Ankylosing spondylitis and its impact on sexual relationships

Emma L. Healey1,2, Kirstie L. Haywood1,3, Kelvin P. Jordan1, Andrew M. Garratt4, Sarah Ryan2 and Jon C. Packham1,2

Objective. To explore the impact of AS on the sexual relationships of a large cohort of patients, across the UK.

Methods. A total of 1000 patients with a confirmed diagnosis of AS under the clinical care of 10 specialist rheumatology centres across the UK were invited to participate in a study evaluating a new quality of life measure. Patients completed a questionnaire, which also included questions relating to the impact of AS on their sexual relationships, sociodemographic and clinical characteristics.

Results. Six hundred and twelve (64%) patients took part in the study. The majority were male (71.6%), mean age 50.8 ± 12.2 years, mean diagnosed disease duration 17.3 ± 11.7 years and mean symptom duration 23 ± 18.6 years. Of those who responded to the question on sexual relationships (n = 552), 210 (38.0%) reported that their sexual relationships were affected ‘moderately’, ‘quite a bit’ or ‘extremely’ by their AS. Males reported greater sexual problems with increasing age. Poor function [odds ratio (OR) 3.64; 95% CI 1.92, 6.87], depression (OR 2.03; 95% CI 1.21, 3.41), greater disease activity (OR 2.10; 95% CI 1.01, 4.40), unemployment (OR 1.99; 95% CI 1.16, 3.40) and poor self-efficacy (OR 1.25; 95% CI 1.09, 1.43) were independently associated with a greater impact on patients’ sexual relationships.

Conclusion. AS has a substantial impact on patients’ sexual relationships. Management of AS and its impact on sexual relationships should be directed not only towards physical outcomes such as disease activity and physical function, but also take into consideration the psychological state of the patient.

Key words: Ankylosing spondylitis, Sexual relationships, Disease impact.

Introduction

AS typically presents in early adulthood and can have a profound impact on an individual’s health status and quality of life [1–3]. The main social roles for any young adult are those of worker, partner and parent [4], and developing a chronic disease at this time of life may affect one’s ability to fulfil these roles [5]. Living with any form of illness can influence a patient’s sex life [6]. Sexuality is an essential part of the whole person, an integral part of being human, contributing to a total sense of ‘self’ [7]. The impact of arthritis on patient’s sex lives has been described in inflammatory arthritis [8–10], but is a frequently neglected area of quality of life in patients with rheumatic disease within clinical practice [11]. One-third of RA patients have reported that their health status considerably influences their sexual activity [12]. The reasons for disturbed sexual functioning are multifactorial [11]. Impaired function, pain, fatigue and stiffness as well as psychological responses to chronic disease such as depression and low-self esteem, can all contribute to a loss of libido [11, 13].

Patients with arthritis may be progressively less satisfied with their sex lives over time [14]. For example, >50% of a sample (n = 112) of female RA patients reported a diminished desire for a sexual relationship since the onset of their illness [9]. Increases in physical disability, pain and depression have all been linked to poor sexual functioning in RA patients [10, 14]. AS and RA have been linked to periods of impotence in men [15], and long-standing AS can, on rare occasions, lead to cauda equina syndrome with erectile dysfunction [16]. Fifty percent of AS patients report issues such as a decrease in desire, satisfaction and frequency of sexual intercourse [17]. Sexual problems also occur more frequently in patients with poor function [18].

Disease-specific sexual problems should be addressed as part of routine care [11]; however, they are often left to the patient to resolve [19, 20]. Patients are often too embarrassed to raise concerns about their sex lives and this may be compounded by the reluctance of health care practitioners to enquire about such personal issues [10, 20].

Research that has considered the sexual problems of AS patients has used relatively small sample sizes (range 28–101) [15, 17, 18, 21], which raises the issue of whether these findings can be generalized. Despite sexual problems being less frequent for RA patients in comparison with RA patients [22], they are still of importance and need further clarification. Sexual problems in AS may be associated with peripheral joint involvement, decreased function, greater disease activity, reduced health status more generally and depression [21]. Few studies have been conducted to address the impact of rheumatic disease on sexual functioning and very little research has been undertaken in relation to AS. The aim of this study was to explore the perceived impact of AS on sexual relationships within a large cohort of patients across the UK, and to identify the associations with demographic and disease-related variables.

Subjects and methods

Subjects

A total of 1000 patients with confirmed diagnosis of AS, (Modified New York Criteria, 1984) [23] under the clinical care of 10 specialist rheumatology centres in the UK, were invited by their consultant to participate in the postal survey (April to July 2007). The sites were specifically chosen to provide a diverse socioeconomic and geographic population. This should allow the results of this study to be generalizable to all AS patients across the UK. Exclusion criteria included learning difficulties and an inability to comprehend English. The number of patients was based on the main study objective of evaluating a new AS measure of quality of life. However, given a response of 60%, a sample size of 600 would give a margin error of ±4% for an estimated prevalence of sexual problems of 50%.

