**Title: Coping strategies, psychological impact and support preferences of men with rheumatoid arthritis: a multicentre survey**

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**Abstract (250 words)**

**Objectives** To investigate the existence and distribution of two typologies (termed ‘Factors’) of men with RA identified through our previous Q-methodology study (n=30) in a larger sample of men with RA, and whether differences in psychosocial impact or support preferences exist between the two factors, and between men and women with RA.

**Methods** A postal survey was sent to 620 men with RA from 6 rheumatology units across England, and the support preferences section of the survey was given to 232 women with RA.

**Results** 295 male patients (47.6%) and 103 female patients (44.4%) responded. Fifteen male participants had missing data, thus 280 were included in the analysis. Of these, 61 (22%) were assigned to Factor A (“accept and adapt”), 120 (35%) were assigned to Factor B (“struggling to match up”) and 99 (35%) were unassigned to either factor.

The two factors differed significantly with Factor B reporting more severe disease, less effective coping strategies and poorer psychological status. For support, men favoured a question and answer session with a consultant (54%) or specialist nurse (50%), a website for information (69%), a talk from researchers (54%), or a symptom management session (54%).

Overall, women reported more interest in support sessions than men, with ≥50% of women reporting interest in nearly every option provided.

**Conclusions** Some men accept and adapt to their RA, but others (43%) report severe disease, less effective coping and poor psychological status. Men’s preferences for support take the practical form, with a focus on expanding their knowledge.

Key Words

Rheumatoid Arthritis; Coping; Self-management; Men’s Health; Masculinity

Introduction

Rheumatoid arthritis (RA) is a long term condition, characterised by painful, swollen and stiff joints, and fatigue (1, 2). RA affects more women than men (approximately 30% 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 recent literature review (5) found the majority of gender-based research on psychosocial impact and self-management in rheumatology either addressed the differences between men and women, reflecting the preponderance of women with the condition, or focussed solely on women. Very little research has focussed solely on men and there is no consensus on whether gender affects a person’s ability to cope with RA. Qualitative research has begun to address the experiences and coping styles of men with RA and its impact on their masculine identity (6-9), suggesting a need to renegotiate masculine identity and re-write masculinity scripts (10) to adapt to life with RA.

In a previous phase of this research a Q-methodology study used qualitative and quantitative methods to group men with RA (n=30) according to their level of agreement with statements about living with and managing their condition (11). Two groups (termed ‘Factors’ in Q-methodology) were identified; the first group (Q-Factor A: “accept and adapt”) were able to take control of other areas of their lives to enable them to accept the loss of control due to RA, and found ways to adapt to their condition. The second group (Q-Factor B: “struggling to match up”) tried to continue taking part in the masculine activities they had taken part in before their diagnosis, despite this causing them further pain. However, they were reluctant to accept physical or emotional support.

Evidence from several long term conditions indicate gender differences on the impact of illness, and ways of coping (12, 13), suggesting that men need their own health strategy (14). The similarities between the qualitative and Q-methodology findings in men with RA, and those identified as specific to men with other long-term conditions suggest that men with RA may need their own tailored support, which has not previously been investigated. Due to their different approach to coping those men in Q-Factors A and B may require different support approaches to each other and to women with RA. However, it is possible that there may be overlap in support preferences between women and the men in Q-Factor A, who seem able to accept and adapt to their condition.

The nature of qualitative and Q-methodology research involves relatively small numbers of participants, it would therefore be useful to understand whether the issues raised by the qualitative work, and the two groups of men identified in the Q-methodology study, exist in a wider population of men with RA. If these two groups do exist it is important to understand whether they have different preferences for support provision, and whether these preferences differ sufficiently from those of female patients to justify the development of a support intervention tailored towards men with RA. Thus, we aim to address the following objectives in the current study:

1. To investigate whether Factors A and B (from the Q-methodology study) are generalizable across men with RA, and whether these Factors can be explained by demographics, disease status, coping strategies or psychological status.
2. To understand whether there is a difference in support preferences between men in Factor A, men in Factor B and women with RA.

Participants and methods

A questionnaire using validated measures and items created by the research team was developed based on themes and issues that emerged as important from the previous qualitative and Q-methodology studies. Two questionnaires were posted to male participants in the same survey pack. The first collected demographic and clinical information, and asked patients to complete numerical rating scales (NRS) of the statements used in the Q-methodology study that distinguished the two Q-methodology factors from each other. Distinguishing statements were chosen if the average scores between the two factors were sufficient to highlight the differences in experience of living with RA (15). Statements were included if there was a ≥4 point difference between the composite scores for each factor, as this was natural cut-off point at which there were a manageable number of statements for participants to rate. From the original sample of 64 statements, 12 statements were included in the survey with each factor represented by 6 distinguishing statements.

