

1 **“Everyone assumes a man to be quite strong”: Men, masculinity**
2 **and rheumatoid arthritis: A case-study approach**

3

4

Abstract

5 **Objective:** Current literature has overlooked the impact of chronic illness on masculine
6 identity. We therefore aimed to investigate the impact of Rheumatoid Arthritis (a long term
7 condition, affecting more women than men) on masculine identity.

8 **Methods:** Six focus groups with 22 men with RA (data reported elsewhere) followed by five
9 one-to-one interviews with men (English, mean age: 59 years) sampled to reflect a
10 heterogeneous experience of life with RA based on knowledge gained from the focus
11 groups. Transcripts were analysed using Thematic Analysis and are presented as individual
12 case studies.

13 **Results:** Whilst the case studies provide five distinct experiences, common themes can be
14 drawn across them, such as the importance of paid work. The men needed to renegotiate
15 their masculine identity to deal with their RA. Two dealt with this by pushing through pain to
16 retain masculine activities, two replaced masculine roles they could no longer do with other
17 roles, and one rejected masculinity completely.

18 **Conclusion:** Men with long term conditions may need to re-write their masculinity scripts to
19 enable them to accept and adapt to their condition. However, some men struggle with this,
20 which should be taken into consideration when designing self-management services for men
21 with long term conditions.

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27

1 **1. Introduction**

2 Postmodern theories of masculinities suggest masculine identity is socially constructed, and
3 therefore propose that gender norms are dictated by social influences rather than biological
4 differences (Addis and Mahalik 2003). Multiple masculinities exist and at different times and
5 places some ways of being a man are culturally more desirable, which has been
6 conceptualised as hegemonic masculinity (Connell 2005). Hegemonic masculinity is the
7 'current most honoured way of being a man' (p832), against which men position themselves
8 (Connell and Messerschmidt 2005).

9 From a young age boys, and as they grown, men, learn to present their masculine selves in
10 situationally appropriate ways (Frosh and Phoenix et al. 2002), thus they are able to
11 emphasise different aspects of the hegemonic ideal enabling them to construct effective
12 manhood acts (Schrock and Schwalbe 2009). This ability to alter displays of masculinities to
13 fit different circumstances encountered across the life course (Spector-Mersel 2006) has
14 been termed 'the chameleonisation of masculinity' (Ward 2015). It is therefore possible that
15 men who live with a long-term condition have needed to adapt their masculinity script to
16 protect their masculine identity (Spector-Mersel 2006). In other words, when masculinities
17 are 'radically disturbed' by illness, men are prompted to reflect on their gendered beliefs and
18 the practices of masculinity they engaged in prior to illness (O'Brien and Hart et al. 2007).
19 Previous research investigating the relationship between masculinity and chronic health has
20 predominantly focussed on typically male diseases (e.g. coronary heart disease) or gender-
21 specific diseases (e.g. prostate cancer) (O'Brien and Hart et al. 2007). However, the impact
22 on masculine identity of living with an incurable long term condition that affects more women
23 than men and has to be self-managed daily has not been previously explored in depth.

24 Rheumatoid arthritis (RA) is a chronic, progressive and systemic autoimmune disease,
25 characterised by fluctuating symptoms such as swollen joints, pain and fatigue (Hill 2006,
26 Newman and Fitzpatrick et al. 1995). RA affects more women than men (approximately

1 30% of the RA population are male) (Humphreys and Verstappen et al. 2013) and is thought
2 to take a different course in men compared to women (Forslind and Hafstrom et al. 2007).

3 There is a paucity of literature exploring the impact of RA on men and their masculine
4 identity nor how they manage this impact. A comprehensive literature review (Flurey and
5 Hewlett et al. 2015) found that whilst there was no consensus on whether gender impacted
6 on ability to cope with or self-manage RA, there was a gender difference in coping styles.

7 It is likely that men with RA would have a different experience of living with and managing
8 their RA to women, it is therefore of note that the majority of qualitative studies exploring the
9 lived experience or self-management of RA have been conducted either solely or
10 predominantly with female participants: ranging from 78% to 100% female (Sanderson and
11 Calnan et al. 2011, Plach and Stevens et al. 2004, Stenström and Bergman et al. 1993) and
12 only two qualitative studies have focussed solely on men. One (Lack and Noddings et al.
13 2011) recruited patients from only one UK Hospital and did not explore coping strategies.
14 The other (Beaton and Hodge et al. 2012) was conducted with USA war veterans, who may
15 have very different experiences of life to the general population and did not explore
16 masculine identity.

17 The current study aimed to explore in depth the experiences of male RA patients in the
18 context of their individual lives, the impact this has on their masculine identity; and how they
19 are currently coping with and managing their RA.

