



**‘Giving a voice to the voiceless’:
The lived experience of health-related
quality of life in Bangladeshi patients with
ankylosing spondylitis**

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Abstract

Background

This study aimed to explore the lived experience of health-related quality of life in ankylosing spondylitis (AS) among Bangladeshi patients who live in a deprived area of London. Ankylosing spondylitis is a complex systemic rheumatologic condition which is often characterised by severe disability and impaired health-related quality of life. Ankylosing spondylitis in Bangladeshi patients is under-researched, compared to the abundance of studies on health-related quality of life in other communities.

Methodology

In order to understand and interpret the essence of meaning behind the lived experience of twenty (20) Bangladeshi patients with ankylosing spondylitis, an interpretive phenomenological approach was used. More specifically, Max van Manen's (1990) methodological framework guided and provided a structure to the enquiry into the life world of the Bangladeshi participants. The research was designed to answer the question: what is the lived experience of health-related quality of life in Bangladeshi patients with ankylosing spondylitis? In order to encourage the Bangladeshi patients to share their narratives and uncover meanings attached to their experiences, semi-structured individual face-to-face interviews were used to collect the data. An interpreter was used to aid translation and interpretation in the interviews with the non-English speaking participants. Data were analysed using van Manen's three method approach of isolating thematic statements.

Findings

A phenomenological interpretation is offered through five identified global themes and twenty- three sub-themes, which are inextricably linked: the struggle to get a diagnosis, the nature of ankylosing spondylitis, the impact of ankylosing spondylitis, managing with ankylosing spondylitis and finding relief. Interpretation demonstrated the complex and often variable ways in which the Bangladeshi participants have experienced and are living with ankylosing spondylitis. Participants have faced a myriad of struggles in their journey to diagnosis and the ankylosing spondylitis symptoms are unpredictable and uncertain affecting every aspect of their lives. The participants narrated ways they are using to manage the illness and how they have found relief from the symptoms.

Conclusion

Ankylosing spondylitis affects the Bangladeshi participants in a significant way. Based on their cultural identity, this group hold onto specific health beliefs which they use to construct meaning about their lived experience of ankylosing spondylitis. There is a need to develop culturally appropriate models of service provision for this group, which are based on an understanding of the lived experience.

Dedication

I lovingly dedicate this thesis to my dearly departed parents, the Rt Rev Bishop P.P Katsande and Mrs Talitha Betty Katsande, who were 'promoted to glory' too soon. They instilled in me the strong principles of putting God before all things, loving others as myself and always striving to be the best that I can ever be in this world. This formed the foundations for my work as a nurse and subsequently fuelled my desire to embark on this journey. I have done it Mum and Dad!



All things are possible to him who believes' Mark 9:23

Acknowledgements

This thesis is the end of my journey in obtaining my Doctorate. I have not journeyed in a vacuum. This work has been completed with the support and encouragement of many people. I am truly grateful to all who journeyed with me and made this whole endeavour possible.

To God almighty, who makes all things possible in my life, I give you glory!

To my children Thandie and Chenjerai, I love you.

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Glossary of Key Terms

| Acronym | Term | Definition |
|-------------------------------|---|---|
| AMED | Allied and Complementary Medicine Database | Resource covers three separate subject areas: professions allied to medicine, including physiotherapy, occupational therapy, rehabilitation, speech and language therapy, and podiatry; complementary medicine; and palliative care. |
| Anti-TNF alpha | Anti-Tumour necrosis factor alpha | Biological agents targeting inflammatory cytokine tumour necrosis factor alpha (TNF-alpha) licensed for a variety of inflammatory conditions |
| ASAS | Assessment of SpondyloArthritis international Association | An international group of experts in the field of ankylosing spondylitis which aims to support and promote the study of ankylosing spondylitis (AS) |
| AS | Ankylosing Spondylitis | Inflammatory disorder of the spine that affects skeletal and extra-skeletal tissues |
| ASQOL | Ankylosing Spondylitis Quality of Life Questionnaire | A patient-reported outcome measure which assesses the quality of life of patients with ankylosing spondylitis |
| BASDAI | Bath Ankylosing Spondylitis Disease Activity Index | Measures patient-reported disease activity in patients with ankylosing spondylitis - consists of 10cm visual analogue scales used to answer 6 questions pertaining to the 5 major symptoms of AS (fatigue, spinal pain, joint pain/swelling, areas of localised tenderness and morning stiffness) |
| BASFI | Bath Ankylosing Spondylitis Functional Index | A set of 10-questions designed to determine the degree of functional limitation in those with AS. The questions are focused on the person's ability to perform specific functional tasks. |
| BASMI (Jenkinson et al. 1994) | Bath Ankylosing Spondylitis Metrology Index | 10-point scale used to quantify the mobility of the axial skeleton in ankylosing spondylitis patients and allow objective assessment of clinically significant changes in spinal movement. |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature | Prime source of Nursing and Allied health literature |

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| DoH | Department of Health | Department of Her Majesty's government responsible for government policy on Health in England. |
| EASiQOL | Evaluation of Ankylosing Spondylitis Quality of Life | Patient reported outcome measure in AS with 20 items across four domains (physical function, disease activity, social participation, emotional well-being) |
| EQ-5D | European quality of life | Standardised non-disease specific instrument for describing and valuing health-related quality of life - one question for each of the five dimensions that include mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. |
| EuroQOL | International network of multidisciplinary researchers | Group was established in 1987 to test the feasibility of jointly developing a standardized, generic instrument. |
| HRQOL | Health-related quality of life | The effects of an illness on the physical, emotional and social well-being of an individual as well as impact of treatment |
| MEDLINE | Medical Literature Analysis and Retrieval System online | Database provides authoritative medical information on medicine, nursing, dentistry, veterinary medicine, the healthcare system, preclinical services, and more. |
| MP | Member of parliament | A person who has been elected by the people in a particular area to represent them in a country's parliament |
| NHP | Nottingham Health Profile | 38-item with six domains patient-completed questionnaire used to determine and quantify perceived health problems |
| p | P-value | The level of marginal significance within a statistical hypothesis test representing the probability of the occurrence of a given event. The p-value is a number between 0 and 1 |
| QOL | Quality of Life | The standard of health, comfort or happiness experienced by an individual or group |
| r | R-squared value | A statistical measure of how close the data are to the fitted regression line. The higher the R-squared, the better the model fits the data |

| | | |
|--------|---|---|
| NASS | National Ankylosing Spondylitis Society | Registered charity in the UK dedicated to the needs of people with AS in the UK. |
| SAARDs | Slow acting anti-rheumatic drugs | Drugs used to treat pain and swelling over time and usually take several weeks or more to work. These drugs are also called disease modifying anti-rheumatic drugs |
| SD | Standard Deviation | A measure of the dispersion of a set of data from its mean |
| SF-36 | Short-form 36 | A 36-item questionnaire which measures Quality of Life (QoL) across eight domains. The percentage scores range from 0% (lowest or worst possible level of functioning) to 100% (highest or best possible level of functioning). |
| UK | United Kingdom | A sovereign state in Northern Europe |
| USA | United States of America | A federal republic composed of 50 states |
| WHO | World Health Organisation | A specialised agency of the United Agency that is concerned with International public health |

Chapter 1: Introduction

1.1 Introduction and Background

This chapter introduces the phenomenon of interest and the study topic: Lived experience of health-related quality of life (HRQOL) in Bangladeshi patients with ankylosing spondylitis (AS). A brief overview of AS is given, followed by an introduction to the complex concept of quality of life (QOL) and HRQOL. The contextual factors influencing research with the Bangladeshi population will be discussed, as well as my personal background that helped influence the choice of research topic. The chapter concludes with the outline of the thesis.

Ankylosing spondylitis is a complex systemic inflammatory rheumatologic condition which is often characterised by severe disability and impaired health-related quality of life. Current evidence suggests that AS patients have poorer health-related quality of life compared to the general public. Health-related quality of life comprises the net effects that a patient perceives an illness to have on their life. As one of the first nurses in the United Kingdom (UK) specialising in inflammatory arthritis, I have developed in this role and become increasingly interested in what the experience of health-related quality of life means to Bangladeshi patients with AS, due to my close contact with this community during my work.

The concept of AS, as an uncommon inflammatory condition has changed in the last two decades. This is due to innovative and breakthrough discoveries in genetics (Thomas & Brown, 2010; Robinson & Brown, 2014), epidemiology (Akkoc, 2008; Stolwijk et al. 2014) and etiopathogenesis (Dougados & Baeten, 2011; Yeremenko et al. 2014). AS usually affects the sacroiliac joints, spine and peripheral joints, with onset typically occurring during the second or third decade of life (Thom et al. 2015; Braun et al. 2014). The disease is thought to exhibit a higher prevalence among those of lower

social status (Braun & Sieper, 2007). Yet despite it now being a relatively common disease, the time from the early signs and symptoms to diagnosis can be as long as 10 years (Jordan & Rhon, 2012). Healthcare professionals have been shown to find it challenging and difficult to distinguish between AS and the much more common non-specific low back pain (Pisetsky, 2013). The symptoms of AS often progress, contributing to emotional distress and reduced quality of life. The complexities of these issues faced by AS patients and the lack of understanding of the concepts associated with this important area of rheumatologic care, amongst ethnic minority populations in the UK, are the key drivers for this study.

1.2 Clinical features of AS

AS is a chronic inflammatory disease and a member of a group of diseases called the spondyloarthropathies (SpA), which includes reactive arthritis, psoriatic arthritis, spondyloarthritis with inflammatory bowel disease, and undifferentiated spondyloarthritis (Braun et al. 2014; Thom et al. 2015). AS is characterised by inflammation and ankylosis of the axial skeleton especially sacroiliitis (Arturi et al. 2013), peripheral arthritis and enthesitis (inflammation at insertion sites of bone to tendons, ligaments, and joint capsules) (Shaikh, 2007). The sacroiliitis is regarded as the hallmark of the disease. The main clinical features are inflammatory back pain, joint stiffness and fatigue resulting in varying degrees of structural changes in the spine and sacroiliac joints (Dagfinrud et al. 2005; Braun et al. 2007; Arnbak et al. 2016). These clinical symptoms and subsequent disease progression lead to significant loss of function, work disability and impaired health-related quality of life (). One third of patients with AS will report large peripheral joint involvement and the disease may also be associated with extra-articular manifestations such as anterior uveitis, enthesitis, bowel and heart disease (Boonen et al. 2001; Maghraoui, 2011). The course of the

disease is unpredictable, however, the initial manifestations emerge around the second and third decades of life (Barlow et al. 2001; Doward et al. 2003). It has been suggested that the condition starts before the age of 30 in about 80% of patients (Rudwaleit et al. 2005). The disease onset occurs during the most productive years of life, hence AS impacts the patients' social, professional and family life with major economic burden for both patients and society (Marengo et al. 2008; Sommerfleck et al. 2018).

1.3 Prevalence of AS

There are geographical differences in disease prevalence. However, few prevalence studies have been conducted in AS compared with other rheumatic disorders such as rheumatoid arthritis. The prevalence of the disease varies across different populations (Klippel et al. 2008), but it is thought to range between 0.6 to 1.9% globally (Sieper et al. 2001; Alamanos et al. 2004; Akkoc, 2008; Helmick et al. 2008; Reveille et al. 2012) with the majority of patients positive for HLA-B27 (Nakashima et al. 2016). It is important to note however that the prevalence of HLA-B27 positivity in the general population differs significantly among races, from over 30% to less than 1% (Reveille et al. 2012). The prevalence of AS in Bangladesh has been reported to be 5.8 per 10 000 (Haq et al. 2005). In the UK, there are approximately 200 000 people who have AS, however there is no evidence on the relative frequency of AS in the different ethnic groups in the UK (McKenna, 2010). AS is clinically more common in men than in women, with a ratio of approximately 5:1, although this may partially reflect under diagnosis in women (McKenna, 2010). Approximately 5% of patients presenting with back pain have AS, with initial symptoms present from late teens to 30s although diagnosis may be later on in life. The disease is thought to exhibit a higher prevalence among those of lower social status (Braun & Sieper, 2007). According to Boonen et al. (2006), the prognosis of AS is variable and is determined by the presence of extra-spinal

manifestations such as uveitis, psoriasis, inflammatory bowel disease, age at diagnosis and treatment provided.

1.4 Diagnostic and classification criteria for AS

The modified New York criteria (van der Linden et al. 1984) have long been recognised to establish diagnosis of AS (Fig.1.1). A definite diagnosis of AS is confirmed with the presence of one radiographic criterion and at least one clinical criterion. AS is therefore distinguished by universal involvement with sacroiliac joint inflammation or fusion, and more prevalent spinal ankylosis (Perez-Alamino et al. 2011). The importance of radiographic changes in the sacroiliac joints makes a diagnosis of AS in patients with early disease very difficult in this criterion. These more advanced sacroiliac changes form the core of the modified New York criteria for the classification of AS.

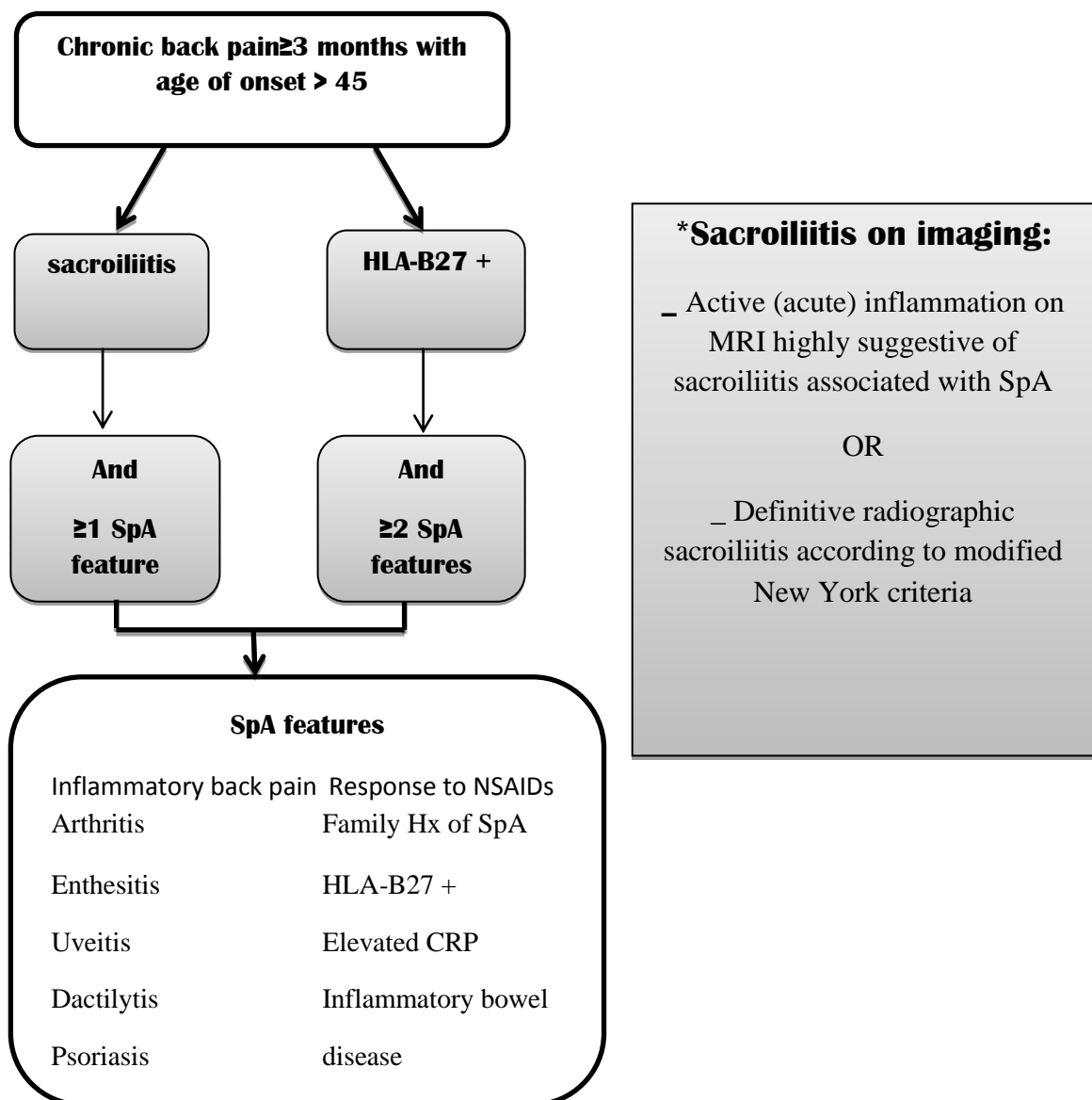
Fig 1.1 The modified New York Diagnostic Criteria for AS (van der Linden et al. 1984)

| |
|---|
| 1. Clinical criteria: <ul style="list-style-type: none">a) Low back pain and stiffness for more than three months, which improves with exercise, but is not relieved by restb) Limitation of motion of the lumbar spine in both the sagittal and lumbar planesc) Limitation of chest expansion relative to normal values correlated for age and sex |
| 2. Radiological criterion: Sacroiliitis grade >2 bilaterally or grade 3–4 unilaterally |
| - Definitive AS if the radiological criterion is associated with at least one clinical criterion |

The symptoms of AS often occur some years before evidence of any radiographic change required for a definitive diagnosis (Gran & Husby, 1993; Dougados, 1995), so cases can be missed particularly in the early stages. The absence of radiologic sacroiliitis should therefore not rule out the diagnosis of AS. Magnetic resonance imaging is now clearly established as a sensitive and specific tool to detect sacroiliitis

(Shaikh, 2007). These complexities have led to a more recent diagnostic classification with greater sensitivity to early AS. Assessment of SpondyloArthritis International Society (ASAS) proposed classification criteria that apply to both patients in the early stage of the disease and those in the later stages, included under the umbrella term axial SpA (Rudwaleit et al. 2009a). This criterion has provided a reliable early diagnosis in the absence of x-ray changes and can therefore be seen as an essential and crucial step for early diagnosis and treatment (see Fig 1.2).

Fig 1.2 Assessment in SpondyloArthritis international society (ASAS) classification criteria for axial spondyloarthritis (Rudwaleit et al. 2009a)



Whilst this new criterion captures a higher proportion of patients with the disease than the modified New York criterion, they do so at a cost of substantially increasing the heterogeneity of the resulting disease group and reducing the utility of these new criteria for both clinical and research applications (Robinson et al. 2013). The term Axial Spondyloarthritis (axSpA) was therefore developed to comprise the whole spectrum of patients with pre-radiographic disease (undifferentiated axial SpA) as well as patients with radiographic disease (AS or radiographic axSpA) (Rudwaleit et al. 2005; Poddubnyy & Sieper, 2014). There is on-going debate however, as to whether radiographic and non-radiographic axSpA should be considered as two different entities or as a continuous disease spectrum (Sieper & van Der Heijde, 2013).

Although there are clinical similarities between AS and non-radiographic axial SpA, in the context of this study, I have considered these conditions separately because studies typically have included either patients with AS or those with non-radiographic axial SpA. The diagnostic criteria used in the quantitative studies reviewed are according to the 1984 modified New York criteria.

1.5 Diagnostic delays in AS

The diagnosis of AS is often missed and markedly delayed. The reasons for the delay in diagnosis are myriad and include: the lack of a diagnostic laboratory test such as autoantibodies in collagen diseases (Van der Linden et al. 1984); the fact that radiological signs in the sacroiliac joints, essential for the diagnosis of AS using the modified New York criteria may take years to appear due to the slow progression of the underlying inflammatory process (Feldkeller et al. 2003); and radiographic sacroiliitis, which has historically been a cornerstone of diagnosing AS, may take several years to develop. The concept of enthesitis has emerged as an important contributor to the

inflammatory process involved in AS. Some of the more common peripheral enthesal sites that can be affected are located around the shoulders, hips, and the plantar fascia and Achilles insertions on the calcaneus (Aydin et al. 2010). Enthesitis was also shown as another related factor to diagnostic delay in a survey by Fallahi and Jamshidi (2016). However, such a relationship was not observed in other countries. The back pain and stiffness associated with AS often begins in late adolescence to early adulthood, with patients tending to postpone reporting symptoms to their general practitioners (GPs) (Jois et al. 2008; Hamilton et al. 2011). This therefore continues to lead to delays in diagnosis of the condition.

The marked variation in the clinical presentation of AS can be pointed out as another cause for the delay in diagnosis, as some patients show high disease activity with both spinal and peripheral joint involvement but others only show mild symptoms (Roussou & Sultana, 2011; Ma et al. 2012). Even if a diagnosis is made, it is difficult to tell how the condition will progress, since the degree of disability ranges from minimal to devastating (Calin, 2001). The degree of functional limitation is an important determinant of health-related quality of life (Ariza-Ariza et al. 2003) and is therefore important as it enables a better understanding of how these limitations develop and would help identify high risk groups of patients and may indicate interventions to prevent functional limitations and improve health outcomes (Ward et al. 2005). Doran (2003) identified predictive factors for functional limitation in AS to include: disease duration, gender, uveitis, smoking, high disease activity and radiographic status at base line. There is a concern therefore, that diagnosis of AS continues to be delayed by about 8-10 years despite knowledge of its clinical signs and symptoms for many years and this leads to poorer quality of life (Gerdan et al. 2012). Clinicians find it difficult to distinguish between AS and the much more common non-specific low back pain (LBP), because of findings on conventional radiographic images in the early stages of AS

(Pisetsky, 2013). Imaging of the spine and sacroiliac joints (SIJ) is one of the major fields of current interest in AS. This is because multi resonance imaging (MRI) in AS permits direct visualisation of inflammation in the spine and sacroiliac joints before conventional radiography shows any abnormality (Maksymowych & Landewe, 2006). MRI can therefore be used to focus on the evaluation of a patient with clinical features of inflammatory back pain where plain imaging is normal and the diagnosis is therefore uncertain. Although there is increasing awareness of the benefits of using MRI in AS, many clinicians and radiologists are unfamiliar with either the spectrum of MRI features in AS or appropriate indications for its use in diagnostic evaluation (Maksymowych, 2012). Equally, the challenges for GPs in identifying within the context of their practice, the minority of people who may have inflammatory rather than mechanical back pain (Brandt et al. 2007) and limited knowledge about AS in the general public (Jois et al. 2008) are also partly to blame for the delays in diagnosis. In a recent systematic literature review of health-related quality of life in AS, Kotsis et al. (2014), argued that this delay results in the spinal movement becoming severely restricted causing a major impact on function and quality of life in affected individuals.

1.6 Assessment of AS

Assessment of AS can be divided into three areas. The first is the physical assessment, (occiput to wall and chest expansion) which may reveal abnormalities in an early presenting patient (Zochling et al. 2006a). The second assessment, involves the questionnaires which are validated for disease activity, function and quality of life (BASDAI; BASFI; ASQOL; SF-36). Finally, there are the radiographic assessments (plain radiographs and MRI) of which MRI is the most sensitive. Assessment of AS therefore requires measuring disease activity, physical function and structural damage

as separate facets of the AS process (Zochling & Braun, 2005). Disease activity reflects acute inflammation and rate of change, physical function reflects the impact the disease has on the patient's ability to perform activities in his/her daily life, and structural damage reflects the end result of the AS process on anatomical structures. Assessments in Ankylosing Spondylitis (ASAS) group is an international collaboration of clinicians, researchers and industry representatives with a particular interest and expertise in AS. This group was established with a goal to improve the assessment of this debilitating disease. ASAS has subsequently reviewed the extensive literature on different outcome measures and instruments which have been used in AS clinical trials and selected the most appropriate measures for each core set domain based on evidence of validity and consensus opinion (van der Heijde et al. 1999). It is important to note that measurement of health-related quality of life is not included in the ASAS core sets (see Appendix 1). Health-related quality of life is an important component of patient assessment, as it incorporates all three facets of disease activity, function, and damage (Bowling, 2014). There are now validated AS-specific instruments to measure disease-related quality of life (Zochling & Braun, 2005). The Ankylosing Spondylitis Quality of Life (ASQoL) questionnaire, an 18-item scale (Doward et al. 2003), is the most thoroughly studied and widely used in research and clinical practice. It is a valid and reliable questionnaire for measuring health-related quality of life in AS. It has been criticised however for omitting important patient factors such as the nature of the lived experience and the impact of the illness from the individual patient's perspective (Haywood et al. 2005). The Medical Outcomes Study Short Form 36 (SF-36) is a generic, validated tool and another widely used measure of health-related quality of life in AS patients (Haywood et al. 2002).

1.7 Management of AS

The mainstays of treatment for AS have been non-steroidal anti-inflammatory drugs (NSAIDs) and exercise, with the additional use of slow-acting antirheumatic drugs (SAARDs) in patients with peripheral arthritis. The past 15 years has seen a revolution in the treatment of AS. This is in terms of improved understanding of the disease mechanisms, criteria for classification, early diagnosis and the use of tumour necrosis factor alpha treatments (anti-TNF) (Braun & Sieper, 2007; O Shea et al. 2007; Rudwaleit et al. 2009b; van der Heijde et al. 2011). New therapies have become available in the treatment of axial SpA including TNF- α antagonists (Braun et al. 2011; van der Heijde et al. 2011), which may slow disease progression. The goals of treatment are to reduce symptoms, maintain spinal flexibility and normal posture, reduce functional limitation, improve quality of life and decrease disease complications (Baeten et al. 2013). The effective management of AS remains complex, however, the traditional approaches to treatment are palliative at best but often fail to control symptoms effectively over the long-term (Hamilton-West & Quine, 2009). The advent of anti-tumour necrosis factor alpha (TNF alpha) has produced clinical improvements; however, it is not always effective and can be unsuitable for some patients (Claudipierre, 2005). Roughly 40% of AS patients do not respond to or tolerate TNF-blockers (Baeten et al.2013), thus this unmet need has been met by medicines with new modes of action (NICE, 2016). Anti-interleukin-17A monoclonal antibody Secukinumab has emerged as a novel therapeutic target for AS which provides significant reductions in the signs and symptoms of AS (Baeten et al. 2015).

1.8 Quality of life

There is an increasing predominance of chronic disorders during the past decades, leading to a large number of people living with chronic diseases that can adversely

affect their quality of life (Megari, 2013). Quality of Life (QoL) is a complex concept which incorporates all aspects of an individual's life (Bowling, 2014), including the entire range of human experience states, perceptions and spheres of thought. It is therefore a broad concept encompassing how an individual measures the 'goodness' of multiple aspects of their life (Theofilou, 2013). A search of the literature suggests the definition of QoL is more complex than the World Health Organisation's (WHO) definition. Skevington et al. (2004) as part of the WHO Quality of Life Group (WHOQOL group) have used this definition of quality of life as:

'not merely the absence of disease, but an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns' (p.299)

The WHOQoL's approach indicates how highly individual the interpretation of the concept is. QOL has been used across many disciplines with different users of the concept using different meanings depending on their understanding of the term, their position and agenda in the political and social structure (Edlund & Tancredi, 1985). Definitions range from the degree to which a person accomplishes life goals (Cella & Cherin, 1987), to the output of the inputs of the physical and spiritual (Liu, 1974). Baker and Intagliata (1982) allege that there are as many definitions of the concept as the number of people studying the phenomenon. This suggests a lack of agreement between those attempting to operationalize the concept and the 'satisfaction of an individual's values, goals and needs through the actualisation of their abilities or life style' (Emerson 1985, p282). From a phenomenological point of view, Ziller (1974) argues that quality of life is dependent upon the interpretation and perceptions of the individual. Rosenberg (1992) goes further to argue for a hermeneutic thinking to be introduced into modern medicine in order to present a 'naturalistic concept of mankind' with a concept of a human being as a reflective individual responsible for his or her own actions. Clearly

there are unresolved questions in quality of life research. Bowling (2014) raises the argument about whether some parameters of quality of life have a different weight for different types of people in different circumstances and in relation to different illnesses. Despite a plethora of research on a wide range of objective and subjective indicators of quality of life, there is no widely accepted theory or measurement instrument of quality of life. QOL must not just be a description of an individual's health status but the way in which they perceive and react to their health status. This suggests that this concept cannot just be reduced to a collection of domains that are affected by one's disease but encompass the individual's perspective. It is beyond the scope of this thesis to explore this macro level of the concept, therefore the QOL aspect to be investigated is HRQOL.

1.8.1 Health-related quality of life

Health-related quality of life (HRQoL) is similar to QoL in that it is challenging due to its multidimensional nature. It consists of at least three broad domains – physical, psychological and social functioning - that are affected by one's disease and treatment (Megari, 2013). This concept is concerned specifically with health aspects and an individual's sense of personal psychological, physical and social well-being and satisfaction with control of disease processes (Theofilou & Panagiotaki, 2011). Sprangers (2002) describes physical functioning as the ability to perform a range of activities of daily living as well as physical symptoms resulting from the disease or its treatment. He goes further to describe psychological functioning as ranging from severe psychological distress to a positive sense of well-being and may also encompass cognitive functioning. On social functioning he refers to it as the quantitative and qualitative aspects of social relationships and interactions and societal integration. HRQoL comprises the net effects that a patient perceives an illness to have on his or her life (Bowling, 2014). This includes the mental, physical and social functions of an

individual incorporating their satisfaction with their current health. The impact of AS on these health-related quality of life domains, has led to a growing interest in this area. HRQoL and QoL are used interchangeably in the literature and this has caused further confusion.

The simplistic manner of listing of HRQoL domains that is widely used (currently) is unsatisfactory as there are no ways of knowing if all the important domains have been included. The approach to quality of life must be through the eye of the experiencer and this according to Ziller (1974) is the phenomenological approach. Most medical and nursing research papers have avoided clearly defining what they intend to measure when researching HRQoL, leading Farquhar (1995, p.1439) to contend that definitions of quality of life are ‘as numerous and inconsistent as the methods assessing it’.

For the purposes of the current study, health-related quality of life was limited to the effects of the illness on the physical, emotional and social wellbeing as well as impact of treatment (Bowling 2014), using a methodology that enabled participants’ (Bangladeshi patients) voices to be heard.

1.8.2 Assessments of health-related quality of life in AS

HRQOL can be assessed either by interview or questionnaire. In the past, the interview methods have been used for the initial creation of items to be used subsequently in questionnaires to discover issues and to describe the experiences of the patients (Staquet et al. 1998). Current HRQOL instruments are questionnaires made up of a number of items. The items add up to a number of domains, which are areas of experience or behaviours that are trying to be measured. According to Guyatt et al. (1993) one of the problems with these questionnaires is that items are equally weighted which assumes that their value is equal. In the context of this research, the concept of HRQoL is similar to that described by Guyatt et al. (1993, p. 622) as ‘the extent to which a

patient's usual or expected physical, emotional, and social well-being are affected by a medical condition and its treatment'.

Two basic approaches are currently used to measure health-related quality of life: generic instruments that provide a summary of quality of life applicable to any disease, and disease specific instruments that focus on problems associated with single disease states such as ankylosing spondylitis (Guyatt et al.1993). The most commonly used generic quality of life measures in rheumatology research are the Medical Outcome Short-Form (SF-36) Health Survey, the European Quality of Life (EUROQOL) or Euro-Qol 5-Dimensions (EQ-5D) and the Nottingham Health Profile (NHP) (Fitzpatrick, 1993; McDowell & Newell, 1996; Ware, 2000). The Ankylosing Spondylitis Quality of Life (ASQOL) is the disease specific questionnaire used in AS (Doward et al. 2003). These measurement scales provide important information about the impact of the disease on different aspects of the patients' health-related quality of life. However, they have been criticised for having a narrow focus which fails to prioritise and capture the personal meanings and lived experience of the illness (Boonen et al. 2003; Zhu et al. 2008). These four instruments have been used to identify quantitative papers for inclusion in the literature review. The choice was prompted by their coverage of items of interest to this study and their validity and reliability (Lenert & Kaplan, 2000; O'Connor, 2004).

1.9 The research context

My study seeks to understand and interpret the lived experience of health-related quality of life in Bangladeshi patients with ankylosing spondylitis. It used an interpretive approach. Researching health in ethnic minority populations is complex due to the interaction of underlying socio-political, cultural, behavioural and biological factors

(Moorley & Corcoran, 2014). Researchers and policy makers therefore need to take these wider determinants into consideration when planning and conducting research (Marmot et al. 2010). Research in these groups could take a participatory approach which includes the relevant stakeholders from the community, patient support groups, healthcare systems, and primary care and policy makers. This approach allows the research to be more relevant and usable. My experiences of engaging with the Bangladeshi community through its gatekeepers during the planning stages of this study, is discussed in Chapter 3 (section 3.7) of this thesis.

The influence of context on research utilisation has been debated in the literature (Adewole et al. 2005). Different research settings will have different outcomes, as what works in one setting might not work in another. Context describes the cues in the environment that define the health experiences of community insiders in terms of what is accessible and what is inaccessible to them (Dutta, 2008). The social and economic contexts of a community influence knowledge, attitudes, and beliefs. In the context of this study, this will highlight issues and concerns within which the research question is located. Context can also regulate access of participants to healthcare services and researchers need to have an understanding, of how and why this occurs.

This section will set some of the contextual issues relevant for the exploration of health-related quality of life experiences of Bangladeshi patients living in the deprived inner London borough of Tower Hamlets.

1.9.1 Research context in qualitative research

Qualitative research is conducted with different stakeholders, and in different settings and situations, with the aim to explore the contextually based lived experience of individuals and social groups. Lincoln and Guba (1985) have suggested that the

interpretive researcher must first understand the constructed and inter-subjective meanings then recognise their own understandings of the meanings and the tools used for enquiry and that these exist within and are products of the same contextual web. These contextual factors include national and organisational policies, socio-cultural and historical issues as well as the characteristics of the patient populations. It was therefore important for me to pay attention to context when designing, conducting and reporting this study.

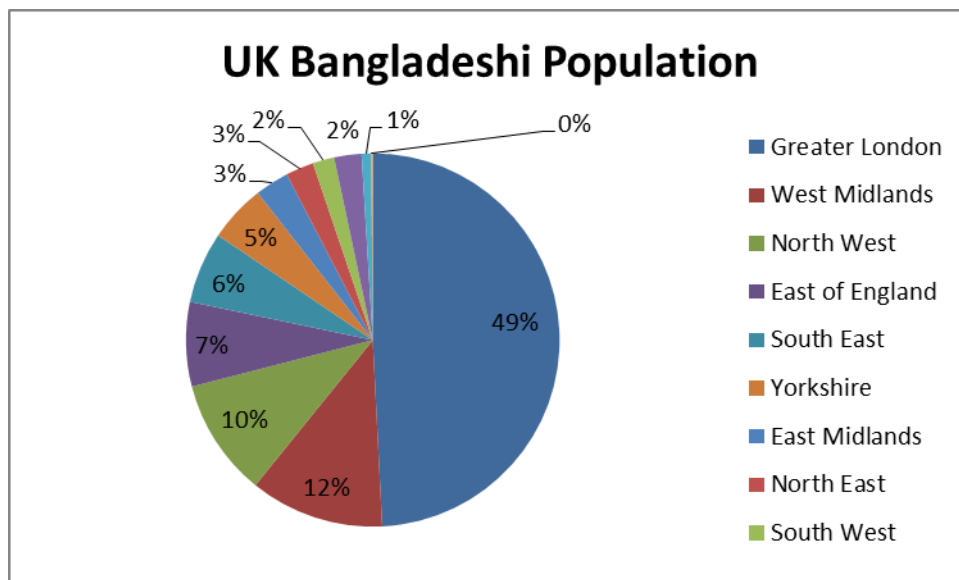
The connection between research, politics, power and decision making has been discussed by Usher and Scott (1996). The differential power of groups sometimes defines what is worthwhile in research knowledge, its focus, methodology and the use of findings. If research is to impact policy making, it has to align itself with the political agenda of governments, strategy of local organisations as well as the priorities of those with vested interests including the participants themselves. All stakeholders might have conflicting agendas, different priorities and interests resulting in implications on the type of the research and how it is conducted. I view the Bangladeshi patients as being under-represented and having no ‘voice’ to influence the research agenda in rheumatology and this is explained in the next sections and section 2.10 of this thesis.

1.9.2 The Bangladeshi community in the UK

The Bangladeshi community in the UK is heavily concentrated in London’s inner boroughs. According to the 2011 Census, London’s Bangladeshi population represented 49.2% of the total UK Bangladeshi population (Fig 1.3). The Bangladeshis are one of the youngest UK and ethnic populations, with 38% under the age of 16, 59% aged between 16 – 64 and only 3% aged 65 and over (Census 2011). The Bangladeshis living in London are amongst the poorest and most deprived communities in the UK, with high rates of unemployment, poverty, and disability (MacInnes & Kenway, 2009). This

is despite significant development activities such as the, Thames Gateway, expansion of Canary Wharf and the Olympic and Paralympic games. The London borough from which the sample lives has the heaviest concentration of the Bangladeshi population in the UK. The borough is therefore an example of a residential pattern reflecting different trends of socioeconomic status, with poor health and high incidence of chronic health problems resulting in large inequalities. A significant number in the population have poor educational qualification and do not speak English as a first language (Chouhan et al. 2011). There are barriers to accessing healthcare services which include language and communication, culture, lack of understanding and utilisation of available services (Nazroo, 2001, Phillipson 2003). As such these factors support my assertions, that the voices of Bangladeshi population can be considered to be ‘silent’ particularly in the research context.

Fig 1.3 The British Bangladeshi population distribution according to the Census 2011.



Source: Census 2011

The Bangladeshi community can therefore be said to be excluded from everyday mainstream society. Nazroo (2006) asserts that by moving to the same area, ethnic

communities are able to develop a strong ethnic identity, have enhanced access to social support as well as a reduced sense of alienation, because of having the same cultural norms and beliefs. This however causes problems with integration of these communities. Ethnic health research has been criticised for excluding the local community and undervaluing their expertise (Purewal, 2006). This group is more likely to be understudied due to the overreliance by some researchers on English. It is therefore not uncommon to see an exclusion criterion stating 'unable to speak English'. Some of the reasons ethnic minorities are excluded in research include communication barriers, access issues, perceived lack of competence, negative stereotypes and the additional resource required to include them as participants (Bonevski et al. 2014).

The Bangladeshi population therefore faces many challenges in the health and social care sector. Blackburn et al. (2010) have suggested some common factors that might ensure a positive and worthwhile experience for research participants or service users. These include: building relationships, engaging the communities at all stages of the research process, and the researcher being sensitive and aware of issues as well as clarifying roles. There is an acknowledgement in the literature, of the importance of participants and researchers working together to design undertake or evaluate research (Morrow et al. 2012). This process however comes with both benefits and challenges. The benefits include improved quality and outcome of research and some of the challenges are to do with tensions over differing agendas.

1.10 The researcher's personal experiences of phenomenon

According to van Manen (1997) the researcher must acknowledge their previous experience, knowledge and beliefs and how these may influence the whole research process. My interest in Ankylosing Spondylitis began some years ago, after a chance

encounter with a 40-year-old Bangladeshi patient in my nurse-led clinic. The consultation highlighted the plight of Bangladeshi-patients with AS, in terms of their lack of understanding of their illness and their perceived difficulties with the disease management from diagnosis throughout their treatment journey. My interest was ignited and I searched for some background information on AS in the Bangladeshi population.

I concluded that the Bangladeshi experience of this condition warranted further exploration and, I decided to embark on this journey. I come to this research with more than 20 years of rheumatology experience gained from clinical practice and attendance at national and international rheumatology conferences, and therefore I have some prior knowledge, beliefs and experience of this phenomenon. These have been revealed through my reflexive accounts at every stage of the research process.

1.11 Thesis structure

This thesis is presented in six chapters. An introduction and background to the context of the study has been presented in Chapter 1. Chapter 2 explores the literature on this topic and places the study in context, ending with the rationale, aims and objectives of the study. Chapter 3 gives an outline of the design of the study. It describes phenomenology and its research methods. The choice of a Heideggerian interpretive phenomenology will be explained. Ethical considerations are explained as well as the sample and the manner in which the Bangladeshi participants were accessed and recruited. Approaches used to collect and analyse data are included. Issues of trustworthiness and reflexivity are addressed. Chapter 4 gives a brief synopsis of how the findings are presented and then presents the detailed findings of the study. The essences and elements from the Bangladeshi participants' lived experiences are described with the support of direct quotes from the interview transcripts. Chapter 5

provides a discussion of the findings in the context of the literature and an examination of theoretical positions is offered. Chapter 6 provides a conclusion for the study by highlighting the study's contribution to knowledge. The implications of the study for Bangladeshi patients with AS, future research, service delivery and policy development are discussed. Finally, strengths and limitations of the study are provided and a final reflection given.

1.12 Summary of Introduction chapter

Ankylosing Spondylitis (AS) is a complex systemic rheumatologic condition which is often characterised by severe disability and impaired health-related quality of life. Current evidence suggests that AS patients have poorer health-related quality of life compared to the general public. This chapter has set the scene for this study, by discussing the background and relevant contextual issues. I have examined the nature of the experience being investigated and opened up the reader to the identity of the phenomenon. I have examined my own experience and engagement with the phenomenon. The next chapter engages with the phenomenon through the work of other authors and identifies gaps in current knowledge that form the basis of the rationale, aims and intended outcomes for this study.

Chapter 2: Literature review

2.1 Introduction

“Many research questions have in some way been addressed before and it is our responsibility to search for these materials” van Manen (1990 p.74)

This chapter gives a critical review of the existing research literature on HRQoL in AS. An assessment of the quality of included studies will be given. A summary of the reviewed literature will be offered within the identified themes and categories. The chapter concludes with an illustration of recommendations from the studies, limitations of the review, aims and objectives of the study.

On investigating experience as we live it, van Manen suggests consulting the literature in order to gain insights of others who have ‘already maintained a conversational relation with that phenomenon’ (van Manen, 1990, p.75). Questions have been raised as to whether a literature search should be done in the initial or later stages of a research study. This is because examining the literature at the very outset of a study might make it difficult for a researcher to suspend or ‘bracket’ their interpretive understanding of the phenomenon (van Manen, 1990). However, it is not my intention, to suspend any prior knowledge and pre-suppositions of the phenomenon, but in true interpretive phenomenological fashion, turn the work of others into a conversational partnership that reveals the limits and possibilities of my own interpretive achievements (van Manen, 1990). On the usefulness of a literature review van Manen asserts that:

“A human science researcher may benefit from studying how other human science scholars have addressed and brought to text their understandings of selected topics. In this way, a phenomenological study of a topic of our interest

may suggest different ways of looking at a phenomenon or reveal dimensions of meaning which we had hitherto not considered” Van Manen (1990, p.76).

The purpose of this review therefore, was to explore HRQoL in ankylosing spondylitis as it is lived rather than as it is conceptualised or theorised through its various manifestations in the world. Bearing in mind that many research questions have in some way been addressed before, the responsibility is to search for these materials (van Manen, 1997). The review was therefore intended to further illuminate essential themes related to the phenomenon, as it stands in January 2018, as well as illustrate any gaps in the existing literature.

2.2 Review of the literature in qualitative research

According to Bowling (2014) a literature review summarises what has been written and found out about a research topic. On the purpose of a literature review, Cronin et al. (2008) contend that it is to ensure the reader is conversant with the topic under investigation and to demonstrate the justification for undertaking the research. The importance of clarity when presenting literature for a specific purpose has been stressed further by Norman and Griffiths (2014) when they offer four possibilities (see Box 2.1).

Box 2.1 Four possibilities for reviewing the literature

- **A systematic review** – addresses a specific question and adheres to a specific method that can be reproduced; identifies all available evidence in relation to a research question, rather than just some of it; typically appraises studies for methodological quality for the purpose of excluding poorer quality studies; demonstrates where knowledge is lacking and uses this to guide future research.
- **A scoping review** – maps out literature in a specific field to identify what is known about the subject but not necessarily assessing the quality of the included studies.
- **A meta-synthesis** – the qualitative equivalent of a systematic review that presents a synthesis of knowledge rather than a precise answer.
- **A narrative review** – provides an overview of a subject for scholarly purposes in a readable format, presenting conclusions that are based upon a comprehensive review of the literature;

Source -Norman and Griffiths 2014

I opted to conduct a narrative review that used a systematic approach in this study. This was in order to critique and summarise the relevant studies and knowledge that address the health-related quality of life in patients with AS, through a systematic search, using key words, search terms and inclusion and exclusion criteria. It has been suggested that this type of review has a primary purpose of providing the reader with a comprehensive background for understanding current knowledge and highlighting the significance of new research (Cronin et al. 2008). This can ‘inspire research ideas by identifying gaps or inconsistencies in a body of knowledge, thus helping the researcher to determine or define research questions or hypotheses’ (p. 38). I was also aware of the limitations of this type of review which include, ‘their subjectivity in terms of included publications and assessment of them’, which could lead to biases (Bowling, 2014 p. 148). Having

selected a specific area to focus my study on in Chapter 1, the next step was to consider comprehensiveness and relevance in my review so that the result would be more focused (Newell & Burnard, 2006).

2.3 Description of the search

The search plan for this review was designed to retrieve relevant and key studies related to lived experience of health-related quality of life in Bangladeshi patients with ankylosing spondylitis, in order to contextualise the study. According to Cronin et al. (2008) any review of the literature must be specific and directly address the issue of interest. Ankylosing spondylitis belongs to a group of interrelated disorders classed under spondyloarthritis or spondyloarthropathy to include psoriatic arthritis, reactive arthritis, enteropathic arthritis (see Chapter 1 section 1.2). This search was therefore restricted to the specific condition of ankylosing spondylitis, due to the focus of the study. The initial search was therefore deliberately confined to the topic being studied in order to avoid irrelevant material that did not address the research question.

2.3.1 Initial literature search with Bangladeshi patients

In the initial search, the following key words were used: health-related quality of life OR quality of life, AND ankylosing spondylitis NOT spondyloarthritis, AND Bangladeshi patients AND lived experience OR living with ankylosing spondylitis. Boolean operators used in the search were AND (to include all truncated forms of the word); OR (to allow any of the terms to show up in an article) and NOT (to narrow my search by eliminating the word). No documents were identified with these search terms. A university librarian was consulted at this stage to assist with a review of the search

strategy, and again no studies were identified. Following discussions with my supervisory team, I decided to widen the boundaries of my search to other literature that might be connected and relevant to my enquiry. I felt this aligned with the wider scoping of a narrative review. The key words in the search were modified to simply: health-related quality of life OR quality of life, AND ankylosing spondylitis NOT spondyloarthritis.

Initial screening of titles and abstracts was performed against the inclusion and exclusion criteria (see Table 2.1) in order to identify only those articles relevant to the review. Studies were excluded if they did not meet these criteria. Grey literature (case reports, conference papers, letters, commentaries, discussion papers) was excluded and only used for background reading to help inform the study.

Table 2.1 Inclusion and exclusion criteria for studies

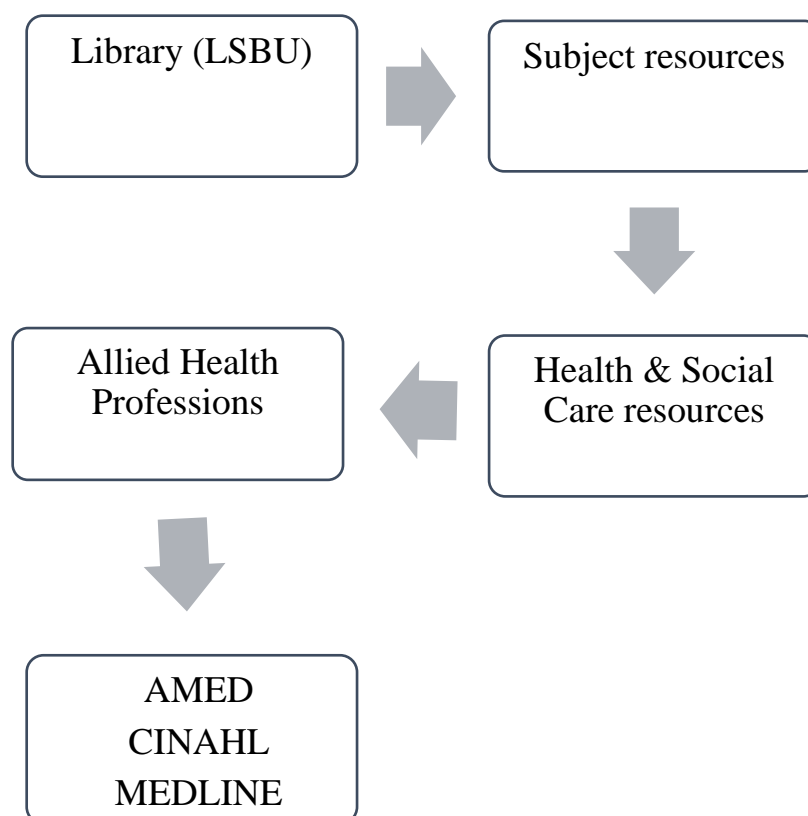
| Inclusion criteria | Exclusion criteria |
|--|---|
| <p>All studies:</p> <ul style="list-style-type: none"> ● Publications from January 1999 to January 2018 ● Studies reported in English ● Adult patients aged 18 years and above ● Study country: Any ● Published articles specific to AS and HRQoL/QOL <p>Quantitative studies:</p> <ul style="list-style-type: none"> ● Diagnosis of AS using modified New York Criteria 1984 ● HRQoL / QoL assessment using SF-36, EQ-5D, ASQOL & NHP quality of life measurement tools. <p>Qualitative studies:</p> <ul style="list-style-type: none"> ● Any diagnostic criteria for AS | <ul style="list-style-type: none"> ● Articles reported in languages other than English ● Children and those below 18 years ● Diagnosis using criteria other than 1984 Modified New York Criteria in the quantitative studies ● Published articles on Spondyloarthropathies (not specific to AS) ● Grey literature ● Conference papers (case reports, conference papers, letters, commentaries, discussion papers) |

2.3.2 Process of selecting relevant studies

The process of selecting relevant studies for this review was done in two stages. The first stage was in December 2014. Professional database searches (AMED, CINAHL

and MEDLINE) were accessed through the university library login (see Fig 2.1) for studies published from January 1999 (due to the seminal study by Ward 1999) to December 2014 initially. The research by Ward (1999) laid the foundations for future research in the area of health-related quality of life in ankylosing spondylitis.

Fig 2.1 Search process for Allied Health Professions databases



Source: Author December 2014

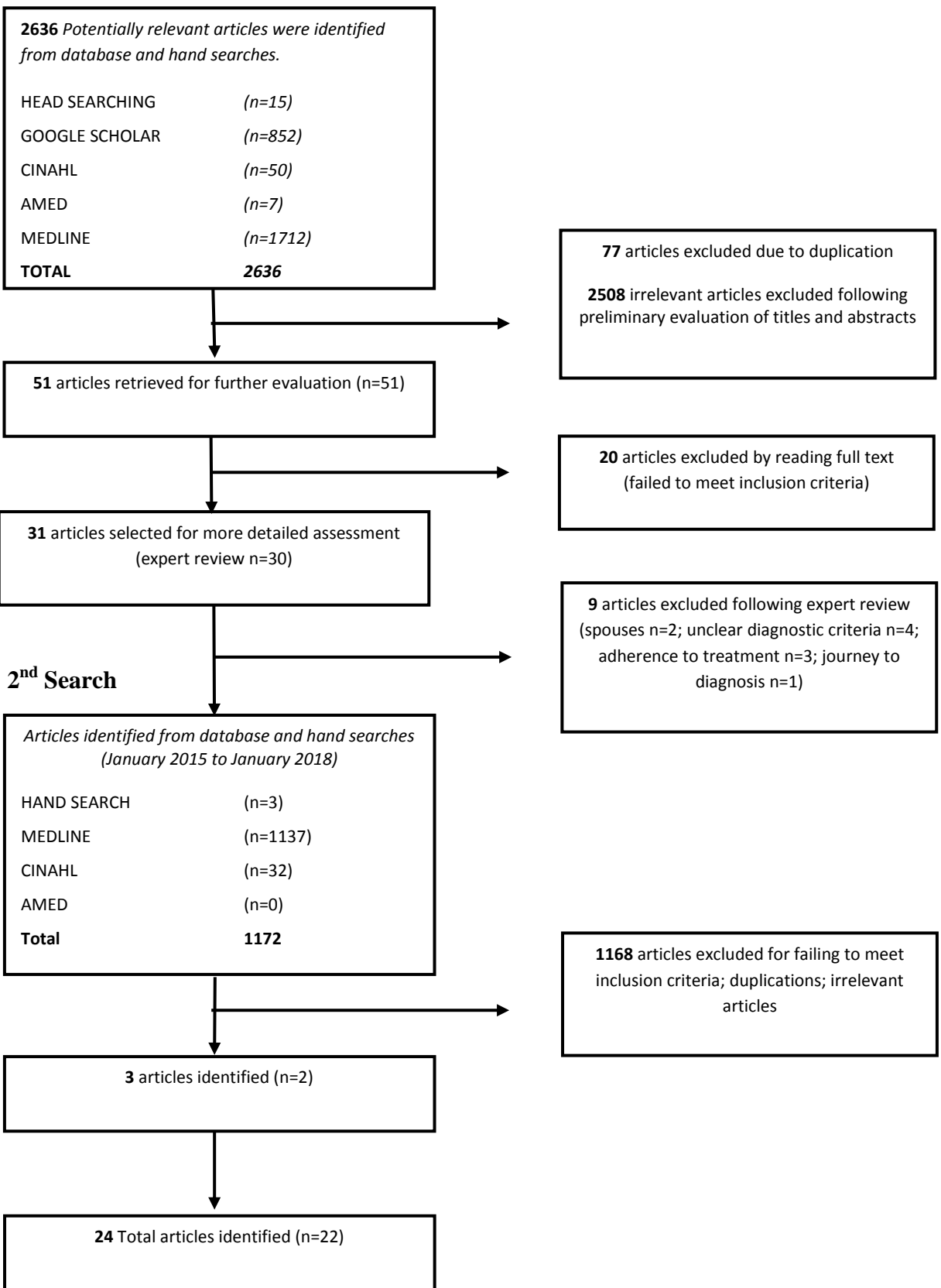
An online Google Scholar search was also conducted using the search terms: Health-related quality of life OR quality of life AND ankylosing spondylitis NOT spondyloarthritis. A citation tracking of included articles was performed to augment this search strategy. The citation tracking was used to identify studies that have referenced the included studies in their work, and as such, may be relevant to this review. Manual reference searching was also used to go through individual references of the finalised list of applicable studies to search for additional relevant studies. Further studies for inclusion were identified from reference lists of papers identified in the database

searches. Hand searches as recommended by Arskey and O'Malley (2005), were performed with the rheumatology journals (Musculoskeletal Care, Arthritis Care and Research, Annals of Rheumatic Disease & Journal of Rheumatology) in the hospital department library, using the contents page to identify further potential studies for inclusion. Removing duplicates and screening the titles and abstracts of the studies was a large task in itself throughout this process.

The second stage of the literature search in January 2018 was in order to identify any new and relevant literature published since the first search. All procedures followed those used in the initial search. The second search yielded 1172 papers that were reviewed for relevance using the previously described inclusion and exclusion criteria. Three further studies were selected, giving a final total of 24 studies (Fig 2.2).

Fig 2.2 Flow chart of study selection process

Initial search



2.4 Quality assessment of included papers

The Critical Appraisal Skills Programme (CASP 2013) tool was used to appraise the quality of the selected studies. I found this online tool to be user friendly and suitable to me as a novice researcher (Hannes et al. 2010). Each of the 10 questions in the CASP tool was given a weighting of 1 if the answer was yes, and 0 if the answer was no, for each paper. Scores out of 10 points were added up and transformed into 0-10 scales. The higher value indicated higher quality. I was mindful at this stage that there is no universal scoring method that can be used to assess the quality of studies in a literature review (Hawker et al. 2002). Accordingly I developed a summed up score: poor quality (0-3), fair quality (4-6) and good quality (7-10). The scoring used gave a clear indication of the strength and weaknesses of each study according to the CASP criteria.

