical use of the model is in motivational interviewing (Miller & Rollnick 2002) which is a client-oriented method for enhancing motivation to change by exploring and resolving

ambivalence. This approach is now being used in a wide range of chronic conditions including type 2 diabetes (Clark & Hampson 2001), and more recently fibromyalgia (Ang et al. 2007).

4.4. Study Limitations

No knowledge is complete or perfect.

Carl Sagan

It would be naïve to suggest that following a single study such as this we now possess a complete understanding of the behaviour of people with AS. Successful qualitative research is ultimately linked to the skills of the researcher; and whilst my skills as a researcher improved a great deal during this project and continue to improve, early pilots and interviews suffered from the researcher's tendency to interrupt the participants rather than allow them freedom of expression. This had its roots in my days as a history-taking clinician and over-adherence to the interview schedule. Furthermore whilst every effort was made to ensure academic rigour, the need for transparency meant that during some of the interviews and focus groups, participants may have been aware that I had been a Chartered Physiotherapist. It is unclear how this might have impacted upon discussions.

Throughout the study no psychometric data were gathered, and whilst this was not one of the projects aims, in hindsight it may have been useful to gather data on, for example, locus of control or depression and anxiety since they may have an impact on a person's ability to undertake or sustain exercise (Arai & Allison et al, 2005; DeMoor et al 2006). Further study might seek to identify any links between psychometric data and specific exercise behaviours.

The comments made by participants in the final focus groups about the model were unanimously positive, and whilst this was reassuring, caution must be exercised, particularly when the participants

have freely admitted to deception to health care professionals and themselves in other aspects of their behaviour. The question of data saturation remains particularly troublesome, in particular the lack of data from people with early disease and those from ethnic groups .

The methodology accessed a cross-section of exercise behaviours, and whilst the project permitted participants to describe their past, present, and future behaviours, anything other than current behaviour is subject to an undetermined degree of recall bias, and therefore a change in exercise behaviours over the course of a person's illness cannot yet be clarified until further longitudinal studies are undertaken. In addition, although this was a multi-centre study, the clinical centres were all in the northwest region of the UK and consequently claims about the generalisability of the results cannot be made until further explored in other areas of the country.

The number of focus group participants did not meet the ideal number proposed in the methods section. This was unforeseen and beyond the control of the researcher (bad weather played a part) however, whilst numbers were lower than desired the level of discussion and engagement within those groups suggests that the group process was not inhibited by low numbers (which is the main concern).

This study aimed to provide a thick description with conceptual depth and a middle range theory that some believe is difficult to attain with purposive sampling, in as much as it results in premature closure of a study and lack of conceptual depth of any model generated (Benoliel 1996). Conversely Holloway (1997) argues that sampling can be purposeful at the outset in a GT study. In this work purposive sampling was advantageous in that the deliberate selection of participants with particular characteristics aided the development of theoretical sensitivity and generation of the theory. Purposively selecting groups where a known phenomenon existed and within which there were subtle differences in exercise behaviour actually was therefore a strength in this study.

4.5. Conclusion

There are a great many dedicated therapists who devote their lives to improving the management of AS and it is Hoped that, this study will help in a positive way towards improving the service that they provide. In recent years there has been a groundswell of interest in disease self-management and increasing acknowledgement of the challenges that chronic disease presents to both sufferers and carers, its effects on every aspect of a person's life, and the need to research the processes of adjustment to it (Rainer 2002). This study adds to the groundswell and increasing emphasis on self-management, the current focus is on mutually agreed client-therapist goals, and the consequent need to understand the decision making processes that people with chronic diseases such as AS use to inform this self-management.

The World Health Organisation has expressed the need for people with chronic disease to be informed about effective strategies to manage and maintain behaviours and adhere to exercise programmes, hence this project is particularly relevant when tailoring the current approach to exercise prescription in AS.
([http://www.who.int/chronic_conditions/implementation/framework/en/.](http://www.who.int/chronic_conditions/implementation/framework/en/))

Although professionals frequently refer to the concept of patient empowerment, responsibility for self-management lies not with health professionals but with the patients themselves. Nearly all decisions that affect patient outcomes are made by the individual (Cradock 2004). However, without a grounded and detailed insight into the complexities of people's exercise behaviour we cannot develop and implement the client-centred therapies that they deserve. This project has added to our knowledge and proposes a

model that has the potential to be further developed and used to explain and predict exercise behaviour with people with AS.