20 **2. Patients and Methods**

21 *2.1 Study design*

22 Focus groups are useful for examining opinions and beliefs about an issue, whilst individual
23 interviews are effective in exploring personal experiences (Molzahn and Starzomski et al.
24 2005) and their combination can provide complementary views of a studied phenomenon
25 (Lambert and Loiselle 2008). To explore both the breadth and depth of men's experiences
26 of living with RA and its impact on their masculine identity, focus groups were conducted

1 with men with RA, and then a sub-set of the focus group participants were invited to take
2 part in individual interviews (Data published elsewhere (Flurey and Hewlett et al. 2016)).

3 The current paper focuses on five men who took part in the individual interviews as case
4 studies to understand the issue of being a man with RA and the impact on masculine identity
5 (Stake 1995).

6 Case studies allow the development of understanding and insight through in-depth
7 examination of a few individual lives, which are of interest for both their uniqueness and their
8 commonality (Stake 1995). We sought to understand individual experiences based on each
9 individual's account in the focus groups; their subsequent individual interview; and in the
10 context of their clinical and societal situation.

11 *2.2 Participant selection and recruitment*

12 Male patients with RA (Arnett 1990) were invited to participate in focus groups by the first
13 author (CF). Patients attending a rheumatology outpatient appointment at one of three NHS
14 Trusts in England were purposively sampled to reflect a range of age, disease duration,
15 disability and drug treatment. A subset of the focus group participants were then invited to
16 participate in semi-structured interviews, sampled to reflect a heterogeneous experience of
17 life with RA, based on knowledge about the participants gained from the focus group
18 discussions. Data saturation of new ideas was reached in the focus groups, thus no new
19 participants were introduced for the interviews phase. Ethics approval was granted by the
20 London-Bromley Research Ethics Committee (ref. 13/LO/0852).

21 *2.3 Focus groups*

22 The focus groups were facilitated by the first author (CF) with a sub-set co-facilitated by a
23 male patient research partner (RN), lasted approximately two hours, were digitally recorded
24 and transcribed verbatim (Flurey and Hewlett et al. 2016).

1 *2.4 Individual interviews*

2 Topic guides were specific to the individual. Participants were asked to expand on areas that
3 emerged in the focus groups as pertinent to their experience of RA and encouraged to raise
4 any topics important to their experience not covered in the focus groups. Participants were
5 given the option of being interviewed at home or in their hospital. The interviews lasted
6 around one hour, were digitally recorded and transcribed verbatim.

7 *2.5 Analysis and interpretation*

8 Data from the focus groups and interviews were analysed using inductive thematic analysis,
9 a method for identifying, analysing and reporting patterns (themes) within data without trying
10 to fit it into a pre-existing coding frame (Braun and Clarke 2006). Data were analysed
11 according to Braun and Clarke's (2006) guidelines and managed using NVivo 8 (QSR
12 International Pty Ltd 2008). Focus group data were analysed first, then interview data.

13 The first author (CF) analysed all transcripts, and a sample was independently analysed
14 (Guba and Lincoln 1994, Sandelowski 1986) by three researchers (AW, KR, SH) and a male
15 patient research partner (RN). Team discussions and comparison showed that they reached
16 comparable conclusions to the first author (CF).

17 Once the individual data sets were analysed, data relating to each individual participant were
18 compared and collated to produce individual case studies. The intention was to provide a
19 credible and authentic account that offers an understanding of the experience of living and
20 coping with RA as a man, within the context of each individual's circumstances (Stake 1995).

21 **3. Results**

22 Six men who had taken part in the focus groups were invited to take part in a one-to-one
23 interview. Only one man (75yrs; disease duration 17yrs) declined to take part. He did not
24 provide a reason, but in the focus group he explained that he is not comfortable talking about
25 himself and does not normally take part in research.

1 Three broad typologies of the impact of RA on masculine identity could be identified from the
2 focus group data: 'Retaining hegemonic ideals of masculinity'; 'Trying to renegotiate
3 masculinity' and 'Rejection of hegemonic masculinity'. The case studies of each of the five
4 men who agreed to be interviewed will be presented within the appropriate typology. The
5 man who declined to take part was considered as belonging to the 'trying to renegotiate
6 masculinity' typology. Characteristics of each participant can be found in Table 1.

7 *3.1 Typology 1: Retaining hegemonic ideals of masculinity*

8 Retaining hegemonic ideals of masculinity seemed to be important to many of the men in the
9 focus groups, who tried to hold on to activities and roles valued by hegemonic masculinity
10 (e.g. sports activities; paid work) that they took part in before being diagnosed with RA. Two
11 men were interviewed to reflect this typology, one was single (David), the other is married
12 and saw being the breadwinner as part of his masculine role (Mark).

13 David is a 58 year old man, who has *"had [RA] now for 20 years [...] when I had it, I was still*
14 *quite a fit young man"*. David works full time in a mechanical engineering role and lives
15 alone. Mark is a 49 year old man, who has had RA for five years, he is self-employed and
16 still works full time: *"I'm a plumbing and heating engineer, I've got to use my hands"*.