The majority of studies were rated good. The research question was clearly identified in all the studies including the aims to explore HRQOL domains of, physical, emotional, psychological and social functioning; contextual factors, fatigue, general health and effects of gender, and educational level. Several papers sought to explore the physical, functional, social, psychological and sexual functioning of patients with AS (Bostan et al. 2003; Ariza-Ariza et al. 2003; Ozgul et al. 2006; Turan et al. 2007; Cakar et al. 2007; Zhao et al. 2007; Mustur et al. 2009;). Other studies specifically sought to gain an overall picture of the impact of anti-TNF treatment on health-related quality of life in AS (Davis et al. 2005, 2007; Stockdale & Goodacre, 2008). Some of the studies sought to identify aspects of health-related quality of life that are mostly affected in patients with AS (Ward, 1999; Gordeev et al. 2010; Ibn Yacoub et al. 2011; Alkan, et al. 2013; Kotsis et al. 2014; Yang et al. 2016). Finally, four studies explored the lived experience of patients with AS (Mengshoel, 2008; Stockdale & Goodacre, 2008; Hamilton-West and Quine, 2009; Madsen et al. 2015).

All the studies included an overview of relevant up to date research, whilst the majority of the studies provided details showing how the focus of the study emerged. Methods of data collection were provided in all the studies however the philosophical basis was not always clarified. The studies used different methods to collect data including interviews, postal diaries and validated questionnaires (Table 2.3). An interview guide was used in all the qualitative studies. Although some quality issues were identified with the selected papers, the majority were rated good. The study by Stockdale and Goodacre (2008) for example, was not clear if they used descriptive or interpretive phenomenology.

The good studies had clear aims and acceptable sample sizes for the type of study. Appropriate statistical tests were used and the methods of data analysis were clearly articulated. Appropriate links were made with relevant literature to justify the studies and limitations were mentioned. Ward's (1999) seminal study is a good quality paper that has been cited by most studies on health-related quality of life in ankylosing spondylitis suggesting its methodology and findings are credible. The fair papers were not clear about recruitment strategy and methods; inclusion and exclusion criteria were not clarified and there was no mention of ethics approval, consent or response rates (Schneeberger et al. 2004; Turan et al. 2007). Hawker et al. (2002) have noted the common problems in evaluating the quality of research output because reports rarely provide enough detail of the methods used for fully informed judgements to be made about the quality of the reporting.

Although the quality assessment of the reviewed studies has shown some weaknesses in some areas, the majority of them were rated to be good. Overall, the studies provided an overview of the health-related quality of life experiences of patients with AS. This has enabled a picture of the challenges these patients face to emerge. Some studies

identified areas where further research needs to be undertaken to explore this topic whilst the majority made recommendations to improve clinical practice.

Two reviews of the literature (one systematic and one comprehensive) on health-related quality of life in AS have been published. The quality of the reviews was assessed using Critical Appraisal Skills Programme (2013) for systematic reviews. The result of the quality assessment is shown in Table 2.2.

Table 2.2 Quality assessment of systematic and comprehensive reviews (CASP 2013)

| Question | Yang et al .2016 | Kotsis et al. 2014 |
|--|-------------------------|---------------------------|
| 1. Did the review address a clearly focused question? | Yes | Yes |
| 2. Did the authors look for the right type of papers? | Yes | Can't tell |
| 3. Do you think all the important /relevant studies were included? | Yes | Can't tell |
| 4. If the results of the review have been combined was it reasonably so? | Yes | Yes |
| 5. Can the results be applied to local population? | Yes | Yes |
| 6. Where all important outcomes considered? | Yes | Yes |
| 7. Are the benefits worth the harms and the costs? | Can't tell | Can't tell |
| Rating: | Good | Fair |

Both reviews summarised quantified health-related quality of life data of a large number of patients. The majority of studies in both reviews were cross-sectional with a few case-controls, longitudinal and randomised controlled studies. There were no qualitative studies included in the reviews. Kotsis et al. (2014) used a comprehensive list of subject

heading terms in their search. They focused on prospective and intervention studies and according to the authors, with adequate sample sizes and an appropriate methodology. They identified 36 studies with a total of 8128 participants although this is not clearly presented. There is no clear quality assessment of the included studies in this review and the limitations of the review are not offered. This review was therefore given a fair rating. In the systematic review by Yang et al. (2016) the mean age of the patients was 41.23 years. The sample size of the included studies ranged from 36 to 962. The mean quality scale of the 38 included studies was 3.58, with 23.7, 71.0 and 5.3% of the articles being of low, moderate and high quality respectively. The review has been rated as good because they have summarised quantified health-related quality of life from a large number of people with AS worldwide and used rigorous and reproducible methods. Their aims were clear, they included relevant papers which were assessed for their quality and the limitations of the review were discussed.

2.5 Results

Following the process set out in Figure 2.1, 21 articles initially met the inclusion criteria and a further three studies were identified for inclusion following the second search in January 2018. Thus 24 studies were finally included in this review (see Table 2.2). Following a brief presentation of the study characteristics, the results will be presented according to identified categories and themes thus presenting an appropriate and coherent picture of the reviewed literature. The details of included studies are shown in Table 2.3, which also includes the quality ratings.

Table 2.3 Summary of included studies

| Reference | Country | Study design | Aim of study | Sample size | Data collection | Sampling method | % women | Setting | Findings | Quality assessment |
|-------------------------|---------|-----------------|--|-------------|----------------------------|-----------------|---------|-----------------------|--|--------------------|
| Alkan et al. 2013 | Turkey | Case-control | To evaluate fatigue & its relationship to disease specific variables., HRQoL & spinal mobility | 110 | SF-36 questionnaire | Convenience | 47.3 | Outpatients. | AS patients defined significantly more fatigue when compared with healthy adults. Fatigue was related to QoL, clinical & functional status | Good |
| Ariza-Ariza et al. 2003 | Spain | Cross-sectional | To determine the physical function and the quality of life of Spanish patients with AS. | 92 | SF-36/EQ-5D questionnaire | Convenience | 25 | Not stated | HRQoL is impaired in a significant way. The physical area is more impaired than the mental and social areas. | Good |
| Bodur et al. 2011 | Turkey | Cross-sectional | To evaluate quality of life & related variables in patients with AS. | 962 | ASQoL/SF-36 questionnaires | Convenience | 23.8 | Database. | Poorest scores in QoL were noted in general health, physical role, bodily pain & emotional role | Good |
| Bostan et al. (2003) | Turkey | Cross-sectional | To evaluate functional disability and QOL in patients with AS and determine the relationship between functional status and measures of clinical condition including QOL. | 51 | NHP questionnaire | Convenience | 11.7 | Hospital/rehab centre | The scores of all sections of the NHP were significantly higher, indicating a poor quality of life in AS patients, | Good |

| | | | | | | | | | | |
|---------------------|------------------------|-----------------|--|-----|----------------------------|-------------|--------------------|----------------------|---|-------------|
| Cakar et al. (2007) | Turkey | Cross-sectional | Focused sexual problems of male patients with AS and relationship with functionality, disease activity, quality of life & emotional status | 53 | SF-36 questionnaire | convenience | 0 | Hospital/rehab | 50.94% participants expressed their sexual life was affected negatively by the AS whilst 49.06% expressed no negative effect. The physical functioning, role limitations due to physical problems, fatigue, general mental health scores of SF-36 were worse in the affected group. | Good |
| Davis et al. 2005 | USA/France/Netherlands | RCT | To evaluate impact of AS on patient HRQoL & to evaluate whether etanercept therapy can reverse impairment in HRQoL due to AS. | 169 | SF-36/ASQoL questionnaires | Random | Predominantly male | Database | Etanercept therapy significantly improves patient HRQoL, active disease and functional disability in AS. | Good |
| Davis et al. 2007 | USA/France/Netherlands | RCT | To evaluate the impact of adalimumab on HRQoL in patients with active AS. | 315 | SF-36/ASQoL questionnaires | Random | 25.1 | Database | Adalimumab is efficacious in improving physical function and HRQoL. | Good |
| Gordeev et al. 2010 | Canada/Australia | Cross-sectional | To assess the effects of a number of contextual factors on self-reported disease specific and health HRQoL in patients with AS | 522 | ASQoL questionnaire | Random | 31.6 | Outpatients/database | AS hinders physical demand domains and patients' work. | Good |

| | | | | | | | | | | |
|----------------------------|----------------|-----------------|--|-----|---------------------|-------------|------|------------------------------|---|-------------|
| Hamilton-West & Quine 2009 | United Kingdom | Qualitative | To contribute to the broader understanding of both the negative and positive implications of AS from the patient's perspective | 68 | Postal diaries | Purposive | 51.1 | Patient support group (NASS) | Negative impacts of AS on participants' lives included, pain, stiffness, postural change & fatigue. AS has negative impact on work, relationships and family life. Difficulties maintaining activities of daily living and leisure pursuits were reported. Fear about the future and the unpredictability of the disease. Positive impacts included increased awareness of importance of exercise, social benefits such as meeting other people with AS, others felt stronger and more determined with a new perspective on life. | Good |
| Ibn Yacoub et al. 2011 | Morocco | Cross-sectional | To assess the aspects of HRQoL in patients with AS & to explore the disease related parameters influencing it. | 130 | SF-36 questionnaire | Convenience | 33.1 | Outpatients | Functional disability, patients' well-being, disease activity & metrology are the main factors associated with deteriorating domains of QoL in AS. | Good |

| | | | | | | | | | | |
|--------------------|---------|--|--|------|---|-------------|---------|---|---|------|
| Kotsis et al. 2014 | Greece | Comprehensive review of prospective & intervention studies | To summarise the impact of AS on patients' QOL Review evidence of factors associated with or predicting QOL in AS | 8128 | Questionnaires (SF-36/ASQOL/SF-12/Euro-QOL 5D/NHP/SF-6D/mHAQ/WHOO (BREF/HADS)), patient reports | Multiple | unclear | Multiple | AS patients report poorer QOL compared with general public Depression and anxiety are frequent in AS patients. Most studies assessing OOL in AS are cross-sectional The most affected aspects of OL in AS are functional disability, pain, fatigue & appearance concerns. Treatment contributes greatly to the improvement of OL in AS. | Fair |
| Madsen et al 2015 | Denmark | Phenomenology | To develop an understanding of how men experience AS and the challenges related to living with this chronic disease | 13 | Interviews | Purposive | 0 | Outpatients | Four categories emerged of the men's experiences: approaching a diagnosis; Ill in a social context; challenged as a man; the importance of remaining physically well | Good |
| Mengshoel (2008) | Norway | Qualitative | To determine the relationship between illnesses and how people with AS adapt to everyday situations | 12 | Interviews | Purposive | 66.6 | Physiotherapy clinic/rehab centre/fair | Three different conditions related to living with AS were identified: ordinary life; slowed down life; disrupted life | Good |
| Mustur et al. 2009 | Serbia | Cross-sectional | To assess functional disability & QoL in patients with AS. | 74 | SF-36/EQ-5D questionnaire | Convenience | 21.6 | Outpatients | Physical function & General health has the strongest correlation with the functional index. | Good |
| Ozdemir 2011 | Turkey | Cross-sectional | To evaluate QoL in patients with AS & to determine the relationship between QoL & clinical variables | 48 | SF-36 questionnaire | Random | 8.3 | Outpatients/Patient association/journal | Disease activity and and functional scores had significantly negative correlations with all SF-36 domains except general health. | Good |
| Ozgul et al. 2006 | Turkey | Cross-sectional | To investigate the emotional & socio-demographic characteristics of AS & the impact of the disease on their social life and quality of life. | 101 | SF-36/ASQoL questionnaire | Convenience | 6.9 | Outpatients | Physical role limitation, general health and pain are the most affected domains of SF-36. | Good |

| | | | | | | | | | | |
|---------------------------|----------------|------------------------------|--|------|----------------------------|-------------|------|-------------|--|------|
| Schneeberger et al. 2014 | Argentina | Case-control | To assess fatigue & its impact on QoL in patients with AS. | 64 | ASQoL questionnaire | Convenience | 10.9 | Outpatients | There is a high prevalence of fatigue in AS patients. The QoL of these patients is significantly reduced. | Fair |
| Stockdale & Goodacre 2008 | United Kingdom | Phenomenology | To explore the impact of anti-tnf alpha on the QoL of AS patients. | 8 | semi-structured interviews | purposive | 0 | Outpatients | Anti-tnf alpha has a positive impact on the lives of people with AS. | Good |
| Turan et al. 2007 | Turkey | Cross-sectional | To evaluate QoL in patients with AS & to determine the relationship between QoL & functional status | 46 | SF-36 questionnaire | random | 19.6 | Unclear | AS patients with lower education have more explicit problems. The QoL subgroups in AS are mostly related to with enthesitis involvement. | Fair |
| Wafa-Hamdi et al. 2012 | Tunisia | Cross-sectional | To examine self-reported health status in patients with AS compared with the general population. | 100 | SF-36 questionnaire | Convenience | 12.3 | Outpatients | There is increased impairment in the QoL related to AS affecting mental health more than physical health. | Good |
| Ward 1999 | USA | Longitudinal | To identify aspects of HRQoL that are mostly affected in patients with AS | 175 | SF-36 questionnaire | Convenience | 32 | Outpatients | The most prevalent QoL concerns involved stiffness, pain, fatigue, poor sleep, medication side effects, and concerns about the future. Education level was significantly associated with differences in QoL. | Good |
| Yang et al. 2016 | China | Systematic literature search | To evaluate impact of ankylosing spondylitis on health-related quality of life assessed by the Medical Outcomes Short-Form-36 questionnaire. | 7903 | SF-36 questionnaire | Multiple | 39.5 | Multiple | AS patients suffer from substantial impaired physical and mental health. | Good |

| | | | | | | | | | | |
|--------------------|--------|-----------------|---|-----|----------------------------|--------|-------|-------------|---|-------------|
| Yilmaz et al. 2013 | Turkey | Cross-sectional | To evaluate HRQoL & related variables in patients with AS. To assess impact of peripheral involvement in various HRQoL domains | 74 | ASQoL/SF-36 questionnaires | Random | 20.27 | Outpatients | Peripheral joint involvement has a negative influence on HRQoL including physical, social & emotional functioning. | Good |
| Zhao et al. 2007 | China | RCT | To evaluate which factors could affect the physical function and QoL in AS patients. To determine the relationship between functional status & QoL in Chinese population. | 116 | ASQoL questionnaire | Random | 11 | Unclear | Physical function & QoL are damaged in a significant way. Anti-tnf alpha therapy improves QoL, physical function and disease activity markedly. | Good |

2.5.1 Characteristics of the reviewed studies

Of the 24 studies included in this review, 20 were quantitative studies (including one systematic literature review and one comprehensive review) and four were qualitative studies. Table 2.3 summarises the studies' features. Among these studies, 10 used the SF-36 questionnaire (Haywood et al. 2002), three used the ASQoL questionnaire (Doward et al. 2003), six used a combination of health-related quality of life assessment questionnaires and one study used the NHP questionnaire (Hunt et al. 1980). The majority of quantitative studies were cross-sectional (n=12) with a few case-control (n=2), randomised control trials (RCTs) (n=3) and longitudinal studies (n=1). Of the qualitative studies, two used phenomenology and the other two used unspecified qualitative methodologies. Of the two reviews, Yang et al. (2016) conducted a systematic review of studies using only the SF-36 questionnaire whilst Kotsis et al. (2014) conducted a comprehensive review of studies using multiple quality of life instruments. For the qualitative studies, some patients were recruited from the National Ankylosing Spondylitis Society (NASS), using postal diaries (Hamilton-West & Quine, 2009) and others from hospital outpatient departments using face to face semi-structured interviews (Stockdale & Goodacre, 2008; Madsen et al 2015). Mengshoel (2008) recruited participants from ambulatory physiotherapy clinic, rehabilitation centre and an invitation from the Norwegian Patient Association Journal, using in-depth individual interviews

In total, 4148 AS patients were included in the quantitative studies, of which 3369 (82%) were male and 779 (19%) were female. The qualitative studies included a total of 101 patients made up of 70 males (69.3%) and 31 females (35.2%). The literature review by Yang et al. (2016) had a total of 7903 patients from 38 eligible studies of which 5675 (71.8%) were males and 2228 (28.2 %) were females. The comprehensive review by Kotsis and colleagues (2014) included 36 studies and 8128 patients, however

this is not clearly presented and the male to female ratio is not stated. The number of women in each study and overall is small (see Table 2.3) suggesting this is an under-researched area or this might support the assertion that AS is more common in males than females. Interestingly Mengshoel's (2008) study in Norway was the only study in the review with more females (66.6%) than men. The sample size in all the studies ranged from 8 to 8128 participants. The studies included in my review are from different populations worldwide: eight from Turkey, two each from the UK and China, one study each for USA, Tunisia, Argentina, Denmark, China, Serbia, Spain, Morocco, Greece, Canada/Australia and two studies were a multicentre collaboration between the USA/France /Netherlands. Thus, some comparisons between different populations with AS could be considered as reported throughout the rest of this chapter. Interestingly, none of the studies were specifically focused on Bangladeshi patients and it is unclear if any of the studies included them as a population sub group.

2.6 Summary of results

The literature review has highlighted some key challenges affecting different aspects of living with AS and these are summarised in Table 2.3. Summaries of the literature review will be presented in two sections. The qualitative studies will be discussed first, because their designs and questions are the closest to mine, which aims to explore experiences of living with AS. The quantitative studies are discussed in the second section.

2.6.1 Experiences of living with AS

Studies that focus on the living with AS from the patient perspective are rare. Only four qualitative studies were identified in this review (Mengshoel, 2008; Stockdale & Goodacre, 2008; Hamilton-West & Quine, 2009; Madsen et al. 2015). These studies offer deeper insights on the participants' perspective and the strategies used in their journey with AS. They also enable researchers to obtain insights into what it feels like to be another person and to understand the world as others experience it (Austin & Sutton, 2014). There is a suggestion here that qualitative studies delve deeper into the thoughts and behaviours that govern processes that people experience, why they respond and more importantly, the context in which they respond. In contrast, quantitative studies provide evidence in terms of appropriate statistical analyses and numbers, failing to provide the 'how' of the individual's experience of an illness. This section will review the study methodologies used and the insight they provide in terms of understanding the lived experience of HRQOL in AS.

Two of the papers used a phenomenological approach (Stockdale & Goodacre, 2008; Madsen et al. 2015) whilst the other papers are not clear on the qualitative methodology used. Face to face in-depth interviews were used for data collection in all the studies apart from Hamilton-West & Quine (2009) who used postal diaries as their method of data collection. The majority of participants in the studies were male. Interestingly Mengshoel's study is the only study in the review with more female participants (66%).

Hamilton-West and Quine (2009) examined individuals' experiences of AS in their own words, using postal diaries. The authors recruited 68 individuals with AS, from Kent in the UK. Participants were provided with booklets in which they were asked to describe ways in which 'AS has had a negative impact on your life' and any ways in which 'AS has had a positive impact on your life'. The participants described both positive

(increased awareness of importance of exercise, social benefits such as meeting others and a new perspective on life) and negative (pain, stiffness, fatigue, work, relationships and family life) impacts of AS. The authors concluded that the experience of AS is not only associated with negative physical and psychosocial outcomes, but also positive physical and psychosocial outcomes. Difficulties in relationships have been reported elsewhere (Doward, et al. 2003), but this study has gone further to consider why the participants may experience the problems in their interpersonal relationships. The participants' narrated feeling irritable, functional limitations, symptoms of pain and stiffness.

Stockdale and Goodacre (2008) used a phenomenological approach with purposive sampling, to conduct their study. The aim was to explore the impact of anti-TNF treatment on the quality of life of 8 men from Lancashire in the UK. Analysis identified an overarching theme, 'It is magic stuff', and four categories were identified within this theme (the world is my oyster now; having a taste of normality; It was too tortuous; small price to pay). It was concluded that anti-TNF treatment has a positive impact on the lives of people with AS and participants feared that the withdrawal of treatment would cause a relapse of their AS. These findings are commensurate with findings from other quantitative studies illustrating the overall impact of anti-TNF treatment on quality of life (Gorman et al. 2002; Braun et al. 2005; Davis et al, 2005)

A more recent study by Madsen et al. (2015) used a phenomenological approach to illuminate men's' experiences of living with AS in Denmark. The data was collected using semi-structured in-depth interviews. Four categories were identified from the interviews: approaching a diagnosis; ill in a social context; challenged as a man and the importance of remaining physically active (Madsen et al. 2015). The authors were also able to conclude that AS impacts men's' perceptions of themselves as men, relationships as a partner and father, social lives and masculine identity. The

methodology allowed the authors to understand the lived experience and the challenges related to living with AS, as a man. The role of being a husband, father and member of the household was described as tiring and difficult to overcome by the participants, suggesting the men's masculinity was challenged. These results are similar to findings from a Danish study (Nielsen et al. 2011) on men living with osteoporosis in which they found themselves vulnerable after their diagnosis.

Mengshoel (2008) in Norway supported Hamilton-West and Quine (2009), using a qualitative approach to examine the relationship between illness and how people with AS adapt to everyday life situations. The findings reported three different life conditions: the ordinary life, the slowed down life and disrupted life. The study concluded that living with AS requires a continuous but varying process of normalisation of symptoms and everyday life, within the framework of these three conditions. In the ordinary life, the participants managed their symptoms by incorporating motion into everyday life routine and adjusting tasks in work situations, home life and social activities. During the slowed down life, there was an acute or insidious onset of symptoms of pain and fatigue that could be reversed by slowing down ordinary life. Finally, during the disrupted life the participants were unable to cope with everyday life because of inexplicable and unmanageable intense and distributed pain. This study has emphasized the fluctuating nature of AS and the continuous process of normalisation of symptoms that is required. Similar findings are reported elsewhere (Ward et al. 1999; Martindale et al. 2006).

The papers selected in this section explored the experience of living with AS from the patient's perspective. What can be seen are many common themes from the participants' voices. These results have echoed the findings from the literature using questionnaires. Furthermore, they have addressed both the 'what' and the 'why' of the lived experience of AS, allowing the experience to be elucidated in its fullness.

2.6.2 Studies using quantitative methods

Twenty papers were selected in this category (Table 2.3) including one systematic literature review (Yang et al. 2016) and one comprehensive review (Kotsis et al. 2014). There is a collective trend, which highlights some key themes affecting quality of life in AS, such as physical and functional disability, social functioning, psychological and emotional limitation, and general health, effects of education, gender, sexual functioning, contextual factors and experiences of treatment. These will be discussed in more detail in this section.

2.6.2.1 Physical function and functional disability

Most studies focused on physical function and functional disability as, AS has a direct impact on the participants' bodily functions. All dimensions of the SF-36 (Haywood et al. 2002) were found to be significantly affected in several studies (Dagfinrud et al. 2004; Davis et al. 2005; Ozgul et al. 2006; Bodur et al. 2011), with poor scores in physical role limitation, physical function, general health and bodily pain. Pain and stiffness were the major symptoms of AS causing different physical limitations. Patients with high disease activity and worse functional status had significantly poorer quality of life scores. One study in contrast found that the ASQOL (Doward et al. 2003) however was less influenced by disease activity (Bostan et al. 2003). Elsewhere (Ward, 1999; Wafa-Hamdi, 2012; Yang et al. 2016) reported similar findings, that physical health was more likely to be affected by the disease than mental health. Social functioning and mental health were the least affected domains. These results concurred with previous findings that chronic musculoskeletal pain was associated with poor health in all dimensions of the SF-36 (Smith et al. 2001) and that physical dimensions of the SF-36

were more seriously affected by pain than the psychological dimensions (Carmona et al. 2001).

Functional disability is the main contributor to the burden associated with AS (Kiltz & van der Heijde, 2009). The association between functional disability and quality of life has been found in various countries (Ariza-Ariza et al. 2003; Bostan et al. 2003; Zhao et al. 2007; Turan et al. 2007; Mustur et al. 2009; Wafa-Hamdi et al. 2012). Results showed physical function, physical role, bodily pain and general health had the strongest correlations with the functional index. Bostan et al. (2003) found that the most important determinants in self-reported quality of life were the levels of functional disability and disease activity. Elsewhere, Ward (2002) indicated that longer disease duration and increasing age are associated with decreased functioning, whereas performing back exercises and having a greater degree of social support improves functioning.

2.6.2.2 Social Functioning and QoL in AS

Social functioning is another area found to be negatively affected by AS (Ward, 1999; Ozgul et al. 2006; Waf-Hamdi et al. 2012; Yilmaz et al. 2013). Wafa-Hamdi et al. (2012) noted significant ($p = 0.002$) impairment in the social functioning domain of the SF-36. A cross-sectional study by Yilmaz et al. (2013) also assessed the impact of peripheral involvement on various health-related quality of life domains in terms of disease activity, functional status, severity of pain and social and emotional functioning. The most affected dimension in SF-36 was general health (39.23%). Physical role (42.23%), emotional role (47.27%) and bodily pain (50.28%) subgroups followed it respectively. Similar findings are reported in other studies (Ariza-Ariza et al. 2003; Ozgul et al. 2006).

2.6.2.3 Emotional and psychological functioning and QoL in AS

Mental health and emotional functioning domains have been found to be impaired in some studies (Ozgul et al. 2006; Turan et al. 2007; Yilmaz, et al. 2013). Turan et al. (2007) concluded that the increase in chest expansion and more comfortable breathing of the patient affects their emotional condition positively while the patient's functional limitations affects the emotional condition negatively causing problems in their daily life. Social functioning (60.1%) and mental health (55.4%) were the least affected domains reported by Ozgul et al. (2006), with higher educational levels of the patients showing higher quality of life scores.

A meta-analysis by Yang et al. (2016) showed that a third of the AS patients reported a high level of depressive symptoms, undermining the stereotype of the 'typical' AS patient as being less depressed than other people with other forms of arthritis ((Barlow et al. 1993). Elsewhere, Kotsis et al. (2014) found that physical and mental quality of life is impaired in AS, compared with the general population and is comparable to quality of life of patients with other rheumatic disorders. These findings were supported by Martindale et al. (2006), who assessed disease and psychological status in AS and found disease scores (BASDAI-Garrett et al. 1994; BASFI-Calin et al. 1994) correlated significantly with anxiety, depression, internality and generic health status.

2.6.2.4 Contextual factors and QoL in AS

Nationality and ethnicity are important when interpreting health-related quality of life. According to commentators (Schmidt & Bullinger, 2003; Goeree et al. 2007) nationality and ethnicity represent the cultural background of subjects that is determined by (cultural) perceptions of illness, the meaning of health-related quality of life and expectations of health care. A cross-sectional study by Gordeev et al. (2010), showed

that contextual factors explained 47% of the variance in ASQoL (Doward et al. 2003) and overall HRQOL was better in the Australian group but was not significantly different from that of the Canadian patients (ASQOL mean SD- 5.8 (5.3) and 6.6 (5.8) respectively). The study demonstrated the importance of helplessness and employment status on self-reported health states in patients with AS. An interaction was seen between education and employment when ASQOL (Doward et al. 2003) was the outcome ($p= 0.001$). Neither nationality nor ethnicity had an independent effect on health-related quality of life despite huge differences in sociodemographic and disease characteristics between both countries. The literature has reported that low socio-economic status is associated with reduced health-related quality of life (Robert et al. 2009), intriguingly Yang et al. (2016) noted that scores of all the domains from developing countries were higher than those patients from developed countries. They speculated that because health-related quality of life was measured by self-reported method in their study, patients from developing countries may be more optimistic in the initial stages of their disease because they know little about the disease. Secondly, people with higher economic status might prefer to put more energy on their health.

2.6.2.5 Fatigue and QoL in AS

Fatigue is an important clinical feature of AS present in a majority of patients (Bodur et al. 2011; Stebbings et al. 2013). Whilst fatigue is a complex phenomenon (Swain 2000), it can be seen as an enduring subjective sensation of generalised tiredness or exhaustion (Bella, 1994). Some studies found that fatigue was significantly associated with all SF-36 dimensions of quality of life (Alkan et al. 2013; Bodur et al. 2011). Elsewhere, van Tubergen et al. (2002) showed that scores on the BASDAI (Garrett et al. 1994) fatigue question were significantly associated with scores on several dimensions of the SF-36

(Haywood et al. 2002) and with the ASQOL (Doward et al. 2003), suggesting that health-related quality of life is influenced by the degree of fatigue. Huibers et al. (2007) also found a close association between fatigue and depression, although they were unclear if the fatigue was caused by psychological distress or a separate entity.

2.6.2.6 Educational level and QoL in AS

Educational level has been found to be an important predictor of health-related quality of life. Ward (1999) reported that quality of life was poorer among the less educated patients. Patients with 12 years education or less were 2 to 4 times more likely than persons with some college education to report problems of at least some importance with medication side effects ($p = 0.06$), mobility ($p = 0.03$), coping with illness ($p = 0.04$), anxiety ($p = 0.01$), self-care tasks ($p = 0.03$) and relationships with spouses or other family members ($p = 0.05$ & 0.04 respectively). Similar findings were reported elsewhere (Ozgul et al. 2006; Turan et al. 2007). These results are however contrasted by Wafa-Hamdi et al. (2012) who found that the higher education group of AS patients reported significantly worse health across all scales of the SF-36 survey.

2.6.2.7 Gender and QoL in AS

Initially AS was considered a predominantly male disease, however in recent years the diagnosis of AS in women has increased (de-Carvalho et al. 2012). The impact of gender differences on AS patients' quality of life has been poorly studied. However, there are conflicting results in the few studies with some suggesting that AS presents more differently according to gender (Ibn Yacoub, et al. 2012), and others finding no differences (Yang et al. 2016). On the influence of gender on the quality of life in AS,

Wafa-Hamdi et al. (2012) found that women had better quality of life than men. All the males in the study reported significantly impaired health on all subscales of the SF-36 whereas women reported poorer health on only three scales (physical functioning, general health and bodily pain). Dagfinrud et al. (2004) found significant differences between men and women in the AS group for physical functioning ($p = 0.01$), role physical ($p = 0.01$), and vitality scales ($p = 0.001$), with women reporting worse health than men. When subjective health was measured in this study, women with AS reported worse physical functioning, more physical limitations, and a greater reduction in vitality than men. Ibn Yacoub et al. (2012) reported that men had lower scores in physical and social domains of quality of life but there were no differences in functional impairment scores. Similarly, Ward (1999) showed that women are more likely to have problems with fatigue, coping, job performance and in general more pain and role limitations due to physical problems. Other studies have shown that some differences exist between men and women in the course of the disease (Kidd et al. 1988; Gran & Husby, 1990). Elsewhere, no difference was found in SF-36 between men and women by Yang et al. (2016) in their meta-analysis, which demonstrated no gender differences in the impairment of quality of life among AS patients.

2.6.2.8 General health and QOL in AS

The concept of quality of life includes different domains of a person's life affected by a particular disease. Concerning the effects of AS on general health, Ward (1999) found the most prevalent concerns to include, stiffness (90.2%), pain (83.1%), fatigue (62.4%), poor sleep (54.1%), appearance (50.6%), worries about the future (50.3%) and medication side effects (41%). Aspects of mental health such as depression (28.7%), anxiety (28.6%), social relationships (8.1%) and coping with illness (32.4%) were not

regarded as very important. These findings are supported elsewhere (Mustur et al. 2009; Bodur et al. 2011; Yilmaz et al. 2012).

On sexual problems in AS, Cakar et al. (2007) reported, that sexual life was affected negatively by the AS in general, in twenty-seven patients (50.94%) and 26 patients (49.06%) expressed no negative effect. Both affected and unaffected patients were compared with each other with regards to educational level, joint involvement, functionality, disease activity, quality of life and depression status. The physical functioning, role limitation due to physical problems, vitality/energy and fatigue, general mental health and general health perceptions subscale scores of SF-36 (Haywood et al. 2002) were worse in the affected group and the differences were statistically significant ($p = 0.027$, $p = 0.023$, $p = 0.013$, $p = 0.005$, $p = 0.045$, respectively). Similar findings were reported elsewhere (Younes et al. 2010).

2.6.2.9 Influence of anti-TNF treatment on QoL in AS

Advances in medicine and biotechnology have led to the development of novel therapeutic agents such as anti- tumour necrosis factor alpha (anti-TNF) agents which may improve quality of life (Wang et al. 2014; Dhillon, 2014). Davis et al. (2005; 2007) evaluated the impact of etanercept and adalimumab therapy on health-related quality of life, with findings from both studies showing that both treatments improve the SF-36 scores (Haywood et al. 2002) significantly. There were consistent and significant improvements across a range of physical function and health- related quality of life outcomes. The findings are similar to those from other studies (Ozgul et al.2006; Zhao et al. 2007; Stockdale & Goodacre, 2008) which have illustrated the overall impact of these therapies on health- related quality of life.

It is important to note however that because randomised- controlled trials have a strict inclusion and exclusion criteria the extent to which the findings can be applied to patients seen in routine clinical practice may be limited. According to Black (1996) patients recruited to this type of study are under more careful observation and these conditions may have little resemblance to routine clinical practice.

2.7 Recommendations from the literature review

The majority of studies in this review have made recommendations to improve the quality of life of patients with AS in clinical practice and highlighted the need for further research in some areas.

2.7.1 Recommendations for research

Ward (1999) suggested that socioeconomic status may have a greater effect on health outcomes in AS than previously recognised and he recommended that in order to improve quality of life in this ‘high risk group’ further research on the mechanisms by which lower socioeconomic status is associated with poorer quality of life is needed. Some studies had no female participants or included a small number, leading others to recommend that further work is needed to explore experiences of treatment in women (Stockdale & Goodacre, 2008) while others recommended additional studies to determine if health-related quality of life reduction can be sustained and improved upon with continued anti-TNF treatment (Davis et al. 2005, 2007). Hamilton-West and Quine (2009) recommended further qualitative research in this area, as an important and necessary step in gaining a deeper understanding of the specific nature of patients’

concerns. This approach, they assert, could also provide an insight into methods patients use to cope with the impacts of AS.

Several authors have suggested that further longitudinal research is required, to identify factors associated with physical function and health-related quality of life (Ariza-Ariza et al. 2003) and to establish the definitive relationship between functional disability and quality of life in AS (Mustur et al. 2009). Kotsis et al. (2014) have recommended additional studies to investigate the course of psychological distress in AS as well as the interplay between clinical variables and distress in the formation of quality of life. Madsen et al. (2015) suggested further research to explore the experiences of partners and children due to the complex process that requires more evidence for support. There is an acknowledgement that the AS does not just affect the individual but the entire family including partners and children.

2.7.2 Recommendations for practice

On the diagnosis of AS, Bodur et al. (2011) have recommended the need for early diagnosis and effective treatment in order to provide the improvement of pain, fatigue, disease activity and prevent functional limitations, therefore improving quality of life. Ward (1999) suggested clinicians should routinely ask patients about common symptoms such as poor sleep, fatigue, pain and stiffness and try to identify ways to improve them. Ward went further to recommend that clinicians should provide information about long-term outcomes of AS, as this might ease the patients' concerns. Yang et al. (2016) have recommended that clinicians should consider measuring health-related quality of life as an essential part of overall assessment of health status of AS patients. This is because this would provide valuable clues for improving the management of disease and making decisions on treatment. Turan et al. (2007)

recommended that management strategies should focus on decreasing pain due to enthesitis, maintaining physical activity, and efforts to improve psychosocial health aspects for increasing quality of life in patients with AS.

Other recommendations regarded psychosocial interventions that could be incorporated into the treatment of AS patients, in order to minimise some of the negative impacts of AS whilst allowing patients to benefit from some of the positive life changes reported. The interventions include, keeping active, minimising work-interference, self-esteem and social support, overcoming irritability and negative mood and balneotherapy for AS patients.

The qualitative study by Madsen et al. (2015) has noted the challenge to adapt to a new life situation with an invisible disease, and they have recommended future health promoting interventions. These include discussions on the experiences of waiting for a diagnosis and the consequences of living with an invisible disease and lifelong medical treatment; guidance to patients on how to remain physically active, knowing possibilities that are available and what is appropriate for the individual.

2.8 Limitations of this review

A structured approach similar to that used in systematic literature reviews was followed in this review: restricting focus to well-defined issues, establishing a clear inclusion and exclusion criteria for the literature search and concentrating on a specific set of studies. This was in order to aid interpretation, the translation and application of published research (Ferrari, 2015). However, there are some limitations to this narrative review. Firstly, although this review has used a systematic approach, subjectivity in study selection is the main weakness ascribed to this type of review and this can potentially lead to selection biases (Pae, 2015). Undertaking a systematic review where a wider range of databases would be searched may have generated additional studies in this

area. Some of the studies included in this review did not state the participation rate of the patients and this affects the interpretation and validity of the results (Cohen et al. 2008). Some factors influencing quality of life have not been included. Only SF-36, ASQoL, NHP and EQ-5D data was obtained in the quantitative studies. Other studies might have used other quality of life measures and this might affect the interpretation of the results. There is a recruitment bias in the studies as patients were recruited from different sources to include, outpatient departments, databases, National Ankylosing Spondylitis Society groups, academic and community groups. Patients from the societies and academic groups might be highly motivated to take an active interest in their condition. Not all AS patients are registered with the support and academic groups and their issues might be different. Patients recruited from hospitals might have more severe disease than those recruited through community centres. The diagnostic criteria used in the quantitative studies were the 1984 Modified New York Criteria suggesting that the included studies had patients with established disease. Patients diagnosed using the more recent diagnostic criteria might have different issues. Some of the parameters in the measurement scales used in the review are weighted differently by different groups of people with the same illness, and this can affect the interpretation of the results. All the studies in the review have a majority of male patients and participants are mainly White and well educated. The excluded women and ethnic minority patients with AS might have different health-related quality of life concerns to the ones highlighted in this review. All these factors may be associated with differences in health-related quality of life.

Grey area literature has not been used in this review. According to Bowling (2014) this type of literature can be useful in reviews to understand concepts, inform policy and practice as well as future research. The exclusion of grey literature in this review therefore means that the findings may still be vulnerable to selective reporting.

2.9 Chapter Summary

The aim of this narrative review was to establish the current state of research in the area of health-related quality of life in AS. One perspective (quantitative approach) using questionnaires in different populations, dominates the discourse on HRQOL in AS. The qualitative approach has challenged this view by calling for a subjective exploration of the concept of HRQOL in AS, arguing that measurement scales fail to capture the essence of the lived experience of the illness.

The literature has demonstrated the complex nature of the experience of health-related quality of life in AS, however there is agreement that patients with ankylosing spondylitis have a poor quality of life. Several authors have highlighted their recommendations for further work in specific areas. There is a lack of awareness of the lived experience of health-related quality of life in Bangladeshi patients with AS in the UK. Only a few studies employed qualitative methods to explore how patients live with AS. Most studies have tended to be conducted in one geographical area, which includes highly educated members of the White population. There is therefore a need for exploratory research, using more detailed qualitative interviewing techniques to gain an in depth understanding of health-related quality of life in AS, as it is experienced by the Bangladeshi population in the UK.

As such the stage has been set for the study conducted for this thesis: an exploration of the lived experience of health-related quality of life in Bangladeshi patients with ankylosing spondylitis.

2.10 Rationale for the study

This narrative review set out to provide an overview of the current knowledge as it stands in health-related quality of life in Bangladeshi patients with AS and identify any

gaps in knowledge. No studies identified were focused specifically on this group of patients. As a result, the review focused generally on health-related quality of life in AS. It is clear from the literature reviewed that the domains related to health-related quality of life using the questionnaires have been comprehensively explored in different populations. The myriad of variables identified in the review, however fail to elucidate the subjective meaning of the experience of the condition as it is lived by the individual. The majority of the evidence presented is not specific to the Bangladeshi population or other ethnic minority populations in the UK, despite evidence to show that there is a negative association between low socioeconomic status and poorer health-related quality of life (Robert et al. 2009). There is therefore a gap in the musculoskeletal research literature on the lived experience of health-related quality of life amongst the Bangladeshi population with AS in the UK. The majority of studies conducted, have been from a positivist approach involving the use of measurement scales that do not capture the essence of the lived experience. This research will add new knowledge to this neglected area by providing information to policy makers and healthcare providers so that they can have a better understanding of the needs of this group of patients. Finally, this research is being carried out using a sample from the Bangladeshi community residing in a deprived area of London, where they are the largest ethnic minority group. This will therefore provide crucial information for future researchers wishing to study health-related quality of life experiences in AS among the Bangladeshi population. This research will capture the participants' meanings of their experience and more importantly the 'silent' voices of the Bangladeshi patients will be heard and their experiences highlighted. Findings will provide an in-depth understanding of this phenomenon.

The identified gaps in the current literature present the foundations for future research in an area of which to date nothing has been published in the UK and allow the exploration

of the research question: What is the lived experience of health-related quality of life in Bangladeshi patients with ankylosing spondylitis?

2.11 Aims, research question and intended objectives

This study seeks to contribute to the limited qualitative literature on lived experience of HRQOL in AS in the UK. Specifically, its overarching aim is to highlight the research base on Bangladeshi patients' experiences of living with AS in their day to day lives, seeking to elucidate a deeper understanding in relation to their context. The critical literature has described how all the published studies in this area so far have used predominantly, male, White and highly educated participants. In addition research suggests that low socioeconomic status affects individuals' quality of life. This thesis therefore considers, within the context of a group of Bangladeshi patients, the lived experience of HRQOL, and their narratives from semi-structured interviews. The intention is to generate the Bangladeshi participants' perspective of the lived experience of AS in an inner London borough and to provide the evidence and recommendations for research, policy and practice.

No research has been carried out to exclusively explore the HRQOL experience of Bangladeshi patients with AS in the UK. The analytic aim of the thesis follows an interpretive approach to address the research question: What is the lived experience of health-related quality of life in Bangladeshi patients with ankylosing spondylitis?

The study will be guided by the following objectives:

1. To gain an in-depth understanding of the health-related quality of life issues among Bangladeshi patients with ankylosing spondylitis from a physical, social and psychological perspective as well as experiences of treatment.

2. To inform policy makers, healthcare providers and healthcare professionals about the experiences of the Bangladeshi population with ankylosing spondylitis and implications for care provision.

The intended study outcomes are:

1. To add new knowledge to the under-researched area of the lived experience of health-related quality of life in Bangladeshi patients with AS and inform healthcare provision.
2. For the 'silent voices' of the Bangladeshi population who are living with AS to be heard.

I have used an interpretive qualitative methodology in this exploration, in order to contribute to the body of knowledge in this under-researched area and potentiate further research in the UK. In Chapter 3, the methods will be explained in detail.

Chapter 3: Methodology

3.1 Introduction

Having identified a gap through the literature review, in the understanding of the lived experience of health-related quality of life in Bangladeshi patients with ankylosing spondylitis, this chapter starts by considering different research paradigms and matters of ontology and epistemology. They can influence the way in which the research is undertaken, from design through to conclusion. In this chapter I present the approach that has guided this study as well as the philosophical assumptions on which the study is based. The differences between the types of phenomenology will be clarified to help explain the choice of interpretive phenomenology in this study. Stubblefield and Murray (2002) have discussed problems faced by qualitative researchers who fail to provide a link between method used and a clear statement of the philosophical underpinnings that should guide the method. They assert that this practice results in research that is ambiguous in its purpose, structure and findings. Other commentators have stressed the need for researchers to be clear about which approach they are using in their research so that data collection suits that method otherwise the value of the research is reduced significantly (Dowling, 2004; Annells, 2007). The use of a Heideggerian interpretive phenomenology in the context of this study will be explained including, van Manen's (1990) framework which has guided my study, recruitment, sampling and data analysis. Finally, ethical considerations and the path used to ensure trustworthiness as well as reflexivity will be demonstrated.

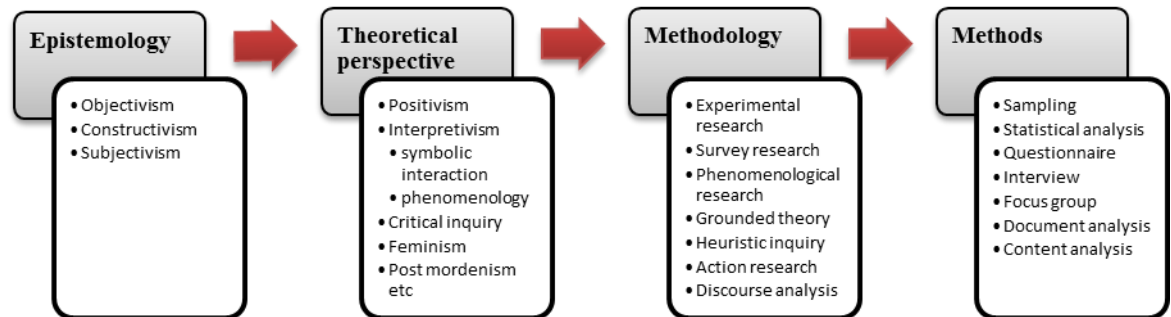
3.2 Philosophical perspectives

The foundations of research are built on ontology and epistemology. Ontology relates to the nature of social reality and its characteristics (Creswell, 2013). There is an

assumption here that what we believe is what constitutes a social reality. The nature of this social reality, perceptions, beliefs and assumptions will influence the way in which research is undertaken (Blaikie, 1993). The researcher therefore considers a series of choices and aligns them to the original research topic. Crotty (1996) has suggested that researchers generally subscribe to either of two tenets, constructivism, where individuals socially and discursively construct reality in different ways or objectivism, where reality is independent of an individual's knowledge of it (see Fig 3.1). I consider my position and own influences on this research to be constructivist with an understanding that meanings are constructed and not discovered. My stance agrees with Crotty (1996) who suggests that different people, even in relation to one phenomenon, construct meaning in their own way.

Epistemology on the other hand is concerned with the theory of knowledge (Blaikie, 2000; Bowling, 2014). Harding (1987, p.2) lists epistemological issues as 'issues about an adequate theory of knowledge or justificatory strategy'. Crotty (1998) has also described epistemology simply as a way of understanding and explaining 'how we know what we know' (p.3). Here the most appropriate ways of enquiring into the nature of the world are considered to include, the research method and how the knowledge can be produced and argued for (Hatch & Cunliffe, 2006). Carter and Little (2007) go further with the argument that it is impossible to engage in knowledge creation without at least tacit assumptions about what knowledge is and how it is constructed. In this study, I see myself as an active creator of the research, inextricably imprinted on it from beginning to end and through reflexivity. I will be transparent about my own subjectivity so that readers can make judgements about it.

Fig 3.1 Relationship between epistemology, theoretical perspectives, methodology & research methods



Source: adapted from Crotty 1998

The knowledge that I am creating from my research is a production of my interactions with the Bangladeshi participants with AS, in this specific context. I bring my own beliefs and philosophical assumptions into this research. Through exploring the multiple forms of evidence from the Bangladeshi participants' individual perspectives and experiences, I embrace the multiple realities that Creswell (2013) describes. Axiologically, I have openly discussed the values that have shaped the narrative in this study and included my own interpretation as well as the interpretation of the participants. My methodology therefore is inductive, emerging and shaped by my experience in collecting and analysing the data (Creswell, 2013).

3.2.1 Positivism

Research paradigms are formed from ontological and epistemological positions and they classify the different approaches used in research. There are three key paradigms

that form the ‘poles’ from which other paradigms are derived, however, positivism and interpretivism are the two dominant traditions. The positivist position is deductive and assumes that the social world exists objectively and externally, and that knowledge is only valid if it is based on observations of this external reality (Blaikie, 1993; Hughes & Sharrock, 1997; Cohen et al. 2008). This position focuses on facts gathered through direct observation and experience, measured empirically using quantitative methods and statistical analysis. Positivism with its quantification techniques, therefore seeks objectivity using rational and logical approaches to research (Cohen et al. 2008). Here human objectivity is negated through strictly controlled methods of data collection and data analysis (Reiners, 2012). As a philosophy, positivism can be seen as having an atomistic, ontological view of the world, which is measurable, quantifiable and usually described as quantitative research. Positivism is criticised by Cohen et al. (2008, p18) for ‘failing to take account of our unique ability to interpret our experiences and represent them to ourselves’. Other critics suggest that it seriously diminishes the very characteristic that makes human beings human (Horkheimer, 1972; Miles & Huberman, 1994).

3.2.2 Interpretivism

In direct contrast to positivism, interpretivist or constructivist paradigm is inductive and believes that our knowledge of the world is ‘socially constructed’. It argues that individuals and groups make sense of situations based on their individual experiences, memories and expectations (Hamersley & Atkinson, 2003). Multiple interpretations are created to construct meaning in a social reality in which people act. Saunders et al. (2007) assert that with the constructivist position, the researcher focuses on understanding the meanings, interpretations and contextual factors of the social actors

from their world point of view. There is an association between constructivism and qualitative methodologies due to its emphasis on language and views on people's thoughts and feelings. There is a focus on meaning and human interpretation, measuring the quality rather than the quantity of phenomena. Some notable writers have summarised this position (Crotty, 1998; Lincoln & Guba, 2000; Schwandt, 2007; Creswell, 2013). They contend that this type of research addresses the processes of interaction among individuals and focuses on specific contexts in which people live and work. This is in order to understand their historical and cultural settings. In terms of epistemology, interpretivism is the theoretical perspective closely linked to constructivism.

The third position termed critical realism can be seen as the middle ground between positivism and interpretivism (May, 2001). It helps people change conditions and improve their world. According to Bhaskar (1998), critical realism addresses the structures which determine, constrain and express the individual's activities. Innate psychological mechanisms as well as wider social mechanisms will therefore influence people's actions. Positivists set out to describe social life, predict and generalise courses of events whilst interpretive researchers aim to understand and interpret the social life. The critical realist researcher aims to explain and change the social world (Blaikie, 2000).

3.3 Choosing a paradigm

All researchers bring a specific underlying philosophy into their research. There is an assumption about reality and understandings of human knowledge and the theoretical perspective which lies behind the methodology used. The term methodology is used loosely in the literature resulting in what Crotty (1998) refers to as unclear, confusing

and contradictory terminology. Schwandt (2001, p.161) defines methodology as 'analysis of the assumptions, principles and procedures in a particular approach to enquiry'. It is not uncommon however to find terms such as approach, perspective and methodologies used interchangeably, with no considerations for their distinct meanings. It is important to note that a methodology is a research design that guides the researcher in 'choosing methods and shapes the use of the methods chosen' (Crotty, 1998 p.3). Crotty argues that it is not enough to describe a methodology but 'to give an account of the rationale it provides for the choice of methods and the particular forms in which the methods are employed' (p.7).

This study aimed to explore the complex phenomenon of lived experience rather than empirically test such understanding. There is a gap in our understanding of the lived experience of health-related quality of life in Bangladeshi patients with AS. This has been established following the literature review conducted in Chapter 2 of this thesis. This type of exploration fits with the interpretivist paradigm which seeks to understand an experience rather than empirically test such understanding. Interpretivism also fits well with my own ontological perspective where individuals create their own meaning and realities. Here I do not aim for a conclusive outcome but suggestion of a way of viewing experience through multiple realities.

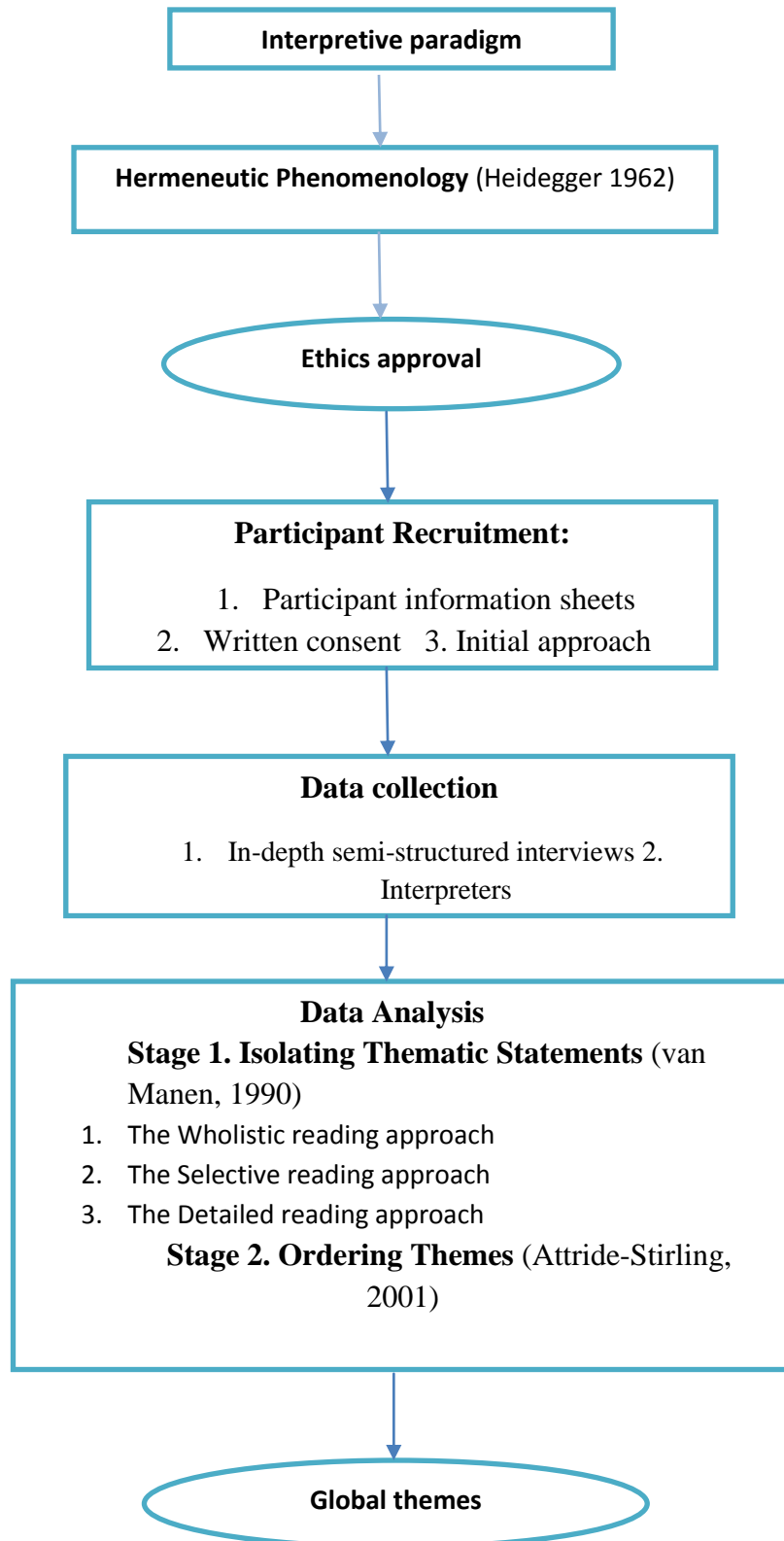
There are a number of research methodologies aligned to the interpretivist paradigm, such as grounded theory, which seeks to develop a theory (Corbin & Strauss, 2007), ethnography, which is concerned with shared and learned patterns of a culture sharing group (Harris, 1968), case study, which seeks to study a case within a real-life, contemporary context or setting (Yin, 2009), narrative research, which reports the experience of an individual (Daiute & Lightfoot, 2004) and phenomenology which describes the common meaning of several individuals of their lived experience (Moustakas,1994). Whilst there are similarities in these approaches to research such as

the general process, data collection techniques and designs, there are some fundamental differences in their foci (Creswell, 2013).