At the outset of this study it was my intention to gain insight into the behaviours of people with this devastating disease. My journey has been a fascinating exploration and has provided great insight into the lives of people with AS and how they manage it on an ongoing basis. The people who took part in this study relayed tremendous willingness to help my in the study and were articulate in the extreme, I thank them for allowing me access to their lives.

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APPENDICES

Appendix I.

Summary of survey of AS exercise group attendance

A randomised retrospective survey of ankylosing spondylitis patients is presented. Data was obtained from the Hospital 1 Physiotherapy Department ankylosing spondylitis database, and coded to preserve patient anonymity. One Hundred physiotherapy records were audited (18 female 82 male.) representing approximately 1/4 of the total client base.

Aims and objectives

1. Obtain demographic data on the ankylosing spondylitis population.
2. Establish frequencies of attendance at the weekly ankylosing spondylitis group.

Demographic data : mean age 46.1yrs(Std. Dev. 11.89), mean time elapsed since diagnosis 9.5 yrs(Std. Dev. 8.63 yrs). Mean attendance frequency for the exercise group was 3.4 times per year (Std.Dev.8.12).

Results showed that 33% of patients did not attend the group during the year long period, and that non-attendance at the group could not be explained by geography alone since 52% of non-attendees live within 10 miles and 29% within 5 miles of Hospital 1.

The data suggests that patient gender and age do not appear to be factors in the behavioural differences. Weak negative correlations were found between time elapsed since initial diagnosis and attendance ($r = -0.145$) and between attendance and distance from Hospital 1 ($r = -0.164$)

The results will be used as a baseline for further study into determinants of health behaviour in the ankylosing spondylitis population. Further study in the form of qualitative interview is indicated for deeper insight into determinants of this behaviour in the ankylosing spondylitis population. Three attendance frequencies are postulated based upon the data.

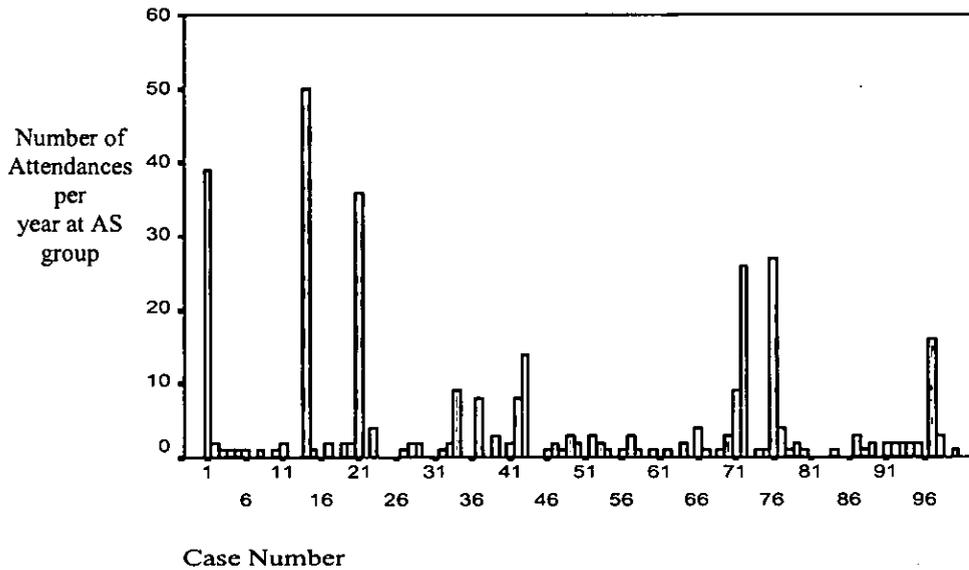


Figure A1. Individual AS group attendance frequencies in one year period.

