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The (un)spoken realities of living with axial spondyloarthritis: a qualitative study focused on couple experiences

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3 **The (un)spoken realities of living with axial spondyloarthritis: a qualitative study**
4 **focused on couple experiences**
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ABSTRACT

Objective: Axial spondyloarthritis is a long-term rheumatic condition. The symptoms, including pain, can impact upon the daily life routines and psychological wellbeing of individuals that are diagnosed with axSpA. Partners are often a main source of support for individuals who manage a long-term condition and they can also be affected by the illness experience, often themselves reporting elevated levels of emotional distress. Few qualitative studies have explored the impact of axSpA on partner relationships. This study addresses the social context of axSpA by investigating the experiences for both individuals with axSpA and their partners.

Design: Semi-structured individual telephone interviews analysed using Thematic Analysis at a dyadic partner level.

Setting: Participants were recruited from the social media pages of a UK based axSpA-specific charity.

Participants: Nine heterosexual partner dyads (23-65 years), who were currently co-habiting, comprising nine individuals diagnosed with axSpA (n=6 female) and nine partners (n=3 female).

Results: Two themes 'Perceived relational closeness' and 'Tensions surrounding a carer role' were identified. The findings illustrate how living with axSpA can influence closeness between partners and dominate daily decisions, particularly surrounding leisure activities. Partners commonly adopted a carer-type role, despite many individuals with axSpA expressing desire for a greater sense of autonomy.

Conclusions: This study provides an important insight into the lived experiences of both individuals with axSpA and their partners. Findings highlight the social context of managing a long-term condition and suggest the need for including partners within consultations, and the need for support provision for partners.

ARTICLE SUMMARY

Strengths and limitations of this study

- In-depth qualitative interviews generated rich and meaningful data providing rich insights into partner dyadic experiences of axSpA.
- As participants were recruited from the social media pages of a single UK based axSpA charity, results represent accounts from participants who sought support from this organisation, suggesting potentially different accounts from participants who had not sought contact with the condition specific charity.
- Recruitment of dyads required a level of communication between partners to discuss participation, with the possibility of couples with poorer relationships being less likely to participate in the study.
- As dyads comprised only White British/Scottish heterosexual couples, participants' experiences may not represent those of other types of couples.

INTRODUCTION

Axial spondyloarthritis (axSpA) is a group of rheumatic conditions primarily affecting the spine and sacroiliac joints (1,2) with chronic pain being the leading symptom.(3) The long-term condition predominantly affects males with symptoms typically developing prior to the age of 30.(4) Major daily living challenges associated with the condition include reduced functional ability, fatigue and depression.(5-7)

The long-term health condition literature has clearly highlighted the importance of partner relationships with regard to health outcomes. One Canadian quantitative study identified that greater satisfaction with spousal responses was associated with reduced feelings of helplessness in individuals with rheumatoid arthritis.(8) Nonetheless, partner support is not always protective, with further studies highlighting associations between inaccurate estimations of their partner's pain or fatigue and increased levels of anxiety and depression in individuals with rheumatoid arthritis.(9) Rheumatoid arthritis has also been shown to have a multifaceted impact upon the lives of partners. Specifically, qualitative research has identified that exposure to their partner's pain is associated with feelings of concern and helplessness.(10-11) To explore partner issues further, the concept of dyadic coping has been identified, referring to the numerous ways that couples may communicate during the

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2
3 management of illness-related stressors.(12) Dyadic coping can be positive or negative,
4 reflecting collaboration or withdrawal between partners.(13-15) Reflective of this increased
5 focus on partners, an evidence base is growing, demonstrating the increased effectiveness of
6 couple-focused behaviour change interventions compared with usual care and individual
7 interventions for individuals with long-term conditions.(16)
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10
11 More recently, qualitative studies have begun to examine the social context of axSpA.
12 Findings have shown that individuals with axSpA report restrictions in their ability to engage
13 in physical and social activities (17,18) and experience sexual problems.(19-21) To contrast
14 these negative outcomes, some qualitative studies have demonstrated strengthened partner
15 relationships.(10,22) Yet, whilst studies have identified the impact of axSpA upon partner
16 relationships, such studies have typically only included the views of the individual with
17 axSpA, excluding partner experiences. One exception included a quantitative study which
18 examined spousal experiences of axSpA. Using psychometrically robust measures of
19 psychological wellbeing, physical wellbeing and depression, this study found that spouses
20 reported significantly reduced social functioning and general health perceptions, and
21 increased levels of depression, respectively, compared to spouses of healthy individuals.(23)
22 However, due to the restrictions associated with self-report questionnaires, this study was
23 unable to provide an in-depth exploration into how and why partners of individuals with
24 axSpA report a reduced quality of life. Considering the potential challenges of having a
25 partner with axSpA, it is problematic that the literature has typically focused on studying the
26 individual with axSpA in isolation.(17) A social contextual focus is required for addressing
27 the interpersonal element of living with axSpA. To meet this knowledge gap, it is important
28 that studies explore perceptions and experiences of the partner relationship held by both
29 individuals with axSpA and their partner.
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43 Consequently this particular study aims to explore how axSpA impacts on partner
44 relationships according to individuals with axSpA and their partners. The adoption of
45 qualitative methods will reveal partner dyad experiences of axSpA in a more meaningful way
46 (24) by identifying how and why axSpA impacts upon partner relationships. Findings, in turn,
47 may inform clinical practice, facilitating support provision for individuals with axSpA and
48 their partners.
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53 **METHODS**

54 **Sample and recruitment**

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3 Sampling was purposive to recruit dyads comprising individuals diagnosed with axSpA (n =
4 9) and their partners (n = 9). A total of 18 participants (9 partner dyads) were recruited via
5 study invitations placed by a UK based axSpA-specific charity on their social media pages
6 (Facebook and Twitter). Interested participants contacted the researcher to receive an
7 information sheet about the study, prior to providing fully informed consent. Eligibility
8 criteria required individuals to be aged at least 18 years, speak English fluently and report no
9 cognitive impairments. Thirty-one individuals requested information about the study, with 22
10 individuals subsequently not participating. Reasons for non-participation included having a
11 partner who did not wish to take part and feeling unwell.
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18 **Patient Involvement**

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20 The development of the research question was informed by earlier work conducted with
21 patients with axSpA. Participants were not involved in the design, recruitment or conduct of
22 the study. Participants will be informed via email about the publication of results.
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26 **Data collection**

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28 Data was collected via in-depth, individual semi-structured telephone interviews by KR
29 (female Masters level psychology student), until data saturation was reached. Telephone
30 interviews facilitated flexible recruitment of participants across the UK,(25) which is
31 significant due to axSpA being a relatively rare condition.(26) Participants were interviewed
32 individually to prevent direct influence from their partner.(27) Topic guides were generated
33 by identifying the main areas of interest (28) and surveying the arthritis literature (see 10).
34 Interview questions were open-ended, asking participants about the impact of axSpA upon
35 daily life and partner relationships. Separate yet similar topic guides were devised for the
36 individuals with axSpA and partners (see supplementary Table 1).
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44 Probe questions prompted for further depth where appropriate.(29) Interview duration ranged
45 between 25 and 73 minutes, with interviews audio-recorded and transcribed verbatim. Prior
46 to interviews, participants completed a brief online survey via Qualtrics (an online survey
47 platform) to provide basic demographic information along with informed consent.
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51 **Data analysis**

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53 Data was analysed in NVivo (a qualitative analysis software) using Thematic Analysis(30),
54 enabling a rich understanding of new data through exploration, alongside the incorporation of
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past research.(31) Thematic Analysis is a flexible method which allowed for an inductive approach to coding and analysis of the idiographic focus on dyads' experiences. Braun and Clarke's (30) stages of Thematic Analysis, which involved familiarisation, coding, producing, reviewing and labelling themes, were followed iteratively from a descriptive to interpretative analysis.(32) Subsequently, accounts of individuals' with axSpA were compared with partner accounts to note similarities and differences.(33) A reflexive journal was used throughout data collection and analysis to prevent biased interpretations of the data from previous knowledge of having met patients with axSpA. Analysis was conducted by KR, with themes reviewed by AJ and HF to ensure reliability. The consolidated criteria for reporting qualitative research (COREQ) (34) were followed (supplementary Table 1) and Yardley's (35) criteria for assessing the quality of qualitative research were met. Previous studies were reviewed (sensitivity to context) and Braun and Clarke's (31) 15-point guidelines on conducting Thematic Analysis were followed (commitment and rigour). Further, a fit between the research question and choice of Thematic Analysis was ensured (coherence). Finally, knowledge about partner relationships within the context of axSpA was enhanced (impact and importance).

RESULTS

The sample comprised 9 individuals with axSpA and 9 partners. All couples were heterosexual and White British/Scottish, with an age range of 23-65 years. Six individuals with axSpA were female (see Table 1).

Table 1. Participant demographics

Pseudonym	Gender	Age	Ethnicity	Employment status	Length of relationship (years)	Live together?	Met before /after diagnosis?	Children
Elizabeth (<i>dyad 1 axSpA</i>)	Female	40	White British	Part-time	3.5	Yes	Before	Unkn now
William (<i>dyad 1 partner</i>)	Male	43	White British	Full-time	3.5	Yes	Before	Unkn now
Sophie	Female	29	White	Full-time	2.5	Yes	After	No

1									
2									
3	<i>(dyad 2</i>			British					
4	<i>axSpA)</i>								
5									
6	Steven	Male	28	White	Full-time	2.5	Yes	After	No
7									
8	<i>(dyad 2</i>			British					
9	<i>partner)</i>								
10									
11	David	Male	45	Scottish	Full-time	25	Yes	Before	No
12									
13	<i>(dyad 3</i>								
14	<i>axSpA)</i>								
15									
16	Phoebe	Female	43	White	Full-time	25	Yes	Before	No
17									
18	<i>(dyad 3</i>			British					
19	<i>partner)</i>								
20									
21	Jack	Male	43	White	Full-time	17	Yes	Before	Yes
22									
23	<i>(dyad 4</i>			British					
24	<i>axSpA)</i>								
25									
26	Ellie	Female	36	White	Full time	17	Yes	Before	Yes
27									
28	<i>(dyad 4</i>			British					
29	<i>partner)</i>								
30									
31	Emily	Female	58	White	Self-	29	Yes	Before	Yes
32					employed				
33	<i>(dyad 5</i>			British					
34	<i>axSpA)</i>								
35									
36	Alexander	Male	65	White	Retired	29	Yes	Before	Yes
37									
38	<i>(dyad 5</i>			British					
39	<i>partner)</i>								
40									
41	Tom	Male	29	White	Full-time	6	Yes	After	Yes
42									
43	<i>(dyad 6</i>			British					
44	<i>axSpA)</i>								
45									
46	Charlotte	Female	23	White	Part-time	9	Yes	After	Yes
47									
48	<i>(dyad 6</i>			British					
49	<i>partner)</i>								
50									
51	Bethany	Female	50	White	Part-time	34	Yes	Before	Yes
52									
53	<i>(dyad 7</i>			British					
54	<i>axSpA)</i>								
55									
56	Oliver	Male	53	White	Full-time	34	Yes	Before	Yes
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<i>(dyad 7 partner)</i>			British						
Rosie	Female	32	White	Part-time	6	Yes	Before	Yes	
<i>(dyad 8 axSpA)</i>			British						
Harry	Male	35	White	Full-time	6	Yes	Before	Yes	
<i>(dyad 8 partner)</i>			British						
Jess	Female	56	White	Retired	17	Yes	After	No	
<i>(dyad 9 axSpA)</i>			British						
Michael	Male	54	White	Full-time	17	Yes	After	No	
<i>(dyad 9 partner)</i>			British						

Two themes, 'Perceived relational closeness' and 'If I wanted a carer, I would have hired a carer', were identified, reflecting how the dyads' daily lives had been altered by axSpA through restrictions and changes in relationship strength, and altered partnership roles. Verbatim quotes from participants exemplify the findings with the use of pseudonyms.

Perceived relational closeness

Managing axSpA within a partner relationship had the potential to either enhance dyadic closeness or place greater distance between individuals. To varying degrees, all dyads experienced restrictions within their daily lives. Notably, chronic pain and fatigue could limit the functional abilities of individuals with axSpA, reducing their engagement in leisure time with their partners. This suggests that axSpA could act as a third party within the relationship by placing an obstacle within dyads' social time:

“It probably stopped me doing more things with (Ellie) and my kids. (Ellie) takes my son to football at the weekend because she knows I'm not really able to handle sitting or standing around in the cold, things like that” *Jack (individual with axSpA)*

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3 Making social comparisons to healthy individuals often highlighted dyads' perceived
4 constraints and differences, further emphasising what they were missing out on together as a
5 result of living with axSpA:
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7
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9 "It's what you want to do and you can't do as much as some of your friends are doing
10 and if some people are going away for like a short weekend or finish work on a Friday
11 then they'll go away [...] well (partner's) too tired once he's finished work to go away
12 on a Friday night" *Charlotte (partner)*.
13
14
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16
17 Whilst Jack and Charlotte expressed an extensive impact of axSpA on their ability to do
18 things and spend time with partners, this was not the case for all participants. William
19 perceived a minimal influence of axSpA on his ability to share activities with his partner:
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23 "We can still go out walking for 10 miles and things like that so it hasn't really been a
24 major impact on our relationship and the things we want to do together" (*William,*
25 *Partner*)
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28
29 However, William and his partner experienced a different challenge of "not sharing the bed
30 all the time" (*William, partner*). Intimacy was frequently reduced or lost between partners
31 because of the symptoms of axSpA, which suggests an element of distance within
32 relationships:
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36 "Sex life vanished quite early on [...] and it isn't something which she can deal with,
37 painkillers are not going to deal with that kind of stress on the body. So, when it all became
38 too painful I just sort of quietly agreed that this is something to stop" *Alexander (partner)*
39
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42
43 Alexander felt a strong sense of reluctance about initiating intimate acts, so as not to cause
44 further pain to his partner. His use of the word 'quietly' reveals a sense of submission to
45 axSpA. Alexander's decision to stop sexual activity was not a desired scenario and it was not
46 explicitly acknowledged or discussed with his partner, emphasising a degree of suppressed
47 communication surrounding the challenges of axSpA.
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52 The constant nature of axSpA made life appear effortful for many of the dyads. The condition
53 often acted as a central feature which their lives subsequently revolved around, sometimes
54 dominating the partner relationship:
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3 “Literally absolutely everything from what we eat, to when we eat, to who does this, to
4 who does that, to when this happens, can it happen? [...] everything is sort of gravitated
5 to AS (referring to Ankylosing Spondylitis, a sub-group of axSpA)” *Harry (partner)*
6
7