The first questionnaire also measured coping strategies, acceptance of illness, perceived stress, depression and anxiety, and mental well-being. Table 1 shows the measures used for each assessment. The second questionnaire concerned patient preferences for self-management support including mode of delivery and practical issues (e.g. time of day). Options for self-management support came from previous qualitative work (8, 9) and a systematic review of effectiveness and acceptability of self-management support for men with long term conditions (16, 17). To assess whether men and women have different preferences for support, the questionnaire for female participants contained the sections on demographic and clinical information, and self-management support preferences. The Q-methodology distinguishing statements were not included since they were developed with men, and may not be appropriate for a female population.

The (longer) male questionnaire was piloted with a male patient research partner (RN), who gave advice about the order of some items and indicated the questionnaire took 30-40 minutes to complete.

To capture a range of views participants were recruited through rheumatology units in six regional hospitals across England, selected to reflect diverse geographical locations and serving different communities in relation to urbanity/rurality and socioeconomic status. Patients were included who were over 18 years old and with a confirmed diagnosis of RA from their rheumatologist reported in their records.

To recruit sufficient male participants within a reasonable time, at each hospital a member of the local team screened their database for male RA patients. A questionnaire was then posted to either a random selection of 100 (using a random number generator in Excel) or every male RA patient on the database (whichever was smaller). For the female participants, at each hospital a member of the local team handed questionnaires to consecutive female patients attending an outpatient appointment. A convenience sample of female participants is sufficient to broadly compare support preferences of men and women. If there is a clear difference between support preferences this would be apparent in any group of women approached without the need for strategic sampling.

Both male and female participants were assigned a study number and if no response was received they were sent a reminder approximately two weeks later. All responses were returned directly to the central research team in a pre-paid envelope.

Analysis

Questionnaire data were entered into SPSS for Windows and Brown’s factor index score method (15, 18) was used to investigate the likely membership of each survey study participant to the two Q-methodology Factors. In Q-methodology, data analysis uses correlation and by-person factor analysis, meaning that statistical analysis is not performed by-variable, but by-person. People correlate with others with similar opinions based on their Q-sorts. Q-methodology therefore results in the grouping of expressed opinion profiles based on the similarities and differences in which the statements are arranged by each participant (19). Thus, to retain this by-person analysis, Brown’s factor index score method was chosen to identify how common the previously identified experiences (Q-Factors A and B) are in the wider population, and whether they relate to patients’ coping styles, psychological status and support preferences.

Participant scores on the NRS for each distinguishing statement are used to calculate a standardised index score for each participant for each factor, which indicates to what extent the participant is associated with each factor. Table 2 demonstrates the scoring procedure for one participant (M049). The first four columns show the Q-factors, the selected distinguishing statements and the Q-factor scores of the statements in the original Q-methodology study. Column five shows the mean item score for each statement, representing mean agreement with the statements across participants. For example, “keeping active helps me manage my RA symptoms” has a mean score of 7.1 indicating male patients in the overall sample tend to agree with this statement. NRS scores of statements with negative factor scores were reverse scored. Statement index scores and factor index scores were calculated for each participant. The statement index score is calculated as the product of the absolute value of the factor score (which is fixed across participants, as it originates from the previous Q-methodology study) and the item score (which varies between participants, based on their NRS scores). For example, the statement ‘I still socialise as much as I used to before having RA’ had a ranking of +3 for Q-Factor A in the Q-methodology study, and participant M049 gave this statement a NRS score of 4, giving participant M049 a statement index score of 12. Thus, the statement index score takes into account the weighting given to each item within the relevant Q-factor as determined by the previous Q-methodology study (20). Factor index scores were calculated for each factor as the sum of the statement index scores of each participant for the relevant factor. Participant M049 had a factor index score of 100 for Factor A and 333 for Factor B, indicating that whilst this participant had some agreement with Factor A, there was clear stronger agreement with Factor B. Table 3 shows mean statement and factor index scores for the participants in the current study.

T-tests, Mann Whitney tests (as appropriate) and Chi2 tests were used to assess demographic, clinical or psychosocial differences between Factors A and B. Distributions of responses were used to describe support preferences. Chi2 tests were used to test whether there are any differences in support preferences between Factors A and B, and between male and female participants.