For the 100 subjects in the one-year period sampled, the population was divided into three category clusters based upon their yearly AS group attendance:

- Category 1 0 attendance during the year
- Category 2 1-5 attendance during the year
- Category 3 5+ attendance during the year

Conclusion

33 % of the sampled population did not attend the Hospital 1 AS group during the 1 year period sampled. The reasons for this behaviour could not be ascertained from this study, however, it was possible to state that these differences could not be explained by geographical distance since 52% of these non-attendees lived within 10 miles and 29% lived within 5 miles of Hospital 1. The data suggested that gender and age did not appear to be factors in the behavioural differences. Three categories of attendance were postulated based upon the data.

Appendix II. Invitation to attend for interview

Dear Sir/Madam

I am writing to ask you if you would be willing to participate in a research study which I am conducting in conjunction with the University of Central Lancashire Postgraduate School of Medicine and Health, and Hospital 1 N.H.S. Trust. The study aims to gain a better understanding of how people manage Ankylosing Spondylitis and the way in which affects their lives. If you agree to take part in the study we would ask you to take part in one interview which would take between one and one and half hours and would be tape-recorded. The interview can take place in your home or at Hospital 1, whichever is most convenient to you.

Please note:

This will not in any way affect any treatment/therapy that you are receiving at Hospital 1 Hospital.

There are no right or wrong answers in the interview.

You may withdraw from the study at anytime.

You will be free to discuss your condition in confidence.

Information that you will give will remain confidential and you will not be identified from the research.

We may contact you in the future to discuss the results of the study

Thank you in anticipation of your co-operation.

Yours sincerely

Stuart Porter (Researcher)

The research to be carried out has been approved by the Local Research Ethics Committee appointed by the Health Authority. This does not imply any endorsement.

Appendix IV. Focus group - Patient information and consent form Invitation to take part in a research study

Study title *Determinants of exercise behaviour in Ankylosing Spondylitis*

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.'

What is the purpose of the study? This is a study which aims to give us a deeper understanding of how people manage their ankylosing spondylitis.

Why have I been chosen? You have been chosen since you are registered on the hospital Ankylosing spondylitis database.

Do I have to take part? Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given an information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part? You will be invited to take part in one group interview with six to eight other people with Ankylosing spondylitis that will last approximately two hours. Myself and another researcher will also be present and will lead the group. The discussion will last approximately two hours and will be tape recorded although when this is written down later, you will not be identified by name. The reason for this group discussion is to gain understanding about the way people manage their spondylitis and to exchange and discuss ideas about this. We will also show you the results of some previous research to see if what we have found in another hospital is also true in your own case.

What do I have to do? You do not need to change anything about the way in which you already manage your ankylosing spondylitis.

What are the possible risks of taking part? There are no risks since this is not a treatment based research project.

What are the possible benefits of taking part? The information that we get from this study will help us to treat patients with Ankylosing spondylitis better in the future.

Will my taking part in this study be kept confidential? All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it.

What will happen to the results of the research study? The results of this study will be published in the form of academic journal articles, the final PhD thesis and presented to patient groups, but you will not be identified by name in any report/publication.

Who is organising and funding the research? This research project is part of a PhD that I am undertaking at the University of Central Lancashire, My employer (the University of Salford) is funding the research

Who has reviewed the study? This study has been checked by the Research Ethics Committee at the University of Central Lancashire and the Rheumatologists and Physiotherapy staff at your Hospital are fully aware of, and support this project.

Contact for Further Information Stuart Porter Lecturer University of Salford Tel (0161) 295 0039 e mail stuartporter@aol.com Thank you for taking part in this study.

You will be given a copy of the information sheet and a signed consent form to keep.