17 Both Mark and David chose to be interviewed in their local hospitals, which could have been
18 due to the convenience of coming straight after work (David) or in a lunch break (Mark).

19 However, it may also be that choosing to separate discussing their RA from the rest of their
20 lives reduces the impact on their masculine identity.

21 This potential separation of identity is reinforced by David's lack of disclosure of his condition
22 to either his employer *"To be honest with you, they [employer] don't even know"* or his
23 friends and family: *"I don't make a big point of it. Er a couple of me friends know about it"*.
24 He explained that this was because most people either *"don't understand anyway"* or forget,
25 due to the invisible nature of the condition:

26 *"There's nothing about you that looks different. Even close friends forget about it at times"*

1 Mark also avoids talking about his RA due to the lack of understanding from friends, who
2 make vicious jokes. Humour can be used to subvert the power and influence of others and
3 to challenge power inequalities. In this way humour can be used as a weapon to be hurtful
4 (Williams 2009). It is possible that this is what is occurring in the following example:

5 *“They go, “Oh yeah, same old injury, you might as well, you might as well go and slit your*
6 *throat, you’re always complaining you’re ill or you can’t play [skittles]” but it’s not, it’s*
7 *physically if I held the ball in my hand, then my elbow would probably hurt. So then I*
8 *don’t do it and they go, “It’s just an excuse.”*

9 By attempting to construct their identity as a person with RA separately to their masculine
10 identity it is possible that David and Mark may be able to avoid being seen as ‘other’ and
11 thus protect their masculine self-image.

12 Both David and Mark have retained physically demanding leisure activities, which seem to
13 contribute to their self-identity. David rides a motorbike, and arrived for both the focus group
14 and the interview in his biker clothes. He highlighted that his abilities and stamina used to be
15 superior to his current abilities: *“I used to ride around all over the place, years ago, don’t so*
16 *much now. I wouldn’t have thought nothing of doing 200 miles”*. His identity as a biker
17 seems particularly important to him, and he told the same story in both the focus group and
18 the interview of having been left behind by his friends due to a flare-up of his RA. This may
19 have been particularly salient to him as he was forced to depart from hegemonic ideals of
20 stoicism and competitiveness, which seem to be valued by this group:

21 *“Just couldn’t go out the hotel. I was so bad I just had to sit in the hotel, and there was*
22 *nothing more frustrating for me, and I was sat at the hotel and all my mates was whizzing*
23 *round Douglas prom[enade] on their bikes. Oh, I was gutted.”*

24 Whilst for Mark, retaining his identity as a fit, sporty man seems important to him (*“exercise*
25 *is the thing”*) and helps him manage his RA (*“I try and keep active because if I sit around on*
26 *a Saturday or Sunday I seize up”*). He cycles often (*“there’s no impact on your body”*) and
27 goes skiing *“every year”* and explains that this seems to help his RA:

28 *“I have just been skiing for a week and before I went [...] everything was hurting and*
29 *within two days of skiing everything loosened up”*.

1 He is aware that his *“stamina levels [have] dropped dramatically”* and explains that *“I would*
2 *go blazing away all day long, I can’t do that anymore”*. However, he has still retained his
3 competitive nature: *“My wife can’t keep up with me, but trying to keep up with my son, who is*
4 *21 [...] he is hard to keep up with”*. This need to retain sporting prowess is a highly valued
5 hegemonic ideal, which is thought to excuse men from the need to participate in other
6 masculine behaviours (Connell 2005).

7 It seemed important to both of them to speak highly of their level of pre-RA ability, which
8 may be a way of reinforcing their masculine identity, and emphasising that any loss of ability
9 is due to their RA and not a lack of masculinity.

10 Remaining in paid employment is also particularly important to both Mark and David. For
11 David this seems to form part of his self-sufficient identity and he was adamant that he would
12 not give up work due to RA: *“the Doctor, he wanted to sign me off, I said ‘no’”*. Working
13 provides David with structure to his day, a goal to aim for: *“I had to get up every day to go to*
14 *work and it gave me a target, else I’d have just stayed in bed [...] It kept me going”* and
15 something to feel proud of (*“you do feel a bit prouder”*), due to the way he thinks others
16 perceive him:

17 *“He [Rheumatologist] also had respect for me that I wasn’t just prepared to throw the*
18 *towel in”*

19 Mark holds a strong masculine identity as the breadwinner (*“We’ve got a living to make so*
20 *we’ve got to keep working and taking painkillers”*). He seems particularly aware of his
21 financial responsibilities to his children: *“My daughter was in University and my son was in*
22 *school, you haven’t really got a lot of choice but to carry on, even to go through the pain”*.