8 Dyadic life was portrayed as regimented with a need to plan ahead for activities. This seemed
9 to reduce spontaneity in their everyday lives. Yet, almost contradictorily, a sudden axSpA
10 flare-up could alter plans at any time: “if he’s feeling really bad then he can’t go” (*Ellie,*
11 *Partner*). Couples often avoided some activities so that the individual with axSpA did not
12 have “a price to pay the next morning” (*Michael, Partner*) through amplified symptoms.
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15 In addition to joint activity restrictions, many partners experienced a pervading sense of
16 helplessness characterised by limited avenues to relieve their partner’s symptoms,
17 exacerbated by the unpredictability of axSpA:
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23 “It was a lack of ability to change things which was difficult and it’s not that you’re
24 looking to be a miracle worker but there aren’t even simple things that you could [do]
25 dramatically, the flare-up or change could happen whenever” *Oliver (partner)*
26
27

28 Helplessness was also experienced by the individuals with axSpA. Being diagnosed with
29 axSpA at a young age altered their future prospects. The long-term nature of managing the
30 condition was sometimes challenging to accept and placed a greater focus upon ‘I’ as
31 opposed to the relationship:
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36 “It is taking an awful lot off the potential side of my life. And that’s a tough thing to
37 swallow, especially when you’re getting that handed to you when you’re in your
38 30’s...you’re going to have to start acting as if you’re an old man” *David (Individual*
39 *with axSpA)*
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43 Despite the ever-present nature of axSpA, some dyads were able to work together to reduce
44 the dominance of the condition on their relationship by making the most out of positive
45 experiences:
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49 “(Michael) and I both do that, we both count our blessings and I hope that, you know, I
50 guess with anything you don’t know what’s around the corner as well as what’s gonna
51 happen to your body” *Jess (Individual with axSpA)*
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54 Beyond a sense of appreciating things in the moment, many dyads also reported strengthened
55 relationships as a consequence of dealing with and overcoming the challenges surrounding
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3 the condition. This created the sense of a ‘team’ within relationships:
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6 “I think it's made us understand each other more, I think it's made us more tolerant of
7 each other, and I think it's kind of made us into the team that we are.” *Ellie (partner)*.
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10 This feeling of strengthening, with enhanced relationship security and unity, was perceived to
11 be superior to that of other healthy couples, suggesting some positive aspects of living with
12 axSpA in a partner relationship:
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16
17 “The sort of bond that we have that way has been kind of strengthened or forged
18 because of needing to [...] be more supportive emotionally [...] we seem as if we show
19 that we care about each other a bit more than your average sort of bloke or woman”
20
21
22 *Michael (partner)*
23

24 However, not all partner relationships were cohesive, with the appearance that some partners
25 were pulling against each other. Irritability caused by axSpA symptoms could result in the
26 perception that the other partner did not fully understand their emotions or needs, placing an
27 unwanted division within the relationship:
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31
32 “Sometimes like I’m not as happy as I could be, if I’m a bit tired, you know, and then
33 maybe they say you take it out on the one’s you love don’t you so you know sort of like
34 a cycle. I like him giving me hugs and kisses but if I’m being a grump I’m not gonna
35 get ‘em am I?” *Rosie (individual with axSpA)*
36
37
38

39 In many cases, partners appreciated that they could not fully empathise with what it was like
40 to have axSpA : “I can't experience what he's experiencing and I can't imagine it” (*Ellie,*
41 *Partner*). This indicates a further degree of distance within partner relationships, despite
42 perceptions of closeness and the intention to understand.
43
44
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46 In some cases, this sense of distance was more profound. Bethany described how her
47 relationship changed as a result of her altered appearance. Specifically, Bethany’s spine
48 “curvature”, caused by axSpA, left her feeling unworthy of her partner which caused her to
49 distance herself from him, resulting in a temporary separation:
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54 “I was exhausted I was in a lot of pain, I was tetchy and we did separate for 12 months.
55 And, (partner) did find somebody else he did have an affair, so it’s a bit, because I was
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3 pushing and pushing away I think because I could not understand why he wanted to be
4 with me anyhow” *Bethany (individual with axSpA)*
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7 **“If I wanted a carer, I would have hired a carer”**
8

9 Roles within the relationship were typically adjusted to meet the needs of axSpA. For
10 partners this meant adopting a carer-type role by providing support for their partner with
11 axSpA. For some, this was an explicit identity, whereas for others this involved a more
12 implicit action of “being there” (*Charlotte, Partner*). Yet, supporting partners sometimes
13 proved demanding:
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16
17
18 “She needs to also accept that she’s not the only sufferer of AS. You know, there’s
19 three people [referring to son too] in this immediate family and actually all of us are
20 suffering as much if not more than she is” *Harry (partner)*
21
22

23 The word ‘sufferer’ emotively portrays a sense of hardship from living with axSpA as a
24 partner, which suggests a sense of resentment towards the condition which acted as an
25 impenetrable barrier within the relationship.
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30 For some partners, the carer role extended beyond providing daily support, progressing
31 towards a protector role. Partners talked about managing mood and disease flare-ups which
32 required constant attention. This sense of responsibility to protect was suggestive of an
33 inequitable relationship between partners at times, with the individuals' with axSpA
34 perceived as vulnerable:
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38
39 “I try to keep the mood from falling too far, it’s basically a constant it’s a constant
40 thing. It shouldn’t be and he doesn’t ask me to, but I’ve taken that burden on I think.
41 That’s almost my job to make sure he’s looking after himself well” *Phoebe (partner)*
42
43

44 It was common for the individuals with axSpA to feel guilty about having to rely on their
45 partners for support, with support focused on the individual with axSpA at the expense of the
46 partners’ well-being:
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50 “I’m actually concerned if it’s too much of a burden and [...] she’s not taking enough
51 time to look after her own health because she’s basically looking after me.” *David*
52 (*individual with axSpA*)
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3 Equally, to relieve the sense of burden and to protect their partners, some individuals with
4 axSpA made adjustments to support their partners:
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7 “He couldn’t sleep in bed with me so then it was impacting on him at work so he just
8 goes off and you know sleeps in the spare room and I can wriggle about as much as I
9 like without worrying about disturbing him” *Elizabeth (Individual with axSpA)*
10
11

12 However, other individuals with axSpA did not always consider their partner in all situations.
13 Emily enjoyed taking part in challenges involving physical activity despite knowing that it
14 could result in additional pain. But she ordinarily did not think beyond her own needs of
15 managing axSpA:
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18
19 “I’ve been way over doing it for weeks [...], I’m prepared to accept the consequences
20 and yes, I’ve got to admit, I very often don’t think how that impacts on him” *(Emily,*
21
22 *Individual with axSpA)*
23
24

25 An element of tension was evident between individuals with axSpA who were striving for
26 greater independence and partners who adopted the carer-type role:
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30 “So I couldn’t go to work, because I couldn’t move. And um he took the day off
31 work, he looked after me all day you know he done everything” (Sophie, Individual
32 with axSpA).
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36 Yet, the notion of dependency for the individuals’ with axSpA on their partners was
37 sometimes incompatible with their sense of identity and desire to lead a ‘normal’ life:
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42 “I have to sometimes rely on her, like I mean it’s like I shouldn’t have to really erm but
43 sometimes I have to [...] not a sexist thing, but I’m sort of like the bloke do you know
44 what I mean, so it’s like in my head that I’m, I’ve got to do certain things” *Tom*
45
46 *(individual with axSpA)*
47
48

49 Further, a line was sometimes crossed where too much help could be offered from partners,
50 contrary to the partners’ aims of making “life easier” (*Phoebe, Partner*) for the individuals
51 with axSpA. Sophie perceived that too much support from her partner had placed her into a
52 weakened position. Yet, she desired greater equality within the relationship through
53 demonstrating self-reliance:
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4 “Sometimes he tried to do too much and that I’m, he makes me feel like I’m you know
5 useless and not capable and I need help. And I always say to him (Steven) you’re not
6 my carer, if I wanted a carer I would have hired a carer. You’re my boyfriend, I want
7 you to be my boyfriend, [...] don’t try to do everything for me, not let me do stuff
8 myself because you know I want to do those things” *Sophie (individual with axSpA)*
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14 Self-reliance was also conveyed by the individuals with axSpA through a determination to
15 overcome the physical restrictions of axSpA. This was particularly significant for Emily who
16 desired:
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19 “Empathy. Not sympathy. Sympathy drives me bananas and he knows that. [...]. He
20 occasionally gets it wrong, I remember on, one of the recent challenges, [...] I started
21 getting ankle pain at 45k, checked if it at 52, I could see blood under the skin so I knew
22 that I’d torn something in there. And he said right you’re going to see a medic, I said
23 right I’m not, you know me better than that. I strapped it up tight and I did finish the
24 challenge.” *Emily (individual with axSpA)*
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30 In several cases, individuals with axSpA avoided displaying problems as a means of coping
31 and to demonstrate autonomy. However, this prevented partners from being able to assist,
32 which partners found distressing. Consequently, partners were sometimes outsiders to the
33 individuals’ with axSpA inner experiences:
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37 “You can tell she’s in pain and she doesn’t really want to talk to you and she just sort of
38 like wants to lay down and you know and it, that that can be challenging cos your like
39 in my head and just kind of like I’ll, you know, I just want to give her a hug and let her
40 know it’s all alright and everything” *Steven (partner)*
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45 DISCUSSION

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47 Partners are often also affected by the illness experience,(10,15), yet partner experiences of
48 axSpA and the impact of the condition on partner relationships has been under-researched.
49 This is the first qualitative study to explore the social context of axSpA according to partner
50 dyads. The study’s findings illustrate how managing axSpA could influence perceived
51 closeness between partners and dominate daily decisions. Furthermore, managing the
52 condition led partners to adopt a carer-type role whilst, simultaneously, many individuals
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3 with axSpA desired greater autonomy. This discrepancy in desired behaviour within the
4 relationships was problematic and resulted in substantial tension.
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7 A prominent feature of managing axSpA together was that joint leisure time for dyads was
8 often limited which could highlight dyads' sense of loss and difference to other couples. This
9 restriction extended a reduction in sexual activity, which is a widely acknowledged issue in
10 the axSpA literature.(19-21) The present study supports and broadens these findings through
11 the inclusion of partner experiences, indicating an element of distance within relationships
12 caused from living with axSpA. Furthermore, consistent with the axSpA literature,(18) many
13 dyads expressed how their lives typically revolved around condition management. Dyads
14 additionally highlighted positive experiences, such as gaining strengthened relationships,
15 analogous to previous reports by individuals with axSpA.(22) This positive change in
16 relational quality can be understood within the context of dyadic coping. Appraisal of axSpA
17 as a shared experience may have increased dyads' confidence in their ability to effectively
18 work together.(15)
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27 Moreover, partners felt a sense of responsibility to care for the individual with axSpA and
28 adopted a carer-type role, consistent with partner reports in the broader long-term health
29 condition literature.(36) Yet, consistent with the findings of Madsen and colleagues,(17)
30 reliance on partners often challenged individuals with axSpA's sense of identity. To
31 demonstrate independence, some individuals with axSpA avoided discussing axSpA with
32 their partner. This was challenging for partners who endeavoured to engage.
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38 Improvements in pain severity, symptoms of depression, and marital functioning have been
39 identified in individuals with a long-term health condition, including arthritis, from partner
40 dyadic interventions involving condition-management education and communication
41 support.(37) Couple-based interventions have also identified positive effects within family
42 members and spouses with regards to lessened feelings of caregiver burden and anxiety.(38-
43 39) Due to the effectiveness of dyadic interventions, there is a clear argument for extending
44 partners' involvement and support provision within healthcare consultations. Involving
45 partners in treatment could reduce the divide between partners' carer-type role and the
46 individuals' with axSpA desire for autonomy. This could confer benefits with regards to
47 lessened daily life restrictions.
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54 The study has several limitations. As all couples were heterosexual and White
55 British/Scottish the experiences may not be applicable to other types of couples. Moreover,
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3 the individuals with axSpA were mainly female which is not reflective of the typical axSpA
4 population where males are predominantly diagnosed. This may be indicative of the
5 demographics of the axSpA-specific charity's social media users. Specifically, participants in
6 this study had sought support from the axSpA-specific charity. Individuals who had not made
7 contact may have had different experiences. Despite these limitations, a key strength of the
8 study concerns its use of qualitative methods to enable an in-depth exploration of partner
9 relationships, thus meeting an important knowledge gap. These findings illustrate how
10 partner dyads experienced shared restrictions, altered relationship strength and changed roles,
11 adding to the rising consensus that managing a long-term health condition is interpersonal.
12 Furthermore, this study indicates the need for interventions aimed at supporting both partners.
13 Future research should examine how a pre-existing relationship becomes affected by the
14 onset of axSpA against a newly formed relationship as they may present important yet
15 differing challenges.
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28
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37 commercial or not-for-profit sectors.
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39

40 **Ethics:** The project was reviewed and approved by a delegated authority from the University
41 of Bath Psychology Department Ethics Committee.
42
43

44 **Data sharing statement:** No additional data are available.
45

46 **Competing interests:** Kerry Raybone and Abbie Jordan declare no conflicts of interest.
47 Hannah Family declares no conflicts of interest, but has received consultancy fees from Astra
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5 KR, AJ, HF and RS made substantial contributions to the study design, interpretation of the
6 findings for the study, manuscript writing and article revision. AJ and RS contributed to the
7 conception of the study. KR contributed to the collection of data and data analyses, with
8 detailed feedback provided by AJ and HF. All authors read and approved the final version of
9 the manuscript.
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Supplementary Table 1.

