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Identifying different typologies of experiences and coping strategies in men with rheumatoid arthritis: A Q-methodology study

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Title: Identifying different typologies of experiences and coping strategies in men with rheumatoid arthritis: A Q-methodology study

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Key Words

Rheumatoid Arthritis; Coping; Self-management; Men's Health; Masculinity; Q-methodology

Abstract

Objective: To identify clusters of opinion related to the experiences and coping styles of men with RA

Design: Q-methodology (a qualitative and quantitative approach to grouping people according to their subjective opinion). Men with RA sorted 64 statements relating to their experience of living with RA according to level of agreement across a normal distribution grid. Data were examined using Q-factor analysis.

Setting: Rheumatology outpatient departments in the UK

Participants: 30 of 65 invited men with RA participated in this study (46%)

Results: All participants ranked highly the need to be well informed about their medication and the importance of keeping a positive attitude.

Two factors describing the experiences of male patients living with RA were identified: Factor A: "Acknowledge, accept and adapt" (n=14) take a pro-active approach to managing the impact of RA and find different ways of doing things; whilst Factor B: "Trying to match up to a macho ideal" (n=8) are determined to continue with their pre-RA lives, and therefore push themselves to carry on even if this causes them pain. They are frustrated and angry due to the impact of RA but they internalise this rather than directing it at others.

Conclusion: Whilst some men adapt to their RA by renegotiating their masculine identity, others struggle to relinquish their traditional masculine roles. Further research is needed to identify whether the finding that there are two distinct groups of men with RA can be generalised, and if so whether the differences can be explained by clinical, social or psychological factors, which may inform different therapeutic approaches.

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Article Summary:

Strengths and limitations of this study

- There is a scarcity of research focussing on men within rheumatology and this is the first study to highlight that men are not homogenous and therefore explore the potential differences in experiences and coping styles between groups of men with rheumatoid arthritis.
- Participants were sampled from five UK hospitals and reflected a range of social circumstances (age, employment status, marital status), disease experiences (disease duration, level of disability) and care pathways.
- Participants sorted pre-determined statements of opinion, which places restrictions on participants expressing views not covered by the statements. However, the statements were developed through focus groups, interviews and a literature review, and were reviewed by the study team including a patient research partner.

Introduction:

Rheumatoid arthritis (RA) is an unpredictable systemic autoimmune disease, characterised by fluctuating symptoms such as pain and fatigue [1, 2]. RA affects more women than men, with approximately 30% of the RA population being male [3], and may take a different course in women compared to men [4].

A comprehensive literature review [5] found the majority of research on psychosocial impact and self-management of men with RA compared gender differences rather than focussing solely on men, and these studies reflect the preponderance of women with RA. There was no consensus on whether gender affects ability to cope with RA. Qualitative research has begun to address the experiences and coping styles of men with RA and the impact on their masculine identity [6-9], suggesting a need to renegotiate masculine identity to adapt to life with RA. However, due to their qualitative nature none of these studies were able to explore whether there was consensus or agreement between the men on their experiences and coping strategies.

If different groups of men have different coping strategies they may also have different support needs. It would therefore be useful to understand the differences and similarities in experiences and coping styles of different groups of men with RA. Thus, the current study aims to identify areas of agreement and any differences between groups of men according to their experience of RA, its impact on their lives and their coping and self-management strategies. Q-methodology, a method that identifies groups of people with similar beliefs according to the way in which they sort statements of opinion, was used to address these aims.

Patients and Methods:

Patients: Male patients with confirmed RA [13] from one of five UK hospitals were invited to participate in this Q-methodology study by the researcher (CF) or local research nurse. Every man with RA attending a rheumatology outpatient appointment on the days of recruitment was invited to take part. Contributing hospitals were Bristol Royal Infirmary, Bristol; Cossham Hospital, Bristol; Royal National Hospital for Rheumatic Diseases, Bath; Weston General Hospital, Weston-Super-Mare; and Haywood Hospital, Stoke-on-Trent.

Patients or participants are treated as variables in Q-methodology, which requires sufficient participants to establish the existence of a factor for the purpose of comparing one factor with another [10]. An adequate sample size to produce a well-defined factor structure is 30 participants [11, 12], which was the target for recruitment.

Participants gave written informed consent and ethics approval was granted (Dyfed Powys Research Ethics Committee, 14/WA/0101).

Methods:

Q-Methodology: Q-methodology combines the strengths of both qualitative and quantitative approaches to identify a number of groups (called ‘factors’). Groups consist of participants who share similar opinions based on their value judgements in prioritising a large set of descriptors. Each group (or ‘factor’) represents a different independent opinion [13]. An appropriate set of descriptors or statements is assembled and each participant sorts them along a continuum of agreement designed to emulate a normal distribution, with very few extreme values and many

central values (Figure 1). Participants sort each statement in approximate rank order of the extent to which they agree with that statement in relation to all the other statements. The positions (scores) of all the statements are included in the analysis for every participant. The statements sorted closer to the outer edges of the distribution have more influence on the factor groupings compared to the statements closer to the middle of the distribution. Factors are calculated and the results then interpreted within the context of the enquiry [11].

Statements: To produce statements regarding the experiences and coping styles of men with RA, data from focus groups and interviews with an earlier sample of 22 male RA patients [8, 9] and a comprehensive literature review [5] were collated. The statements were refined through discussion with the research team, including a male patient research partner (RN). After removing repeated or ambiguous items, 64 statements were included, each worded to answer the question “What is your own personal experience of living with RA?” The statements were printed onto cards and laminated, each card was the size of one space on the Q-sort grid.

Procedure: The study, lasting approximately one hour, was conducted by an independent researcher (CF) in non-clinical outpatient rooms in the participant’s hospital. A pre-study questionnaire captured demographic data and disability (Health Assessment Questionnaire) [14].

First, participants were asked to consider each statement in relation to the question “What is your own personal experience of living with RA?” and sort them into three broad categories: most like me; least like me; neutral. The statements were presented to each participant in a different random order.

Participants were then asked to take each of their broad categories in turn (starting with 'most like me') and arrange each statement in approximate rank order of the degree to which they felt that statement reflected their own experience of living with RA, relative to the other statements. They placed each of the 64 statements in a single box on the Q-sort grid of 64 boxes (Figure 1), which had been printed A1 size and laminated. The grid pattern allows for the majority of statements to be agreed or disagreed with mildly or neutrally (for example there were 8 "0" boxes and 7 "+1" or "-1" boxes each) but only one statement could be placed in the "most like me" box (" +7") or least like me box (" -7"). Thus, each participant's opinion on the statements were constrained into a quasi-normal distribution of degrees of agreement between the statements. The precise shape and limits of this distribution (and the grid) are dependent on the number of statements. Participants were encouraged to rearrange the position of each statement within the grid until they were satisfied with the distribution.

Finally, participants were interviewed about their statement positioning. They were asked to discuss the statements placed at either end of the grid (+7,+6,-6,-7) and any other statements they found interesting. Interviews were digitally recorded and transcribed verbatim.

Analysis: Patient characteristics are presented as mean and standard deviation (SD) or median and inter-quartile range (IQR) as appropriate. The Q-methodology analysis combines qualitative and quantitative methods to produce a rounded interpretation of a single dataset [15]. Factor extraction and rotation uses the PCQ software package [16], and the output is interpreted by the researchers. Participants are treated as variables and are inter-correlated and subjected to by-person factor

analysis. The software searches for shared patterns (or sorting configurations) in the data and extracts portions of common variance (factors). For each Q factor to be interpretable, an eigenvalue >1.0 (indicating factors are unlikely to have grouped participant views by chance), and at least one Q-sort loading significantly upon each factor alone is required [17]. Following extraction, the factors were rotated using orthogonal varimax rotation to ensure each Q-sort defined (has a high factor loading in relation to) only one of the study factors, so the overall solution maximises the amount of study variance explained [11]. For ease of interpretation it is standard Q-methodological practice to generate a single exemplary Q-sort for each factor by merging (according to a procedure of weighted averaging) the Q-sorts of all significantly loading participants on the given factor (termed the factor array) [11]. A decision on the final selection of the optimum factor solution was undertaken collectively by the authors, examining the outputs from the different factor analysis solutions (e.g. number of factors, weightings, explained variance and number of participants excluded from factors). Factor interpretation was based on the factor arrays and the interview data from the significantly loading participants, which were combined to provide a single gestalt explanation of each factor [11, 18].

Consensus statements given similar or the same weighted average by both Factors are presented first, followed by the characteristics of Factors A and B individually. Illustrative examples of the post-sort interview quotes are included in the results (Table 4).