23 He describes how he has previously continued working despite experiencing an intense
24 amount of pain:

25 *“I was trying to work, I was in that much pain in my hands, I had to go to work and I was*
26 *crying in pain when I used the tools that much, but you still had to do it every day, day in*
27 *and day out. I think you could probably overdose yourself with painkillers, but I didn’t.”*

1 Both Mark and David seem to have enough autonomy in their roles that they can manage to
2 work around their RA. Whilst David has control over his hours and the tasks he undertakes
3 (“I can plan my day”), Mark is self-employed and alters his work to accommodate his RA:

4 *“I am getting into more servicing of boilers and maintenance, because obviously the*
5 *installs are getting harder and harder”.*

6 He explained that “every day [the job] is getting harder [...] it is a manual job but my strength
7 is probably down 50% to what it was” and there are things that he can no longer do:

8 *“I have to get other people now to lift heavy things, or where I used to lift a heavy boiler*
9 *off the wall, I can’t do it anymore, it’s impossible”*

10 Productivity and breadwinning are defining features of hegemonic masculinity, reinforced by
11 societal expectations and the media (Vigorito and Curry 1998). For men in relationships
12 occupational status and income are important for eliciting deference from their partners
13 (Schrock and Schwalbe 2009), which may be even more important in the face of illness as a
14 threat to masculinity. Men from working class backgrounds may distance themselves from
15 intellectual work (seen as feminine) and embrace physical work (seen as masculine) to
16 produce self-protective displays of toughness (Fine and Weis et al. 1997). It is therefore
17 possible that remaining in paid physical work is key to Mark and David positioning
18 themselves as masculine.

19 In the focus group, both Mark and David seemed comfortable speaking in front of others and
20 were often the first people to answer my (CF) questions in their respective groups. David
21 reflected on this during our interview, which seems to explain the role he took on in the focus
22 group:

23 *“It needs one to fire the others off. Erm if they’re all a bit restrained you ain’t going to get*
24 *much information...you’ve got to get a bit of a leader [...] Got to get one person that’s*
25 *you know forefront in their views, and happy to talk about it, then that brings the others*
26 *on”*

27 This way of positioning himself in the group may provide David with a justification for being in
28 the group. This allows him to protect his masculine identity by fulfilling the masculine script
29 that men should give to rather than receive something from a group (Seymour-Smith 2008).

1 Both David and Mark easily opened up about their limitations and how their frustration had
2 previously driven them to tears:

3 *“I was in tears on the garage floor, because I’d got a drill and I couldn’t get up off the*
4 *floor.”(David)*

5
6 *“When it’s bad, I mean you’re crying because you can’t physically use your hands” (Mark)*

7 Crying is assumed to violate masculine norms regarding the importance of emotional control
8 (Wong and Rochlen 2005). However, the expression of ‘manly emotion’ can be permissible
9 as it conveys a degree of self-control that remains consistent with hegemonic masculinity
10 (Warner and Shields 2007). Their disclosure of being *“in tears”* fits the description of ‘manly
11 emotion’ as it relates to the experience of frustration with physical limitations that the majority
12 of the group are likely to have experienced. However, in the interview setting, David was
13 able to open up about more vulnerable feelings of helplessness:

14 *“You end up in tears because you just can’t understand what’s going on [...] that was why*
15 *it was so downing because it come on so fast, you didn’t know where it was going to stop”*

16 He was reluctant to use the word ‘depressed’ and settled on *“it’s aggravation rather than*
17 *depressed”*, perhaps because this more acceptable term retains his self-image of being
18 *“mentally strong”*.

19 Interestingly, both Mark and David use the third person narrative (e.g. David: *“you end up in*
20 *tears”*) when discussing their distress, which could be a way of distancing themselves from
21 difficult emotions.

22 Mark and David’s narratives indicate that it is important to them to retain their hegemonic
23 masculine ideals and their pre-RA masculine activities, whilst acknowledging that their
24 abilities have declined. Their newly adopted masculinity script enabled them to portray an
25 outward image of managing well with their condition and continue their pre-RA lifestyle.
26 However, RA was a challenge to their masculinity, which they deal with by
27 compartmentalising their identity as a man with RA and by attempting to hide this impact
28 from other people. Thus, they may be skilfully wearing what (Pollack 1998) termed the
29 ‘mask of masculinity’ to hide feelings of vulnerability, powerlessness or isolation.

1 3.2 Typology 2: 'Trying to renegotiate masculinity'

2 Men who were no longer able to take part in certain masculine activities, which had been
3 important to them before being diagnosed with RA had to deal with this loss to their
4 masculine identity. Two men were interviewed to capture this typology, one of whom was
5 learning to replace previous masculine activities with re-defined masculine activities (Ron),
6 and the other who was struggling to cope with this loss (Peter).