This research aims to ‘lift up the voices’ of the Bangladeshi patients with ankylosing spondylitis, who are an under-researched group, through an exploration of their lived experience of health-related quality of life. Van Manen (1990, p.177) aptly describes the essence of a phenomenological investigation as, ‘a grasp of the very nature of the thing’. Phenomenology is the chosen methodology for this study. As a term phenomenology refers to the study of phenomena, where a phenomenon is anything that appears to someone in their conscious experience (Moran, 2000). There is a variety of phenomenological methodologies available for investigating individuals’ experiences. However, there is little guidance to help researchers choose between these variants to meet the specific needs of their studies (Gill, 2014). As a novice researcher, I have found it difficult and confusing to access what it is that constitutes appropriate or ‘sound’ phenomenological research. Examples of those available are, Giorgi’s framework, based on the reduction and imaginative variation (Giorgi, 1989), the open life world approach of Dahlberg et al. (2008), van Manen’s lived experience human science enquiry based on the Utrecht tradition (1990), and Smith’s Interpretive Phenomenological Analysis (IPA) that is idiographic and inductive (Smith, 2004). I have tended to agree with Finlay (2009) whose position on phenomenological research is that it involves a rich description of the life world or lived experience, where the researcher has adopted a special, open phenomenological attitude which, at least initially refrains from importing external frameworks and sets aside judgements about the realness of the phenomenon. According to Adams and van Manen (2017) phenomenological research is never a prescribed procedural or step by step form of inquiry. Rather, the methods employed need to be commensurate with the phenomenon being studied and pursued with an appreciation for the original literature. The

Hermeneutic approach that I have chosen for this research is therefore, a method that lies in interpretation, constituting an inevitable and basic structure of our 'being-in-the-world' (Heidegger, 1962, p.37). An overview of the research approach used in this study is shown in Fig 3.2.

Fig 3.2 Study methodology



3.4 Historical development of Phenomenology

Social scientists (Oakley, 2000; Merton, 1968) in the 1960s led the charge against traditional scientific approaches to knowledge gathering. They criticised science and quantification 'due to its effects in closing off from view, not only the experiences of ordinary people, but what these could tell social scientists about the way in which society itself is constructed' Oakley (2000, p.32). Feminism emerged around the same time and this added onto the rivalry on the issue of conceptualising society. The feminist movement's critique of the statistical dominance of men and the use of quantitative methods claimed that, experiences and voices were not accounted for, the questions asked were inappropriate to women's lives and women were excluded from research samples (Sherman & Beck, 1979; Stanley & Wise, 1983).

Phenomenology has its roots in both philosophy and psychology. Husserl, who is known as the father of phenomenology, initiated the phenomenological movement at the beginning of the 20th century, and later Heidegger elaborated it towards an existential and hermeneutic dimension (Finlay, 2009). Closely linked to Heidegger, Gadamer's philosophy which is seen as an extension of Heidegger's school of thought, advocates that people experience the world through language (Gadamer, 2006). Through language you can engage the horizons of the researcher and locate participants within their historical context. Gadamer's hermeneutic phenomenology therefore brings language as the medium for understanding the complex human experience.

Many schools of thought have criticised the dominant philosophy underlying scientific methodology, alleging that it is misleading and emphasizes superficial facts without an understanding of the underlying mechanisms observed and their meanings to individuals (May, 2001). Phenomenology aims to understand peoples' everyday life experiences (Polit & Beck, 2012) and there are several variants and methodological

interpretations of phenomenology. However, the two main ones are descriptive and interpretive phenomenology. Whilst descriptive phenomenology is not the chosen methodology for this research, a brief discussion to differentiate the two is warranted.

3.4.1 Descriptive phenomenology

Husserl's descriptive phenomenology, also referred to as transcendental phenomenology, emphasizes descriptions of human experience (Husserl, 1962). Its aim is to discover and describe the lived world whilst suspending personal opinion. There is an emphasis on descriptions of things as people experience them. The descriptions are the raw data which are then systematically and methodically analysed and compared to the essences of the identity of the phenomenon (Giorgi, 1985; Patton, 2015). Husserl used the three terms of phenomenological reduction, epoch and bracketing (Crotty, 1998). Husserl refers to a method of 'reduction', which underpins the analytical process of several phenomenological methodologies. This reduction requires the phenomenological *epoché* or bracketing, where a phenomenologist suspends their assumptions and presuppositions about a phenomenon (Gill, 2014). Descriptive phenomenology holds a commitment to bracketing, which is done so that what is essential in the phenomena of consciousness can be understood without prejudice (LaVasseur, 2003). Bracketing has been described as an attempt to hold prior knowledge or belief about the phenomena under study in suspension in order to perceive it more clearly (Powers & Knapp, 1995).

By disconnecting from, or transcending, the natural attitude of the 'everyday life', Husserl believed his method of phenomenological reduction provided an outlook 'upon transcendently purified phenomena' (Husserl, 2012, p. 3), where purified means free from everyday assumptions. Another tenant of descriptive phenomenology is the search

for essences. This further reduction to the eidos or essence refers to 'that without which an object of a particular kind cannot be thought' (Husserl, 1973, p.341). The essences are the foundations on which all phenomenological methodologies that draw on Husserl's work share his goal to describe these essences.

The technique of bracketing has been a source of unresolved debate in the nursing literature (Omery, 1983; Ray, 1994; Carpenter, 1994). Omery (1983, p.61) claims that the primary requisite of phenomenology is that 'no preconceived notions, expectations, or frameworks be present to guide the researcher as they gather and analyse data'. Others have however presented bracketing as an important technique of phenomenology employed in nursing research (Polit & Hungler, 1999; Denzin & Lincoln, 2013). It is my argument in this study that it is not possible to suspend my assumptions and pre-suppositions of the phenomenon I am studying, as I bring my knowledge, experience and beliefs about the topic into the research process which Heidegger (1962) recognised.

3.4.2 Interpretive phenomenology

A student of Husserl, Martin Heidegger, differed in his phenomenology in terms of both subject and method. His seminal work in 'Being and Time' presents a shift from Husserl's epistemological focus, to an ontology - exploring the human experience of being, which he terms 'Dasein' (Heidegger, 1962). Heidegger's interpretive phenomenology, which is also referred to as hermeneutics argues that lived experience is an interpretive process and not simply describing. The goals of this methodology are to move beyond the descriptive and seek meanings that are embedded in everyday occurrences (van Manen, 1990). Heideggerian phenomenology rejects bracketing asserting that it is not possible to bracket one's 'being in the world' and negate our

experiences related to the phenomenon under study (Heidegger, 1962). A researcher therefore cannot remove themselves from the meanings extracted from the texts but becomes part of the phenomenon. According to Heidegger, phenomena needs to be examined in their existence as removing the lived world from its rich context is to remove meaning and possibilities of understanding the experience as it is lived (Smythe et al. 2008). Crotty (1998, p.91) asserts that skilled hermeneutic enquiry has the potential to ‘uncover meanings and intentions that are hidden in the text’. There is an assumption of the prospect of gaining a deeper understanding of the text, which goes further than the author’s own understanding. Here the role of interpretation is crucial to explore this concept in any phenomenological study. Crotty (1996, p.33) further explains that, ‘phenomenology of Daesin is *hermeneutics* in the original signification of that word, which designates the work of interpretation’. There is a suggestion that interpretation is an integral part of any research drawing on the work of Heidegger, who challenges the notion that we can ever be free of assumptions. Heidegger disputes Husserl’s idea of bracketing presuppositions to articulate essence (Gill, 2014), and he asserts that an individual exists in a culturally and historically conditioned environment from which they cannot step outside (Heidegger, 1962).

Existential phenomenology is a third type of phenomenology whose position states that the pre-reflected experiences, live world and the phenomena constitute existence (Merleau-Ponty (1962). According to Dowling and Cooney (2012) there is no single way to conduct a phenomenological study. As a result, there are many approaches, different labels and different descriptions. Researchers using this type of methodology therefore need to have a clear understanding and knowledge of the approach to be used in order to suit the aims of the study. The aim of my study therefore fits with the Heideggerian interpretive philosophy and its intentions,

3.4.3 Hermeneutics

Questions have been raised as to whether phenomenology is a philosophy or research method (Morse, 1991; Creswell, 2013). According to Cohen and Omery (1994), there are different schools of phenomenology. The descriptive school which is guided by Husserl's work; hermeneutics or interpretive phenomenology which is guided by the work of Heidegger and Gadamer and then a third which is a combination of the descriptive and interpretive phenomenology drawing on the work of Max van Manen and others. These different schools (Smith et al. 1997; van Manen, 1990; Moustakas, 1994; Dahlberg & Dahlberg, 2004, Giorgi 2009) are widely used in nursing research and they demonstrate the multifaceted nature of phenomenology (Smith, 1992; Clarke, 1992). Whilst all schools are concerned with the lived experience, it is clear that their use can be misleading. Paley (1997, 2005) has commented on this misuse and the diversity of phenomenological approaches.

Hermeneutics is a method within the interpretive research paradigm which according to Schwandt (2001) challenges the researcher to reflect deeply on what it is that the texts of the field have to say and encourages deep conversations with it. The researcher enters into the world opened up by the texts and 'loses' themselves in it. Hermeneutic phenomenology uses different procedures for investigation. According to Van Manen (1990) hermeneutical phenomenology is a combination of hermeneutics and phenomenology and he has gone further to propose an approach to help researchers in hermeneutic phenomenology in his six-step framework which has been used commonly in nursing research.

The literature review (Chapter 2) on the chosen topic revealed that the health-related quality of life issues of Bangladeshi populations in the UK with ankylosing spondylitis is under-researched and poorly understood, in terms of lived experience. Most research

in this area has adopted a quantitative approach, however; qualitative research is suited to this type of research where little is known about the phenomenon. Researching lived experience in ethnic populations with UK is complex and requires an approach that asks for the nature of the phenomenon, uncovers meaning and describes the phenomenon through interpretation (van Manen, 1997; Pringle et al. 2011).

3.4.4 Rationale for using Interpretive Phenomenology

The aim of this study was not to test any hypothesis but to discover and understand Bangladeshi patients' shared sense of meaning. Qualitative researchers study in-depth purposeful samples of people who have experience with the phenomenon of interest (Shorten & Moorley, 2014). A qualitative methodology is deemed appropriate for this research because of the human interaction necessary to its methods and its grounding in individual experience (Glaser & Strauss, 1967). A hermeneutic phenomenology that goes further and focuses not simply on describing but understanding individual experience from the ontological perspective of 'being in the world' (Heidegger, 1962) will be used. This process acknowledges the researcher's inevitable influence of their own situatedness.

Spiegelberg (1995) describes phenomenology as being grounded in the belief that truth can be found in lived experience. This methodology is therefore well suited to phenomena that are not well understood and that are central to the lived experience of human beings similar to Carpenter's assertions (Carpenter, 1995). I bring into this study some knowledge from many years' experience of working with patients with AS. The systematic literature review conducted previously in Chapter 2, has shown gaps in research in this area amongst this patient group and this has increased my interest in the area. According to Bowling (2014) appropriate topics for phenomenology are those that

are fundamental to the life experience of humans such as quality of life with a chronic illness.

3.5 Researching Lived Experience – Max van Manen (1990)

Van Manen's (1990) hermeneutic phenomenology emerged from the discipline of pedagogy. In a clear point of departure from other types of phenomenology, van Manen straddles both descriptive and interpretive phenomenology:

'hermeneutic phenomenology tries to be attentive to both terms of its methodology: it is descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena' (1990, p. 180).

This study has utilised Heidegger's interpretive phenomenology informed by van Manen's work (van Manen, 1997) to explore and interpret the lived experience of health-related quality of life in Bangladeshi patients with AS. In rejecting Husserl's view of bracketing van Manen (1990, p.47) poses the question, 'How does one put out of play everything one knows about an experience that one has selected for study? If we simply try to forget or ignore what we already know, we might find that the presupposition persistently creeps back into our reflections'. I agree with van Manen that it is better to make explicit my understandings, beliefs, biases, assumptions, presuppositions and theories. That way I can expose the shallow or concealing character of those assumptions (Van Manen, 1990). Van Manen's dynamic interplay among six research activities (Table 3.1) has been adopted in this research. This was in order to bring structure to this study and focus the work on revealing the life world of health-related quality of life in 20 Bangladeshi patients with AS.

Table 3.1 Methodological structure of human science research, applied to the study (van Manen 1990, p.30).

| | |
|---|--|
| <p>1. Turning to a phenomenon which seriously interests us and commits us to the world</p> | <p>Involves developing the research question based on my personal background as an advanced nurse practitioner and influenced by previous work. This research seeks to illuminate the experience of HRQoL by Bangladeshi patients with AS. The research question is: What is the ‘lived experience’ of HRQoL in Bangladeshi patients with AS? This question will be referred back to continuously throughout this research process in order to ensure the methods continue to be appropriate to answer it.</p> |
| <p>2. Investigating experience as we live it rather than as we conceptualise it</p> | <p>Semi-structured in-depth interviews were the data collection method employed to investigate the experiences of HRQoL in the Bangladeshi patients with AS. The interviews were audio recorded and transcribed verbatim. The participants described their experiences in their own words allowing the researcher to re-live their original experiences with the participants as they relate them. The narratives provide in-depth understanding of the phenomenon as a whole.</p> |
| <p>3. Reflecting on the essential themes which characterise the phenomenon</p> | <p>Prominent themes and sub-themes were identified from the data resulting in a reflection on the essential/global themes. Probing and elaboration of participant responses was encouraged during the interviews to ensure sufficient data was collected for analysis. Reflexive notes were kept after the interviews to assist analysis and influence the direction of following interviews. Common themes were identified and meanings were assigned to these experiences (Polkinghorne, 1983). Immersion in the data was achieved through reading and re-reading the transcripts, looking for common meanings and experiences in the Bangladeshi patients with AS. Significant statements, words and phrases were selected and formed into themes and sub-themes.</p> |
| <p>4. Describing the phenomenon through the art of writing and rewriting</p> | <p>There was a cyclical process of writing and rewriting, reading and re-reading, with constant revising and refining of thoughts throughout the research process. Questioning and reflection on emerging themes allowed a deeper understanding of the lived experience.</p> |

| | |
|---|--|
| <p>5. Maintaining a strong and oriented pedagogical relation to the phenomenon</p> | <p>Maintaining a reflexive diary throughout the research process and having regular debriefing sessions with my academic supervisors helped me remain focused on the research question. Regular contact with peers in the post-graduate support group meetings has also helped me to stay focused and concentrate on the research process.</p> |
| <p>6. Balancing the research context by considering parts and whole</p> | <p>Throughout this research process there has been: a constant awareness of the possible negative and positive effects of the research methods on the participants. The interviews led to new levels of awareness and increased thoughtfulness for both the participant and the researcher. Contextual considerations were taken into account while keeping in view the fundamental research question. There was a constant reading of the interview transcripts and understanding of the whole while scrutinizing parts as well. There has also been a constant consideration of my position as a nurse and researcher.</p> |

3.6 Ethics

Ethical approval for any study must be obtained from the relevant Ethics committees before a research study can commence. Ethical issues may arise from any methodology used to obtain valid and reliable data. This is in terms of robustness of the research, research honesty and transparency, whether the research will lead to distress amongst participants, the demands on people's time, guarantees of privacy, confidentiality and anonymity, data protection and security or ensuring informed consent (Bowling 2014). These issues are related to reducing harm to participants.

Ethical approval for the study was obtained from the London South Bank University (Appendix 2) and London's Queens Square Research Ethics Committee as part of the Health Research Authority (HRA) UK Policy for Health and Social Care Research (Appendix 3). The process for HRA approval was in multiple stages. The first was the completion and submission of the research application form on the Integrated Research

Application System (IRAS). Initial submission through the central booking office had indicated that the study met criteria for proportionate review however due to some ethical issues raised around possible distress to participants when recalling painful experiences of their illness, it was considered for a full Research Ethics Committee (REC) meeting. The other stage involved my attendance at a full Research Ethics Committee meeting at London's Queens Square, with my supervisor. The proposal was approved with no amendments and then forwarded to the local study centre's Research and Development office for final approval, which was granted (Appendix 4).

3.6.1 Informed Consent

Informed consent involves informing the research participants about the purpose of the research and the main design features, as well as any possible risks and benefits from participation in the study (Kvale 1996). Participants must not feel at any time that they are being coerced into taking part in research. Participation must therefore be voluntary and the participants must have the right to withdraw from the study at any time. A consent form in English and Bengali (Appendix 5) which included explanations of the interview process, topics to be explored and assurances of anonymity and confidentiality was used as appropriate with interpreters as needed for those participants who did not have proficiency in English. It is important to note however that informed consent is not a one-off activity in research but a continual dialogue throughout the research process.

Holloway and Gavin (2017) assert that the researcher as a nurse, might find herself drawn into that role away from that of researcher during the research process, particularly during the qualitative interview. This might make the participant feel obliged to take part in the interview because of the relationship they have with the

researcher. There must be therefore, a consideration of these multiple roles and how they might affect the research as discussed by other commentators (Robson, 1993; Corbin & Strauss, 2007).

3.6.2 Anonymity, confidentiality and secure storage

Confidentiality in a research context implies that any personal data that can identify the participant will not be reported. This can be maintained by assigning pseudonyms to participants (Creswell, 2013). The researcher's involvement in the process of accessing and recruiting participants is crucial. Houghton et al. (2010) have discussed the complex dual role of a clinician and researcher and issues about weighing the professional obligation against the role as a researcher. The participants chose their own pseudonyms based on 'nick names' which were assigned from a range of nicknames used within this community. During my engagement with the Bangladeshi community, I was made aware that it was common for members of the community to have a nick name assigned by family members (Appendix 6). I identified easily with this as it is also a common practice in my Zimbabwean culture. Consent forms and transcripts of the audio-recorded interviews were scanned and stored on my NHS computer in password protected files. Hard copies were stored in a locked cabinet in my office which is locked and only accessible to me.

3.7 The setting and gaining access to the Bangladeshi community

This study took place at a large teaching hospital in a deprived inner London Borough in England. The London borough ranks highest in London, in the number of Bangladeshi residents, accounting for 34% of the total population (Office of National

Statistics, 2011). According to the Lead Clinician and the AS expert, the rheumatology outpatient department where the study took place, is the second largest in the country, seeing approximately 24000 patients with rheumatologic conditions who live in the area and beyond, annually. The AS patients make up 15 to 20% of the total patients seen in the department, with the Bangladeshi population making up half of this number. There is therefore a high number of Bangladeshi patients with AS in this area. Access to the Bangladeshi patients was agreed by the Lead Clinician in the Outpatients department (Appendix 7). It was felt preferable to research Bangladeshi patients with AS in depth as the experiences of health-related quality of life from their own perspective is relatively unexplored in the UK.

3.7.1 Accessing the AS clinics

As an experienced Advanced Nurse Practitioner in rheumatology care, I had a network of existing relationships on which to draw. These include the rheumatology community, the national patient support group (NASS) and the rheumatology outpatients' department staff. This enabled me to gain access to the participants through their direct care teams of nurses and doctors in the AS clinics. I was aware that in some areas other researchers have found access to participants' difficult (Lawton, 2000). I was quite familiar with the department so I did not need to be shown around or to be introduced to the other members of staff in the department. Following ethics approval, I had a real sense of trepidation as I feared that I might encounter the same difficulties as Lawton (2000). I made myself visible to the direct care teams in the AS clinics and I was able to gain their trust and corporation. My first point of contact was with the clinical lead for the AS service and the senior clinical nurse specialist in the outpatient department. They showed some interest in my research and I had opportunities to explain the purpose of the study and the process. In some way, the direct care team can be seen as gatekeepers

for the patients directly under their care and it was important that they give their support for the project. I was also aware from my own experience as a nurse that sometimes hospital staff can understandably feel protective towards patients particularly those with a chronic disabling condition such as AS. Information about the research was given verbally and through the information sheets and I was available to address any concerns from staff, luckily there were none. The team also viewed me as an expert in my own right and from the outset there was a mutual respect. This was an important step as I would rely on them to make the initial approaches to the participants.

The concept of Dasein and historicity in relation to nursing has been articulated by McConnell-Henry et al. (2009) when they suggested that when a nurse leaves a hospital he/she does not leave the world of nursing. There is a suggestion here that a nurse will always be able to comprehend Being-in-the-world of nursing. As part of reflexivity, I was aware of the influences on my internal and external responses, whilst at the same time being aware of my relationship to the research topic and the participants. Reflexivity challenged me to identify and acknowledge my own taken for granted values and to think about how they impinged upon my judgements towards the Bangladeshi participants in my study, whose values and experiences were different to mine (Clancy, 2013). My taken for granted assumptions about the nature and impact of AS were challenged in this research process. For example, I have always considered AS as a form of arthritis that is mild and only affects older people. Meeting Faz, a 23 year old participant with a 4 year history of severe AS, was unexpected. I wrote in my journal:

'Today I have met this young man who does not look like a typical patient with AS. He is unable to work and has given up pursuing a career. Could this be a case of a wrong diagnosis or the patient just 'playing up' Journal entry 10/09/2016

The following note from the reflexive journal describes my tension in the dual role of nurse and researcher:

'Today 2 participants that I interviewed appeared to be suggesting poor standards of care in the department since their diagnosis. I felt as if I was being drawn into a difficult situation and was uncomfortable when names of colleagues were mentioned. It was obvious that the issues raised were a source of distress to the participants. It appeared to me that we had failed to provide the expected quality of care on those occasions although the impulse at times was for me to jump to the defence of my colleague. I hope I can do justice to the participants with this project and highlight the experiences in their entirety' Journal entry 02/10/2016

3.7.2 Identifying the Bangladeshi gatekeepers

It was crucial for me to engage gatekeepers in my research, as I was not involved in the direct approach to the participants. Gatekeepers within the research process are typically described as the individuals, groups or organisations that act as intermediaries between researchers and participants (De Laine, 2000). I was mindful that recruiting Bangladeshi participants to my study might be challenging. In the planning stages of my research, I approached a patient partner who attends the local NASS group and is also a member of the Bangladeshi community with AS. He pointed me to key figures (gatekeepers) in the Bangladeshi community who would pave the way for me to access the community in terms of backing for my research project. In the Bangladeshi community, people may

approach Imams, community centres or Members of Parliament to facilitate access to the community. Having the gatekeepers' support was very important because when the potential participants heard about the study at clinic, I sensed they were already aware of it and knew the community was supportive to it. This gatekeeper involvement is described further in this section and helped validate the study in the community's eyes.

During the development of my recruitment strategy in this study, I therefore needed to identify the gatekeepers in the Bangladeshi community, and how the relationship between me as a researcher and the gatekeepers could be established and maintained. According to McAreevey and Das (2013), access must be negotiated by researchers in the field and will have important implications for the inclusion and participation of minority groups. The strategies for gaining access through gatekeepers as well as issues of researcher positionality have been examined by a number of researchers (Corra & Willer 2002; Knight et al. 2004; Yancey et al. 2006; Clark & Sinclair, 2008; Yu, 2009). There is however, a lack of guidance that might provide insight into practical strategies for dealing with issues of participation and working with gatekeepers. My experiences of accessing the Bangladeshi community were highlighted in a symposium presentation at the RCN International research conference in Birmingham, abstract number 217, 2018 (Appendix 8). I could be considered an outsider to the research participants in my study because I am a black African from sub-Saharan Africa and have lived most of my life there, before moving to England some 22 years ago. Said's (1995) work has shown how minority communities are often misrepresented, pathologized, or problematized by research processes. This has inevitably led to exclusion or limited participation of minority experiences (Mitra, 1998).

Gatekeepers play an important role in social research, especially in the Bangladeshi communities that do not trust mainstream research and are seldom heard (Yancey &

Ortega, 2006). By acting as cultural mediators the gatekeepers in this study helped me to become more culturally competent and, in a way acted as guarantors of my legitimacy as a researcher within the Bangladeshi community. I established relationships with diverse community members by approaching community centres, mosques and a local member of parliament (MP) who is from the Bangladeshi community. Through this I was able to be seen in the community as someone who was willing to engage openly and transparently. I strongly felt that these gatekeepers had a community presence and could have links with potential participants for my study or could spread the word to reach potential participants.

3.7.3 Approaching the gatekeepers

The Imams at the mosque and the local MP, had high visibility, and strong links in the community and could transfer and disseminate information to others in the community. My engagement with the gatekeepers provided them with an opportunity to scrutinise the ethics of my research. For example, the gatekeepers asked why I was doing this research and why the Bangladeshi participants should share their personal experiences of illness with me. I shared information about my identity as a nurse, my thoughts, and feelings around the subject of AS in Bangladeshi patients, to enable gatekeepers to gauge my authenticity. I also shared my 'insider' status, coming from an ethnic minority background although different to theirs and having lived in Tower Hamlets for all the 22-years that I have been in England. This self-disclosure enhanced rapport and trust, similar to Lee's (1993) assertions. On a personal level, I shared that my own experience and background from an ethnic minority group, helped shape my desire to study this illness in the Bangladeshi population, and this history affected my ability to empathise on arising sensitive matters. This helped them assess my interest and place their trust in

me. On the benefits of the study, the gatekeepers (MP) wanted to know what the benefit of the study would be to the participants who would be sharing or reliving some painful experiences of their illness:

'I know some people will come to you and reopen, 'old wounds' about their experiences of this illness. It is unfair to exploit their experience for research, although I also understand that this information is important. What are the benefits of participating?'
Gatekeeper comment (Reflexive journal notes, 11th May 2016).

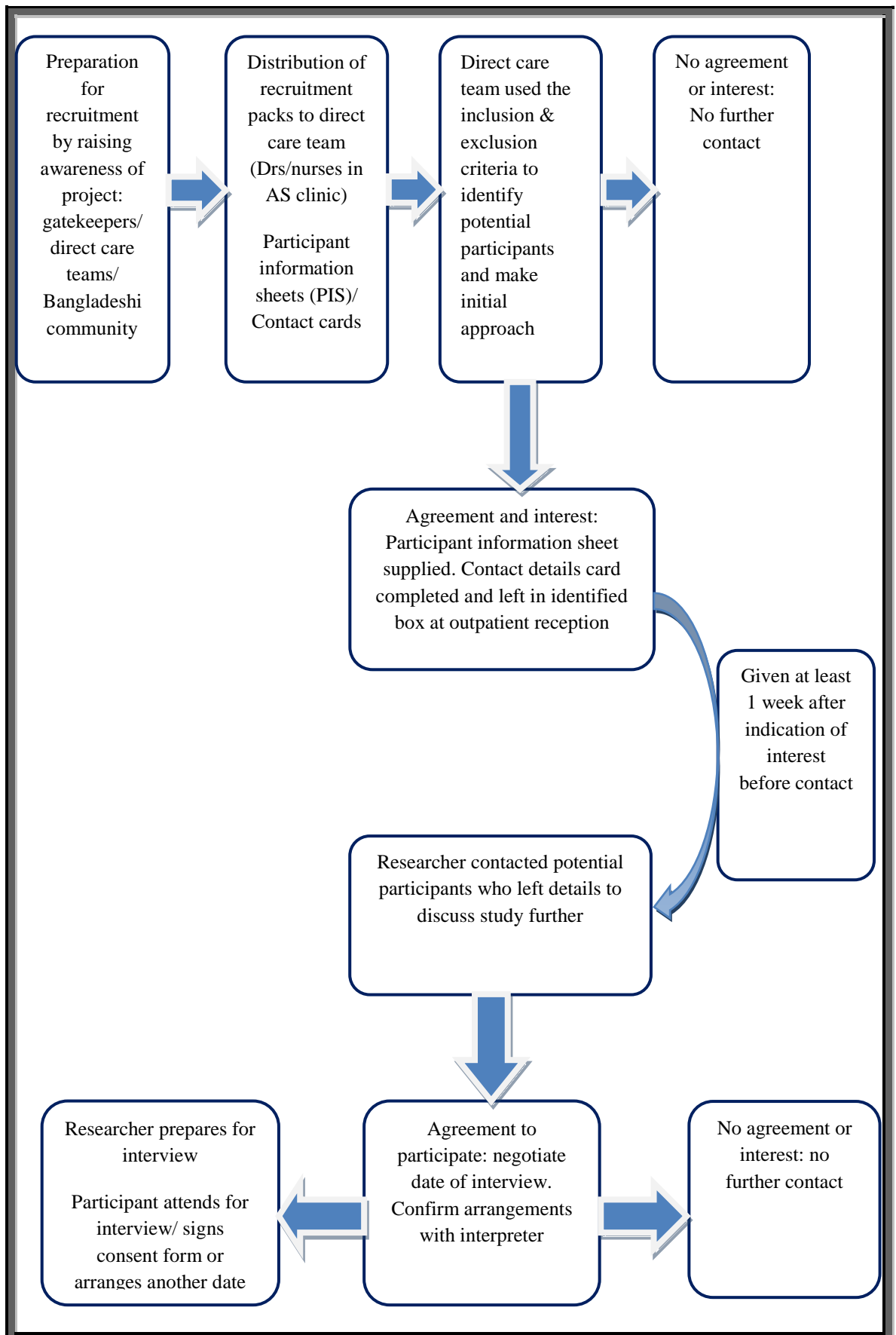
I explained that participating in the study would highlight and raise awareness of the Bangladeshi experiences of living with AS, to healthcare providers and policy makers. I also explained that, in line with ethics approval, informed consent would be sought and participants were free to stop the interview or opt out of the study at any time. I informed the gatekeepers that counselling would be offered as needed through, 'The Mind' counselling service in Tower Hamlets, which provides a free, safe and confidential space to explore thoughts and feelings. The way that I discussed my study and negotiated with the powerful gatekeepers was significant in shaping the study. Most issues raised by the gatekeepers had been addressed through the ethics processes, so I was able to address the gatekeepers' concerns. Through my considerations and reflections on the challenges of conducting this research with the Bangladeshi population, I was able to adopt strategies that helped me to build trust, to develop rapport, and to overcome some of the previously identified limitations.

3.8 Recruitment

The recruitment process involved more than one person (see Fig 3.3). Participants who met the inclusion criteria were approached by the direct care teams of nurses and doctors in the AS clinics. In accordance with ethical approval, the direct care teams

made the initial approach to potential participants in the AS clinics. Those indicating an interest were supplied with participant information sheets (Appendix 9) and they gave permission to the direct care team of nurses and doctors in the AS clinics, for me to contact them (Appendix 10), at a later date. The contact cards were dropped in an identified box at the main reception in the department. I was available in the department for those who wished to get further clarification on the study on the same day. The direct care teams made the initial approach and discussed the study with the participants at the end of the consultation. This was so that the potential participants were not put under undue pressure to agree to participate.

Fig 3.3 Recruitment Process flowchart



A week was deemed sufficient time according to professional guidance (Royal College of Nursing, 2009) for me to contact the potential participants and invite them for the interview. The interview date or meeting for further discussion was agreed with the potential participants. After the pilot study, I realised that I could only conduct a maximum of 2 interviews a day.

3.8.1 Sampling method and data collection

Sample selection is a key factor in research design and it can determine whether the research question will be answered, before the start of the study (Shorten & Moorley, 2014). The aim of the study therefore, determines the sampling methods used. The focus of my study was not on a predetermined hypothesis or generalizable results but to explore patients' lived experience. Bowling (2014) has discussed the four broad qualitative research sampling approaches: convenience sampling, purposive sampling, snowballing and theoretical sampling.

Purposive sampling was used in this research in order to select individuals and a site for my study that could purposefully inform an understanding of the research problem and central phenomenon (Creswell 2013). Purposive sampling involves 'selecting participants on the basis of the particular characteristic being sought' (Cohen et al. 2008, p.115) and is used by many qualitative researchers in order to capture high quality data. This approach is deliberately non-random and it aims to sample a group of people or settings with a particular characteristic (Bowling 2014). The size of the sample is considered adequate when interpretations are visible and clear, new informants reveal no new findings and meanings from all previous narratives became redundant (Benner 1994). The size of the sample in qualitative research however, remains a subject of debate particularly in the interpretive paradigm (Sandelowski, 1995; Brocki & Weadon,

2006; Bowling, 2014); Malterud et al. 2016). Sample sizes range from 3 to 10 (Dukes, 1984), to up to 10 participants (Riemen, 1986) and up to 325 participants (Polkinghorne, 1989). Others have argued against collecting so much data that researchers are unable to report fully on (Collins & Nicholson, 2002). The intent in qualitative research is not to generalise information but to elucidate the particular, the specific (Pinnegar & Daynes, 2007).

The intention in this study was to obtain full, in-depth and rich personal accounts and because each person's experience is so individual, true data saturation could never be fully achieved (Hale et al. 2008). Phenomenological studies aim to search for the essence of a phenomenon and as such the final number is often unknown before the research has commenced (Halloway 2008). Although some commentators have suggested that the sample can be the judgement of the researcher (Sandelowski, 1995), as a novice researcher, I was keen to allow the 'voices' of the participants to be heard and waited until no new themes were emerging. The initial aim was to interview 15 participants. It was considered this number would enable sufficient, in-depth qualitative data to be gathered to develop an understanding of the phenomenon under examination. In addition, this number was felt to be realistic within the limitations of both time and other resources (single researcher and the cost of translation and using interpreters).

Following the initial interviews of 15 participants, new findings and meanings were still emerging. It was therefore felt, following discussions with my supervisory team that the sample be increased to 20. This number allowed me to describe the meaning of the experience of health-related quality of life in the Bangladeshi participants who have experienced it.

A minor amendment was submitted to HRA and approved (Appendix 11). Inclusion criteria were used (Table 3.2). According to Patton (2015) inclusion criteria are

established to ensure that a homogeneous sample is obtained in order to reveal what an experience means to a particular group.

In order to gain the co-operation of colleagues and disseminate information about the research in the rheumatology department, I presented my proposed research in the weekly postgraduate rheumatology meeting. This was an opportunity for colleagues and AS experts, to ask any questions and give feedback about the research and for me to clarify any unclear information. This was also an important part of peer review (Appendix 12).

Table 3.2 Inclusion/Exclusion Criteria

| Inclusion criteria | Exclusion criteria |
|---|--|
| <ul style="list-style-type: none"> ➤ Bangladeshi patients with Ankylosing Spondylitis ➤ Aged 18 years and above ➤ Ankylosing Spondylitis diagnosis according to 1984 modified New York Criteria (van der Linden et al. 1984) ➤ Willing to be interviewed ➤ Male or female Bangladeshi patients living in Tower Hamlets attending the rheumatology outpatients department | <ul style="list-style-type: none"> ➤ Bangladeshi patients with other Spondyloarthritis ➤ Aged below 18 years ➤ Diagnosis of Ankylosing Spondylitis outside of the 1984 modified New York Criteria ➤ Unwilling to be interviewed ➤ Adults lacking mental capacity to give informed consent ➤ Male or female Bangladeshi patients who do not live in Tower Hamlets |

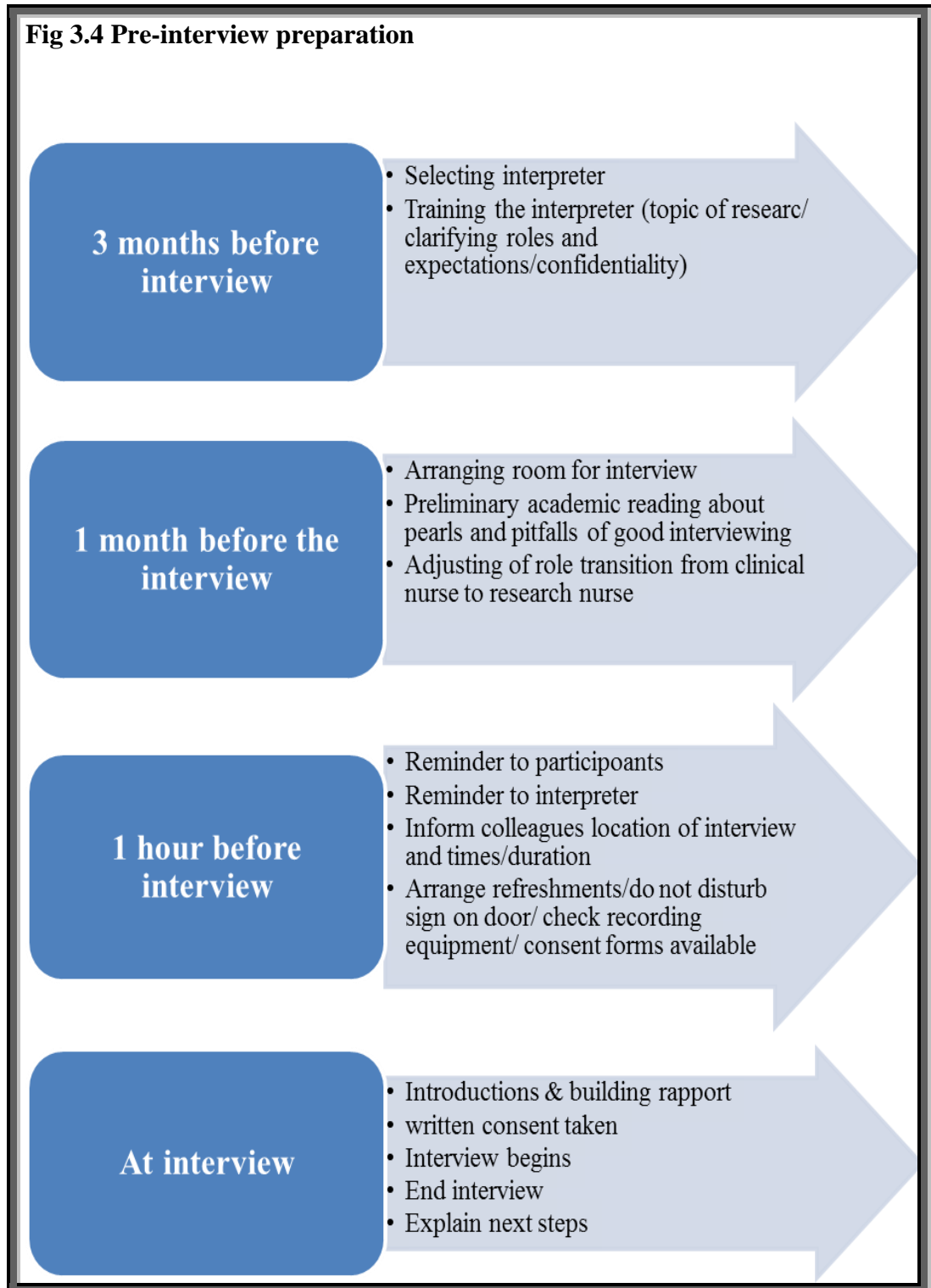
3.9 Interview preparation

I took steps to prepare for the role of interviewing, in keeping with the tradition of interpretive phenomenological in-depth interviews. I realised that I had to adjust from the clinical conversations that I normally have with patients in my role as a nurse practitioner to a researcher. I did some background reading on how to conduct phenomenological interviews (Kvale, 1996; Brinkman & Kvale, 2014). This background reading provided me with insights on how to build a rapport with the

participants so that I could ask follow up or probing questions based on their responses to my pre-constructed questions from the interview topic guide. As part of the preparation I also applied McNamara's eight principles to the preparation of interviewing (McNamara, 2009). An interpreter was used for the non-English speaking participants (full preparation and decisions made can be seen in section 3.9.4). Another important element of the interview preparation was the implementation of a pilot interview (section 3.9.2). There was also the practical aspect of the interview preparation that had to be considered, for example, confirming the interview date and time, place of interview, reminders and creating an environment conducive to an in-depth exploration of the experience (Fig 3.4). I carefully negotiated with the participants the venue for the interviews, prepared an interview topic guide, and armed myself with a digital Dictaphone – in essence, the guidelines were followed in detail.

Although the interviews took place in a familiar environment, commentators (Walker, 2011; Doody & Noonan, 2013) have highlighted the importance of making practical arrangements such as preparing the room, checking the equipment and training the interpreter. As an advanced nurse practitioner with experience of conducting nurse-led clinics in my consultations with patients, I was already aware of the challenges of conducting research interviews. I therefore needed to find a way to make that transition from clinical nurse to a nurse researcher. I took time to consult texts on conducting research interviews paying particular attention to the pearls and pitfalls. One of the sessions on this topic in our monthly research support group at the University was very helpful. I managed to plan and prepare for the interview as a novice researcher.

Fig 3.4 Pre-interview preparation



By this stage I was already familiar with some of the issues related to living with AS from the literature review I conducted (see Chapter 2) as well as the background reading. I was therefore confident that I had a reasonable amount of up to date information on the topic under study. I made practical arrangements to ensure that my office was available, comfortable and well ventilated. The paperwork for the

participants, tissues, refreshments and recording equipment and a 'do not disturb' sign were checked and put in place. The emphasis by Harris (2010) on the skills required by a researcher during an interview investigation also helped in providing a critical interpretive component to this process.

3.9.1 The interview topic guide

An interview topic guide was developed and used in the interviews, to ensure the interviews progressed in a focused yet flexible manner (Fossey, 2002) and would allow me access into the participants' life-world. To achieve this, I held discussions with my supervisors, searched the literature (Silverman, 2013) and I sought advice from a Bangladeshi patient partner with AS, who is also a member of the local NASS group. I was able to gauge if the questions in my interview topic guide had meaning for the Bangladeshi participants with AS and if they could engage with them. The patient partner found the questions easy to understand and quite liked that they were open allowing the participants the flexibility to narrate their lived experience fully. On my part, the patient partner brought a unique perspective to the process by providing useful insights and making my research relevant to the Bangladeshi participants. More importantly, the patient partner suggested the importance of forming a support group specific to the Bangladeshi patients with AS, in order to provide education and support about the illness and its management.

The topic guide included some demographic data (Appendix 13) and was made up of five parts (introduction, demographics, warm up, main part and closing) and comprised of a total of five questions. Each question sought to address the phenomenon of health-related quality of life as articulated in Chapter 1 of this thesis. Here, I was mindful to ensure, as suggested by Kvale (1996) that the questions related to the topic of the

interview, the theoretical conceptions at the root of the investigation and to the subsequent analysis. I also aimed for a dynamic interview that promoted a good interaction between me and the participant. According to van Manen (1990, p.66) a hermeneutic phenomenological interview serves specific purposes. The first is as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon. The second purpose of the interview is as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience. I was therefore mindful to let the research question determine the direction of the interview and avoid getting carried away with an interview that was going everywhere and nowhere. I wanted to stay as close to experience as lived and explore the whole experience to the fullest (van Manen, 1990).

The questions were open ended, brief and simple with prompts that were used as recommended by Denzin and Lincoln (2005). My introduction question was: 'Can you tell me how long you have been living with AS? And this was followed by: Can you share with me what it felt like when you received your diagnosis of AS? This type of questioning at the beginning, yielded rich descriptions with the participants themselves providing what they were experiencing. My nods and 'mm' and pauses helped to indicate to the participants that I was listening attentively and they could go on with their descriptions. Probing was used to pursue answers but without stating according to Kvale (1996), what dimensions are to be considered. In a way the probing and prompts helped refocus the interviews when participants tended to stray from the research topic. This also allowed the participants to do most of the talking whilst I listened attentively and only spoke to clarify points or when I needed to probe. This helped to turn the conversation back to the level of concrete experience. For example, when I asked: *Can you share with me what a typical day is like for you living with AS?* The prompt was: *Is*

there any part of the day that is better for you? What was it like? (Kvale 1990). This line of questioning allowed me to gain access to the participants 'innermost' thoughts.

3.9.2 Patient partner

It is important in nursing and overall health care research that service users are actively involved in research, from planning to post data collection. In my study I set out to achieve this in a number of ways. First, it was through the use of a patient partner and secondly through engaging the Bangladeshi community through gate keepers (section 3.7.2). A patient partner in the context of this research is a description of a patient who identifies and recognises themselves as sharing common characteristics (e.g. culture, illness) with the population being studied. I identified the Bangladeshi patient partner through the local NASS group. The patient partner enabled me to get a better understanding of AS through the lens of their own experience and this together with their views and direct input, helped in guiding the design and delivery of my study. They gave me suggestions about the important gatekeepers whom I could approach in the Bangladeshi community. They also reviewed my study documentation and gave suggestions which helped improve the quality of my study and increased the potential of the study findings to impact patient care and services positively.

3.9.3 The pilot study

The first two participants were recruited for the pilot study, which was conducted following all procedures as planned for the main study. The interview process and the data obtained were critically reviewed with the supervisors and improvements were made. Data from the pilot has been included in the analysis. It was apparent immediately after the first interview that I had underestimated how long transcription could take. The first interview lasted 40minutes and it took me up to 4 hours to

transcribe and this went up to 6 hours with the re-reading and checking for accuracy. Kvale (1996, p169) has discussed the importance of the interviewer to transcript one or two interviews themselves in order for them to ‘sensitize themselves to the importance of the acoustic quality of the recording, to paying attention to asking clear audible questions and getting equally clear answers in the interview situation’. A Phillips DVT6500 hand held audio and voice recorder was used to record the interviews. I elected to go for this recorder due to past experience where there was a malfunction of the equipment which resulted in me losing a whole interview! The main attraction with this recorder is its auto-adjust, clear-voice function and the ability to transfer my recording directly to my password encrypted PC. Through the pilot study, I was able to refine the final design of my study and get practical experience to enhance my experience and confidence. More importantly, in the context of this phenomenological qualitative inquiry, I was able to produce culturally competent research similar to Kim’s (2011) assertions.

3.9.4 Conducting the interviews

Through my preparation for the interviews, I was able to create an atmosphere in which the participants felt safe enough to talk freely about their experience and feelings of AS. In line with an open phenomenological approach, Spradley (1979, p.34) sums up learning from an interview in this introduction:

‘I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel them, to explain things as you explain them. Will you become my teacher and make me understand?’

In-depth semi-structured tape-recorded interviews were used in this research. A hermeneutic phenomenology aims at gaining a deep understanding of an unknown phenomenon; therefore, the interview must be unstructured, open and aimed to encourage the participant to speak freely. Kvale (1996) asserts that the in-depth phenomenological interview is centred on the interviewee's life-world and his or her relation to it and it is with this in mind that I used his general interview guide approach. The approach outlines 12 aspects (Table 3.3) that represent a description of the main considerations of the qualitative research interview. These were a useful guide for me as a novice in the interview process in this research.

Table 3.3 Aspects of Qualitative Research Interviews (Kvale 1996, p.30)

| |
|--|
| <ol style="list-style-type: none"> 1. Life world: The topic of the qualitative interview is the everyday lived world of the interviewee and his or her relation to it. 2. Meaning: The interviewer registers and interprets the meaning of what is said as well as how it is said. 3. Qualitative: The interview seeks qualitative knowledge expressed in normal language; it does not aim at quantification. 4. Descriptive: The interview attempts to obtain open nuanced descriptions of different aspects of the subjects' life worlds. 5. Specificity: Descriptions of specific situations and action sequences are elicited, not general opinions 6. Deliberate Naivete: The interviewer is open to new and unexpected phenomena, rather than having ready-made categories and schemes of interpretation. 7. Focused: The interview is neither strictly structured with standardised questions, nor entirely 'non-directive'. 8. Ambiguity: Interviewee statements can sometimes be ambiguous, reflecting contradictions in the world the subject lives in. 9. Change: The process of being interviewed may produce new insights and awareness leading to a change in description and meaning about a theme. 10. Sensitivity; Different interviewers can produce different statements on the same themes, depending on their sensitivity to and knowledge of the interview topic. 11. Interpersonal situation: The knowledge obtained is produced through the interpersonal interaction in the interview. 12. Positive experience: A well carried out research interview can be a rare and enriching experience for the interviewee, who may obtain new insights into his or her life situation. |
|--|

The data collected in this study, therefore consists of the participants' descriptions of their experience of health-related quality of life in AS expressed in their own words in a

dialogue with me as the researcher. It is a co-creation, a product of the interaction between the participant and the researcher (Finlay, 2002). Van Manen (1997) favours the use of in-depth semi-structured interviewing; stating that reflective interview transcripts require interpretive analysis by the researcher in order to produce a human science (phenomenological) description of the experience of the interviewee. Creswell (2013) also supports interviews as the primary means of collecting information for a phenomenological study.

I have been an advanced nurse practitioner for many years with a wealth of experience in talking and listening to patients and their families in my nurse-led clinics. However, I had to ensure that I was familiar with the techniques involved in conducting research interviews. For example, preparation for the interview and other practicalities of conducting the actual interview such as the seating arrangement, maintaining eye contact and the use of non-verbal expressions (Silverman, 2000). I opted for a triangular seating arrangement in the interviews with the interpreter for two reasons. The first was that I did not want the participants to feel that we (the researcher and interpreter) were placed in a superior position over them and the second was in order to emphasize the impartial role of the interpreter (Temple, 2002). I began the interviews by thanking the participants for agreeing to take part. I felt it was important to show my appreciation as they were giving up their time to attend without any payment and I needed to show them that their contribution was important. Following introductions, I reminded the participants of the duration of the interview (it would take no more than 60 minutes) and their right to stop or withdraw from the interview and that the interview was being audio recorded. The purpose of the interview was reinstated before the warm up question, so that the interview would remain focused on the topic under study.

3.9.5 The use of Interpreters in research

This study required the use of an interpreter in order to give a voice to and hence empower the non-English speaking participants. The Bangladeshi population can be considered as a 'hard to reach' group, due to difficulties that can be encountered to reach or involve them in research. The Bangladeshi community are also under-represented in research. This according to Khan et al. (2015) and MacNeil et al. (2013), results in healthcare practice based on research with limited external validity for the South Asian context. Lack of English language proficiency, unfamiliarity with local services and lack of attention to cultural factors by healthcare providers may pose a challenge (Mason et al. 2003; Office of National Statistics, 2012).

The complexities of using interpreters in qualitative research have been noted extensively in the literature (Edwards, 1998; Bradby, 2002; Almalik et al. 2010; Plumridge et al. 2012). There is however very little guidance available on how researchers using this method can work with interpreters. I have highlighted these issues and the strategies that I used to overcome them, in an abstract that I presented at the Royal College of Nursing International Research Conference in Oxford in 2017, abstract 310 (Appendix 14).

People who lack English language skills are excluded explicitly in research when resources for recruitment and translation or interpretation are inadequate (Plumridge et al. 2012). Commentators have criticised the exclusion of certain groups from research as constituting poor science (Hussain-Gambles, 2006) as regards the validity and generalisation of research findings (Oakley et al. 2003). Others have cited issues of social justice (McLean & Campbell, 2003) as research may affect the allocation of healthcare resources. I did not want these issues to deter me. I approached the National

AS Society (NASS) with my research proposal and I was awarded a research grant to assist with translation and interpretation (Appendix 15).

Clearly very early in my study I encountered the difficulties posed through lack of published guidance with regards to conducting ‘outsider’ research with participants who do not share the researcher’s first language. It was important for me to use interpreters to conduct my study with members of the Bangladeshi community in order to access their experiences of AS. The issues faced by researchers who conduct interviews with interpreters are well documented (Squires, 2008). In keeping with the approach used in this study, the interpreters are seen as active producers of knowledge (Squires, 2008). Before I began with my interviews, there were a variety of issues that I had to consider. These issues will be discussed in this section.

3.9.5.1 Choosing an interpreter

Through the Trust’s bilingual service, I was able to find an interpreter who had some experience with conducting qualitative interviews. Her proficiency in both English and Bengali was helpful as an indicator of ‘reliability’ that the information gathered was a faithful representation of the participants (Westermeyer, 1990; Twinn, 1997). Although some family members volunteered to act as interpreters, I preferred an independent interpreter. The main reason was that as a nurse practitioner who is used to conducting my own clinics I have first-hand experience, where I have used families to interpret but was left in some instances ‘doubting’ if the information was being passed between the parties correctly. Phelan and Parkman (1995) have pointed out the advantages of using families as interpreters; however, I felt that the participants might feel inhibited in talking about personal issues in the presence of a family member.

The same interpreter was used in all the interviews that required an interpreter. My Bengali/Sylheti interpreter used in this study is in her 30s and she has a Higher National Diploma in Health and Social Care. She is employed by the Trust as a senior health advocate and liaison for the Long-Term Conditions Service. She is married with two children. She has been in this post for four years and prior to this she was employed in Primary Care as a community social work liaison officer, and this is where she gained her interviewing experience. Her father has rheumatoid arthritis, and she is very involved in his appointments and consultations. She has lived in the Borough for the past 15 years and she was keen to participate in the interviews because this was 'familiar territory' for her.

3.9.5.2 Role identification and training the interpreter

My training with the interpreter took half a day and it involved discussions around the purpose of the interview, ethical issues and my own concerns about interviewing someone from a different culture. We were able to clarify roles and functions and the terms used within the interview. We both agreed from the outset on how to deal with any arising issues of a sensitive or personal nature. If any such issues arose, it was my responsibility as the researcher to pursue them and the interpreter would only act to seek advice from me. This helped to avoid the interpreter taking a more active role than was intended by crafting their own questions for example. The interpreter was aware of confidentiality issues and was bound by Trust policies on confidentiality. She was also able to reveal her own opinions and assumption in our discussions.

We discussed how the exchange of information in the actual interview would be carried out and how directive the interpreter would be in the interview process. The interpreter did not have any prior knowledge of the actual questions that would be asked in the

interviews and the interview topic guide was not provided. I briefed the interpreter to translate the dialogue as spoken and she provided third person narratives during the translations. In order to make the interpreter visible in this research, I followed Edwards (1998) proposal of making the interpreter visible, by encouraging her to translate in the third person. This was so that it was clear in any publication that the participant's words were subject to a linguistic interpretation. This is demonstrated in the narrative from participant Iyaz (Appendix 16). This more directive role allowed me to prompt and probe the participant for particular information. Other commentators have argued that this type of interviewing constrains the researcher due to their greater involvement (Murray & Wynne 2001). However, I was able to gain in-depth information about the phenomenon.

3.9.5.3 Practicalities of conducting the interview

The interpreter was drawn from the same culture as the participants. Westermeyer (1990) suggested that the interpreter might be reluctant to recount experiences, thoughts, feelings which reflect their community in an unfavourable way. I however felt that similar to Rana (1998) and Freed (1988) this common culture and background between the interpreter and the participant would encourage the participants to talk frankly.

I held debriefing sessions with the interpreter after each interview. These sessions helped to alert me to any possible presenting cultural issues that the interpreter was able to bring to the interpretation process, by virtue of their increased knowledge of the participants' culture (Hennings et al. 1996). I was able to improve my familiarity with the cultural norms of the participants. The interpreter was therefore not only there to

translate the conversation between the participants and myself but as a gatekeeper and cultural guide (Hennings et al. 1996)

My experiences of using interpreters in this research have highlighted the practical considerations and the potential difficulties of using an interpreter in qualitative research. Some rich data has been collected from the participants through the third person translations by the interpreters. The key for me was to attempt to make the interpreter's work visible so that their values, assumptions and beliefs which may structure their interpretive work were revealed.

3.9.6 Transcription of the interviews

A professional transcriptionist well known to me and fully aware of confidentiality transcribed the interviews verbatim. This was following discussions about the study. The issues of who should transcribe interviews have been highlighted by Dearnley (2005), who cites the conflicts that can arise when considering the advantages of the researcher self-transcribing to promote data emersion, over practical issues such as the cost, typing ability and time. Following transcription any identifying characters relating to the participants or outpatient department they were attending, were changed. Notes made on the participants' body language, tone of voice, laughter, crying and hand gestures as well as the researcher's feelings about their accounts were attached to the interview transcript. Sandelowski (1994) has discussed the problems inherent in transcription, where only certain features of the interview can be preserved and has alerted us to the potential for misrepresentation. Her texts on transcription have been essential reading for me before undertaking this part of my study. Expressions such as 'ehm', 'um' and various others were written verbatim.

In order to remain faithful to the interview, expressions indicating participants' thoughtfulness such as a hesitation were included. Laughter, chuckle or crying was indicated to allow the transcript to reflect the spirit of the interview. The interviews were typed very simply with rows of questions asked by the researcher followed by the participant's response. I followed Sandelowski's method of proofing the interview (Sandelowski 1995) whereby the transcript is read again alongside the source of the audio recording. This allowed me to immerse myself in the data and start highlighting any significant points which I added to the margins of the transcript. Lines of text on the transcript were numbered to aid the analysis.

3.10 The nurse as a researcher

The challenges for nurses as researchers, when conducting a hermeneutic phenomenological research have been highlighted by McIlfatrick et al. (2006). This is more so when using interpreters in the research. The researcher is the primary data collection tool and there is always the potential of being led into unintended areas of the participants' lives. Participants may assume transferrable skills and specific knowledge about other diseases (McIlfatrick et al. 2006). For example, one participant in this study talked about his irritable bowel syndrome (Iyaz, line 155):

'I have lots of gastric problems. You know ehm with my irritable bowel syndrome, I cannot take drugs like meloxicam but I need it for my AS. So, I don't know what else I can take without aggravating the bowel?'