Results

Study population: Of 65 men with RA invited to participate 30 (46%) did so. Their mean age was 64.6yrs, SD:10.3; median disease duration: 5yrs, IQR 2-13; mean age at diagnosis: 54.8yrs, SD:14.1 (Table 1). Of the 35 men who declined to take

part 10 spontaneously volunteered one of the following reasons: being busy with other commitments (e.g. work); having recently taken part in a research study; and not wanting to return to the hospital for a reason other than their care.

Q-methodology factor solution: A two-factor solution emerged based on maximum explained variance; a maximum number of Q-sorts loading significantly onto a single factor; all factors having eigenvalues >1.00; all factors containing statements distinguishing them from other factors; a minimum number of confounded participants (i.e. significantly loading onto more than one factor); and expert judgement. The two factors explain 34% of the variance and account for 22 of the 30 (73%) participants. Participant loading of $\geq \pm 0.32$ reached significance at $p < 0.001$, indicating that each loading participant closely exemplifies the factor they load onto [11]. Five participants were confounded (had a significant loading on both factors) and three did not have a significant loading on either factor. These eight participants had similar characteristics to the overall study population (Table 1).

Table 1 presents participants' demographic data and the Q-sort factor outcome.

Table 2 provides a summary of characteristics of the two factors. Table 3 presents the weighted average scores for each statement for each factor.

Consensus statements: Of the statements with the same or similar weighted average score by both factors (highlighted bold in Table 3), those with factor scores $\geq \pm 3$ indicated that male patients valued being well-informed about their medication [Statement (St) 26: factor scores +6, +6], and they will not change the day or amount without medical advice [St44: -3, -4; St45: -4, -5]. They also would not drink too much alcohol with their medication [St43: -5, -6] or use alcohol to avoid their problems [St10: -6, -6]. Participants reported having a positive attitude [S40: +7, +5]:

they try not to complain; [St55: +4, +4]; do not get annoyed with other people [St07: -3, -3]; nor think life is unfair [St09: -4, -4] (Table 4: Quote reference: Q1.1)

Being teased by friends was least like these men's experience of having RA [St49: -4, -3]. However, whilst for some this issue was irrelevant, for others this did happen but was not a concern for them (Q1.2; Q1.3). These male patients valued regular appointments with their doctor [St27: +4, +4] and keeping themselves informed about RA [St53: +3, +3] (Q1.4). Finally, consensus across patients within both factors suggests fatigue is 'the worst thing about having RA' [St29: +5, +4] (Q1.5).

Characteristics of Factor A: This factor consisted of 14 participants (mean age: 66.8yrs, SD:10.3; median disease duration: 4.5yrs, IQR:2-13; mean age at diagnosis: 56.6yrs, SD:14.7) who were predominantly retired, reported less disability and were on less intensive medication regimens than those in Factor B (Table 2).

Factor A participants acknowledge their limitations due to RA, but refuse to allow these to affect their independence [St14: -5] (Q2.1). Although the majority of these participants are retired they still rate work as important [St54: +4]. The discourse suggests these participants have (or had) sufficient autonomy in their job to enable them to manage this alongside their RA (Q2.2). This ability to control other aspects of their lives may explain why these participants seem able to accept some loss of control due to RA (Q2.3). Further, the ability to continue to work full time or to have continued until retirement has enabled these participants to be less concerned about finances [St16: -5] (Q2.4)

RA has not affected the confidence of these men [St63: -4], which the discourse indicates is due to retaining their independence (Q2.7). They do this through accepting limitations, finding different ways of doing things for themselves [St29: +5]

(Q2.5; Q2.6) and being willing to accept help when they need to [St15: +3; St24: +1]. They take a pro-active approach to managing RA, being careful of what they eat (to avoid weight gain) [St19: +3] and keeping active [St37: +5] (Q2.8)

These men refuse to get angry [St05: -7] or become aggressive [St08: -6] and are less likely to get frustrated by their RA [St06: -2]. The discourse suggests they do not see an emotional response as helpful (Q2.9; Q2.10). Factor A participants report socialising as much as they did before they developed RA [St47: +3]; feel more able to talk about their RA to their friends [St48: +2] or other men with RA [St51: 0] than those in Factor B. These participants also feel more able to contact their rheumatology team for either medication advice [St30: +6] or emotional support [St31: +2].

Characteristics of Factor B: This factor consisted of eight participants (mean age: 62.0 yrs, SD: 12.3; median disease duration: 5.0yrs, IQR:4.5-21.8; mean age at diagnosis: 49.4yrs, SD: 16.5) and is a combination of men who are retired, working full time or unemployed due to RA. These participants report more disability and are taking more intensive medication than those in Factor A and two of these participants were in a disease flare at the time of taking part in this study (Table 2).

Factor B participants report negative feelings of frustration [St06: +7] and anger [St05: +6] due to the effect of RA on their independence [St14: +2] and abilities. They are annoyed by the need to adapt to accommodate their RA and struggle to accept a new normality (Q3.1). The discourse suggests that their anger is directed at themselves rather than towards others (Q3.2; Q3.3). Their frustration is driven by the (perceived) effect RA has on other people, causing them to feel guilty [St11: +5] because they feel unable to fulfil their role as a husband or father (Q3.4; Q3.5).

These men try to continue living as they did before they had RA. They therefore will never say to anyone 'I can't do that' [St03: +3] and will always finish a task once they've started it [St56: +5] even if this means regretting it later (Q3.6). They will not accept the need to use disability aids [St39: -5; St38: -2], and will not ask for help from anyone, especially not from strangers [St15: -3; St24: -5] (Q3.7)

These participants withdraw socially [St47: -3] because they can no longer keep up with their friends (Q3.8). They report negative thoughts such as worrying about their RA getting worse [St13: +4], feeling that their body has changed [St18: +3] and they use critical language in relation to themselves and their bodies (Q3.9; Q3.10).

They disagreed with the statement 'I avoid shaking hands with people' [St23: -4], which could indicate an acceptance of other people knowing about their RA. However, the discourse suggests that they do hide their RA, but because they don't often meet new people the issue of shaking hands is not salient to them (Q3.11; Q3.12).

These participants do not use faith to help them cope with RA [St56: -7] as this is not a belief they hold. They are not interested in talking about their RA to their friends [St48: -2] or other men with RA [St51: -4] because this isn't the way 'real men' behave (Q3.13) and they do not think it would be helpful (Q3.14). They also do not feel their medical team are interested in their emotional well-being [St31: -2] (Q3.15).

Discussion

There was consensus across participants about some aspects of their experience of living with RA. However, there were also areas of difference between participants, which provides initial evidence for two distinct experiences and coping strategies for men with RA.

Collectively, there is broad consensus amongst the men in this study that it is important to be well-informed about their medication, supporting previous findings that for men with long-term conditions receiving ‘factual’ information can offer reassurance and increase feelings of control [19]. It has been suggested that men may use alcohol to avoid emotional distress [20]. However, consensus across both factors suggests that these men do not use alcohol to avoid their problems. This may be due to the knowledge that alcohol can affect their medication and they may therefore be trying to retain as much control as possible over their unpredictable RA.

Although there were agreements on these elements of living with RA, differences also emerged that identify two relatively distinct groups. One group of men (Factor A) seemed able to accept their RA and adapt to it. The second group of men (Factor B) seemed to be trying to live up to a masculine ideal of being strong, capable and self-sufficient despite having RA. These men therefore fight the impact of RA by pushing themselves to keep going despite being in pain, and refuse to accept help. For these two groups of men we have coined descriptive labels: ‘Acknowledge, accept and adapt’ (Factor A); and ‘Trying to match up to a macho ideal’ (Factor B).

The resistance to the impact of RA expressed by participants in Factor B supports the suggestion that some men perceive ill health as a threat to their masculine identity, and that addressing health concerns challenges their health-related beliefs of men being self-reliant and resilient [21]. Further, the men in Factor B report experiencing anger and frustration that they direct inwards. This supports the theory that some men behave according to a learned ‘boy code’ of independent stoicism (‘everything’s fine’), which causes them to wear a ‘mask of masculinity’ to hide feelings of vulnerability [22]. These findings highlight a need for healthcare

professionals to be vigilant to the emotional needs of men with RA, who may be experiencing distress not expressed externally. Clinicians should be encouraged to explicitly ask men about psychological and emotional issues [8].

Dealing with health concerns can be perceived as taking action and gaining control when men's health status begins to jeopardize their independence [23]. This may be the cognitive mechanism employed by participants in Factor A, who seem to have begun a process of renegotiating their masculine identity [24] and may therefore be drawing from a new masculinity that involves adapting to their RA, enabling them to maintain control. In contrast, participants in Factor B seem to be trying to maintain the roles and values traditionally associated with masculinity.