Results

**Are Factors A and B generalizable across men with RA, and can they be explained by demographics, disease status, coping strategies or psychological status.**

Responses were received from 295 of 620 male patients (47.6%) and 103 of 232 female patients (44.4%). A total of 280 male participants fully completed the Q-methodology NRS and were therefore included in the analysis. Of these, 61 (22%) had factor index scores that indicated their opinions belong to Factor A (“accept and adapt”), 120 (43%) could be assigned to Factor B (“struggling to match up”) and 99 (35%) had less than one standard deviation between their factor index scores and were therefore unassigned to one factor or the other. A similar proportion of male participants were assigned to Factor A, Factor B or unassigned in the present survey study as in the original Q-methodology study.

Demographic and clinical data are presented in Table 4. For male participants these data, and coping strategies and psychological status are presented as combined and separately for the groupings according to Q-methodology factors.

There were no significant differences between the men assigned to Factor A or Factor B for age, comorbidities, marital status or disease duration. However, participants assigned to Factor B (“struggling to match up”) were less likely to be retired (p<0.000) and if working were significantly less likely to consider their role particularly physically active (p=0.040) or autonomous (p=0.007). Those assigned to Factor B reported a significantly higher patient global score (p<0.000) and more were taking biologic therapies (p=0.010).

Participants assigned to Factor B were more likely to use the coping strategies of confrontation (p=0.15), avoidance (p<0.001) and resignation (p<0.001) and were less accepting of their RA (p<0.001).

Participants assigned to Factor B reported poorer psychological status, with significantly more cases or borderline cases of both anxiety and depression than those assigned to Factor A (p<0.001; p<0.001); a higher level of perceived stress (p<0.000); and a lower level of mental well-being (p<0.001).

**Is there a difference in support preferences between men in Factor A, men in Factor B and women with RA?**

Preferences for self-management support are shown in Table 5. The most popular methods of support selected by men with RA (reaching ≥50%) were: a one to one with a consultant (83%), specialist nurse (80%) or physiotherapist (53%); a question and answer session with a consultant (54%) or specialist nurse (50%); a website for information (69%); an organised talk by research experts (54%); or an education session on managing their symptoms (54%). Members of Factor B were significantly more likely than those in Factor A to select an education session on managing stress and anger (Factor A: 18%; Factor B: 34%) or an education session managing symptoms (Factor A: 54%; Factor B: 63%).

Men were least interested in either a one to one (28%) or a question and answer session with another patient (20%). Although these were not the most popular options with the female participants (49%, 45%), they nevertheless were significantly more interested in interacting with another patient (p=0.003; p<0.001, respectively).

Generally, women reported being interested in support sessions more than men, with ≥50% of women reporting being interested in nearly every support option provided. Thus, there were no options selected more highly by men than women.

The preferred time of day for a support intervention for men was in the morning (9am-midday: 39%) and for women in the afternoon (2-5pm: 43%). Both men and women would prefer a modular approach to self-management support with an advertised programme that they can access at their convenience (72% and 76% respectively). The majority of both men (63%) and women (68%) reported no preference over group gender. Further, only 17% of men and 9% of women report that a support group should be for people with RA only. Conversely, 41% of men and 55% of women would like the option of inviting a friend or family member, whilst 42% of men and 35% of women report that although they would not bring someone they wouldn’t mind if others did. Men and women reported being more likely to be motivated to attend a self-management session if they were sent an appointment letter (men:52%, women:61%), or invited to attend by their rheumatologist (men:68%, women:69%) or specialist nurse (men:56%, women:71%).

Discussion

The current study found in a large and diverse sample of patients with RA that there are two groups of men with different coping styles. One group (Factor B: “struggling to match up”) reported using less effective coping strategies, less acceptance and lower psychological well-being than the other group (Factor A: “accept and adapt”). The experience of RA and coping styles of men in Factor A support the suggestion that men perceive ill-health as a threat to their masculine identity, and addressing health concerns can challenge their health-related beliefs of men being self-reliant and resilient (21). However, dealing with health concerns can be perceived as taking action to gain control when men’s health status begins to threaten their independence (22), which may be the cognitive mechanism being employed by the participants in Factor A.

The characteristics of participants in Factor B indicate that these men would be less likely to engage with healthcare and therefore less likely to take part in a research study. It is therefore possible that we may have under-recruited participants who would form factor B (52.4%) of invited participants declined to take part). Therefore the size of Factor B as reported here (43% of participants) may be an underestimate of the number of men with RA who have these coping strategies.