Appendix V. Consent form focus groups Hospitals 2 and 3

Title of Project: *Determinants of exercise behaviour in Ankylosing Spondylitis*

Name of Researcher: Stuart Porter

Please initial each line

I confirm that I have read and understand the information sheet dated 4th October 2005 for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that sections of any of my medical notes may be looked at by responsible individuals from the University of Central Lancashire or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

Name of Patient	Date	Signature
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Name of Person taking consent	Date	Signature
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1 copy for patient; 1 copy for researcher; 1 copy to be kept with hospital notes

Appendix VI. Interview Field Notes

A

Sept 2000 39 yr old single teacher whose symptoms developed in a way that was similar to her father who also had AS, meaning that she had demanded a B27 blood test. She now uses her father as a first line of information and the physiotherapists second. She was articulate and very motivated to attend the hydrotherapy part of the group although she discussed at length the fact that there were two components to the group, one who were more interested in the social than the physical benefits her job (which she shied away from) and one who went to the group to “work”. Her work as a primary teacher meant that she had to make many adjustments to the height of objects in her workplace; before the interview began she showed me examples of this in her home e.g. a kettle on a raised stand. She also commented that she would be having a sleep after the interview since this was the only way that she coped with the tiredness that the AS caused.

C

Feb 2002 this 58 year old lady lives in a bungalow with her retired husband, she is a retired teacher. Before the interview her husband was particularly keen to tell me that in his opinion, she was gradually getting worse in terms of pain and suffering. She was extremely kyphotic, with very little neck movement and appeared to be in some discomfort in the low chair in which she sat. She and her husband do not have any children and she is the sole carer for her Mother, this has caused her some emotional stress over the past few years. Before the recording she told me that she was hopeful that her brother would soon be moving in with her mother and that this would ease the physical and emotional caring demands. She incorporates modified exercises into her daily life and as her default strategy and she is a keen gardener. Mid way through the interview she became tearful and I stopped the recording, she was upset about the combination of having to deal with the AS and her mother, but after five minutes she was adamant that she wanted to continue the interview. I also found this rather upsetting. After the interview we discussed hobbies and she showed me her genealogy records which she has traced back to the 17th Century. My overall impression was that she believed that she was deteriorating but not at a rate which would cause her to change her behaviour. She was however keen to impart her views about management since she had been misdiagnosed and mismanaged for many years.

D

Feb 2002 This is an interview with a 46-year-old man who was married with 3 children, he lives 2 miles from Hospital 1 From the outset he appeared fit and well and had no obvious limitation of spinal movement or deformity. He seemed to be in some denial, example – when asked about the Internet he became animated about the potential of this but then added that he had not looked due to fear of what he might discover. He did not rate spinal assessment as being especially useful in terms of informing his future exercise behaviour actually stating during the interview that he felt the group’s arrangement was “deplorable” He had issues with the format of the group assessment and exercise sessions, when asked to expand on this further he talked about how embarrassing it was to stand topless in a busy gym against a cold metal cabinet to be measured. He discussed this both on and off tape. The interview was interesting in that he seemed very happy to answer questions but I had the feeling that some answers were rehearsed or deflected from my original question. He contradicted himself in that he complained about the lack of access to information, yet admitted that he was afraid to learn more. This interview highlighted how social interactions may bias results, when this interview transcript was examined by the principal supervisor it became clear that my reactions to this man were not as open as they had been with the other participants, (It had been unaware of this at the time) possibly because of his “anti- physio” approach. This was one of the early people I interviewed who did not undertake traditional exercises and I believe that my approach to interviews changed radically after this interview when I had time to reflect on his opinions and comments.

E

Feb 2002 Interview with a married man of 46 with 3 teenage children, one of whom has AS and was interviewed immediately after this interview. The interview was shorter than usual due to the fact that Mr E now said that he had no pain or symptoms whatsoever, all this despite the fact that he was extremely kyphotic, appeared to be fused in the lower cervical and thoracic spine and had to sit with his head in his hands for a large part of the interview. He frequently referred to the current approach to physiotherapy management of AS as “not active” and was dismissive of the effectiveness of current management of AS. He was extremely keen to stress to me that his son should exercise since it was not too late for him (the son) who had been diagnosed in the last year. This caused some ethical difficulties in that the father wanted me to recommend exercise to his son on a one to one basis during the forthcoming interview. I explained to the father that this was not possible since I was not there in a therapy capacity, and that a discussion with his physiotherapist would need to be undertaken- the father understood this.