7 Ron is a 60 year old man, who has had RA for "*about 20 years now*", whilst Peter is a 61
8 year old man, who has "*had RA for about 5 years*". Both Peter and Ron chose to be
9 interviewed in their own homes, which may be due to the convenience of the researcher
10 visiting them as they both have a more severe impact of RA on their mobility than David and
11 Mark. However, it may also indicate that they see RA as such a large part of their lives that
12 their home cannot be separated from their experience.

13 A big loss to both Ron and Peter was having to take early retirement due to their RA. Peter
14 explained this had a "*massive impact*" on him and led to him being diagnosed with
15 depression. In the focus group he explained: "*I had a job that I enjoyed [...] Took a package*
16 *[severance pay] and came out*"). In the interview Peter explained that it wasn't necessarily
17 the physical ability to do his job that was the problem, but the "*psychological aspect*" ("*the*
18 *stress and strain*"). He doesn't feel that his employer supported him "*as [he] would like to*
19 *have been supported*" to remain working ("*I worked for banks [...] just really want to make*
20 *money don't they?*"). This seems particularly difficult for him as he "*loved what [he] did*" and
21 seemed to have held a lot of responsibility in the job.

22 Before being diagnosed with RA Ron was "*in the building trade*". He explains that the
23 "*hands on*" work "*became a struggle*". However, when his RA was under control with
24 medication "*it made a big difference*" and Ron expected to be able to return to working full
25 time: "*You didn't like to say 'no' to anyone so you were working 12 hours a day, after being*
26 *out of work for three years. Then within about three and a half months it all came back and*

1 *that was hard*". He therefore stopped working due to his RA, and didn't feel able to take on a
2 non-manual job ("*The education wasn't there, the brains weren't there [...] That's why I was*
3 *always manual like, I couldn't go on a computer*").

4 The loss of full time employment for both Peter and Ron seems to have impacted strongly on
5 their identity as working men. Ron holds the hegemonically masculine view that the man
6 should be the breadwinner ("*He is the head of the home, when he is a family man*") and so
7 felt uncomfortable stopping working ("*a guilt complex that you're not earning your money*").
8 He also explained that "*a man is happier working [...] a man can thrive on work [...] the*
9 *rewards of work is not just money, it's the satisfaction of a job well done*". The use of the
10 third person narrative seems to be used to normalise his views of traditional male roles and
11 expectations of how men should think and behave.

12 Being able to complete tasks around the home was important to Ron: "*consequently that*
13 *[gardening work] is troubling my legs, but the bonus is you achieve something [...] and when*
14 *you achieve something, that gives you a boost*". As men get older they remain involved in
15 activities that define them as men, even if these activities take on a different form, thus a
16 'busy ethic' can replace a 'work ethic' (Thompson and Whearty 2004) and in this way it
17 seems that Ron is able to renegotiate his masculine identity from his role as the
18 'breadwinner' to being useful in the home.

19 However, Peter still seems to be struggling to find new ways to keep himself busy. Peter
20 lives in a quiet cul-de-sac and explained that he moved to this area with his wife to be closer
21 to his daughter and grandson. However, for Peter, moving house has meant that he has lost
22 his social support network ("*The only people that I know really down here are my daughter*
23 *and her husband*"), which is not easy to rebuild due to his difficulty leaving the house ("*I don't*
24 *get out a lot*").

25 Peter will often pay someone to do the things he can no longer do around the house. This
26 supports the social exchange theory (Jackson and Rodriguez-Barraquer et al. 2012), which

1 proposes that human relationships rely on negotiated exchanges based on a cost-benefit
2 analysis by both parties. It is likely that in his previous social network Peter would have built
3 up 'credit' and thus feel more comfortable asking for favours. However, in his new home
4 Peter no longer has a familiar network around him and therefore is concerned that if he
5 accepted a favour he would not be able to repay it in kind, thus he feels more comfortable
6 paying for any services he receives:

7 *"It's just easier to pay someone and fortunately at the moment I am in a position where I*
8 *can afford to pay someone [...] if you can afford it it's better to pay people isn't it rather*
9 *than think 'am I getting on their nerves by asking too much?'"*

10 It is possible that through acting as an employer rather than a person accepting a favour that
11 this is an alternative method of renegotiating masculine identity.

12 Peter explained that due to his RA he is *"pretty limited in what [he] can do"*. He particularly
13 feels he is missing out on being able to play with his grandson: *"There's things I can't do with*
14 *him that I'd like to. I can't pick him up"*, which is particularly difficult because *"he's at the age*
15 *where you'd like to do more throwing around, picking him up and playing with him"*. This loss
16 of the way that hegemonic masculinity would dictate a man should behave with a male child
17 is particularly pertinent when considered in the context of research that suggests positive
18 interactions between grandfathers and grandsons are related to fewer depressive symptoms
19 and positive affect in older men (Bates and Taylor 2012). Whilst some grandfathers choose
20 to engage in potentially risky embodiments of masculinity such as physical play, others
21 emphasize their wisdom and experience (Tarrant 2013). At 61 years Peter is still a relatively
22 young grandfather and seems to hold expectations of himself to be able to perform
23 masculinities that he used to enact as a father, thus this discrepancy may be acting as a
24 threat to his masculinity.