1Arthritis Research Campaign National Primary Care Centre, Primary Care Sciences, Keele University, Staffordshire, 2RCN Research Institute, School of Health and Social Studies, University of Warwick, Coventry, UK and 3National Resource Centre for Rehabilitation in Rheumatology, Diakonhjemmet Hospital, Oslo, Norway.

Submitted 27 November 2008; revised version accepted 27 April 2009.

Correspondence to: Emma L. Healey, Arthritis Research Campaign National Primary Care Centre, Primary Care Sciences, Keele University, Staffordshire ST5 5BG UK. E-mail: e.healey@cphc.keele.ac.uk
AS and its impact on sexual relationships

Method

The multicentre cross-sectional survey was approved by the North Staffordshire Local Research Ethics Committee and the 10 site-specific National Health Service Trusts. Written consent was obtained from all patients according to the Declaration of Helsinki.

 Patients were invited to self-complete a mailed questionnaire. Those who did not wish to participate were asked to return uncompleted, pre-coded questionnaires in a pre-paid envelope. Non-responders were sent reminders at 2 and 4 weeks.

Data collection and analysis

The questionnaire included a question asking them to indicate, if applicable, how much during the last week their AS affected their intimate or sexual relationships on a 5-point scale of ‘not at all’, ‘a little bit’, ‘moderately’, ‘quite a bit’ or ‘extremely’. This question was developed taking into account face validity, relevance and acceptability through face-to-face patient interviews. A sexual problem was defined as the patient reporting their sexual relationship had been at least moderately affected.

The questionnaire also included questions relating to disease duration, function, disease activity and pain. The Bath AS Functional Index (BASFI) [24] and the Bath AS Disease Activity Index (BASDAI) [25] assessed functional impairment and disease activity, respectively. Both the BASFI and BASDAI indices are scored between 0 and 10, with higher values indicating worse function and disease activity, respectively. Patients also completed a 100-mm numerical rating scale (NRS) for pain (0 = no pain, 100 = most severe pain). Stiffness was assessed separately using question 5 from the BASDAI, whereby patients were asked to describe the overall level of morning stiffness between 0 and 10, with a higher value indicating greater stiffness.

Fatigue was assessed, with a descriptive scale relating to how much of the time patients felt tired or lacking in energy because of their AS.

The depression scale from the Hospital Anxiety and Depression Scale (HADS-d) [26], which contains seven questions on depressive symptoms, was used to assess depression. A HADS-d score of ≥ 8 defines probable depression. Self-efficacy was assessed by an AS-specific modification of the Arthritis Self Efficacy Scale [27]. This 8-item scale asks patients to score from 1 (very uncertain) to 10 (very certain) how certain they are about their ability to do certain tasks at the present time.

Finally, sociodemographic information, including age, sex and level of education and social deprivation, was collected. A social deprivation score was calculated for each patient within the cohort using the Townsend Index [28], which is based on 2001 census data of unemployment, overcrowding, non-car ownership and non-home ownership for the patient’s local area.

The prevalence of reporting a sexual problem (with 95% CI) was determined. Factors that may be associated with reporting sexual problems were assessed in line with previous research [12]. For analytical purposes, the five response categories of the dependant variable (sexual impact) were dichotomized, that is the responses ‘not at all’ and ‘a little bit’ were collapsed into ‘minimal impact’, and the responses ‘moderately’, ‘quite a bit’ or ‘extremely’ were collapsed into ‘large impact’. Each of the remaining demographic and disease-related variables, except age, disease duration and self-efficacy, were dichotomized to reflect national guideline cut-offs (NICE guidelines, 2008) [29] to aid the interpretation of the results. Comparisons between different patient groups within the cohort were performed using t-tests or chi-square tests as appropriate. Factors significant (P < 0.05) in unadjusted analyses were included in a logistic regression model to determine factors independently associated with sexual impact, with results presented as odds ratios (ORs) with 95% CI. Interaction effects between significant factors were also examined. A final analysis stratified by gender to assess whether the strength of associations varied between males and females. For all statistical tests, the threshold of significance was set at α ≤ 0.05. All analyses were performed using SPSS version 15.0 for windows (SPSS, Chicago, IL, USA).

Results

Response

Six hundred and twelve patients gave written consent to participate in the study (Table 1). After taking into account deaths and changes of address (n = 44) the adjusted response rate was 64%.