Topic guides for individuals with axSpA and partners

Question number	Topic guide for partners	Topic guide for individual with axSpA
1	When where you first aware that your partner had axSpA?	To start with, can you tell me about when you first noticed your axSpA symptoms? <i>Prompts: How have your symptoms changed (or not) until now? At what point did you receive your diagnosis?</i>
2	How do you think axSpA has impacted on your partner's life?	Can you talk through a typical day for you living with axSpA?
3	Can you tell me about any ways that your partner's condition has impacted on your life? <i>Prompts: How has your partners' axSpA affected your ability to engage in your choice of leisure activities? How has your partners' condition affected your home life? What is it about the illness that has impacted your life the most? Which symptoms/treatments have impacted the most? Why do you think these aspects of axSpA have impacted on your life the most? If any, what are the positive factors of your partner's axSpA on your life? What are the more negative factors of your partner's axSpA on your life?</i>	Can you tell me about any ways that the condition has impacted on your life? <i>Prompts: How has axSpA affected your home life? How has axSpA affected your ability to work? How has axSpA affected your ability to engage in your choice of leisure activities? What is it about the illness that has impacted on your life the most? Which symptoms have impacted the most? Which treatments have impacted the most? Why do you think these aspects of axSpA have impacted on your life the most? If any, what are the positive factors of axSpA in your life? What are the more negative factors of axSpA in your life?</i>
4	If it has, how has your life changed as a result of your partners' condition? <i>Prompts: what changes in your life have occurred as a result of your partners' condition? What alterations (if any) have you had to make in your life? What were the reasons behind these changes? How do you feel about the changes? What have been the more</i>	If it has, how has your life changed since developing axSpA? <i>Prompts: What changes in your life have occurred as a result of the axSpA diagnosis? What alterations (if any) have you had to make in your life? What were the reasons behind these changes? How do you feel about the changes? What have been the more negative changes? What have been the more positive changes?</i>

negative changes? What have been the more positive changes?

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|----|---|---|
| 5 | <p>What have you found particularly challenging about your partners axSpA on your life?
<i>Prompts: Can you tell me about any concerns/complications related to axSpA which have arisen? What particular symptoms have been challenging? Why were those particular symptoms challenging? How did you help resolve them (if you have)?</i></p> | <p>Can you tell me about any particular challenges you have experienced living with axSpA?
<i>Prompts: Can you tell me about any concerns/complications related to axSpA which have arisen? What particular symptoms have been challenging? What particular treatments/appointments have been challenging? Why have those particular treatments/symptoms/appointments been challenging? How have you resolved them (if you have)?</i></p> |
| 6 | <p>What do you think defines a good quality partner relationship?</p> | <p>Can you tell me about some of the things that you do to manage your axSpA in your everyday life?
<i>Prompts: What kinds of strategies do you use to manage the symptoms? What do you do to manage your home life? What do you do to manage your work life? Why do you manage axSpA this way? What impact does this management have? How effective are these strategies?</i></p> |
| 7 | <p>How would you describe your relationship with your partner generally?</p> | <p>What do you think makes a good quality partner relationship?</p> |
| 8 | <p>What support (if at all) do you receive as a result of supporting your partner with axSpA?
<i>Prompts: What kinds of support would you like to receive?</i></p> | <p>How would you describe your relationship with your partner generally?</p> |
| 9 | <p>If you do, what aspects of axSpA would you typically talk about with your partner?
<i>Prompts: Can you think why you would talk about these aspects in particular? How does your partner typically respond?</i></p> | <p>If you do, what aspects of axSpA would you typically talk about with your partner?
<i>Prompt: Can you think why you would talk about these aspects in particular? How does your partner typically respond?</i></p> |
| 10 | <p>Can you recall in what instances</p> | <p>Can you recall in what situations your partner</p> |
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1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	<p>you were a source of support for your partner in relation to their axSpA? <i>Prompts: How did you support your partner in managing their condition? In what circumstances would you typically support your partner in managing their condition? Why do these circumstances require your support? Can you think of any circumstances where you have not been so supportive? Why were you not so supportive?</i></p> <p>11 How has the condition impacted on your relationship with your partner? <i>Prompt: Why do you think these aspects of axSpA have impacted on your relationship? Has this changed over the course of the condition? How has this changed over the course of the condition? What are the more positive factors on your relationship? What are the more negative factors on your relationship? What roles do you and your partner take within the relationship? Have these roles changed since the development of axSpA?</i></p> <p>12 How (if at all) do you think axSpA will impact on your relationship with your partner in the future? <i>Prompt: Why do you think axSpA will have this impact?</i></p> <p>13 Is there anything else that you would like to say or any final thoughts you would like to mention about your experiences of axSpA?</p>	<p>has been a source of support in relation to your axSpA? <i>Prompts: How were they supportive? Why do you think they were supportive in those situations? In what situations were they not so supportive? How were they not as supportive? Why do you think they were not supportive?</i></p> <p>How has the condition impacted on your relationship with your partner? <i>Prompts: Why do you think these aspects of axSpA have impacted on your relationship? Has this changed over the course of the condition? What are the more positive factors on your relationship? What are the more negative factors on your relationship? What roles do you and your partner take within the relationship? Have these roles changed since the development of axSpA?</i></p> <p>How (if at all) do you think axSpA will impact on your relationship with your partner in the future? <i>Prompt: Why do you think axSpA will have this impact?</i></p> <p>Is there anything else that you would like to say or any final thoughts you would like to mention about your experiences of axSpA?</p>
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Supplementary Table 2: COREQ checklist

Domain 1: Research team and reflexivity		Location in Manuscript (Section, Page no.)
Personal characteristics		
1. Interviewer/facilitator	KR	Methods - 5
2. Credentials	BSc MSc	Title page – 1
3. Occupation	Masters in psychology student	Title page – 5
4. Gender	Female	Methods - 5
5. Experience and training	KR had completed the taught programme of the MSc programme which covered the principles of qualitative research in detail.	Not mentioned in text.
Relationship with participants		
6. Relationship established	No	Not mentioned in text
7. Participant knowledge of the interviewer What did the participants know about the researcher? E.g. personal goals, reasons for doing the research	Participants were briefed on the purpose of the study and the fact that its completion comprised part of the researcher's requirements for completion of a Masters in Health Psychology degree.	Methods - 5
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? E.g. bias, assumptions, reasons and interest in the research topic	KR had met some individuals with axial spondyloarthritis on a hospital-based exercise programme prior to interviewing which was a potential source of bias. No other interviewer-related biases were identified.	Methods – 5
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study?	Thematic analysis	Results – 5-6
Participant selection		
10. Sampling How were participants selected?	Purposive sampling	Methods – 5
11. Method of approach How were participants approached?	Advertisements for the study were made on an axSpA-specific social media pages where participants were invited to contact the researcher through email.	Methods – 5
12. Sample size	18 (9 individuals with axSpA; 9 partners).	Methods - 5
13. Non-participation	Thirty-one individuals	Methods – 5

1 2 3 4 5 6 7 8 9 10	How many people refused to participate or dropped out? Reasons?	requested information about the study, with 22 individuals subsequently not participating. Reasons for non-participation included living outside the UK, having a partner who did not wish to take part and feeling unwell.	
11	Setting		
12 13	14. Setting of data collection Where was the data collected?	Data was collected via telephone interviews.	Methods – 5
14 15 16 17 18 19	15. Presence of non-participants Was anyone else present besides the participants and researchers?	No. Mention is made of interviews being conducted individually.	Methods – 5
20 21 22 23 24 25	16. Description of sample What are the important characteristics of the sample? E.g demographic data, date.	Heterosexual couples; age range 23-65; 9 individuals with axSpA (N = 6 female) and 9 partners (N = 3 female). Data was collected between 23 rd May and 28 th June 2018.	Results – 6-8
26	Data collection		
27 28 29 30 31 32 33 34 35 36 37	17. Interview guide Were questions, prompts, guides provided by the authors?	Interviews were semi-structured and guided by a topic guide (table). Participants were interviewed individually, and separate but similar topic guides were used for individuals with axSpA and partners. Prompts were used, where appropriate, to encourage further depth.	Methods – 5
38	18. Repeat interviews	No	Not mentioned in text
39 40 41	19. Audio/visual recording	Interviews were audio-recorded using a digital recorder.	Methods – 5
42 43 44	20. Field notes	A reflexive journal was used to record thoughts after interviews.	Methods – 6
45 46 47 48	21. Duration What was the duration of the interviews?	The semi-structured interview durations ranged from 25 to 73 minutes.	Methods – 5
49 50	22. Data saturation Was data saturation discussed?	Yes	Methods -5
51 52 53 54	23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	No	Not mentioned in text
55 56 57 58 59 60	Domain 3: analysis and findings		

24. Number of data coders	One (KR)	Methods -6
25. Description of coding tree	No	Not mentioned in text
26. Derivation of themes	Themes were derived from the data	Methods – 6
27. Software	NVivo	Methods – 5
28. Participant checking Did participants provide feedback on the findings?	No	-
Reporting		
29. Quotations presented Where quotations presented to illustrate the themes/findings? Was each quotation identified?	Yes, specific comments were supported with verbatim quotes attributed to anonymous participant pseudonyms.	Results – 8-14
30. Data and findings consistent	Yes	Results – 8-14
31. Clarity of major themes Where major themes clearly presented in the findings?	Yes	Results – 8-14
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	Yes	Results – 8-14

BMJ Open

The (un)spoken realities of living with axial spondyloarthritis: a qualitative study focused on couple experiences

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Complete List of Authors:	Raybone, Kerry; University of Bath, Psychology Family, Hannah; University of Bath, Pharmacy and Pharmacology Sengupta, Raj; The Royal National Hospital for Rheumatic Diseases, Bath, Jordan, Abbie; University of Bath, Psychology and Centre for Pain Research
Primary Subject Heading:	Rheumatology
Secondary Subject Heading:	Qualitative research
Keywords:	axial spondyloarthritis, partner, relationship, long-term health condition, ankylosing spondylitis

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Manuscripts

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3 **The (un)spoken realities of living with axial spondyloarthritis: a qualitative study**
4 **focused on couple experiences**
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8 Kerry Raybone¹, Hannah Family², Raj Sengupta³, Abbie Jordan^{1,4}

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ABSTRACT

Objective: Axial spondyloarthritis is a long-term rheumatic condition. The symptoms, including pain, can impact upon the daily life routines and psychological wellbeing of individuals that are diagnosed with axSpA. Partners are often a main source of support for individuals who manage a long-term condition and they can also be affected by the illness experience, often themselves reporting elevated levels of emotional distress. Few qualitative studies have explored the impact of axSpA on partner relationships. This study addresses the social context of axSpA by investigating the experiences for both individuals with axSpA and their partners.

Design: Semi-structured individual telephone interviews analysed using Thematic Analysis at a dyadic partner level.

Setting: Participants were recruited from the social media pages of a UK based axSpA-specific charity.

Participants: Nine heterosexual partner dyads (23-65 years), who were currently co-habiting, comprising nine individuals diagnosed with axSpA (n=6 female) and nine partners (n=3 female).

Results: Three themes 'Perceived relational closeness', 'Playing third wheel to axSpA' and 'Tensions surrounding a carer role' were identified. The findings illustrate how living with axSpA can influence closeness between partners and dominate daily decisions, particularly surrounding leisure activities. Partners commonly adopted a carer-type role, despite many individuals with axSpA expressing desire for a greater sense of autonomy.

Conclusions: This study provides an important insight into the lived experiences of both individuals with axSpA and their partners. Findings highlight the social context of managing a long-term condition and suggest the need for including partners within consultations, and the need for support provision for partners.

ARTICLE SUMMARY

Strengths and limitations of this study

- In-depth qualitative interviews generated rich and meaningful data providing rich insights into partner dyadic experiences of axSpA.
- The first study to recruit both individuals with axSpA and their partners, enabling exploration of both similarities and differences between perceptions regarding living with axSpA.
- As participants were recruited from the social media pages of a single UK based axSpA charity, results represent accounts from participants who sought support from this organisation, suggesting potentially different accounts from participants who had not sought contact with the condition specific charity.
- Recruitment of dyads required a level of communication between partners to discuss participation, with the possibility of couples with poorer relationships being less likely to participate in the study.
- As dyads comprised only White British/Scottish heterosexual couples, participants' experiences may not represent those of other types of couples

INTRODUCTION

Axial spondyloarthritis (axSpA) is a group of rheumatic conditions primarily affecting the spine and sacroiliac joints [1-2] with chronic pain being the leading symptom.[3] The long-term condition predominantly affects males with symptoms typically developing prior to the age of 30.[4] Major daily living challenges associated with the condition include reduced functional ability, fatigue and depression.[5-7]

The rheumatoid arthritis (RA) literature has highlighted the importance of examining partner relationships with regard to health outcomes which, to our knowledge, is not evident within the axSpA literature. Due to similarities between RA and axSpA, with both being inflammatory rheumatic conditions which are associated with increased pain and related disability,[8-9] the RA literature is considered here as a helpful context in which to consider the importance of partner relationships in axSpA. One Canadian quantitative study identified that greater satisfaction with spousal responses was associated with reduced feelings of

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3 helplessness in individuals with RA.[10] Nonetheless, partner support is not always
4 protective, with studies highlighting associations between inaccurate estimations of their
5 partner's pain or fatigue and increased levels of anxiety and depression in individuals with
6 RA.[11] RA has also been shown to have a multifaceted impact upon partners, with
7 qualitative research identifying that exposure to their partner's pain is associated with
8 feelings of concern and helplessness.[12-13] To explore partner issues further, the concept of
9 dyadic coping has been identified, referring to the numerous ways that couples may
10 communicate during the management of illness-related stressors.[14] Specifically, the
11 Cognitive Transactional Model of dyadic coping with a chronic illness highlights how a
12 couple may assign illness ownership as 'my', 'your' or 'our' problem before appraising how
13 to manage the condition.[15] Dyadic coping can be positive or negative in nature,
14 acknowledging either collaboration or withdrawal between partners.[15-17] If the coping
15 strategy is perceived as effective this can increase dyadic efficacy, a sense of confidence with
16 working together, and influence relationship outcomes.[15] Reflective of this increased focus
17 on partners, an evidence base is growing, demonstrating the increased effectiveness of
18 couple-focused behaviour change interventions compared with usual care and individual
19 interventions for individuals with long-term conditions.[18]

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22 More recently, qualitative studies have begun to examine the social context of axSpA.
23 Individuals with axSpA report restrictions in their ability to engage in physical and social
24 activities [19-20] and experience sexual problems.[21-23] To contrast these negative
25 outcomes, some-qualitative studies have demonstrated strengthened partner relationships.[12,
26 24] Yet, such studies have typically only included the views of the individual with axSpA
27 regarding partner relationships, excluding partner experiences. One exception included a
28 quantitative study using psychometrically robust measures of psychological wellbeing,
29 physical wellbeing and depression, to find that spouses reported significantly reduced social
30 functioning and general health perceptions, and increased levels of depression, respectively,
31 compared to spouses of healthy individuals.[25] However, due to the restrictions associated
32 with self-report questionnaires, this study was unable to provide an in-depth exploration into
33 how and why partners of individuals with axSpA report a reduced quality of life. Considering
34 the potential challenges of having a partner with axSpA, it is problematic that the literature
35 has typically focused on studying the individual with axSpA in isolation.[19] A social
36 contextual focus is required for addressing the interpersonal element of living with axSpA.
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Consequently, this study aims to explore how and why axSpA impacts on partner relationships according to individuals with axSpA and their partners, which the adoption of qualitative methods will reveal in a more meaningful way.[26] As the Cognitive Transactional Model [15] explores the social context, it's both appropriate and useful to use this model to investigate the impact of axSpA on partner dyadic relationships. Findings, in turn, may inform clinical practice, facilitating support provision for individuals with axSpA and their partners.