 These groups had previously been identified as Factors in a Q-methodology study (11), but might have been a reflection of the relatively small sample size of that study. The current results show that these groups do exist in a wider sample of men with RA, and that a significant proportion of male RA patients (43% in the current study) are in need of an appropriately targeted support or self-management intervention from their rheumatology team. This adds to the more general perception that men need their own health strategy (14).

The preferences for support amongst men belonging to both Factors A and B, and those participants who were unassigned to either Factor are broadly similar, indicating that a common method of support provision across male patients may be acceptable. Recent research in other conditions suggest support services need to be gender sensitive to ensure interventions do not undermine masculine values, and address men’s concerns (13).

The most popular form of support identified by men was a one-to-one session with their rheumatologist, specialist nurse or physiotherapist. This reflects the current provision of care, but men were also interested in a question and answer session with their rheumatologist or specialist nurse, the opportunity to hear about current research, and education sessions for symptom management. This is similar to evidence from other long term conditions suggesting support services for men should have a practical focus (16), provide opportunities to gather new information (23, 24) and that men use information exchange as a form of emotional support (25). Despite this finding, men are under-represented in trials focussing on symptom management in RA (e.g. on a fatigue management programme 85.4% of the participants were female (26)). Further, despite those in Factor B reporting poor psychological well-being, only 34% of these patients recognised the need for an education session on managing stress and anger. It may therefore be necessary to take a gender-sensitised approach to advertising and delivering an intervention for men with RA to increase engagement; an approach that has been successfully carried out in an intervention for obesity (Football Fans in Training: (27)).

Male participants were less interested than women in hearing from other RA patients, which may reflect men’s preferences for seeking out information rather than experiences (16). Although this may call into question the appropriateness of providing interventions involving co-delivery with patients for men, previous qualitative work found co-facilitation by a patient research partner in focus groups was helpful for engaging men in discussion (8).

Female participants indicated greater acceptance than males of all support options, in line with previous findings in RA (28). Engaging in health practices for well-being rather than physical health can be perceived as less masculine (29). Thus, the men in this study may show less interest in support than women as they are engaging in the masculine ideal of being ‘strong and silent’ (30).

Previous research comparing interactions of men and women in online forums about breast cancer (aimed at women) and prostate cancer (aimed at men) found that quantitatively women dominated both forums. Qualitatively, whilst the men made attempts to accommodate their communication to the norms of the opposite gender, the women did not (31). Thus, despite both the male and female participants reporting no clear preference for a single-gender group, it may be important to provide men with RA with an all-male intervention to enable them to engage according to masculine norms. Evidence from the obesity literature suggest male-only groups are qualitatively different from mixed-gender groups, with different levels of engagement, styles of language and success (32, 33).

Both male and female participants reported a preference for a modular approach to support, whereby different topics would be covered in each session and patients could access support according to an advertised timetable. This approach may be more complex to evaluate in a randomised controlled trial, but is a potential way forward for intervention delivery.

Further, both male and female participants reported being more likely to attend a self-management intervention if they received an appointment letter or personal recommendation from their rheumatologist or specialist nurse. This supports the view that self-management should be seen as integral to treatment, rather than a ‘nice optional extra’ (34).

This study asked participants about support preferences, but it is not known how this would translate into uptake in clinical practice. It is possible some of the responses given reflect social desirability, such as male participants reporting no preference for group gender. However, the responses were anonymous, and participants were advised of this. It is possible that those men who may have belonged to Factor B were under-recruited as the very characteristics included in Factor B may have reduced the proportion of participants taking part who could be assigned to this Factor. This potential recruitment bias would reduce the likelihood of identifying Factor B, which nevertheless emerged.  Thus, the size of Factor B as reported here (43% of participants) may be an underestimate of the number of men with RA who use these coping strategies. This survey sampled from patients across six hospitals in England, thereby accessing a range of disease experiences and care pathways, it also involved a patient research partner (RN) from design through to interpretation. Although this study was in the UK, the literature suggests commonalities in psychological impact of inflammatory arthritis, such as RA, across Europe and North America (35, 36). Masculinity is thought to be socially constructed (37), thus these results may be specific to a Westernised culture and may not be relevant in a different socio-cultural context. However, qualitative studies suggest commonalities on the impact of inflammatory arthritis on masculinity between the UK and other European countries (38-40). Thus, men’s coping strategies and preferences for psychological support may be relevant to patients internationally.