Another participant talked about his Crohns disease of which I have limited knowledge (Raul, line 100)

'They also told me I have crohns disease as you know, it can flare anytime as well. But I need to know how to control it'.

These were awkward situations for me and I had to steer the conversation back to the topic under discussion without sounding dismissive, by asking the participants to discuss the issues with their GP. I was able to avoid what Kvale (1996, p.125) termed, 'allowing the interview to turn into a therapeutic situation which the researcher may not be able to handle'. I reminded the participants of the purpose of the interviews at the beginning of each interview.

I was constantly aware in this study that as the interviewer I was the main instrument for obtaining data. As such I needed the sensitivity to identify any ethical issues and the responsibility to feel committed to acting appropriately in regard to such issues (Eisner & Peshkin, 1990). On a scientific level, I am a nurse and I have a responsibility to the nursing profession and to the participants to ensure that the research project 'yields knowledge worth knowing and that it is controlled and verified as possible' Kvale (1996, p.118). As a qualitative researcher it is easy to assume different roles and the ethical issues in those different roles need to be considered. I was mindful as the data collection instrument, not to let my own biases and opinions affect my behaviour in this process as pointed out by Maykut and Morehouse (1994). In the context of this study, I had to be aware of the risk of 'going native' (Serrant-Green, 2002). During the interview process, I did not wear my nurse's uniform because I felt that I would be seen more as a nurse than a researcher and this would affect the responses and interactions with the participants. My familiarity with some of the participants as a nurse practitioner in the department aided the research in that the participants knew and already trusted me. However, during the pilot interviews my familiarity proved to be a hindrance as the responses to my questions were more guarded than anticipated. For the rest of the interviews I gave a brief introduction about the purpose of the research and

my role in it and this seemed to settle the participants into a comfortable ‘place’ where they could open up about their experiences.

3.11 Data analysis

Several approaches to data analysis have been used within the different schools of phenomenology (van Kaam, 1966; Collaizi, 1973; Giorgi, 1985; Smith, 2004). The preferred method of thematic data analysis in this research is informed by van Manen (1990, p78), who describes it as ‘a process of insightful invention, discovery and disclosure---not a rule-bound process but a free act of seeing meaning’. Although he provides some steps, van Manen (1990, p.30) believes that ‘the method of phenomenology is that there is no method’. Sandelowski (1994) asserts that during interpretation the researcher must stay close to the data in order to present findings fairly, even though the data might contradict their assumptions and expectations. According to van Manen (1990) when a researcher analyses a phenomenon, he or she is ‘trying to determine what the themes are, the experiential structures that make up that experience’ (p.79). The intent is not to ‘code’ the lived experience description but rather to use the lived experience description as a starting point to ask, ‘What might this particular lived experience description, passage, phrase or even word say about the phenomenon of interest’ (Adams & van Manen, 2017).

At this stage of the research process, I found myself confronted with a large amount of narratives from the interview transcripts and found it difficult to gain insights into these whilst busy with my work, my family and other distractions. In total I had 109 pages of text from the twenty interviews. I quickly realised that I needed to create or experience what van Manen termed ‘an empty moment’ and submit myself to a mood of openness in order to seize an insight by letting it seize me (van Manen, 2017). Smith et al. (2009)

have discussed the difficulties encountered when using hermeneutic phenomenology as a method of analysis in qualitative research. They contend that it is easy to make mistakes in identifying experiences and it is difficult to know that one has got it right, that one has extracted proper lived experience and defined the meaning of a research participant's experience. They go further to discuss the complexities of the phenomenological view of experience. With this in mind, I decided to put less emphasis on the essences that are important to descriptive phenomenology. Instead, my focus turned to understanding the meaning of experience by searching for themes and engaging with the data interpretively.

In phenomenological research, the legitimate source of the data is the individual who has lived the reality being investigated. I was mindful at the start of data analysis that I had to remain true to participants' words and meanings and to represent their experiences in what van Manen (1990, p.77) termed a process of 'reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience'. All quotes and lines of continuous text used have been presented with the participant's name and line number from the transcript in brackets at the end. This has helped to build a word picture of the different participants and their individual experiences.

I was always attentive and prepared to write notes and emerging ideas on the margins of the transcript; this was an on-going process and even when I did not have something to write with at hand, insights still came to me in various surprising situations and contexts. Every corner of my house had pens and paper, just so that I was ready to scribble things down if and when a moment of inspiration attacked me! I turned a wall facing my bed in my bedroom into 'my space' covered with blank flip charts anticipating those moments of inspiration, so that when an insight 'seized me' I was ready to write it down on 'my space'. Through manual cutting and pasting, I managed

to create directories of the participants' phrases that support related themes (Appendix 17).

At times, I felt as if 'I was losing my mind'! During the data analysis process my whole life seemed to have been taken over by another being, a being just looking for, searching and waiting for inspiration and meaning. According to van Manen (2017) these insights can occur as a 'fleeting evanescent Kairos moment, serendipitously, luck, playful providence not necessarily through straightforward systematic analysis but as if through the back door' (p. 823). Although several authors (Braun & Clarke, 2006; Creswell, 2013) have provided guidance on how to analyse qualitative data, as a novice when faced with the raw data I found it overwhelming and keeping focus was challenging. I realised that I had under-estimated the task ahead in-terms of time to analyse and how to organise the data in a way that I would stay true to the participants' narratives. I wrote in my journal:

'This is frustrating for me, just as I thought I was getting there, now this! I have so many pages of data, where do I start? My mind has gone blank and I am panicking! Maybe I have collected too much information? How can I even begin to make sense of all this' Journal entry 10/12/2017

This was overcome by reminding myself of the research questions and aims. I went back to reading the texts and I started grasping it. I turned a wall in my bedroom into my work space and I used this to copy and paste significant statements from the transcripts, and post it notes on initial thoughts about meanings (Appendix 17).

The manual analysis of data took a long-time, was complex and at times frustrating. As a starting point for this analysis, I wanted to reflect upon my own experience as a female from an ethnic minority background, although different from the participants. I

have also lived and worked for many years among the Bangladeshi community being studied. By being explicit and acknowledging my personal history, this can be used as a filter through which readers can contextualise my work (Sutton & Austin, 2015). I used the traditional way of manual analysis. On the hard copy of the transcripts, I made notes in the margins, using post-it notes and by highlighting and naming sections of the text. Through this I began to understand the world from each participant's perspective.

The process of data analysis was done in two stages. The first stage involved the process of uncovering thematic statements from the transcripts (van Manen, 1990), and the second stage involved the identification of themes. These will be discussed in the following sections.

3.11.1 Stage 1 analysis: Uncovering thematic aspects of the lived experience

Phenomenological themes are presented by van Manen (1990, p.90) as 'more like knots in the webs of our experiences, around which certain lived-experiences are spun and thus lived through as meaningful wholes'. There is therefore no conceptual formulation or single statement that can possibly capture the full mystery of an experience. Van Manen (1990) goes further to suggest that thematic phrases only serve to point at, to allude to or hint at an aspect of a phenomenon. In every lived-experience therefore, some descriptions are richer than others and as a result the researcher will learn more from some people than others. I have found this to be so true in this research. Some participants gave very vivid descriptions of their lived experience whilst others proved more difficult to gather. Van Manen (1990) points out however, that for all the shared experiences there will always be something there for us to gather.

I conducted all the 20 interviews and following transcription, I listened to all the recordings whilst checking for any errors in transcription. This assisted in the process of emersion with the data and allowed an increasing familiarity with the data (Rubin & Rubin, 2005). Each transcript was read through multiple times to get a sense of the whole. Thematic statements were isolated using van Manen's (1990, p92 - 93) holistic, selective and highlighting approach and a line-by-line thematic reflection.

Van Manen's three stages of thematic analysis include:

1. *The holistic or sententious approach*
2. *The selective or highlighting approach*
3. *The detailed or line by line approach*

The first method involves the selective or highlighting approach in which the researcher selects specific phrases or sentences in the text that capture the essence of the phenomena. The selected statements are copied onto a new document and grouped together. These direct phrases and sentences were reported in the analysis so that the 'researcher can stay faithful to the exact words used by the participants' (Cohen et al. 2008, p.462). The wholistic and sententious approach is the second method, in which the interpreter reads the text as a whole and then formulates a phrase that captures the fundamental meaning. Through sifting, scaling, reviewing and reflecting on the data the salient features of the phenomenon emerge (Parlett & Hamilton, 1976). The phrase is listed next to the corresponding sentence on the created document. Clusters of meanings from significant statements were developed into themes. Finally, the detailed reading approach, in which every sentence is examined to determine what it reveals about the experience. Here the verbatim transcripts were read through several times, line by line to get a sense of the whole and become familiar with the narrative. The revealing statement was copied onto the created document next to the wholistic phrase. Themes began to emerge, as these three stages were repeated for each transcript. Ullah's lived

experience description from his transcript (Appendix 18) has been used to show how the three approaches have been used in the initial stage to uncover thematic statements in this study (Appendix 19).

The preliminary or basic themes that emerged from Ullah's transcript were noted in the right –hand margins and these are shown in Box 3.1. In this initial list the order was chronological, according to the sequence they presented in the transcript. Similar to the hermeneutic circle which is made up of the whole and its parts, the parts of the text can be understood from understanding the whole. The hermeneutic circle constantly moves back and forth between the 'parts' and the 'whole' that we seek to understand, it is the process of understanding (Lindseth & Norberg, 2004). On the hermeneutic circle, Heidegger (1962) has described that:

'in this lies hidden the positive potentiality of the most original knowledge, which of course is genuinely grasped if the interpretation has understood the crucial task is to work these out of subject matter itself and thereby to secure the topic under study' p195

Certain experiential themes recurred as possible commonalities in the various descriptions. The aim here was not just to leave the themes implicit but to attempt in phenomenological fashion to 'systematically develop a narrative that explicates themes whilst remaining true to the universal quality or essence of the experience' (van Manen 1990, p97).

Box 3.1 Identified basic themes from Ullah’s transcript

| | |
|--|----------------------------------|
| Unpredictability | Delays in treatment uptake |
| Body seizes up | Cultural beliefs about treatment |
| Self-diagnosis | Treatments not always effective |
| GPs’ limited knowledge | Treatments have side effects |
| Seeking alternative opinion | On and off periods |
| Struggle to get a diagnosis | Functional limitations |
| Self-diagnosis | Body setting agenda/dictating |
| Google my symptoms | Body slows down |
| Physical disabilities/functional limitations | Slowed down body reaction |
| Hiding illness | Staying positive |
| Legitimation of symptoms | Body has a different plan |
| Family support | Spousal support |
| Acting normal | Worries about the future |
| Worries about passing AS to children | |

3.11.2 Stage 2 Analysis: Thematic networks- moving from basic themes to organising and global themes

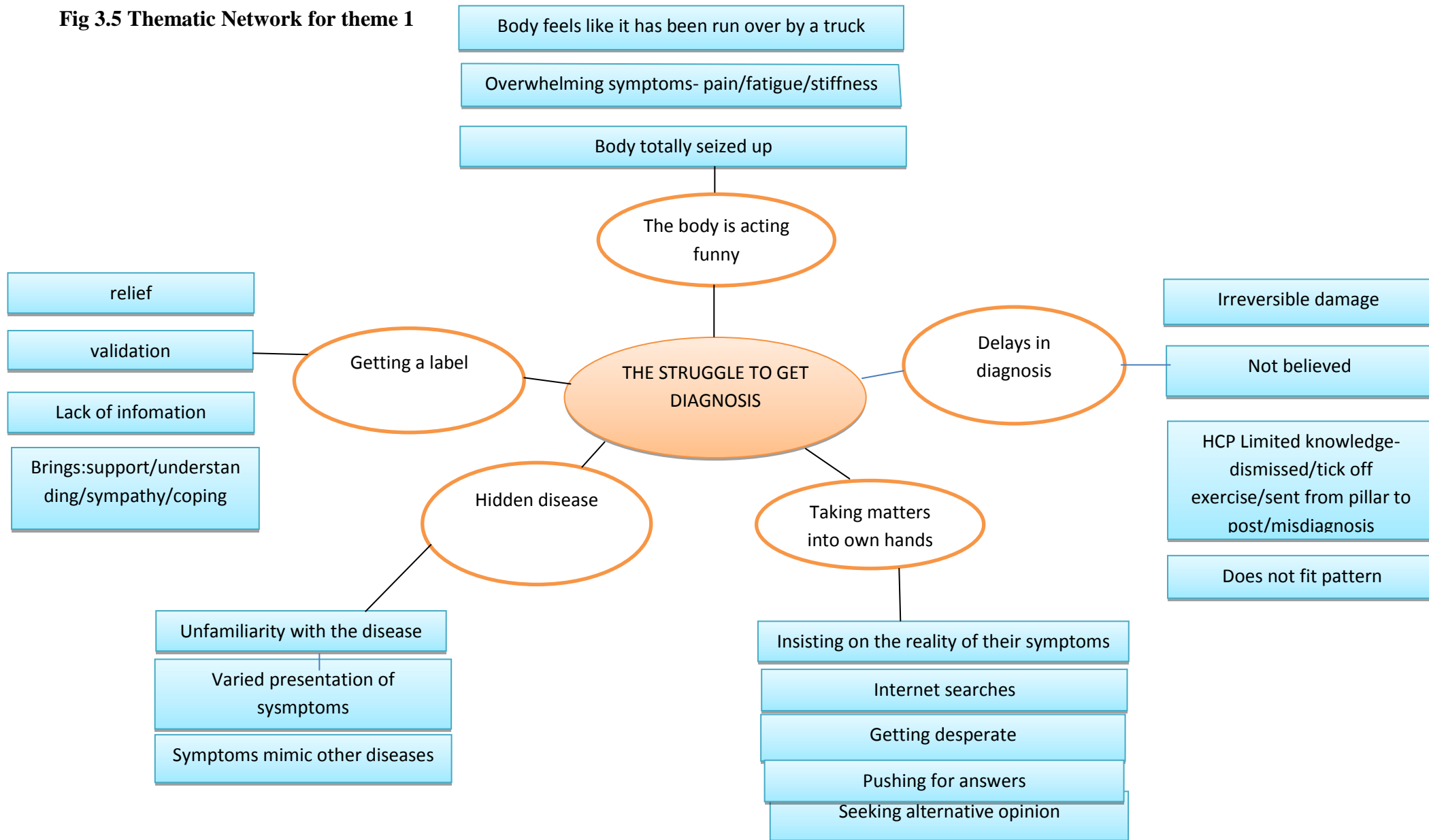
Following the isolation of the basic themes in the first stage of analysis, I used Thematic networks (Attride-Stirling, 2001) as a tool to systemize the further extraction of basic themes grouped together to summarise more abstract principles (organising themes), and the super-ordinate themes encapsulating the principle metaphors in the text as a whole (global themes). This was more a process of trying to make connections between the emerging themes, with some clustering together and some emerging as superordinate or global concepts. This process was iterative involving a close interaction between me and the text – a going back to the actual words of the participant. My experience of conducting this research has shown that researchers traditionally tend to omit the ‘how’ question from accounts of their analyses, leaving gaps in the recording, systematising and disclosing of their methods of analysis. I have chosen to use this technique for two reasons. Firstly, to enhance the value of my

interpretation and according to Diversi (1998), aid researchers wishing to carry out similar projects and secondly because this technique shares the key features of any hermeneutic analysis. It offers a web-like illustration that summarises the main themes constituting a piece of text (Attride-Stirling 2001). Once a collection of basic themes has been derived, they are classified according to the underlying story they are telling about the experience and these become the organising themes (Attride-Stirling 2001). The organising themes are then interpreted in light of their basic themes and are brought together to illustrate the global theme. The three classes of themes are briefly described below:

- *Basic theme*: the most basic (micro) or lowest order theme which on its own says very little about the text or group of texts as a whole.
- *Organising theme*: the middle order themes, group the main ideas proposed by several basic themes.
- *Global themes*: the super-ordinate themes are the macro themes that tell us what the texts as a whole are about within the context of a given analysis

Starting from the basic theme a thematic network is developed working towards a global theme. Five thematic networks were developed to represent the five global themes and their sub-themes and basic themes (Appendix 20). These are explored further in the findings chapter (see Chapter 4). An illustration of the thematic network for one of the global themes, is shown in Fig 3.5, as a web-like map depicting the salient themes at each of the three levels and illustrating the relationships between them (Attride-Stirling, 2001).

Fig 3.5 Thematic Network for theme 1



3.12 Measures for ensuring trustworthiness

The issue of trustworthiness in qualitative research is a contentious one, with no agreement about the standards by which such research should be judged (Rolfe, 2006). This is particularly evident in the theoretical interpretive phenomenological research. The issues of contention are centred on arguments over philosophical interpretation (Lawler, 1998; Draucker, 1999; Barkway, 2001) and a dialogue about which criteria fully express the rigour of phenomenological nursing research (Ray, 1994; Corben, 1999; Maggs-Rapport, 2001). The debate on the use of terms such as validity, reliability and generalizability to evaluate qualitative research continues (Sandelowski, 1993; Long & Johnson, 2000). Positivists have generally questioned the trustworthiness of qualitative research because the concepts of validity and reliability cannot be addressed in the same way in naturalistic work (Shenton, 2004). They cite the lack of scientific rigour with poor transparency in the analytical processes and the findings being merely a collection of personal opinions subject to researcher bias (Rolfe, 2006). Qualitative research has been criticised in the scientific ranks for its failure to adhere to ‘canons of reliability and validation’ (LeCompte & Goetz, 1982, p.31). Naturalists on the other hand, have argued against the use of positivist terminology asserting that this tends to be a defensive measure that muddies the waters and that ‘the language of positivist research is not congruent with or adequate to qualitative work’ (Ely et al. 1991 p 95). This lack of consensus according to Koch and Harrington (1998) places evaluators of research in a dilemma concerning its legitimacy. This has led writers such as Silverman (2001) and Lincoln and Guba (1985) to demonstrate how qualitative researchers can incorporate measures that deal with these issues.

The seminal work by Lincoln and Guba (1985) has stated the case for a criterion, which uses alternative terms, which they contend adhere more to naturalistic research. To

establish trustworthiness in a study, they use terms such as, credibility, authenticity, transferability, dependability and confirmability as the naturalist's equivalents for internal and external validation, reliability and objectivity (Creswell 2013). Lincoln and Guba's criteria (1985) for trustworthiness has been utilised in this study. I was attracted to their preferred terminology which is more in line with naturalistic work in the way it distances itself from the positivist paradigm. Their four criteria for trustworthiness of a research study involve establishing credibility (confidence in the truth of the findings); transferability (showing that the findings have applicability in other contexts); dependability (showing that the findings are consistent and could be repeated) and confirmability (a degree of neutrality or the extent to which the findings of a study are shaped by the researcher and not the researcher bias, motivation or interests) (Lincoln and Guba 1985). These will be explored in more detail next, in an attempt to show how they were operationalized in this research.

3.12.1 Credibility

Lincoln and Guba (1985) argue that credibility is one of the most important factors in ensuring trustworthiness. The researcher is the major instrument of data collection and analysis therefore their credibility is especially important in qualitative research (Patton, 2015). In this research this equally applies to the interpreter used. Maykut and Morehouse (1994) have recommended that the researcher must include any personal or professional information relevant to the phenomenon under study. I have highlighted my personal and professional information in Chapters 1 and 3 of this thesis. In this research, I have undertaken several strategies to ensure credibility. Prolonged engagement between the researcher and the participants is one of the strategies that has been recommended (Erlandson et al. 1993) with attention also being drawn to the dangers of researchers becoming so immersed in the culture being studied that their

professional judgements are influenced (Lincoln & Guba, 1985). I have made attempts to develop an early familiarity with the culture of the Bangladeshi community through consultations with key gatekeepers in the community (local MP, Imams and community centres). This has provided some prolonged engagement between me and the participants. I have made myself visible in the outpatients' department where the participants have been recruited and I have attended some community centres in the local area thereby gaining an adequate understanding of the culture of the Bangladeshi community and establishing trust. Opportunities for peer scrutiny of this research project have been provided, initially through presentation of my proposed research to medical and nursing colleagues in the department of Rheumatology, amongst whom are experts in the field of AS. Presentations of work in progress to other doctoral students in the research support group sessions at the university and attending research panels with academics outside of my supervisory team has allowed further scrutiny of my research. This has given a fresh perspective and allowed them to challenge my assumptions. I am aware that being close to the research might inhibit my ability to view things with real detachment. I have also been challenged to refine my methods, develop greater explanation of the research design used and strengthen arguments in the light of comments made. During the course of this research attending conferences and presenting my work has provided further opportunities for scrutiny. Monthly debriefing sessions with the supervisory teams have been conducted throughout this research. The discussions have helped widen my vision as well as draw attention to any flaws in my proposed course of action. This has also provided a sounding board for me to test my developing ideas and interpretation as well as recognise my own biases and preferences.

A wide range of participants were included in this study. Both male and female participants were recruited with an age range of 23 – 54 years and interviews were conducted in both English and Bengali. This has allowed individual experiences to be

verified against others. A rich picture of the experiences of those being studied has been constructed based on the contribution of this range of people. The sample size in this research was increased from 15 to 20 participants to try and achieve this further. Van Manen (1983) has stressed the importance of checking out bits of information across informants.

3.12.2 Transferability

Positivist researchers are concerned with demonstrating that their work can be applied to the wider population. Naturalistic researchers on the other hand believe that in practice, conventional generalizability is never possible as all observations are defined by the specific contexts in which they occur (Erlandson et al. 1993). Koch (2006) compares transferability to external validity in quantitative research. Here, information gleaned from the research by the reader should be meaningful and applicable to their own experience. In this research, Lincoln and Guba's argument that the researcher has the responsibility to ensure and provide sufficient contextual information so that any reader can relate the study findings to their own position is preferred (Lincoln & Guba 1985). In this respect, in Chapter 1, I made attempts to give a dense description of the phenomenon under study including the cultural and social relationships. This allowed comparison of instances of the phenomenon described in the report with those that the readers have seen emerge in their situations (Shenton, 2004). A comprehensive description of the methods used, was given in some sections of this Chapter, to include the type of sampling, setting, recruitment strategy and inclusion/exclusion criteria, data collection methods used and the time period over which the data were collected. This according to Marchionvini and Teague (1987) helps convey the boundaries of the study. This is the first study of its kind among the Bangladeshi community in the UK as indicated by the literature review in Chapter 2. This study has therefore provided a

baseline understanding which can be used as a springboard to conduct or compare any subsequent work in this area.

3.12.3 Dependability

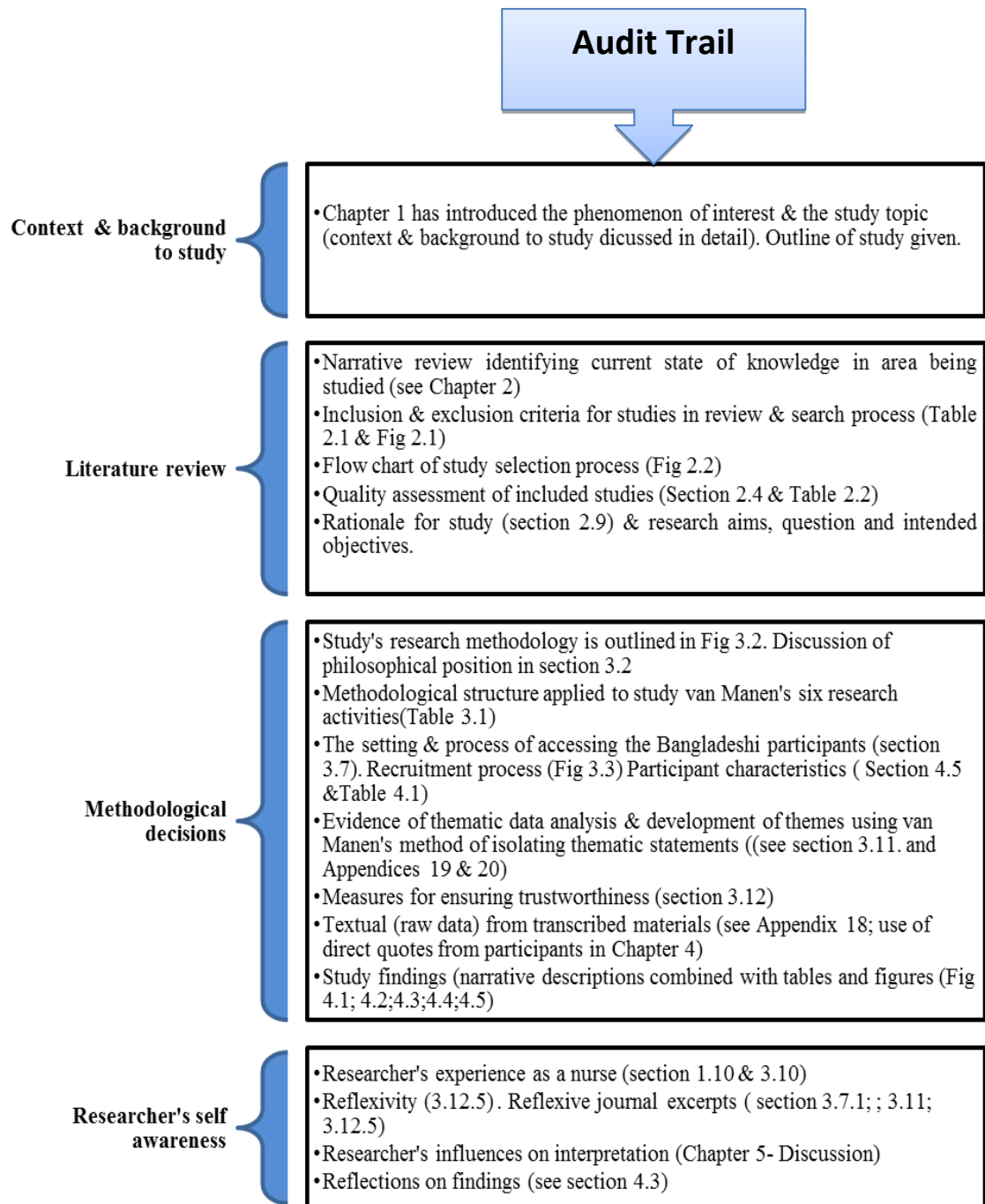
Dependability is about reporting in detail the research processes within the study in order to enable a future researcher to repeat the work. Positivists use techniques to show that if the research were repeated, in the same context, with the same methods and with the same participants, similar results will be obtained (Shenton, 2004). In qualitative research the changing nature of the phenomena scrutinised renders such provision problematic (Marshall & Rossman, 1999). Some of the strategies that have been employed to show credibility in this research can apply to dependability, similar to Lincoln and Guba's (1985) assertion that there are close ties between the two and, in practice a demonstration of one goes some distance in demonstrating the other. In this regard, the research design and its implementation, and the operational details of collecting the data have been reported in detail, to enable future researchers to repeat the work without necessarily aiming to get the same results. The reader is also able to assess the extent to which proper research practices have been followed due to the in-depth coverage (Shenton, 2004). The way that I have structured my work around van Manen's six research activities, with sections devoted to design, implementation, data collection and reflective appraisal, allows the reader of my research report to have a thorough understanding of the methods and their effectiveness. A consensus discussion between me and the supervisors was held to identify sub-themes and global themes at the data analysis stage.

3.12.4 Confirmability

Confirmability is about taking steps to ensure as far as possible that the work's findings are the result of the experiences of the informants rather than the characteristics and preferences of the researcher (Shenton, 2004). This according to Miles and Huberman (1994), has to do with the extent the researcher admits his or her predispositions. In this research I have taken steps to help ensure as far as possible that my findings are the result of the lived experience and ideas of the Bangladeshi participants rather than my characteristics or preferences. I have acknowledged my beliefs underpinning the decisions made and methods used in my report. My rationale for favouring interpretive phenomenology over other methodologies has been explained including weaknesses in the techniques employed such as the interviews with interpreters and the narrative literature review. There has been an on-going reflexive commentary throughout the report. An 'audit trail' has been provided in some cases with the use of figures and diagrams to allow the reader to trace the research process step-by-step through the decisions made and procedures described. This is particularly evident in the literature review in Chapter 2, and the process of isolating thematic statements in this chapter.

According to Koch (2006) an audit trail is where others can examine the researcher's documentation of data, methods decisions and end product. In order to communicate my audit trail, I have provided an account of all research decisions and activities throughout the study (see Fig 3.6)

Fig 3.6 Presentation of audit trail in the thesis



The strategies addressed in this section have helped ensure that the research findings reflect the aim of my study. By tackling this contentious issue in qualitative research, I hope that the reader of my report can be convinced of its quality when appraised against Lincoln and Guba's (1985) criteria.

3.12.5 Reflexivity

Reflexivity plays a significant role in many qualitative methodologies (King, 1994; Koch & Harrington, 1998; Robertson, 2004). Koch & Harrington (1998) suggest that the researcher must engage in continuous self-critique and self-appraisal and explain how their own experience has influenced all stages of the research process. There is a suggestion here that the researcher is intimately involved in both the process and the product of the research, which Dowling (2006) views as the personal and epistemological principles. Personal is in terms of the researcher being aware of what is influencing their internal and external responses and epistemological is in terms of the researcher being aware of their relationship to the research topic and the participants. I have examined and made explicit the decisions that I have made at each stage of this project. With my professional experience in mind, I took steps to implement some reflective practice in order to highlight my influences on the research process. Firstly through the monthly supervision meetings and the peer support groups and secondly by keeping a reflexive journal. The reflexive journal helped to articulate my personal views and insights about the phenomenon. My effect as a researcher on the whole research process, from gaining access to the Bangladeshi community, recruitment, data collection, analysis and interpretation have been acknowledged and I also recognise how I have been affected by conducting this research.

My research was conducted within the medical specialty of rheumatology care with a focus on the health-related quality of life experiences of Bangladeshi patients with AS. The setting is an outpatient department. In designing my research, I was concerned with a number of issues, one of which was recruitment of members of the Bangladeshi community who would be willing to share their in-depth experiences of this illness. I was aware that some of the experiences could potentially involve some sensitive issues, such as reliving painful experiences of living with AS. I therefore wished to sensitize

myself with these issues and recognise any signs of distress in the participants. Most rheumatology research is positivist and when I presented my proposal to medical colleagues; I was not too sure how they would receive it. Surprisingly there was a lot of interest from the group although I could sense that they were not too familiar with phenomenological research.

I am very familiar with the rheumatology setting as an advanced nurse practitioner in the department. This includes its specialised language and culture, so it is fair to say that I felt at home in this 'world'. I was also aware that this familiarity might blind me to certain aspects of the specialty that I might take for granted. For example, I might be biased in defending our practice in the department against any negative experiences that the participants might highlight. This was reflected in my diary after an interview with Mo who expressed the following experience of diagnosis:

'I wish someone had gone through with me what to expect when I was diagnosed. Someone to say 'this is normal' it wouldn't have been such a shock to me. I don't know if anyone else has this condition, it would be good for someone to say, 'this is what you have got, this is what to expect, other people have got it, this is where to go for support'. If someone had actually said these things to me, it would have helped me to deal with it within myself. To know that I am not alone in this fight. I would feel normal and not the odd one out. I really suffered emotionally when I got diagnosed; Mo, Line 108

At times I was concerned that I was being positioned as an expert in the area of AS which I am not. My area of expertise is rheumatoid arthritis which has similarities but is quite different to AS. So, in a way I considered myself as an outsider within the context of the research topic. I was concerned that the direct teams might see me as someone who was in some sense intruding and attempting to evaluate the quality of care they provide. I clarified my role in the research and the purpose of the research, answered

any queries or questions they had. This helped us to build a good working relationship and ultimately led to me accomplishing my goals.

When explaining my study, I emphasized that I was a part-time Doctoral student. The direct care team described me as an expert, an experienced nurse when introducing me to the participants. This in some ways was true because I come with 20 years' experience in rheumatology nursing, but not necessarily in the field of AS. I was mindful that this might create an impression that the participants would expect more from me or even approach me with some of their issues in the interviews. To avoid this, when I introduced myself to the participants I made it clear that I was an expert nurse in another area of rheumatology but would be happy to refer them to expert nurses in AS who would address any issues that they might have. This helped to reduce expectations about my role.

The use of a reflexive journal throughout the research process therefore helped me to remain reflexive, as I used it as a stimulus to deepen my understanding of the research process. The journal served as a log of events such as meetings with my supervisors & panel meetings; important notes on articles read and feedback from my presentations; thoughts and feelings about the challenges and milestones that I faced. Dowling (2006) advocated using a journal when conducting qualitative research. For me an additional benefit of the journal was to capture my thoughts and feelings about how I was doing and progressing in my doctoral research trajectory (including all the frustrations that I sometimes faced!). I have tracked my development as a researcher through this journal. For example the extract below shows how I prepared for undertaking interviews:

'I am really excited about data collection now that I have the ethics approval. However I am unsure if I am ready for this and apprehensive about using an interpreter in the interviews. I have read that sometimes participants do not turn up at the last minute and I want to ensure that I get the full stories from the participants. I have to choose the

right interpreter who will understand the aims of my research. But then again, if my experiences with the interpreters in my clinical role are anything to go by, there is always a chance of misinterpretation! I have to do my bit and train the interpreter and put everything in place to avoid too many problems'. Journal entry 12/07/2016

In my journal entry reflecting upon the pilot interviews, I recognised how I had underestimated the time it would take to transcribe an interview. It was also emotionally draining for me as the researcher listening to the experiences being narrated by the participants:

'I have found the interview preparation useful in that I have been able to talk freely to the participants and they have narrated their experiences of AS in-depth. However I did not anticipate the amount of time it has taken me to transcribe just one interview. I have had to go through the recording several times in some instances just to ensure I got it right. It has taken me almost 6 hours to transcribe a single 40minute interview!' Journal entry 07/08/2016

'One participant just wanted to talk about his experiences of AS and I struggled to stick to my topic guide questions at times. On one side I did not want to stop the flow of the narration but I also wanted to balance this with the research aims. He made me feel quite emotional when he talked about how some people are not kind to sick people and went on about his daily struggles to do the basic tasks like toileting, dressing and sleeping. These are things that I take for granted as I just 'do them', but hearing this almost made me want to take a break from the interview. This was very emotional for me as well' Journal entry 10/08/2016

Following the pilot interviews, I sought support from my supervisors. I reported in the journal afterwards:

'Talking to my supervisors today was very helpful in terms of putting into words my fears about my first interview experience. In a way this has been an important debriefing session for me and I have got some action points going forward. I feel more relaxed about the next interview' Journal entry 22/08/2016

3.13 Chapter summary

This chapter has outlined the research methodology and methods used in this study. I began by addressing issues of epistemology and ontology as they can influence the way in which the research is undertaken, from design through to conclusion. The philosophical foundations of my research followed, to include the rationale for choosing a Heideggerian interpretive phenomenology guided by van Manen's framework. The actual process that was carried out in the research to include, preparation, and recruitment, conducting the interviews, transcription and method of analysis has been presented. The chapter concluded with the process of data analysis used and how the themes were developed. Van Manen's thematic approach to data analysis has helped provide phenomenological structure to the analytic process. The procedures of ensuring trustworthiness and reflexivity in this research were specified in the final sections. The findings from the use of the outlined methodology will now be presented as interwoven themes in Chapter four.

Chapter 4: Findings

4.1 Introduction

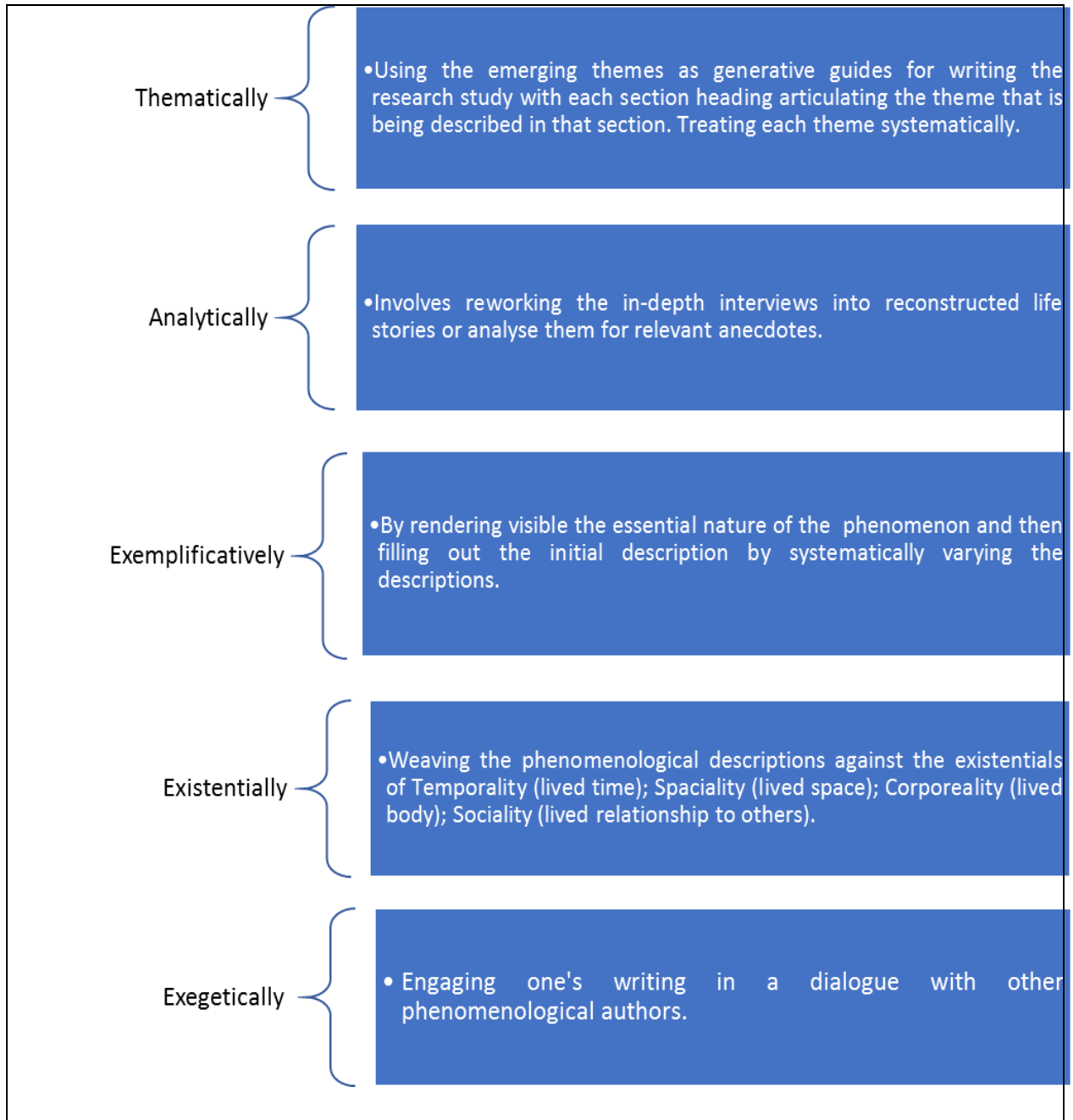
This chapter gives a brief introduction to the style of presentation and organisation of the findings of the study, followed by an introduction to the participants and finally the findings themselves. The findings will be presented thematically in order to capture the complexity and the ambiguity of the lived world being described (van Manen, 1990). Staying true to phenomenological research, examples and quotations from the data will be used to illustrate points made. This is in order to bring readers into a close relationship with the phenomenon (Halling, 2002). Here the notion of truth contrasts with the more positivistic concepts of truth, revealing an in-depth insight into the lived experience under investigation: a truth (a-letheia) that must reveal itself into unconcealment (Heidegger 1962).

4.2 Style and organisation of findings

My findings will represent the story that I am going to tell in response to the research question: What is the lived experience of health-related quality of life in Bangladeshi patients with AS? I was the only person involved in the isolation of thematic statements in this study. However, each stage leading to the final identification of the basic, organising and global themes was presented to my research supervisors for discussion and their guidance as appropriate. I preferred manual coding throughout as I felt the use of computer software would diminish my 'staying immersed' in the lived experience. My engagement in this process and how I arrived at the global and sub-themes was discussed in detail in Chapter 3. In phenomenological research, there are different patterns of presenting the research findings. Van Manen (1990) has offered a model of the overall writing structure of a phenomenological study. On 'working the text' he

recommends five options for structuring one's research findings (van Manen 1990, p.167) and these are illustrated in Box 4.1. I have chosen to present my description and interpretation of the phenomenon, Health-related quality of life experiences of Bangladeshi patients with AS, thematically using emerging themes as a guide. With this option, parts are seen to elaborate an essential aspect of this phenomenon. This experience is the beginning and the end point of the research and the written product illuminates the essence that makes the experience 'what it is'. According to van Manen (1990, p.168) each theme must be treated systematically although one theme implicates the meaning dimensions of other themes. The studied lifeworld which Heidegger further embodies as Dasein or Being-in-the-world is that of 'everyone as the other and no one as himself' (Heidegger, 1962, p.165). I have used a manual exegesis to once again familiarise myself with the themes and the experience as a whole.

Box 4.1 Structures for presenting a phenomenological description (van Manen, 1990 p.168)



4.3 Reflections on findings

I have found it challenging to try to represent the wealth of my material in a coherent way and craft a report which is faithful to the original material whilst at the same time allowing my stylistic contribution. I am new to the art of writing up research findings and as such, I did not feel confident at the beginning of the process. This was mainly to

do with how I was going to choose which material to use and how much of it. Finding a balance between verbatim quotations and narrative text was hard to learn. I however, developed some of my techniques through trial and error and through reading reports written by other researchers. I have learnt a lot from this. I was also aware at this stage of the process that I needed to remain true to the participants' lived experience whilst revealing my influences. The interpretation of the participants' words is a function of the background, experience and beliefs of the researcher involved and as such my journal helped illuminate the value in the process of interpretation and discussion of the participants' data. True to hermeneutic phenomenological research, van Manen (1997, p.129) argues for text that makes readers feel directly addressed by it: 'textual emotion, textual understanding can bring an otherwise sober-minded person to tears and to a more deeply understood worldly engagement'. All the participants narrated details about their lives and not just the experiences of living with the AS, often including their aspirations, hopes and expectations. From this I was able to gain an insight into the participants' attitudes and frame of mind and construct an interpretation of them based on this. In my reflexive diary (22/10/2016) I noted, 'I can appreciate what the participants are talking about and I want to allow their stories of how it all started to emerge, so that it can assist me to understand what lay behind their AS'. Some of these quotes illustrate the essence for each participant and will contribute to my interpretation.

4.4 Use of direct quotes

Direct quotations from the research participants have been used in order to enable the participants to speak for themselves. This has given the Bangladeshi patients a 'voice' by empowering them as well as achieving maximum impact of the findings. In sections where most participants have similar strong views on an issue, I have included separate

quotations from different people, presented in series and then after explanatory text, a single quotation illustrating the different view. In some areas, several quotations are presented from different people to illustrate one point made, as my way of wanting to be inclusive rather than exclusive. This inclusive approach is important in order to include some spoken word from everyone who took part in the study and avoid what Beck (1993) termed, the overuse of the words of those participants who were particularly articulate or had more to say about the phenomenon. Verbatim quotes have been italicised to distinguish them from my narrative

This chapter will show the interpretation in detail with participants' words employed as an introduction to illuminate each global theme. Being mindful to keep the evolving part-whole relation of my research, overall the themes give an impression of what characterises the phenomenon of health-related quality of life experiences of Bangladeshi patients with AS. The themes are interwoven as will be evident in the following discussion.

4.5 The participants and the phenomenon

The 20 participants who were recruited to the study are listed according to the order in which they were interviewed and represented by their chosen pseudonym to maintain confidentiality and anonymity (Table 4.1). All the participants were diagnosed with AS using the 1984 Modified New York Criteria and were living in the local borough attending the rheumatology outpatient department. The participants had a long illness history of between 4 and 22 years and they had gone through stages from the onset of symptoms, searching for answers, delays in diagnosis, through diagnosis and treatment, to living a life where the AS gradually affected all aspects of their lives, adjusting to an

ever-changing body, renegotiating roles, and aiming at getting support, independence and control in their everyday life.

Of the 20 participants, five were female (20%) and 15 were male (80%). Six (30%) of the participants required translation and interpretation. The majority of participants were born in Bangladesh (70%). The average age of the participants was 39 years with the ranges being from 23–54 years. At the time of the interview 19 participants were married with the one being single. The interviews lasted between 33–51 minutes. Four participants who had initially indicated an interest in the study, declined when contacted for different reasons (n=1 moved out of area; n=1 no time busy with family issues; n=1 prefers to be interviewed in his office; n=1 changed his mind about being interviewed).

Table 4.1 Demographic Details of the participants

| Pseudonym | Age (years) | Gender M-male F-female | Interpreter | Marital status | Country of birth | Interview Duration (minutes) |
|-----------|-------------|------------------------------|-------------|----------------|------------------|------------------------------|
| Jay | 37 | M | No | M | Bangladesh | 50.17 |
| Nas | 40 | F | No | M | UK | 44.00 |
| Mo | 40 | F | No | M | UK | 49.33 |
| Faz | 23 | M | No | M | UK | 35.20 |
| Ali | 48 | M | Yes | M | Bangladesh | 44.36 |
| Rafiq | 40 | M | No | M | Bangladesh | 37.21 |
| Soji | 54 | M | Yes | M | Bangladesh | 57.40 |
| Zak | 47 | M | Yes | M | Bangladesh | 55.50 |
| Zia | 35 | M | No | M | Bangladesh | 33.18 |
| Ullah | 25 | M | No | S | UK | 30.34 |
| Jaz | 34 | M | Yes | M | Bangladesh | 43.21 |
| Iyaz | 50 | M | Yes | M | Bangladesh | 44.30 |
| Ravi | 54 | M | No | M | Bangladesh | 40.11 |
| Rihanna | 48 | F | No | M | UK | 39.26 |
| Zaeed | 44 | M | No | M | Bangladesh | 53.05 |
| Raj | 36 | M | No | M | Bangladesh | 38.10 |
| Shumi | 36 | F | No | M | UK | 40.46 |
| Raul | 30 | M | No | M | Bangladesh | 38.13 |
| Naseeb | 31 | M | yes | M | Bangladesh | 40.11 |
| Zaza | 35 | F | No | M | Bangladesh | 36.43 |

The findings will now be presented thematically, as five themes ordered and reordered from twenty-three sub-themes. Each section heading articulates the theme that is being

described in that section. The themes are colour coded to show the global and sub-themes (see Box 4.2). Each sub-section begins with a direct quote, taken from the transcript to illustrate the kind of data classified by each theme, as suggested by Breakwell (1995) and an explanation of the theme follows. This is followed by a figure showing the global theme and its sub-themes. In the figure, the global theme is written in capital letters whilst the sub-themes are in small letters and underlined, in order to make a distinction between them. Using the themes as a horizon of interpretation, it is possible to describe the lived experiences in both a detailed and specific manner. Although the phenomenon is presented thematically, Heidegger suggests returning to the thing itself to show the real essence (Heidegger, 1962). The overall presentation of the lived-experience of the Bangladeshi patients with AS, will therefore be woven throughout the findings. According to Gadamer (1995), an interrogation of the text must involve a dynamic workup of the life world descriptions which supports the seeing of the pattern of meanings, and thus the essence. An essence is a way of being and as such cannot be separated from the phenomenon that it is the essence of (Dahlberg, 2006).

Box 4.2 Global themes and sub-themes

| Global Theme | Sub-themes |
|------------------------------------|--|
| 1. The struggle to get a diagnosis | <ul style="list-style-type: none"> ➤ My body is behaving funny ➤ It's a hidden disease ➤ Delay in diagnosis ➤ Taking matters into own hands ➤ Getting a label |
| 2. The Nature of AS | <ul style="list-style-type: none"> ➤ Physical symptoms ➤ Emotional symptoms ➤ Persistent disease ➤ Fluctuating ➤ Mind and body disconnect |
| 3. The Impact of AS | <ul style="list-style-type: none"> ➤ The body as a cue to illness ➤ Emotional impact ➤ Social impact ➤ Relationships ➤ Life goals |
| 4. Managing with AS | <ul style="list-style-type: none"> ➤ Adjusting ➤ Finding support ➤ Taking control ➤ Building a new life |
| 5. Finding relief | <ul style="list-style-type: none"> ➤ Drug treatment ➤ Complementary therapies ➤ Physiotherapy ➤ Traditional health-related beliefs and practices |

4.6 Life before the AS

The participants knew I was interested in their experiences of living with AS. I started each interview by reminding each participant of the purpose of the interview before

going into the interview questions: 'I would like to explore your experiences of AS and how it affects your life' followed by, 'Can I start by asking you how long you have been living with AS? Each participant started their story from before their diagnosis, in terms of their initial symptom presentation and how it all began. This was an interesting aspect of their experience of AS, from which I was able to reflect on the experience of initial presentation of their disease and how that had an impact on their life world. It was clear that the participants did not see the experiences of initial presentation as a separate entity from having the label of AS and living with the condition but as more of a continuum. Through reading and re-reading the transcripts there was indeed a great deal of background information from the participants. It was as if they wanted me to know that they had a normal life before it all began. For instance, most of the participants lived a 'normal' active life, with hopes of achieving great things:

'I had very high hopes of achieving great things. I wanted to be the secretary of the UN, yes United Nations secretary. I wanted to protect people's rights; I wanted to give a voice to the voiceless. I wanted to be able to lead my people and deal with their issues and problems' Zaeed Line 102

'I was studying for my PhD. My late father was a doctor and my father in-law is also a doctor, a neuro-scientist so yeh my brain works very well' Rihanna Line 48

'He was very active and had a normal life' Jaz Line 3 (via an interpreter)

This background information on the participants allowed me to understand the participants not only from their illness perspective but from their life when it was 'normal' before the disruptions from the AS. The information also helped to provide some background information on the participants' socioeconomic status. This has become an important part of how I can understand the frustrations, the anger and the regret at what could have been for them. Although I did not consider this background

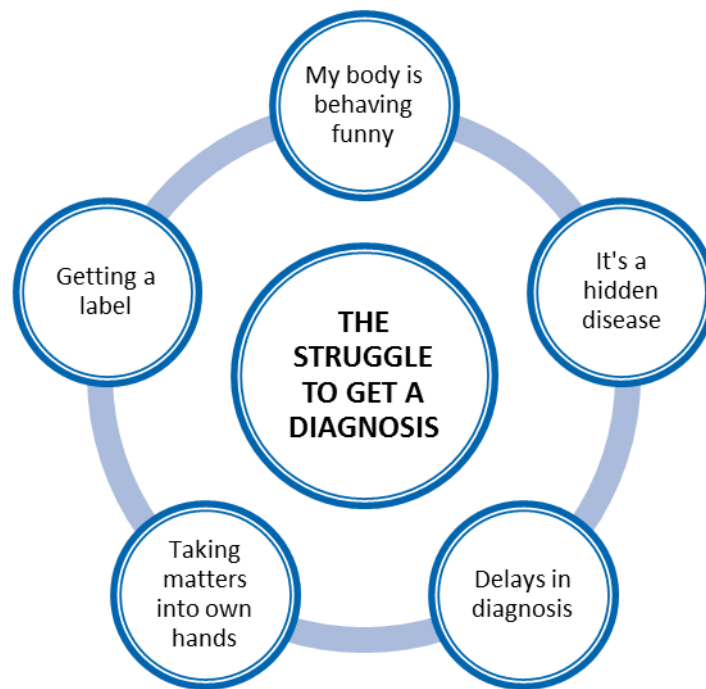
information to constitute a specific theme, I have incorporated it into the theme, ‘the impact of AS’. The reason is that the AS appears to have impacted the participants’ lives in many ways even before they had the label and this is indeed a part of their whole experience of the illness. Each individual participant had a ‘normal’ life before the AS, which they have interpreted through their own world view. I can equally apply this principle to myself, through reflexivity and I have presented the influences upon myself in a separate section (Chapter 3).

4.7 Global Theme 1: The struggle to get a diagnosis

‘I suffered with the lower back pain and stiffness for 10 years before I could get any answers’ (Rafiq Line 11)

A common theme was ‘the struggle to get a diagnosis’, which the participants were engaged in since their symptoms began. It conveys the challenges of living through a period of unexplained symptoms that impacted on all aspects of their lives. From the initial presentation of their symptoms to the eventual diagnosis of AS the participants were desperate to find answers for what was happening to them and why the illness had been visited upon them. Their lives were turned upside down and this caused them to try and find an explanation or meaning in this which was often expressed as: Why me? Equally, they struggled to get answers or convincing explanations for the overwhelming symptoms of pain, stiffness and fatigue from the healthcare professionals. The eventual diagnosis brought some relief and validation to some but to others, questions remained about the impact of the disease on their future in terms of family roles, social interactions and work. The theme has five sub-themes which will be presented woven together through the text (Fig 4.1).

Fig 4.1 The struggle to get a diagnosis



The first sub-theme ‘the body is behaving funny’, uncovers the confusion experienced by one of the participants at the beginning of their symptoms, where something was wrong, the body was seizing up without warning and there were overwhelming symptoms of back pain, fatigue and stiffness. Other participants expressed their experience in a similar way. Sub-theme two, ‘it’s a hidden disease’ describes how most of the participants and healthcare professionals were unfamiliar with AS and how its symptoms mimic other diseases making it difficult to diagnose. Sub-theme three, ‘delay in diagnosis’, acknowledges the limited knowledge about AS by both participants and health-care professionals, who missed the diagnosis over many years and tended to dismiss the symptoms leading to irreversible damage. Sub-theme four ‘taking matters into my own hands’ shows how the participants through frustrations in the diagnosis delays, decided to do their own searches online for information, self-referred for second opinion or insisted on the reality of their symptoms. Finally, sub-theme five, ‘getting a label’ narrates examples of the conveyance of the diagnosis by the healthcare

professionals and the participants' feelings of relief at the validation of their symptoms brought support and understanding from their families and others.

4.7.1 The body is behaving funny

When I posed my opening interview question, 'Can I start by asking you how long you have been living with AS?' this appeared to have been a prompt for the participants to talk about their 'struggle to get a diagnosis'. All the participants frequently talked vividly about their initial symptom presentation and investigation as well as the experiences of seeking help from the healthcare professionals and searching for meaning. Raul who is now 30, attributed the back pain that he was experiencing to a one-off incident, but over time due to the recurrent nature of the pain he realised that this was not the case. His GP dismissed his symptoms as a vitamin deficiency.

'I was about 17 then. I lifted a gear box and after that started feeling pain. I went to the GP in 2006 then he run a diagnostic on me. You know he done no x-ray, no MRI just blood test and he goes 'Eh you are low on vitamin D' and he gave me vitamin D tablets. I was going backwards and forwards to the GP for some years' Raul Line 1

On another visit to his GP, Raul became more insistent, due to the increasing severity of the pain, however he got more of the same from the GP, in the form of pain killers and in desperation changed his GP.

'I went back to my GP because the pain was not going away and told him, 'Look something is not right' but more co-codamol. I kind of lost faith with my GP and decided to change to another GP' Line 23

Zia had a similar experience with his GP who attributed his symptoms to muscle pain:

'Next time I went back, the GP said' Oh this is muscle pain, no worries, you will be fine, it will be okay. I will give you co-codamol and ibuprofen' Line 8

Two female participants' symptoms started following their first pregnancies and their GPs dismissed them suggesting they were related to their pregnancies and child birth:

'My symptoms started with my first pregnancy but I was diagnosed when I had my fourth. I know people who have had a C-section and they have been fine so why am I struggling? I saw my GP first but it was out of his depth really' Nas Line 23

'They said it's pregnancy problem, misalignment, probably sciatica or stuff like that. Several months went by and I was like,' this cannot be related to sciatica or child birth coz nothing happened. I didn't have forceps delivery or anything like that. So, I went to the doctor and I explained something was wrong and they just dismissed it. They just said it's part of giving birth, they just dismissed it completely' Shumi Line 7

Ravi a 56-year-old unemployed male participant, narrated the start of his symptoms and how he was confused about what was happening to his body. He could not get any explanation:

'I had been suffering for quite some time with lower back pain, tiredness and lethargic all the time umm pain without knowing what was going on with my body. I was confused and my GP had no answers for me' Line 1

Jay's pain 'attacked him without warning' leaving him very stiff and unable to move all of a sudden. This led to some confusion:

'I couldn't understand what was happening to me. My body was behaving funny. The pain would just attack without warning, then I was stiff as a board especially in the morning' Line 2.

