“We all keep schtum”: The experiences and coping styles of men with rheumatoid arthritis

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Surprising results about struggling men

- Participants were asked to sort statements about their experiences of living with RA across a grid.
- Then statistically grouped according to their shared opinions based on how they sorted the statements.
- One group was nearly all male, who experienced life with RA as a constant struggle.

*Flurey et al 2012*
## Living with RA day by day means...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Score (+5 to -5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being angry because of my RA</td>
<td>+5</td>
</tr>
<tr>
<td>Experiencing unexplainable fatigue/exhaustion daily</td>
<td>+4</td>
</tr>
<tr>
<td>Experiencing pain daily</td>
<td>+4</td>
</tr>
<tr>
<td>Getting frustrated due to my RA</td>
<td>+3</td>
</tr>
<tr>
<td>Exercising as much as I can</td>
<td>-5</td>
</tr>
<tr>
<td>I have periods of being completely symptom free</td>
<td>-4</td>
</tr>
<tr>
<td>Not letting my RA get me down</td>
<td>-3</td>
</tr>
</tbody>
</table>

I get very frustrated with it, the problem is then I get irritated and take it out on the wife

RA gets me down every single day
What do we know about RA and gender?

• 1/3 of RA patients are male  
  *(Crownson et al, 2011)*

• Women report more pain and disability than men, but this could be because the measures capture what matters to women  
  *(Barksy et al, 2001; Sherrer et al 1987)*

• Self-management interventions are weighted more towards the needs of women (due to more women having RA)

• Men report struggling to cope with their RA, yet found current education and support systems unhelpful (“lovey dovey”)  
  *(Flurey et al, 2012)*
What do we know about men and health?

“Women are sicker, but men die quicker” (Annandale, 2003)
What do we know about men and health?

- Illness threatens masculinity

  Kahn (2009)
What is a ‘real man’?

Illness can compromise all of these

What do we know about men and health?

- Illness threatens masculinity *Kahn (2009)*
- Men receive less social support than women *Conrad (2010)*
- The gender paradox in suicide *Canetto (1998)*
- Delaying help-seeking (heart attack):
  - **Women:** Too busy, integrity of role as mother/wife/employee (finishing the school run) *Turris & Johnson (2008)*
  - **Men:** Not sure if symptoms are bad enough – would other men complain about this or am I being a wimp? *White & Johnson (2000)*
Gendered advertising
Men’s health campaigns

Banks (2007)
Men’s sheds

Supporting each other shoulder to shoulder, not face to face

Morgan et al (2007)
What did we want to know?

• How do men experience RA?
• How do men cope with their RA?
• What type of support would be acceptable to men for their RA?
• Do men with RA need their own tailored support?
What did we do?

Step 1:
• 6 x Focus groups (group discussions)
• 3 different NHS sites

Patients selected from focus groups

Patients:
• Age range: 44-75 (mean = 64yrs)
• Range of medications
• Disease duration: 3mnths-19 yrs (mean = 9yrs)
I’ve got rheumatoid arthritis, I’ve had about four different joints replaced, so I’ve had a rough time as well, but you’ve got to think positive about it. That’s all I’d say to you.

Bob Noddings

- Member of steering committee
- Expertise: he is a man with RA
- Co-facilitated focus groups
What did we find?
“Treat it as a death”: RA as a bereavement

Experiencing loss

**Loss of strength**

**MARK:** I do now say to people “I can’t do that”, “I can’t lift that”. Some of these radiators I have to lift up are so heavy. Years ago I’d just sling them on my shoulder and walk about, so not anymore.

**Loss of independence (physical)**

**DAVID:** I couldn’t get up. I didn’t have the strength in my knees to … couldn’t believe it.

**JAMES:** It sounds funny, but it’s so soul destroying because what it does, it takes away your self … you’re sort of dependent …

**ROBERT:** Yeh, your dignity.

**JAMES:** Your own ability to look after... just your basic life, you know what I mean?
“Treat it as a death”: RA as a bereavement

Experiencing loss

Loss of independence (financial)

EDWARD: Financially and all that sort of thing, you lose your independence and that's what I found now I've stopped, err, earning extra money. I've got pensions, I'm not hard up for not working but then the bit I was making on the side with hairdressing, erm, you know alright go out to dinner once or twice a week or something like that where you stop and think now.
“Treat it as a death”: RA as a bereavement

Negative emotions

Anger and frustration
STEVE: With me the biggest thing is just the anger, I’m just so angry with myself. I’m angry with my body because it’s not doing what I want it to do, it’s just ... you know, I just want to scream and shout and everything else.

Low mood or depression
MARK: I had to go to work and I was crying in pain when I used the tools that much, but you still had to do it every day, day in and day out. I think you could probably overdose yourself with painkillers, but I didn’t, but it was every day.

Worries about the future
BRIAN: I think that’s one of the drawbacks that there’s no light at the end of the tunnel, there’s no cure. When you’ve got it, you can only think it’s going to get worse, that’s the worrying thing.
"It's not a very macho thing": Maintaining masculine identity

Keeping RA hidden

DAVID: Everyone assumes a man to be quite strong, and if a man says “I can’t undo that tap” they think, what’s the matter with you?