Conclusions

Our findings suggest there are at least two groups of men with RA, one of which (≥43%) appears to be struggling to accept and cope with their RA and are not being served by current self-management interventions because of their personal coping strategies. Men’s preferences for support take the practical form, with a focus on expanding their knowledge about their condition and how to manage it. Men report being more likely to take part in a self-management session if it were legitimised by their clinical team. Further research should pilot potential self-management support for men to test appropriate content, delivery style and recruitment techniques.

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Tables and figures

**Table 1: Items included in the questionnaire**

|  |  |  |  |
| --- | --- | --- | --- |
| Section | Validated measure | Measure | Description |
| A: About You | No | Age | Open response  |
|  |  | Co-morbidities | Open response |
|  |  | Marital status | Tick options |
|  |  | Employment status | Tick options |
|  |  | Level of physical activity in job | NRS 1-5 |
|  |  | Level of autonomy in job | NRS 1-5 |
| B: About your RA | No | Medication | Open response |
|  | No | Disease duration | Open response |
|  | Yes | Patient-based disease activity score (PDAS) (41) | Patient-reported measure of disease activity |
| C: Your own experience of RA | No | Distinguishing statements from two Q-methodology factors  | 21 statements taken from our previous research (20). NRS 0-10 asking how much each statement relates to their experience of living with RA |
| D: Coping with RA | Yes | Medical Coping Modes Questionnaire (MCMQ) (42, 43) | 19 items measuring the extent to which participants are using three coping strategies (Confrontation, Avoidance and Acceptance-Resignation) in dealing with their RA |
| E: How do you feel about your arthritis | Yes | Acceptance of illness scale (AIS) (44) | 8 items measuring the extent to which participants have accepted their RA |
| F: Life in general | Yes | Short-form perceived stress scale (PSS-4) (45) | 4-item measure of stress that focuses on elements of control |
|  | Yes | The Hospital Anxiety and Depression Scale (HADS) (46) | 14-items measuring levels of anxiety and depression |
|  | Yes | Short-form Warwick and Edinburgh Mental Well-being Scale (SWEMWBS) (47, 48) | 7-items measuring mental well-being |

NRS = Numerical rating scale

**Table 2: Calculation of Brown’s factor index score using participant M049 as an example**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Distinguishing statements by Factor** | **Factor Score** | **Mean NRS statement scorea for study population** | **NRS score for statementsa for participant M049** | **Statement index score for participant M049** | **Factor index score for participant M049** |
| **Factor A** | **Factor B** |
| **Factor A** | Keeping active helps me manage my RA symptoms | **+5** | +1 | 7.1 | 8 | 40 | 100 |
| I am able to find different ways of doing things I want to, or different activities to replace those I’ve lost | **+5** | -1 | 6.8 | 6 | 30 |
| I still socialise as much as I used to before having RA | **+3** | -3 | 6.7 | 4 | 12 |
| RA has taken away my independence | **-5** | +2 | 6.7**a** | 2**a** | 10 |
| I worry more about money now I have RA | **-5** | +1 | 6.9**a** | 0**a** | 0 |
| Since being diagnosed with RA I have lost a lot of confidence | **-4** | 0 | 6.5**a** | 2**a** | 8 |
| **Factor B** | I feel frustrated because of my RA | -2 | **+7** | 5.3  | 10 | 70 | 333 |
| I get angry because of my RA | -7 | **+6** | 4.2 | 9 | 60 |
| I sometimes feel guilty about the effect my RA has on the people around me | -1 | **+5** | 4.6 | 10 | 50 |
| My faith helps me cope with my RA | -1 | **-7** | 7.7**a** | 9**a** | 63 |
| If I need a tool/device/gadget to help with my RA I will make it myself | 0 | **-5** | 7.1**a** | 9**a** | 45 |
| I don’t mind having to ask stranger for help when I need to | +1 | **-5** | 6.8**a** | 9**a** | 45 |