Shumi's body felt like it had been 'run over by a truck':

'I was like very unwell, so like my entire body felt like it had been run over by a truck. So, every morning it was the fatigue, painful to get up, I just couldn't get up, I couldn't get out of bed. Throughout the day I would be in so much pain'. Line 13

On the search for meaning Ali was struggling to understand what was going on and questioning, Why me? Nothing was making sense in his new reality. It appeared to be an 'existential 'cry of despair. Soji had similar sentiments with fatalistic views of his illness. Their lives were turned upside down, with some participants trying to find the answer of why the illness had been visited upon them:

'I was living in my own world, thinking why me? What have I done to deserve this? Did I do something wrong' Ali Line 19

'He says Allah knows why he has it. He has not wronged anyone. He is good to everyone. He is a good person'. Soji, Line 49 via an interpreter.

Others like Ali even thought they had brought the disease on themselves by some act of wickedness on their part and they were asking for forgiveness to wish the disease away.

'Please help me, if I have done anything wrong forgive me. I know maybe I have done something wrong maybe that's why he gave me this. I pray to Allah to forgive me' Ali, Line 141

The lack of a definitive diagnosis for most of the participants, resulted in them attributing the onset of their symptoms to a specific injury following an accident or incident, surgery, back injury or a slipped disc. Others went further to take a fatalistic view believing their symptoms were a form of punishment from Allah (God). The unfamiliarity with the disease by the GPs who came into contact with the participants generated uncertainties.

4. 7.2 Its a hidden disease

The sub-theme 'it's a hidden disease' reflected several meanings for the participants. The first meaning is centred around, how many participants are not aware of the AS symptoms which mimic other diseases. The second suggests that AS is not a known or familiar disease amongst the participants (who did not discuss it openly for fear of stigmatisation and isolation) and the healthcare professionals who found themselves puzzled and confused about it. Finally, the AS is not a visible disease that can be seen from someone's outward experience.

Much remains unknown about the disease and this has resulted in problematic encounters with healthcare professionals who could not recognise the disease symptoms. When the participants experienced the strange pains and other unexplained symptoms they hoped a trip to the doctor would solve their problems. But the doctors had just as much trouble identifying the condition.

One participant suffered quietly and hid his illness because no one understood what was going on:

'The GP always said 'its common back pain, just do stretches and take pain killers, it will go away'. I think for me the most difficult part was explaining to my coz if I told my family I had back pain they would say, 'it's probably just a cold, it's a general issue' so I went through a period of suffering quietly. Even after the diagnosis it was difficult to explain because no one had heard of the illness' Faz, Line 52

Rafiq a driving instructor also felt it best to hide his illness:

'My friends and other people wouldn't know what I was suffering from that time or even that I had this condition. To them I am okay'. Rafiq, Line 125

Another participant narrated how people do not understand his struggles with the symptoms:

'He says it is a hidden disease that no one knows or understands so when people see him struggle they do not understand'. Iyaz, Line 57 via an interpreter.

Because the GP was not familiar with the disease, Rihana was treated for different problems whilst her disease was progressing:

'They called it growing pains, then it's like period pain and then lack of vitamin D, lack of calcium. And then eventually after 8 years I was told, because of the severe sacroiliitis, I have had the condition for a very long time'. Rihanna Line 5

Soji found other people around him were not aware of the illness and as a result he was ostracised:

'He says he does not like to explain his illness to others. He can't understand it himself so how can they. He says other people just stay away'. Soji, Line 56.

Other participants like Zak found that the healthcare professionals were puzzled by the initial symptoms:

'In the beginning the doctors were puzzled' Zak, Line 22

Rihanna said the Bangladeshi community was more aware about diabetes than AS.

'This condition is not common in the Bangladeshi community, no one seems to know about it. It's not like diabetes where you know someone who has it and people talk about it. I think I am the only one with this illness'. Rihanna Line 54

Another participant gave an analogy of a disease with no face:

'I look normal on the outside. You look at me you wouldn't know I have the disease, but it is inside my body, like it cannot be seen. You can't tell the face of this disease, in a sense it can be deceiving' Raj Line 125

4.7.3 Delays in diagnosis

The delays in diagnosis were upsetting and distressing for the participants. Participants were ill for a long time before any doctor they saw believed they had a disease. Some of the participants believed they developed irreversible damage due to diagnostic delays. Most of the participants had to demand or fight to get tests done or to be referred to the specialist rheumatologist. The majority of delays in the UK were therefore due to 'primary care delays', in the recognition and onward referral of or investigation of presenting symptoms. Those who went abroad to seek answers seemed to experience much shorter delays. Three people paid for private consultations in the UK and two participants travelled to India through Bangladesh to speed up diagnosis. Almost all the participants perceived some form of reluctance or negativity from GPs who would not order any investigations or make referrals to rheumatologists or physiotherapists. In some cases, they described a constant 'banging on the door' while insisting to be referred. Rafiq was one of those who took desperate measures to travel to India in search of answers:

'So, I went to India because of the frustrations of not knowing what was causing my back pain. It was worth it though, coz when I came back here with the result it was clear that I had ankylosing spondylitis, so that's why I was referred to rheumatology straight away' Line 11

Rihanna decided to go private due to the frustrations from the delays in diagnosis. She presented to her GP and described being dismissed. The Oxford Dictionary defines 'to

dismiss' as treating as unworthy of serious consideration. In many ways she felt the dismissal was due to not being believed, receiving no diagnostic tests and having her symptoms explained away as growing pains:

'It wasn't diagnosed until 8 years ago. It was diagnosed privately. My GP was not doing scans or anything and I complained, that's when I went private to speed things up. I had a doctor who just touched the joints, no scans or anything. I felt it was unfair, I was very upset. I'll tell you why I felt upset, because I wasn't believed' Line 12

Rihanna also felt she was not believed because her outward appearance was deceiving, making her look 'normal'. She did not fit the pattern of illness. In my journal (12/12/2016) I wrote about my first impressions of Rihanna. 'It is hard to believe that this young, well spoken, well dressed lady has AS. There are no obvious abnormalities of her spine or any other joints. She is walking perfectly fine'. So, in a way when she mentioned being dismissed I could easily relate to that. I am equally guilty of judging her, just from her outward appearance and this could be due to my limited knowledge of this illness'.

'I was not believed you see. I had been complaining about back pain for a very long time and I wasn't believed and that was a massive problem for me, not being believed coz you are judged by what you look like most of the times. From the way I look you can't tell, can you?' Rihanna Line 17

Faz, had the same experience of not fitting the pattern of the disease, but from the rheumatologist. He even doubted the legitimacy of his label:

'The professor's comments made me confused. Even he was surprised that I have this condition when I first saw him. After the tests he wrote to my GP, 'I am surprised he has this condition'. I guessed that maybe there was a mistake, he was not sure and I did not fit the pattern of the illness' Faz, Line 74

Some participants lamented the lack of knowledge of the GPs who could not understand what was going on despite being trained healthcare professionals:

'I then saw another doctor by chance, my spine had gone completely bent. He did a lot of tests and he just said to me, 'man, this is beyond my expertise' Raul Line 44

Participants expressed feelings of frustration and anger about the time 'wasted' by the GPs.

'It was a very upsetting moment at that time, eh and obviously I was angry that it was taking so long. I had to go to India to find out what was wrong with me' Rafiq Line 40

Iyaz expressed the same feelings through an interpreter and appeared to take out his frustrations on everyone:

'He says he feels angry towards the system. In fact, he says he feels bitter at everyone. He had back pain for 16 years but he was diagnosed 4 years ago' Line 32

Ali's anger was directed more at himself as he seemed to blame himself for the illness. With the feeling that the underlying problem cannot be found, he feels a sense of injustice. He has lost a valued level of functioning physically and mentally.

'I am always angry with myself, coz why me, why me? I was a good footballer I played football but look at me now. When I used to go college, I was a very good student, getting good grades, but now my brain is not working properly'. Line 122

The suffering in some was evident in their feelings of depression due to the persistent and unpredictable nature of the symptoms.

'He says he felt very low in mood, he got depressed' Jaz Line 22 via an interpreter.

4.7.4 Taking matters into own hands

The frustrations in the delays in diagnosis were very evident from the participants' narratives with most of them taking desperate measures to get some answers. Some participants did their own searches online to find answers for themselves whilst others pushed for answers from the GP.

Ullah was disappointed when he was told there was nothing wrong on his MRI scan. He did his own search on the internet to find a diagnosis:

'I had to do a bit of research myself, yeh and the only reason I knew it was ankylosing spondylitis was because of my eye condition. This came first. I have uveitis and it says on the NHS website, that people with AS sometimes suffer from uveitis and I was getting regular episodes of this. So, I though right, I must have this condition'. Ullah, Line 23

Some participants made self-referrals to other specialist areas in their search for answers:

'I self-referred myself to physiotherapy for my back, I was getting desperate' Faz Line 8

'I had to take matters into my own hands. I went to see a chiropractor. They did x-ray and obviously they are not rheumatologists so they didn't diagnose, they just said 'my neck is a bit curved and possible malalignment, so I spent like a 'grand' on that' Shumi Line 27

Shumi would not be set back by her GP. She sought another opinion for her symptoms. She also debated whether her self-referral to the chiropractor could have done her more harm than good. She explains:

'Before diagnosis, people should not be set back by experts who dismiss you. You know what you are feeling and if you feel what the other doctor is saying is not appropriate, that they haven't got it, then see someone else. Don't get disheartened'. Line 55

'I had 20 sessions with the chiropractor, desperate measures. The chiropractic, I did what I thought was the right thing. It did help my hips though. I don't know if I won or lost. I used to drag myself from the sofa, I was walking like a zombie literally, that's how I felt, dead but alive. It was sudden onset and rapid progression' Line 50.

Even after getting his diagnosis Rafiq took it upon himself to search for information about the condition:

'When I got my diagnosis, I needed to get information about the condition. I just google, Ankylosing Spondylitis, and it was just there. There is also a face book page for Humira junkies. Some people on it have other conditions, it's not just the AS, Crohns, skin problems and things like that. So yeh I am glad I took the initiative to find out more'. Zaza line 68.

When they failed to get answers for their symptoms, the participants used their own initiative to find the answers. Some were disillusioned by the inconsistencies and the lack of improvement in their symptoms and they decided to take matters into their own hands.

4.7.5 Getting a label

In the immediate period following their diagnosis, participants felt relieved and validated. They also described in detail how their diagnosis was conveyed by the healthcare professionals. Some found the comments from the healthcare professionals

confusing. The majority of participants had feelings of relief after so many years of trying to find out what was wrong with them.

For Shumi the diagnosis brought validation and support and understanding from everyone around her:

'Oh, I felt sort of validated, because I had become like a constant whiner and moaner, and somebody who just was so tired and didn't want to get out of bed because I wasn't motivated to do anything. After getting the diagnosis, everybody understood and everything so I like got a lot more support and sympathy from my family' Shumi Line 47.

Faz expressed his relief at his diagnosis as he was beginning to think that his symptoms were not real, that he was making it all up:

'When they diagnosed me, I was quite relieved although I did not understand what they were saying. I felt relieved coz there was a name to all I was feeling. I just wasn't making it up' Line 21

Getting a confirmation of the illness for some meant that going forward they could find ways to make themselves feel better:

'I felt like all the things that were happening to me in the past, I now knew what was causing them and going forward now I know to make myself feel better. I know what I need to do so I don't feel like how I was in the past'. Faz, Line 83.

However, others like Raul did not feel relieved, they were faced more with the realisation that this illness was with them for the rest of their life:

'When I got my diagnosis, it wasn't really a relief for me, it was more the realisation that this is something that's gonna be there and it's never gonna be cured. It's just living with that knowledge and the label' Raul, Line 157.

In terms of the information given at the time of diagnosis, some participants struggled to take all the information in at the time of diagnosis:

'When I came back, I saw a different doctor who said I have spondylitis affecting my hips and my spine. I was given a prescription. I had so many questions but maybe now was not the right time for them. I struggled to take all the information in' Line 21

Others just chose to 'brush it off' and were in denial:

'When they told me that I had AS, I just brushed it off. I thought, what is this? I did not want to accept it because there is always a certain criteria people normally fit into you know'. Jay Line 54

'To be honest you feel like a guinea pig, trial and error. These massive names are really just there to almost kind of confuse the patient, make them accept but in reality, they don't know what it is themselves' Zaza Line 68

Jay described how his diagnosis was conveyed and he was not given a chance to ask any questions:

'When I got my diagnosis, it was a very monotone, linear approach. It was like 'you have this condition, this is what you have to do'. Is there any alternative? 'No'. So, you are telling me other than this there is nothing? 'No seriously there is nothing else, no no no'. To me this was peculiar, coz in life there is no one approach to a thing'. Jay, Line 88

In some cases, participants expressed mixed emotions about their diagnosis. Nas was relieved that it was not her caesarean section that was causing her symptoms and she felt validated:

'I was 2 emotions. One was confused, upset and angry at once. I have come to a stage where my disease is really bad and then relieved to know why this was happening to me,

because here I am bed ridden thinking why am I, why is my body reacting like this to a caesarean? I know people who have had C-sections and they have been fine, so why am I struggling'. Nas, Line 23

Others relived their past when asked how they felt following their diagnosis:

'Well my feelings? Let me talk about my journey with this illness so far. When I turned 20 I was very active, I played football in the college team. I can't claim to have been a professional footballer, but I was good at it. It's very vivid in my mind. But now look at me.' Zaza Line 20

For some the diagnosis made them realise that the uncertainties would continue and they worried about the future and how they would cope:

'When he got his diagnosis, he was worried about how long the things would remain uncertain and what his life would be like from then on'. Iyaz Line 40 via an interpreter

Iyaz also felt indifferent about his diagnosis:

'He says he feels indifferent about his situation. He does not understand much about his condition and he does not want to know' Line 13 via an Interpreter.

Mo felt that if she had been given the appropriate information when she was diagnosed, this would have helped her cope better with the illness and make her feel that she was not alone in the fight:

'I wish someone had gone through with me what to expect when I was diagnosed. Someone to say 'this is normal' it wouldn't have been such a shock to me. I don't know if anyone else has this condition, it would be good for someone to say, 'this is what you have got, this is what to expect, other people have got it, this is where to go for support'. If someone had actually said these things to me, it would have helped me to deal with it within myself. To know that I am not alone in this fight. I would feel normal

and not the odd one out. I really suffered emotionally when I got diagnosed; Mo, Line 108

4.7.6 Theme 1 summary

This theme has highlighted the confusion experienced by the participants at the initial presentation of their symptoms of AS. The participants have struggled to get a diagnosis for an illness that has turned their lives ‘upside down’. When the AS was eventually diagnosed, for some this brought relief and validation, but for others there were uncertainties about the future. The conveyance of the diagnosis by the healthcare professionals was often unhelpful, adding to their worries about coping with the illness.

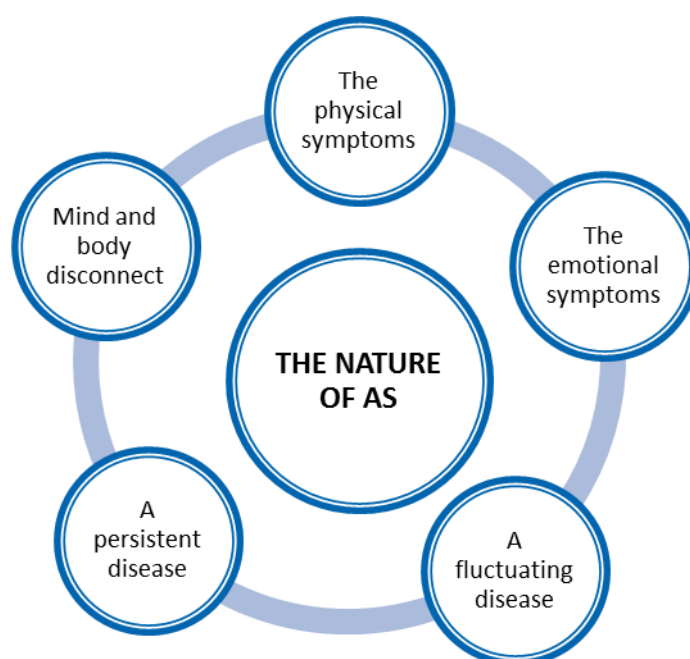
4.8 Global Theme 2- The Nature of AS

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| <p>‘He says no matter what he does, the spondylitis can decide to flare up or subside at any time. He does not have any control over that. He says the condition is like a dictator. It controls his life, it has absolute power and he obeys’ Soji Line 37 via an interpreter</p> |
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This global theme narrates how participants expressed their disease in terms of their everyday lives. In response to my question: Can you tell me about your illness in as much detail as possible? The participants talked about a range of symptoms (pain, fatigue, stiffness) that they commonly experienced and the limitations and demands the illness has brought. The opening quote above just about sums up the 5 sub-themes: the physical and emotional symptoms of the AS, the persistent and fluctuating nature of the illness and the way the mind and the body are out of ‘sync’. Soji used the metaphor of a ‘dictator’ to refer to how the AS has absolute control over his life. The AS appeared to have total power to dictate what things the participants can do, when and how they can

do those things. The participants appeared to have no control over their lives. According to Gadamer, a chronic illness ‘confronts us as something opposed to us and which forces itself on us’ (Gadamer 1996, p107). It prevents the normal flow of life with disruptions that require adjustment. The theme has five sub-themes which express the disease and its meaning to the participants (Fig 4).

Fig 4.2 The nature of AS and sub-themes



The AS presents with: physical symptoms of pain, stiffness and fatigue that are a predominant feature of the participants’ daily lives; emotional symptoms that manifest through depression, fears and worries about the future and a sense of resignation and helplessness; fluctuations of the disease with ‘on and off’ periods that are frustrating and make it difficult to plan anything as each day can bring a new surprise; persistent features of the AS which weigh the participants down so the AS is seen by most as a ‘life sentence’; and finally the disconnection between the mind and the body where the participants want to do things but the body will not let them as if the body has a different plan. These sub-themes will be discussed separately in the following section.

4.8.1 The physical symptoms of AS

This theme presents an in-depth view of how the participants' daily life unfolds in regard to the physical symptoms of living with AS. Their experience of pain, stiffness and fatigue had varied presentation and intensity. The AS is marked by unpredictable physical symptoms, whose timing and duration are erratic leading to a life full of unknowns. The participants described symptoms that just attack them without any warning with no telling when a bad moment was coming or what it might look like:

'I completely seized up just like that no warning with a lot of lower back pain' Ullah
Line 2

'An active person becomes immobile. I have always been an active person. I was never one to lie around or sit still. I would always enjoy going out, doing things' Nas, Line 4

For Iyaz, because the AS attacks without warning there is no routine in his life. The AS got in the way and plans had to change:

'He says there is no routine coz the illness is like that. He can't plan anything' Iyaz
Line 39 via an interpreter.

The symptoms were so severe that some participants couldn't function, as Faz explains:

'Severe fatigue is a big part of my condition. You can't function with the tiredness' Faz
Line 28

The intensity of the pain was a cause for concern and worry for other participants because they know they have to stop everything:

'I get very upset, I don't know why because once I see the symptom, then you know I can't do anything. Life as I know it stops and I kind of breakdown' Raj Line 132

Ravi described his attacks of pain as crippling, whilst holding the area affected to emphasize his point:

'I have these attacks; this side is crippling (holding his right hip and changing his facial expression). When this attacks me, when this hip goes I can't even move. My wife has to help me' Ravi Line 52

Other participants experienced severe early morning stiffness and an 'out of body experience':

'When I wake up, it's like my body is eh not my own. It takes between 2-4 hours to loosen up' Ravi Line 114.

Jay, a bus driver described excruciating pain. His family was also suffering and he saw this as a 'collective' suffering. He also acknowledged the physical limitations of the illness:

'The pain can be excruciating that you really almost pass out and stuff like that. You can't truly understand what it is like. If you come and live with me for 2 weeks and see what people around me go through, they are suffering as well. So yeh collectively we all suffer. I can't put on socks, I can't put my joggers on, I can't do shoe laces' Jay Line 129

Zaza expressed similar sentiments:

'So, you can say this illness has robbed not just me of a normal life but my brother too and others around me. It touches everyone and this makes me sad' Zaza Line 44

The nature of the symptoms meant that the participants found it difficult and frustrating to convey what they were experiencing and there was a sense that they were not being understood:

'I don't see my friends that much anymore and I think it's for the best. I have told them I have a condition and I can only do certain things. They don't understand. Sometimes they will say, 'let's do this, let's do that' and I say 'I can't'. That's the difficult part trying to explain things. It's frustrating' Faz Line 123

For Rihanna the pain had become a normal part of her life:

'I have learnt to live through the pain. It's now a normal part of my life to be in pain'
Rihanna Line 37

Taken for granted tasks became very hard to achieve for one participant:

'At its worst my condition was bad especially in the morning. The simple things I couldn't do. I couldn't wear or remove my socks. I cried all the time, I couldn't bend. 2 to 3 hours I was stiff, I couldn't put on my clothes. When I tried to bend I would get a crushing pain in my chest. All my bone (holding the spine) was like a bamboo. I couldn't turn to this side (indicating left) or that side (indicating right).' Zia Line 62

4.8.2 Emotional symptoms

The participants expressed emotional and psychological symptoms of feeling sad, and excessive fears and worries about the future with AS. The psychological responses to the AS are mainly to do with the participants' anxieties and depression. The unpredictable nature of the AS and the uncertainties impede adjustment to the illness and this increases the emotional and psychological distress. As a result, some participants grieve and then adjust to the illness whilst others' distress is more protracted leading to depression. Some participants withdrew from friends and activities, as they experienced significant tiredness and pain. The symptoms also led to a reduced ability to concentrate. For Raj, there was no future and he was thinking the worst-case scenario:

*'To be honest, at that time I did not see a future for myself. Everything was bleak' Raj
Line 46*

'I was thinking I don't know what will be my future, so am I going to be paralysed or something like that. It was scary to even think about, so yeh all those things were going through my mind' Raj Line 43

Raj continued to describe the functional limitations imposed by the illness and how this resulted in depression:

'Sometimes I don't have any control of my bodily functions. I can't go toilet sometimes, I can't do nothing, I just feel like eh the disease has taken over my life. I have stopped everything, my work, college coz sometimes 2 months 3months I am in bed, completely paralysed. I can't even move. I can't even go from my bed to the toilet. I have been put on antidepressants.' Raj Line 72

Similar to Raj, Raul, found it difficult to cope with the illness which added to his depression:

'It's not easy to cope with this illness, it's definitely not easy especially with the depression. A lot of things on my mind' Raul, Line 109

One participant expressed fears about being seen as a burden due to their disabilities and the fear drove them to try anything to appear and feel normal:

'The disabled people are seen as a super burden, for now that's my biggest fear that I don't want to be like someone that can't do anything for themselves that's why I will try anything just to feel normal' Jay Line 117

The participants described the limitations and restrictions in performing their daily routines and how this brings a sense of helplessness and hopelessness into their lives:

'Like now he says he is struggling with pain and stiffness which limits him from doing things. He spends most of his time at home sleeping or just sitting. He feels his life is not worth living. He says this is what occupies his mind most of the time.' Iyaz, Line 50 via interpreter.

4.8.3 A fluctuating disease

Participants describe the fluctuating nature of the AS which involves some variations in the overall pattern of the disease. Their AS is unpredictable and symptoms vary over the course of the week, day or even an hour. When the symptoms are at their worst, the participants need support with activities of daily living such as washing, dressing and toileting. The participants can become socially isolated due to the difficulties in getting out and about. The AS attacks without warning making it difficult for participants to plan anything and this is a source of frustration as Raj explains:

'When the flare is coming without any warning within 2 days suddenly it's there and then it's very difficult to manage' Raj Line 95

Mo's experience was the same:

'The pain just kind of comes and attacks you without warning. I couldn't stand, I couldn't do household chores, I couldn't walk. I felt as if it was kind of draining me' Mo Line 8

Raul explained how the unpredictable on and off symptoms have affected his concentration leading him to abandon his studies:

'The pain and stiffness were on and off. I couldn't walk without crutches. I stopped college altogether, couldn't concentrate on school stuff' Raul, Line 11

The unpredictable fluctuations in the symptoms of AS affected participants' ability to plan as they could never know if the body would be stable in the future. They learnt to take each day as it comes:

'He says no matter what he does the spondylitis can decide to flare up or subside at any time. He takes each day as it comes' Soji Line 37.

'There is no routine coz the illness is like that. He can't plan anything' Iyaz, Line 39 via interpreter

'With this sort of condition, you can be feeling fine one minute and the next you can be in horrible pain. One day you can be walking and the other day you can't even stand up, that's the frustration of it all, it changes without warning'. Zaeed, Line 123.

At their worst moments participants required the support of spouses and families to cope:

'At its worst, I can't comb my hair, I can't change my clothes without help. My husband has to do it for me. When the pain is really bad getting in and out of bed is a very slow and painful process. I just sit there and let the pain kind of roll down or something. I don't know how to explain it but that's how it feels to me' Mo Line 85

Interestingly although the uncertainties and unpredictability of the AS symptoms presented serious obstacles for the participants, this was a cue for providing useful information. Some of the participants, learnt to 'listen to their body' and pace their activities. They learnt to know when their body was telling them to slow down or stop doing something:

'My every action now requires me to just pay attention to how I am feeling coz my situation can change just like that. Before, I had the luxury of not having to think of these things.' Naseeb, Line 77

4.8.4 A persistent disease

The participants describe an illness that is chronic in nature, lasting for long periods. The illness presents with a series of exacerbations and remissions; however, the participants find that symptoms such as pain, fatigue and stiffness persist. In some participants the pain and stiffness come and go and in others these symptoms are constant with the disease getting worse over time. The participants describe their AS, as a life-long illness with no cure:

'Then it hit me. The realisation that this is a life- long illness coz I always thought after the chiropractic or physiotherapy, after being aligned again I would be okay. I could have like a proper life with my kids and enjoy motherhood and everything. It was just realising that I was never going to get better. It was going to get worse long-term'
Shumi, Line 60.

For others, stiffness was a major worry as it is unrelenting and has no boundaries:

'Every day the disease has spread all over my body. All day I have stiffness, it is especially there in the morning and at night time, very very difficult, everywhere, all my joints, my back very very stiff' Ali, Line 61

'I have good and bad periods with this illness but I wake up with stiffness all the time'
Ullah Line 113

Shumi used the metaphor of feeling like 'being run over by a truck' to describe her fatigue and feeling wracked with pain:

'I was like, very unwell so like my entire body felt like it had been run over by a truck. So, every morning it was, the fatigue, painful to get out of bed. Throughout the day I would be in so much pain'. Shumi, Line 13

For others, there was no part of the body that the illness does not reach and they had to learn to live with the symptoms:

'The condition attacks the entire skeleton and there is no cure and its progression. I thought I was going to live with pain forever and I have to live with myself, I know my limits, I know what I can do' Shumi Line 66.

Naseeb found that the illness had taken over his life. He was unable to function normally, and he had given up his employment and social relationships:

'Every day is a struggle for me with this illness, ehm the pain and fatigue are always a big reminder of the disease. I can no longer work and I don't see my friends as much as I used too.' Naseeb, Line 81.

4.8.5 Mind and body disconnect

The physical changes due to the AS result in the body not working as usual whilst the unpredictability is setting the agenda on the body, as if the body has 'acquired a life of its own'. Some participants become uncomfortable around social settings leading to withdrawal as Soji explains:

'He says he can't plan anything coz the condition can just stop everything. He listens to the condition first. He keeps to himself pretty much, not much socialising' Soji Line 80

Ali described his AS in a powerful way. He loved his job as a chef which commanded a lot of respect from his staff and community. His account of the illness is dense with meaning and his anguish and distress can be felt. The AS violated his role expectation as the head of the family, relinquishing his position to his son. He considered that he was no longer able to fulfil his responsibilities as a father and is feeling helpless and hopeless:

'My job as a head chef was very demanding. So many people under me in a busy restaurant. I was slowing down, forgetting things. My mind was not there, it was in another world. I could not carry on. I had to stop. It was very sad because I enjoyed my job. I was proud of my job as a head chef, well respected but I lost everything. Since I retired my mind is getting smaller and smaller. I don't know what the future holds. I have been sick for a long time. My brain is narrow, the mind is not working. I have told my son, 'Look after the family, and don't think about me. I am no longer the defender, I am sick' Ali Line 237

There is a sense that he was shifting his responsibilities of defending the family to his son by surrendering the motivation to recover from the illness as Ali continues:

'I do not accept it like this anymore, I am so fed up with this illness. It just touches every part of my life. I am so angry at times' Ali Line 244

Some participants realised the importance of exercising and staying fit and they wanted to do this, however they felt let down by the body which would not allow them to undertake such activity. They described a 'missing link' between the body and the mind, resulting in slowed down body reactions:

'Right now, I want to go gym, I want to stay fit and healthy but my back, my body says 'no', my mind says 'yes'. Most people their mind says 'no' but mine says 'yes let's go' but my body is just stuck, it's stuck' Ullah Line 84

'But there are times when I do want to jump up and do things and I can't. Like for instance someone is ringing at the door, but my body is still a bit behind. That's the thing and yes, the body is just slowing down'.

Participants described how the body is in control and they have to 'listen' to it before they decide what they can or can't do:

'He says it is better to listen to the disease and then fit his life around that. Whether he is going shopping, helping around the house, he just has to listen to it' Soji Line 45

'He has also learnt to listen to his body, to understand what his body is telling him before making decisions' Iyaz Line 43

Nas took this point further by suggesting that she had to be selfish in order to make things easier for herself:

'You have to listen to your body and become very selfish in a sense where you think about yourself. I need to listen to my body. Nobody else comes first, because if I fall I suffer, if I fall everybody suffer. So, for me first take care of number one and kind of do things in a way that makes it easier for me' Nas Line 51

Nas describes how she had to 'tune into' the signs and signals from her body or face the consequences:

'So, if I ever do anything that I shouldn't, I know I will pay the price so I just leave it and not do it. I don't go out that much and if I walk then my whole leg like becomes so achy and that gets to my brain and I get so irritable and everything seems so unbearable so then I just stay at home kind of isolated' Nas Line 70

Some participants experienced feelings of a social isolation that was both imposed on them and reinforced by the self, due to the AS. Sustaining relationships as they were prior to the illness entering their lives was difficult. There was reduced motivation to engage with others or seek past relationships. The former self no longer existed.

Shumi's withdrawal from social life was voluntary:

'I used to invite people round my house. I would go to functions, parties. I would go attend you know socialise. I don't do that anymore. I am scared when somebody wants

to come to my house because you have to entertain them not just you know cook for them and things like that. I can't do that anymore' Shumi Line 41

Iyaz found himself in a similar situation:

'He says he is struggling with pain and stiffness which limits him from doing things. As a result, he keeps to himself. He spends most of his time at home sleeping or just sitting. He does not want to talk to his friends about his illness' Iyaz Line 50 via an interpreter.

Ali's isolation was imposed on him and he felt alone. The withdrawal from his friends meant that he is unable to discuss his uncertainties and fears about his well-being:

'I was a good footballer, I used to play football with my college friends, but look at me now. They don't want to know. I am alone in the fight' Ali Line 48

4.8.6 Theme 2 summary

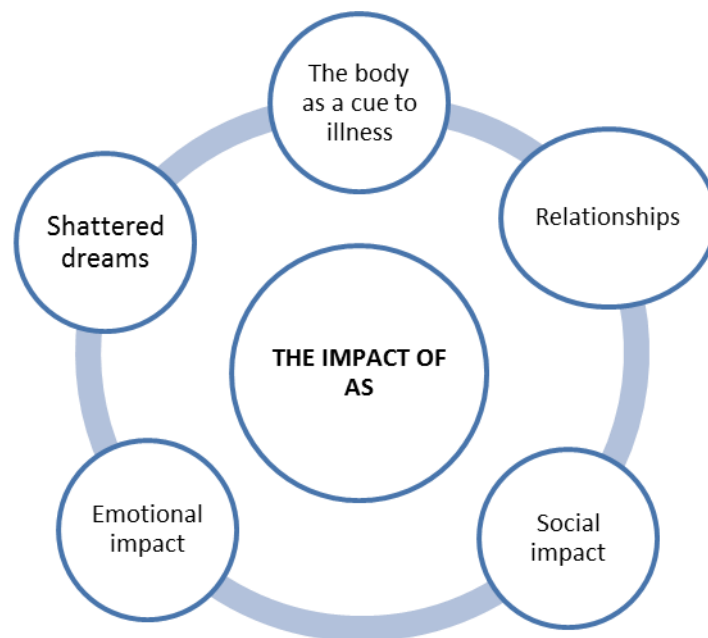
The participants described a multitude of symptoms of the AS that interfere with their daily lives. These findings emphasized the importance of looking at AS, as a complex multidimensional illness, rather than just a painful limiting condition. The AS threatened the participants' every day activities. The unpredictable nature of the illness and the severity of the symptoms were regarded by the participants as a major source of worry and distress, as they have had to give up previous pursuits. The participants' experienced unpredictable symptoms of pain, fatigue and stiffness which made it difficult for them to make any plans as each day could present new challenges. The reactions and emotional processing involved in having the illness, were very different from one participant to another.

4.9 Theme 3: the impact of AS

'When you are young, you have high hopes, you want to do so many things, but I couldn't because of this illness. I am so fed up of this illness. I am so angry at times' Ali, Line 208

In this global theme, participants described how the AS has had an impact on a wide range of areas in their lives including social wellbeing, emotional wellbeing, life goals, their bodies and their relationships with others (Fig 4.3). The AS has a profound effect on the participants' lives creating distress in response to the losses it imposes.

Fig 4.3 The impact of AS



Participants have narrated how the AS disrupted the homeostasis (the normal dynamic and routine) within family members' roles, responsibilities and boundaries. This results in uncertain and unpredictable futures which in turn triggers distressing emotions of anxiety, depression and feelings of helplessness. The participants also experienced permanent changes in physical appearance and bodily function due to the illness. The AS appeared to have a significant impact on the families of the participants who have to give them support throughout all stages of the illness. These areas are covered by the five sub-themes which will be discussed in this section.

4.9.1 The body as a cue to illness

Participants with AS find that others react in different ways to bodily cues of their disease. The detectable cues are in the form of changes to the physical structure of their bodies and the other cues are centred around the disease label itself. When the participants are given a diagnosis of AS, this becomes a visible sign of disease (a label), but people around them do not know what the label means. The participants are then stigmatised, avoided and isolated due to this, as one participant found out:

'If you go to some Muslim party, they look at you and whisper. Some people just hate the sick person, they say, 'Oh he is filthy, sick person stay away' Ali, Line 131.

Faz always suffered from severe fatigue and he got similar comments:

'In school I used to get comments of being lazy, tired all the time and slow. Even with my friends I couldn't keep up. Little did they know what I was going through. I just stopped attending gatherings' Faz Line 134

The participants' bodies send numerous cues that reveal the illness to the participants and others:

'Every time when I walk I try to be normal, but my spine is bent. People still comment about my walking. People will say, 'Why are you walking like that?'. I realise they must see me walking funny'. Ullah, Line 34.

Naseeb found that his friends had disappeared after telling them about his illness. He felt guilty about revealing his illness to his friends. He thought that because they don't understand the illness they might be thinking the worst:

'I told my friends about my illness after they noticed that I don't walk properly. You see one leg is now shorter because of the surgeries. I had to say something but maybe I

shouldn't have. I don't think they understand what I am going through. I even told one friend that the spondylitis is not like cancer.' Naseeb, Line 69

4.9.2 Relationships

The symptoms and physical limitations of the AS took away independence. Most of the participants narrated how they have to rely on their families and spouses to care for them, assisting with their activities of daily living (washing, dressing, toileting, mobility), thus the AS affects the quality of life of families in a significant way. The participants relied on family members especially their spouses, to care for them. There was a role change to carer for the spouses. Raul described how his wife was always there to help him with the most private activities:

'My wife is the best support that anyone can get in this 21st century. She is with me through the lowest points. Sometimes I don't have any control of my bodily functions. I can't go toilet, sometimes I can't do nothing. I just feel like eh the disease has taken over my life.' Raul, Line 76.

Some participants chose to keep to themselves because they did not want to keep explaining things to their friends:

'I hardly get time to dwell on things. I don't see my friends often, mostly I keep to myself. I have told my friends I have a condition and I can only do certain things so I hope they can understand and do not think I am avoiding them' Faz Line 122

The illness also affected the participants' sexual relationships. Many participants have reported a negative effect on their sex life. There was a decline in the sexual relationship due to the physical effects of the illness and lack of interest. Mo described the dilemma she was facing in her sexual relationship. She described being torn between her sense of

duty as a wife which she was unable to fulfil and not having the 'urge'. She decided to bear it as she has no one to talk to about such an intimate issue:

'This thing has affected my sexual relationship quite a lot. I feel tired all the time you know and I don't have the urge to want him as how it used to be. I don't know if this is normal. I think he understands to some extent, but I am his wife, I have my duties as his wife, I cannot fulfil them. Sometimes it is hard when you do not have someone to talk to about such private stuff so I tend to just bear it and carry on' Mo Line 99

Jay expressed a similar experience in his relationship:

'Even intimacy, frankly speaking, weeks even months on end go by but she never pressurises me. You can imagine that my involvement in that area is very limited' Jay Line 171

For Ravi, the pain and the side effects of the medications he was taking for the AS, added to the sexual difficulties, but he found ways to 'work around this':

'Also because of this illness, sometimes the relationship eh ehm, relationship with my wife is not the same. The sexual relationship, yes, we work around it. Still from here (holding his hip area) this is the most painful place, but we work around it. It hasn't really strained the relationship, so because of all the medications, sometimes it is not all there'. Ravi, Line 145

Some participants were forced to withdraw from friendships because they did not want pity:

'I just needed to cut down on my circle of friends and live in my own little bubble. It's not so much that I didn't want to be with them, I didn't want them to feel bad for me' Jay Line 112

Some of the male participants described feelings of vulnerability and inadequacy because they were no longer the ‘supermen’ or breadwinners who are able to fend for their families and protect them:

‘To be honest nothing prepares you for life with this illness. Everything, I mean everything changes. Your space is invaded, so you can’t control what you do and how you do it. You have to rely heavily on others for support you know, just to do everything even the small things and it makes you feel ‘useless’ as a man. I was raised to provide for and look after my family as a man, but the way I am is just so eh what word can I use (pause) right eh pathetic like’ Zia Line 83

Male participants with small children found it particularly challenging as they were unable to play with them or do things that other fathers would do with their children (play football). They described this as:

‘... the worst part of the disease. He is sad and regrets that when the children were younger he missed out a lot. They also missed out a lot too. There are things that he would have liked to do with his kids and for his children, but he couldn’t. He is very sad about this and he hopes they can understand’ Zak, Line 146 via an interpreter.

The negative effect of the AS on daily life was reported by some. These involved aspects of personal hygiene need and functional limitations. The participants valued and appreciated the support they get from their families however, some expressed feelings of regret and guilt about the demands the AS makes on their families fearing they were a burden:

‘My parents are very supportive. They want me to get better, they want the best for me. I try to manage without being a burden to them coz I should look after them not the other way around. I don’t want them to feel that my life is wasted so I try to be normal, to just push myself for them’ Ullah Line 89

For Shumi friendships had become a one-way affair causing them to drift apart:

'My friends do understand but slowly slowly they drift apart because the meeting has sort of become one way. They come to see me but I don't go to see them' Shumi Line 26

A small number of participants identified positive effects of the AS. They described improved relationships with their families as they pulled together and supported each other. For example, Rihanna's support was more about a family that understands what she is going through:

'This condition gets you to a point where you get tired of being tired. I am lucky to have an understanding husband and family. My late father was a doctor and my father-in-law is also neuroscientist so that has helped me in a way.' Rihanna Line 48

Other participants have had to overcome the challenges from the illness by appreciating their own lives:

'Until you suffer from this type of illness, you don't realise how lucky you are to eh just be alive. So yeh even though I am struggling, I have my life.' Naseeb Line 55

4.9.3 Social impact

The participants portrayed how the AS affected their social lives. The disruption from the illness is an everyday occurrence and this makes it harder to accept or identify with. Personal relationships suffer when plans are constantly cancelled or rescheduled. The friends and families of participants find it difficult to understand why they cannot function normally, for example why they cannot attend social gatherings and functions. Some participants are concerned about how friends will react to their illness, especially with the disabilities. One participant with obvious damage to his spine described via an interpreter:

'His spine is completely fused and he is in constant pain. He can't bend or turn sideways. He says he does not like to explain his illness to others. He keeps to himself. He can't understand it himself so, how can they? He says other people just stay away. He says some people are looking at him and wondering what it is. It is hard for him.'

Soji Line 56

Soji's narrative has explored how this theme intertwines with the other themes. His social life has been constricted by the limitations brought about by the damage from the AS and the pain. He keeps to himself and his friends isolate him. His world has shrunk. Soji does not like to explain his illness to others because he thinks they do not have the knowledge to understand what the AS is all about. Here we see how the themes converge at the same time with an interplay among the themes.

Some participants withdrew from social life because the AS physically prevented them from social activities. Raul's social life was disrupted by the illness similarly to Soji's:

'I haven't got a social life. The disease will not let me. Where do I get a social life? How, tell me? I don't get, I used to have a social life but not anymore, That's in the past.' Raul Line 122

Other participants lost confidence around other people:

'I don't socialise. I don't socialise coz I don't have the confidence. I see other people same age group as me and they are fit as a fiddle, I am not. They are successful and I am not' Ravi Line 107.

Others were aware of the functional limitations from the illness, they have isolated themselves because they do not want pity. They expressed worries about passing the illness to their children:

'I spend most of my time at home. I eh sort of isolate myself coz I don't like pity, people look at you and they feel sorry coz you can't do normal things. My biggest worry though is I do not want to pass this to my children, In Shah Allah' Naseeb, Line 60

'I tend to isolate myself and I don't do much. You see I do not like the pity, some people look at you and they feel pity.' Zaza, Line 74.

For others, the former self no longer existed and the social isolation was voluntary:

'I used to invite people around to my house. I would socialise and party. But now I keep to myself' Nas 41.

'He stays at home and makes excuses especially to his friends. Sometimes he tells them he is not well but most of the time he tells them he is busy doing things in the house. Some people just think he prefers to stay at home' Zak, Line 80.

Others felt like no one understood what they were going through, they did not want to confront themselves with having to explain their situation to their friends:

'I just want to be left alone without having to explain anything to anyone' Shumi Line 81.

Jay lost interest in everything due to the AS:

'With this condition what actually happened which I realised is that I used to have a lot of interest in everything but would you believe it if I told you I have no hobbies, I have no hobbies.' Jay Line 51.

4.9.4 Emotional impact

The AS affects the way in which the participants think and feel. They expressed feelings of sadness and regret, being frightened, self-blame, worry and anger. This is mainly

because they feel helpless and their body is out of control. They feel lonely and isolated from family and friends, because at times it is difficult to talk about their AS with them. The emotional impact of AS is overwhelming as it stops the participants from doing the things they need to do in their daily lives. Others express worries about a future with AS where they will be unable to take care of their responsibilities:

'If I am unable to do things now, what's going to happen to me in 10 or 20 years' time. I want to be as independent as I can right now. When the baby comes, my wife tells me she will concentrate on the baby more. I worry about lots more responsibility and taking care of the baby' Faz Line 230

Similarly, an uncertain future presented worry for Zak who felt he was too young to have the illness:

'He was worried at such a young age having arthritis. No one in his family has this illness. They have diabetes and heart disease but this, no. He felt uncertain about the future, like with his work and how he was going to cope and his family as well. He was just worried and stressed, his kids were still very young' Zak line 35

Zak also worried about losing his job and the prospect of not working was too much to bear:

'He says he was worried about losing his job, not being able to work that's his main worry' Zak Line 19 via an interpreter.

Another participant valued the support from his wife but was worried about passing the illness to his children:

'My wife is very supportive. We want to start a family soon but I worry about the future, about passing the disease to my children. I am searching for information about this' Ullah Line 94

Raul felt suicidal and was lost for words when asked about his feelings:

'I cannot begin to describe my feelings about this illness. I can't even, sometimes I just feel like committing suicide. I do coz what kind of a life is this? I was such an active man now. I feel this life is not enjoyable, it is full of depression' Raul Line 84

Some participants found that living with AS made them more vulnerable and with this came a lot of guilt. The guilt was mostly about the things the participants could not do. Guilt about mile stones in their children's lives they missed out on and the struggles with the many limitations that came with living with AS. Shumi felt guilty because the AS would not allow her to do things with her daughter:

'My daughter keeps asking me, 'Why can't you do things with me?' she gets upset and says I don't chase after her, I don't play with her, why don't I run, why do I sleep all the time. She's five you see and she is beginning to want to do girlie things with me. I just feel like I am letting her down.' Shumi, Line 86

She continued:

'I would get up and do things out of duty and not because you want to. It's a drag and the children can tell. It's not a nice place to be and at the end of the day you feel guilty.' Shumi, Line 150

4.9.5 Life goals

All the participants had some goals they wanted to achieve before their lives were overwhelmed by the AS. When the AS entered their lives, everything changed. They found that they were unable to achieve the most valued things they wanted and this was a cause of frustration and anger. Just getting through the day for some was like an uphill

battle. Others were unsure how they would feel from day to day whilst most were unable to function well enough to complete normal day to day tasks. The AS could not allow them to strive to successfully meet their life goals. This sub-theme describes the shattered dreams, the lost opportunities, the hampering effect of the AS and the feelings of a life 'taken away in an instant'.

Rihanna's education was hampered when she had to stop her PhD studies:

'I had to stop my PhD because there was so much going on with me. I couldn't sit for long periods because of the pain and I needed to be able to do that to study at that level, so this has been a huge let down for me, big time. I am a very intelligent person'
Rihanna Line 63

She continued about how she has had to stop working due to the AS. Rihanna wanted to keep her brain active despite this:

'I had to give up my work and this has really affected me coz I loved my work. I still keep my brain working though. I read a lot and follow through things that are happening in my profession. I worked as an analyst' Rihanna Line72

Participants described their anger at the illness which has shattered their dreams and left them in a hopeless situation:

'I feel cheated by this illness really and robbed. Now I can only think of what could have been. So, I feel angry and frustrated and all those other things all the time every day. It's like losing something so dear to you. You get to a point where you no longer feel anything, you are just there, that is me, that is where I am right now' Naseeb Line 59

Although the AS has hampered their employment, some participants refused to give up completely and carried on working reduced hours to remain relevant:

'I have reduced my working hours, reduced my working week because it was impossible for me to manage full-time, it was really difficult for me' Nas Line 113

'I felt like, as a man if I stopped working somehow you are worthless, as a disabled person you are already worthless anyway whether you want to admit it or not. That's how the system dictates to us, that people with a disability are a burden and I didn't want to fit into that model' Jay Line 73.

Shumi expressed how the AS has taken her life away and blamed this on the delay in diagnosing the condition:

'This condition takes over your life. It limits your life, I think like drastically also because I was diagnosed so late when it got so bad' Shumi Line 110

Others gave up their businesses due to the AS:

'He says he used to own a fast food restaurant but he had to give this up due to the illness. He couldn't cope with it. He takes each day as it comes now' Iyaz via an interpreter Line 46

Zak tried to stay in work in order to provide for his family but had to give up eventually:

'He had to continue to work so that he could provide for his family. After a while he was no longer able to work' Zak Line 45 via an interpreter.

Raj's hopes of qualifying as an accountant have been dashed by the illness:

'I was studying. I came here to do ACCA, that was my dream, to become a chartered accountant, but I couldn't continue because of the disease. You can't concentrate, you can't do anything. It was hampering my job, it was hampering my education, hampering my everything' Raj Line 72.

4.9.6 Theme 3 summary

Before the AS, the participants had their whole life planned personally and professionally. Following the diagnosis, life had lost its meaning. Some of their physiological and psychological needs were not being met, which inhibited them from reaching their potential. Some participants had become susceptible to loneliness, anxiety and depression. The AS had an impact on the families of the participants who had to assume the role of carer. The participants' bodies with AS adapted in different ways to the new order in terms of relationships and life goals. Theirs was an uncertain journey with an unknown destination.

4.10 Theme 4: Managing with AS

'It's a condition that will never go away, but knowing what I am up against is the key for me, knowing each part of the steps enables me to help myself, that's the big thing' Nas Line 121

This theme describes how the participants were managing to live with their AS on a day to day basis. The participants' greatest concerns related to managing with the new chronic illness and its symptoms. The participants were starting to build a new life and adjust to the new order in their lives. In spite of the AS and its limitations, the participants narrated the different efforts directed towards taking control of their lives and finding support. The majority of participants accepted the new order and use active coping strategies to manage with their AS. They were aware that they could not control certain aspects of the AS, but they were managing elements of the AS that are within their control. A few of the participants however, felt helpless and resigned to their 'fate' and accepted that there is not much they can do to control the AS. The five sub-themes that are centred around this global theme (Fig 4) will be explored further in this section.

Fig 4.4 Managing with AS



4.10.2 Adjusting to the AS

The participants learnt to put up with the illness and adjust their lives around the AS. They negotiated new roles, in their work, social and home lives. Some participants accepted the lifestyle changes that the AS required thinking about their needs first, as Soji explained via an interpreter:

'He also says the condition has made him more selfish. He has to think about himself first and foremost. He says it is sad in a way but that's how it is. He is the centre of attention in his family and everyone wants to know that he is okay. They don't want to see him suffer'. Soji, Line 45.

Others like Faz, were more confident to live within the constraints of the AS and know how to make themselves feel better:

'I felt all the things that were happening to me in the past I now knew what was causing them and going forward now I know what to do to make myself feel better. I know what I need to do so I don't feel like how I was in the past.' Faz, Line 83

As a former administration assistant, Naseeb developed new skills, learning to drive so that he could be a minicab driver. He enjoyed his previous job, but he needed a less demanding job with more flexible working hours, to suit his condition:

'My job as an admin assistant at a University was too demanding. I had to learn to drive. I do cabbage now and that suits me better, the hours are flexible. I chose the hours that I can work depending on how I am feeling. It is no longer about job satisfaction but I have to survive.' Naseeb, Line 71

Knowing what works best allowed others to manage better with the illness:

'He goes out with friends sometimes but he also knows when to say no because he always suffers if he overdoes things. He keeps to himself that way he doesn't have to explain things.' Iyaz, Line 54 via an interpreter

Naseeb took steps to know the limitations that the AS brought and explained the challenge of finding a balance between doing too much or too little:

'For me it's about knowing what I can or can't do with this illness. If I do too much I suffer, if I do too little I suffer. It's about finding the balance, that's the challenge. I have missed out on doing things with my family, the shopping and just being together. I get irritable sometimes so I keep to myself.' Naseeb Line 66

Others learnt to manage the increased financial pressure brought on by the AS. Zak is now working part-time and cannot afford to provide for the needs of his family:

'It's hard for my family because I have stopped working full time. I can no longer provide for their needs coz you need money to buy stuff. My son wanted a new bicycle but it's not a priority right now.' Zak, Line 64

The participants learnt to listen to their bodies by paying special attention to what seemed to ease the symptoms of AS or make them worse. But sometimes this caused family members who do not understand the nature of the illness to label them as being lazy:

'My mom every time though used to say to me' Oh, the girl next door, she has got twins and a job but she never stops. How is she managing to do those things that you can't do yourself? She just seems to manage to do everything' and this would annoy me. She did not understand what I was going though'. Shumi, Line 49

4.10.3 Building a new life

This sub-theme is about how the participants begin to let go of the past, relinquish some roles and find ways to manage with the AS. Most participants found they had limited time to dwell on the AS. They did not want to spend too much time explaining or talking about their illness especially, to people who do not understand:

'I don't want to talk about my illness. That's my own way of coping. I don't dwell on it. My friends just say, 'Oh it's nothing serious, it's for a short time'. Some people do not understand unless it happens to them so what's the point? Most people don't realise the impact of the illness' Ravi, Line 133

The participants learnt to let go of relationships that add more stress than support to their lives as Faz explains:

'A lot of people especially my friends, when they see you they expect you to do the normal things. I can't do that anymore with this illness. I can't keep on explaining things to them. They don't understand so I always have an excuse not to spend time with them. That part has been hard for me coz everyone needs friends to talk to, share things.' Faz, Line 137

Some participants found they had limited time and energy for socialising. Friends and families did not understand the challenges they were facing, they withdrew from social and family activities and occasions. This was their way of dealing with the new order in their life:

'I used to go out partying and attend gatherings but not anymore. The pain and the tiredness just attack you and spoil everything. You do not want to moan to your friends or keep making excuses so yeh you keep to yourself' Raul, Line 92.

'I feel tired all the time so I am used to getting comments of being lazy. No one understands that this is the illness and not me. So, I kind of push myself to do things but to be honest most of the times, I just stay indoors, away from everyone and just listen to my body.' Zia, Line 89.

Faz had similar experiences:

'So even if a day comes and I say I am really knackered and I can barely move, they will say 'look its nothing'. That's quite difficult for me to make other people understand my situation, what I am going through. I deal with things better on my own.' Faz, Line 63

Others accepted their fate and they found ways to adjust to the AS:

'Initially he thought there was a cure for it, but now he is getting around to the idea that it is there for life. He now accepts what Allah has given him. He has found ways to manage and support himself.' Iyaz, Line 16 via an interpreter.

4.10.4 Taking control

The participants adapted to the AS in different ways and found ways to maintain their independence. They did not want to be a burden to their families nor allow the AS to take control of their lives and stop them from doing the things they enjoyed doing. There was also a sense of engendering hope in that the participants believe that there is life after an AS diagnosis, as a result the AS is not the focus of their life.

One participant constructed a sense of self in which he proclaimed:

'The AS is only a small part of my life, it does not control my life'. Naseeb, Line 77

And another participant echoed similar sentiments:

'I have to be positive. I am still here and I am not in a wheelchair. I can even talk about holidays. You see those are things that actually give me strength'. Zaeed, Line 19

Another participant was staying positive and would not take his body for granted anymore but was grateful. His perspective on life appeared to have changed due to the limitations of the AS:

'I appreciate every little thing that I am able to do, coz when you can't do these things that's when it hits you. I am not perfect but I can function to some degree and I am happy'. Zaeed, Line 23

Rihanna would not take ownership of the AS and referred to it as 'the arthritis' not 'my arthritis' that way she felt she is in control of the situation:

'If I say my arthritis it means I am not taking ownership of the disease. I don't want that. It doesn't rule my life. I want to continue to be in control. So yes, it's the arthritis. It's so easy to fall into the trap that you are ill and that's not me. Some people wallow in self-pity', Rihanna, Line 33

The participants learnt to manage their emotions through spending quality time with their families:

‘He says his family has been very supportive. He spends more time around his family now and he values this. They have accepted the situation and they are moving on. He says he can be himself around them and that is important for him.’ Zak, Line 66 via an interpreter.

4.10.5 Finding support

The participants founded ways of minimising stress in their lives by letting go of unnecessary obligations. The families and friends of the participants are part of a social network that play a significant role in supporting them to adapt to the AS. However, healthcare professionals appeared to be providing little or no support to most participants.