METHODS

Sample and recruitment

Sampling was purposive to recruit dyads comprising individuals diagnosed with axSpA (n = 9) and their partners (n = 9). It was anticipated that between 5 and 10 dyads would be recruited based on previous related qualitative research studies,[27-29] and the scope of the study which was conducted as part of a four month Masters placement. A total of 18 participants (9 partner dyads) were recruited via study invitations placed by a UK-based axSpA-specific charity on their social media pages (Facebook and Twitter). Interested participants contacted the researcher to receive an information sheet, prior to providing fully informed written consent. Eligibility criteria required individuals to be aged at least 18 years, speak English fluently and report no cognitive impairments. Thirty-one individuals requested information about the study, with 22 individuals subsequently not participating. Reasons for non-participation included having a partner who did not wish to take part and feeling unwell.

Patient Involvement

The development of the research question was informed by earlier work conducted with patients with axSpA. Participants were not involved in the design, recruitment or conduct of the study. Participants will be informed via email about the publication of results.

Data collection

Data was collected via in-depth, individual semi-structured telephone interviews by KR (female Masters level psychology student), until data saturation was reached as defined by no new information being attained at data collection.[30-32] Telephone interviews have been shown to be as rich as face-to-face interviews with similarities in the type and depth of discussions elicited.[33] In particular, telephone interviews are appropriate for discussion of

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3 sensitive topics [34] and for recruitment of participants with a rare condition such as
4 axSpA,[35] resulting in a wide geographical spread of potential participants across the
5 UK.[34] Participants were interviewed individually to prevent direct influence from their
6 partner.[36] Topic guides were generated by identifying the main areas of interest [37] and
7 surveying the arthritis literature (see 12). Interview questions were open-ended, asking
8 participants about the impact of axSpA upon daily life and partner relationships. Separate yet
9 similar topic guides were devised for the individuals with axSpA and partners (see
10 supplementary Table 1).
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18 Probe questions prompted for further depth where appropriate.[38] Interview duration ranged
19 between 25 and 73 minutes, with interviews audio-recorded and transcribed verbatim.
20 Telephone interviews ceased once all questions had been asked and after prompting the
21 participants had no further information to share.[32] Telephone interviews have been reported
22 to induce greater levels of fatigue in participants compared with face-to-face interviews, with
23 an interview duration of 30 minutes considered to be appropriate for a telephone interview to
24 account for potential fatigue.[39]
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31 Prior to interviews, participants completed a brief online survey via Qualtrics (an online
32 survey platform) to provide basic demographic information along with informed consent.
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35 **Data analysis**

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37 Interview transcripts were prepared in a Word document. All individual interview transcripts
38 were uploaded into NVivo version 11 [40] (qualitative data analysis software) and analysed
39 using Thematic Analysis (TA) [41] at all stages of the analytical process. This enabled a rich
40 understanding of new data through exploration alongside the incorporation of past
41 research.[42] TA is a flexible method which allowed for an inductive approach to coding and
42 analysis of the idiographic focus on dyads' experiences. Braun and Clarke's [41] stages of
43 TA, which involved familiarisation, coding, producing, reviewing and labelling themes, were
44 followed iteratively from a descriptive to interpretative analysis.[43] Subsequently, accounts
45 of individuals' with axSpA were compared with partner accounts to note similarities and
46 differences.[44] A reflexive journal was used throughout data collection and analysis to
47 prevent biased interpretations of the data from previous knowledge of having met patients
48 with axSpA. Analysis was conducted by KR, with themes reviewed by AJ and HF to ensure
49 reliability. The consolidated criteria for reporting qualitative research (COREQ) [45] were
50 followed and Yardley's [46] criteria for assessing the quality of qualitative research were
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met. Previous studies were reviewed (sensitivity to context) and Braun and Clarke's [42] 15-point guidelines on conducting TA were followed (commitment and rigour). Further, a fit between the research question and choice of TA was ensured (coherence). Finally, knowledge about partner relationships within the context of axSpA was enhanced (impact and importance).

RESULTS

The sample comprised 9 individuals with axSpA and 9 partners. All couples were heterosexual and White British/Scottish, with an age range of 23-65 years. Six individuals with axSpA were female (see Table 1).

Table 1. Participant demographics

Pseudonym	Gender	Age	Ethnicity	Employment status	Length of relationship (years)	Live together?	Met before /after diagnosis?	Children
Elizabeth (dyad 1 axSpA)	Female	40	White British	Part-time	3.5	Yes	Before	Unknown
William (dyad 1 partner)	Male	43	White British	Full-time	3.5	Yes	Before	Unknown
Sophie (dyad 2 axSpA)	Female	29	White British	Full-time	2.5	Yes	After	No
Steven (dyad 2 partner)	Male	28	White British	Full-time	2.5	Yes	After	No
David (dyad 3 axSpA)	Male	45	Scottish	Full-time	25	Yes	Before	No
Phoebe (dyad 3 partner)	Female	43	White British	Full-time	25	Yes	Before	No

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3	Jack	Male	43	White	Full-time	17	Yes	Before	Yes
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5	<i>(dyad 4</i>			British					
6									
7	<i>axSpA)</i>								
8	Ellie	Female	36	White	Full time	17	Yes	Before	Yes
9									
10	<i>(dyad 4</i>			British					
11									
12	<i>partner)</i>								
13	Emily	Female	58	White	Self-	29	Yes	Before	Yes
14									
15	<i>(dyad 5</i>			British	employed				
16									
17	<i>axSpA)</i>								
18	Alexander	Male	65	White	Retired	29	Yes	Before	Yes
19									
20	<i>(dyad 5</i>			British					
21									
22	<i>partner)</i>								
23	Tom	Male	29	White	Full-time	6	Yes	After	Yes
24									
25	<i>(dyad 6</i>			British					
26									
27	<i>axSpA)</i>								
28	Charlotte	Female	23	White	Part-time	9	Yes	After	Yes
29									
30	<i>(dyad 6</i>			British					
31									
32	<i>partner)</i>								
33	Bethany	Female	50	White	Part-time	34	Yes	Before	Yes
34									
35	<i>(dyad 7</i>			British					
36									
37	<i>axSpA)</i>								
38	Oliver	Male	53	White	Full-time	34	Yes	Before	Yes
39									
40	<i>(dyad 7</i>			British					
41									
42	<i>partner)</i>								
43	Rosie	Female	32	White	Part-time	6	Yes	Before	Yes
44									
45	<i>(dyad 8</i>			British					
46									
47	<i>axSpA)</i>								
48	Harry	Male	35	White	Full-time	6	Yes	Before	Yes
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50	<i>(dyad 8</i>			British					
51									
52	<i>partner)</i>								
53	Jess	Female	56	White	Retired	17	Yes	After	No
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55	<i>(dyad 9</i>			British					
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57	<i>axSpA)</i>								
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Three themes, 'Perceived relational closeness', 'Playing third wheel to axSpA' and 'If I wanted a carer, I would have hired a carer', were identified. The themes reflect how the dyads' daily lives had been altered by axSpA through restrictions, changes in relationship strength, and altered partnership roles. Verbatim quotes from participants exemplify the findings. Pseudonyms have been used to both ensure confidentiality of participants and explore the idiographic nature of participant experiences.[42, 47]

Perceived relational closeness

Managing axSpA within a partner relationship had the potential to either enhance dyadic closeness or place greater distance between individuals. Many dyads reported strengthened relationships as a consequence of overcoming the challenges surrounding the condition. This created the sense of a 'team' within relationships. This feeling of enhanced relationship security and unity was perceived to be superior to other healthy couples. This suggests that through shaping relational interactions, axSpA had the capacity to characterise the relationship as something unique:

“The sort of bond that we have that way has been kind of strengthened or forged because of needing to [...] be more supportive emotionally [...] we seem as if we show that we care about each other a bit more than your average sort of bloke or woman”

Michael (partner)

However, not all partner relationships were cohesive, with the appearance that some partners were pulling against each other. Irritability caused by axSpA symptoms could result in the perception that the other partner did not fully understand their emotions or needs, placing an unwanted division within the relationship:

“Sometimes like I'm not as happy as I could be, if I'm a bit tired, you know, and then maybe they say you take it out on the one's you love don't you so you know sort of like a cycle. I like him giving me hugs and kisses but if I'm being a grump I'm not gonna get 'em am I?” *Rosie (individual with axSpA)*

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3 Intimacy was frequently reduced or lost between partners due to the symptoms of axSpA.
4 William and his partner experienced a challenge of “not sharing the bed all the time”
5 (*William, partner*). Further, Alexander explains:
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9 “Sex life vanished quite early on [...] and it isn’t something which she can deal with,
10 painkillers are not going to deal with that kind of stress on the body. So, when it all
11 became too painful I just sort of quietly agreed that this is something to stop” *Alexander*
12 (*partner*)
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18 Alexander felt a strong sense of reluctance about initiating intimate acts, so as not to cause
19 further pain to his partner. His use of the word ‘quietly’ reveals a sense of submission to
20 axSpA. This suggests that Alexander’s decision to stop sexual activity was not a desired
21 scenario and it was not explicitly acknowledged or discussed with his partner, emphasising a
22 degree of suppressed communication surrounding the challenges of axSpA.
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28 In some cases, this sense of distance was more profound. Bethany’s spine “curvature”, caused
29 by axSpA, left her feeling unworthy of her partner which caused her to distance herself from
30 him, resulting in a temporary separation:
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34 “I was exhausted I was in a lot of pain, I was tetchy and we did separate for 12 months.
35 And, (partner) did find somebody else he did have an affair, so it’s a bit, because I was
36 pushing and pushing away I think because I could not understand why he wanted to be
37 with me anyhow” *Bethany (individual with axSpA)*
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42 **Playing third wheel to axSpA**

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44 To varying degrees, all dyads experienced restrictions within their daily lives. Notably,
45 chronic pain and fatigue could limit the functional abilities of individuals with axSpA,
46 reducing their engagement in leisure time with their partners. This suggests that axSpA could
47 act as a third party within the relationship by placing an obstacle within dyads’ social time:
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52 “It probably stopped me doing more things with (Ellie) and my kids. (Ellie) takes my
53 son to football at the weekend because she knows I’m not really able to handle sitting
54 or standing around in the cold, things like that” *Jack (individual with axSpA)*
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58 Making social comparisons to healthy individuals often highlighted dyads’ perceived
59 constraints and differences, further emphasising what they were missing out on together as a
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3 result of living with axSpA. This reflects a tension between what is desirable and what is
4 possible:
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8 “It’s what you want to do and you can’t do as much as some of your friends are doing
9 and if some people are going away for like a short weekend or finish work on a Friday
10 then they’ll go away [...] well (partner’s) too tired once he’s finished work to go away
11 on a Friday night” *Charlotte (partner)*
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17 William, contrastingly, perceived a minimal influence of axSpA on his ability to share
18 activities with his partner:
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21 “We can still go out walking for 10miles and things like that so it hasn’t really been a
22 major impact on our relationship and the things we want to do together” (*William,*
23 *partner*)
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29 The constant nature of axSpA made life appear effortful for many of the dyads, who adopted
30 joint ownership of managing axSpA. The condition often acted as a central feature which
31 their lives subsequently revolved around, sometimes dominating the partner relationship and
32 pulling behaviours towards managing axSpA over tending to the relationship:
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37 “Literally absolutely everything from what we eat, to when we eat, to who does this, to
38 who does that, to when this happens, can it happen? [...] everything is sort of gravitated
39 to AS (referring to Ankylosing Spondylitis, a sub-group of axSpA)” *Harry (partner)*
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43 Dyadic life was portrayed as regimented with a need to plan ahead for activities, reducing
44 spontaneity in their everyday lives. Yet, almost contradictorily, a sudden axSpA flare-up
45 could alter plans at any time: “if he’s feeling really bad then he can’t go” (*Ellie, Partner*)
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49 In addition to joint activity restrictions, many partners experienced a pervading sense of
50 helplessness characterised by limited avenues to relieve their partner’s symptoms,
51 exacerbated by the unpredictability of axSpA. Use of the phrase ‘miracle worker’ illustrates
52 an acknowledging sense of powerlessness against the prevailing condition, further
53 highlighting the dominance of axSpA:
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3 “It was a lack of ability to change things which was difficult and it’s not that you’re
4 looking to be a miracle worker but there aren’t even simple things that you could [do]
5 dramatically, the flare-up or change could happen whenever” *Oliver (partner)*
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9 Despite the ever-present nature of axSpA, some dyads were able to work together to reduce
10 the dominance of the condition on their relationship by making the most out of positive
11 experiences:
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15 “We both count our blessings and I hope that, you know, I guess with anything you
16 don’t know what’s around the corner as well as what’s gonna happen to your body”
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18 *Jess (Individual with axSpA)*
19