aItem scores of statements with a negative factor score were reverse scored

**Table 3: Mean statement and factor index scores for Q-methodology Factor A and Factor B**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Distinguishing statements by Factor** | **Factor Score** | **Mean statement scorea** | **Statement index score** | **Factor index score** |
| **Factor A** | **Factor B** |  | **Mean** | **SD** | **Range** | **Mean** | **SD** | **Range** |
| **Factor A** | Keeping active helps me manage my RA symptoms | **+5** | +1 | 7.1 | 35.4 | 12.1 | 0-50 | **203.1** | **64.4** | **24-310** |
| I am able to find different ways of doing things I want to, or different activities to replace those I’ve lost | **+5** | -1 | 6.8 | 33.8 | 12.9 | 0-50 |
| I still socialise as much as I used to before having RA | **+3** | -3 | 6.7 | 19.8 | 18.8 | 0-60 |
| RA has taken away my independence | **-5** | +2 | 6.7 | 33.3 | 16.4 | 0-60 |
| I worry more about money now I have RA | **-5** | +1 | 6.9 | 34.5 | 16.6 | 0-50 |
| Since being diagnosed with RA I have lost a lot of confidence | **-4** | 0 | 6.5 | 26.1 | 12.8 | 0-40 |
| **Factor B** | I feel frustrated because of my RA | -2 | **+7** | **5.3**  | **37.2** | **23.1** | **0-70** | **209.4** | **66.5** | **32-350** |
| I get angry because of my RA | -7 | **+6** | **4.2** | **25.2** | **20.8** | **0-60** |
| I sometimes feel guilty about the effect my RA has on the people around me | -1 | **+5** | **4.6** | **23.2** | **17.7** | **0-50** |
| My faith helps me cope with my RA | -1 | **-7** | **7.7** | **54.2** | **22.3** | **0-70** |
| If I need a tool/device/gadget to help with my RA I will make it myself | 0 | **-5** | **7.1** | **35.3** | **17.5** | **0-50** |
| I don’t mind having to ask stranger for help when I need to | +1 | **-5** | **6.8** | **33.9** | **16.8** | **0-50** |

aItem scores of statements with a negative factor score were reverse scored

**Table 4: Demographic, clinical and psychosocial data according to gender and Q-methodology factor**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Variable** | **Male patients****Factor A (“*accept and adapt”*)*****n=61*** | **Male patients Factor B (*“struggling to match up”*)*****n=120*** | **Male patients unassigned to a factor*****n=99*** | **Male patients total*****n=280*** | **Female patients total*****n=103*** |
| **Age, years** |  |  |  |  |  |
|  Mean (SD) | 68 (10.1) | 64 (10.9) | 67 (11.0) | 65.7 (10.9) | 62 (12.0) |
|  Range | 37-85 | 28-82 | 32-90 | 28-90 | 28-83 |
| **Comorbidities** |  |  |  |  |  |
|  Yes | 61% | 71% | 68% | 68% | 66% |
| **Marital Status** |  |  |  |  |  |
|  Married | 69% | 77% | 77% | 75% | 65% |