Participants within Factor A reported less disability and were receiving less intensive medications, indicating that their disease was less severe than those in Factor B. It is therefore possible that having less severe disease enabled them to accept and adapt to their RA more easily. However, due to the small sample size conclusions about disease severity cannot be drawn from these data. Further exploration is necessary in a larger population as such differences may have important implications for how support is targeted to these two groups of men.

The characteristics of participants in Factor B (such as being unwilling to talk about their RA and accept help) indicate that these men would be less likely to engage with healthcare and thus less likely to take part in a face-to-face research study such as this one. These very characteristics may have reduced the proportion of participants that form Factor B. This potential recruitment bias would reduce the likelihood of identifying Factor B, which nevertheless emerged. Therefore the size of Factor B as

reported here (27% of participants) may be an underestimate of the number of men with RA who have these coping strategies.

Evidence from several long term conditions indicate gender differences on the impact of illness, and ways of coping [25, 26], suggesting that men need their own health strategy [27]. However, despite these indications from other conditions, there is a scarcity of research addressing the impact of RA on men and their coping strategies [5]. The analysis presented here suggests that while some men can accept their RA and adapt to it, others fight the impact of their condition, trying to retain their masculine activities and causing internalised anger and frustration. The similarities between these findings and the issues identified as specific to men with other long term conditions suggest these experiences and coping styles may not be shared with women.

This study may have limitations because the whole sample was white British. However, the statements were developed in a white British population and a separate study would be necessary to fully capture the potentially different experiences of men with RA from different ethnic backgrounds. Q-methodology requires predetermined statements for participants to sort and is therefore dependant on their appropriateness to the judgements being made [28]. In the present study, the statements to be sorted came from recent focus groups and interviews with men with RA [8, 9] and the literature [5] and therefore included a wide range of relevant issues. They were also reviewed by a male patient research partner (RN). In addition, patients were sampled for a range of age, disease duration and disability and from eight consultants across five UK hospitals, thereby accessing a range of disease experiences and care pathways.

Our findings suggest that there is a realistic possibility that many men with RA are not being served by current self-management interventions because of their personal coping strategies. Further research should identify whether the finding that there are two distinct groups of men is generalizable, and if so whether any clinical, social or psychological factors can explain the difference between the groups. This is now being addressed through a survey study informed by these findings, which will enable an informed judgement of whether there is a clinical need to provide services tailored towards the potentially different needs of men, and if so inform the design of such an intervention.

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Contributors: All authors were involved in the design and planning of the study. CF prepared the statements for participants to sort, which were reviewed and revised by SH, JK, KR, AW and RN until all were satisfied. CF and local research nurses invited patients to participate. CF conducted the Q-methodology study and the post-study interviews. CF conducted the initial Q-methodology analysis, then all authors participated equally in deciding on the most appropriate factor solution and the qualitative interpretation of the chosen solution. CF led the writing of the manuscript with guidance and input from SH, JK, KR, AW and RN. All authors read and approved the final manuscript.

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Data sharing statement: Raw data from individual participants' Q-sort scores are available on request by emailing Dr C Flurey: Caroline2.Flurey@uwe.ac.uk

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Tables

Table 1: Participant demographic and clinical data

ID	Age	Dis Dur (yrs)	HAQ	Med	In Flare?	Employment status	Marital status	Q-sort Factor outcome
P1	61	1	1.75	DMARDs Steroids	No	PT	Married	Factor A
P2	66	3	0.75	DMARDs	No	FT	Married	Confounded
P3	41	1.5	0	DMARDs	Yes	FT	Married	Factor B
P4	55	3	0.125	DMARDs Steroids	No	FT	Married	Factor A
P5	56	3	0.375	DMARDs	No	FT	Married	Factor A
P6	64	4	1.875	DMARDs	No	Retired	Married	Factor A
P7	65	25	1.875	DMARDs	No	Retired	Married	Factor A
P8	70	2 months	0	DMARDs	No	FT	Married	Factor A
P9	71	5	0	NSAIDs only	No	Retired	LwP	Factor B
P10	68	8	0.25	DMARDs	No	Retired	Widowed	Factor A
P11	67	1	0.75	DMARDs	No	Retired	LwP	Factor A
P12	74	8 months	0	DMARDs	No	Retired	Married	Factor B
P13	73	24	2.875	Biologics	Yes	Retired	Married	No significant loading
P14	56	5	1.5	DMARDs	No	Unemp (RA)	Married	Confounded
P15	50	7	0	DMARDs	No	FT	Married	Factor B
P16	69	5	2.375	Biologic DMARDs	No	Retired	Divorced	Factor B
P17	77	5	2	Biologic DMARDs	Yes	Retired	Married	Factor A
P18	68	5	2.125	Biologic DMARDs	No	Retired	Married	Factor A
P19	45	1.5	0.375	DMARDs	No	FT	Single	Factor B
P20	70	25	2.5	DMARDs	No	Retired	Divorced	Factor A
P21	73	2	0.25	DMARDs	No	Retired	Married	Factor A
P22	66	31	0.875	DMARDs Steroids	No	PT	Married	Factor A
P23	68	15	0.75	DMARDs	No	Retired	Married	Confounded
P24	76	4	0	DMARDs	No	Retired	Married	Factor A
P25	84	8 months	1	No medication	No	Retired	Married	Confounded
P26	48	2	0	DMARDs	No	FT	Married	No significant loading
P27	75	16	0.375	DMARDs	Yes	Retired	Widowed	No significant loading
P28	68	36	1.625	DMARDs	Yes	Retired	LwP	Confounded
P29	49	21	2.625	DMARDs Steroids	No	Unemp - RA	Married	Factor B
P30	65	7	1.125	DMARDs	No	Retired	LwP	Factor B
Mean (SD)	65 (10.3)	-	-					
Median (IQR)	-	5.0 (11.3)	0.75 (1.69)					

Dis Dur = Disease Duration
HAQ = Health Assessment Questionnaire score 0-3, high bad
Medication: NSAIDs = Non-steroidal anti-inflammatory DMARDs = Disease Modifying Anti-Rheumatic Drug
Employment status: FT = Full time PT = Part time Unemp (RA) = Unemployed due to RA
Marital status: LwP = living with partner

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Table 2: Summary characteristics of factor groups

Factor	Eigenvalue	% variance explained	Age (yrs) Mean (SD)	Dis Dur (yrs) Median (IQR)	Age at diagnosis Mean (SD)	HAQ Mean (SD)	Medication	Employment status	Marital status
Study sample n=30	10.22	34	64.6 (10.3)	5.0 (11.3)	54.8 (14.1)	0.75* (1.69)	DMARDs: 67% Biologics: 17% DMARDs & steroids: 10% NSAIDs only: 3% None: 3%	Retired: 60% Full time: 26% Part time: 7% Unemp (RA): 7% Unemp (other): 0%	Married: 70% Living w/ partner: 13% Widowed: 7% Divorced: 7% Single: 3%
Factor A (n=14)	6.25	21	66.9 (10.1)	4.5 (11.8)	56.6 (14.7)	0.78* (1.25)	DMARDs: 86% Biologics: 7% DMARDs & steroids: 0% NSAIDs only: 0% None: 7%	Retired: 79% Full time: 21% Part time: 0% Unemp (RA): 0% Unemp (other): 0%	Married: 58% Living w/ partner: 14% Widowed: 14% Divorced: 7% Single: 7%
Factor B (n=8)	3.97	13	62.0 (12.3)	5.0 (17.3)	49.4 (16.5)	1.59 (0.99)	DMARDs: 37.5% Biologics: 50% DMARDs & steroids: 12.5% NSAIDs only: 0% None: 0%	Retired: 37.5% Full time: 25% Part time: 12.5% Unemp (RA): 12.5% Unemp (other): 0%	Married: 100% Living w/ partner: 0% Widowed: 0% Divorced: 0% Single: 0%

Dis Dur = Disease Duration HAQ = Health Assessment Questionnaire score 0-3, high bad Unemp (RA) = Unemployed due to RA Unemp (other) = Unemployed for other reason