F

Feb 2002 Interview with a 46 year old divorced man with 2 children who was living at his sisters house at the time. He had a very pronounced Wigan accent making interaction and transcription difficult. His main reason for continued regular home exercise was stated as the desire to remain physically straight in appearance i.e. the cosmetic and body image aspects of exercise. The interesting thing about this gentleman was his zealous adherence to prescribed exercise every day which stemmed from his being told on one occasion that this is what he should do. His reasons for undertaking this related to maintenance of his overall appearance and posture. It was also interesting to note that he had joined a local arthritis care group but not NASS although he was aware of the existence of NASS, he could not articulate his reasons behind this.

G

Feb 2002 Interview with man who lived with his wife and 2 children approximately 8 miles from Hospital 1 He was self employed and had had a busy day at work, [manual work] his neck appeared stiff although I did not have chance to see him move a lot. During the interview, a £5 note fell out of his pocket onto the floor and he struggled to pick it up. He did not attend classes because of the new time of the class. (3pm whereas it had been 4.30pm) His reason for enjoying the class was the motivation, freely admitting that he did not push himself as hard at home as in a group setting, this in itself justified his group attendance in the past. After the recording, he told me that he longed to find fellow sufferers in the area with whom he could exercise.

H

March 2002 Interview with a 39- year old married businessperson. This interview was conducted in the physiotherapy department at his request. This did affect the context of the discussion slightly. He reassured me that the reason for this was geography as the Physiotherapy department was on his way home from work- he had just commenced a new managerial job. He has a wife and four - year old son. For the three years following his diagnosis he attended the Hospital 1AS group every week, gradually tailing this off. He does not do spinal exercises but attends for 6 monthly assessment, he was clear that should the need arise he would recommence daily exercise, indeed he felt that this might be the case as a recent promotion now means that he will be doing less physical work, this had been considered as a form of exercise in his old employment.

J

Feb 2002 This Interview was with a single 39-year-old female who lives alone, she was diagnosed with AS as a teenager and has always been sporty, particularly enjoying badminton and football. Before the interview I noticed that the house was extremely cold and felt damp- although this may have been because she had only just come in from work and not put on the heating. This seemed at odds with her comments on the benefits of heat and warmth. We talked about the journey and then she moved on to talk about her job in the benefits agency and that she had only just got in from work .Her working hours are a major problem to her at the moment and is causing her a great deal of tiredness. Although she appeared to move freely she propped up her lumbar spine with pillows during the interview, she told me that she had recently had pleurisy. She said that she was very sporty and often referred to fitness when asked about spinal mobility exercises, the cost-benefit analysis for her came down to the fact that the social and competitive side of badminton outweighed the two days of pain that invariably followed every game, yet she did not feel that the prescribed spinal exercises were worthwhile. After the recording she talked about her nervous breakdown being related to the death of her mother 2 years ago. Interestingly she had researched malignant melanoma in depth at local libraries and Universities to learn more about her mother's illness but has not done the same for her own AS.

K

March 2002 Interview a 31-year-old mother of three, although pleasant, she proved a challenge to interact with and subsequently interview, appearing rather blasé in her answers and often simply saying, "I don't know" to my questions without volunteering any further information. This was in a rather deprived area of Wigan and the home was in some disrepair. Before the recording, she told me that she had recently had a bad experience in a local physiotherapy department where she had been given high impact gym work, which had made her joints very painful for some time. She spoke highly of the therapy staff at Hospital 1and was particularly grateful for the fact that they had put her "back on the books" following failure to do so by her GP. She gave me the impression that she did not want to learn any more about her spondylitis, which may have explained her short answers. Considering this, it is not clear why she agreed to be interviewed although on reflection I believe that this may be due to her loyalty to the staff at Wrightington.

L

March 2002 Interview conducted with 55 year old man who was divorced, interviewed just prior to discharge from 10 days intensive therapy and injections to the costochondral joints. He recognised that his condition was now deteriorating and quite a large amount of time was devoted to this and the discussion about how he would now change his behaviour, particularly start swimming, since the cost of not so doing was too great. The setting may have stifled free speech in this interview as the patient was about to be discharged from the ward.