|  Single | 10% | 8% | 6% | 7% | 3% |
|  Divorced | 6% | 4% | 6% | 7% | 6% |
|  Widowed | 8% | 5% | 7% | 5% | 15% |
|  Living with partner | 7% | 4% | 4% | 5% | 10% |
|  Prefer not to say | 0% | 2% | 0% | 1% | 1% |
| **Employment Status** |  |  |  |  |  |
|  Full time | 21% | 26% | 24% | 24% | 11% |
|  Part time | 13% | 7% | 13% | 10% | 18% |
|  Retired | 66% | 54%a | 62% | 60% | 55% |
|  Unemployed  (due to RA) | 0% | 12% | 1% | 5% | 13% |
|  Unemployed (other) | 0% | 0% | 0% | 0% | 2% |
|  Prefer not to say | 0% | 1% | 0% | 1% | 1% |
| **Level of physical activity in job** |  |  |  |  |  |
|  Not at all | 3% | 1% | 3% | 2% | 5% |
|  A little | 5% | 3% | 8% | 5% | 8% |
|  Somewhat | 2% | 6% | 10% | 6% | 3% |
|  Quite a bit | 10% | 15% | 12% | 13% | 7% |
|  A great deal | 16%b | 10% | 4% | 9% | 5% |
|  Not answered | 64% | 64% | 63% | 65% | 72% |
| **Level of autonomy in job** |  |  |  |  |  |
|  Not at all | 2% | 1% | 3% | 2% | 1% |
|  A little | 0% | 6% | 1% | 3% | 3% |
|  Somewhat | 2% | 8% | 7% | 6% | 5% |
|  Quite a bit | 10% | 14% | 15% | 13% | 13% |
|  A great deal | 22%c | 7% | 11% | 11% | 6% |
|  Not answered | 64% | 64% | 63% | 65% | 72% |
| **Disease duration, years** |  |  |  |  |  |
| Mean (SD) | 15.0 (10.1) | 14.6 (11.1) | 14.2 (12.2) | 14.6 (11.2) | 12 (11.2) |
| Range | 1-37 | 1-53 | 0.5-69 | 0.5-69 | 0.2-55 |
| **Patient Global** |  |  |  |  |  |
| Mean (SD) | 18.3 (17.3) | 51.0 (24.9)a | 35.2 (26.3) | 38.2 (27.1) | 47.4 (26.8) |
| **PDAS** |  |  |  |  |  |
|  Mean (SD) | 3.3 (0.6) | 4.7 (0.9) | 4.0 (1.1) | 4.2 (1.9) | 4.5 (1.0) |
| **Medication** |  |  |  |  |  |
|  DMARDs | 50% | 92% | 79% | 81% | 88% |
|  Biologics | 18% | 40%d | 29% | 31% | 40% |
|  Steroids | 26% | 28% | 31% | 30% | 31% |
|  No medication | 8% | 4% | 5% | 5% | 5% |
| **Coping strategies, Mean (SD)** |  |  |  |  |  |
|  Confrontation | 16.0 (3.2) | 17.3 (3.2) e | 17.1 (3.7) | 17.0 (3.5) | - |
|  Avoidance | 13.5 (3.3) | 15.7 (3.0)a | 14.5 (3.5) | 14.8 (3.4) | - |
|  Resignation | 7.3 (1.0) | 8.8 (1.7)a  | 7.7 (1.5) | 8.1 (1.6) | - |
| **Acceptance** |  |  |  |  |  |
| Mean (SD) | 35.0 (5.2)a | 21.6 (6.7) | 28.9 (7.0) | 27.1 (8.4) | - |
| **Depression** |  |  |  |  |  |
|  Case | 2% | 22%a | 5% | 11% | - |
|  Borderline case | 2% | 25%a | 8% | 15% | - |
|  Non-case | 96% | 53%a | 87% | 74% | - |
| **Anxiety** |  |  |  |  |  |
|  Case | 2% | 22%a | 10% | 13% | - |
|  Borderline case | 2% | 23%a | 14% | 15% | - |
|  Non-case | 96% | 55%a | 76% | 72% | - |
| **Perceived stress** |  |  |  |  |  |
|  Mean (SD) | 2.5 (2.7) | 6.6 (3.3)a | 4.3 (3.1) | 4.9 (3.5) | - |
| **Mental well-being** |  |  |  |  |  |
|  Mean (SD) | 27.7 (4.9)a | 21.7 (4.2) | 25.1 (5.1) | 24.3 (5.3) | - |