The 60 (9.8%) patients who did not complete the question relating to intimate or sexual relationships were more likely to be female (18.3% compared with 6.4%), older (mean difference in age 7.1 years; 95% CI 3.9, 10.4), unemployed (P < 0.001) and, although not statistically significant, reported greater levels of pain and disease activity and poorer function. The females in this group were also more likely [n = 21/31 (67.8%)] to be divorced or widowed compared with the males [8/28 (28.6%), P = 0.003].

Of those who completed the question, 342 patients (62%) reported that their sexual relationships were affected ‘not at all’ or ‘a little bit’ by their AS (minimal-impact group) and 210 (38.0%; 95% CI 34.1, 42.2) reported that their sexual relationships were affected ‘moderately’, ‘quite a bit’ or ‘extremely’ by their AS (high impact group). There was a significant trend by age (P = 0.004) with 30.6% of those aged 18-49 years reporting sexual problems compared with 49.2% of those aged ≥65 years.

The non-completing group did not share general demographic or AS characteristics with either the high or minimal impact group and were removed from all further analyses.

Logistic regression analysis showed that poor function (OR 3.64; 95% CI 1.92, 6.87); depression (OR 2.03; 95% CI 1.92, 6.87), greater disease activity (OR 2.10; 95% CI 1.01, 4.40), unemployment (OR 1.99; 95% CI 1.16, 3.40) and poor self-efficacy (OR 1.25 per unit decrease in score; 95% CI 1.09, 1.43) were independently associated with a greater impact on patients’ sexual relationships (Table 2). A significant interaction effect was found between disease activity and depression (P = 0.01), suggesting the association of depression with sexual problems was stronger in those with high disease activity.

When comparing males with females, there was no gender effect regarding the overall impact of AS on sexual relationships (P = 0.98), whereby 37.6% of males and 37.7% of females reported an impact. The extra-stratified regression analysis was conducted to examine the factors associated with sexual impact in males and females separately. Although the number of females was low, this demonstrated that the impact of AS on sexual relationships also appeared to be psychologically and socially driven in males. For example, both groups demonstrated factors related to disease severity as having an impact on sexual relationships, whereas the sub-analysis demonstrated psychological issues

Table 1. Health-related and sociodemographic characteristics of patients

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>n = 612</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (male), %</td>
<td>71.6</td>
</tr>
<tr>
<td>Age, years</td>
<td>50.8 ± 12.2</td>
</tr>
<tr>
<td>Disease duration, years</td>
<td>17.3 ± 11.7</td>
</tr>
<tr>
<td>Symptom duration, years</td>
<td>23 ± 18.6</td>
</tr>
<tr>
<td>Disease activity (BASDAI)</td>
<td>4.6 ± 2.9</td>
</tr>
<tr>
<td>Function (BASFI)</td>
<td>4.6 ± 2.6</td>
</tr>
<tr>
<td>Pain (visual analogue scale)</td>
<td>48 ± 27</td>
</tr>
<tr>
<td>Probable anxiety, %</td>
<td>44.6</td>
</tr>
<tr>
<td>Probable depression, %</td>
<td>32.4</td>
</tr>
<tr>
<td>Anti-TNF use</td>
<td>71 (11.6%)</td>
</tr>
</tbody>
</table>

Values are given as mean ± S.D. unless otherwise stated.
such as self-efficacy ($P = 0.002$) and depression ($P = 0.04$) were important for males, but weaker and non-significant for females. Increasing age appeared to have a detrimental impact on sexual relationships in males only (males $P < 0.001$, females $P = 0.81$).

**Discussion**

Despite its importance, sexuality is a frequently neglected area of quality of life in patients with rheumatic disease [11], and few investigations have focused on the impact of rheumatic disease on the sexual relationships of patients. The majority of work that has been carried out either combined all rheumatic diseases together [8, 11, 30] or focused solely on the impact of RA [9, 20, 31]. Little research has been conducted on AS patients; therefore, the focus of this study was to explore the patients’ perceived impact of AS on sexual relationships.

In line with research examining the impact of RA on sexual activity [12], about a third of the patients ($n = 210$) in the current study reported that their sexual relationships were affected ‘moderately’, ‘quite a bit’ or ‘extremely’ by their AS, indicating that this is a common problem. The reasons for disturbed sexual functioning are multifactorial in RA [11, 12], and this also appears to be the case for AS. Physical factors such as poor function and greater disease activity, and psychological factors such as low self-efficacy and depression were all associated with a greater impact on sexual relationships. These findings are consistent with previous AS research, which demonstrated that changes in patients’ sex lives are associated with their emotional state and disease-related physical limitations [17]. The interaction effect found between disease activity and depression shows that these issues are closely linked. In the clinical situation, health care professionals need to be aware of patients exhibiting symptoms indicative of both depression and elevated disease activity and acknowledge the impact this could have on sexual relationships.