M

April 2002 Interview conducted with a lady in her home, her husband came in and out of the interview at different times before the interview they asked me about where I was doing my research and told me that they had been to an arthritis care meeting a few days earlier on the developments in the management of rheumatoid arthritis. This person seemed reluctant to expand her answers and frequently looked across the room as if searching for approval from her husband who came in and out of the room intermittently. At the end of side one he came into the room and talked about how his wife occasionally became "tongue tied"

N

April 2002 Interview with 49 year old deputy head master who is a regular attendee at the group he was articulate and well motivated to attend almost every week. This gentleman by his own admission is something of ring leader trying to motivate new patients to maintain attendance at the group. This gentleman was the most articulate and also the most pro exercise person that I interviewed. Off tape he discussed his concerns that funding for the as group would be pulled in the near future.

O

November 2002 Interview undertaken with a man who does not attend the Hospital 1 group, this gentleman was an expert patient in terms of his self medication with drugs. Whilst he was articulate and happy to talk it was clear that exercise in any form did not feature on his list of priorities for self management. Any change in symptoms were handled by changes in medication which he had discussed in depth with his rheumatologist, pharmacist and ophthalmologist for a prolonged period. I found his answers very pragmatic and refreshing in that he exhibited none of the guilt that had been evident in some of the other non exercisers when asked about their failure to exercise.

P

April 2001 This is a 62 yr old gentleman. Before the interview we talked about difficulty parking outside his home and the fact that his wife had just passed me on the street walking the dog. He experienced symptoms for many years before requesting a rheumatological opinion. We also discussed his daughter who was a nurse just about to embark on a post graduate course. He also was keen to let me borrow some printouts given to him by a fellow regular group attendee downloaded from an American Internet web site. His stooped posture was highlighted several times and he is able to recall his tragus to wall measurement clearly which is a test for stooping posture. He has had one in-patient admission which was investigative/diagnostic then subsequently therapeutic in nature. This in-patient session coincided with the end of his working life. His spondylitis is (in his opinion) stable and he does not adhere to exercise sessions during the week but he is a very regular attendee at the AS group. He has not had a flare up for one year. Interestingly Brian stated that on the rare occasions he missed the group he would supplement his week with extra exercises. Although he is a very regular attendee he admits that during a three month absence post hip surgery, his measurements had not deteriorated as much as he would have expected, interestingly this has not diminished his attendance at the group.