25 Ron and Peter's narratives indicate that the loss of paid work through illness has a strong
26 and lasting impact on masculine identity. It is suggested that retirement can prompt a crisis
27 of masculine identity due to the estrangement from masculine assumptions (Olliffe and
28 Rasmussen et al. 2013). However, it is possible that this crisis is further pronounced by the

1 need for early retirement due to illness, with a stepped reduction often not being possible,
2 and often with little choice or control. It therefore seems important to learn to renegotiate
3 masculinity by adopting new masculine tasks, but this can be a difficult and slow process.

4 3.3 Typology 3: 'Rejection of hegemonic masculinity'

5 A more unusual experience of living with RA amongst those in the focus groups was the
6 experience of being comfortable enough within one's identity to reject or be unconcerned
7 with the need to behave in a hegemonically masculine way. One man was interviewed to
8 capture this typology (Charles)

9 Charles is a 69 year old man (*"celebrating my seventieth birthday soon"*), who lives alone
10 and was retired prior to his diagnosis of RA two years ago. My (CF) first impression of
11 Charles was of a softly spoken, polite man, who asked for permission to speak (*"Can I come
12 in on this one?"*). He seemed comfortable being himself in the all-male focus group (*"no
13 problem presenting myself"*), and talked easily about the activities he enjoys, which may not
14 be considered traditionally masculine according to westernised hegemonic ideals (Connell
15 2005): *"I've always been active with dancing, playing badminton and playing musical
16 instruments"*.

17 Charles opted to be interviewed in his own home. The first thing I noticed as I walked in was
18 his immersion in music, with musical instruments and sheet music covering every surface. It
19 was therefore not surprising that Charles' relationship with music characterised his
20 experience of RA and seemed to define his identity.

21 Charles explained how his RA has impacted on his ability to play his mandolin (*"it was a
22 great loss to me not to be able to play certain tunes"*) and he discussed the impact this has
23 on being able to help his grandson:

24
25 *"...especially when I'm trying to show my grandson some finger-work or, well yeah it can
26 be, erm, it can be disheartening because the tunes I played for hundreds of times and I*

1 *now can't manage and if I play them slowly they're not effective, I mean you can't play a*
2 *jig in slow time. So that is my current loss"*
3

4 Despite this activity not conforming to the hegemonic standards of physical or rough games
5 that a grandfather 'should' engage in with his grandson, it is important to note that Charles
6 still misses being able to pass on his skills and knowledge to the younger generation.

7 Charles seems to have a strong identity as a musician and a dancer (*"I think your life should*
8 *include dancing"*), thus he seems to be finding ways of retaining this identity by adapting to
9 his RA:

10 *"I'm in a group, a musical group, but in order to stay with the group I have to reduce my*
11 *repertoire to the tunes I can manage.*

12 Charles argued that it is easier to deal with RA when retired: *"not having to work gives you*
13 *the time to cope"*. He seems satisfied with the position he is in at his age: *"We've got*
14 *television, music, reading, that's fine for a seventy year old. And my family nearby, so I'm*
15 *doing quite well."*

16 Charles does not come across as a 'typical man' within the confines of our understanding of
17 traditional hegemonic heterosexual masculinity. His soft voice, calm demeanour, and
18 interest in activities that do not conform to hegemonic ideals of masculinity, could be
19 considered as *"hiding in the shadow of masculinity"* (Heasley 2005). Whilst not conforming to
20 masculine ideals, men *"in the shadow of masculinity"* know enough about hetero-normative
21 expectations to be able to fit in (or "pass") with a group of men (Buchbinder 2010).

22 However, a further explanation is that Charles may be so comfortable in his own identity that
23 he rejects the need to behave in hegemonically masculine ways, or feels so comfortable
24 within his masculinity that he doesn't feel the need to 'prove himself' as a man and therefore
25 can engage in activities such as dancing without his masculinity being threatened. This
26 ability to reject the demands of hegemonic masculinity seems to be both physically and
27 psychologically protective for him: *"All I'm doing is taking pills and enjoying life"*.