*Median (Interquartile range) reported

Table 3: By-factor ranking of statements

	Factor Scores	
	Factor A	Factor B
1. I feel like I have lost all of my strength because of my RA	-1	+2
2. I hate seeing other people pick things up that are too heavy for me	0	+1
3. I would never say to anyone 'I can't do that'	0	+3
4. I have sometimes been in tears because of my RA	-1	-1
5. I get angry because of my RA	-7	+6
6. I feel frustrated because of my RA	-2	+7
7. I find myself getting resentful, critical, or annoyed with other people	-3	-3
8. I find myself becoming aggressive towards other people / animals (e.g. shouting)	-6	-3
9. Sometimes I think my life is completely unfair	-4	-4
10 I tend to use alcohol to avoid the problems I am facing	-6	-6
11. I sometimes feel guilty about the affect my RA has on the people around me (e.g. friends/family)	-1	+5
12. I worry about whether I will be well enough to do things that are important to me (e.g. work/holidays)	0	+3
13. I worry about whether my RA will get any worse	+1	+4
14. RA has taken away my independence	-5	+2
15. I will ask for help from people when I need to	+3	-3
16. I worry more about money now I have RA	-5	+1
17. I feel like my body has let me down	-2	0
18. My body has changed a lot since having RA	+1	+3
19. I am careful of what I eat as I don't want to put on weight	+3	-2
20. I miss having well-defined muscles	-2	0
21. Having RA makes me feel less able to be the man I wanted to be	-1	+1
22. It's important to me that when I'm out in public, people don't notice that I have RA	-1	+1
23. I avoid shaking hands with people	0	-4
24. I don't mind having to ask strangers for help when I need it	+1	-5
25. I would rather pay someone to do something that I can't do than to ask for a favour	+1	+2
26. I know which medication I'm taking for my RA and why I take it	+6	+6
27. It's important to me that I have regular RA check-ups with my doctor	+4	+4
28. The worst thing about having RA is the pain	+3	0
29. The worst thing about having RA is the fatigue	+5	+4
30. I feel I can call the rheumatology team if I need medication advice	+6	+3
31. I feel I can call the rheumatology team if I need emotional support	+2	-2
32. My Rheumatologist only needs/wants to know how I am physically (not emotionally or psychologically)	-2	-1
33. I prefer not to talk to my family about my RA	-3	-1
34. Other people get frustrated with me not being able to do things	-3	0
35. When I have a task to do, I am able to pace myself (do a little bit, have a rest and then do a bit more)	+4	+1
36. I set myself targets to motivate myself to do things	+2	+1

37. Keeping active helps me manage my RA symptoms	+5	+1
38. I buy different gadgets and tools to make my life easier	+2	-2
39. If I need to use a tool/device/gadget to help with my RA I will make it myself	0	-5
40. I try to focus on things that are positive in my life	+7	+5
41. I sometimes exercise to the point that I know I will regret it later	0	0
42. I use exercise as a way of releasing anger/frustration due to my RA	-2	-2
43. I sometimes drink more alcohol than I should with the medication I take	-5	-6
44. I change the day I take my medication when I think that taking it will affect my work or social life	-3	-4
45. I sometimes take extra medication without seeking medical advice	-4	-5
46. Once I have started a task I will finish it, even if this means pushing my body too far	+2	+5
47. I still socialise as much as I used to before having RA	+3	-3
48. I talk openly to my friends about my RA	+2	-2
49. My friends make jokes or tease me about my RA	-4	-3
50. If I can't join in with the activities my friends are doing I would rather stay at home	-1	-1
51. I would like the opportunity to talk to / socialise with other men with RA	0	-4
52. I tend to find I want to be on my own more than I used to before I had RA	-2	0
53. It's important to me that I keep myself informed about RA	+3	+3
54. The most important thing to me is to keep working despite my RA	+4	+2
55. I try not to moan or complain about my RA	+4	+4
56. My faith helps me cope with my RA	-1	-7
57. I am finding things are becoming increasingly out of my control	-3	-1
58. My RA affects my choice of clothes and shoes	0	-1
59. I am able to find different ways of doing things I want to, or different activities to replace those I've	+5	-1
60. There are things that I no longer do or take part in, because if I can't do something properly I would rather not do it at all	+1	+2
61. I prioritise pleasurable activities (e.g. spending time with friends/family) over work or chores	+2	0
62. I have discovered new hobbies or activities as a result of having RA	+1	-2
63. Since being diagnosed with RA I have lost a lot of confidence	-4	0
64. Having RA has changed the way I see the world	+1	+2

Statements highlighted in **bold** text show that consensus on the average score was reached across the factors. Reading the table by column shows the comparative ranking of statements that characterise a particular factor. Reading the table by row shows the comparative ranking of a particular statement across factors.

Table 4: Quotes from participants' post-sort interviews for each Factor

	Quote reference	Quote	Participant
Consensus	Q1.1	It's just the way the cookie crumbles isn't it?	P08
	Q1.2	I suppose I am not really in that kind of [social] context	P30
	Q1.3	I can take stick as well as give it so it doesn't bother me	P06
	Q1.4	I would rather know what's wrong and be on top of it all the time	P19
	Q1.5	If I am going to be stopped doing things, fatigue is one of the things that will really stop me doing it, not joint pain, I can usually push through the joint pain	P30
Factor A	Q2.1	There are things I know I can't do I mean that comes with the job like I say you can't kneel down [...] I would hate to think you know that I couldn't just be independent.	P28
	Q2.2	Well they [employer] are very good so any appointments they let me have the time off	P26
	Q2.3	I'm not proud. If I drop something and I can't bend down and pick it up, I will ask a stranger to do it, no problem at all	P28
	Q2.4	Financially I've worked hard all my life and I've put myself in a position, I don't have to worry about money	P07
	Q2.5	It is far easier to cope with it if you accept it and say I can't do this and I can't do that	P16
	Q2.6	It has been important to me just to be flexible, I think the attitude that really wouldn't work for me is to say I am going to fight this disease...I think to try and be as creative as possible about how you approach it is the way that things work best for me.	P30
	Q2.7	It makes a massive difference to me, having a car because I can get around, I can do the shopping. Erm, and you know I can get around the shops and do what I want to do.	P06
	Q2.8	I do try and walk every day. I have to walk every day, I have to keep going because I think eventually there will be a time when I won't be able to do these things	P16
	Q2.9	The more you get angry, the more frustrated you get, the more annoyed you get. It's really only spoiling your day.	P8
	Q2.10	I never saw the purpose of sort of jumping up and down and screaming, anger doesn't come into it.	P27
Factor B	Q3.1	I get angry because I am extremely fit, healthy, active lifestyle going from that down to hardly anything, you know still able to go out on my bike and go for a swim but just got to be at certain times.	P03
	Q3.2	I do get frustrated more. I only get angry when I am on my own and can't do it. I'll throw something.	P14
	Q3.3	When I say I get angry I don't get physically angry or scream and shout I get angry inside	P22
	Q3.4	I feel guilty now because I can't help the wife, like driving anything like that.	P14
	Q3.5	I couldn't even throw a ball to my son...there is this sort of male bonding thing with your son I think that you want to play a few sort of semi rough games, and I couldn't do that so that was a big miss in my life.	P22
	Q3.6	I know if I do little bits I will never get anything done so I push myself, make myself really sore. But at the end of it I can, even if I am collapsed in a chair I can look at what I have done, I am happy.	P29

	Q3.7	I'm very pig-headed I'm afraid, no I don't do that [ask for help].	P02
	Q3.8	Well I tend to find I can't keep up with people.	P29
	Q3.9	Body has changed a lot, it's got slower, uglier.	P14
	Q3.10	I'm a real wreck man, really I am a wreck but that's because I'm bored and fat.	P02
	Q3.11	I do sometimes avoid shaking hands with people if I can help it...But I usually meet the same people most of the time.	P13
	Q3.12	It's sort of a hiding thing, trying to be a proper man or something or a proper person, able to do everything anyone else can do.	P22
	Q3.13	I don't talk about it with my friends, they'd think I'd gone soft if I did...men don't cry you know this don't you? No we don't not in front of anybody you never would.	P02
	Q3.14	I talk to anyone who can give me some help or information or anything like that, but I am not going to sit down and talk to a load of old men about what, how, you know I've got this and I've got that, I don't want to know.	P18
	Q3.15	Well I've been coming here now for probably near 5 years and all the talk has been about medication. Err, in fact you [researcher] are the first person to talk about it, emotional support.	P17

Please sort the provided items in order to best describe that experience

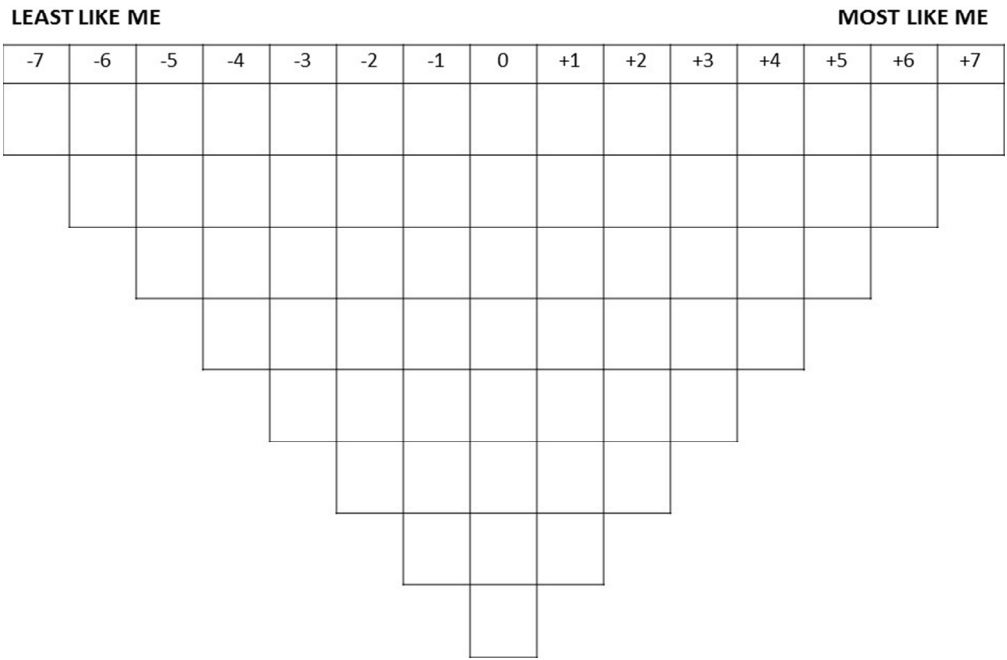


Figure 1: The sorting matrix
254x190mm (96 x 96 DPI)