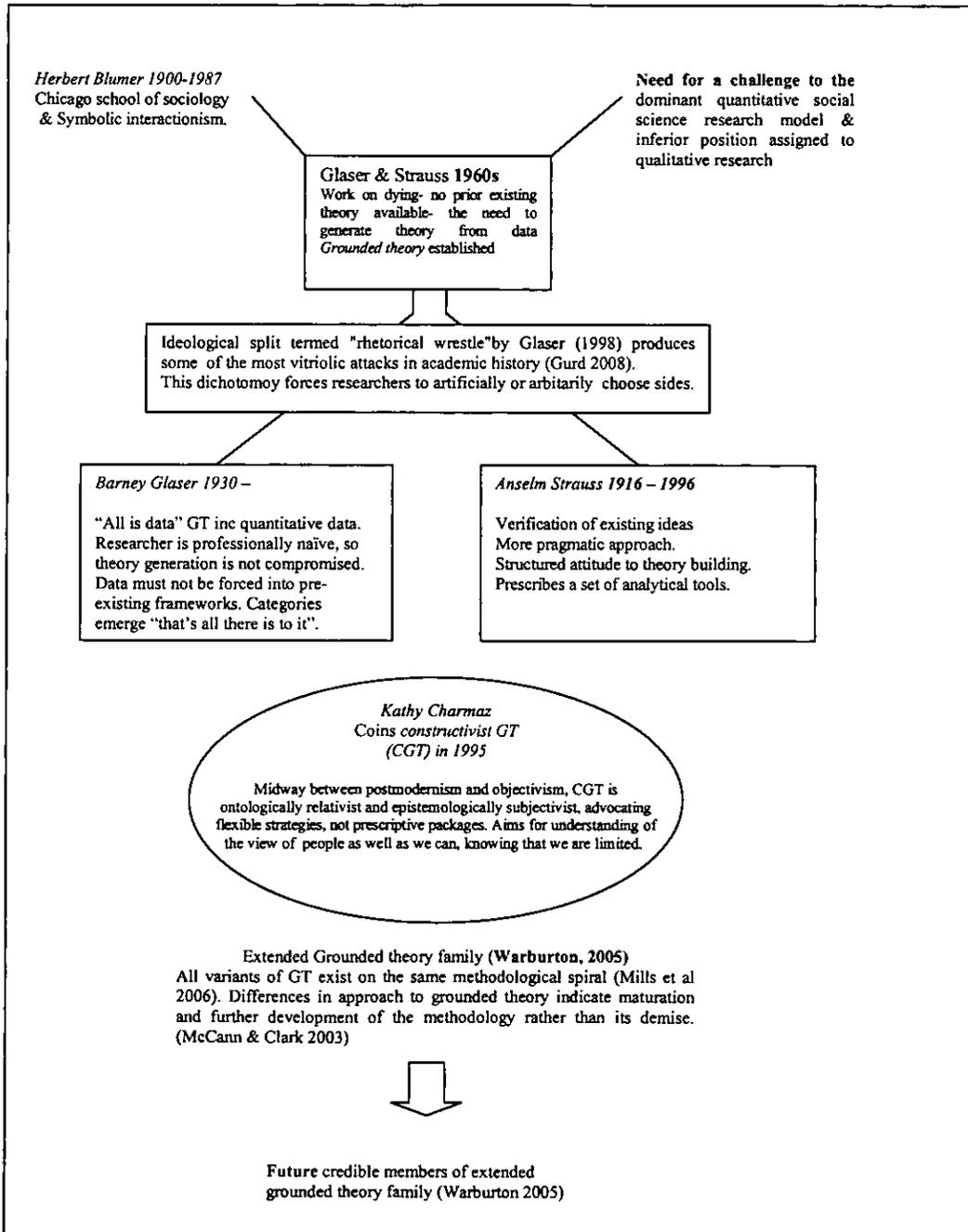
Q

April 2001 This gentleman is a 40 year old electrician has not worked for the past 2 years owing to bilateral hip replacements, performed 14 and 3 months ago. He is married with three children, his wife works whilst he looks after his children, who were out of the home at the time with a relative whilst the interview took place. He was pleasant and co-operative, although he did not volunteer information and although his answers were often brief, he was not afraid to answer questions put to him. The interview was curtailed as he was not happy to discuss his condition in front of his youngest son. He does not attend the Hospital 1AS group but believes that he copes well. From the outset it was clear that he had a marked kyphosis and virtually no cervical motion. Conversations about exercise were consistently described in relation to his employment as being his exercise, he blamed not working for his decrease in spinal movement and expressed no regret at not adhering to "Physio" exercises, making it very clear that if anything, these exercises exacerbated his pain and stiffness. He discussed this both on and off tape. Before the recording he discussed the positive impact of a recent in-patient admission, describing the value of meeting fellow sufferers.

R

April 2001 This is a middle aged married man with two grown sons, cheerful from the outset, he was very articulate and happy to discuss his feelings and his philosophy about his condition. He rarely attends for assessment and never attends the AS group. He was rather stoic about the severity of his symptoms despite a lack of spinal mobility which was evident from the moment he had difficulty opening the door for me when I arrived. The discussion ended with a conversation and tour of Mr Bs garden and the pleasure he gained from maintaining it and a discussion relating to Mr Bs work and how he was involved in formulating a staff data protection policy. This followed on from a discussion earlier when Mr B had been given the information/consent forms. This gentleman had a real interest in my research project and we discussed it at length after the interview had formally ended.

Appendix VII. The origin and development of grounded theory



Appendix V111 the stages of the project.