20 21 **-“If I wanted a carer, I would have hired a carer”** 22

23
24 Roles within the relationship were typically adjusted to meet the needs of axSpA. For
25 partners this meant adopting a carer-type role. For some, this was an explicit identity,
26 whereas for others this involved a more implicit action of “being there” (*Charlotte, Partner*).
27 Yet, supporting partners sometimes proved demanding:
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31 “She needs to also accept that she’s not the only sufferer of AS. You know, there’s
32 three people [referring to son too] in this immediate family and actually all of us are
33 suffering as much if not more than she is” *Harry (partner)*
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37 The word ‘sufferer’ emotively portrays a sense of hardship from living with axSpA as a
38 partner, which suggests a sense of resentment towards the condition which acted as an
39 impenetrable barrier within the relationship.
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44 For some partners, the carer role extended beyond providing daily support, progressing
45 towards a protector role by managing mood and disease flare-ups which required constant
46 attention. This sense of responsibility to protect was suggestive of an inequitable relationship
47 at times, with the individuals' with axSpA perceived as vulnerable:
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52 “I try to keep the mood from falling too far, it’s basically a constant it’s a constant
53 thing. It shouldn’t be and he doesn’t ask me to, but I’ve taken that burden on I think.
54 That’s almost my job to make sure he’s looking after himself well” *Phoebe (partner)*
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58 Individuals with axSpA commonly felt guilty relying on their partners, with support focused
59 on the individual with axSpA at the expense of the partners’ well-being:
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3 “I’m actually concerned if it’s too much of a burden and [...] she’s not taking enough
4 time to look after her own health because she’s basically looking after me.” *David*
5
6 (*individual with axSpA*)
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9 Equally, to relieve the sense of burden and to protect their partners, some individuals with
10 axSpA made adjustments:
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12

13 “He couldn’t sleep in bed with me so then it was impacting on him at work so he just
14 goes off and you know sleeps in the spare room and I can wriggle about as much as I
15 like without worrying about disturbing him” *Elizabeth (Individual with axSpA)*
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19 However, for other individuals with axSpA the desire to regain control over the condition
20 could, at times, result in their attention being directed away from their partner. Emily enjoyed
21 taking part in physical challenges despite knowing that it could result in additional pain:
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23

24 “I’ve been way over doing it for weeks [...], I’m prepared to accept the consequences
25 and yes, I’ve got to admit, I very often don’t think how that impacts on him” (*Emily,*
26
27 *Individual with axSpA*)
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33 The notion of dependency for the individuals’ with axSpA on their partners was sometimes
34 incompatible with their sense of identity:
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38 “I have to sometimes rely on her, like I mean it’s like I shouldn’t have to really erm but
39 sometimes I have to [...] not a sexist thing, but I’m sort of like the bloke do you know
40 what I mean, so it’s like in my head that I’m, I’ve got to do certain things” *Tom*
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42 (*individual with axSpA*)
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46 Adopting a carer-role had the capacity to overrule the role of partner, and could result in an
47 element of tension between the individuals’ with axSpA seemingly opposing needs for
48 support with managing axSpA and desire to lead a ‘normal’ life. A line was sometimes
49 crossed where too much help could be offered from partners, contrary to the partners’ aims of
50 making “life easier” (*Phoebe, Partner*) for the individuals with axSpA. Sophie desired greater
51 equality within the relationship through demonstrating independence:
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58 “Sometimes he tried to do too much and that I’m, he makes me feel like I’m you know
59 useless and not capable and I need help. And I always say to him (Steven) you’re not
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3 my carer, if I wanted a carer I would have hired a carer. You're my boyfriend, I want
4 you to be my boyfriend, [...] don't try to do everything for me, not let me do stuff
5 myself because you know I want to do those things" *Sophie (individual with axSpA)*
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10 Self-reliance was also conveyed by the individuals with axSpA through a determination to
11 overcome the physical restrictions of axSpA. This was particularly significant for Emily who
12 desired:
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14

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16 "Empathy. Not sympathy. Sympathy drives me bananas and he knows that. [...]. He
17 occasionally gets it wrong, I remember on, one of the recent challenges, [...] I started
18 getting ankle pain at 45k, checked if it at 52, I could see blood under the skin so I knew
19 that I'd torn something in there. And he said right you're going to see a medic, I said
20 right I'm not, you know me better than that. I strapped it up tight and I did finish the
21 challenge." *Emily (individual with axSpA)*
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27 In several cases, individuals with axSpA avoided displaying problems as a means of coping
28 and to demonstrate autonomy. However, this prevented partners from being able to assist,
29 which partners found distressing. Consequently, partners were sometimes outsiders to the
30 individuals' with axSpA inner experiences:
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35 "You can tell she's in pain and she doesn't really want to talk to you and she just sort of
36 like wants to lay down and you know and it, that that can be challenging cos your like
37 [...]I just want to give her a hug and let her know it's all alright and everything" *Steven*
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(partner)

DISCUSSION

Partners are often also affected by the illness experience,[12, 15] yet partner experiences of axSpA and the impact of the condition on partner relationships has been under-researched. This is the first qualitative study to explore the social context of axSpA according to partner dyads. The study's findings illustrate how a joint approach was taken to manage axSpA, in line with the Cognitive Transactional Model of dyadic coping.[15]. This could influence perceived closeness between partners and dominate daily decisions. Furthermore, tensions could arise between partners' adoption of a carer-type role and individuals' with axSpA desire for autonomy. Avoiding talking about axSpA symptoms, which incited frustration in partners who endeavoured to help, can be perceived as a dyadic coping strategy of

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3 withdrawal.[16] Separate strategies may indicate increases in self-efficacy, as opposed to
4 dyadic efficacy.[15]
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7 Joint leisure time for dyads was often limited which could highlight dyads' sense of loss and
8 difference to other couples. This restriction extended to a reduction in sexual activity, which
9 is a widely acknowledged issue in the axSpA literature.[21-23] The present study supports
10 and broadens these findings through the inclusion of partner experiences, indicating an
11 element of distance within relationships caused from living with axSpA. Furthermore,
12 consistent with the axSpA literature,[20] many dyads expressed how their lives typically
13 revolved around condition management. Dyads additionally highlighted positive experiences,
14 such as gaining strengthened relationships, analogous to previous reports by individuals with
15 axSpA.[24] This positive change in relational quality can be understood within the context of
16 dyadic coping. Appraisal of axSpA as a shared experience may have increased dyads'
17 confidence in their ability to effectively work together.[15] Moreover, partners felt a sense of
18 responsibility to care for the individual with axSpA, adopting a carer-type role, consistent
19 with partner reports in the broader long-term health condition literature.[48] Yet, consistent
20 with the findings of Madsen and colleagues,[19] reliance on partners often challenged
21 individuals with axSpA's sense of identity.
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33 Improvements in pain, depression, and marital functioning have been identified in individuals
34 with arthritis, from partner dyadic interventions.[49] Couple-based interventions have also
35 identified lessened feelings of caregiver burden and anxiety within spouses.[50-51] Due to
36 the effectiveness of dyadic interventions, there is a clear argument for extending partners'
37 involvement and support provision within healthcare consultations, which could reduce the
38 divide between partners' carer-type role and the individuals' with axSpA desire for
39 autonomy. This could lessen daily life restrictions.
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47 The study has several limitations. As all couples were heterosexual and White
48 British/Scottish the experiences may not be applicable to other types of couples. Moreover,
49 all participants in this study had sought support from the axSpA-specific charity through
50 social media, suggesting that participants may have greater perceived support needs and/or a
51 more aggressive disease trajectory than individuals with axSpA who did not make contact
52 with the axSpA charity's social media pages. Telephone interviews usefully facilitated the
53 discussion of a sensitive topic about partner relationships within the context of axSpA.[34]
54 However, it is recognised that visual communication, such as facial expressions, are absent
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3 during telephone interviews, which may potentially limit interaction.[52] Despite these
4 limitations, a key strength of the study concerns its use of qualitative methods to enable an
5 in-depth exploration of partner relationships, thus meeting an important knowledge gap.
6 These findings add to the rising consensus that managing a long-term health condition is
7 interpersonal and indicate the need for interventions aimed at supporting both partners.
8 Additionally, this study did not collect data on individuals' medication use and self-reported
9 disease activity. Since such data may potentially influence findings, it would be helpful for
10 future research to focus on these aspects in individuals with axSpA with regard to their
11 partner relationships. Future research should also examine how a pre-existing relationship
12 becomes affected by the onset of axSpA against a newly formed relationship as they may
13 present important yet differing challenges.
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26 **Acknowledgements**

27
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29 stories with us and the relevant axSpA based charity for facilitating the recruitment process.
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34

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36 commercial or not-for-profit sectors.
37
38

39 **Ethics:** The project was reviewed and approved by a delegated authority from the University
40 of Bath Psychology Department Ethics Committee.
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42

43 **Data sharing statement:** No additional data are available.
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45

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58 **Author Contributions:** The project was conducted as part of a Masters in Health
59 Psychology dissertation under the supervision of Dr Abbie Jordan and Dr Hannah Family.
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3 KR, AJ, HF and RS made substantial contributions to the study design, interpretation of the
4 findings for the study, manuscript writing and article revision. AJ and RS contributed to the
5 conception of the study. KR contributed to the collection of data and data analyses, with
6 detailed feedback provided by AJ and HF. All authors read and approved the final version of
7 the manuscript.
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For peer review only

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Supplementary Table 1.

Topic guides for individuals with axSpA and partners

Question number	Topic guide for partners	Topic guide for individual with axSpA
1	When were you first aware that your partner had axSpA?	To start with, can you tell me about when you first noticed your axSpA symptoms? <i>Prompts: How have your symptoms changed (or not) until now? At what point did you receive your diagnosis?</i>
2	How do you think axSpA has impacted on your partner's life?	Can you talk through a typical day for you living with axSpA?
3	Can you tell me about any ways that your partner's condition has impacted on your life? <i>Prompts: How has your partner's axSpA affected your ability to engage in your choice of leisure activities? How has your partner's condition affected your home life? What is it about the illness that has impacted your life the most? Which symptoms/treatments have impacted the most? Why do you think these aspects of axSpA have impacted on your life the most? If any, what are the positive factors of your partner's axSpA on your life? What are the more negative factors of your partner's axSpA on your life?</i>	Can you tell me about any ways that the condition has impacted on your life? <i>Prompts: How has axSpA affected your home life? How has axSpA affected your ability to work? How has axSpA affected your ability to engage in your choice of leisure activities? What is it about the illness that has impacted on your life the most? Which symptoms have impacted the most? Which treatments have impacted the most? Why do you think these aspects of axSpA have impacted on your life the most? If any, what are the positive factors of axSpA in your life? What are the more negative factors of axSpA in your life?</i>
4	If it has, how has your life changed as a result of your partner's condition? <i>Prompts: what changes in your life have occurred as a result of your partner's condition? What alterations (if any) have you had to make in your life? What were the reasons behind these changes? How do you feel about the changes? What have been the more</i>	If it has, how has your life changed since developing axSpA? <i>Prompts: What changes in your life have occurred as a result of the axSpA diagnosis? What alterations (if any) have you had to make in your life? What were the reasons behind these changes? How do you feel about the changes? What have been the more negative changes? What have been the more positive changes?</i>

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negative changes? What have been the more positive changes?

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| 5 | <p>What have you found particularly challenging about your partners axSpA on your life?
<i>Prompts: Can you tell me about any concerns/complications related to axSpA which have arisen? What particular symptoms have been challenging? Why were those particular symptoms challenging? How did you help resolve them (if you have)?</i></p> | <p>Can you tell me about any particular challenges you have experienced living with axSpA?
<i>Prompts: Can you tell me about any concerns/complications related to axSpA which have arisen? What particular symptoms have been challenging? What particular treatments/appointments have been challenging? Why have those particular treatments/symptoms/appointments been challenging? How have you resolved them (if you have)?</i></p> |
| 6 | <p>What do you think defines a good quality partner relationship?</p> | <p>Can you tell me about some of the things that you do to manage your axSpA in your everyday life?
<i>Prompts: What kinds of strategies do you use to manage the symptoms? What do you do to manage your home life? What do you do to manage your work life? Why do you manage axSpA this way? What impact does this management have? How effective are these strategies?</i></p> |
| 7 | <p>How would you describe your relationship with your partner generally?</p> | <p>What do you think makes a good quality partner relationship?</p> |
| 8 | <p>What support (if at all) do you receive as a result of supporting your partner with axSpA?
<i>Prompts: What kinds of support would you like to receive?</i></p> | <p>How would you describe your relationship with your partner generally?</p> |
| 9 | <p>If you do, what aspects of axSpA would you typically talk about with your partner?
<i>Prompts: Can you think why you would talk about these aspects in particular? How does your partner typically respond?</i></p> | <p>If you do, what aspects of axSpA would you typically talk about with your partner?
<i>Prompt: Can you think why you would talk about these aspects in particular? How does your partner typically respond?</i></p> |
| 10 | <p>Can you recall in what instances</p> | <p>Can you recall in what situations your partner</p> |
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1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	<p>you were a source of support for your partner in relation to their axSpA? <i>Prompts: How did you support your partner in managing their condition? In what circumstances would you typically support your partner in managing their condition? Why do these circumstances require your support? Can you think of any circumstances where you have not been so supportive? Why were you not so supportive?</i></p> <p>11 How has the condition impacted on your relationship with your partner? <i>Prompt: Why do you think these aspects of axSpA have impacted on your relationship? Has this changed over the course of the condition? How has this changed over the course of the condition? What are the more positive factors on your relationship? What are the more negative factors on your relationship? What roles do you and your partner take within the relationship? Have these roles changed since the development of axSpA?</i></p> <p>12 How (if at all) do you think axSpA will impact on your relationship with your partner in the future? <i>Prompt: Why do you think axSpA will have this impact?</i></p> <p>13 Is there anything else that you would like to say or any final thoughts you would like to mention about your experiences of axSpA?</p>	<p>has been a source of support in relation to your axSpA? <i>Prompts: How were they supportive? Why do you think they were supportive in those situations? In what situations were they not so supportive? How were they not as supportive? Why do you think they were not supportive?</i></p> <p>How has the condition impacted on your relationship with your partner? <i>Prompts: Why do you think these aspects of axSpA have impacted on your relationship? Has this changed over the course of the condition? What are the more positive factors on your relationship? What are the more negative factors on your relationship? What roles do you and your partner take within the relationship? Have these roles changed since the development of axSpA?</i></p> <p>How (if at all) do you think axSpA will impact on your relationship with your partner in the future? <i>Prompt: Why do you think axSpA will have this impact?</i></p> <p>Is there anything else that you would like to say or any final thoughts you would like to mention about your experiences of axSpA?</p>
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COREQ checklist