Participants are grateful for the support they got from their families:

‘At least it matters a lot who you surround yourself with, with regards to the condition. I was very fortunate that my parents were not very far from me, so they asked me to move back in coz obviously I couldn’t manage. I don’t know what I would have done without their support.’ Jay, Line23

‘He says but, ‘In Sha Allah’ all his family has been there for him. They have covered all his needs. He used to work full-time but he has been off sick for some time now, so financially there is an effect there. His family is helping with that’. Jaz, Line 57 via an interpreter.

Communication between healthcare professionals and participants about the AS was considered inadequate. Some participants searched for information themselves online to try and understand the AS and how to manage it:

'But here they just said autoimmune disease and gave me a booklet of arthritis to read. When I was reading all the stuff from the booklet it was confusing. I went on line and I also wrote to the Arthritis UK and they sent me all the brochures on AS, and exercises that I do at home every day. They also got me in touch with the support group and that has helped.' Ravi, Line 34

Participants began to build a strong network that they could rely on. For them it was about understanding their AS by searching and getting information from the internet and other sources. Zaza explains:

'I picked up something from the internet, the Humira website. I enjoy the chats online as I am sitting at home most of the time. We chat, so yeh, we share our frustrations on there. I must say I was relieved to find out on the chats that there are other people whose stories are a whole lot like mine.' Zaza, Line 82

Raj found support and encouragement from a friend who had the same condition and he no longer felt alone:

'One of my friends has the same condition but his is only affecting his spine. He is also taking anti-TNF treatment. He has encouraged me a lot. I now browse a lot and I read comments on the website, the NASS website. So yeh I stay connected through that.' Raj, Line 140

Others were in a supportive work environment:

'My current work place is very supportive. They allow me to rest when I need to.' Raj, Line 140

'My boss could see that I was struggling so he reduced my working hours'. Zia, Line 77

'He works at the food counter and his branch is in a busy network rail station. He spends a lot of time standing but his manager provides him with a stool for him to sit and work. This has helped him a lot.' Jaz, Line 62 via an interpreter.

Some participants bemoaned the lack of support in terms of information and counselling, which left them feeling alone. They found it difficult to cope with the diagnosis and suffered emotional distress:

'I wish someone had gone through with me what to expect when I was diagnosed. Someone to say, 'this is normal' it would not have been such a shock to me. I don't know if anyone else has this condition. It would be good for someone to say, 'this is what you have got, this is what to expect, other people have got it, this is where to go for support'. If someone had actually said these things to me, it would have helped me to deal with it within myself. To know that I am not alone in this fight. I would feel normal and not the odd one out. I really suffered emotionally when I got the diagnosis'
Mo, Line 108

Not everyone felt that there was a lack of information and support from the healthcare professionals for example:

'I don't know how thankful I can be, it's not even enough, fantastic all my doctors, all my medical staffs, the nurses, every single person has been kind. They have made the burden of the disease easier to bear. Fantastic people, dignified people, very kind and professional'. Zaeed, Line 66

Zia had also found support from his community and healthcare professionals, which helped him, manage with the illness. He compared his experience from when he was

living in a rural area of England to the inner London Borough where he felt at ‘home’ amongst his community:

‘Since I moved to this area, I am very happy with everything, very happy. I have my community around me and when I came to see the doctor here I actually met a guy from Bangladesh with the same condition. We now keep in touch and he has encouraged me to try the injections. So yeh I am pleased I moved from the rural area, I felt alone there now I have other people around me who understand. My professor is a very good man, the nurses are nice here. They listen to you, they don’t ignore what you are saying. So yes, coming to London was the best thing that could have happened to me’. Zia, Line 53

4.10.6 Theme 4 summary

The participants found practical ways to respond to the disruptions and limitations from the AS, when faced with the altered situation in their lives. They had started to build a new life and adjust to life with AS. While some were able to take control of their lives and adjust others described some fatalistic views to the new order in their lives. The friends and families as well as the internet, have been the best source of support for the participants. The majority of participants, felt that there was a lack of support from the healthcare professionals throughout their illness journey.

4.11 Theme 5: finding relief

‘Initially I was given naproxen, but it was not very effective. I was moved to meloxicam and it was irritating my stomach. Now I am on anti-TNF injections and I have seen a difference. I am more awake. I have more energy, that’s the significant difference.’ Faz Line 143

This theme concerns participants' experiences of trying to control their AS and ease its symptoms. There are four sub-themes (Fig 4.5). The first is the experiences of drug treatment where patients have tried several different medications or combinations of these medications, to determine what works best for them. Some participants get side effects from the treatments, whilst others simply find that their symptoms do not improve. From the participants' narratives, the anti-TNF treatment appears to be the best treatment with good efficacy reports. The second sub-theme is about physiotherapy, which is aimed at improving the range of motion and strengthening of the muscles. Some participants found this helpful but others found it too difficult to do the exercises due to pain. The third sub-theme is around the use of complementary or alternative treatment. The participants were desperate to try anything to ease their symptoms and they tried cupping, acupuncture and chiropractic. The complementary treatments only gave short term relief and some participants found them ineffective and uncomfortable. The final sub-theme was about the participants' traditional health-related practices and beliefs, which influenced the type of treatment individuals chose. Some participants were sceptical about the effectiveness of western medicine, opting to try complementary therapies first. Others believed that changing their diet had helped improve their symptoms. Some had a fatalistic belief which according to Keeley et al (2009) suggests negative outcomes may occur to oneself regardless of attempts for personal control. These sub-themes will now be discussed in greater detail.

Fig 4.5 Finding relief



4.11.1 Drug treatment

All the participants had faced the upheaval from the AS, and they used drug treatment to find relief of their symptoms such as pain, stiffness and fatigue at different points in their illness journey. They had moved from seeking medical help, to identifying the problem and now they tried multiple strategies to improve their symptoms, with varying results. Some participants tried many drug treatments, but were not satisfied due to experiencing unwanted side effects which they were unable to tolerate:

'I have tried many treatments. Ibuprofen minimises the pain but it is always there. I have used steroids but they are for short term use although they make you normal again. I have experienced rashes, acne, and spots all over with some tablets, I had to stop. I know these treatments have lots of side effects.' Ullah, Line 50

Because of the side effects from treatment and the aggressive presentation of the illness, Shumi's treatment was quickly escalated to anti-TNF injections, which were very effective:

'I got side effects from most treatments, even steroid injections. It gave me shingles and that was a disaster then they put me straight onto Humira instead of doing methotrexate. That's how bad my situation was. The Humira really gave me my life back. It has helped with the overwhelming tiredness. I am allergic to ibuprofen.' Shumi, Line 141.

Ali was scared to stop his anti-TNF treatment despite repeated infections, for fear of his condition flaring up:

'I used to get lots of infections on the treatment but I was scared to stop for fear that the pain and stiffness would come back. I couldn't go back to the ibuprofen coz it affected my kidneys. In fact, I was taking too much so they stopped it.' Ali, Line 164

Other participants expressed that the effects of the oral drug treatment were not long lasting. The perceived benefits of the drug treatment were unsatisfactory:

'He says he has mainly had pain killers, paracetamol, co-codamol and ibuprofen. They only help for a short time and his pain comes back.' Iyaz, Line 62 via an interpreter

'He says he has used many treatments for his condition, codydramol, paracetamol and ibuprofen. He says he was disappointed all these did not get rid of the pain.' Jaz, Line 76 via an interpreter

Some participants expressed frustration, sadness and anger because they tried many drug treatments for a long time, but the symptoms persisted. No information has been given by the healthcare professionals, about how the drugs work and what to expect:

'I am suffering, no medication is working. I am very sad and angry thinking to myself, nearly 30 years now why is it not working. The specialist is not saying anything just changing the medication.' Ali, Line 182.

'Honestly speaking with my GP, it was just pain killers. First it was diclofenac, then naproxen for many years. It was just pain killers and this added to my frustration as the pain was still there.' Rafiq, Line 24

The anti-TNF treatment was not the first line of treatment for AS, however when the participants were put on it, most of them had dramatic improvement:

'With this injection, I feel as normal as I can possibly be. I would say this injection is the best thing since sliced bread. It changes your quality of life totally. I have experienced it first-hand.' Ullah, Line 179

'He is now taking the Humira injections and it works better than the other drugs.' Iyaz, Line 70

'I am now on the Humira injections and these seem to keep the pain under control.' Nas, Line 76

Ali's experiences were different from the others, in that the anti-TNF treatment only worked for a short time just like the other drug treatments. He expressed disappointment as his is not what he expected:

'I have tried many different treatments even the expensive injections but they worked for a short time and slowly slowly they stopped working. I expected better results.' Ali, Line 158

One participant was happy with the anti-TNF treatment, although the weekly injections did not last the seven days and he was worried about the long-term side effects:

'He is now taking the anti-TNF injection Enbrel, once a week and it is controlling his symptoms, but when it wears off the pain and stiffness comes back. He says he worries about taking these injections for the rest of his life, about the long-term side effects. He says he feels on top of the world for four days after taking the injection then the pain creeps back.' Jaz, Line 81

Zia was happy that he was getting relief from the Humira injections, however he also realised that there are other things he had to do to improve outcomes:

'I am now on the injection. This medication helps you 40-45% but you need to manage yourself for the other 50-55%. I do minimal exercises but bending for me is painful, but when pain is less I exercise.' Zia Line 77

Others suggested that while the anti-TNF treatment was working, it only eased some aspects of the AS:

'He is on Humira injections now. The injection is helping him particularly pain levels, but the pain does not go away completely. He sleeps better but his stiffness and fatigue are still a problem.' Zak, line 109

Soji stopped taking tablets because of the undesirable side effects. The anti-TNF provided hope and with hope came meaning to a hopeless situation, where the tablets caused him more harm than good:

'He says the injection has given him hope. To him a life without hope is meaningless. Long-term pain killers have affected his kidneys. So now when they prescribe other tablets he just doesn't take them. For him medicines should cure him and not give him another illness. This is how he sees it.' Soji, Line 65 via interpreter.

Raj offered similar sentiments suggesting having many different drugs was a form of trial and error by the professionals, to see which one works:

'I took methotrexate but I didn't feel good. I had lots of side effects, mainly fatigue and nausea I took ibuprofen and meloxicam and I even tried sulphasalazine, but I had some problems with skin rashes that's why I couldn't continue. They were trying everything to see if it worked.' Raj Line 102.

Raj was finally put on the anti-TNF treatment which was managing to control his symptoms. He was experiencing no side effects and he even reduced his pain killers:

'Currently I am taking anti-TNF treatment and I feel much better. I think it's working. After taking the injection, I don't feel anything, no sickness nothing eh I even take less pain killers you know, once a day or even up to a few days so it seems that it is working.' Raj, Line 119

Mo had tried everything including physiotherapy to no effect. The anti-TNF however seemed to have reduced his pain levels:

'I have tried everything. Ointments, deep heat, voltarol, pain killers, physio, acupuncture, no effect. I am now taking the injection. The back pain is slightly less since the injection compared to how I used to be.' Mo Line 69.

Rihanna tried many tablets but was concerned about their side effects so she stopped taking them:

'I have tried every treatment you can think of. Now I have gotten to a point where I realise that I might cause myself more harm than good from popping pills, so I have stopped some of the tablets.' Rihanna Line 70.

Some realised that the treatment had come too late for them and the damage has already been done:

'I still have occasional back pain and stiffness but nothing like before. This is because of previously not being treated properly and now there is some damage.' Faz, Line 162

'The Humira injection, I think it was already too late for me because they said the injection slows down the illness but mine is too far gone with all the damage.' Zaza Line 72.

A fear of needles meant that it has took longer for some to come around to having the anti-TNF injection. Soji associated the stigma of diabetes with administering the anti-TNF injection and opted to have his GP practice administer his injections for him, otherwise he would not take the injection:

'He says it took him a whole year to decide whether to take the injection or not. He has a fear of needles and he doesn't want people to think that he has diabetes. The GP practice administers his injection and it suits him.' Soji Line 72 via an interpreter.

Sometimes the participants had to make the difficult choices between starting a family or continuing with treatment. Zaeed remembered how bad his AS was before the treatment and did not want to go back there:

'Sometimes it's a choice of whether I stop the medications and start a family or just concentrate on staying on treatment and keeping well. That's always tricky, but I never want to go back to the time when I couldn't function and I was existing without any quality to my life, that was a horrible place to be.' Zaeed, Line 118.

For Jay everything was about maintaining a 'routine'. His medication, how and when he took it, was up to his family and he liked to keep things that way. He had tried many ineffective treatments and he was now intending to try the injections a go, but without disrupting his 'routine':

'I have tried all sorts of treatments, they don't work. So, I will try the injection because people say they are very effective. I don't need to worry about what time I take my medications, everything gets done for me. I don't want to know that side. I have this

routine, I would like to maintain it. Even with all the stuff that I can't do, I would like to call this normal. It is still my life, I can still function.' Jay Line 156.

4.11.2 Physiotherapy and exercise

Participants used physiotherapy at different stages of their experiences with AS, as a means to find relief of the symptoms. Exercise was seen as a big part of their effort to improve the symptoms. However, some admitted that the physiotherapy was not always helpful, giving little benefit:

'Physiotherapy can be useful to some extent eh it doesn't take it totally away, it kind of gives you that little relief' Nas, Line 72

'He had physiotherapy and hydrotherapy treatment and this only helped with his stiffness. His pain was still there.' Jaz, Line 77 via interpreter

For others it was a catch 22 situation because they were in so much pain they couldn't tolerate the exercises:

'I don't know how they expected me to do the physio with all the pain. I was in pain everywhere and it was very difficult for me and distressing. So yeh I stopped after the one visit. The doctor was not happy but I just could not do what was expected with this the pain' Naseeb, Line 65

However, Ravi found the physiotherapy sessions useful and would have liked more sessions, but each time he had to be referred and the doctor was not always keen to do this. Ravi realised that exercise is important in his treatment but he lacked the motivation to do it on his own:

'Well the physiotherapy works for me and I know it's important with this illness, but it's not something that you can have as and when you want it. Even my doctor seems reluctant to send me to them. I guess there is no money in the system. I do not have the motivation to exercise on my own that is the problem.'
Ravi, Line 88

4.11.3 Complementary and alternative treatment

The use of complementary and alternative therapies has been widely discussed in health and illness research (Cant and Sharma, 2003). These include herbal treatment and traditional therapies used to manage the participants' chronic pain and improve their quality of life. The participants recognised and acknowledged the contribution of complementary and alternative treatment for their AS finding their use as an adjunct to conventional therapy helpful but the cost prohibitive. Some participants have used alternative treatment in the initial stages of their illness whilst others have used the treatments throughout their illness. The most frequently used alternative treatments by the participants were, homeopathy, massage, meditation, chiropractic and acupuncture. Ravi used a combination of conventional and complementary treatments before going onto Cimzia injections:

'I have taken anti-inflammatories, co-codamol all those things apart from ibuprofen. When I take ibuprofen, I feel a burning sensation in my stomach. I went to a chiropractor but he said he wouldn't touch me. I tried cupping, they cut you and use suction. I prefer the dry cupping coz I don't like the cutting. It can be comforting. Now the Cimzia injection works well.' Ravi Line 118

Ullah expressed the use of complementary therapy as common in the Bangladeshi culture due to the mistrust of western medicine. He tried yoga and massage and found that he could stay calm and forget about his pain for a while:

'I know a lot of people from my culture don't trust western medicine. It got me thinking you know about complementary treatment. To tell you the truth, that's why it took me so long to come for anti-TNF treatment, I wanted to explore other things. I find that the

massages help to calm things but when I do yoga, my mind switches off from the pain, only for that time though. 'Ullah, Line 40

Nas found the effects of complementary treatments did not last:

'I have tried herbal medicine, acupuncture and the tens machine however these things have worked for a short time and then gradually they just don't give me relief anymore.'
Nas, Line 74

Jaz was scared of acupuncture as a result he did not attend the sessions:

'He says he was referred for acupuncture but he got scared and he did not attend.' Jaz,
Line 80 via interpreter

Others tried chiropractic treatment in desperation but found it distressing:

'I had 20 sessions with the chiropractic and Allah saved me. The chiropractor is really rough. Basically, they move your bones out of place and it would stretch to the max and because of the stretch it bounces back and realigns. I was desperate.' Shumi, Line 171

Some families used up a lot of money on complementary therapy trying to find a cure for the AS to no avail:

'My father has spent literally thousands on alternative treatments, traditional Chinese medicine, homeopathy, whatever. He has sent me abroad, he has basically done various other things to get me back to normal. The only thing is none of them has a cure.' Jay
Line 43.

Other participants would have liked to try herbal medicine initially however the aggressive nature of the AS meant that they needed to be put on medication straight away to try and 'calm down' their symptoms:

'I would have liked to try herbal medicine first but I had no time for this coz my attack was so severe, I had to be straight away on drugs. I didn't have time to think about other things by the time I thought about it I was fully on medication, very high doses.'
Mo, Line 121.

Naseeb found relaxation helped his illness. He tried homeopathy in desperation, but his doctor discouraged it:

'When I am relaxed I feel better in myself, so yeh in a way relaxation helps. I tried homeopathy and I think it was doing something. The doctor did not encourage this treatment in combination with all the other drugs that I am taking. In fact, he told me to stop taking it. Sometimes the doctors don't realise how desperate you can get with this illness.' Naseeb, Line 75

4.11.4 Traditional health-related beliefs

The participants had health beliefs and attitudes about illness that affected their experiences of illness. Some participants seem bound to tradition and believe that disease is a direct punishment of God for sins committed (Bhopal et al 1999). Not doing evil therefore is seen as an integral part of staying healthy. Others believed that illness is a test from God, and accept this, asking God to reduce the suffering. Naseeb hinted that his illness is as a result of punishment for his previous behaviours therefore taking medication might not control his symptoms:

'I never thought of the consequences of my actions. I used to smoke heavily and uhm I still do. Now it's payback time. I realise I have to take care of my body now but maybe this is too late. I don't know if the treatments will work for me.' Naseeb Line 101

The cupping practice is common among the Bangladeshi community. It is believed to be good for general wellbeing and a cure for many ailments. However, some participants used it with no effect:

'I have tried acupuncture, cupping and many different treatments. A lot of people from my religion believe in cupping, but it did not work for me.' Faz Line 170

Zia used wet cupping out of desperation but questioned the safety of the procedure although his pain was relieved temporarily:

'I have used wet cupping a few times. My pain went away a little. But I am not sure about the safety aspect. They take blood out, like, from where you are getting the pain. They used a razor on my knee.' Zia, Line 80

Some participants viewed their physical degeneration as an inevitable result of aging. They saw their illness as a consequence of advancing age, and felt helpless to try and change the course believing that Allah would intervene through prayer:

'I do my prayers 5 times a day. I am 44 years old now, so I am expected to have some health problems. I don't know if the treatments will change anything. I leave everything to Allah.' Naseeb Line 89

Faz believed that changing his diet has improved his symptoms and he was convinced of this following an internet search:

'I have changed my diet and I don't feel like I am crushing anymore. I have seen the difference in just changing what I eat. My wife and I were just searching on the internet trying to find information on this illness and what makes it better, that's when we came across the diet thing. So yeah, I got the confirmation although my doctor thinks otherwise.' Faz, Line 90

4.11.5 Theme 5 summary

The participants used different ways to find relief for the physical and emotional symptoms associated with their AS. However, some participants found that some of the symptoms were an ongoing process despite drug treatment, physiotherapy and complementary treatment. Faced with this insufficient manageability of their symptoms, some resigned themselves to a life of pain whilst some put their trust in divine intervention. The anti-TNF treatments were very effective for some but they came too late for others, whilst some had fears about long term side effects.

4.12 Lifeworld existentials and lived experience of AS in Bangladeshi patients

The themes in my study could have been developed using van Manen's four existentials of lived body (corporeality), lived space (spatiality), lived time (temporality) and lived relation (relationality) van Manen (1990). These core qualities of human experience are usually taken for granted. However when an individual is struck by an illness such as AS, the natural order of things is breached and they are forced to face that which they previously took for granted. We witness this in the participants' narratives as they examine what has been lost, their ability to perform daily tasks, their jobs, aspirations and spending quality time with families and friends. According to van Manen (1990) the approach used to develop themes in a study is neither exhaustive nor mutually exclusive. I preferred the thematic approach due to the nature of the phenomenon being addressed, however the participants' narratives have in a way, been conveyed in powerful existential terms.

The lived body existential can assist us to understand the changes experienced by the Bangladeshi participant in terms of, the process of AS, its limitations and the demands that it brings. The AS has forced itself on the participants and they are struggling to understand what is going on. They can no longer take their bodies for granted, but 'listen to their bodies' and interpret the disruption.

The lived time existential can show how the participants have experienced losses whose consequences impact on their perceptions of their past, present and future. The participants' old self is no more, because the AS has fundamentally changed their lives. Their aspirations and life goals are over. Their lives that were once meaningful have been 'turned upside down'. The participants are focusing on the evolution of their AS. They had plans professionally and personally but what seemed important has now lost its meaning. They take each day as it comes. Lived time for them is about the physical, social, economic, cultural and political forces that have shaped their lived experience of AS.

The relationality existential intertwines with the other existentials of lived body, lived time and lived space. This is similar to how the themes used in my study interlink. The participants' social lives have been circumscribed by the limitations of the body due to the AS. Their bodies do not allow the participants to maintain the same relationships with friends leading to isolation and withdrawal from others. The participants have lost key relationships in their lives. The resulting isolation is conveyed in powerful existential terms. For Ali (section 4.8.5), the loss of his status as a father figure gives us a glimpse of the palpable psychological impact of the AS. The very thing which gave his life meaning has gone. Other participants feel 'alone in the fight' whilst others do not want to be a burden.

Spaciality is the space that human beings move and live. The AS has a profound effect on the participants' lives, imposing losses that create grief amongst the participants. The unpredictability and uncertainties brought on by the AS require some adjustments by the participants in terms of their personal, professional and social lives.

This brief synopsis of the existentials has shown how the AS, has in a way changed the participants' sense of time and priorities, their experiences of space, their felt relations with others and their sense of self and the body (van Manen, 1998).

4.13 Summary of findings

The use of van Manen's (1997) thematic analysis has been a helpful approach through which to gain a deeper insight into the phenomenon of health-related quality of life in Bangladeshi patients with AS. The thematic interpretation of the findings has provided guidance for us to understand the phenomenon under study. This was an important way of staying true to the interpretive nature of the methodology and in supporting methodological trustworthiness. The participants' AS is powerfully shaped by the context in which it occurs (Carmago-Plazas, 2011). As a researcher I have been able to examine my own preunderstandings and prejudices prior to the interpretation described and apply preconceived theories and conceptualisations. The participants have experienced AS, as a disintegration of their world and this can be seen to represent a change in their being in the world.

This chapter presented the findings that arose from using van Manen's method of isolating thematic statements (van Manen, 1990). The five global themes identified, have revealed the essence behind the everyday lived experience of HRQOL in the Bangladeshi participants with AS and these have been illustrated using examples and

quotations from the participants' own words and phrases. The discussion that follows in Chapter 5 is framed around a thematic presentation that captures the participants' struggles to get a diagnosis, the nature of the AS and its impact on the individual. This is considered alongside the way the participants manage the AS and navigate their relief. These will be explored within the context of existing literature and in terms of theoretical frameworks.

Chapter 5: Discussion

5.1 Introduction

This study set out to explore the lived experience of health-related quality of life in Bangladeshi patients with AS. Data were collected from 20 Bangladeshi patients with AS attending an outpatient clinic, using semi-structured face to face interviews. The narratives from the interviews were interrogated in order to generate an informed perspective of the participants' lived experience. Relatively few studies have explored the lived experience of health-related quality of life in AS. This is particularly true for the Bangladeshi population in the UK. In fact, no studies were found on this specific population suggesting this is an unexplored area. The findings from this study have provided in-depth insights for understanding the lived experience of health-related quality of life in Bangladeshi patients with AS, and this is considered as 'phenomenologically informative' (Hycner, 1985 p. 295). There are some differences and similarities in the findings from those reported in previous research, discussed in Chapter 2. This could be because of the shift in the focus from quantitative methods to a deeper exploration and understanding of the essence of meaning for the study participants. On essence van Manen (1997, p. 39) reminds us that:

'...the term essence may be understood as a linguistic construction, a description of a phenomenon...so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way'.

In my desire to contribute to the body of knowledge in this area and close the existing gap, the essence of meaning that has evolved from the themes anchored in the participants' narratives will be explored further in this Chapter. Whilst no claim is being

made that all patients with AS, have similar experiences, the methodology used was adopted in order to explore the lived experience as fully as possible and allow the 'hidden voices' of the Bangladeshi patients to be heard. I used an interpretive phenomenology based on the philosophy of Martin Heidegger (1962) and guided by van Manen's (1990) framework of six research activities to identify five global themes. The themes are inextricably linked and have presented the explored phenomenon as the 'structures of experience' (van Manen, 1990, p. 79), demonstrating the 'being in the world' nature of the lived experience of health-related quality of life in Bangladeshi patients with AS. The Bangladeshi participants cannot be separated from their worlds and as such Chapter 4 has shown how the fundamental ontology is formed (Rapport, 2005).

This Chapter discusses the findings detailed in Chapter 4 of this thesis and relates them to the research aims and question. Any congruence, conflicting and unexpected explanations between these findings and the literature will be discussed. The discussion will be framed by themes identified in Chapter 4, the reviewed literature and any background reading undertaken. I will refer to this research as 'my study' throughout this chapter, in order to take ownership of my work and avoid any confusion when discussing the work of other researchers. Sociology offers an understanding of the social contexts in which individuals operate and the importance of narrative in shaping the experience of illness and maintaining self and group identity. In the context of my study, its relevance to the insider's orientation, the chronic nature of the illness and the material, affective and subjective consequences of the illness on how people organise their lives and interpret what is happening to them, is crucial (Pierret 2003). However, in line with true Heideggerian fashion, the discussion will return to the 'thing itself to show the real essence' (Heidegger 1962). The Chapter concludes with a summary of the discussion and presentation of novel findings. Each global theme (Table 5.1) will be

discussed in the context of the reviewed literature in order to highlight the contribution of this work.

Table 5.1 the phenomenon and twenty-three sub themes within five global themes.

| Global themes | Sub-themes |
|---|--|
| <p>The struggle to get a diagnosis</p> | <ul style="list-style-type: none"> • The body is acting funny • Delays in diagnosis • It's a hidden disease • Taking matters into own hands • Getting a label |
| <p>The nature of AS</p> | <ul style="list-style-type: none"> • The physical symptoms • The emotional symptoms • It's a persistent disease • It's a fluctuating disease • Mind and body disconnect |
| <p>The impact of AS</p> | <ul style="list-style-type: none"> • Emotional impact • Social impact • Impact on relationships • The body as a cue to illness • Impact on life goals |
| <p>Managing with AS</p> | <ul style="list-style-type: none"> • Finding support • Taking control • Building a new life • Adjusting to AS |
| <p>Finding relief</p> | <ul style="list-style-type: none"> • Drug treatment • Physiotherapy • Complementary and alternative therapy • Traditional health-related beliefs and practices |

5.2 Sociological theories and the experience of chronic illness

Sociological theories have been used in the past to further understand the experience of living with a chronic illness (Bury, 1982; Williams, 2000; Bury & Taylor, 2007). The

participants in my study equally suffer from a long-term chronic illness, therefore it is appropriate to consider the sociologically defined theoretical perspective in the interpretation of my study findings. My phenomenological study has made explicit the dynamic relationship between the body and the world, by providing insights into the disruption of space and time. The sociological approaches to the body are situated in two main perspectives. The first is the body-as-object inscribed by political and social discourses from outside (Toombs, 1992). The second focuses on the experience of the body–subject within her social world or ‘what the body does’.

Toombs’s paradigm of body unites body and mind and situates body in the midst of the enviroing world (Toombs, 1988). Accordingly individuals have access to and experience the world by means of their bodies. The AS has disrupted the participants’ usual phenomenological anatomy. Practices, roles and relationships with others in everyday life are disrupted. For the participants’ in my study, the AS has struck at the fundamental features of embodiment. For example, the symptom of lower back pain is not experienced simply as pain in the spine, but as the participants’ inability to do concentrate on their college work. To them the AS does not represent inflammation of the joints or spine but an inability to carry out normal day to day activities. This has led to a realignment of body and mind, self and society through a range of biographical and practical adjustments leading to a restoration of what Bury (1982) termed a sense of continuity or normality.

Pickard and Rogers (2012) have identified three dominant traditions from sociological research into the experience of people living with chronic illness. The first is the social constructionist tradition, which examines the role of medicine in constructing discursive categories of sickness and disease, by defining what is ‘normal’ for the body and shaping the subjectiveness of patients accordingly. Narrative identity is the second approach which looks at the experience of illness and disability by adopting a

predominantly cognitive view of the self, paying emphasis to the way the self restores biographical meaning and adjusts to changes in identity following impairment or other changes to the body. Finally, is the lived body paradigm, which draws on Merleau-Ponty's phenomenology by focusing on the corporeal experience of illness and disability within the life world (Merleau-Ponty, 1962). This paradigm highlights the experiential aspects such as changes to embodied, self-awareness, motility, spaciality and temporality. For Merleau-Ponty embodiment is the essential element of human existence, which is defined by what he calls the symbolic function (Merleau-Ponty, 1962). I have argued for the more grounded and embodied aspects of living with AS and an appreciation of the particular type of knowledge underpinning it.

5.3 Summary of findings

AS is a life long illness that is unpredictable and it presents with uncertain and fluctuating symptoms. A pivotal finding is how the participants experience frustrating struggles in their journey to diagnosis and how the AS impacts on family life, relationships, roles, personal identities, emotions and employment. The disease is unfamiliar to the participants and their community as well as some healthcare professionals (GPs). Participants however have found different ways to manage with the AS and relieve its symptoms. In my study, the sample had more men (n=15) than women (n=5) attending the outpatient clinic, giving a ratio of 3:1. This male to female ratio is consistent with current literature (Lee et al. 2008). It is important to note however that studies for a long time considered AS a predominantly male disease, with estimated ratios of 9:1 (Polly & Slocomb, 1947; West, 1949). This misconception could account for why the majority of AS populations studied in the past have consisted predominantly of male patients (Webers et al. 2016). According to McKenna (2010), AS is clinically more common in men than women, with a ratio of approximately 5:1,

although this may partially reflect under-diagnosis in women. There were no older patients (over 65 years) identified at the recruitment stage and this supports assertions by Martindale and Goodacre (2014) that there is a gap in research amongst older people with AS. The meanings from the themes will be discussed further in this section.

5.3.1 The struggle to get a diagnosis for Bangladeshi patients with AS

Undertaking this research has highlighted a number of pertinent aspects of the lived experience of AS in Bangladeshi patients that I previously took for granted - 1.) there is a lack of answers or convincing explanations from the healthcare professionals, for the overwhelming symptoms of pain, stiffness and fatigue suffered by the participants (sub-theme : the body is acting funny); 2.) the participants faced challenges of living through lengthy periods of unexplained symptoms that impact on all aspects of their lives (sub-theme: taking matters into own hands); 3.) the disease is little known and this has resulted in problematic encounters with healthcare professionals who could not recognise the disease symptoms (sub-theme: it's a hidden disease); 4.) participants were dismissed and not believed or they 'did not fit the pattern' and the delays in diagnosis were upsetting and distressing for the participants (sub-theme: delays in diagnosis) and 5.) eventually, diagnosis brought relief, validation, support and understanding from families to some, but questions remained about the confusing conveyance of the diagnosis by the healthcare professionals and worries about the future (sub-theme: getting a label). The findings suggest that the participants face a multiplicity of problems in the period between the onset of symptoms and getting a diagnosis. These problems will be discussed in greater detail in this section.

In the beginning, something was wrong, the back pain was severe, attacking without warning, resulting in stiffness and inability to move all of a sudden. There would be a feeling of pain and fatigue every morning with one participant using an analogy of the

body being crushed, for example, 'run over by a truck'. Another participant felt 'as stiff as a board' due to the early morning stiffness. On the fatigue, some participants felt it was a big part of their condition, with descriptions of their bodies' failure to function as they 'completely seized up'. This was recalled as a time of confusion with participants asking: What is wrong with me? Why is this happening to me? All the participants narrated how they struggled to understand what was going on and how their lives were 'turned upside down' by the initial symptoms. The symptoms that the participants were experiencing were inexplicable and unmanageable leading to frustrations. Some of the participants expressed that their 'body was behaving funny' when referring to the initial presentation of their symptoms. The participants wanted to find out why they had been 'visited' by this illness that had disrupted every aspect of their life. Many participants described the frustration of having their symptoms remain undiagnosed, for many years. The participants described the psychological as well as physical impact of having their symptoms dismissed or not believed. This study affirms findings from other studies which described the process associated with trying to understand a changing body experience complicated by the variability and the severity of the symptoms involved (Martindale & Goodacre, 2014) and the main category of concerns such as pain, stiffness, fatigue, postural changes and reduced mobility (Hamilton-West & Quine, 2009; Ward, 1999). Furthermore, Martindale and Goodacre (2014) showed there was a feeling that their participants were not being believed, being perceived as 'playing on it', being too young to have back problems and being non-compliant'. In my study, when there was no confirmed diagnosis, this compounded the participants' feelings of inadequacies in relation to their perceived role in the family, society and in the work place.

The Bangladeshi community's unfamiliarity with AS caused some negative and discriminatory attitudes towards the participants suffering from this condition. As a

result, some hid their illness ‘because no one understood’ what they were going through. Equally others acknowledged, that the AS ‘is a hidden disease’ and some found the healthcare professionals were ‘puzzled’ by their symptoms. This concept of the ‘hidden disease’ analogy, describes the individual’s own perception of themselves and then the view from the outside which is the external representation of the illness. One participant also felt the Bangladeshi community was more familiar with diabetes than AS and she thought she was the only person with the illness. Similar to the findings in my study, Hamilton-West and Quine (2009) found that there was a feeling of being stigmatised for some participants, which in some cases led to withdrawal from social situations. Some participants decided to isolate themselves for fear of being labelled as ‘lazy’ or ‘acting up’. Their study was conducted in Canterbury (England) where 95% of the population is recorded as White and with a higher than national average level of education (National Office of Statistics, 2011). This emerging trend of congruence in findings with my study suggests that the experiences of chronic illness are similar irrespective of cultural, social and geographic background.

AS amongst the Bangladeshi community can be considered a ‘hidden’ disease in a ‘hidden’ population. Researchers often struggle to access, engage, and retain participants from socially disadvantaged groups (Sateren et al. 2002) resulting in labels such as ‘hard to reach’ or ‘hidden’ population. AS is not a familiar disease amongst the general public (Jois et al. 2008) and in the context of this study amongst the Bangladeshi community. My interactions with the Bangladeshi community during the planning stages of this research support this, as not many were familiar with the illness including the gatekeepers who are regarded as the cultural custodians in the community. For the participants in my study, the physical, emotional and social changes brought challenges that were not always visible. As a consequence, patients can be invalidated resulting in exclusion of social exchanges (Kool & Geenen, 2012). The subjective

experience of having a chronic illness has been investigated by others in terms of chronic pain (back pain, neck pain, osteoarthritis, fibromyalgia, pelvic pain, lupus, unexplained abdominal pain) (Dow, et al. 2012) and chronic lymphocytic leukaemia (Evans, et al. 2012). Findings from these studies have shown how the invisibility related to either the disease or the symptoms makes it difficult to discuss the illnesses with others. When the participants in my study experienced the strange pains and other unexplained symptoms they hoped a visit to the doctor would give them some answers. Their often-non-specific symptoms were dismissed by the healthcare professionals as being minor ailments that would go away, in spite of causing severe distress. In particular the participants were frustrated at the lack of knowledge and recognition of AS and its symptoms by the GPs. For example, one female participant whose symptoms started with her first pregnancy but was diagnosed after the fourth pregnancy, expressed that for the GP, it was ‘out of his depth really’. Another participant simply found that the GP had ‘no answers for him’ after ten years of going backwards and forwards, whilst another ‘lost faith’ with his GP and changed to another. This lack of knowledge amongst the healthcare professionals has been identified in the literature (Brandt, et al. 2007). Equally, participants volunteered that they did not discuss the condition with friends and family as they did not know much about the illness. This confirms assertions in the literature about the lack of knowledge of AS in the general public (Jois et al. 2008).

In my study all the participants expressed the delays they experienced in trying to get a diagnosis. The delay in diagnosis for the participants was between 4 and 22 years. This is not a new phenomenon in AS, as these findings are comparable with a number of previous studies (Rudwaleit et al. 2005; Hamilton et al. 2011; Gerdan et al. 2013). Diagnostic delay is a major challenge in AS with periods of 8 – 10 years generally reported between symptom onset and diagnosis (Feldtkeller et al. 2003). In Chapter 1

section 1.5, a myriad of reasons was put forward to try and explain these delays. Martindale and Goodacre (2014) used an interpretive phenomenological approach (IPA) to explore the journey to diagnosis in ten patients with AS from the Northwest of England. The location where the study was conducted has one of the lowest ethnic minority populations, with the 2011 census reporting 98.8% of the population as white, 0.4% Asian and 72% listed as skilled, working class and middle class. Findings suggested that the delay in diagnosis experienced may be associated with a lack of familiarity and knowledge of AS/axial SpA in the population and in healthcare professionals, and creates a multiplicity of problems, including psychological distress. Whilst Martindale and Goodacre's (2014) population differs markedly from the Bangladeshi population in my study, findings from the two studies regarding delays in diagnosis are similar, which can be explained in several ways. Firstly, there is a commonality of methodology (Dixon-Woods et al. 2004) and rigor in interpretation of results (Lincoln et al. 2011) which has brought some coherence to the conclusions in both studies. Secondly, the experiences of the journey to diagnosis for AS patients across different demographic and geographic features appear to be similar.

It is important to note however that some of the reasons for the delays in my study differ from those reported in the quantitative studies in the literature. This could be because of the qualitative nature of my study and the population being studied. A study by Sykes et al. (2015) set out to determine whether there had been any recent improvement in the interval between symptom onset and diagnosis. They reviewed routinely recorded clinical data held on AS patients attending two large UK secondary care centres (Bath & Norwich) as part of an assessment of service provision. They concluded that delay in diagnosis has not yet improved and it remains a huge challenge in AS. Sykes et al. (2015) further contend that one of the reasons why the delay in diagnosis has not improved is because GPs continue to find it difficult to distinguish inflammatory type

back pain from the more common types of back pain and are often unaware of the extra-articular manifestations of AS, so patients may be investigated appropriately or referred to the rheumatologist (Jois et al. 2008). The GP appeared to be the first point of contact for the participants in my study. As such, GPs they are best placed to make an early diagnosis or refer onto specialists for further investigations. Some participants in my study felt that they were too young to have this illness and this was reinforced by the GPs who felt that some participants did not ‘fit the pattern’ of AS. This led to the participants not being believed or being dismissed. Other commentators (Rudwaleit et al. 2002; Bandt et al. 2007) have described how AS often mimics other conditions and patients are often misdiagnosed with other disease possibilities over a long period before the AS is finally diagnosed. In the absence of appropriate education on how to identify the symptoms of the condition and specific guidance or pathways that can point GPs to an earlier diagnosis, this remains a problematic area. It is important to point out that, diagnosis of AS in the UK is primarily made in secondary care services with only a small proportion diagnosed in primary care (Hamilton et al. 2011). This could explain why the participants were consulting their GPs for many years before they were eventually referred to the rheumatologists for a diagnosis. None of the participants were diagnosed in Bangladesh before coming to the UK.

The patients’ perspectives highlighted in my study as contributing to the delays in diagnosis include: not being believed and being dismissed by the healthcare professionals; participants being told that they do not fit the pattern of AS; the reluctance by healthcare professionals to refer or investigate persistent problems leading to progression of disease and structural damage. This led participants to take matters into their own hands and search for answers elsewhere due to frustrations. These findings reinforce findings from a previous study which described participants having to ‘push’ to get something done, and experiences of negativity and reluctance from GPs to

order investigations or refer to other healthcare professionals (Martindale & Goodacre, 2014).

Fallahi and Jamshidi (2016) also found a long interval between symptom onset and correct diagnosis of AS. Similar to my study's findings they identified wrong initial diagnosis might be another explanation for delayed diagnosis in AS. It is evident from the participants' narratives in my study that the lack of answers and delays in diagnosis led them to take matters into their own hands. Through frustrations of being pushed from 'pillar to post' the participants searched for answers themselves. Some did searches on the internet whilst others insisted that the healthcare professionals do more and refer them to the specialists. The majority of findings from the literature review have not fully explored the participants' perspective on the frustrations faced by AS patients. However, two qualitative studies have explored the AS patients' frustrations, which are similar to my study's findings. Madsen et al. (2015) explored men's experiences of living with AS. On the period before diagnosis, the men stated that it was a crucial time, characterized by frustration caused by constant pain and interrupted sleep. Martindale & Goodacre (2014) in their study on newly diagnosed AS patients, explored in detail the journey to diagnosis in AS and the impact of delay. The participants in their study described the potentially negative psychological impacts, including feelings of stigmatisation, not being believed, self-doubt, anger and frustration. Interestingly similar to the findings in my study, the participants' overall frustration with doctors' and allied health professionals' inability to recognise the condition was evident and pivotal for many. In my study a few of the participants were pushed to seek answers abroad.

In my study, the participants were involved in a long process through which they sought medical help to identify the problems they were experiencing. They had difficulties dealing with the AS symptoms which were non-specific and the GPs put their

symptoms down to other causes not AS. Frosch et al. (2012) on the barriers patients face on their diagnostic journey, cite suboptimal communication and a hierarchical relationship with the physicians. The uncertainties of the symptoms brought distress to the participants who expected the GPs to have the expertise and knowledge to make a diagnosis but were frustrated at being dismissed or being misdiagnosed.

Some participants in my study felt relieved and validated when they eventually got their diagnosis. Finally after so many years someone had named their illness! The participants now knew what was causing their symptoms and now they could find different ways to give the AS a place in their lives. Others had resigned themselves to their fate, believing that their illness was a punishment for some wrongs they had committed in the past. Their perception of illness in this context is influenced by both spiritual and personal beliefs. The impact of spirituality on health has been reviewed extensively in the literature on other diseases such as cancer which has similarities to AS, in terms of how it can lead to damage in the physical, psychological, social and spiritual dimensions of an individual's life (Tabei et al. 2016). Sadati et al. (2015) studied the effects of spirituality and religious beliefs on life experiences of Islamic women with breast cancer in Iran. They found that the religion of Islam plays a key role in helping people cope with disease. Elsewhere patients with spiritual vision have been found to have a more positive perspective on life and report a better quality of life (Tate & Forchheimer 2002; Leak et al. 2008). All the participants in my study were of Islamic faith. Patients who are spiritual may use their beliefs to cope with disease, pain, and stressful situations (Nahjolbalaqe, 2001; Levin 2002). The lives of the participants in my study were disrupted and there was a threat to the normal order in their lives. Fatalism became a meaningful concept for some participants to make sense of the new order in their lives. Some participants turned to prayer as a way of wishing away the disease in their belief that prayer has an impact on physical and psychological health.

Others believed that praying according to Islam, five times a day would bring healing. Prayer, religious practices and spirituality have also been shown to help people, prevent diseases and promote health (Koenig, 2009; Chida et al. 2009), deal with their illness (Cigrang et al. 2003) and manage pain (Taylor, 2005). Whilst these beliefs might not fit into the biomedical model which is based on the Cartesian philosophy (Lee, 2012), they are influenced by personal context and personal choice (beliefs, attitudes, expectations, values). According to Ahmad et al. (2011) Islamic faith is based on the words of God as expressed in the Quran (Muslims' Holy Book) and cannot be grounded in human speculation. Accordingly, the Bangladeshi participants tried to seek help from God, the Quran, and prayer. My in-depth study has explored some of the participants' beliefs and experiences about their illness and how they responded to the symptoms. Bartlett et al. (2003) evaluated spirituality and its relationship with functional level, psychological well-being and quality of life in people with RA. They found that a spiritual orientation may provide social support and act as a buffer against stress and facilitate adaptive coping.

Two emotions were experienced when participants got their diagnosis. On the one side there was a feeling of relief because of the struggle for many years with uncertainties and symptoms that could not be explained. The participants were relieved because they now had a label for their illness which brought some legitimacy to their symptoms. This finding of relief is consistent with results from studies in systemic lupus erythematosus (Waldron et al. 2012) and AS (Martindale & Goodacre 2014). On the other hand, getting a diagnosis brought some worries about the future for the participants, who had experienced the symptoms for lengthy periods and they had negative expectations for how to manage their life in the future. This underscores the need for an early diagnosis and the importance on the part of the healthcare professional, to convey relevant information about the illness, its presentation, treatment, ways of adapting and available

support. When the AS was diagnosed the manner in which the information was conveyed by the healthcare professionals was often inappropriate and the participants felt they were not supported and this in turn affected their adjustment to the illness and the management of the condition. It can be argued that patients do not retain a lot of information at the time of diagnosis (Margolis, 2004), however opportunities should be allowed for the patient to let everything sink in, ask any questions they might have or understand what the disease means to them as an individual. Waldron et al (2012) highlighted the need for the healthcare professionals to have a greater understanding of the patient experience prior to receiving a diagnosis of lupus, due to the direct impact on the patient's subsequent acceptance of their diagnosis and response to management. As there are similarities with AS in the presentation of the lupus symptoms that are invisible and unpredictable in nature, Waldron et al.'s (2012) suggestions could be relevant for people being diagnosed with AS too.

5.3.2 The nature of AS

The theme 'Nature of AS' has five sub-themes (Table 5.1) that will be presented in this section interwoven together through the text. In my study, the irruption of an illness affected the participants and those close to them, as a disruptive experience. The AS upset everyday routines turning the participants' lives upside down. The uncertainties affected every part of their lives and those close to them. Merleau-Ponty (2005) asserts that 'being in the world' means existing in a reciprocal and communicative relationship with the world. Carel (2016) goes further to add that, illness disrupts habitual ways of thinking about and being in the world, preventing us from having the ability to take our bodies, projects, relationships, and our very existence as givens

Inflammatory back pain and fatigue as a first symptom of AS were reported more often by the men in my study whilst the women tended to report more pelvic and widespread

pain. This led the women's symptoms to be associated with childbirth or pregnancy by the healthcare professionals, leading to further delays in diagnosis and frustrations. My interpretation has been addressed elsewhere in the literature, by Slobodin et al. (2011) who looked at gender differences and factors related to delay in diagnosis in AS. They found that inflammatory back pain was less dominant in women with AS compared to men at the disease onset. The women in their study described radiation of pain to the pelvis or lower abdomen leading frequently to referral to gynaecologists, gastroenterologists or general surgeons. Elsewhere, Farren et al. (2013) explored patients' experiences of living with and managing fatigue in AS. The descriptions of fatigue in their study bore similarities to that of fatigue in my study, being described as severe, relentless and unresolving. There was a distinction between tiredness and fatigue with some participants in my study describing 'feeling drained' and unable to cope with any physical activity. The fatigue also impacted on their college work, employment, social and leisure activities leading to withdrawal or change in roles and isolation. In both studies the participants found ways to manage their fatigue. In my study the participants obtained help particularly from family members and they used strategies such as pacing activities and 'listening to their body'. In other studies, anti-TNF treatments have been found to improve fatigue in AS (Gorman et al. 2002; Calin et al. 2004; van der Heijde et al. 2005). However, despite treatment with anti-TNF drugs, more than half of the participants in my study continued to complain of fatigue. These continued symptoms, could be connected to other factors such as medication and pain (Brophy et al. 2013) or psychological health and lack of sleep (Guyandin et al. 2009).

The participants in my study experienced varied presentation and intensity of their pain, fatigue and stiffness. The AS is marked by unpredictable physical symptoms where timing and duration are erratic leading to a life full of uncertainties. The participants described the on-going never-ending struggle with the unpredictability of the AS. The

AS invades all aspects of the participants' lives and the unpredictability appeared to upset the participants as much as the symptoms themselves. This unpredictability appeared to be a constant in their lives, not being able to predict the type of pain for instance and their lives could come to a halt due to the pain, fatigue and stiffness. The participants could not plan their lives, as the symptoms forced them to adjust or even cancel outings with families and friends. Unpredictability has been found to be a major issue in other rheumatic diseases too (Shlotzhauer 2014; Ryan, 2014; Short et al 2017). Short et al. (2017) interviewed eleven women with RA, through RA charities across England and found that pain, fatigue, poor sleep and low mood had an impact on QOL. Ryan (2014) asserts the unpredictability of symptoms and the presence of pain and fatigue may lead to daily plans having to be changed. Similarly, to my study findings, the fluctuating, unpredictable and challenging nature of the symptoms affected ability to work, family and social relationships, self-worth, ability to feel "in control", threats to future plans and appearance. The daily or hourly variations of AS in terms of its symptoms were challenging for the participants in my study. This in turn resulted in anticipatory anxiety and mood fluctuations. The physical symptoms were well described during the interviews, with the participants stating the frustrations caused by functional limitations, constant pain and interrupted routines. Van Manen (1990) suggests that we are always bodily in the world, the lived body (corporeality) refers to our physical or bodily presence through which we 'reveal something about ourselves or conceal something at the same time' (p.103). According to Merleau-Ponty (1996) the body is our orientation to the world. Therefore, when that body is struck by an illness such as AS, the previously taken for granted state reveals itself and the body loses its 'silence'. The AS threatened the taken for granted state of the participants' existence with their bodies by drawing their attention to the body. This in turn disrupts the way they experience their world. The participants begin to 'listen to their bodies' before deciding

on any plans. The functional limitations of AS have been described extensively in the literature with the physical function of the SF-36 subgroup being the most affected by the disease (Ward, 1999; Ariza-Ariza et al. 2003; Turan et al. 2007; Mustur et al. 2009). Maintaining physical activity has been found to be important in other disease areas, rheumatoid arthritis (Loeppenthin et al. 2014) and osteoporosis (Nielsen et al. 2011) where the findings suggest that it can be used as a resource to resist disability and remain healthy. Similar experiences were found by Madsen et al. (2015) who studied men's experiences of AS. Their qualitative study found that the men were limited in their physical abilities, had trouble accomplishing daily life tasks, including work, sports and social events. In my study, physical function was not only related to being a functional limitation but as being a part of a social group limitation. Some participants withdrew from social relationships because of the AS and stated that they did not want to explain the illness to anyone or to get their pity. The physical symptoms of the AS therefore negatively affected other areas of the participants' lives.

Emotional disorder is common in individuals suffering from a physical illness (Guthrie 1996, Ryan, 2014). Ryan (2014) discussed the psychological effects of living with RA to include the reaction to the diagnosis, initial helplessness, to a sense of being in control. The participants in my study expressed emotional and psychological symptoms of feeling sad, and excessive fears and worries about the future with AS. The psychological responses to the AS were mainly to do with the participants' anxieties and depression. The unpredictable nature of the disease and the uncertainties impeded adjustment to the AS and this increased the emotional and psychological distress in the Bangladeshi participants. This work converges with the findings of other studies. Martindale et al. (2006) investigated the association between AS and psychological status and found that disease status and some psychological factors (anxiety, depression, internality) are closely linked. Likewise, a study by Boonen et al. (2003) found patients

with AS to have high levels of psychological distress, especially depressive symptoms, which significantly impair their health-related quality of life. Some participants in my study grieved and then adjusted to the illness whilst for others, distress was more protracted leading to depression. Depression and anxiety are frequent in AS patients similarly to other rheumatologic conditions (Hopkins & Moulton 2016).

The physical changes due to the AS result in the body not working as usual whilst the unpredictability is setting the agenda on the body. For the participants in my study, it was as if the body had acquired a life of its own' and the AS would not allow the participants to do what the mind was commanding. For example, one participant wanted to respond to a knock on the door. According to him, his mind was already at the door but the body would not let him move to open it. The body was refusing to cooperate, announcing itself in its objectiveness (van Mannen, 1998). An unfamiliar body beyond one's own control can be described as an assault on our being in the world (Helman, 2007). Osborn and Smith (2006) have pointed out that having chronic unmanageable back pain separates body from self. Some participants had to learn to 'listen to their body' first in order to know what they could or could not do. Merleau-Ponty (1962) believed that we experience being-in-the-world through our bodies and so our experiences of the world are always embodied experiences. As such, the body cannot be seen as if it were something cut off from both mind and world. Merleau-Ponty (1962) goes further to assert that we develop stable patterns of experience that tell us how to move our bodies, how to respond to various psychological and social situations, and how to understand our everyday ordinary life-world.

The on and off nature of the AS was disabling and it was a major problem for the participants. They could not plan anything because they did not know how the body would act. This made most of the participants feel uncomfortable at social gatherings when they had profound symptoms, and the unpredictability was dictating the agenda in

their everyday life. The chronic nature of AS means that it lasts for long periods and the symptoms of pain, fatigue, and stiffness are persistent. In some participants, the pain and stiffness would come and go and in others these symptoms were constant with the disease getting worse over time. On living with AS Hamilton-West and Quine (2009) found that the unpredictability of not knowing when the AS would flare was problematic. This meant that the participants could not plan breaks at short notice. They found that it was necessary to plan ahead in order to undertake any activities and social life. The Bangladeshi participants in my study had similar problems where they experienced variations in the overall pattern of the disease leading to frustrations. For others the on and off symptoms affected their concentration and they had to abandon their studies. The lack of knowing if the body would be stable in the future meant that plans were shelved or abandoned and they learnt to take 'each day as it comes'. Other studies have investigated illness fluctuations in AS with similar findings (Brophy & Calin, 2002; Mengshoel, 2008).

The inquiry into the meaning of the illness experience has been pursued in the sociology of health and illness literature (Pierret, 2003). Bury's (1982) seminal work stands out, owing to his emphasis on chronic illness as an experience that disrupts the patient's everyday life and the forms of knowledge underpinning it. In my study, the search for meaning, coupled with the problem of uncertainties that had to be managed on a daily basis by the Bangladeshi patients, was an important feature in their accounts of the lived experience of AS. Bury's (1982) work can be seen as a widely acknowledged turning point in the understanding and conceptualisation of lay experiences of chronic illness. His classic sociological formulation of the notion of chronic illness as a 'biographical disruption' highlights the complex and multi-faceted ways in which the experience of chronic illness can lead to a fundamental rethinking of a person's biography and self-concept (Lawton, 2003). In my study, the AS disrupted every part of the participants'

lives, as they physically depended on others. On how people make sense of the arrival of chronic illness in their life, Williams (1984) used narrative construction to look at how people with RA tried to make sense of the arrival of a chronic illness in their lives. He explored how a chronic illness may assault the individual's sense of identity and the limitations of medical science in explaining the physical and social breakdown to which such an illness can lead. The participants in my study had to assume new roles and identities due to the AS and healthcare professionals had no answers for their symptoms. This caused a lot of frustration and confusion. Bury (1982) sees chronic illness as that kind of experience where the structures of everyday life and the forms of knowledge that underpin them are profoundly disrupted. Some participants in my study referred to their AS, as a form of 'arthritis'. They appeared to find it difficult to come to terms with their AS and this could be because of the significance assigned to 'arthritis' as a disease of older age. The AS affects people in their most productive years. Similar to my findings, Bury's (1982) participants with RA, were relatively young and they perceived the onset of RA as a premature assault on the self. Before the AS, the participants in my study led normal active lives, so they too tended to experience the AS as biographically disruptive. They were not used to living their lives with uncertainties and un-predictabilities. Their lives were untouched by illness struggles before the AS and they had high hopes and dreams of achieving great things in life. Clearly there are similarities in the way RA and AS both disrupt and cause upheaval in people's lives.

Charmaz's concept of 'loss of self' (1983) is another area worth discussing on this subject. The concept focuses on a type of suffering that goes beyond physical symptoms to include a 'crumbling away of their former self' (p168), and this was echoed by some of my study participants' in their extreme experiences of AS. Charmaz (1983) used strategies of grounded theory to draw data from semi-structured interviews with chronically ill persons with various diagnoses such as cardiovascular disease, diabetes,

cancer, multiple sclerosis and lupus erythematosus. Findings showed the participants lived a restricted life due to the physical effects and the unpredictable course of the illnesses. Social isolation, loneliness, depression, and a feeling of being a burden followed as a consequence of a restricted life. The participants in my study became a burden due to the physical dependency and the feelings of uselessness. Although the participant characteristics in Charmaz's study are quite different from those in my study, the experiences of illness are quite similar. In my study the participants are likewise severely debilitated from the AS and their loss of self is a multifaceted experience.