When examining the differences between males and females, it was evident that females were less likely to answer the question about sexual relationships. Females not completing the question tended to be divorced or widowed. These findings probably reflect the fact that females tend to outlive their partners, and hence lack of applicability may be the main reason that females did not complete the question. Although the number of females was low in this cohort, the analysis also demonstrated that the impact of AS on sexual relationships appeared to be more psychologically and socially driven in males and to be more disease severity driven in females. This could be something that health care professionals should take into account when dealing with patients experiencing difficulties within their sexual relationships.

Sixty (9.8%) patients did not complete the question about their sexual relationships. As patients were only required to complete this question if it was deemed applicable, we could assume that patients read the question correctly and chose not to complete it because it was not relevant. In support, the remainder of the questions demonstrated excellent completion rates in excess of 97.7%, suggesting that the vast majority found the questions easy to understand and complete. Alternatively, some patients may have chosen not to disclose such private information. Unfortunately, it is impossible to estimate to what extent this occurred.

Obtaining responses to questions about patient’s sexual relationships is an important issue. Helland et al. [12] found that ~20% of the respondents to their questionnaire did not complete the question addressing sexual problems. They found that those who did not complete this question were more likely to be older, female, report higher levels of disability and were less likely to be married. Similarly, the non-completers in the current study were more likely to be females (18.3% compared with 6.4%), older (mean difference in age 7.1 years; 95% CI 3.9, 10.4), unemployed ($P < 0.001$) and, although not statistically significant, reported worse levels of pain, disease activity and function. These patients may be hindered by their AS to such an extent that they cease to be sexually active and have not completed the question because it is no longer applicable. Future research should consider the inclusion of an additional question that asks if this is the case.

As this study was cross-sectional, it was not possible to determine the direction of any causality; whether factors such as depression cause sexual problems or the presence of sexual problems cause depression. This should be considered by future studies that include a follow-up of patients.

A level of sexual dysfunction exists within the general population although definitions of sexual dysfunction vary. A study investigating the sexual dysfunction, attitudes and behaviours of a northern European population aged >40 years, found that 23% of men and 31% of women reported being affected by at least one sexual dysfunction, such as erectile dysfunction and infrequent orgasm [32]. Similarly, a British study investigating middle-aged women found 33% reported sexual problems, such as vaginal dryness causing difficulties during intercourse [33].

The current study specifically asked patients to report how their AS affected their intimate or sexual relationships, but it is possible that patients may be reporting overall rather than disease-specific problems in their sexual relationships. However, as our results demonstrated significant associations with disease-specific measures (e.g. disease activity and function) this would suggest that there is a large AS element to the sexual problems reported by the patients. In addition, the self-reported impact of AS on sexual relationships in this study is greater than the levels of sexual dysfunction previously reported for the general population from northern Europe [32].
This study is the largest of its kind to focus on a nationally representative AS population to investigate the impact of the condition on sexual relationships. Our cohort represents a sample obtained from ~9% of the rheumatology services across the UK. This large UK-wide sample suggests that the results can be generalized to patients with AS across the UK.

The patient sample was taken from a secondary care setting and, therefore, may have more severe disease than a community-based cohort. However, normal practice in the UK dictates that if a primary care physician (GP) suspects AS they usually refer the patient to a rheumatologist within secondary care for diagnosis and ongoing treatment.

As we only used a single-item question to determine the impact of AS on sexual relationships we have no data about other sexual problems the patients may have experienced which they felt were not related to AS. The current study has shown that AS patients do experience significant problems with their sexual relationships. However, future research should focus on a detailed exploration of these issues through in-depth patient interviews and the use of appropriate questionnaires in an attempt to further detail the burden of AS on sexual relationships when compared with the general population.

Unfortunately, we do not have access to any data concerning the non-responders to this study; therefore, it is impossible to determine if any response bias exists.

Conclusion

Despite its clear importance, the consequences of AS on a patient’s sexual relationship are largely left to the patient to resolve [21]. Patients are often too embarrassed to raise concerns about their sex lives and this is compounded by the reluctance of many health care practitioners to enquire about such issues [10, 21]. The increasing awareness of the impact of AS and identification of the main factors associated with poor sexual relationships, should help health care professionals identify those who are more likely to have sexual problems and target them in clinical practice. Management of AS and its impact on sexual relationships should be directed not only at physical outcomes such as disease activity and physical function, but should also take into consideration the psychological state of the patient.

References