Domain 1: Research team and reflexivity		Location in Manuscript (Section, Page no.)
Personal characteristics		
1. Interviewer/facilitator	KR	Methods - 5
2. Credentials	BSc MSc	Title page – 1
3. Occupation	Masters in psychology student	Title page – 5
4. Gender	Female	Methods - 5
5. Experience and training	KR had completed the taught programme of the MSc programme which covered the principles of qualitative research in detail.	Not mentioned in text.
Relationship with participants		
6. Relationship established	No	Not mentioned in text
7. Participant knowledge of the interviewer What did the participants know about the researcher? E.g. personal goals, reasons for doing the research	Participants were briefed on the purpose of the study and the fact that its completion comprised part of the researcher's requirements for completion of a Masters in Health Psychology degree.	Methods - 5
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? E.g. bias, assumptions, reasons and interest in the research topic	KR had met some individuals with axial spondyloarthritis on a hospital-based exercise programme prior to interviewing which was a potential source of bias. No other interviewer-related biases were identified.	Methods – 5
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study?	Thematic analysis	Methods – 6-7
Participant selection		
10. Sampling How were participants selected?	Purposive sampling	Methods – 5
11. Method of approach How were participants approached?	Advertisements for the study were made on an axSpA-specific charity's social media pages where participants were invited to contact the researcher through email.	Methods – 5
12. Sample size	18 (9 individuals with axSpA; 9 partners).	Methods - 5
13. Non-participation	Thirty-one individuals	Methods – 5

1 2 3 4 5 6 7 8 9 10 11	How many people refused to participate or dropped out? Reasons?	requested information about the study, with 22 individuals subsequently not participating. Reasons for non-participation included living outside the UK, having a partner who did not wish to take part and feeling unwell.	
12	Setting		
13 14	14. Setting of data collection Where was the data collected?	Data was collected via telephone interviews.	Methods – 5
15 16 17 18 19 20	15. Presence of non-participants Was anyone else present besides the participants and researchers?	No. Mention is made of interviews being conducted individually.	Methods – 5
21 22 23 24 25 26 27	16. Description of sample What are the important characteristics of the sample? E.g demographic data, date.	Heterosexual couples; age range 23-65; 9 individuals with axSpA (N = 6 female) and 9 partners (N = 3 female). Data was collected between 23 rd May and 28 th June 2018.	Results – 7-9
28	Data collection		
29 30 31 32 33 34 35 36 37 38 39 40 41	17. Interview guide Were questions, prompts, guides provided by the authors?	Interviews were semi-structured and guided by a topic guide (supplementary table 1). Participants were interviewed individually, and separate but similar topic guides were used for individuals with axSpA and partners. Prompts were used, where appropriate, to encourage further depth.	Methods – 6
42	18. Repeat interviews	No	Not mentioned in text
43 44 45	19. Audio/visual recording	Interviews were audio-recorded using a digital recorder.	Methods – 6
46 47 48	20. Field notes	A reflexive journal was used to record thoughts after interviews.	Methods – 6
49 50 51 52	21. Duration What was the duration of the interviews?	The semi-structured interview durations ranged from 25 to 73 minutes.	Methods – 6
53 54	22. Data saturation Was data saturation discussed?	Yes	Methods -5
55 56 57 58 59	23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	No	Not mentioned in text
60	Domain 3: analysis and		

findings		
24. Number of data coders	One (KR)	Methods -6
25. Description of coding tree	No	Not mentioned in text
26. Derivation of themes	Themes were derived from the data	Methods – 6
27. Software	NVivo	Methods – 5
28. Participant checking Did participants provide feedback on the findings?	No	Not mentioned in text
Reporting		
29. Quotations presented Where quotations presented to illustrate the themes/findings? Was each quotation identified?	Yes, specific comments were supported with verbatim quotes attributed to anonymous participant pseudonyms.	Results – 9-14
30. Data and findings consistent	Yes	Results – 9-14
31. Clarity of major themes Where major themes clearly presented in the findings?	Yes	Results – 9-14
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	Yes	Results – 9-14

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The (un)spoken realities of living with axial spondyloarthritis: a qualitative study focused on couple experiences

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3 **The (un)spoken realities of living with axial spondyloarthritis: a qualitative study**
4 **focused on couple experiences**
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ABSTRACT

Objective: Axial spondyloarthritis is a long-term rheumatic condition. The symptoms, including pain, can impact upon the daily life routines and psychological wellbeing of individuals that are diagnosed with axSpA. Partners are often a main source of support for individuals who manage a long-term condition and they can also be affected by the illness experience, often themselves reporting elevated levels of emotional distress. Few qualitative studies have explored the impact of axSpA on partner relationships. This study addresses the social context of axSpA by investigating the experiences for both individuals with axSpA and their partners.

Design: Semi-structured individual telephone interviews analysed using Thematic Analysis at a dyadic partner level.

Setting: Participants were recruited from the social media pages of a UK based axSpA-specific charity.

Participants: Nine heterosexual partner dyads (23-65 years), who were currently co-habiting, comprising nine individuals diagnosed with axSpA (n=6 female) and nine partners (n=3 female).

Results: Three themes 'Perceived relational closeness', 'Playing third wheel to axSpA' and 'Tensions surrounding a carer-type role' were identified. The findings illustrate how living with axSpA can influence closeness between partners and dominate daily decisions, particularly surrounding leisure activities. Partners commonly adopted a carer-type role, despite many individuals with axSpA expressing desire for a greater sense of autonomy.

Conclusions: This study provides an important insight into the lived experiences of both individuals with axSpA and their partners. Findings highlight the social context of managing a long-term condition and suggest the need for including partners within consultations, and the need for support provision for partners.

ARTICLE SUMMARY

Strengths and limitations of this study

- In-depth qualitative interviews generated rich and meaningful data providing rich insights into partner dyadic experiences of axSpA.
- The first study to recruit both individuals with axSpA and their partners, enabling exploration of both similarities and differences between perceptions regarding living with axSpA.
- As participants were recruited from the social media pages of a single UK based axSpA charity, results represent accounts from participants who sought support from this organisation, suggesting potentially different accounts from participants who had not sought contact with the condition specific charity.
- Recruitment of dyads required a level of communication between partners to discuss participation, with the possibility of couples with poorer relationships being less likely to participate in the study.
- As dyads comprised only White British heterosexual couples, participants' experiences may not represent those of other types of couples

INTRODUCTION

Axial spondyloarthritis (axSpA) is a group of rheumatic conditions primarily affecting the spine and sacroiliac joints [1-2] with chronic pain being the leading symptom.[3] The long-term condition predominantly affects males with symptoms typically developing prior to the age of 30.[4] Major daily living challenges associated with the condition include reduced functional ability, fatigue and depression.[5-7]

Reducing the progression of functional disability in individuals with axSpA is an important clinical and research focus. Studies have suggested that social support can play an important role, noting that social support has been shown to lessen the rate of functional disability progression over the course of five years in individuals with axSpA.[8] Specific to partner relationships, the rheumatoid arthritis (RA) literature has highlighted the importance of examining partner relationships with regard to influencing health outcomes which, to the best of our knowledge, is currently non-existent within the axSpA literature. Due to similarities

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2
3 between RA and axSpA, with both being inflammatory rheumatic conditions associated with
4 increased pain and related disability,[9-10] the RA literature is considered here as a helpful
5 context in which to consider the importance of partner relationships in axSpA. One Canadian
6 quantitative study identified that greater satisfaction with spousal responses was associated
7 with reduced feelings of helplessness in individuals with RA.[11] Nonetheless, partner
8 support is not always protective, with studies highlighting associations between inaccurate
9 estimations of their partner's pain or fatigue and increased levels of anxiety and depression in
10 individuals with RA.[12] To explore partner issues further, the concept of dyadic coping has
11 been identified, referring to the numerous ways that couples may communicate during the
12 management of illness-related stressors.[13] Specifically, the Cognitive Transactional Model
13 of dyadic coping with a long term health condition highlights how a couple may assign
14 illness ownership as 'my', 'your' or 'our' problem before appraising how to manage the
15 condition.[14] Dyadic coping can be positive or negative in nature, acknowledging either
16 collaboration or withdrawal between partners.[14-16] If the coping strategy is perceived as
17 effective this can increase dyadic efficacy, a sense of confidence with working together, and
18 influence relationship outcomes.[14] Reflective of this increased focus on partners, an
19 evidence base is growing, demonstrating the increased effectiveness of couple-focused
20 behaviour change interventions compared with usual care and individual interventions for
21 individuals with long-term conditions.[17]

22
23
24 Qualitative studies have also begun to examine the social context of axSpA. Individuals with
25 axSpA report restrictions in their ability to engage in physical and social activities [18-19]
26 and experience sexual problems.[20-22] To contrast these negative outcomes, a qualitative
27 study has demonstrated strengthened partner relationships.[23] Yet, a study using a
28 questionnaire to examine social roles has shown that whilst individuals with axSpA place
29 greater importance on partner relationships compared to a control group, their satisfaction
30 with the ability to participate in this role is lower.[24] Studies examining partner
31 relationships within axSpA have typically only included the views of the individual with
32 axSpA, excluding partner experiences. One exception included a quantitative study using
33 psychometrically robust measures of psychological wellbeing, physical wellbeing and
34 depression, to find that spouses reported significantly reduced social functioning and general
35 health perceptions, and increased levels of depression, respectively, compared to spouses of
36 healthy individuals.[25] However, due to the restrictions associated with self-report
37 questionnaires, this study was unable to provide an in-depth exploration into how and why
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3 partners of individuals with axSpA report a reduced quality of life. Considering the potential
4 challenges of having a partner with axSpA, it is problematic that the literature has typically
5 focused on studying the individual with axSpA in isolation.[18]
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9 Consequently, using an idiographic exploratory qualitative approach,[26] this study aims to
10 explore how and why axSpA impacts on partner relationships according to individuals with
11 axSpA and their partners.
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14 15 **METHODS**

16 17 **Sample and recruitment**

18
19 Sampling was purposive to recruit dyads comprising individuals diagnosed with axSpA (n =
20 9) and their partners (n = 9). It was anticipated that between 5 and 10 dyads would be
21 recruited based on previous related qualitative research studies,[27-29] and the scope of the
22 study which was conducted as part of a four month Masters placement. A total of 18
23 participants (9 partner dyads) were recruited via study invitations placed by a UK-based
24 axSpA-specific charity on their social media pages (Facebook and Twitter). Interested
25 participants contacted the researcher to receive an information sheet, prior to providing fully
26 informed written consent. Eligibility criteria required individuals to be aged at least 18 years,
27 speak English fluently and report no cognitive impairments. Thirty-one individuals requested
28 information about the study, with 22 individuals subsequently not participating. Reasons for
29 non-participation included having a partner who did not wish to take part and feeling unwell.
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40 41 **Patient Involvement**

42 The development of the research question was informed by earlier work conducted with
43 patients with axSpA. Participants were not involved in the design, recruitment or conduct of
44 the study. Participants will be informed via email about the publication of results.
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49 50 **Data collection**

51 Data was collected via in-depth, individual semi-structured telephone interviews by KR
52 (female Masters level psychology student), until data saturation was reached as defined by no
53 new information being attained at data collection.[30-32] Telephone interviews have been
54 shown to be optimal choices for collecting rich data, examining sensitive topics and for
55 facilitating recruitment of geographically diverse participants such as those with rare
56 conditions such as axSpA.[33-35] Participants were interviewed individually to prevent direct
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3 influence from their partner.[36] Topic guides were generated by identifying the main areas
4 of interest [37] and surveying the literature (see 12). Interview questions were open-ended,
5 asking participants about the impact of axSpA upon daily life and partner relationships.
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8 Separate yet similar topic guides were devised for the individuals with axSpA and partners
9 (see supplementary Table 1).
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12 Probe questions were used to prompt for further depth where appropriate.[38] Interview
13 duration ranged between 25 and 73 minutes, with interviews audio-recorded and transcribed
14 verbatim. Telephone interviews have been reported to induce greater levels of fatigue in
15 participants compared with face-to-face interviews, with an interview duration of around 30
16 minutes considered to be appropriate for a telephone interview.[39]
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19 Prior to interviews, participants completed a brief online survey via Qualtrics (an online
20 survey platform) to provide basic demographic information along with informed consent.
21
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23 **Data analysis**

24 Interview transcripts were prepared in a Word document. All individual interview transcripts
25 were uploaded into NVivo version 11 [40] (qualitative data analysis software) and analysed
26 using Thematic Analysis (TA) [41] at all stages of the analytical process. This enabled a rich
27 understanding of new data through exploration alongside the incorporation of past
28 research.[42] TA is a flexible method which allowed for an inductive approach to coding and
29 analysis of the idiographic focus on dyads' experiences. Braun and Clarke's [41] stages of
30 TA, which involved familiarisation, coding, producing, reviewing and labelling themes, were
31 followed iteratively from a descriptive to interpretative analysis.[43] Subsequently, accounts
32 of individuals' with axSpA were compared with partner accounts to note similarities and
33 differences.[44] A reflexive journal was used throughout data collection and analysis to
34 prevent biased interpretations of the data from previous knowledge of having met patients
35 with axSpA. Analysis was conducted by KR, with themes reviewed by AJ and HF to ensure
36 reliability. The consolidated criteria for reporting qualitative research (COREQ) [45] were
37 followed and Yardley's [46] criteria for assessing the quality of qualitative research were
38 met. Previous studies were reviewed (sensitivity to context) and Braun and Clarke's [42] 15-
39 point guidelines on conducting TA were followed (commitment and rigour). Further, a fit
40 between the research question and choice of TA was ensured (coherence). Finally, knowledge
41 about partner relationships within the context of axSpA was enhanced (impact and
42 importance).
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RESULTS

The sample comprised 9 individuals with axSpA and 9 partners. All couples were heterosexual and White British/Scottish, with an age range of 23-65 years. Six individuals with axSpA were female (see Table 1).