5.3.3 The impact of AS

This theme demonstrates how the nature of Dasein (being in the world), evolves as the participants in my study started adjusting and reorganising their lives in the context of the day to day activities of their lived experience as they experienced permanent changes in physical appearance and bodily function due to the illness. Participants found that other individuals and society as a whole reacted in different ways to bodily cues of their disease. The dominant symptom of AS is lower back pain and it is highly prevalent and stigmatising which according to Holloway et al. (2007) increases the impact of the condition. The participants' lives were restricted by the illness and they experienced social isolation as well as feeling that they were a burden to others. These findings demonstrate a move away from the narrow, medicalised view of suffering as physical discomfort, to a focus on the participants' perspectives and their day to day contexts within which they live. Lawton (2003) has described a complex overlapping of the different aspects of the illness experience, which can either reinforce or amplify another. Ohman et al. (2003) have taken this further in their study of the meaning of living with a serious chronic illness. They concluded that the serious chronic illness

experience hovers between suffering and enduring but also included the process of reformulation of the self. In my study, some participants were stigmatised by friends and the community and this led them to withdraw from social engagements, stop work and give up previous pursuits. Their lives took on a whole new meaning as they moved through a complex trajectory that involved turmoil and distress, and they made a transition towards a phase that involved incorporating the AS into their lives. The participants' narratives showed an emerging construct of AS, as an illness, that has changed their lives and how they have confronted and reconstructed life with the illness. According to Bury (1982) people who have chronic illness or acquired disability may experience a shattering of self and begin to reconstruct a meaningful sense of self that fits with the many changes that have occurred in their lives. My study findings resonate with the work of Ohman and colleagues (2003) who define serious chronic illness as an illness that exists when people can no longer participate in daily life as they did when they were healthy, due to their illness. They investigated illnesses including cancer, lung, neurological, kidney and rheumatological diseases. As such, AS would fit into the latter category. The limitations due to their AS increased the participants' feelings of worthlessness as they were unable to interact meaningfully with others. Bury and Anderson (1988) related the chronic illness experience to 'environmental conditions, material resources and the demands of contemporary culture and social structure' (p2). The themes running through their book are: stigmatisation, the impact of illness on family life and employment, its effects on personal identities; the use of the health system; and medical regimens. In my study the stigma of AS affected the participants in two ways. On one side, the public's ignorance about AS caused a negative and discriminating attitude towards the participants. On the other hand, there was a 'felt stigma', similar to Scambler's (2009) reworked stigma, which encompassed a feeling of shame, associated with having a disabling condition such as AS. Some participants had

feelings of shame and guilt about having AS, and they tried to tell their friends that their illness was not as bad as cancer. The shame was central to their interpretation of the meaning of their illness, as they withdrew from social relationships (Pierret, 2003).

AS is associated with a relatively early age at onset, therefore the impacts of the symptoms on the individual are likely to be long term and far reaching. In my study, AS had a negative impact on work as participants became subject to close scrutiny due to frequent absences and symptoms such as pain, fatigue and discomfort which may affect their productivity. Similar to Charmaz's (2006) assertions, the participants' involvement at work was limited. The impact of AS on work was described by many, but one participant in my study articulated it more profoundly. He used to be a proud chef who commanded a lot of respect amongst his colleagues, in a fast food restaurant. As he began to slow down due to the AS, he could no longer cope with the fast pace and the demands of the job and realised he had to give it up. In a way he felt 'forced to resign' by the illness because his performance lagged behind the expectations of a chef in a busy restaurant. Another participant tried to stay in work in order to provide for his family but had to give up eventually. In sharp contrast, another participant found that he did not need to camouflage his symptoms in the work environment. His manager was very supportive and he was able to reschedule his day to handle his symptoms. Barlow et al. (2001) investigated work disability amongst people with AS. Their findings showed that similar to my study, participants had changed the way they worked by reducing working hours, changing roles, becoming self-employed, and resigning from work. Fatigue and pain were major challenges limiting physical functioning and the ability to work.

Relationships play a role in how people attempt to live with chronic illness. The impact of AS on family relationships was extensively described by the participants. Most of the participants have narrated how they had to rely on their families and spouses for their

activities of daily living (washing, dressing, toileting, mobility), suggesting that the AS affected the quality of life of families in a significant way. Hamilton-West and Quine (2009) found that the pain and fatigue of AS had a negative impact on relationships causing 'irritability with partner', 'worry to my wife' and making 'sustaining a sexual relationship difficult'. In their study, one participant even reported that these factors were contributory in the breakdown of his marriage. Similarly, in my study, the AS had an impact on the everyday life of the participants including their families, friends, relationships and work. The family were the closest and first line support available to the participants, assisting them to cope with the disruptions to their lives as well as mental and social support. Most participants expressed strong feelings about not being able to assume their roles as wives, husbands, mothers, fathers or workers due to the AS. These findings support those of Younes et al. (2010), who found that AS adversely affects the relations of the patients with their family members by decreasing the frequency of family visits and of attendance at family events. Nevertheless, families have been found to be a valuable source of relief and support for patients with AS (Rkain et al. 2007). The AS causes chronic pain, functional problems, depression and activity limitation as well as participation restriction, which makes it unlikely that patients' family members, who have become primary caregivers, or spouses, remain untouched. The participants lost some independence and needed assistance for the performance of everyday activities.

Some participants in my study have described the negative effect of AS on their sexual relationships. According to the literature, only a few studies concerning sexual problems in patients with AS have been conducted. Most of these have been in male patients (Cakar et al. 2007; Dincer et al. 2007). This suggests that sexual activity is a neglected area in AS research. In my study the illness led to a decline in the sexual relationship due to the physical effects of the illness affecting both male and female participants.

Some participants cited a lack of interest due to not having the 'urge' but at times decided to just 'bear it' out of a sense of duty. For others, the fatigue, the physical limitations of the illness and the side effects of the medication they were taking for the AS, added to their difficulties in their sexual relationship. However, one participant expressed that his sexual relationship was not the 'same' but he managed to 'work around it', suggesting that he found other ways to manage his sexual relationship. Cakar et al. (2007) found that sexual problems were common in patients with AS and might usually be associated with decreased functionality, decreased health quality and depression. Ozgul et al. (2006) similarly reported that 52.7% of AS patients claimed a decrease in sexual intercourse frequency. Healey et al. (2009) investigated gender differences on the sexual functions of AS patients and found that female patients were as much affected as male patients. A more recent Turkish study by Sariyidiz et al. (2013) has found that sexual dysfunction in female patients with AS has multifactorial origins. These include, pain, disease activity, the limited mobility of the axial skeleton, deterioration in physical function and the medication used to treat AS. Studies in other areas (RA) have found that male patients felt less sexual desire than controls (Van Berlo et al. 2006) and partners of patients have described the negative impact of illness on their sex life (Rolland, 1994; Basra & Finlay, 2007; Eghlileb et al.2007). Elsewhere, Ryan et al. (2008) assessed the effects of fibromyalgia on patients' sexual activity. The main theme from all the participants in their study was the impact of pain that often led to avoidance or affected the duration of sexual intercourse. A majority of participants (63%) in the study identified symptoms of pain and fatigue as the reasons the fibromyalgia had altered their sexual relationship. Similarly, in my study, for some participants the pain, fatigue and stiffness were dominating factors that limited their sexual activity and affected their urge for sex.

Participants in my study also narrated how the AS disrupted the normal dynamic and routine (homeostasis) within family members' roles, relationships, responsibilities and boundaries. One participant expressed feeling useless as a man whilst another described himself as having resigned himself to the illness. It seemed he retreated fully into the role of illness in a way previously described as the sick role by Parsons (1951) and played out that role in full even relinquishing his responsibilities to his son. Parsons (1951) has described the resultant uncertain and unpredictable futures which in turn trigger distressing emotions of anxiety, depression and feelings of helplessness. According to the participant in my study, he was sick and he could no longer look after the family. He did not see a future for himself as he could no longer 'defend' his family. His narrative was dense with meaning as his sense of self was taken over by the illness and he wanted to be seen as a sick person. Whilst Parson's original conceptualisation of the sick role was criticised for applying only to acute illness where patients were expected to make a full recovery (Young, 2004), his revised account (Varul, 2010) is more applicable to chronic illnesses such as AS, which can be managed but not cured.

5.3.4 Managing with AS

When asked to describe how they manage with the AS on a day to day basis, the participants' greatest concern was related to managing with the new chronic illness and its symptoms. Charmaz's (1995, 2006) postmodernist work gives a more optimistic view of the illness experience by describing it as a form of self-development and liberation via narrative expression. Williams's (2000) 'narrative construction' describes the conceptual strategies people employ to create a sense of order and stability following the disruptive onset of an illness. Although Williams focuses on the longer-term effects of chronic disease, he seeks to explore how participants use narrative

construction to reconstitute and repair ruptures between body, self and world. According to Kelly and Dickinson (1992) the way that people talk to others about their illness provides important clues to the way they are responding to it.

Normalisation has been used as a behavioural attempt to maintain a normal life, including strategies of keeping-up, covering up and pacing (O'Neil, 2007; Weiner, 1975). Some participants in my study used strategies of normalisation, accommodation and resignation as ways of responding to the AS. For some participants, the AS was quite visible in terms of their disabilities but for others they exhibited no outside signs of the illness or the signs were subtle. Goffman (1963) emphasized the role of illness visibility in his work about stigma. He differentiated the responses of individuals who were discredited by visible stigma versus responses of individuals who were discreditable by a stigma that may be concealed and covered. The visibility of chronic illness may influence the choice to normalize or the ability to normalize successfully. In my study, the female participant described how their outward appearance was deceiving as they showed no signs of having the illness. As a result, they found it difficult to convince others that they had AS. But on a more positive note, they did not want the AS to stop them from achieving their goals. They did not want to 'own it' and saw it as a separate entity to their being, by referring to it as 'the arthritis' and not 'my arthritis'. The majority of participants were however starting to build a new life and adjust to the new order in their lives.

The participants in my study knew the limitations of their AS and they were finding ways to take control. Whilst all the participants found support from their families, only a few searched the internet for information about the illness and how to manage it. This was after the healthcare professionals failed to give them information about the illness, its treatment and what to expect. Ryan et al. (2003) set out to identify factors that patients perceive as prerequisites in obtaining a sense of control over living with the

consequences of rheumatoid arthritis. Their research demonstrated that a patient's perception of control is not a static entity but will be influenced by both internal and external factors. They concluded that patients perceived that they were in control of the daily consequences of their RA until they experienced an alteration to their situation which was manifested either in their symptoms, e.g. pain, or in the level of social support they were receiving and either of these occurrences could alter perceived control unfavourably. The participants in my study similarly expressed that the provision of information by the healthcare professionals would have equipped them with the skills and knowledge to manage their AS.

In a way this theme concerns the practical response, successful or otherwise, of the participants to Bury's (1982) notion of chronic illness as a disruptive event. Bury's study describes the response to the disruption which involves the mobilisation of resources (p.169). His study was with predominantly female patients with RA and it can be argued that it might not be directly applicable to patients with AS. However, his work and that of other sociology scholars facilitate an understanding of the range of consequences of chronic illness. According to Bury (1982) people who have a chronic illness may experience a shattering of self and begin to reconstruct a meaningful sense of self that fits with the many changes that have occurred in their lives. Some participants in my study have been labelled and they have received negative reactions from others and this may feed into the sense of self and result in shifts in identity. As a result, they invested enormous effort in appearing normal despite the conflict that this invoked for them. For example, one participant expressed that his friends expected him to do 'normal things', otherwise they would label him as a 'lazy' person, but he always suffered afterwards. As a result, he withdrew from friendships in order to manage his AS. Others managed by 'hiding' the illness from friends and went through the period of suffering quietly. Mathieson and Stam (1995) in their cancer narratives have added that

for patients, maintaining meaning or finding a new meaning for their disrupted lives involves the quest to establish continuity as they learn how to cope with the illness by redefining the self, reconstructing biographies or renegotiating identities. The participants in my study learnt to adjust to the new order in their lives in different ways by reorganising their lives.

By upsetting everyday routines, becoming ill and being ill were causes of uncertainty for participants and those close to them in my study. This uncertainty affected various activities or even the person's whole existence. Participants work out strategies for coping with this upheaval and use various resources to reorganise their lives. For the women in my study, living with AS was centred around a lack of control over issues that mattered to them most such as their family life, missed opportunities and their sexual relationships. The uncertainties and the persistence of the symptoms had become a constant in their everyday life. Interestingly the women positioned the AS, as a separate entity to their subjective body by referring to AS in their narratives as 'the AS', 'it' and 'the disease'. This was a way for them not to take ownership of the illness. Through the AS, the women's bodies were brought under the medical gaze (Michel Foucault, 1973) as something within their bodies, thus positioning the women's bodies within medical discourse. Foucault (1973) theorised that the medical gaze abstracts the suffering person from her sociological context and reframes her as a condition with the patient being seen as sick and powerless. In my study however, the women did not want to be seen as sick and powerless, in this medical paradigm created by the abusive power structure described in the medical gaze. The women strove to resist the symptoms or sought a means of alleviation by declaring that, 'life goes on' even though their bodies were refusing to cooperate. They became sensitive to their bodies and they used this as a way to manage with the AS. They had responsibilities to take care of despite experiencing living in a new reality. These findings resonate with descriptions by Carel

(2008) of how a new life descended on him following a diagnosis with an unfamiliar condition and how his life changed beyond recognition. Similarly, to my participants' experiences, Carel learnt more about his embodied existence and about people's attitudes towards illness and disability. He had to reinvent his life and give up some friendships. He also learnt to rethink his aspirations and plans as well as relinquish a sense of control over his life that he previously had. In my study, the AS has changed the women's sense of time and priorities, their experience of space, their relations with others and the sense of self and the body. They learnt to live with the AS, similar to van Manen's (1998) assertions of the experiences of the body in illness. Two of the women found it difficult to understand or describe their condition in terms of the pain, stiffness and fatigue they were experiencing. Their relationships were affected and they felt isolated with no desire to socialise with others.

All the participants had a wide support network from their families and my study has highlighted two elements of the social aspect of the participants experiences of AS. The first concerned the importance of support for someone whose life has been disrupted by the illness particularly in terms of their limited physical function and the severity of the symptoms. The participants narrated how important it was to have the support they needed from their families and friends. The support enabled the participants to manage with the illness. Previous literature has shown the importance of social support in chronic illness. Pitsilka et al. (2015) have shown how quality of life is enhanced by social support in Greek patients with RA. Other research such as that conducted by Holtzman et al. (2004) and Kool and Geenen (2012) has highlighted the importance of close others in promoting adaptive coping strategies. In my study, participants talked about their bad days when they needed support with all activities of daily living and acknowledged that only their families could provide that kind of support. They narrated how they would not have managed without the families' support. The second element

concerns how having the AS changed the participants' relationships with others, and how they tried to navigate through life with the illness and renegotiate relationships with others. Although the effects of social support in AS have been poorly studied, social support has been linked with better health amongst patients with various rheumatic diseases (Ryan et al. 2003; Neugebauer & Katz, 2004; Treharne et al. 2005). The participants in my study had experienced both negative and positive social interactions. The negative interactions were mainly to do with not being believed, being stigmatised and a lack of understanding of the illness. Kool et al. (2009) studied patients with fibromyalgia and similarly to AS, they contended that the invisible pathology and symptoms of fibromyalgia, made it difficult for the patients and those who interacted with them. A later study by Kool and Geenen (2012) included 152 patients with AS and they found that perceived invalidation and lack of social support may contribute to loneliness feelings in patients with rheumatic diseases. Many patients with fibromyalgia report similar challenges with the AS participants in my study. Families and friends do not understand the illness (Arnold et al. 2008), medical professionals dismiss them (Paulson et al. 2002; Cunningham & Gillings, 2006) and they are stigmatised (Asbring & Narvanen 2002). Kool et al. (2009) found that negative social responses and a lack of positive social responses resulted in invalidation of the patient and the condition of the patient. More importantly they concluded that their findings may also be replicated in other syndromes with inherent invisibility of symptoms combined with the absence of clear pathologic evidence.

The positive interactions involved bringing participants closer together with their families and getting the support to manage with their AS on a day to day basis. The experience of coping and managing the AS successfully as a family brought the participants and their families closer together in my study. This may have been enhanced by the presence of working toward a common goal, of trying to improve

symptoms of the AS. This is a new finding in this area as no other studies have reported on this previously. All the participants expressed that they were getting very good support from spouses, parents and other family members. Caring for a dependent relative appears to be an important part of the Bengali culture. According to Atkin and Rollings (1996), Bangladeshi family relations are strong particularly when faced with an illness and Asians will 'look after their own' (p.76). Caring for family members in the Asian community is an accepted and expected part of family duties (Adamson & Donovan, 2005) and this could be viewed as an aspect of their ethnic identity. This resonates with my own African cultural identity where I would be expected to care for members of my family rather than surrender them to care services. The ethos of family caring can also be seen as a sign of good upbringing, can enhance the family status in a community, be seen as a way of being loyal and keeping everything within the family circle. Jewson et al. (2003) contend that there is a perception within the Asian communities that family and community members would view the use of respite services for example, as abandoning one's relatives. In addition to receiving social support, individuals and families that normalize are likely to maintain social ties, a positive outcome in and of itself (Rehm & Franck, 2000).

5.3.5 Finding relief

The participants used different ways to find relief for the physical and emotional symptoms associated with their AS. The treatment of AS is multi-disciplinary, involving multiple professionals who normally form part of a rheumatology team (physiotherapists, nurses, pharmacists and doctors). Treatment with non-steroidal anti-inflammatory agents and physiotherapy remains an important approach to long-term management of patients with AS (Braun & Sieper, 2007). Studies have demonstrated the ability of NSAIDs to provide rapid and dramatic relief of inflammatory back pain

(Dougados, 2001; Dougados et al. 2001)). However, the participants in my study found that the effects did not last, brought little relief to others, whilst some developed adverse effects resulting in stopping the treatment.

Pharmacological treatment has made significant advances in the last few decades with the availability of anti-TNF drugs (Coates et al. 2010). Until their introduction, options were limited for those patients for whom non-steroidal anti-inflammatory drugs (NSAIDs) were either contraindicated or ineffective. All the participants in my study were taking different types of anti-TNF treatments (adalimumab, etanercept, certolizumab pegol, golimumab). The majority of participants defined their present experiences as improved and more hopeful following treatment with anti-TNF drugs. They narrated their past retrospectively, as a time of major upheaval in their lives, due to an unpredictable illness with an uncertain future. However, their pain had now improved and they no longer suffered as greatly as they did in the past. On the effects of the anti-TNF treatment they used phrases and statements such as, ‘this is the best thing since sliced bread’ and ‘I have my life back’ to express the dramatic improvement from this treatment. In this regard, my study has moved forward from the seminal work of Bury (1982) and Williams (1984) by allowing insights into the worlds of Bangladeshi patients whose lives have been transformed by the anti-TNF treatment. The transformation has heralded a shift from the concepts of biographical disruption developed by Bury (1982). Sanderson et al. (2011) have challenged the salience of Bury’s biographical disruption by suggesting a ‘biographical reinstatement’ or a ‘shifting of normalities’ depending on changing severity of symptoms, efficacy of treatment, ability to adjust to treatment and the influence of contextual factors. By capturing both the life experience before and after the AS diagnosis, I have been able to link the journey through diagnosis, to living with AS and its treatment. The participants’ narratives strongly resonate with those identified by Bury (1982) and Williams (1984)

in examining the impact of chronic disease and physical changes that affect their everyday life. However, after the treatment with anti-TNF drugs, there was a change in narrative that assumes a new lease of life for most of the participants. Some were able to go back to work as the functional ability, pain and stiffness improved, whilst others resumed roles that they had relinquished due to the AS. Due to the perceived efficacy of the anti-TNF treatment resulting in marked improvement in QOL or even remission in some participants we cannot assume in the context of this research that biographical disruption will result in continued disruption (Sanderson et al.2011). The participants in this study were struggling before the treatment but they had now returned to normality whilst a few were redefining their normality. This improvement in quality of life on anti-TNF treatment in AS is consistent with conclusions reached by other studies (Davis et al. 2007; Strand & Singh, 2008; Stockdale & Goodacre, 2008; van der Heijde et al. 2011; de Machado et al. 2016) as well as the National Institute of Health and Care Excellence (NICE 2016). Unfortunately, anti-TNF treatments can also have side effects as some participants experienced. The treatment is not always effective and is unsuitable for some patients (Claudpierre, 2005). Aggrey-Fynn et al. 2016 set out to establish the effect of ethnicity on response to anti-TNF treatment in severe AS. They found that the patient proportion that achieved an adequate response was higher amongst the Caucasians (73.5%) versus 45.5% of the South Asians. They concluded that they may be yet undiscovered ethnic influences affecting treatment response that merits further investigation. The cost of anti-TNF treatment is similarly prohibitive, at around £10000 per patient per year, and their use is subject to NICE guidelines (NICE, 2016). Decisions about whether to use the treatment are challenging for both patients and professionals.

Physiotherapy and exercise to improve mobility, fitness, and overall health are widely prescribed in AS (Dougados et al. 2002) and have been found to be beneficial (Kotsis et

al. 2014). Exercise is viewed as the cornerstone of management for AS and patients are encouraged to carry out daily stretching exercises designed to maintain and improve spinal mobility and pain (Zochling et al. 2006b). Physiotherapists are often involved in recommending and assessing the effects of these exercises. However, in my study some participants found that they could not exercise due to the pain and the physical limitation of the AS and others felt that the effects of physiotherapy were not long-lasting. Exercise was viewed as important but it exacerbated their AS symptoms and they had to stop. This reflects an acknowledgement of the negative effects of AS symptoms on the ability to pursue interventions that would otherwise improve the participants' AS and quality of life. From another perspective, one participant in my study bemoaned that the few sessions of physiotherapy, which they had been prescribed, were not enough to give them any meaningful benefit.

Some participants in my study had adopted complementary and alternative medicine (CAM) to help manage their AS. These therapies were used to complement the traditional treatment approaches or as a stand-alone treatment due to frustrations at the unrelenting symptoms of the AS despite conventional treatments. Holland (1999) has questioned the stereotype of patients seeking alternative treatment. He questions whether patients seek these treatments because they are depressed by their illness or if it is due to the apparent failure of western medicine to relieve their symptoms. Acupuncture, herbal medicine, cupping and chiropractic were the main therapies used by the participants. The use of CAM has increased in recent years in rheumatology (Rao et al. 2003) and in general (Wotton & Sparber, 2001) although their effectiveness is controversial. The use of CAM has also been found to vary by racial or ethnic groups in patients with rheumatologic conditions (Wootton & Sparber, 2001; Katz & Lee, 2007). Acupuncture, herbal medicine, cupping and chiropractic were the main therapies used by the participants. Most participants in my study wanted an improvement in their

symptoms and quality of life, but more importantly they were looking for an explanation and understanding of what was happening to them. They were not getting the answers from the healthcare professionals so they went elsewhere. This experience resonates with results from studies that found patients who are dissatisfied with conventional treatment may have high expectations of complementary therapies (Mitchell & Cormack, 1998; Richardson, 2004). An unusual finding from this study is that only one participant described using herbal medicine. This is in sharp contrast to suggestions in the literature that herbal medications, a major component of CAM therapy, are becoming increasingly popular and are of much interest to the public and health care providers (Setty & Segal, 2005). One explanation could be that herbal medications are being used but their use is often not volunteered to healthcare professionals. This could be because many physicians are somewhat sceptical of non-traditional therapies (Rao et al 1999). The practice of cupping is an ancient Chinese practice in which a cup is applied to the skin and the pressure in the cup is reduced so that the skin and the superficial muscle layer is drawn into and held in the cup (Bilal et al. 2011). There is a dry cupping (using a vacuum on different areas of the body to gather the blood in the area without incision) and a wet cupping (using a vacuum at different points but with incisions in order to remove harmful blood which lies just beneath the surface of the skin) (Michalsen et al. 2009). There appears to be a spiritual aspect to this practice as it is reported that the Messenger of Allah said, 'Indeed the best remedies you have is cupping 'hijama' and if there was something excellent to be used as a remedy then it is cupping 'hijama' (Al Jauziyah & Abdullah, 2003). Faced with a lack of explanation for the cause of their symptoms the participants who practised cupping in this study believed that something had entered their body causing the pain and suffering. In a way the cupping was seen as drawing out the disease. Similarly, in the literature some healers of super naturalistic traditions of illness causation, applied

oral suction to the surface of the body to withdraw the effects of these malevolent influences (Jackson, 2001). The participants however expressed that the effects of the cupping were not long-lasting.

The participants in my study had health beliefs and attitudes about illness that affected their experiences of illness. Their AS was attributed to events outside the body rather than to a failure of an organ within it. Some participants attributed their AS to a one-off incident at work (lifting heavy object), or childbirth (triggered by the process of giving birth) or punishment (for past wrong doings or unhealthy lifestyle) and as an act of Allah. For others the AS was an expected consequence of aging. On aging as a consequence of AS, one of the participants volunteered, 'it was bound to happen. I am over 40 now'. The health beliefs of South Asians are diverse and they are rooted in place, history, context and person (Fleming & Gillibrand, 2009).

5.4 Summary of discussion chapter

This study set out to explore the lived experience of health-related quality of life in Bangladeshi patients with AS. I have approached the study from an interpretive phenomenological perspective and a deeper insight; about the experience of living with AS in this group has been acquired. I have used themes and systematically explored their meaningful aspects of the phenomenon and it is evident that one theme always implicates the meaning dimensions of other themes (van Manen 1990). Indeed, there are complex and often variable ways in which the participants in this study have experienced and are living with AS. The lived experience of AS in the Bangladeshi participants does not adopt the 'Cartesian' paradigm of 'lived body' with its dualistic notion which separates mind and body and conceptualises the physical body in purely mechanistic terms (Zaner, 1981). Instead, I am of the view that we cannot discount the

subjective experiences of the patient as unreliable or irrelevant but understand the experience of AS in the Bangladeshi patients, similar to Toombs (1988), as the disorder of body, self and whole.

The participants faced a myriad of struggles in their journey to diagnosis and the symptoms of the AS are unpredictable and uncertain affecting every aspect of their day to day lives. This has had an impact on their emotional, functional and social lives. The participants have described ways they are managing with the illness and how they have found relief for their symptoms. Simply put, the participants are in effect saying: ‘This is what it is like to be a Bangladeshi patient with AS’. This chapter built on the findings of my study by providing an in-depth exploration of the main themes and elements that evolved from the Bangladeshi participants’ narratives, I have described in detail how the experience of living with AS is compounded by many factors and have examined these in the context of previous research and theories. This study has focused on Heidegger’s ‘Dasein’, a fundamental ontology, of what it means ‘to be’ for Bangladeshi participants with AS.

The final Chapter, Chapter 6, will highlight the original contribution made by my study. Recommendations for future studies and implications for practice will be outlined. The strengths and limitations of the study will be provided together with a final reflection.

Chapter 6 Conclusion, recommendations and implications for practice

6.1 Introduction

The aim of this interpretive phenomenological study was to explore the lived experience of health-related quality of life in Bangladeshi patients with AS, who live in a deprived inner London borough. Ethnic minority populations are under-represented in rheumatology research in the UK, particularly in research using qualitative methodologies. Van Manen's (1990) methodological approach was used to provide structure and a guide to the phenomenological enquiry into the lifeworld of the Bangladeshi participants. The study was designed to answer the question: What is the lived experience of health-related quality of life in Bangladeshi patients with AS?

My doctoral study was undertaken for several reasons. The main reason was to give a 'voice' to the 'voiceless' Bangladeshi patients with AS. This is because their lived experience and insights have not been previously explored in the UK literature nor have they been focused on in clinical practice. Secondly, this research was carried out to add new knowledge to this neglected area, by providing information for practitioners and healthcare providers so that they can have a better understanding of the needs of this group of patients. Finally, by using a sample from the Bangladeshi community residing in a deprived area of London, I have provided crucial information for future researchers wishing to study health-related quality of life experiences in AS among the Bangladeshi population, particularly inclusion of interpreters in the design. On a personal level this research has been a celebration of finding my research 'voice', from novice to researcher.

Chapters 1 and 2 in my study elucidated the background to this study and the context of the existing literature. Chapter 3 gave a detailed description of the research methods used and the rationale. This was in order to give new insights into the Bangladeshi

patients' meanings of their lived experience of AS in the findings chapter (Chapter 4). Chapter 5 further explored the themes in the findings and brought an exploration and deeper insights of the lived experience, including the perspectives of existing literature and the link to the essence of meaning of 'living with AS', to existing theories of health and illness. Thus, the lived experience became embedded within an established philosophical and conceptual framework.

Chapter 6 is the final chapter that concludes my thesis by providing a summary on how my research contributes new knowledge to this area. Recommendations and future directions for the care of Bangladeshi patients with AS, will be highlighted. Tentative suggestions will be made to improve and influence service provision in order to create better outcomes for Bangladeshi patients in the future. The chapter concludes with a description of the study's strengths and limitations and a final personal reflection as a researcher.

6.2 Contribution to knowledge

This study brought the lived experience of Bangladeshi patients with AS to the forefront, investigating their everyday life experiences. The thesis has captured the meaning of what it is like to live with AS on a day to day basis, illuminating a deeper understanding of various aspects of the lived experience of the Bangladeshi community. Despite evidence that AS has a negative effect on the health-related quality of life of patients (Ward,1999; Hamilton-West & Quinn, 2009) and the magnitude of its impairment (Kiltz & van der Heijde (2009), the experiences of the Bangladeshi patients of AS have not been explored in the UK and their voices are largely silent in the literature.

This study is the first to represent the lived experience of health-related quality of life in AS conducted exclusively with Bangladeshi patients in the UK. By listening carefully to the narratives being shared by the participants, we hear that the AS is challenging to diagnose and it forces changes to participants' familiar life due to its persistent and fluctuating nature. The AS interrupts the participants' vision for the future due to its physical symptoms (pain, fatigue, stiffness) and resulting functional limitations. The invisible nature of the AS has been addressed by creating an opportunity for the Bangladeshi patients in this study to make their voices heard and therefore visible. The participants found ways to manage with the AS by 'listening to their bodies' and 'pacing activities'. The psychological consequences of the illness cannot be underestimated, most often leading to depression. There is hope for the participants in the form of novel targeted anti-TNF treatments, however these need to be prescribed earlier on in the disease to avoid irreversible damage.

These findings justify my claim that this interpretive phenomenological study has added to the body of knowledge in the area of lived experience of health-related quality of life in Bangladeshi patients with AS. The differences between this study and the existing literature are:

1. The voices of Bangladeshi patients with AS are largely silent in the literature and the lived experience of health-related quality of life are under-explored.
2. Before the diagnosis of AS, the participants had to overcome significant barriers associated with delays in diagnosis and the lack of culturally sensitive services available to them.
3. Some participants felt pushed to seek answers for their symptoms abroad, which they found frustrating and costly and they could not understand why the illness was difficult to diagnose. The patients living in the UK would travel abroad specifically to India directly or via Bangladesh in search for answers. It seemed

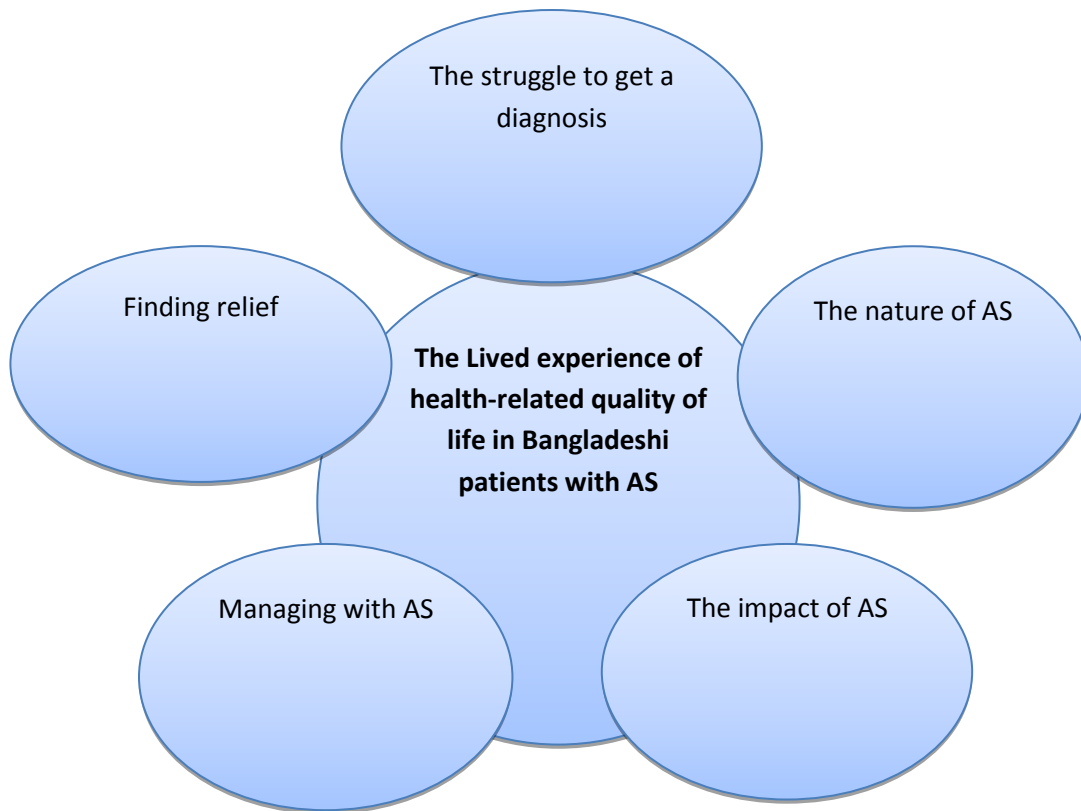
that patients were returning to the country of their heritage, or to India which has close links to Bangladesh, as they were losing trust in the UK health system. No other studies have been found where Bangladeshi patients travelled abroad to seek a diagnosis for AS.

4. The participants' families and spouses are a valuable source of support and relief for the participants with AS by providing mental, physical, financial and social support. All the participants were married and marriage provided a primary source of social support that was beneficial. These findings are different from those from the USA (Ward et al. 2008) in which patients were more likely to have never been married or were divorced. Elsewhere (Morocco – Rkain et al. 2007) patients remained connected to their social networks unlike the Bangladeshi patients in this study who withdrew from friendships and social networks.
5. There is an unmet need for specific healthcare services for Bangladeshi patients with AS. Identifying the needs of the participants and their informal carers (families and spouses) should be prioritised in order to plan appropriate services for this group.
6. There is an unmet need for psychological support in terms of counselling on the illness, its presentation and coping mechanisms in clinical practice.

6.3 Recommendations for future directions and practice

From the discussion of my findings in chapter 5, it is clear that the five identified themes are inextricably linked. The recommendations in this final chapter will therefore be offered within these five themes (Fig 6.1):

Fig 6.1 The phenomenon as five global themes



Source: Author April 2018

6.3.1 Recommendations for the theme ‘the struggle to get a diagnosis’

The findings point out the struggles the Bangladeshi participants experienced in getting a diagnosis, leading to frustrations and delays in diagnosis. There is a lack of awareness of AS and its presenting symptoms amongst the Bangladeshi community at large, as well as the healthcare professionals. The GPs appear to be the first healthcare point of contact when participants experience their initial symptoms. It is necessary to establish an early diagnosis based on the patient history and presenting symptoms. Education about AS, its presenting symptoms and possible impact on everyday living is crucial. This can be done through community outreach work involving the gatekeepers and at day centres and mosques, as these are the places that the Bangladeshi community tend

to frequent. Allowing the participants to understand their disease is another area that will empower them to take control and participate in the decision-making process about managing their AS. From the findings, a ‘symptom diagnostic criteria’ to assess the frequency, severity, duration and location of symptoms and their evolution, in Bangladeshi individuals presenting at the GP practice can be developed.

Further, education about what to look out for in the early presentation of this disease is required, to cover the referral pathways to the rheumatology specialists and specific criteria the GPs can use to help them distinguish inflammatory back pain from the more common mechanical back pain they usually see in their practice. Through this approach, refinement of diagnostic criteria for use in primary care to predict AS development in patients presenting with unclassified back pain, fatigue and stiffness may be achieved. Importantly, tools also need to be developed for use in primary care to direct management pathways including determining which patients with AS symptoms should be investigated and who should be referred to a rheumatologist and at what point. The patient’s history is available to us as clinicians through our assessment and we therefore have opportunities to maximise value from this history and assessing the predictive utility of the different components in the early stages of the AS. However, the cultural and language barriers continue to present problems in gaining this history. Although translators are used, these are not always available, leading to the use of family members to aid communication.

6.3.2 Recommendations for the theme ‘the nature of AS’

This study suggests that based on their cultural identity the Bangladeshi patients hold onto certain health beliefs which are based on the roles they are brought up to fulfil. As such, when the Bangladeshi participants found themselves confronted with the AS

symptoms, they utilised past experience and culturally-bound health beliefs to construct an explanation about their experience of AS. These were then brought into healthcare encounters. There is therefore a need for healthcare professionals to accommodate this holistic and contextual view of health, by prioritising not only the physical but the social and psychological well-being of Bangladeshi patients. Rheumatology services for Bangladeshi patients must acknowledge the importance of spiritual values in determining attitudes to AS and the challenges faced due to their disrupted lives. This can be achieved through the development of culturally appropriate models of service provision which are based on an understanding of their lived experience.

6.3.3 Recommendations for the theme ‘the impact of AS’

This study has given the Bangladeshi participants the opportunity to freely express themselves in their own words and in their preferred language, allowing them to vent their feelings and emotions of distress, anger and frustration regarding their illness and the struggles and challenges in their daily lives caused by the AS. Developing specific cross-language evaluation tools can assist healthcare professionals to determine the impact of AS on the Bangladeshi patients’ experiences of illness and healthcare. I propose the establishment of a tool that can be used to measure awareness of the signs and symptoms of AS in this group. The tool can also include questions about the emotional, practical or service issues the Bangladeshi patients face.

6.3.4 Recommendations for the theme ‘managing with AS’

These results may provide important information to establish effective interventions for Bangladeshi patients with AS, their families and the healthcare professionals, through

understanding the various aspects of the lived experience. Implications for practice should be how:

- a) Bangladeshi patients can be empowered to believe they can be valuable partners in care and can take control of their illness and their lives. Engaging with the community and a communication strategy aimed at making this condition more visible is crucial. For example, the provision of presentations, posters or leaflets (in local languages) through the community centres and mosques in the community as well as GP surgeries. The leaflets could draw attention to the presenting symptoms of AS for example, 'lower back pain and stiffness for more than three months which improves with exercise but is not relieved by rest'.
- b) Highlighting the experiences and the needs of this population with AS to healthcare professionals, specifically the GPs, may be facilitated by raising awareness through publications, oral and poster presentations at GP conferences. Some rheumatology clinics could be run at GP health centres in Primary Care so that there can be a sharing of knowledge and experience between the teams in the local communities.

This study has shown how the patients build up and rely on their families for support (spouses, partners, parents) when faced with a chronic illness. Social support appears to have a buffering effect on the psychosocial demands of the depressive symptoms of the AS in the participants. In my study the majority who perceived greater social support appeared to have fewer depressive symptoms. The social support must be provided in a planned manner and not just as a response to crises. Inviting families and partners to attend consultations and get involved might provide a channel for them to feel valued. The provision of a point of contact for the Bangladeshi patients with AS, their carers and the community in the form of local AS support groups run by them with support from the healthcare professionals might be helpful. Understanding the cultural roles and

definitions within the Bangladeshi community as well as the individuals' perceptions of the experience of AS, is important in healthcare and nursing. In previous studies, it was hard to find literature to understand life and emotional states of patients with AS, more so for the Bangladeshi patients with AS. This study may therefore provide a good opportunity to understand various life aspects of Bangladeshi patients with AS. In this study, the psychological response to the AS was mainly to do with anxiety and depression and the findings indicated that information and support given at the time of diagnosis was inadequate. As a result, the psychological distress in these participants was high. The inclusion of a psychologist in the AS clinics may help the Bangladeshi patients with AS, to adapt to their illness symptoms and improve their quality of life.

Healthcare professionals need to develop a cultural sensitivity which focuses on the Bangladeshi values and systems. This can be achieved through training of healthcare professionals and discussions at community support groups for AS. Through the discussions an awareness of cultural and spiritual beliefs in this group can be made as these impact on how they understand their illness, contextualise it and view the treatment. As a result of this the Bangladeshi patients can see the healthcare professionals as partners in care who have credibility and can be trusted.

6.3.5 Recommendations for the theme 'finding relief'

Early treatment of AS is important for slowing down disease progression before the installation of severe structural damage (Ibn Yacoub, et al 2012). My study population had an average of 7.8 years delay in diagnosis which led to more severe functional disability and radiologic damage. It has been shown in this study and the literature that anti-TNF treatment has an impressive effect on disease activity, function, mobility and other disease parameters. However, for some participants in this study, these treatments have come too late when the structural damage has already been done. Earlier diagnosis

will allow timely identification of patients suitable for this treatment so that this can be initiated earlier in the disease process.

Healthcare professionals need to be culturally sensitive and look beyond the ethnic background of AS patients and focus on the value systems the patients belong to. This will contribute towards a better understanding and management of AS in this group. Gatekeepers in the Bangladeshi community can be used to bridge the cultural and linguistic gap and assist in 'reaching' this group by raising awareness of the unique cultural and health beliefs held by the Bangladeshi patients. These will in turn assist clinical teams and policy makers in mapping out strategies that are tailored to the Bangladeshi patients.

6.4 Implications for future research

This study has highlighted the lived experience of Bangladeshi patients with AS and has provided a springboard for future research in this area. Embedded in the findings of this research were the unique contextual factors that characterise the Bangladeshi participants' lived experience. All the participants had aspirations of achieving great things in life, however the onset of AS, disrupted their plans and contributed to the development of anxiety and depression. Research that centres on experiences of life before the AS might help towards the provision of appropriate support and services for Bangladeshi patients with AS. Further work needs to be carried out into a wider population of patients with AS using different methodologies to identify their specific experiences and needs so that care can be tailored to those specific needs.

This study has recognised the important role played by informal carers (families and spouses) in supporting Bangladeshi participants with AS in terms of managing their illness. The lived experience of these carers is also neglected in research (Rees et al.

2002). Uludag et al. (2012) assessed quality of life and depression in spouses of patients with AS. Findings showed that being a spouse of a patient with AS significantly interferes with quality of life and increases frequency of depression. Further studies in this area are warranted.

Future research must make use of any existing networks and expertise in the Bangladeshi community, to guide it to ensure that the agenda serves both the healthcare professionals and the Bangladeshi patients with AS. The resulting sense of ownership might lead the Bangladeshi patients to directly communicate their needs in a formal setting in which they are comfortable and familiar with. Services can then be developed to meet those needs.

The age range of the Bangladeshi participants in this study was 23–54 years and a gap has been identified in the literature on the lived experience of AS in older patients (Martindale & Goodacre, 2014). Future studies could explore the experiences of older Bangladeshi patients with AS in order to inform policy and practice.

6.5 Patient and public involvement

Involving patients and members of the public in research design and conduct can increase the relevance of research and improve research quality (Gibson et al. 2012). The UK's national body for patient and public involvement has defined involvement as, research being carried out 'with' or 'by' members of the public rather than 'to', 'about', 'with' or 'for' them (Involve, 2012). A next step following my study will be to find mechanisms that can be used to deliver involvement activities in identification of research priorities, design, informing policy and practice among the Bangladeshi patients with AS. This work is already in progress with the help of NASS. I have shown how I took steps to engage with the Bangladeshi community in the conduct of my study, but more work remains. The gatekeepers were concerned about possible exploitation of

the participants (section 3.7.3) and this is indeed a complex issue. Goberman-Hill et al. (2013) have suggested that in order to reduce potential for exploitation and inequality, researchers should apply and reflect principles of ethical practice as part of design and conduct of patient involvement. More work needs to be done, to allow the Bangladeshi patients with AS to take a more central driving role in research that affects their health and healthcare.

6.6 Strengths and limitations of the study

This interpretive phenomenological study was carried out in an area where little is known with the aim of exploring the phenomenon, ‘the lived experience of health-related quality of life in Bangladeshi patients with AS in the UK’. The study has achieved its aim and as such, the previously ‘unheard voices’ of the Bangladeshi participants have been highlighted. The study will act as a springboard for future researchers using both qualitative and quantitative methodologies. I have offered my interpretation of the experiences of this homogenous group of participants so that the reader can ‘understand better than they otherwise might, by providing them with information in the form in which they usually experience it’ (Lincoln & Guba, 1985, p.120). The inclusion of non-English speaking participants in this study has increased representation and the development of culturally competent health knowledge. I have provided details about how I worked with the Bangladeshi community and with an interpreter for this study, which could be valuable information for future research.

The findings from my study cannot be generalised. According to van Manen (1990) the results of a hermeneutic phenomenological research make no claims as to the generalisability of the knowledge produced, ‘instead, the tendency to generalise may

prevent us from developing understanding that remain focused in the uniqueness of human experience' (p 22). The Bangladeshi participants in my study have their experiences, views and feelings that are unique to them and not necessarily the same as other patients' perceptions of the illness. The aim was to produce an in-depth understanding of the lived experiences of health-related quality of life and the essences attached to the experiences. However, I would argue that they can be transferred to similar contexts (Ricour, 1976, p.298). Ricour asserts that interpretation must always be one that is more likely than any other interpretation. The interpretation rendered in my study was carried out using a perspective from my experiences and understanding of people living with AS such as a nurse and nurse researcher. The interpretation presented is therefore one that I found most probable.

The sample size in qualitative research has some limitations (Sandelowski, 1995). I recruited participants from an Outpatient department and therefore failed to access those patients with AS, who do not seek Western medicine or attend hospital in any form. I recruited no elderly patients (above 60 years) suggesting that the elderly population with AS in the Bangladeshi community have not been accessed and their experiences might be different. This could be a reflection of the demographic presentation of this group in this outpatient department or lack of access of the older patients in this group to healthcare.

I come from an ethnic background although different from the Bangladeshi community. The cultural background of a researcher plays an important role in phenomenological studies. Cultural differences may influence how Bangladeshi patients answer interview questions. I am a nurse in the department where this research was carried out. Therefore, a power dynamic might have affected the responses from the participants. Hofstede (1997) has named the following four dimensions of culture: power distance,

collectivism versus individualism, femininity versus masculinity, and uncertainty avoidance (from weak to strong).

In qualitative research, although researchers may conduct pilot interviews to see how the interview questions solicit answers, every participant is different. It is even more difficult if the participants have not developed language proficiency. On the researcher's part, understanding language and cultural implications takes time to develop. Miller (2003) has cautioned against the danger of changing the meaning of data by the addition of researcher interpretation. I have used interpreters in my study. Conducting interviews with an interpreter was a time-consuming process that came with an added cost. I was mindful during the planning stages that there is less flexibility and spontaneity in this type of interview than in the direct interviewing (Kvale 1996) and some words and concepts commonly used in some languages have no equivalent single-term meaning in English. Issues of validity and equivalence of meaning when using interpreters in interviews have been discussed in the literature (Edwards, 1998; Temple, 2002). Despite these limitations, I collected rich and meaningful data and therefore interpreters can be seen as active partners with the researcher working together with the interpreter as the research instrument.

In a way, I have an existing relationship with the participants as I work in the rheumatology department. This relationship had the potential to influence the participants' responses. However this relationship may have provided a safe environment and the confidence for the participants to share their experiences of AS. This is reflected in the participants' narratives when they were able to express negative experiences.

I attempted to communicate the 'silent voices' of the Bangladeshi participants through their lived experiences, perspectives, feelings and thoughts. The findings therefore

represent my interpretation of the data. Similar to Higgs et al. (2009), I am aware that others might have different interpretations.

6.6 Dissemination of findings

The journey does not end here, however. It is important for me to consider ways in which the findings will be disseminated. I will share my findings with the wider rheumatology community nationally and internationally through publications, and presentations at conferences. I have also started working closely with the National Ankylosing Spondylitis Society in the UK, to highlight the experiences of this group of patients and their needs and how we can find ways to engage and respond to those needs. Findings will also be shared with the Bangladeshi community and primary care teams through different forums in Tower Hamlets. This is to ensure that the ‘silent’ voices of the Bangladeshi patients with AS are heard. Locally, I will present my findings to colleagues in the rheumatology department in the weekly post-graduate meetings. Finally, an opportunity will be taken to present a summary of my findings to the participants as previously indicated in our initial conversations and this will also be a way of showing my gratitude to them for allowing me into their life worlds.

6.7 Personal reflections

My curiosity concerning the Bangladeshi patients and lived experience of health-related quality of life in AS developed through my clinical experience and the realisation that there is a paucity of published research in this area. Interpretation of the findings further revealed the complexities of living with AS and this has led to my acquiring further knowledge about the Bangladeshi participants’ experience of the illness. The use of

interpretive phenomenology in my study has helped me to understand fully, an area that I previously took for granted in my clinical practice. The way in which Bangladeshi patients experience their AS has been reported through their narratives of everyday living. My study has addressed an important and previously under-explored area in health research in the UK. This study has used the participants' accounts of their illness as the main basis for understanding their lived experience of health-related quality of life in AS. It was important to view this experience from their point of view and in their own words.

I was the instrument for obtaining, analysing and interpreting the data in this study. I have therefore gained considerable experience at each stage of this research process from start to finish. Reflexivity has been crucial in terms of how preconceptions have shaped the analytic and interpretation processes. My experience as an advanced nurse practitioner in inflammatory arthritis and my knowledge of the disease and lessons learnt throughout this research process has enhanced my reflexivity. According to Koch (2006) it is impossible to separate these experiences, views and values.

During data analysis my supervisors reviewed the thematic statements and themes derived to ensure that I stayed true to the intentions of the participants' narratives. Identifying the different sub themes and global themes in this study has deepened my understanding of the lived experience of health-related quality of life in Bangladeshi patients with AS. It was an honour and a privilege, but at times painful, to encounter the lived experiences of the Bangladeshi patients with AS. The temptation was always there during the interviews for me to want to revert to my familiar role as a nurse, advocate, counsellor, advisor and teacher. I also felt vulnerable at such times, however there was also the freedom that came from not being constrained by my clinical role. Van Manen (1990) asserts that phenomenological studies often have a transformative effect on the researcher as well as the participant. The research experience was rewarding for me and

it reaffirmed Schmidt's (2005) assertions of what it is to be human for both myself as the researcher and my participant as the researched.

Through this research process, not only did I come to know more about what it is like to be a Bangladeshi patient with AS. I also learnt a lot about myself as a human being, a woman, a researcher and a member of an ethnic minority group. The narratives from the participants held immense value both for myself and the participants. I had previously taken this for granted and did not consider it an important aspect in the therapeutic relationship in my role as a nurse practitioner. It is through this journey with the Bangladeshi participants with AS that I have found answers to previously unanswered questions in terms of their lived experience of AS.

6.8 Conclusion

Through this study I explored the lived experience of health-related quality of life in Bangladeshi patients attending an outpatient department in an inner London borough. The participants' narratives of their lived experience reflected, and in some ways shared commonalities with members of the wider community with AS, on how people with AS adapt to everyday life situations, on the exploration of the negative and positive implications of AS and the journey to diagnosis of people with AS. I was deeply moved by how the narratives provided by the Bangladeshi participants captured the lived experience of AS and their accounts were extremely enriching. This thesis has demonstrated how a group of Bangladeshi patients with AS reported their lived experience of health-related quality of life from their own perspective. Through the lived experience, they attempted to make sense of the onslaught of the AS, how to manage the symptoms and make adjustments in order to accept the new order in their lives; and how their culture influenced the way in which they found control and

adjusted to the changes. I have made an attempt to transform van Manen's (1997) lived experience into 'textual expression of its essence' (p.36), in order for the reader to gain an understanding of each participant's journey with the illness. Although I have revealed the meanings embedded in the human experience and brought the phenomenon to light for the Bangladeshi participants, I am mindful that the 'richness and depth of lived experience can never be fully appreciated. This is because it is situated within the totality of life, rather than a decontextualized, lived experience', van Manen 2007 (p.16). Nevertheless, the narratives have enabled me to understand the meaning of the experience from the participants' perspective. The cultural practices and beliefs of the Bangladeshi participants may contribute to the way they perceive and respond to the AS. My study findings suggest that based on their cultural identity, the Bangladeshi patients hold onto certain beliefs which are based on the roles they are brought up to fulfil.

I took the opportunity to explore the lived experience of HRQOL in Bangladeshi patients with AS in the UK, as this area has not been investigated previously. As such I have offered the reader my phenomenological interpretation based on the narratives of the 20 Bangladeshi participants. It is beyond the scope of this study neither is it the intended goal to generalise findings to Bangladeshi patients in other deprived parts of London, the wider Bangladeshi community and the rheumatology outpatient clinics in the UK. However certain principles from this study may be extracted regarding how the Bangladeshi participants and other populations experience AS. The work does not end here. There is scope for an ongoing conversation that will hopefully result in improving the experiences of HRQOL in Bangladeshi patients with AS.

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Appendices

Appendix 1. ASAS core sets for assessment in Ankylosing Spondylitis

| Domain | CR | Core set SMARD-PT | DC-ART | Instruments |
|---|----|-------------------|--------|--|
| Patient global assessment | x | x | x | VAS in the last week |
| Spinal pain | x | x | x | VAS pain at night, average in the last week, and VAS, average in the last week |
| Spinal mobility | x | x | x | VAS morning stiffness |
| Spinal stiffness | x | x | x | Chest expansion, modified Schober index, and occiput to-wall distance |
| Physical function | x | x | x | Bath Ankylosing Spondylitis Functional Index, or Dougados Functional Index |
| Peripheral joints and entheses | x | | x | Number of swollen joints; no preferred instrument for enthesal disease |
| Fatigue | | | x | No preferred instrument |
| Acute phase reactants | x | | x | ESR |
| Imaging | | | x | AP and lateral x-rays lumbar spine, lateral cervical spine, pelvis (SI and hip joints) |
| CR: clinical record keeping; DC-ART: disease-controlling anti-rheumatic therapy; SMARD: symptom modifying anti-rheumatic drugs; PT: physical therapy. VAS: Visual analogue scale; ESR: Erythrocyte sedimentation rate; AP: antero-posterior; SI: sacroiliac | | | | |

Appendix 2 London South Bank University approval

16th March 2016

Dear Sir

Title of study: Health-related Quality of Life Experiences of Bangladeshi patients with Ankylosing Spondylitis

Name of applicant: Deborah Matengerwa Chagadama

LONDON SOUTH BANK UNIVERSITY is willing to take on the role of sponsor in relation to this research project, to be carried out by Deborah Matengerwa Chagadama who is currently a student studying for Professional Doctorate in Nursing. The research study is part of that award. The academic supervisors for the project are Professor Lesley Baillie and Dr Calvin Moorley.

I confirm that indemnity will be in place covering this project the details of the cover are in the attached statement of insurance cover.

All correspondence for the sponsor should be marked for the attention of Professor Lesley Baillie.