1 3.4 Representations of masculinity

2 Previous research with school age boys suggests that they present their masculinity
3 differently depending on the situation (Frosh and Phoenix et al. 2002). The authors reported
4 that boys were 'serious and softer' in the interviews, yet 'free and funny' in the focus groups.
5 This is supported by our findings that many of the men were able to expand on more
6 sensitive issues in the interviews than focus groups. Further, in the focus groups men used
7 more humour and 'banter' both as a way of bonding with each other in the group, and to deal
8 with difficult issues:

9 *"Trying to put a shelf up because you don't trust your wife with the electric drill, things like*
10 *that [all laugh]" (Mike 60yrs, focus group participant)*

11

12 *"I have to laugh at myself, levering myself out of the car"* (David)

13 Whilst in the focus groups it seemed important for many of the men to act as 'one of the lads'
14 and in doing so the female researcher (CF) could be treated as an outsider who they (as a
15 group) could explain their experience to, although traditional values of the way 'real men'
16 should treat women often made them censor their views, to protect the researcher from
17 being insulted:

18 *"I'd always prefer a woman [physiotherapist]. I just imagine I can carry it a stage further,*
19 *I'm on the beach..."* (Charles)

20

21 *"I do enjoy working, I mean, I enjoy being with the lads and everything else. It's all, all*
22 *fellows, I'm with, no women. But it's a, it's a very heavy job, so, you know, women*
23 *couldn't do that. I suppose they could but. I don't mean to be..."* (Will 61yrs, focus group
24 participant)

25

26 Further, the group steered individual men away from topics seen as problematic such as
27 Ron discussing his Christian faith (*"I didn't think I was coming here to be converted today"*
28 Edward, 60yrs, focus group participant) and Peter discussing his depression:

29 *"I think most males will try and fight the depression, they will, within reason. To be honest*
30 *I'm running a business and I haven't got a choice"* (Mark)

31

1 However, in the interviews the men seemed to set themselves apart from behaviours that
2 they felt were stereotypically masculine or inappropriate:

3 *“Men’ll say ‘oh no I don’t want to go to that group because all you do is talk about your*
4 *problems”* (Ron)

5

6 *“I remember him [participant] saying he nearly punched him [health care professional who*
7 *hurt him] and I thought ‘oh dear, that’s dreadful’, you know when people are there trying*
8 *to help”,* (Charles)

9 Thus, in the more private setting of the interview it seemed men were more comfortable
10 departing from expectations to behave in a way that conforms to hegemonic masculinity.

11 (Frosh and Phoenix et al. 2002) proposed that neither of these interactions are more
12 ‘authentic’ than the other but that each setting draws out a different manifestation of
13 masculine identity construction or different ways of ‘doing boy’. Our findings suggest that
14 this construction of multiple masculine identities depending on the setting still seems to
15 remain in adulthood.

16 **4. Discussion**

17 These case studies provide three typologies for explaining the impact of RA on masculine
18 identity: ‘Retaining hegemonic ideals of masculinity’; ‘Trying to renegotiate masculinity’ and
19 ‘Rejection of hegemonic masculinity’. Despite the heterogeneity of these experiences some
20 important commonalities can be drawn across these case studies that may improve our
21 understanding of men with long term conditions, such as rheumatoid arthritis.

22 The importance of paid employment was a theme that arose across all five case studies.
23 This was highlighted through the fierce determination of both Mark and David to stay in work;
24 the loss experienced by Peter and Ron through having given up work; and by Charles
25 explaining that his RA is easier to manage as he was diagnosed post-retirement. This
26 supports previous findings in RA that men in paid work report significantly lower levels of
27 emotional distress than women in paid work, but that men who have stopped working report
28 significantly higher distress than women who have stopped working (Fifield and Reisine et

1 al. 1996). This may be due to men having difficulty relinquishing their role as the
2 'breadwinner' (Stamm and Machold et al. 2010), which reflects findings in other conditions
3 such as coronary heart disease (O'Brien and Hart et al. 2007). The majority of the men are
4 or were engaged in paid work, which enables or enabled them to enact masculine ideals
5 such as financial dominance, being in a position of authority, or displaying physical strength
6 (Connell 2005). However, Charles' role as a musician and dancer did not fulfil hegemonic
7 ideals of masculinity, and therefore although an important part of his identity, this may not
8 have contributed to the way he positions himself as a man. Although retired, Charles
9 continues to play music, thus his expertise in this may be more important in his construction
10 of masculinity than paid work.

11 Previous RA research has suggested the need for men to 'depart from their masculinities' to
12 allow them to adjust and accept their RA (Lack and Noddings et al. 2011). However, these
13 data suggest renegotiation of rather than departure from masculinity. For Mark and David
14 retaining their masculine identity as strong, working men, able to 'keep up with the boys' in
15 their social life seemed particularly important. They both dealt with their RA by carrying on
16 despite the pain, making adjustments to their working life and continuing to take part in
17 masculine activities such as sports and motorcycling. Peter and Ron, were in a
18 renegotiation process (Thompson and Whearty 2004) involving trying to find ways of holding
19 onto their masculine identity despite a reduction in abilities. Both have struggled to accept
20 this and are still adjusting to their limitations. This need to renegotiate the meaning of
21 masculinity in the face of illness reflects findings within other conditions such as prostate
22 cancer (Maliski and Rivera et al. 2008). In contrast, Charles deals with his RA by staying
23 positive and focussing on pleasurable events in the future, he doesn't seem to allow RA to
24 impact on his life, and RA does not appear to have a clear impact on his masculine identity.
25 This could be due to more acceptance of a slower pace of life due to his older age and being
26 retired at disease onset. However, he has also experienced losses of activities he previously
27 enjoyed, thus it is possible that other role identities may be more salient to him than his

1 gender identity, or that he feels so comfortable in his masculinity that he does not allow RA
2 to impact on this.