**a***p*=<.001 b*p*=.040 c*p*=.007 dp=.010 e*p*=0.15

**Table 5: Preferences for self-management support services compared according to gender and Q-methodology factor**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Male patients****Factor A (“*accept and adapt”*)*****n=61*** | **Male patients Factor B (*“struggling to match up”*)*****n=120*** | **Male patients unassigned to a factor*****n=99*** | **Male patients total*****n=280*** | **Female patients total*****n=103*** |
| **Mode of delivery for support** | **(%)\*** | **(%)\*** | **(%)\*** | **(%)\*** | **(%)\*** |
|  **Discussion group** |  |  |  |  |  |
|  About experiences of RA | 32 | 35 | 30 | 34 | 59c |
|  To exchange tips about RA | 36 | 44 | 40 | 41 | 64c [10th] |
|  To discuss research (e.g. papers) | 34 | 24 | 31 | 29 | 53c |
|  **One to one consultation** |  |  |  |  |  |
|  with Consultant  | 82 [1st] | 82 [1st] | 84 [1st] | 82 [1st] | 86 [1st] |
|  with Specialist nurse | 79[2nd] | 80 [2nd] | 81 [2nd] | 79 [2nd] | 87 [2nd] |
|  with Physiotherapist | 55 [5th] | 53 [6th] | 51 [6th] | 53 [6th] | 56 |
|  with Occupational Therapist | 40 | 49 [10th] | 40 | 43 | 59d |
|  with Psychologist | 27 | 21 | 26 | 23 | 39e |
|  with another patient | 32 | 26 | 27 | 27 | 49c |
|  **Question and answer session** |  |  |  |  |  |
|  with Consultant  | 55 [6th] | 54 [5th] | 53 [5th] | 54 [5th] | 67 [7th] |
|  with Specialist nurse | 50 [9th] | 51[7th] | 48 [7th] | 51 [7th] | 67d [7th] |
|  with Physiotherapist | 41 | 31 | 37 | 35 | 43 |
|  with Occupational Therapist | 34 | 31 | 29 | 31 | 45 |
|  with another patient | 30e | 20 | 20 | 22 | 45c |
|  **Organised talks** |  |  |  |  |  |
|  Lifestyle experts  | 54 [7th] | 45 | 42 [8th] | 45 [8th] | 76c [4th] |
|  Expert patients | 30 | 24 | 28 | 27 | 55c |
|  Research experts | 63f [4th] | 49 [9th] | 56 [4th] | 55 [4th] | 70f [6th] |
|  **Education sessions** |  |  |  |  |  |
|  Managing stress/anger | 18 | 34a | 23 | 27 | 48c |
|  Managing symptoms | 54 [8th] | 63b [4th] | 42 [8th] | 53 [6th] | 75c [5th] |
|  **Physical activity sessions** |  |  |  |  |  |
|  To develop skills e.g. balance | 36 | 35 | 40 | 37 | 64c [10th] |
|  To improve fitness | 39 | 51 [8th] | 39 | 44 [9th] | 53 |
|  Organised game  (e.g. walking football) | 23 | 25 | 23 | 24 | 24 |
|  **Raising awareness of RA event** |  |  |  |  |  |
|  Attend | 39 | 38 | 34 | 36 | 65c [9th] |
|  Take part in  | 18 | 22 | 18 | 19 | 27 |
|  Help organise | 13 | 12 | 17 | 14 | 25 |
|  **Online services** |  |  |  |  |  |
| To read information | 73 [3rd] | 65 [3rd] | 71 [3rd] | 69 [3rd] | 81 [3rd] |
| To read others patients’ stories | 46 [10th] | 45 | 42 [8th] | 44 [9th] | 64g [10th] |
| To read question and answers | 21 | 20 | 30 | 24 | 27 |
| To communicate with other patients about emotions | 20 | 23 | 24 | 23 | 44c |
| To communicate with other patients about practical issues | 27 | 27 | 30 | 28 | 49c |
| A chat room | 18 | 17 | 20 | 18 | 27 |
| A message board | 49 | 39 | 39 | 42 | 59h |
| **Time of day for support services** |  |  |  |  |  |
|  Early morning (pre-9am) | 12 |  6 | 13 | 10 |  6 |
|  Morning (9am-midday) | 44 | 32 | 45 | 40 | 30 |
|  Lunchtime (Midday-2pm) | 18 | 26 | 28 | 24 | 33 |
|  Afternoon (2-5pm) | 28 | 32 | 32 | 31 | 43 |
|  Evening (After 5pm) | 24 | 29 | 24 | 25 | 22 |
| **Frequency** |  |  |  |  |  |
|  Single on off group | 17 |  9 | 20 | 15 | 10 |
|  A fixed time period (e.g. each week for six weeks) |  6 | 17 | 17 | 14 | 17 |
|  No fixed commitment, an advertised timetable to dip into | 77 | 76 | 64 | 72 | 76 |
| **Gender of the group** |  |  |  |  |  |
| Same gender |  6 |  4 |  9 |  7 |  4 |
| Mixed gender: Equal numbers of men and women | 14 | 18 | 31 | 19 | 17 |
| Mixed gender: My gender should outnumber the other |  2 |  0 |  0 |  1 |  2 |
| Mixed gender: I don’t mind if the other gender outnumbers me | 22 | 11 |  9 | 13 |  8 |
| No preference | 56 | 67 | 61 | 62 | 68 |
| **Other people** |  |  |  |  |  |
| A service for people with RA only | 22 | 13 | 20 | 17 |  9 |
| Would like to invite a friend/family member | 37 | 50 | 32 | 41 | 54 |
| Wouldn’t bring someone, but wouldn’t mind a group open to friends/family | 41 | 38 | 48 | 42 | 38 |
| **Motivators** |  |  |  |  |  |
| An appointment letter | 57 | 47 | 54 | 52 | 61 |
| Invitation from rheumatologist | 63 | 71 | 67 | 68 | 69 |
| Invitation from specialist nurse | 57 | 61 | 51 | 57 | 71 |
| Reimbursement of travel costs | 22 | 25 | 19 | 21 | 32 |
| Money or vouchers for attendance |  7 | 12 | 14 | 11 | 18 |
| Location away from the hospital |  9 | 21 | 20 | 17 | 30 |

\*Top 10 most popular modes of delivery in each group are ranked in square brackets

Comparison between factors: a*p*=0.046; b*p*=0.010

Comparison between men and women: c*p*<0.001; d*p*=0.006; e*p*=0.003; f*p*=0.010; g*p*=0.001; h*p*=0.007