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Identifying different typologies of experiences and coping strategies in men with rheumatoid arthritis: A Q-methodology study

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Title: Identifying different typologies of experiences and coping strategies in men with rheumatoid arthritis: A Q-methodology study

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Key Words

Rheumatoid Arthritis; Coping; Self-management; Men's Health; Masculinity; Q-methodology

Abstract

Objective: To identify typologies of experiences and coping strategies of men with RA

Design: Q-methodology (a qualitative and quantitative approach to grouping people according to their subjective opinion). Men with RA sorted 64 statements relating to their experience of living with RA according to level of agreement across a normal distribution grid. Data were examined using Q-factor analysis.

Setting: Rheumatology outpatient departments in the UK

Participants: 30 of 65 invited men with RA participated in this study (46%)

Results: All participants ranked highly the need to be well informed about their medication and the importance of keeping a positive attitude.

Two factors describing the experiences and coping strategies of male patients living with RA were identified: Factor A: "Acknowledge, accept and adapt" (n=14) take a pro-active approach to managing the impact of RA and find different ways of doing things; whilst Factor B: "Trying to match up to a macho ideal" (n=8) are determined to continue with their pre-RA lives, and therefore push themselves to carry on even if this causes them pain. They are frustrated and angry due to the impact of RA but they internalise this rather than directing it at others.

Conclusion: Whilst some men adapt to their RA by renegotiating their masculine identity, others struggle to relinquish their traditional masculine roles. Further research is needed to identify whether the finding that there are two distinct groups of men with RA can be generalised, and if so whether the differences can be explained by clinical, social or psychological factors, which may inform different therapeutic approaches.

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Article Summary:

Strengths and limitations of this study

- There is a scarcity of research focussing on men within rheumatology and this is the first study to highlight that men are not homogenous and therefore explore the potential differences in experiences and coping styles between groups of men with rheumatoid arthritis.
- Participants were sampled from five UK hospitals and reflected a range of social circumstances (age, employment status, marital status), disease experiences (disease duration, level of disability) and care pathways.
- Participants sorted pre-determined statements of opinion, which places restrictions on participants expressing views not covered by the statements. However, the statements were developed through focus groups, interviews and a literature review, and were reviewed by the study team including a patient research partner.

Introduction:

Rheumatoid arthritis (RA) is an unpredictable systemic autoimmune disease, characterised by fluctuating symptoms such as pain and fatigue [1, 2]. RA affects more women than men, with approximately 30% of the RA population being male [3], and may take a different course in women compared to men, with male gender being a potential predictor of remission in RA [4].

A comprehensive literature review [5] found the majority of research on psychosocial impact and self-management of men with RA compared gender differences rather than focussing solely on men, and these studies reflect the preponderance of women with RA. There was no consensus on whether gender affects ability to cope with RA. Qualitative research has begun to address the experiences and coping styles of men with RA and the impact on their masculine identity [6-9], suggesting a need to renegotiate masculine identity to adapt to life with RA. However, due to their qualitative nature none of these studies were able to explore whether there was consensus or agreement between the men on their experiences and coping strategies.

If different groups of men have different coping strategies they may also have different support needs. It would therefore be useful to understand the differences and similarities in experiences and coping styles of different groups of men with RA. Thus, the current study aims to identify typologies of experiences and coping strategies in men with RA, according to areas of agreement and any differences between groups of men about their experience of RA, its impact on their lives and their coping and self-management strategies. Q-methodology, a method that

identifies groups of people with similar beliefs according to the way in which they sort statements of opinion, was used to address these aims.

Patients and Methods:

Patients: Male patients with confirmed RA [13] from one of five UK hospitals were invited to participate in this Q-methodology study by the researcher (CF) or local research nurse. Every man with RA attending a rheumatology outpatient appointment on the days of recruitment was invited to take part. Contributing hospitals were Bristol Royal Infirmary, Bristol; Cossham Hospital, Bristol; Royal National Hospital for Rheumatic Diseases, Bath; Weston General Hospital, Weston-Super-Mare; and Haywood Hospital, Stoke-on-Trent.

Patients or participants are treated as variables in Q-methodology, which requires sufficient participants to establish the existence of a factor for the purpose of comparing one factor with another [10]. An adequate sample size to produce a well-defined factor structure is 30 participants [11, 12], which was the target for recruitment.

Participants gave written informed consent and ethics approval was granted (Dyfed Powys Research Ethics Committee, 14/WA/0101).

Methods:

Q-Methodology: Q-methodology combines the strengths of both qualitative and quantitative approaches to identify a number of groups (called ‘factors’). Groups consist of participants who share similar opinions based on their value judgements in prioritising a large set of descriptors. Each group (or ‘factor’) represents a different independent opinion [13]. An appropriate set of descriptors or statements is

assembled and each participant sorts them along a continuum of agreement designed to emulate a normal distribution, with very few extreme values and many central values (Figure 1). Participants sort each statement in approximate rank order of the extent to which they agree with that statement in relation to all the other statements. The positions (scores) of all the statements are included in the analysis for every participant. The statements sorted closer to the outer edges of the distribution have more influence on the factor groupings compared to the statements closer to the middle of the distribution. Factors are calculated and the results then interpreted within the context of the enquiry [11].

Statements: To produce statements regarding the experiences and coping styles of men with RA, data from focus groups and individual interviews with an earlier sample of 22 male RA patients [8, 9] and a comprehensive literature review [5] were collated. The statements were refined through discussion with the research team, including a male patient research partner (RN). Two male patient research partners were involved in early discussions about this study, but one had to cease involvement due to personal commitments. After removing repeated or ambiguous items, 64 statements were included, each worded to answer the question "What is your own personal experience of living with RA?" The statements were printed onto cards and laminated, each card was the size of one space on the Q-sort grid.

Procedure: The Q-methodology study, lasting approximately one hour, was conducted by an independent researcher (CF) in non-clinical outpatient rooms in the participant's hospital. A questionnaire captured demographic data, disability (Health Assessment Questionnaire) and self-reported flare status [14].

First, participants were asked to consider each statement in relation to the question “What is your own personal experience of living with RA?” and sort them into three broad categories: most like me; least like me; neutral. The statements were presented to each participant in a different random order.

Participants were then asked to take each of their broad categories in turn (starting with ‘most like me’) and arrange each statement in approximate rank order of the degree to which they felt that statement reflected their own experience of living with RA, relative to the other statements. They placed each of the 64 statements in a single box on the Q-sort grid of 64 boxes (Figure 1), which had been printed A1 size and laminated. The grid pattern allows for the majority of statements to be agreed or disagreed with mildly or neutrally (for example there were 8 “0” boxes and 7 “+1” or “-1” boxes each) but only one statement could be placed in the “most like me” box (“+7”) or least like me box (“-7”). Thus, each participant’s opinion on the statements were constrained into a quasi-normal distribution of degrees of agreement between the statements. The precise shape and limits of this distribution (and the grid) are dependent on the number of statements. Participants were encouraged to rearrange the position of each statement within the grid until they were satisfied with the distribution.

Finally, participants were interviewed about their statement positioning by the researcher (CF). They were asked to discuss the statements placed at either end of the grid (+7,+6,-6,-7) and any other statements they found interesting. Interviews were digitally recorded and transcribed verbatim.