Table 1. Participant demographics

Pseudonym	Gender	Age	Ethnicity	Employment status	Length of relationship (years)	Live together?	Met before /after diagnosis?	Children
Elizabeth (dyad 1 axSpA)	Female	40	White British	Part-time	3.5	Yes	Before	Unknown
William (dyad 1 partner)	Male	43	White British	Full-time	3.5	Yes	Before	Unknown
Sophie (dyad 2 axSpA)	Female	29	White British	Full-time	2.5	Yes	After	No
Steven (dyad 2 partner)	Male	28	White British	Full-time	2.5	Yes	After	No
David (dyad 3 axSpA)	Male	45	Scottish	Full-time	25	Yes	Before	No
Phoebe (dyad 3 partner)	Female	43	White British	Full-time	25	Yes	Before	No
Jack (dyad 4 axSpA)	Male	43	White British	Full-time	17	Yes	Before	Yes
Ellie (dyad 4 partner)	Female	36	White British	Full time	17	Yes	Before	Yes

Emily (<i>dyad 5</i> <i>axSpA</i>)	Female	58	White British	Self- employed	29	Yes	Before	Yes
Alexander (<i>dyad 5</i> <i>partner</i>)	Male	65	White British	Retired	29	Yes	Before	Yes
Tom (<i>dyad 6</i> <i>axSpA</i>)	Male	29	White British	Full-time	6	Yes	After	Yes
Charlotte (<i>dyad 6</i> <i>partner</i>)	Female	23	White British	Part-time	9	Yes	After	Yes
Bethany (<i>dyad 7</i> <i>axSpA</i>)	Female	50	White British	Part-time	34	Yes	Before	Yes
Oliver (<i>dyad 7</i> <i>partner</i>)	Male	53	White British	Full-time	34	Yes	Before	Yes
Rosie (<i>dyad 8</i> <i>axSpA</i>)	Female	32	White British	Part-time	6	Yes	Before	Yes
Harry (<i>dyad 8</i> <i>partner</i>)	Male	35	White British	Full-time	6	Yes	Before	Yes
Jess (<i>dyad 9</i> <i>axSpA</i>)	Female	56	White British	Retired	17	Yes	After	No
Michael (<i>dyad 9</i> <i>partner</i>)	Male	54	White British	Full-time	17	Yes	After	No

Three themes, 'Perceived relational closeness', 'Playing third wheel to axSpA' and 'Tensions surrounding a carer-type role' were identified. The themes reflect how the dyads' daily lives

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2
3 had been altered by axSpA through restrictions, changes in relationship strength, and altered
4 partnership roles. Verbatim quotes from participants exemplify the findings. Pseudonyms
5 have been used to both ensure confidentiality of participants and explore the idiographic
6 nature of participant experiences.[42, 47]
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10 **Perceived relational closeness**

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14 Managing axSpA within a partner relationship had the potential to either enhance dyadic
15 closeness or place greater distance between individuals. Many dyads reported strengthened
16 relationships as a consequence of overcoming the challenges surrounding the condition. This
17 created the sense of a ‘team’ within relationships. This feeling of enhanced relationship
18 security and unity was perceived to be superior to other healthy couples. This suggests that
19 through shaping relational interactions, axSpA had the capacity to characterise the
20 relationship as something unique:
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28 “The sort of bond that we have that way has been kind of strengthened or forged
29 because of needing to [...] be more supportive emotionally [...] we seem as if we show
30 that we care about each other a bit more than your average sort of bloke or woman”
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32

33 *Michael (partner)*
34
35

36 However, not all partner relationships were cohesive, with the appearance that some partners
37 were pulling against each other. Irritability caused by axSpA symptoms could result in the
38 perception that the other partner did not fully understand their emotions or needs, placing an
39 unwanted division within the relationship:
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44 “Sometimes like I’m not as happy as I could be, if I’m a bit tired, you know, and then
45 maybe they say you take it out on the one’s you love don’t you so you know sort of like
46 a cycle. I like him giving me hugs and kisses but if I’m being a grump I’m not gonna
47 get ‘em am I?” *Rosie (individual with axSpA)*
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51 Intimacy was frequently reduced or lost between partners due to the symptoms of axSpA.
52 William and his partner experienced a challenge of “not sharing the bed all the time”
53 (*William, partner*). Further, Alexander explains:
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57 “Sex life vanished quite early on [...] and it isn’t something which she can deal with,
58 painkillers are not going to deal with that kind of stress on the body. So, when it all
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3 became too painful I just sort of quietly agreed that this is something to stop” *Alexander*
4
5 (*partner*)
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8 Alexander felt a strong sense of reluctance about initiating intimate acts, so as not to cause
9 further pain to his partner. His use of the word ‘quietly’ reveals a sense of submission to
10 axSpA. This suggests that Alexander’s decision to stop sexual activity was not a desired
11 scenario and it was not explicitly acknowledged or discussed with his partner, emphasising a
12 degree of suppressed communication surrounding the challenges of axSpA.
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18 In some cases, this sense of distance was more profound. Bethany’s spine “curvature”, caused
19 by axSpA, left her feeling unworthy of her partner which caused her to distance herself from
20 him, resulting in a temporary separation:
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24 “I was exhausted I was in a lot of pain, I was tetchy and we did separate for 12 months.
25 And, (*partner*) did find somebody else he did have an affair, so it’s a bit, because I was
26 pushing and pushing away I think because I could not understand why he wanted to be
27 with me anyhow” *Bethany (individual with axSpA)*
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32 **Playing third wheel to axSpA**

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34 To varying degrees, all dyads experienced restrictions within their daily lives. Notably,
35 chronic pain and fatigue could limit the functional abilities of individuals with axSpA,
36 reducing their engagement in leisure time with their partners. This suggests that axSpA could
37 act as a third party within the relationship by placing an obstacle within dyads’ social time:
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42 “It probably stopped me doing more things with (*Ellie*) and my kids. (*Ellie*) takes my
43 son to football at the weekend because she knows I’m not really able to handle sitting
44 or standing around in the cold, things like that” *Jack (individual with axSpA)*
45
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49 Making social comparisons to healthy individuals often highlighted dyads’ perceived
50 constraints and differences, further emphasising what they were missing out on together as a
51 result of living with axSpA. This reflects a tension between what is desirable and what is
52 possible:
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57 “It’s what you want to do and you can’t do as much as some of your friends are doing
58 and if some people are going away for like a short weekend or finish work on a Friday
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3 then they'll go away [...] well (partner's) too tired once he's finished work to go away
4 on a Friday night" *Charlotte (partner)*
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8 William, contrastingly, perceived a minimal influence of axSpA on his ability to share
9 activities with his partner:
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12 "We can still go out walking for 10miles and things like that so it hasn't really been a
13 major impact on our relationship and the things we want to do together" (*William,*
14 *partner*)
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20 The constant nature of axSpA made life appear effortful for many of the dyads, who adopted
21 joint ownership of managing axSpA. The condition often acted as a central feature which
22 their lives subsequently revolved around, sometimes dominating the partner relationship and
23 pulling behaviours towards managing axSpA over tending to the relationship:
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28 "Literally absolutely everything from what we eat, to when we eat, to who does this, to
29 who does that, to when this happens, can it happen? [...] everything is sort of gravitated
30 to AS (referring to Ankylosing Spondylitis, a sub-group of axSpA)" *Harry (partner)*
31
32
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34 Dyadic life was portrayed as regimented with a need to plan ahead for activities, reducing
35 spontaneity in their everyday lives. Yet, almost contradictorily, a sudden axSpA flare-up
36 could alter plans at any time: "if he's feeling really bad then he can't go" (*Ellie, Partner*)
37
38
39

40 In addition to joint activity restrictions, many partners experienced a pervading sense of
41 helplessness characterised by limited avenues to relieve their partner's symptoms,
42 exacerbated by the unpredictability of axSpA. Use of the phrase 'miracle worker' illustrates
43 an acknowledging sense of powerlessness against the prevailing condition, further
44 highlighting the dominance of axSpA:
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49 "It was a lack of ability to change things which was difficult and it's not that you're
50 looking to be a miracle worker but there aren't even simple things that you could [do]
51 dramatically, the flare-up or change could happen whenever" *Oliver (partner)*
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56 Despite the ever-present nature of axSpA, some dyads were able to work together to reduce
57 the dominance of the condition on their relationship by making the most out of positive
58 experiences:
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3 “We both count our blessings and I hope that, you know, I guess with anything you
4 don’t know what’s around the corner as well as what’s gonna happen to your body”

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6 *Jess (Individual with axSpA)*
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9 **Tensions surrounding a carer-type role**

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11 Roles within the relationship were typically adjusted to meet the needs of axSpA. For
12 partners this meant adopting a carer-type role. For a number of individuals, this was an
13 explicit identity, whereas for others this involved a more implicit action of undertaking
14 caregiving behaviours. Supporting partners sometimes proved demanding as demonstrated by
15 Harry below:
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21 “She [wife with axSpA] needs to also accept that she’s not the only sufferer of AS. You
22 know, there’s three people [referring to son too] in this immediate family and actually
23 all of us are suffering as much if not more than she is” *Harry (partner)*
24
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27 The word ‘sufferer’ emotively portrays a sense of hardship from living with axSpA as a
28 partner, which suggests a sense of resentment towards the condition which acted as an
29 impenetrable barrier within the relationship.
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34 For some partners, the carer role extended beyond providing daily support, progressing
35 towards a protector role by managing mood and disease flare-ups which required constant
36 attention. This sense of responsibility to protect was suggestive of an inequitable relationship
37 at times, with the individuals' with axSpA perceived as vulnerable:
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42 “I try to keep the mood from falling too far, it’s basically a constant it’s a constant
43 thing. It shouldn’t be and he doesn’t ask me to, but I’ve taken that burden on I think.
44 That’s almost my job to make sure he’s looking after himself well” *Phoebe (partner)*
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48 Individuals with axSpA commonly felt guilty relying on their partners, with support focused
49 on the individual with axSpA at the expense of the partners’ well-being. In these instances
50 some individuals with axSpA made adjustments to attempt to relieve this burden on their
51 carers:
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55 “He [partner] couldn’t sleep in bed with me so then it was impacting on him at work so
56 he just goes off and you know sleeps in the spare room and I can wriggle about as much
57 as I like without worrying about disturbing him” *Elizabeth (Individual with axSpA)*
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6 The notion of dependency for the individuals' with axSpA on their partners was sometimes
7 incompatible with their sense of identity:
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11 "I have to sometimes rely on her, like I mean it's like I shouldn't have to really erm but
12 sometimes I have to [...] not a sexist thing, but I'm sort of like the bloke do you know
13 what I mean, so it's like in my head that I'm, I've got to do certain things" *Tom*
14
15 (*individual with axSpA*)
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19 Adopting a carer-role had the capacity to overrule the role of partner, and could result in an
20 element of tension between the individuals' with axSpA seemingly opposing needs for
21 support with managing axSpA and desire to lead a 'normal' life. A line was sometimes
22 crossed where too much help could be offered from partners, contrary to the partners' aims of
23 making life easier for the individuals with axSpA. Sophie desired greater equality within the
24 relationship through demonstrating independence:
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31 "Sometimes he tried to do too much and that I'm, he makes me feel like I'm you know
32 useless and not capable and I need help. And I always say to him (Steven) you're not
33 my carer, if I wanted a carer I would have hired a carer. You're my boyfriend, I want
34 you to be my boyfriend, [...] don't try to do everything for me, not let me do stuff
35 myself because you know I want to do those things" *Sophie (individual with axSpA)*
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41 Self-reliance was also conveyed by the individuals with axSpA through a determination to
42 overcome the physical restrictions of axSpA. This was particularly significant for Emily who
43 desired:
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47 "Empathy. Not sympathy. Sympathy drives me bananas and he knows that. [...]. He
48 occasionally gets it wrong, I remember on, one of the recent challenges, [...] I started
49 getting ankle pain at 45k, checked if it at 52, I could see blood under the skin so I knew
50 that I'd torn something in there. And he said right you're going to see a medic, I said
51 right I'm not, you know me better than that. I strapped it up tight and I did finish the
52 challenge." *Emily (individual with axSpA)*
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58 **DISCUSSION**

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3 This is the first qualitative study to explore the social context of axSpA according to partner
4 dyads, with findings highlighting that couples adopted a joint approach to managing axSpA,
5 which is resonant with the Cognitive Transactional Model of dyadic coping.[14] Managing
6 axSpA together as a dyad dominated daily decisions and took precedence over shared
7 activities. Study findings demonstrated how axSpA could influence the perceived closeness
8 between partners and consequently, alter the specific characteristics and function of dyadic
9 roles. Tensions could arise between partners' adoption of a carer-type role and individuals'
10 with axSpA desire for autonomy. In order to demonstrate self-reliance some individuals with
11 axSpA refused help from their partners at times which can be perceived as a dyadic coping
12 strategy of withdrawal.[15] Separate strategies may indicate increases in self-efficacy, as
13 opposed to dyadic efficacy.[14]

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23 Joint leisure time for dyads was often limited which could highlight dyads' sense of loss and
24 difference to other couples. This restriction extended to a reduction in sexual activity, which
25 is a widely acknowledged issue in the axSpA literature.[20-22] The present study supports
26 and broadens these findings through the inclusion of partner experiences, indicating an
27 element of distance within relationships caused from living with axSpA. Furthermore,
28 consistent with the axSpA literature,[19] many dyads expressed how their lives typically
29 revolved around condition management.