Yours sincerely,

Professor Lesley Baillie Professor of Clinical Nursing Practice

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Professor Lesley Baillie School of Health & Social Care T: 020 7815 6797 F: 020 7815 8490 Email: bailli2@lsbu.ac.uk

Appendix 3 – HRA Research Ethics Approval



Health Research Authority

National Research Ethics Service

London - Queen Square Research Ethics Committee

HRA NRES Centre Manchester
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Please note: This is the favourable opinion of the

REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Ms Deborah M Chagadama
Lead Nurse Rheumatology
Barts Health NHS Trust
Department of Rheumatology
Mile End Hospital
Bancroft Road
E1 4DG

Dear Ms Chagadama

| | |
|-------------------------|---|
| Study title: | Health-related Quality of Life Experiences of Bangladeshi patients with Ankylosing Spondylitis |
| REC reference: | 16/LO/1098 |
| Protocol number: | N/A |
| IRAS project ID: | 202906 |

The Research Ethics Committee reviewed the above application at the meeting held on 16 June 2016. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Rachel Heron, nrescommittee.london-queensquare@nhs.net Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

A Research Ethics Committee established by the Health Research Authority

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

You and Dr Baillie were welcomed to the meeting.

Social or scientific value; scientific design and conduct of the study

The Committee agreed that the study had social and scientific value – there was a gap in the knowledge around the experience of the Bangladeshi population with this condition. The Committee praised the level of patient and public involvement in the design of the study.

The Committee asked about interpreters for the study. *You advised that the funding was from the National Ankylosing Spondylitis Society.* The Committee asked if you had considered that concepts would be expressed differently in Bengali to in English. *You advised that there would be a period of training with interpreters to ensure that misunderstandings were minimised.*

The number of participants (stated as 10-15) was clarified – 15 was the intended number.

Recruitment arrangements and access to health information, and fair participant selection

The Committee noted that recruitment was via out-patient clinics; participants would have a week to decide whether they wished to participate.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

The Committee asked what would happen to the data collected during the interviews if the participant decided to withdraw. *You advised that you would continue to use this data as per consent, unless specifically asked not to.*

The Committee asked you to describe the interview arrangements. *You explained that the interviews would take part in your office, which was in a private area outside the outpatients department. You clarified that you would be alone with participants unless they needed an interpreter. You would place a sign on the door (stating 'interview in progress') to avoid disruption.* The Committee asked how you would ensure your own personal safety.

You discussed the risk to participants of becoming distressed, and how you could signpost participants for support if they needed it. In terms of your own safety you advised that you could access hospital security. The Committee advised that you should let someone know when you were about to begin an interview, and tell them when you expected to finish, in order to ensure your own safety (lone worker policy). You agreed to this.

In answer to a query from the Committee, you confirmed that you would not be able to pay expenses to participants.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

| | |
|-------------------|---|
| 16/LO/1098 | Please quote this number on all correspondence |
|-------------------|---|

With the Committee's best wishes for the success of this project.

Yours sincerely



Signed on behalf of
Dr Eamonn Walsh
Chair

E-mail: nrescommittee.london-queenssquare@nhs.net

London - Queen Square Research Ethics Committee

Attendance at Committee meeting on 16 June 2016

Committee Members:

| <i>Name</i> | <i>Profession</i> | <i>Present</i> | <i>Notes</i> |
|--------------------------|--|----------------|--------------|
| Dr Yogi Amin | Consultant in Neuroanaesthesia & Neurocritical Care | No | |
| Miriamtha Dahdal | Teaching Assistant | No | |
| Dr Simon Eaton | Senior Lecturer in Paediatric Surgery and Metabolic Biochemistry | No | |
| Miss Sarah Gregory | Clinical Research Officer | Yes | |
| Dr Katie Harron | Statistician | Yes | |
| Dr Khalil Hassanally | GP | No | |
| Dr Ciaran Scott Hill | Neurosurgery Speciality Registrar | Yes | |
| Mrs Jenny Johnson | Charity Trustee | No | |
| Eleanor Rose Lee-Millais | Nurse | No | |
| Mrs Claire Reynolds | Radiotherapy Radiographer | No | |
| Miss Sheetal Sumaria | Pharmacist | No | |
| Dr Eamonn Walsh | Lecturer | Yes | |
| Mr Jonathan Watkins | Social Worker | No | |
| Miss Zalika Xavier | Vaccine Sales Representative | No | |

Also in attendance:

| <i>Name</i> | <i>Position (or reason for attending)</i> |
|-----------------|---|
| Ms Rachel Heron | REC Manager |

Appendix 4 – Trust Research & Development Approval



FINAL R&D APPROVAL

03 August 2016

Debbie Chagadama
Lead Nurse/Matron
Department of Rheumatology
Mile End Hospital
Bancroft Road,
E1 4DG

Joint Research Management Office
Queen Mary Innovation Centre
5 Walden Street
London
E1 2EF

Tel: 020 7882 7260
Fax: 020 7882 7276
Email: Sponsorsrep@bartshealth.nhs.uk

Dear Debbie,

Protocol: Health-related Quality of Life Experiences of Bangladeshi patients with Ankylosing Spondylitis.

ReDA Ref: 011407
CSP: N/A
REC Ref: 16/LO/1098

I am pleased to inform you that the Joint Research Management Office for Barts Health NHS Trust and Queen Mary University of London has approved the above referenced study and in so doing has ensured that there is appropriate indemnity cover against any negligence that may occur during the course of your project. Approved study documents are as follows:

| Type | Version | Date |
|--|---------|-------------|
| Protocol | 1 | 16 May 2016 |
| Participant Information Sheet | 1 | 16 May 2016 |
| Participant Consent Form | 1 | 16 May 2016 |
| Participant Questionnaire | 1 | 16 May 2016 |
| Summary CV for student | 1 | 16 May 2016 |
| Summary CV for Supervisor | 1 | 16 May 2016 |
| Summary CV for Supervisor (2 nd) | 1 | 16 May 2016 |

Please note that all research within the NHS is subject to the Research Governance Framework for Health and Social Care, 2005. If you are unfamiliar with the standards contained in this document, or the BH and QMUL policies that reinforce them, you can obtain details from the Joint Research Management Office or go to:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962

You must stay in touch with the Joint Research Management Office during the course of the research project, in particular:

- If there is a change of Principal Investigator
- When the project finishes
- If amendments are made, whether substantial or non-substantial

This is necessary to ensure that your R&D Approval and indemnity cover remain valid. Should any Serious Adverse Events (SAEs) or untoward events occur it is **essential** that you inform the Sponsor within 24 hours. If patients or staff are involved in an incident, you should also follow the Trust Adverse Incident reporting procedure or contact the Risk Management Unit on 020 7480 4718.

We wish you all the best with your research, and if you need any help or assistance during its course, please do not hesitate to contact the Office.

Yours sincerely



Gerry Leonard, Head of Research Resources

Copy to:

Appendix 5 - Consent form

Title of Study: Health-related Quality of Life Experiences of Bangladeshi patients with Ankylosing Spondylitis.

Name of Participant: _____

Please initial to consent in boxes:

- I have read the attached information sheet on the research in which I have been asked and agree to participate and have been given a copy to keep. I have had the opportunity to discuss the details and ask questions about this information

- The Researcher has explained the nature and purpose of the research and I believe that I understand what is being proposed
- I understand that my personal involvement and my particular data from this study will remain strictly confidential. Only researchers involved in the study will have access.
- I have been informed about what the data collected will be used for, to whom it may be disclosed, and how long it will be retained
- I have received satisfactory answers to all of my questions
- I understand that I am free to withdraw from the study at any time, without giving a reason
- I consent to have the interview audio recorded using a digital recorder and transcribed
- I consent to having anonymised direct quotations from the interviews used in publications
- I consent to have an interpreter present during the interview if needed
- I hereby fully and freely consent to participate in the study which has been fully explained to me

Participant's Name :(Block Capitals)

Participant's Name: Signature

Date

As the Researcher responsible for this study I confirm that I have explained to the participant named above the nature and purpose of the research to be undertaken.

Researcher's Name: Debbie Chagadama

Researcher's Signature:

Date

Appendix 6 NASS patient advisor letter of appreciation

Department of Rheumatology
Barts Arthritis Centre
Mile End Hospital
Bancroft Road
E1 4DG
Tel: 020 8223

8859

Main Switchboard: 020 7377 7000
Fax: 020 8223 8807

1st March 2016

Dear Mr Ali
NASS Group (Physiotherapy Dept)
Mile End Hospital
Bancroft Road
E1 4DG

Dear Mr Ali,

I would like to thank you for your generous time and involvement as a patient advisor in my study.

Your collaboration with me has been invaluable by bringing in your experience of living with Ankylosing Spondylitis and enabling me to get a better understanding of the condition through the lens of your experience.

Your views, experiences and direct input have helped in guiding the design and delivery of the study: Health-related Quality of Life Experiences of Bangladeshi Patients with Ankylosing Spondylitis. You have helped in making sure the research is relevant to the patients. Thank you for reviewing the study documents and giving suggestions for pseudonyms appropriate for my participants. This in turn has been helpful in improving the quality of the research study and increasing the potential of the study findings to impact patient care and services positively.

I do hope you have enjoyed collaborating with me on this project as much as I have with you and look forward to working with you again.

Thank you

Yours sincerely,

Debbie Chagadama

Appendix 7 – Departmental access approval



Department of Rheumatology

Barts Arthritis Centre

Mile End Hospital

Specialist Rheumatology Clinics:

Adolescent Rheumatology/ High Risk Pregnancy

Ankylosing Spondylitis

Inflammatory arthritis

Connective Tissue Disease

Inflammatory arthritis

Osteoporosis/Bone Disease

Sports Injuries

Tel: 020 8223 8859
Main Switchboard: 020 7377 7000
Fax: 020 8223 8807

‘I confirm that project: Lived experience of health-related quality of life in Bangladeshi patients with ankylosing spondylitis, Version 1 Date: 05/05/2016 can be undertaken by the Rheumatology department and can be accommodated in terms of space, resource and facilities and that the department can see no reputational risk for this project being undertaken by the department’

Print Name:

D. PYNE

Signature:

Job Title:

CONSULTANT RHEUMATOLOGIST / CLINICAL LEAD

Date:

5/5/16

Appendix 8 RCN International research conference abstract 217

Paper 4 Accessing the ‘hidden voices’: Experiences of recruiting and interviewing within the Bangladeshi community with Ankylosing Spondylitis

Debbie Chagadama, Lead Nurse Rheumatology, Barts Health, London, UK

Background

There are longstanding calls for research to give a voice to and empower minority groups (Nichols-Casebolt and Spakes 1995). However, researchers continue to struggle to access, engage and retain participants from ethnic minority groups, resulting in exclusion from research (Hussain-Gambles et. al 2006). Reasons include: a lack of English language proficiency, mistrust of research, healthcare providers’ lack of attention to cultural factors, little awareness of health research, cultural beliefs prohibiting participation, and gate keepers (health professionals and key community figures) restricting access (Sheikh et.al 2009). This study explored the lived experiences of health-related quality of life in Bangladeshi patients with Ankylosing Spondylitis (AS), which is a complex systemic rheumatologic condition, often resulting in severe disability. There has been little research into the difficulties faced by Bangladeshi people with AS in the United Kingdom.

Aim

This paper will discuss experiences of preparing for, and conducting, a study using in-depth interviews with Bangladeshi patients with AS.

Methodological discussion

Engagement and building trust with community gatekeepers was essential and they also acted as cultural mediators, helping me to become more culturally competent. All study documentation was translated to Bengali and interpreters were incorporated as research partners. Despite the potential challenges of recruiting from this ‘hard-to-reach’ group, I successfully managed to build trust and develop a rapport, collecting rich and meaningful data from 20 men and women, aged 25-54 years, over 7-months. Six interviews were conducted in Bengali, with interpreters; the rest were in English.

Conclusion:

Participants expressed that they had never had the opportunity to relate their experiences before and spoke openly and in depth about struggling to gain a diagnosis, how the condition affected their lives and how they were managing. Through this research, the ‘hidden voices’ of the Bangladeshi patients are being heard and will inform healthcare for this population.

Funding: Barts Health and National Ankylosing Spondylitis Society

References:

Hussain-Gambles, M. Atkin, K. & Leese, B. (2006) South Asian participation in clinical trials: the views of lay people and health professionals. *Health Policy*; 77:149- 65

Nichols-Casebolt, A. & Spakes, P. (1995) Policy research and the voices of women. *Social Work Research*, 19(1): 49-55

Sheikh, A., Halani, L. Bhopal, R. et. al (2009) Facilitating the recruitment of minority ethnic people into research: Qualitative care study of South Asians and asthma. *PLoS Med*; 6: e1000148

Appendix 9- Participant Information Sheet

Health-related quality of life Experiences of Bangladeshi patients with Ankylosing Spondylitis.

What is the purpose of the study?

The aim of this study is to find out your experiences of what it is like to be a member of the Bangladeshi community living with Ankylosing Spondylitis. There is limited information about the health-related quality of life experiences of Bangladeshi patients with Ankylosing Spondylitis. This research is being carried out to find out more about this.

Why have I been chosen?

We are inviting you to take part in this study as you are a member of the Bangladeshi community living with Ankylosing Spondylitis. In total 20 people will be included in the study and they will be interviewed about their experiences.

Do I have to take part?

There is no pressure for you to take part in the study. It is up to you to decide whether or not to take part. If you do, you can keep this information sheet and you will be asked to sign a consent form. You will also have a chance to talk to the person carrying out the research so that they can give you more information and answer any questions you might have. An interpreter will be available if you need this to help with translation. You are still free to withdraw from the study at any time, without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the care that you receive in the department.

What will be expected of me if I take part?

If you are willing to take part, you will be invited to come to the outpatients' department for a one off face-to-face interview lasting no more than one hour. The interview will be arranged at a date and time convenient to you. You do not need to bring anything to the interview. During the interview, the researcher will ask you questions about living with Ankylosing Spondylitis. If you agree, she will record the interview so there is a good record, as well as taking notes.

What are the possible disadvantages and risks of taking part?

It is not expected that you will be disadvantaged or suffer any harm from this study. However, you may find it uncomfortable to talk about your experiences of this condition. If you feel upset, the interview will be stopped and you are free to withdraw from the research. I will give you information about different types of support that are available to you and how to access them should you need this.

What are the benefits of taking part?

It is unlikely that you will gain any personal benefit from taking part in this research. However, the information you share will help inform our practice by gaining a better understanding of patients' needs. Some people may benefit from discussing their experiences.

What happens if something goes wrong?

You can withdraw from the study and not have your information included, at any time up to the completion of the study.

Any complaints about the conduct of the study may be discussed with the researcher's supervisor. Their name and contact details are listed in this leaflet. You can also complain to the London South Bank University, 103 Borough Road, London, SE1 0AA Telephone: 0207 815 6797.

Will my taking part in this study be kept confidential?

All information received from you during the study will be handled in a confidential manner and stored in a locked filing cabinet and on a password protected computer (encrypted), in an office locked when not in use. Only the researcher and supervisor will access the information. This information will be held until 2020, after which it will be destroyed by the researcher. The reports from the study will not include any information that will identify you. Direct anonymised quotes will be used in the write up. Your name will not be used anywhere.

What will be done with the results of the research study?

The results will be included in a report, presented to the Trust and conferences, and published in journal articles.

Who has reviewed the study?

This study has been reviewed by the supervisors at the School of Health and Social Care London South Bank University, as well as colleagues in the rheumatology department.

Contact for further Information:

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions.

Name: Debbie Chagadama email: Debbie.chagadama2@bartshealth.nhs.uk

Telephone: 02082238868 **Mobile:** 07957449387

If you wish any further information regarding this study or have any complaints about the way you have been dealt with during the study or other concerns you can contact: Professor Lesley Bailie, who is the Academic Supervisor for this study, at London South Bank University, 103 Borough Road, London, SE1 0AA Telephone: 0207 815 6797, baillii2@lsbu.ac.uk

Finally, if you remain unhappy and wish to complain formally, you can contact the Patient Advice and Liaison Service (PALS), Central Complaints Team, 3rd Floor, 9 Prescott Street, London E1 8PR. Telephone; 02035942040. Email: pals@bartshealth.nhs.uk

Appendix 10 - Potential Participant Contact card

Health-related quality of life Experiences of Bangladeshi patients with Ankylosing Spondylitis.

I have given permission to my care provider, Dr -----/Nurse -----
----- for you to contact me. I am interested in learning more about this study.
Please contact me using the following information:

Name:

Telephone:

Email contact (optional):

Best time and day to call:

Appendix 11 – HRA Approval for minor Amendment

Dear Debbie,

| | |
|--|---|
| IRAS Project ID: | 202906 |
| Short Study Title: | Experiences of Health-related Quality of Life in Bangladeshi patients |
| Date complete amendment submission received: | 06/02/17 |
| Amendment No./ Sponsor Ref: | NSA 1 |
| Amendment Date: | 01/02/17 |
| Amendment Type: | Non-substantial |

Thank you for submitting the above referenced amendment. In line with the [UK Process for Handling UK Study Amendments](#) I can confirm that this amendment has been categorised as:

- **Category A** - An amendment that has implications for, or affects, ALL participating NHS organisations

You should now provide this email, together with the amended documentation, to the research management support offices **and** local research teams at your participating NHS organisations in England.

If you have participating NHS organisations in Northern Ireland, Scotland and/or Wales, you should communicate directly with the relevant research teams to prepare them for implementing the amendment, as per the instructions below. You do not need to provide this email or your amended documentation to their research management support offices, as we will pass these to the relevant national coordinating functions who will do this on your behalf.

Subject to the three conditions below, you will be able to implement the amendment at your participating NHS organisations in England **35 days after you notify them of the amendment**. A template email to notify participating NHS organisations in England is provided [here](#).

Subject to the same three conditions, you will be able to implement your amendment at participating NHS organisations in Northern Ireland, Scotland or Wales on **[Insert date that is 35 calendar days after validation date]**.

- You may not implement this amendment until and unless you receive all required regulatory approvals, including REC favourable opinion where applicable, (for participating organizations in England, please see 'Confirmation of Assessment Arrangements' below). You should provide regulatory approvals to the research management support offices and local research teams at your participating NHS organisations in England, plus to local research teams at any participating NHS organisations in Northern Ireland, Scotland or Wales*.
- You may not implement this amendment at any participating NHS organisations which inform you within the 35 day period that they require additional time to consider the amendment, until they notify you that the considerations have been satisfactorily completed.

- You may not implement this amendment at any participating NHS organisation that informs you that it is no longer able to undertake this study.

Note: you may only implement changes described in the amendment notice or letter.

If you receive required regulatory approvals (for participating organizations in England, please see 'Confirmation of Assessment Arrangements' below) after the 35 days have passed, you may then immediately implement this amendment at all participating NHS organisations that have not requested additional review time, or are no longer able to undertake this study.

There is no need for you to receive a letter of confirmation from the participating organisation that the amendment can be implemented, as the intended date of implementation is communicated through the above process. However, you may be able to implement this amendment ahead of the 35-day deadline, if all necessary regulatory approvals are in place and the participating organisation has confirmed that the amendment may be implemented ahead of the 35 day date.

* Where the study involves NHS organisations in Northern Ireland, Scotland or Wales, the HRA will forward regulatory approvals to the relevant national coordinating function to distribute to their research management support offices.

Participating NHS Organisations in England – Confirmation of Assessment Arrangements

Further to the details above, I can confirm that no HRA assessment of this amendment is needed.

- If this study has HRA Approval, this amendment may be implemented at participating NHS organisations in England once the conditions detailed in the categorisation section above have been met
- If this study is a pre-HRA Approval study, this amendment may be implemented at participating NHS organisations in England that have NHS Permission, once the conditions detailed in the categorisation section above have been met. For participating NHS organisations in England that do not have NHS Permission, these sites should be covered by HRA Approval before the amendment is implemented at them, please see below;
- If this study is awaiting HRA Approval, I have passed your amendment to my colleague in the assessment team and you should receive separate notification that the study has received HRA Approval, incorporating approval for this amendment.

Please do not hesitate to contact me if you require further information.

Kind regards

Ali Hussain
Amendments Co-ordinator



Health Research Authority

HRA, Ground Floor, Skipton House, 80 London Road, London, SE1 6LH

E: hra.amendments@nhs.net

www.hra.nhs.uk

The HRA is keen to know your views on the service you received – our short feedback form is available [here](#)

From: Ornelas, Safia (RGC) Development Administrator
Sent: 08 February 2017 14:58
To: Chagadama, Debbie
Cc: 'baillil2@lsbu.ac.uk'
Subject: Ankylosing Spondylitis Minor Amendment 1 BARTS HEALTH and QMUL
Acknowledgment
Importance: High

Dear Ms Chagadama,

Study: Health-related Quality of Life Experience of Bangladeshi patients with Ankylosing Spondylitis.

ReDA: 011407

Amendment: Minor amendment 1 – increase in participants

Please accept this email as amendment acknowledgment for the above study Minor amendment 1

This can be implemented

Thank you

Kind Regards

Safia Ornelas

Research Management and Governance Officer

Joint Research Management Office

Barts Health NHS Trust

QM Innovations Centre

5 Walden Street

Whitechapel

London

E1 2EF

Appendix 12 - Peer Review

**Department of Rheumatology
Barts Arthritis Centre
Mile End Hospital
Bancroft Road
E1 4DG
Tel: 020 8223 8859
Main Switchboard: 020 7377 7
Fax: 020 8223 8807**

To whom it may concern

RE: Peer Review

'I confirm that I have read and understood Experiences of Health-related Quality of Life in Bangladeshi Patients with Ankylosing Spondylitis, **Version1 Date: 16th May 2016** and feel that the project objectives are clear, that the project has merit in its rationale and methodology and is of value'.

Print Name:

Ali Jawad

Signature:



Job Title:

Professor of Rheumatology

Date:

12/5/16

Appendix 13 - Interview Topic Guide

Introduction

Thank you for agreeing to take part in this study and be interviewed. This interview will take no more than 1 hour to complete. Please feel free to stop at any time during the course of the interview. The aim of this research is to explore your experiences of Ankylosing Spondylitis and how it affects your life.

Demographic details:

First can I collect a few details about you?

1. Age
2. Employed/Unemployed/Retired
3. Dependents

Warm up – How long have you been living with AS?

Q1.Can you share with me what it felt like when you received your diagnosis of ankylosing spondylitis?

Explore responses.

Main Interview

Q2. Can you tell me about your illness in as much detail as possible?

Prompts:

1. Functional/Physical effects
2. Emotional effects of illness
3. Social effects of illness

Treatment

Q3. Can you describe your experiences of the treatment for this illness so far?

Explore responses.

Day to day living

Q4.Can you share with me what a typical day is like for you living with AS?

Prompts

1. Is there part of the day that is better for you?
2. Have you had to change how you plan your day based on the AS?

Ending the interview

I have no further questions. Is there anything else you would like to add or share about your experiences of AS besides what we talked about? (Gives additional opportunity to deal with any additional or other worrying issues). Thank you once again for taking part in the interview.



Reflections on working with an interpreter when conducting qualitative in-depth interviews

Debbie Chagadama

Barts Health NHS Trust, Department of Rheumatology, London, United Kingdom

Background/Context

This paper will provide a reflective review of the experience of conducting qualitative in-depth interviews through an interpreter, with Bangladeshi people who are living with Ankylosing Spondylitis. The complexities of using interpreters in research (Edwards 1998) have often led to the exclusion of people whose preferred language is not English. However, there is little guidance available on working with interpreters when conducting research interviews (Squires 2008). I had no previous experience of this process and being from an ethnic minority background (though a different one from the participants), I was aware there are not always equivalent words between languages. I was also concerned about feeling a lack of control in the interview. According to Kvale (1996: 147) the ‘interviewer is him or herself the research instrument’, therefore the interpreter’s role needs consideration too.

Preparation and process

The same Bengali interpreter assisted throughout and she had previous experience of conducting research interviews as a health advocate in a community social work team. The preparation included selection of the interpreter, building a relationship with the interpreter, clarifying the interpreter’s role, agreeing the style of interpretation (active or passive), training and preparation for the interpreter, practicalities (e.g. seating arrangements during the interview) and agreeing the process for reflection. All study documents including the interview topic guide were translated to Bengali and the interpreter found them clear and easy to use. Reflective review following each interview allowed the interpreter to raise any difficulties in translation, identify any other problems and consider solutions.

Conclusion:

Despite the complexities of interviewing with an interpreter, I collected rich and meaningful data and therefore interpreters can be seen as active partners with the researcher working together with the interpreter as the research instrument.

References:

Edwards, R. (1998) A critical examination of the use of interpreters in the qualitative research process *Journal of Ethnic Migration Studies* 24: pp197-208

Kvale, S. (1996) *Inter Views. An Introduction to Qualitative Research Interviewing*. Sage Publications. Thousand Oaks, London.

Pitchford, E. & van Teijlingen, E. (2005) International public health research involving interpreters: a case study from Bangladesh. *BMC Public Health* 5, pp71 – 7

Squires, A. (2008) Language barriers and qualitative nursing research: methodological considerations. *International Nursing Review*, 55, pp265-73

Appendix 15 – NASS Research Grant

NATIONAL ANKYLOSING SPONDYLITIS SOCIETY

4 ALBION COURT, HAMMERSMITH, LONDON W6 0DT

TEL 020 8741 1515 • ADMIN@NASS.CO.UK



Ms Debbie Chagadama
Barts Arthritis Centre
Department of Rheumatology
Mile End Hospital
Bancroft Road
E1 4DG

24 May 2016

Dear Ms Chagdama

Thank you for your recent application to the NASS Research Fund.

After careful consideration the NASS Medical Advisory Board and NASS Council of Management have decided that your application has been successful.

Project title: Health-related Quality of Life Experiences of Bangladeshi patients with Ankylosing Spondylitis

Grant amount requested: £2,290.95

Grant awarded: £2,290.95

I have enclosed our Terms and Conditions for your consideration. If you agree to adhere to these, please sign and return 2 copies to me by **Friday 10 June**.

We look forward to working with you on this project.

Yours sincerely

Debbie Cook
Chief Executive

Appendix 16 Iyaz narrative via interpreter

Researcher (directing question to participant): Can I start by asking you how long you have been living with ankylosing spondylitis?

Interpreter (following consultation with participant): He says he has had back pain for 16years but he was diagnosed 12years ago. He went to his GP for 4 years with severe back pain and stiffness. He was being given pain killers and these were not helping. He says he had to beg to get a referral to see the specialist. He was then referred to Rheumatology where he had many tests. He had blood tests and x-rays and he was told he has ankylosing spondylitis. He says before coming to rheumatology the GP diagnosed him with arthritis.

Researcher (directing question to participant): Can you share with me what it felt like when you received your diagnosis of ankylosing spondylitis?

Interpreter (following consultation with participant): He says on one side he feels indifferent about his situation. He does not understand much about the condition and he does not want to know. Initially he thought there was a cure for it but now he is getting round to the idea that it is there for life. He now accepts what Allah has given him. He says when he received his diagnosis there was no information about what it is and how to eh cope with it.

On the other side he says he feels angry towards the system. In fact, he says he is bitter at everyone so he isolates himself. He does not like it when people focus on his illness.

Researcher (directing question to participant): Can you explain why you feel angry and bitter?

Interpreter (following consultation with participant): He says he feels angry about the uncertainties that come with the illness. He mentions mainly to do with the symptoms and treatments. There is no routine coz the illness is like that. He says he can't plan anything. When he got his diagnosis, he was worried about how long the things would remain uncertain and what his life would be like from then on. He feels restricted by the illness and he says in a way he has become a burden to his family.

Appendix 18 Ullah transcript

Ullah, Interview 05/12/2016

Duration: 30minutes34s

Employed & Single

Thank you for agreeing to be interviewed. The interview will take no more than an hour and please feel free to stop at any time during the course of the interview. I would like to explore your experiences of Ankylosing Spondylitis and how it affects your life. Can I start by asking you how long you have been living with Ankylosing Spondylitis?

Ullah: Eh at the age of 22 and I am 25 now. So, eh at the age of 22 I came back from abroad, holiday and I completely seized up just like that no warning with a lot of lower back pain.

Can you share with me what it felt like when you received your diagnosis of AS?

Ullah: Now, I used to work out in the gym a lot, keeping fit and I just thought it's probably not my spine and I just said I will rest whatever. Now things got gradually worse. The pain was I mean, it was in my lower back and it was spreading so the area of pain got bigger. Anyway, I left it for another 4 to 5 months and I was just taking pain killers and this and that. And then I went to the GP after a couple of months and I told my GP 'I am getting a lot of pain, this and that. I think I have slipped a disc'. That's what came out of my mouth and he said 'take some pain killers and I will send you for an MRI'. After a month's time I came back from the MRI scan and he goes 'nothing wrong there, you are fine. This is good news'. I could not understand what was good about it coz my situation was getting worse. Then I thought 'right I think I should go see someone different eh and that time I had started a new job at a BUPA insurance project so Dr (name) he looked at me he looked at my symptoms and he said 'right I think you have potentially ankylosing spondylitis' now remember I had to go see him privately at the (name of private hospital) and from first appointment he thought I had ankylosing spondylitis. I was relieved to be getting somewhere. He sent me for MRI, he said he confirmed and he believed I had it, the ankylosing spondylitis.

So how did you feel at this point?

Ullah: Yeh 'you are fine' he said. 'Just carry on taking the pain killers and you will get better'. I was disappointed coz this is not what I wanted to hear. I wanted to know my problem. My main question to him was 'I like to lift weights and stuff so even though I am having these symptoms is it okay'. He goes like 'that's fine, lift your weights just keep the correct posture and stuff. Your back is not in a bad way. Not like you think'. I think before I went to seek a second opinion privately with Dr (name) when I went to my GP and stuff I also did a bit of research myself, yeh the only reason I knew I had ankylosing spondylitis was because of my eye condition. This came first. I have uveitis and it says on the ankylosing NHS website, it says people with AS sometimes suffer

from uveitis and I was getting regular episodes of this, and I just thought, 'right I must have this condition'.

This is an interesting point please tell me more?

Ullah: I just said to myself 'I must have something like this' and that's what prompted me to seek a second opinion. So that actually helped me in a way, searching things for myself. There is another experience that I will share with you. I went to the dentist just for a check-up and as I was walking to the chair she asked if I had back pain. You know every time when I walk I try to be normal so this was a surprise. She is a Bengali dentist. She asked me 'have you got a back problem?' and I am like 'yeh I have ankylosing Spondylitis which causes inflammation'. She nodded, I don't know if she knew what it was but she nodded and then at the end before I was leaving she said 'if you are having treatment here fair enough but all I can tell you to do is explore, explore the treatment' that's the only thing she said.

That's interesting

Ullah: Yeh I think what she meant by that is fair enough there is treatment in the United Kingdom but ehm you might wanna look elsewhere. Why she said that I don't know. I don't know if she knows what the condition is but I know some people from my culture don't trust uhm western medicine. It got me thinking about you know complementary treatments. She is my dentist and I trust her opinion. So, I tried other things. To tell you the truth that's why it took me a while to come for the anti-TNF treatment. I wanted to explore other things.

Can you tell me more about the treatments you have had for your condition from the time you were diagnosed?

Ullah: So, the doctor at the private hospital, he tried me with methotrexate or some sort of suppressant drug something he said is given to cancer patients I believe, that was at the private hospital. Eh that didn't work and then he basically said 'right what you need is anti-TNF treatment, but it will not be possible for you to get it privately' So here I am thinking finally I have a name for my symptoms but I can't get the treatment, so what next? So, he said he was going to refer me to an NHS hospital to Professor (name) and so a year ago I was referred to this department for specialist care.

I have tried many treatments. In fact, I am taking 2g of ibuprofen and 6 tablets of ibuprofen. That's how I managed to come today. Without ibuprofen it would not be possible. The ibuprofen minimises the pain but it is always there. The pain is always there but I am more comfortable because I took it 2hours before coming here. It will wear off in another 2 hours and I will take another dosage that's the cycle. For my uveitis they have me steroid drops. The inflammation in my eye was really bad. Obviously, steroids are for a short term, but when I have steroids I feel normal again, I feel on top of the world. When I come off the steroids things get worse. I know these treatments have lots of side effects I started getting rashes, acne and spots all over eh I

was experiencing all these. I came off them immediately. They were literally for short term, to quickly counter the inflammation coz it was really bad.

I can't get up from a chair without holding onto the arm rest, I can't I can't do that (trying to get up from chair). The drugs work 10-20%, the rest is diet and exercise. The one thing no one has ever mentioned to me is an anti-inflammatory diet. I mean I eat a lot of lamb? I don't know if that's a good thing? I guess I will just have to do a search on this, that's my next thing.

Can you tell me about your illness in as much detail as possible – please explain in much detail how the condition affects you on a day to day basis?

Ullah: I carried on and things just got worse. I just didn't think anything was wrong coz my GP told me I was completely fine. So why would I worry? Things were slowly progressing; my flexibility was going out the window and I was limping more often. There were times when you see how sometimes there is good period and there is bad period, I was having a lot of bad periods. There were times when I, the first thing I noticed I couldn't bend down and pick stuff up. If I do bend it has to be at the hip eh you see those things that normally you would expect not to struggle with. When I saw the Professor in this department he did more tests even though I had MRI privately, he sent me for chest x-ray as well. He sent me for quite a few tests. Professor (name) actually told me a lot of things. But I think a lot of times when I come here regardless of what I am told, I only understand the condition based on what I am feeling, so my spine my hip my shoulders, stiffness this is what I understand. I know it's an autoimmune disorder where eh my body is attacking the tissues, I understand that but it's like for me it's like back pain, it's just all the stiffness as well.

For me the way I walk is normal but other people will say like, people who don't know me or at work will say 'why are you walking like that?' and I realise they must see me limping or walking funny. I don't realise I am limping eh but a lot of people it's nothing they have heard of. I am very fit I exercise a lot, I go gym. I have the mentality. I understand working out is very important because when I do work out even if its 30minutes on eh on the 'crush trainer' coming off it afterwards and going home showering coz my body has just warmed up, it's the best time ever. I still wake up with stiffness but exercise is important Right now I want to go gym I want to stay fit and healthy but my back, my body says 'no', my mind says 'yes'. Most people their mind says no but mine says yes let's go but my body is just stuck, its stuck. So, if the anti-TNF treatment can help me a little bit the better I can feel.

Are there situations where you have had change your plans to fit in with the condition?

Ullah: My parents, they are very loving and caring and they want me to get better and stuff but even if I told them the name of my condition I don't think they will understand it but they know like, they understand it's not curable but there is treatment available out there eh they want the best for me. I try to manage without being a burden to them

coz I should look after them and not the other way around. I don't want them to feel that my life is wasted so I try to be normal, to just push myself for them like.

I am looking to getting married next year.

That is good news

Ullah: Yeh thanks but I still worry about my condition getting worse. My partner is very supportive and stuff so it makes me feel good. We want to start a family soon so I worry about passing the disease to my children so I don't know if there are tests that I need to do to avoid this. I am searching for information.

I have no further questions. Is there anything else you would like to add or share about your experiences of AS besides what we talked about?

You know a lot of times when my friends used to see me and they did not understand, how can someone have such a back problem for so long? Before I got diagnosed with it they used to say it's all in my head, they always felt that I act it out more or I just don't realise. But there are times when eh when I do want to jump up and do things and I can't. Like for instance someone is ringing at the door right, my mind is already there opening the door, but my body is still a bit behind that's the thing and yes, I think with everything you have to have a positive attitude. I have good and bad days with this illness but I wake up with stiffness all the time.

Thank you once again for taking part in the interview

Appendix 19 Uncovering thematic statements (1st stage of data analysis from Ullah transcript)

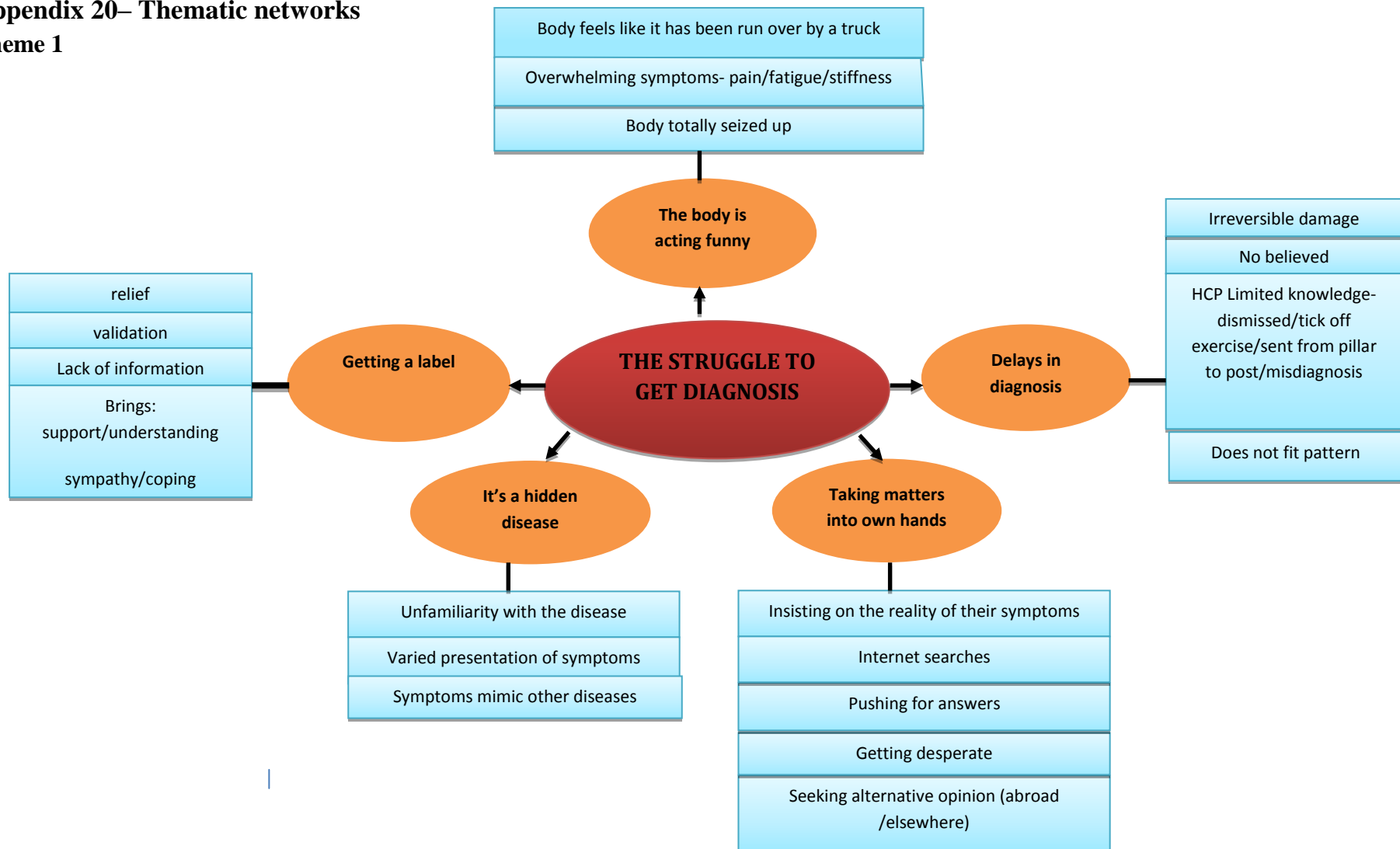
| The Selective or Highlighting Approach | The wholistic or sententious approach | The detailed or line by line approach | Basic Themes |
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| <i>'I completely seized up just like that no warning with a lot of lower back pain' Line 2</i> | AS symptoms attack participants without any warning. | Shows the unpredictable nature of AS and how it invades the participant's life. | Unpredictability Body seizes up |
| <i>'I told my GP I am getting a lot of pain. I think I have a slipped disc. That's what came out of my mouth and he said 'take some pain killers' Line 8</i> | The participant with AS will try to find the cause of their pain. | Shows how the participants can try to find other explanations for their pain. | Self-diagnosis |
| <i>'I came back from the MRI scan and he goes 'nothing wrong there, you are fine. This is good news'. I could not understand what was good about it coz my situation was getting worse' Line 11</i> | GPs do not always make the correct diagnosis of AS from the MRI scans. Participants end up seeking another opinion. | Shows the limits of GPs knowledge in diagnosing AS even from MRI scans. Shows how participants get frustrated and go to seek alternative opinion | GPs' limited knowledge Seeking alternative opinion |
| <i>'I was disappointed coz this is not what I wanted to hear' Line 19</i> | Participants with AS do not always get confirmation of diagnosis. | Shows how participants struggle between onset of symptoms and getting a diagnosis. | Struggle to get a diagnosis |
| <i>'I did a bit of research myself, yeh and the only reason I knew I had Ankylosing Spondylitis was because of my eye condition. This came first. I have uveitis and it says on the NHS website, people with AS sometimes suffer from uveitis and I was getting regular episodes of this</i> | Participants can end up resorting to searching for answers on AS symptoms from the internet. | Shows participants' desperate search for answers on the internet | Self-diagnosis Google my symptoms |

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| <i>and I thought 'right, I must have this condition' Line 23</i> | | | |
| <i>'Every time when I walk I try to be normal but people still comment about my walking. People will say 'why are you walking like that? I realise they must see me limping or walking funny' Line 34</i> | Participants experience physical disabilities from AS which are obvious to others. Participants with AS will pretend that they are 'normal' | Shows the physical disabilities caused by the AS Shows how participants can hide illness from others. | Physical disabilities/functional limitations Hiding illness |
| <i>'Before my diagnosis they used to say it's all in my head, they always felt that I act it out more' Line 99</i> | Participants with AS are not always believed by others | Shows that getting a diagnosis legitimises symptoms of AS | Legitimisation of symptoms |
| <i>'I know some people from my culture don't trust western medicine. It got me thinking you know about complimentary treatments. To tell you the truth that's why it took me a long time to come for anti-TNF treatments. I wanted to explore other things' Line 40</i> | Participants with AS are suspicious of western medicine and this can be a cultural thing. The suspicions can lead to delays in the uptake of treatment. | Shows how cultural beliefs can influence uptake of treatment from participants | Delays in treatment uptake Cultural beliefs about treatment |
| <i>'I have tried many treatments. Ibuprofen minimises the pain but it is always there. I have used steroids but they are for short term use although they make you feel normal again. I have experienced rashes, acne, and spots all over with some tablets. I know these treatments have lots of side effects' Line 50</i> | Participants try many treatments which do not always work and some they stop due to side effects | Shows that treatments for AS are not always effective and some have side effects. | Treatments not always effective Treatments have side effects |
| <i>'I have good and bad periods with this illness but I wake up with stiffness all the time.' Line 94</i> | Participant experiences remissions and flares of their AS. | Shows that AS has it's good and bad periods. Shows morning stiffness is a constant feature of AS | On and off periods Functional limitations |
| <i>'The Professor has told me a lot of things about this illness, but to be honest a lot of</i> | Participant is given lots of information about his AS but only understands his AS | Shows that physical symptoms of AS take | Body setting |

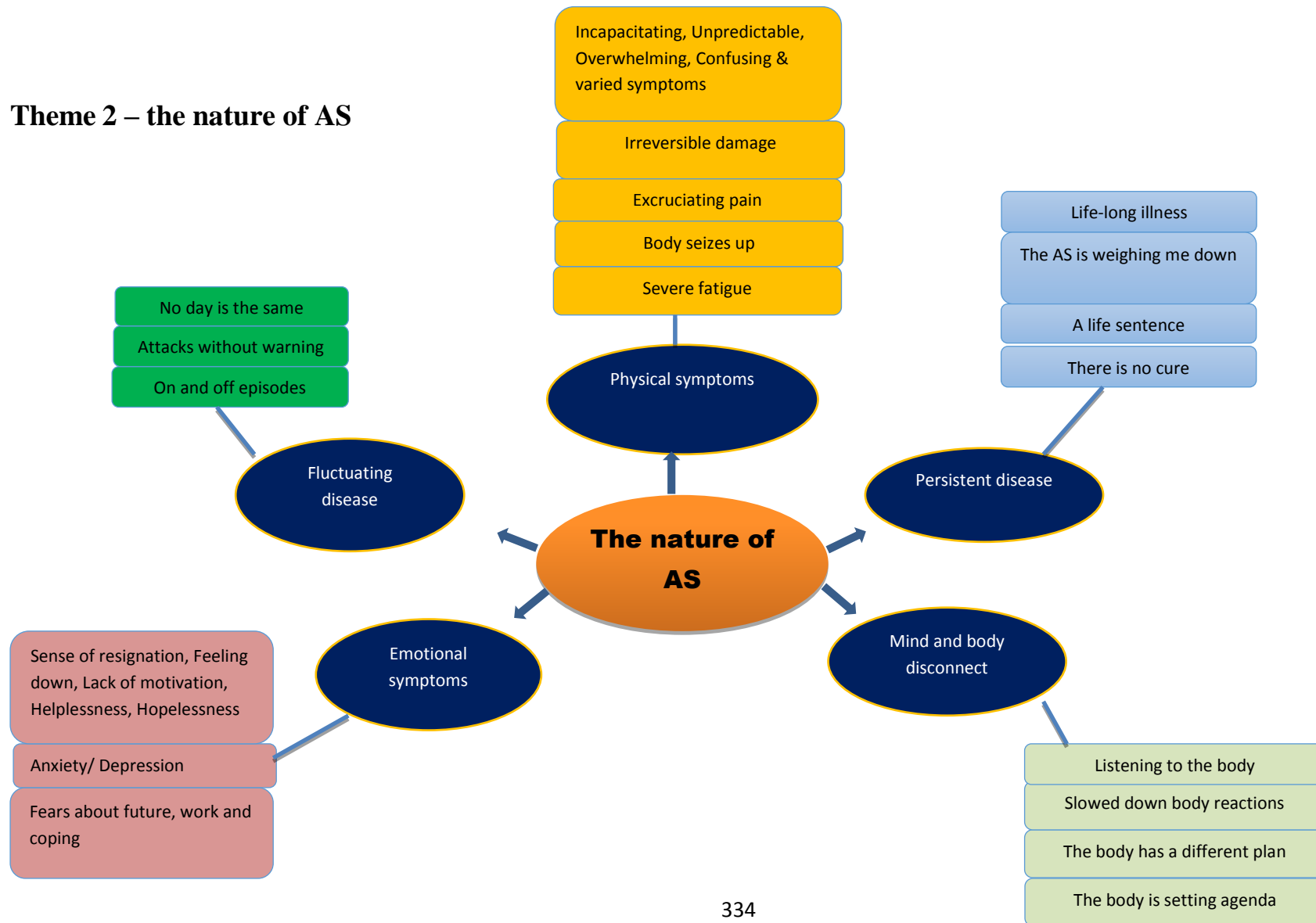
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| <p><i>times when I come here regardless of what I am told, I only understand the condition based on what I am feeling, so my spine, my hip, my shoulders, stiffness this is what I understand'. Line 72</i></p> | <p>in terms of how he is feeling</p> | <p>priority over other aspects of disease.</p> | <p>agenda/dictating</p> |
| <p><i>'Right now, I want to go to the gym, I want to stay fit and healthy but my back, my body says 'no', my mind says yes. Most people their minds say yes let's go and the body obeys but my body is just stuck' Line 83</i></p> | <p>The participant with AS wishes to exercise but his body won't let him.</p> | <p>Shows that the body with AS will not always do what the brain is telling it to do.</p> | <p>Body has a different plan</p> |
| <p><i>'When I do want to jump up and do things, I can't. Like for instance someone is ringing at the door right, my mind is already there opening the door, but my body is still behind, that's the thing. I think with everything you have a positive mind' Line 99</i></p> | <p>The participant with AS find that their bodies are slow to react but they stay positive.</p> | <p>Shows that AS slows down body reactions. Shows that the participant with AS stays positive despite</p> | <p>Body slows down Slowed down body reaction Staying positive</p> |
| <p><i>'My parents are very supportive. They want me to get better, they want the best for me. I try to manage without being a burden to them coz I should look after them not the other way around. I don't want them to feel that my life is wasted so I try to be normal, to just push myself like for them' Line 89</i></p> | <p>Participant with AS has supportive parents but he does not want to be a burden to them so he hides the illness from them.</p> | <p>Shows how AS participant acts normal as if illness has no impact on his life</p> | <p>Family support Acting normal</p> |
| <p><i>'My wife is very supportive. We want to start a family soon but I worry about the future, about passing the disease to my children. I am searching for information about this' Line 94</i></p> | <p>The participant with AS has a supportive partner but he still worries about the future. He worries about passing the disease to his children</p> | <p>Shows how participant with AS gets support from his partner Shows how AS makes you worry about the future Shows how AS makes you worry about</p> | <p>Spousal support Worries about the future Worries about passing AS to children</p> |

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| | | passing it to your children. | |
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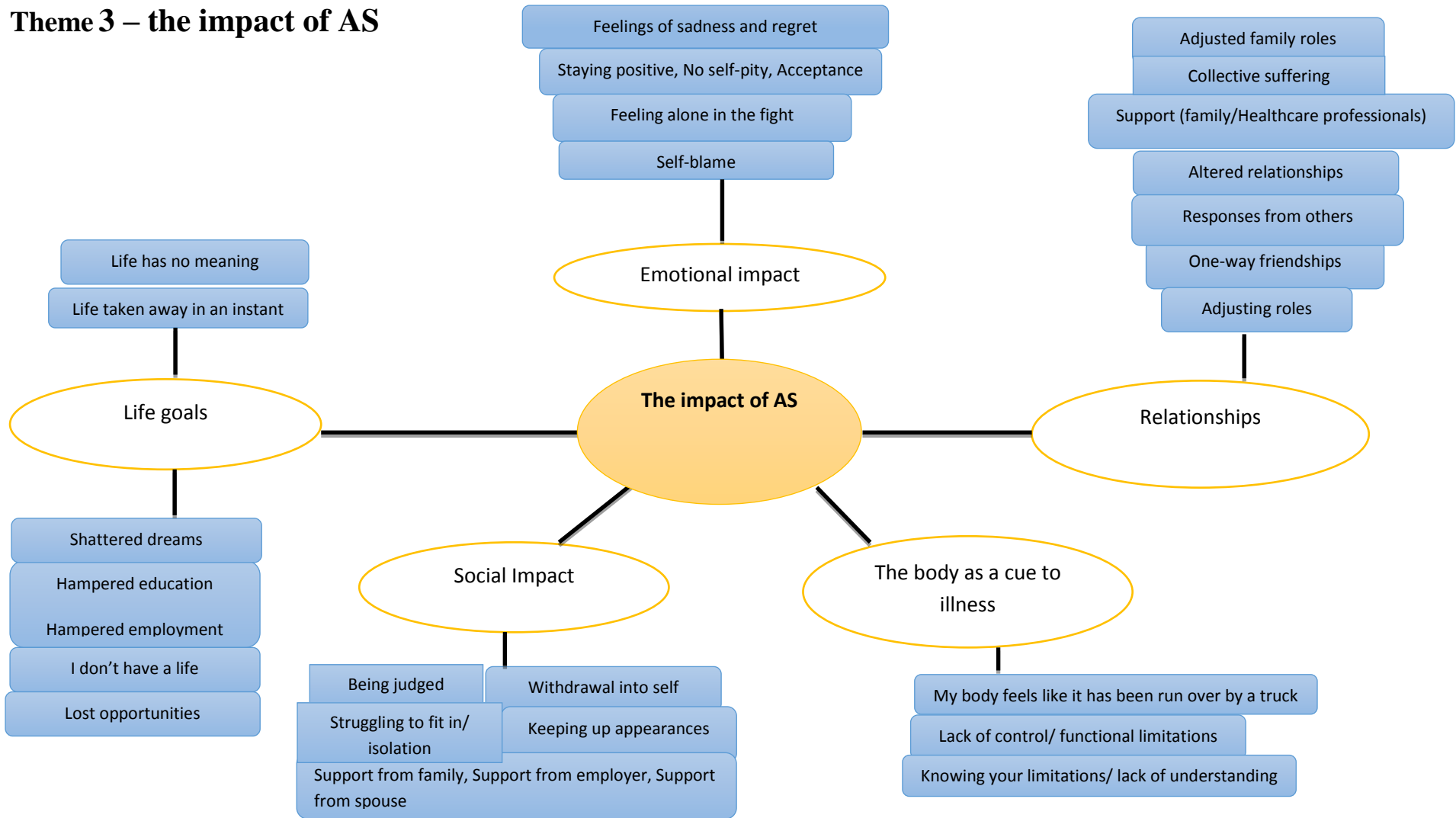
Appendix 20– Thematic networks
Theme 1



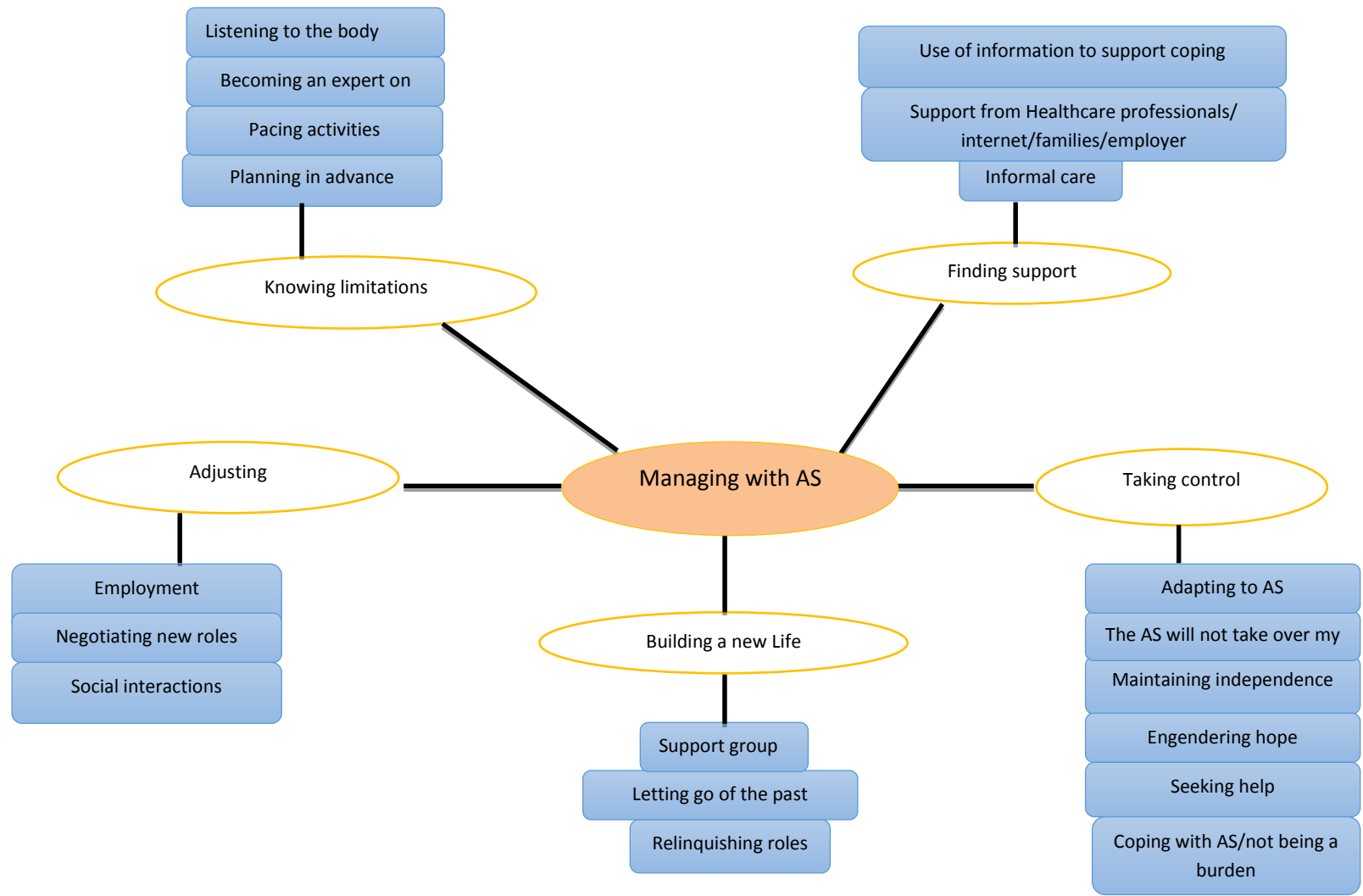
Theme 2 – the nature of AS



Theme 3 – the impact of AS



Theme 4- managing with AS



Theme 5 – finding relief