Analysis: Patient characteristics are presented as mean and standard deviation (SD) or median and inter-quartile range (IQR) as appropriate. The Q-methodology

analysis combines qualitative and quantitative methods to produce a rounded interpretation of a single dataset [15]. Factor extraction and rotation uses the PCQ software package [16], and the output is interpreted by the researchers. Participants are treated as variables and are inter-correlated and subjected to by-person factor analysis. The software searches for shared patterns (or sorting configurations) in the data and extracts portions of common variance (factors). For each Q factor to be interpretable, an eigenvalue >1.0 (indicating factors are unlikely to have grouped participant views by chance), and at least one Q-sort loading significantly upon each factor alone is required [17]. Following extraction, the factors were rotated using orthogonal varimax rotation to ensure each Q-sort defined (has a high factor loading in relation to) only one of the study factors, so the overall solution maximises the amount of study variance explained [11]. For ease of interpretation it is standard Q-methodological practice to generate a single exemplary Q-sort for each factor by merging (according to a procedure of weighted averaging) the Q-sorts of all significantly loading participants on the given factor (termed the factor array) [11]. A decision on the final selection of the optimum factor solution was undertaken collectively by the authors, examining the outputs from the different factor analysis solutions (e.g. number of factors, weightings, explained variance and number of participants excluded from factors). Factor interpretation was based on the factor arrays and the interview data from the significantly loading participants, which were combined to provide a single gestalt explanation of each factor [11, 18].

Consensus statements given similar or the same weighted average by both Factors are presented first, followed by the characteristics of Factors A and B individually.

Results

Study population: Of 65 men with RA invited to participate 30 (46%) did so. Their mean age was 64.6yrs, SD:10.3; median disease duration: 5yrs, IQR 2-13; mean age at diagnosis: 54.8yrs, SD:14.1 (Table 1). Of the 35 men who declined to take part 10 spontaneously volunteered one of the following reasons: being busy with other commitments (e.g. work); having recently taken part in a research study; and not wanting to return to the hospital for a reason other than their care.

Q-methodology factor solution: A two-factor solution emerged based on maximum explained variance; a maximum number of Q-sorts loading significantly onto a single factor; all factors having eigenvalues >1.00; all factors containing statements distinguishing them from other factors; a minimum number of confounded participants (i.e. significantly loading onto more than one factor); and expert judgement. The two factors explain 34% of the variance and account for 22 of the 30 (73%) participants. Participant loading of $\geq \pm 0.32$ reached significance at $p < 0.001$, indicating that each loading participant closely exemplifies the factor they load onto [11]. Five participants were confounded (had a significant loading on both factors) and three did not have a significant loading on either factor. These eight participants had similar characteristics to the overall study population (Table 1).

Table 1 presents participants' demographic data and the Q-sort factor outcome.

Table 2 provides a summary of characteristics of the two factors. Table 3 presents the weighted average scores for each statement for each factor.

Table 1: Participant demographic and clinical data

ID	Age	Dis Dur (yrs)	HAQ	Med	In self-reported flare?	Employment status	Marital status	Q-sort Factor outcome
P1	61	1	1.75	DMARDs	No	PT	Married	Factor A
P2	66	3	0.75	Steroids	No	FT	Married	Confounded
P3	41	1.5	0	DMARDs	Yes	FT	Married	Factor B
P4	55	3	0.125	DMARDs	No	FT	Married	Factor A
P5	56	3	0.375	Steroids	No	FT	Married	Factor A
P6	64	4	1.875	DMARDs	No	Retired	Married	Factor A
P7	65	25	1.875	DMARDs	No	Retired	Married	Factor A
P8	70	2 months	0	DMARDs	No	FT	Married	Factor A
P9	71	5	0	NSAIDs only	No	Retired	LwP	Factor B
P10	68	8	0.25	DMARDs	No	Retired	Widowed	Factor A
P11	67	1	0.75	DMARDs	No	Retired	LwP	Factor A
P12	74	8 months	0	DMARDs	No	Retired	Married	Factor B
P13	73	24	2.875	Biologics	Yes	Retired	Married	No significant loading
P14	56	5	1.5	DMARDs	No	Unemp (RA)	Married	Confounded
P15	50	7	0	DMARDs	No	FT	Married	Factor B
P16	69	5	2.375	Biologic	No	Retired	Divorced	Factor B
P17	77	5	2	DMARDs	Yes	Retired	Married	Factor A
P18	68	5	2.125	Biologic	No	Retired	Married	Factor A
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P27	75	16	0.375	DMARDs	Yes	Retired	Widowed	No significant loading
P28	68	36	1.625	DMARDs	Yes	Retired	LwP	Confounded
P29	49	21	2.625	DMARDs	No	Unemp - RA	Married	Factor B
P30	65	7	1.125	Steroids	No	Retired	LwP	Factor B
Mean (SD)	65 (10.3)	-	-	DMARDs	-	-	-	-
Median (IQR)	-	5.0 (11.3)	0.75 (1.69)	-	-	-	-	-

Dis Dur = Disease Duration

HAQ = Health Assessment Questionnaire score 0-3, high bad

Medication: NSAIDs = Non-steroidal anti-inflammatory DMARDs = Disease Modifying Anti-Rheumatic Drug

Employment status: FT = Full time PT = Part time Unemp (RA) = Unemployed due to RA

Marital status: LwP = living with partner

Table 2: Summary characteristics of factor groups

Factor	Eigenvalue	% variance explained	Age (yrs) Mean (SD)	Dis Dur (yrs) Median (IQR)	Age at diagnosis Mean (SD)	HAQ Mean (SD)	Medication	Employment status	Marital status
Study sample n=30	10.22	34	64.6 (10.3)	5.0 (11.3)	54.8 (14.1)	0.75* (1.69)	DMARDs: 67% Biologics: 17% DMARDs & steroids: 10% NSAIDs only: 3% None: 3%	Retired: 60% Full time: 26% Part time: 7% Unemp (RA): 7% Unemp (other): 0%	Married: 70% Living w/ partner: 13% Widowed: 7% Divorced: 7% Single: 3%
Factor A (n=14)	6.25	21	66.9 (10.1)	4.5 (11.8)	56.6 (14.7)	0.78* (1.25)	DMARDs: 86% Biologics: 7% DMARDs & steroids: 0% NSAIDs only: 0% None: 7%	Retired: 79% Full time: 21% Part time: 0% Unemp (RA): 0% Unemp (other): 0%	Married: 58%% Living w/ partner: 14% Widowed: 14% Divorced: 7% Single: 7%
Factor B (n=8)	3.97	13	62.0 (12.3)	5.0 (17.3)	49.4 (16.5)	1.59 (0.99)	DMARDs: 37.5% Biologics: 50% DMARDs & steroids: 12.5% NSAIDs only: 0% None: 0%	Retired: 37.5% Full time: 25% Part time: 12.5% Unemp (RA): 12.5% Unemp (other): 0%	Married: 100% Living w/ partner: 0% Widowed: 0% Divorced: 0% Single: 0%

Dis Dur = Disease Duration HAQ = Health Assessment Questionnaire score 0-3, high bad Unemp (RA) = Unemployed due to RA Unemp (other) = Unemployed for other reason
*Median (Interquartile range) reported

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Table 3: By-factor ranking of statements

	Factor Scores	
	Factor A	Factor B
1. I feel like I have lost all of my strength because of my RA	-1	+2
2. I hate seeing other people pick things up that are too heavy for me	0	+1
3. I would never say to anyone 'I can't do that'	0	+3
4. I have sometimes been in tears because of my RA	-1	-1
5. I get angry because of my RA	-7	+6
6. I feel frustrated because of my RA	-2	+7
7. I find myself getting resentful, critical, or annoyed with other people	-3	-3
8. I find myself becoming aggressive towards other people / animals (e.g. shouting)	-6	-3
9. Sometimes I think my life is completely unfair	-4	-4
10 I tend to use alcohol to avoid the problems I am facing	-6	-6
11. I sometimes feel guilty about the affect my RA has on the people around me (e.g. friends/family)	-1	+5
12. I worry about whether I will be well enough to do things that are important to me (e.g. work/holidays)	0	+3
13. I worry about whether my RA will get any worse	+1	+4
14. RA has taken away my independence	-5	+2
15. I will ask for help from people when I need to	+3	-3
16. I worry more about money now I have RA	-5	+1
17. I feel like my body has let me down	-2	0
18. My body has changed a lot since having RA	+1	+3
19. I am careful of what I eat as I don't want to put on weight	+3	-2
20. I miss having well-defined muscles	-2	0
21. Having RA makes me feel less able to be the man I wanted to be	-1	+1
22. It's important to me that when I'm out in public, people don't notice that I have RA	-1	+1
23. I avoid shaking hands with people	0	-4
24. I don't mind having to ask strangers for help when I need it	+1	-5
25. I would rather pay someone to do something that I can't do than to ask for a favour	+1	+2
26. I know which medication I'm taking for my RA and why I take it	+6	+6
27. It's important to me that I have regular RA check-ups with my doctor	+4	+4
28. The worst thing about having RA is the pain	+3	0
29. The worst thing about having RA is the fatigue	+5	+4
30. I feel I can call the rheumatology team if I need medication advice	+6	+3
31. I feel I can call the rheumatology team if I need emotional support	+2	-2
32. My Rheumatologist only needs/wants to know how I am physically (not emotionally or psychologically)	-2	-1
33. I prefer not to talk to my family about my RA	-3	-1
34. Other people get frustrated with me not being able to do things	-3	0
35. When I have a task to do, I am able to pace myself (do a little bit, have a rest and then do a bit more)	+4	+1
36. I set myself targets to motivate myself to do things	+2	+1