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36 Moreover, this study uniquely adds to the axSpA literature by clearly detailing the specific
37 and unique nature of the demands perceived by partners of individuals with axSpA; namely
38 to provide a constant source of support, both emotionally and physically, to their partner with
39 axSpA. Additionally, findings are novel in terms of identifying how overcoming the
40 challenges of axSpA together resulted in dyads perceiving strengthened relationships and
41 enhanced closeness. The use of an idiographic approach to the study of dyadic relationships
42 resulted in new knowledge concerning the specific nature of the challenges faced by couples
43 in the context of living with axSpA and how dyads attempt to manage such challenges. This
44 positive change in relational quality can be understood within the context of dyadic coping.
45 Appraisal of axSpA as a shared experience may have increased dyads' confidence in their
46 ability to effectively work together.[14]

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56 Improvements in pain, depression, and marital functioning have been identified in individuals
57 with long-term health conditions, from partner dyadic interventions.[48] Couple-based
58 interventions have also identified lessened feelings of caregiver burden and anxiety within
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3 spouses.[49-50] Due to the effectiveness of dyadic interventions in other long-term health
4 conditions,[48-50] there is a clear argument for extending partners' involvement and support
5 provision within healthcare consultations. Such changes may reduce the divide between
6 partners' carer-type role and the individuals' with axSpA desire for autonomy, potentially
7 resulting in a reduction in daily life restrictions within dyads.
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12 The study has several limitations. As all couples were heterosexual and White British the
13 experiences may not be applicable to other types of couples. Moreover, all participants in this
14 study had sought support from the axSpA-specific charity through social media, suggesting
15 that participants may have greater perceived support needs and/or a more aggressive disease
16 trajectory than individuals with axSpA who did not make contact with the axSpA charity's
17 social media pages. Additionally, users of the axSpA-specific charity's social media pages
18 may be more inclined to share their experiences than non-users. Nevertheless, social media
19 has been usefully applied as an acceptable recruitment method within health research.[51]
20 Telephone interviews usefully facilitated the discussion of a sensitive topic about partner
21 relationships within the context of axSpA, providing rich insight.[33-34] However, it is
22 recognised that visual communication, such as facial expressions, are absent during telephone
23 interviews, which may potentially limit interaction and rapport building.[52-53] Yet, to our
24 knowledge there is no evidence that the quality of data is limited when interviews are
25 conducted via telephone.[54] Additionally, this study did not collect data on individuals'
26 medication use and self-reported disease activity. As some treatments can markedly improve
27 symptoms of axSpA, it is important that future research addresses differences in treatment
28 between individuals with axSpA and how this may impact on the quality and nature of their
29 partner relationships. Future research should also examine how a pre-existing relationship
30 becomes affected by the onset of axSpA against a newly formed relationship as they may
31 present important yet differing challenges. Despite these limitations, a key strength of the
32 study concerns its use of qualitative methods to enable an in-depth exploration of partner
33 relationships, thus meeting an important knowledge gap.
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51 In conclusion, as the first qualitative study to adopt a dyadic approach to studying the impact
52 of axSpA on partner relationships, study findings highlighted the importance of adopting an
53 interpersonal approach when treating individuals with axSpa. All dyads experienced
54 difficulty with managing axSpA, from activity restrictions to changes in relational strength
55 and altered relational roles. Specifically, findings identified a need to provide support which
56 meets the needs of both individuals with axSpA and their partners. Information should be
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3 provided to educate and prepare partner dyads about axSpA's potential impact on
4 relationships and effective methods of dyadic coping and thought given to more extensively
5 including partners in treatment where appropriate.
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13
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15 stories with us and the relevant axSpA based charity for facilitating the recruitment process.
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22 commercial or not-for-profit sectors.
23
24

25
26 **Ethics:** The project was reviewed and approved by a delegated authority from the University
27 of Bath Psychology Department Ethics Committee.
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30 **Data sharing statement:** No additional data are available.
31

32 **Competing interests:** Kerry Raybone and Abbie Jordan declare no conflicts of interest.
33
34 Hannah Family declares no conflicts of interest, but has received consultancy fees from Astra
35 Zeneca (in 2016) to produce educational materials on medicine errors. Raj Sengupta declares
36 no conflicts of interest, but has received speaker fees, consultancy and/or grants from Abbvie,
37 Celgene, MSD, Novartis, Pfizer and UCB.
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42 **Data availability statement:** All data relevant to the study are included in the article or
43 uploaded as supplementary information.
44
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47 Psychology dissertation under the supervision of Dr Abbie Jordan and Dr Hannah Family.
48 KR, AJ, HF and RS made substantial contributions to the study design, interpretation of the
49 findings for the study, manuscript writing and article revision. AJ and RS contributed to the
50 conception of the study. KR contributed to the collection of data and data analyses, with
51 detailed feedback provided by AJ and HF. All authors read and approved the final version of
52 the manuscript.
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Supplementary Table 1.

Topic guides for individuals with axSpA and partners

Question number	Topic guide for partners	Topic guide for individual with axSpA
1	When were you first aware that your partner had axSpA?	To start with, can you tell me about when you first noticed your axSpA symptoms? <i>Prompts: How have your symptoms changed (or not) until now? At what point did you receive your diagnosis?</i>
2	How do you think axSpA has impacted on your partner's life?	Can you talk through a typical day for you living with axSpA?
3	Can you tell me about any ways that your partner's condition has impacted on your life? <i>Prompts: How has your partner's axSpA affected your ability to engage in your choice of leisure activities? How has your partner's condition affected your home life? What is it about the illness that has impacted your life the most? Which symptoms/treatments have impacted the most? Why do you think these aspects of axSpA have impacted on your life the most? If any, what are the positive factors of your partner's axSpA on your life? What are the more negative factors of your partner's axSpA on your life?</i>	Can you tell me about any ways that the condition has impacted on your life? <i>Prompts: How has axSpA affected your home life? How has axSpA affected your ability to work? How has axSpA affected your ability to engage in your choice of leisure activities? What is it about the illness that has impacted on your life the most? Which symptoms have impacted the most? Which treatments have impacted the most? Why do you think these aspects of axSpA have impacted on your life the most? If any, what are the positive factors of axSpA in your life? What are the more negative factors of axSpA in your life?</i>
4	If it has, how has your life changed as a result of your partner's condition? <i>Prompts: what changes in your life have occurred as a result of your partner's condition? What alterations (if any) have you had to make in your life? What were the reasons behind these changes? How do you feel about the changes? What have been the more</i>	If it has, how has your life changed since developing axSpA? <i>Prompts: What changes in your life have occurred as a result of the axSpA diagnosis? What alterations (if any) have you had to make in your life? What were the reasons behind these changes? How do you feel about the changes? What have been the more negative changes? What have been the more positive changes?</i>

negative changes? What have been the more positive changes?

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| 5 | <p>What have you found particularly challenging about your partners axSpA on your life?
<i>Prompts: Can you tell me about any concerns/complications related to axSpA which have arisen? What particular symptoms have been challenging? Why were those particular symptoms challenging? How did you help resolve them (if you have)?</i></p> | <p>Can you tell me about any particular challenges you have experienced living with axSpA?
<i>Prompts: Can you tell me about any concerns/complications related to axSpA which have arisen? What particular symptoms have been challenging? What particular treatments/appointments have been challenging? Why have those particular treatments/symptoms/appointments been challenging? How have you resolved them (if you have)?</i></p> |
| 6 | <p>What do you think defines a good quality partner relationship?</p> | <p>Can you tell me about some of the things that you do to manage your axSpA in your everyday life?
<i>Prompts: What kinds of strategies do you use to manage the symptoms? What do you do to manage your home life? What do you do to manage your work life? Why do you manage axSpA this way? What impact does this management have? How effective are these strategies?</i></p> |
| 7 | <p>How would you describe your relationship with your partner generally?</p> | <p>What do you think makes a good quality partner relationship?</p> |
| 8 | <p>What support (if at all) do you receive as a result of supporting your partner with axSpA?
<i>Prompts: What kinds of support would you like to receive?</i></p> | <p>How would you describe your relationship with your partner generally?</p> |
| 9 | <p>If you do, what aspects of axSpA would you typically talk about with your partner?
<i>Prompts: Can you think why you would talk about these aspects in particular? How does your partner typically respond?</i></p> | <p>If you do, what aspects of axSpA would you typically talk about with your partner?
<i>Prompt: Can you think why you would talk about these aspects in particular? How does your partner typically respond?</i></p> |
| 10 | <p>Can you recall in what instances</p> | <p>Can you recall in what situations your partner</p> |
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you were a source of support for your partner in relation to their axSpA?

Prompts: How did you support your partner in managing their condition? In what circumstances would you typically support your partner in managing their condition? Why do these circumstances require your support? Can you think of any circumstances where you have not been so supportive? Why were you not so supportive?

has been a source of support in relation to your axSpA?

Prompts: How were they supportive? Why do you think they were supportive in those situations? In what situations were they not so supportive? How were they not as supportive? Why do you think they were not supportive?

11 How has the condition impacted on your relationship with your partner?
Prompt: Why do you think these aspects of axSpA have impacted on your relationship? Has this changed over the course of the condition? How has this changed over the course of the condition? What are the more positive factors on your relationship? What are the more negative factors on your relationship? What roles do you and your partner take within the relationship? Have these roles changed since the development of axSpA?

How has the condition impacted on your relationship with your partner?
Prompts: Why do you think these aspects of axSpA have impacted on your relationship? Has this changed over the course of the condition? What are the more positive factors on your relationship? What are the more negative factors on your relationship? What roles do you and your partner take within the relationship? Have these roles changed since the development of axSpA?

12 How (if at all) do you think axSpA will impact on your relationship with your partner in the future?
Prompt: Why do you think axSpA will have this impact?

How (if at all) do you think axSpA will impact on your relationship with your partner in the future?
Prompt: Why do you think axSpA will have this impact?

13 Is there anything else that you would like to say or any final thoughts you would like to mention about your experiences of axSpA?

Is there anything else that you would like to say or any final thoughts you would like to mention about your experiences of axSpA?

COREQ checklist

Domain 1: Research team and reflexivity		Location in Manuscript (Section, Page no.)
Personal characteristics		
1. Interviewer/facilitator	KR	Methods - 5
2. Credentials	BSc MSc	Title page – 1
3. Occupation	Masters in psychology student	Methods – 1
4. Gender	Female	Methods - 5
5. Experience and training	KR had completed the taught programme of the MSc programme which covered the principles of qualitative research in detail.	Not mentioned in text.
Relationship with participants		
6. Relationship established	No	Not mentioned in text
7. Participant knowledge of the interviewer What did the participants know about the researcher? E.g. personal goals, reasons for doing the research	Participants were briefed on the purpose of the study and the fact that its completion comprised part of the researcher's requirements for completion of a Masters in Health Psychology degree.	Methods - 5
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? E.g. bias, assumptions, reasons and interest in the research topic	KR had met some individuals with axial spondyloarthritis on a hospital-based exercise programme prior to interviewing which was a potential source of bias. No other interviewer-related biases were identified.	Methods – 5
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study?	Thematic analysis	Methods – 6
Participant selection		
10. Sampling How were participants selected?	Purposive sampling	Methods – 5
11. Method of approach How were participants approached?	Advertisements for the study were made on an axSpA-specific charity's social media pages where participants were invited to contact the researcher through email.	Methods – 5
12. Sample size	18 (9 individuals with axSpA; 9 partners).	Methods - 5
13. Non-participation	Thirty-one individuals	Methods – 5

1 2 3 4 5 6 7 8 9 10 11	How many people refused to participate or dropped out? Reasons?	requested information about the study, with 22 individuals subsequently not participating. Reasons for non-participation included living outside the UK, having a partner who did not wish to take part and feeling unwell.	
12	Setting		
13 14 15	14. Setting of data collection Where was the data collected?	Data was collected via telephone interviews.	Methods – 5
16 17 18 19 20	15. Presence of non-participants Was anyone else present besides the participants and researchers?	No. Mention is made of interviews being conducted individually.	Methods – 5
21 22 23 24 25 26 27	16. Description of sample What are the important characteristics of the sample? E.g demographic data, date.	Heterosexual couples; age range 23-65; 9 individuals with axSpA (N = 6 female) and 9 partners (N = 3 female). Data was collected between 23 rd May and 28 th June 2018.	Results – 7-8
28	Data collection		
29 30 31 32 33 34 35 36 37 38 39 40 41	17. Interview guide Were questions, prompts, guides provided by the authors?	Interviews were semi-structured and guided by a topic guide (supplementary table 1). Participants were interviewed individually, and separate but similar topic guides were used for individuals with axSpA and partners. Prompts were used, where appropriate, to encourage further depth.	Methods – 5-6
42	18. Repeat interviews	No	Not mentioned in text
43 44 45	19. Audio/visual recording	Interviews were audio-recorded using a digital recorder.	Methods – 6
46 47 48	20. Field notes	A reflexive journal was used to record thoughts after interviews.	Methods – 6
49 50 51 52	21. Duration What was the duration of the interviews?	The semi-structured interview durations ranged from 25 to 73 minutes.	Methods – 6
53 54	22. Data saturation Was data saturation discussed?	Yes	Methods -5
55 56 57 58 59	23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	No	Not mentioned in text
60	Domain 3: analysis and		

findings		
24. Number of data coders	One (KR)	Methods -6
25. Description of coding tree	No	Not mentioned in text
26. Derivation of themes	Themes were derived from the data	Methods – 6
27. Software	NVivo	Methods – 6
28. Participant checking Did participants provide feedback on the findings?	No	Not mentioned in text
Reporting		
29. Quotations presented Where quotations presented to illustrate the themes/findings? Was each quotation identified?	Yes, specific comments were supported with verbatim quotes attributed to anonymous participant pseudonyms.	Results – 9-13
30. Data and findings consistent	Yes	Results – 9-13
31. Clarity of major themes Where major themes clearly presented in the findings?	Yes	Results – 9-13
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	Yes	Results – 9-13