MARK: I don't know what it is about certain guys, but they’ve got to really grip you [when they shake hands] and sometimes you obviously just have to put on a brave face because it really hurts.

EDWARD: He’s [partner] just very, very discrete and he's there and his arm goes under my arm and I'm up.

PAUL: No, I had a nice shop, good sales, good footfall, fishing tackle, in the end I had to tell the customers, “Yes sir, that’s £44.99, could you bring it to the counter?” because I couldn’t pick it up.

TOM: You feel such a plonker.

PAUL: And that embarrassment stuck with me for a long time that.
“It’s not a very macho thing”: Maintaining masculine identity

Making asking for help acceptable

**RICHARD:** It [RA] puts you in a position where you have to ask for help and it’s not a very sort of macho thing.

**FRANK:** I find it easier to get a stranger in than a friend of the family, a lot easier, personally. I've got a grandson, he's a carpenter [but] he won't take any money and I find that embarrassing. So I don’t ask him anymore.

**MIKE:** I went up there to see Meatloaf, and er, my seat was about two thirds of the way back, two thirds of the way up, and the ticket actually said, please be aware that people around you may stand. [...] So I had a word with one of the stewards there and [asked] would it be okay if I went and leant on [the barrier]. And he sort of went off, he came back and said, “follow me”. Took me down, front row, half way along.
“It’s not a very macho thing”: Maintaining masculine identity

Impact on role

Man of the house

**RICHARD:** You know, as a man, yes, I suppose you always feel that as a man you should be the main person doing the lawns, the gardens, round the house.

Breadwinner

**RON:** I say, a man is happier working, yeah. He is the head of the home, anyway, when he is a family man.

Father

**STEVE:** I can put up with everything else, but when my boy turns around and says to me, “Why can’t you come and play football with me dad?” that really, really hurts.
Getting through life with RA

STEVE: I use [running] as a way of getting rid of the frustration and the anger.

DAVID: It’s always floating in the back of your mind. Every single thing you do, it floats in the back of your mind.

ROBERT: And then you get that flare up.

INTERVIEWER: How do you deal with it, if it’s floating in the back of your mind?

ROBERT: Just get on with it.

DAVID: It’s just there, isn’t it, you’ve got to get on with it.

ROBERT: Just get on with it.

MIKE: I gave up going to pubs completely because I just didn’t feel right going into a pub and having soft drinks.

WILL: [Rheumatologist] said you can drink, as long as it’s within moderation. He said, just don’t go out and get falling down drunk, like, you know. Well, I’m going on holiday in 6 weeks time. I mean, what do you go on holiday for? To get drunk and fall down.

TOM: That’s one thing my doctor did say, they did say keep as active as long as you can, keep active.

GEORGE: Mine says the same.

TOM: Keep going, I suppose it must be right because we’re all saying that, aren’t we.
“We all keep schtum”: The experience of support

Availability of support and barriers to support

Wives/partners

FRANK: Yeah. Luckily I've got a very understanding wife

ALAN: She’ll [wife] still say, “When are you doing it?” I’ll say, “When I can, when I can”.

Health care professionals

JOHN: They [rheumatology team] probably ask how, well they ask how I’ve been and how I am being, I mean I tend to take that from an RA perspective rather than an overall perspective
“We all keep schtum”: The experience of support

Availability of support and barriers to support

Friends

JAMES: I go shooting every Saturday afternoon right, clay shooting and if I complain just for a minute like, to say hold on, they’ll say “stop bloody moaning”. That’s all you get

MARK: No, they’re [friends] not understanding at all, no, not unless they’ve got something wrong with them.

PAUL: That’s why we all keep schtum

Not talking about it

INTERVIEWER: Do you talk to anyone about those feelings?

HENRY: No, not really.

ALL: No, no

INTERVIEWER: So you wouldn’t talk to friends or ...?

ALAN: What burden them with it, no.
What type of support is acceptable?

**FRANK:** I don’t know what I’d say [in a support group]. I’m here to help you. Just speaking to other people with the same complaint, I can't see what good that would do. Cos all we’d end up is just moaning at one another.

**GEORGE:** If I could sort of have something coming the other way in relation to what research has been done and what the findings are, and you’re coming in and you're listening to that.

**MARK:** I think both [information and support], yeah I mean it’s sort of a mix in-between it’s really good.

**INTERVIEWER:** Okay, information with a chance for coffee and a catch up?

**MARK:** Yeah that’s right, yeah.
What have we learnt from men with RA?

- It is important to men to maintain their masculine identity and to hold onto masculine roles.
- Men are well-supported by wives, but they don’t always understand.
  - This should be taken into consideration when designing appropriate support.
- Men are often not well supported by their friends.
  - Making it even more important to build support networks within rheumatology.
What have we learnt from men with RA?

• Health care professionals need to ask the right questions to find out how men are coping
  – Men may respond to direct questions, but vague or general questions will be presumed to be about their physical well-being

• We need to carefully consider how to market RA support for men
  – Information sessions are preferable to support

• Men found the focus groups useful
  – ?Supporting each other shoulder to shoulder
“Until I got [RA] I thought I was invincible” (Steve)