37. Keeping active helps me manage my RA symptoms	+5	+1
38. I buy different gadgets and tools to make my life easier	+2	-2
39. If I need to use a tool/device/gadget to help with my RA I will make it myself	0	-5
40. I try to focus on things that are positive in my life	+7	+5
41. I sometimes exercise to the point that I know I will regret it later	0	0
42. I use exercise as a way of releasing anger/frustration due to my RA	-2	-2
43. I sometimes drink more alcohol than I should with the medication I take	-5	-6
44. I change the day I take my medication when I think that taking it will affect my work or social life	-3	-4
45. I sometimes take extra medication without seeking medical advice	-4	-5
46. Once I have started a task I will finish it, even if this means pushing my body too far	+2	+5
47. I still socialise as much as I used to before having RA	+3	-3
48. I talk openly to my friends about my RA	+2	-2
49. My friends make jokes or tease me about my RA	-4	-3
50. If I can't join in with the activities my friends are doing I would rather stay at home	-1	-1
51. I would like the opportunity to talk to / socialise with other men with RA	0	-4
52. I tend to find I want to be on my own more than I used to before I had RA	-2	0
53. It's important to me that I keep myself informed about RA	+3	+3
54. The most important thing to me is to keep working despite my RA	+4	+2
55. I try not to moan or complain about my RA	+4	+4
56. My faith helps me cope with my RA	-1	-7
57. I am finding things are becoming increasingly out of my control	-3	-1
58. My RA affects my choice of clothes and shoes	0	-1
59. I am able to find different ways of doing things I want to, or different activities to replace those I've	+5	-1
60. There are things that I no longer do or take part in, because if I can't do something properly I would rather not do it at all	+1	+2
61. I prioritise pleasurable activities (e.g. spending time with friends/family) over work or chores	+2	0
62. I have discovered new hobbies or activities as a result of having RA	+1	-2
63. Since being diagnosed with RA I have lost a lot of confidence	-4	0
64. Having RA has changed the way I see the world	+1	+2

Statements highlighted in **bold** text show that consensus on the average score was reached across the factors. Reading the table by column shows the comparative ranking of statements that characterise a particular factor. Reading the table by row shows the comparative ranking of a particular statement across factors.

Consensus statements: Of the statements with the same or similar weighted average score by both factors (highlighted bold in Table 3), those with factor scores $\geq \pm 3$ indicated that male patients valued being well-informed about their medication [Statement (St) 26: factor scores +6, +6], and they will not change the day or amount without medical advice [St44: -3, -4; St45: -4, -5]. They also would not drink

too much alcohol with their medication [St43: -5, -6] or use alcohol to avoid their problems [St10: -6, -6]. Participants reported having a positive attitude [S40: +7, +5]: they try not to complain; [St55: +4, +4]; do not get annoyed with other people [St07: -3, -3]; nor think life is unfair [St09: -4, -4] (Table 4: Quote reference: Q1.1)

Being teased by friends was least like these men's experience of having RA [St49: -4, -3]. However, whilst for some this issue was irrelevant, for others this did happen but was not a concern for them (Q1.2; Q1.3). These male patients valued regular appointments with their doctor [St27: +4, +4] and keeping themselves informed about RA [St53: +3, +3] (Q1.4). Finally, consensus across patients within both factors suggests fatigue is 'the worst thing about having RA' [St29: +5, +4] (Q1.5).

Table 4: Quotes from participants' post-sort interviews for each Factor

	Quote reference	Quote	Participant
Consensus	Q1.1	It's just the way the cookie crumbles isn't it?	P08
	Q1.2	I suppose I am not really in that kind of [social] context	P30
	Q1.3	I can take stick as well as give it so it doesn't bother me	P06
	Q1.4	I would rather know what's wrong and be on top of it all the time	P19
	Q1.5	If I am going to be stopped doing things, fatigue is one of the things that will really stop me doing it, not joint pain, I can usually push through the joint pain	P30
Factor A	Q2.1	There are things I know I can't do I mean that comes with the job like I say you can't kneel down [...] I would hate to think you know that I couldn't just be independent.	P28
	Q2.2	Well they [employer] are very good so any appointments they let me have the time off	P26
	Q2.3	I'm not proud. If I drop something and I can't bend down and pick it up, I will ask a stranger to do it, no problem at all	P28
	Q2.4	Financially I've worked hard all my life and I've put myself in a position, I don't have to worry about money	P07
	Q2.5	It is far easier to cope with it if you accept it and say I can't do this and I can't do that	P16
	Q2.6	It has been important to me just to be flexible, I think the attitude that really wouldn't work for me is to say I am going to fight this disease... I think to try and be as creative as possible about how you approach it is the way that things work best for me.	P30
	Q2.7	It makes a massive difference to me, having a car because I can get around, I can do the shopping. Erm, and you know I can get around the shops and do what I want to do.	P06

	Q2.8	I do try and walk every day. I have to walk every day, I have to keep going because I think eventually there will be a time when I won't be able to do these things	P16
	Q2.9	The more you get angry, the more frustrated you get, the more annoyed you get. It's really only spoiling your day.	P8
	Q2.10	I never saw the purpose of sort of jumping up and down and screaming, anger doesn't come into it.	P27
Factor B	Q3.1	I get angry because I am extremely fit, healthy, active lifestyle going from that down to hardly anything, you know still able to go out on my bike and go for a swim but just got to be at certain times.	P03
	Q3.2	I do get frustrated more. I only get angry when I am on my own and can't do it. I'll throw something.	P14
	Q3.3	When I say I get angry I don't get physically angry or scream and shout I get angry inside	P22
	Q3.4	I feel guilty now because I can't help the wife, like driving anything like that.	P14
	Q3.5	I couldn't even throw a ball to my son...there is this sort of male bonding thing with your son I think that you want to play a few sort of semi rough games, and I couldn't do that so that was a big miss in my life.	P22
	Q3.6	I know if I do little bits I will never get anything done so I push myself, make myself really sore. But at the end of it I can, even if I am collapsed in a chair I can look at what I have done, I am happy.	P29
	Q3.7	I'm very pig-headed I'm afraid, no I don't do that [ask for help].	P02
	Q3.8	Well I tend to find I can't keep up with people.	P29
	Q3.9	Body has changed a lot, it's got slower, uglier.	P14
	Q3.10	I'm a real wreck man, really I am a wreck but that's because I'm bored and fat.	P02
	Q3.11	I do sometimes avoid shaking hands with people if I can help it...But I usually meet the same people most of the time.	P13
	Q3.12	It's sort of a hiding thing, trying to be a proper man or something or a proper person, able to do everything anyone else can do.	P22
	Q3.13	I don't talk about it with my friends, they'd think I'd gone soft if I did...men don't cry you know this don't you? No we don't not in front of anybody you never would.	P02
	Q3.14	I talk to anyone who can give me some help or information or anything like that, but I am not going to sit down and talk to a load of old men about what, how, you know I've got this and I've got that, I don't want to know.	P18
	Q3.15	Well I've been coming here now for probably near 5 years and all the talk has been about medication. Err, in fact you [researcher] are the first person to talk about it, emotional support.	P17

Characteristics of Factor A: (subsequently labelled 'Acknowledge, accept and adapt'): This factor consisted of 14 participants (mean age: 66.8yrs, SD:10.3; median disease duration: 4.5yrs, IQR:2-13; mean age at diagnosis: 56.6yrs, SD:14.7) who were predominantly retired, reported less disability and were on less intensive medication regimens than those in Factor B (Table 2).

Factor A participants acknowledge their limitations due to RA, but refuse to allow these to affect their independence [St14: -5] (Q2.1). Although the majority of these participants are retired they still rate work as important [St54: +4]. The discourse suggests these participants have (or had) sufficient autonomy in their job to enable them to manage this alongside their RA (Q2.2). This ability to control other aspects of their lives may explain why these participants seem able to accept some loss of control due to RA (Q2.3). Further, the ability to continue to work full time or to have continued until retirement has enabled these participants to be less concerned about finances [St16: -5] (Q2.4)

RA has not affected the confidence of these men [St63: -4], which the discourse indicates is due to retaining their independence (Q2.7). They do this through accepting limitations, finding different ways of doing things for themselves [St29: +5] (Q2.5; Q2.6) and being willing to accept help when they need to [St15: +3; St24: +1]. They take a pro-active approach to managing RA, being careful of what they eat (to avoid weight gain) [St19: +3] and keeping active [St37: +5] (Q2.8)

These men refuse to get angry [St05: -7] or become aggressive [St08: -6] and are less likely to get frustrated by their RA [St06: -2]. The discourse suggests they do not see an emotional response as helpful (Q2.9; Q2.10). Factor A participants report socialising as much as they did before they developed RA [St47: +3]; feel more able

to talk about their RA to their friends [St48: +2] or other men with RA [St51: 0] than those in Factor B. These participants also feel more able to contact their rheumatology team for either medication advice [St30: +6] or emotional support [St31:+2].