3 The men who took part in this study were willing to talk about their experiences of RA in both
4 a focus group and a one-to-one interview setting, adding further weight to the evidence that
5 suggests generalisations about men being 'strong and silent' can be misleading. Similar
6 results have been found when interviewing men with depression (Emslie and Ridge et al.
7 2006) and prostate cancer (Oliffe and Mróz 2005). Thus, given the right supportive
8 environment (preferably one with a practical focus) and permission to talk about sensitive
9 issues men are willing to talk about not only their physical but also their emotional
10 experiences (Galdas and Darwin et al. 2014). Others suggest that men are more likely to
11 attend support services as a volunteer (Milligan and Dowrick et al. 2013). Thus, the research
12 interview setting may be seen as task-orientated volunteering, and men may find it easier to
13 justify speaking openly as a way of furthering research rather than for their own benefit.

14 It is of note that these men seemed more able to open up about more sensitive issues in the
15 interviews than the focus groups and portrayed their masculinity differently in both,
16 supporting previous findings with school age boys (Frosh and Phoenix et al. 2002). This
17 may be due to the interviews being the second meeting and thus having gained more trust in
18 the researcher. It may also be due to the one-to-one nature of the interviews meaning the
19 men did not feel the need to position themselves as they might within a group of other men.
20 The findings from this study indicate that this changing construction of masculine identity is
21 not something men grow out of, it is likely that this (re)negotiation of masculine identity is
22 constant and often unconscious amongst men as they navigate different relationships and
23 attempt to 'pass' as 'one of the boys' (Buchbinder 2010).

24 Our study consists of a group of men with RA who were willing to take part in focus groups
25 and follow-up one-to-one interviews. It is therefore possible that we are missing the voices
26 of the 'strong and silent' men (O'Brien and Hunt et al. 2005). Indeed, the one man who

1 declined to take part in the interview phase was invited due to his perspective as a 'strong
2 and silent' man. However, his voice has been included elsewhere (Flurey and Hewlett et al.
3 2016). The strengths are that this study sampled for a range of age, disease duration and
4 disability; from seven consultants across three NHS trusts; and then further sampled based
5 on knowledge gained from the focus groups about these men's experiences and coping
6 styles, thus providing five distinct and heterogeneous disease experiences. Further, a male
7 patient research partner contributed to the study design, data collection, and interpretation
8 (RN).

9 These data provide important information on the experiences and coping styles of men with
10 RA and the impact this has on their masculine identities. These novel data about the impact
11 of a long term condition (RA) on masculine identity indicate that to incorporate RA into
12 masculine identity it is necessary for masculinity scripts to be re-written, which some men
13 find challenging. These five distinct case studies highlight the different coping strategies and
14 support needs that should be considered when designing support and self-management
15 services for men with long term conditions.

16 Further research should investigate whether there are common issues relevant to men with
17 similar characteristics. This is now being addressed through a Q Methodology study
18 informed by these findings, to investigate whether men can be grouped according to the
19 impact of RA and their coping styles, which would have the potential to inform the design of
20 a support intervention. Further research should also investigate the generalisability of these
21 findings, which will enable an informed judgement of whether there is a clinical need to
22 provide services tailored towards the potentially different needs of men.

23

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- 3

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9

10

1 **7. Tables**

2 Table 1: Participant characteristics

| Pseudonym | Age | Age at diagnosis | Disease duration | Employment status | Current or previous role | Retired pre-diagnosis? | Marital status |
|------------------|------------|-------------------------|-------------------------|--------------------------|---------------------------------|-------------------------------|-----------------------|
| David | 58 | 39 | 19 | Full time | Mechanical engineering | No | Single: Never married |
| Mark | 49 | 44 | 5 | Full time | Plumbing and heating engineer | No | Married |
| Ron | 60 | 43 | 17 | Retired | Builder | No: early retirement* | Married |
| Peter | 61 | 56 | 5 | Retired | Banker | No: early retirement* | Married |
| Charles | 69 | 67 | 2 | Retired | Musician and dancer | Yes | Widowed |

3

4 *Still working when they were diagnosed but eventually took early retirement due to their RA