Characteristics of Factor B: (subsequently labelled 'Trying to match up to a macho ideal'): This factor consisted of eight participants (mean age: 62.0 yrs, SD: 12.3; median disease duration: 5.0yrs, IQR:4.5-21.8; mean age at diagnosis: 49.4yrs, SD: 16.5) and is a combination of men who are retired, working full time or unemployed due to RA. These participants report more disability and are taking more intensive medication than those in Factor A and two of these participants were in a disease flare at the time of taking part in this study (Table 2).

Factor B participants report negative feelings of frustration [St06: +7] and anger [St05: +6] due to the effect of RA on their independence [St14: +2] and abilities. They are annoyed by the need to adapt to accommodate their RA and struggle to accept a new normality (Q3.1). The discourse suggests that their anger is directed at themselves rather than towards others (Q3.2; Q3.3). Their frustration is driven by the (perceived) effect RA has on other people, causing them to feel guilty [St11: +5] because they feel unable to fulfil their role as a husband or father (Q3.4; Q3.5).

These men try to continue living as they did before they had RA. They therefore will never say to anyone 'I can't do that' [St03: +3] and will always finish a task once they've started it [St56: +5] even if this means regretting it later (Q3.6). They will not accept the need to use disability aids [St39: -5; St38: -2], and will not ask for help from anyone, especially not from strangers [St15: -3; St24: -5] (Q3.7)

These participants withdraw socially [St47: -3] because they can no longer keep up with their friends (Q3.8). They report negative thoughts such as worrying about their RA getting worse [St13: +4], feeling that their body has changed [St18: +3] and they use critical language in relation to themselves and their bodies (Q3.9; Q3.10).

They disagreed with the statement 'I avoid shaking hands with people' [St23: -4], which could indicate an acceptance of other people knowing about their RA. However, the discourse suggests that they do hide their RA, but because they don't often meet new people the issue of shaking hands is not salient to them (Q3.11; Q3.12).

These participants do not use faith to help them cope with RA [St56: -7] as this is not a belief they hold. They are not interested in talking about their RA to their friends [St48: -2] or other men with RA [St51: -4] because this isn't the way 'real men' behave (Q3.13) and they do not think it would be helpful (Q3.14). They also do not feel their medical team are interested in their emotional well-being [St31: -2] (Q3.15).

Discussion

There was consensus across participants about some aspects of their experience of living with RA. However, there were also areas of difference between participants, which provides initial evidence for two distinct experiences and coping strategies for men with RA.

Collectively, there is broad consensus amongst the men in this study that it is important to be well-informed about their medication, supporting previous findings that for men with long-term conditions receiving 'factual' information can offer reassurance and increase feelings of control [19]. It has been suggested that men may use alcohol to avoid emotional distress [20]. However, consensus across both

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factors suggests that these men do not report using alcohol to avoid their problems. This may be due to the knowledge that alcohol can affect their medication and they may therefore be trying to retain as much control as possible over their unpredictable RA.

Although there were agreements on these elements of living with RA, differences also emerged that identify two relatively distinct groups. One group of men (Factor A) seemed able to accept their RA and adapt to it. The second group of men (Factor B) seemed to be trying to live up to a masculine ideal of being strong, capable and self-sufficient despite having RA. These men therefore fight the impact of RA by pushing themselves to keep going despite being in pain, and refuse to accept help. For these two groups of men we have coined descriptive labels: 'Acknowledge, accept and adapt' (Factor A); and 'Trying to match up to a macho ideal' (Factor B).

The resistance to the impact of RA expressed by participants in Factor B supports the suggestion that some men perceive ill health as a threat to their masculine identity, and that addressing health concerns challenges their health-related beliefs of men being self-reliant and resilient [21]. Further, the men in Factor B report experiencing anger and frustration that they direct inwards. This supports the theory that some men behave according to a learned 'boy code' of independent stoicism ('everything's fine'), which causes them to wear a 'mask of masculinity' to hide feelings of vulnerability [22]. These findings highlight a need for healthcare professionals to be vigilant to the emotional needs of men with RA, who may be experiencing distress not expressed externally. Clinicians should be encouraged to explicitly ask men about psychological and emotional issues [8].

Dealing with health concerns can be perceived as taking action and gaining control when men's health status begins to jeopardize their independence [23]. This may be the cognitive mechanism employed by participants in Factor A, who seem to have begun a process of renegotiating their masculine identity [24] and may therefore be drawing from a new masculinity that involves adapting to their RA, enabling them to maintain control. In contrast, participants in Factor B seem to be trying to maintain the roles and values traditionally associated with masculinity.

"Our finding that there are at least two groups of men who experience and cope with RA differently to each other has the potential to inform support provision for men. These two groups of men may have different preferences for support to suit their different coping strategies. However, further exploration is necessary to understand the support preferences of these two groups. Further, to explore whether patients can move between coping strategies (and therefore support needs) depending on either clinical or personal circumstances. Previous findings do suggest that men with early RA may adapt their coping strategies to their situation [25].

Participants within Factor A reported less disability (lower HAQ scores) and were receiving less intensive medications, indicating that their disease was less severe than those in Factor B. It is therefore possible that having less severe disease enabled them to accept and adapt to their RA more easily. However, due to the small sample size conclusions about disease severity cannot be drawn from these data. Further exploration is necessary in a larger population as such differences may have important implications for how support is targeted to these two groups of men.

The characteristics of participants in Factor B (such as being unwilling to talk about their RA and accept help) indicate that these men would be less likely to engage with healthcare and thus less likely to take part in a face-to-face research study such as this one. Although every man who attended clinic during the recruitment period was invited to take part, the very characteristics included in Factor B may have reduced the proportion of participants that this Factor (54% of invited patients declined to take part). This potential recruitment bias would reduce the likelihood of identifying Factor B, which nevertheless emerged. Therefore the size of Factor B as reported here (27% of participants) may be an underestimate of the number of men with RA who have these coping strategies.

Evidence from several long term conditions indicate gender differences on the impact of illness, and ways of coping [26, 27], suggesting that men need their own health strategy [28]. However, despite these indications from other conditions, there is a scarcity of research addressing the impact of RA on men and their coping strategies [5]. The analysis presented here suggests that while some men can accept their RA and adapt to it, others fight the impact of their condition, trying to retain their masculine activities and causing internalised anger and frustration. The similarities between these findings and the issues identified as specific to men with other long term conditions suggest these experiences and coping styles may not be shared with women.

This study may have limitations because the whole sample was white British. However, the statements were developed in a white British population and a separate study would be necessary to fully capture the potentially different experiences of men with RA from different ethnic backgrounds. Q-methodology

requires predetermined statements for participants to sort and is therefore dependant on their appropriateness to the judgements being made [29]. In the present study, the statements to be sorted came from recent focus groups and interviews with men with RA [8, 9] and the literature [5] and therefore included a wide range of relevant issues. They were also reviewed by a male patient research partner (RN). In addition, patients were sampled for a range of age, disease duration and disability and from eight consultants across five UK hospitals, thereby accessing a range of disease experiences and care pathways.

Our findings suggest that there is a realistic possibility that many men with RA are not being served by current self-management interventions because of their personal coping strategies. Further research should identify whether the finding that there are two distinct groups of men is generalizable, and if so whether any clinical, social or psychological factors can explain the difference between the groups. This is now being addressed through a survey study informed by these findings, which will enable an informed judgement of whether there is a clinical need to provide services tailored towards the potentially different needs of men, and if so inform the design of such an intervention.

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Contributors: All authors were involved in the design and planning of the study. CF prepared the statements for participants to sort, which were reviewed and revised by SH, JK, KR, AW and RN until all were satisfied. CF and local research nurses invited patients to participate. CF conducted the Q-methodology study and the post-study interviews. CF conducted the initial Q-methodology analysis, then all authors participated equally in deciding on the most appropriate factor solution and the qualitative interpretation of the chosen solution. CF led the writing of the manuscript

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Please sort the provided items in order to best describe that experience

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Figure 1: The sorting matrix
130x97mm (300 x 300 DPI)